Psychological coping styles in mothers of children with rare genetic syndromes: Associations with mental health

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Aim: To document coping styles used by mothers of children with rare genetic syndromes and explore how these relate to positive and negative maternal mental health. Method: 89 mothers of children with rare genetic syndromes completed questionnaires assessing maternal mental health (Hospital Anxiety and Depression Scale, Positive and Negative Affect Scale) and maternal coping styles (Brief COPE).

Results: The most frequently reported coping style was problem-focussed coping, and the least frequent was religious/denial. Coping styles were not associated with child age or ability, but were significantly associated with maternal mental health. Higher levels of active avoidance were associated with higher levels of negative affect and increased levels of anxiety and depression. Conversely, higher levels of problem-focussed and positive coping styles were associated with higher levels of positive affect.

Conclusions: Although this study cannot comment on causation between coping styles and mental health, the identification of a relationship between coping styles and mental health (both positive and negative) highlights a key area for intervention.

Aging with intellectual disability: A prevalence study of older people in Sweden

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Aim: Life expectancy of people with intellectual disability (ID) has increased along with that in the general population. The aims were to estimate prevalence of older people with intellectual disabilities (ID) during 2004-2012, and identify differences in prevalence across counties in Sweden. Method: Individuals aged 55+ years were identified through two national registers; the LSS register and the death register from the Swedish National Board of Health and Welfare. Results: The prevalence of ID was 444 per 100,000 population among the youngest age group 55-59 years old, and it decreased steadily to 65 per 100,000 population among those aged 80+ years old. Higher prevalence was found among men in the youngest age group. Northern counties in Sweden had higher prevalence, whereas prevalence in the middle and the southern regions demonstrated a more widespread distribution. Conclusions: This national study fills the knowledge gap about spatial distributions of older people with ID in Sweden. There is a need to investigate allocated resources and the quality of social service and care provided to individuals with ID in different counties in Sweden.

Parents’ perspectives on stigma and IDD in Kinshasa

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Aim: Families of children with intellectual and developmental disabilities (IDD) in Kinshasa, Democratic Republic of the Congo (DRC) face significant stigma within their communities. This can lead to shame, blaming, and stress within the family and reduced opportunities for the child. This study used a participatory action research approach to understand this stigma and propose community action to
reduce it. **Method:** Congolese parents of children with IDD (trained in qualitative research methods and research ethics) conducted semi-structured interviews with individual family members of children with IDD in Kinshasa, the capital city of the DRC. Interviews were audio recorded and transcribed. The research team, inclusive of the family member researchers, adopted a grounded theory approach to analyse the interviews. **Results:** Results of this study demonstrate how stigma is felt and understood by family members in Kinshasa and identify coping or mitigation strategies employed by these families. **Conclusions:** This study provides a family-driven perspective on stigma and IDD in the DRC. Insight from this study may inform stigma reduction efforts in the DRC or in other similar contexts.

**Beyond show & tell: The state of on-the-job training for those with intellectual disabilities**

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**Aim:** To investigate the training that employees with intellectual disabilities (ID) are receiving from open employment and ADE (Australian Disability Enterprise) staff and the factors influencing that training.  
**Method:** 49 staff and 15 employees with ID from nine South Australian and New South Wales disability employment organisations participated in a mixed method study. Training staff completed an online questionnaire. Both groups were interviewed to obtain views and perceptions regarding the provision of on-the-job training. **Results:** Data revealed that there was a failure to match the tertiary qualifications of employees with ID, their workplace goals and on-the-job training. Training staff have a vast array of competing demands and challenges associated with their role. **Conclusions:** To assist disability employment staff in their training role, a multi-dimensional approach is required such as increasing staff knowledge of effective training strategies to increase skill acquisition for people with ID, government needs to be attentive to the policies that provide competing pressures on disability organisations, and management within organisations need to provide staff time and systems to support training of employees with disabilities.

**Who are we? Identity orientation and augmentative and alternative communication**

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**Aim:** Despite over 40 years in research and practice on the area of Augmentative and Alternative Communication (AAC) little attention has been paid to the issue of identity of the person who uses AAC. The aim of this paper is to give an overview of key themes found in the literature about identity and people who use AAC and to discuss why this is an important topic.  
**Method:** 15 databases and some grey literature were searched for research on identity and AAC. **Results:** The literature review identified a number of key themes that will be the key focus of a study with people who use AAC with a life-long disability. These themes include stigma, belonging and loneliness. **Conclusions:** Knowledge about AAC identity is important if we are to understand the steps that must be taken to support people who use AAC to manage a positive self-identity, to maintain a healthy outlook on life, and to be included in communities of their choice.

**The voice of persons with intellectual disabilities about family quality of life**
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Aim: Research in the field of disability has typically omitted the voice of individuals with intellectual disabilities (ID), despite the acknowledgement that these individuals are the experts on their own experiences. Family quality of life (FQoL) has demonstrated a lot of potential in terms of evaluation and intervention with families of persons with ID. The aim of this work is to give voice to persons with ID and explore their perspectives about their family QoL. Method: For this purpose, four focus groups were conducted with 17 persons with ID (mild and moderate) 16 to 53 years old; nine women and eight men. The transcriptions were analysed with the NVivo software. Results: Family relationships emerged as the most important domain for the FQoL and some specificities in the older age group appeared. Conclusions: The inclusion of individuals with ID as informants in research is a way of highlighting the value of their point of view, empowering them and recognising the unique contribution that they are able to make to the research.

Understanding neurodevelopment in very preterm children

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Aim: Very preterm children have high rates of neurodevelopmental impairments, although the pattern of impairments varies. The Victorian Infant Brain Study (VIBeS) was designed to investigate brain injury and development in very preterm infants, with the intention of identifying neurological biomarkers for later impairments. Method: 224 infants born <30 weeks gestation or birthweight <1250 grams were recruited. Brain magnetic resonance imaging (MRI) was performed at term equivalent age and 7 years of age, with neurodevelopmental assessments performed at 2, 5, and 7 years of age. Brain scans have been assessed using a combination of qualitative and advanced quantitative measures. A control group of 77 term/normal birth weight infants were also recruited and have undergone the same assessments. Results: This study has demonstrated that most very preterm infants have brain injury and altered brain development. Importantly, it has shown that features observed on neonatal MRI are significantly predictive of 7-year outcomes, and more predictive than all other risk factors. Conclusions: Brain MRI of very preterm infants is helpful in predicting the severity and pattern of impairments observed in middle childhood.

What is the lived experience of institutionalisation?

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Aim: To identify the lived experience of persons with intellectual disabilities (ID) who have resided in institutions. Method: A two-phase systematic literature review was conducted: an analysis of peer-reviewed journal articles identified in nine international social sciences databases was followed by a review of a broader catchment of a university library database – identifying all other relevant literature. Selection criteria focussed on accounts that were either autobiographical, facilitated first-person accounts, or ethnographic and observational approaches. Results: There is a scarcity of first-person or
reconstructed accounts – although it is a growing genre. Analysis revealed common experiences of persons with ID who have lived in institutional care as well as outlier findings. First-person accounts provide insights into the impacts of institutionalisation, deinstitutionalisation, demonstrating the effects of government policies of institutionalisation on the lives of persons with ID. These accounts may also be a restorative component in an individual’s healing and self-empowerment post institutionalisation. **Conclusions:** Accounts of the lived experience of persons with ID who have resided in institutions is key to “witnessing” the human impact of the era of institutionalisation.

**ASD, ID and anxiety: Identifying and treating the unseen**

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**Aim:** To explore the identification and behavioural manifestation of anxiety in individuals severely impacted by ASD and ID. **Method:** The Dynamic Model of Autism (Bartak, Bottroff & Zeitz, 2006) was tested as a possible theory to explain how anxiety develops in individuals with ASD and ID. Matched case studies were used to investigate how anxiety developed in some individuals and not in others. A longitudinal cluster analysis will examine possible behavioural clusters that may aid in the identification and diagnosis of anxiety in this population. Of particular interest are variable such as sensory processing, sensory over-responsivity, behavioural patterns, communication skills and ASD symptomology. **Results:** Preliminary results suggest that the Dynamic Model of Autism offers an explanation for how anxiety develops for this population, and also offers some insight into possible treatment pathways. The longitudinal cluster analysis is still underway, however it appears that behavioural clusters may offer a diagnostic criteria for identifying anxiety. **Conclusions:** By considering broader definitions and diagnostic criteria, we can better understand how anxiety affects individuals with ASD and ID, and therefore offer better treatment options.

**Collaborative mental health teams within schools: Supporting students with ASD and ID**

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**Aim:** To identify and treat mental health concerns in individuals with autism spectrum disorder (ASD) and intellectual disabilities (ID) through a multidisciplinary team. **Method:** An onsite behavioural and psychiatric clinic, bringing a psychiatrist and a developmental paediatrician to work with the existing transdisciplinary school team was developed at a school for children with ASD. The clinic runs several times a term with the medical professionals visiting students in situ. Family and key stakeholders are involved in discussions, with the school team presenting relevant behaviour data, video and analysis. Student behaviour changes were tracked using the Developmental Behaviour Checklist (DBC). **Results:** Clinic outcomes include drastically reduced wait times, timely access to professional support, frequent follow-up visits, lengthy appointment times for complex cases, coordinated care across environments, strong behaviour and physical care monitoring and ultimately faster resolution for crisis cases. DBC data shows decreases in problem behaviour over time. **Conclusions:** A special school run mental health clinic is a viable and practical way to support mental health in individuals with ASD and ID.
Racial/ethnic disparities in mammography utilisation among women with intellectual disabilities in the United States

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Aim: This study explores racial/ethnic disparities in mammography utilisation among women with ID who are Black/African American, Hispanic, and non-Hispanic White in an American city - Philadelphia.

Method: Participants included women with ID, 46 years and older. Mammogram data from 2010-2013 (n=100) were collected. Chi-square analysis was used to determine relationships between mammogram receipt and race/ethnicity, age and living situation. Data from interviews with participants (or primary caregivers) to understand factors that affect mammography receipt (n=27) were analysed using grounded theory. Results: Preliminary results show that women with ID are significantly more likely to have a mammogram done if they live in a state-owned home. Race/ethnicity and age do not appear to significantly affect having a mammogram. Women with ID are poorly prepared for mammography and offer recommendations.

Conclusions: State-owned homes have the potential to increase mammogram rates for women with ID via health coordination. Families of women with ID are less able to access preventive care without health coordination support. Results from this research may be considered when planning interventions and may be used to enhance the quality of healthcare for women with ID.

Subjective well-being and its correlates among adults with intellectual disabilities

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Aim: The present empirically explores subjective well-being (SWB) and its correlates among adults with intellectual disabilities (ID).

Method: The Theory of Subjective Well-being Homeostasis was used as a conceptual framework. 263 adults receiving residential support completed questionnaires measuring their SWB, functional limitations and the internal (self-determination) and external resources (financial resources, and social support).

Results: SWB was found within the normative range. Functional limitations directly predicted reductions in SWB but, in accordance with the theory, this effect was fully mediated by the individual’s internal and external resources. Conclusions: Main findings support the applicability of the theory of subjective well-being homeostasis for understanding SWB in individuals with ID. Study findings shed light on psychosocial determinants of SWB and highlight the importance of psychosocial resources as buffers of the effect of health and environmental conditions.

A family experience when a member has an intellectual disability: What does aging bring?

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Aim: The present study examines the different perspectives of family members’ experiences of aging when a member has an intellectual disability (ID).

Method: Relying on the qualitative paradigm, 10 family units were interviewed (each family unit was comprised of at least three members: aging parent, an adult sibling, and an adult with ID). Data were analysed on two dimensions: the subjective experience.
of each family member as well as the common narrative of the family as a whole. **Results:** Three major themes emerged: “I don’t see myself age” – a family dialog between aging and caring; “Now I’m not alone” – beneficial intergenerational relationships; and “Undesired blessing” – reviewing lifetime experience of family life. **Conclusions:** These multiple analyses allow in-depth exploration that goes beyond the "lived experience" of each family member and offers a unique opportunity to examine the contextual view in which the subjective perceptions are woven into a common family narrative. Theoretical and practical implications will be discussed.

**Social workers’ attributions toward individuals with dual diagnosis of intellectual disability and mental illness**

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**Aim:** The present study aimed to explore the applicability of the attribution model to social workers’ stigma of individuals diagnosed with dual diagnosis of intellectual disability and mental illness. Specifically, the study examined the relations between social workers’ attribution of responsibility, causality and dangerousness, emotional responses and behavioural reactions toward clients with dual diagnosis. **Method:** 279 social workers completed questionnaires measuring attributions of responsibility, causation and dangerousness, and reported on emotional and behavioural reactions to clients diagnosed with a dual diagnosis. **Results:** Most social workers reported high levels of helping behaviours. The strongest predictor of discriminatory behaviours was the stereotype of dangerousness. Social workers who reported feeling less anger and more pity toward clients with dual diagnosis tended to report higher levels of helping behaviour. Contrary to attribution theory, fear and anger did not predict discriminatory behaviours. **Conclusions:** The results are discussed in relation to the core values of social work and to professional identity.

**Advocating for needed supports using a standardised assessment of support needs**

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**Aim:** Under the Australian National Disability Insurance Scheme (NDIS), participants must self-advocate for support and individualised funding needed at a planning session upon entry to the scheme. This paper briefly overviews the NDIS and the standardisation of the Instrument for the Classification and Assessment of Support Needs (I-CAN). Participants can take I-CAN assessment reports with them to their NDIS planning session. **Method:** To assist in advocating for needed supports, an “hours of direct support needed algorithm” was developed for the I-CAN, in addition to the “individual funding needed” and “support classification” algorithms. De-identified data drawn from the I-CAN v5 database were analysed using stepwise regression. **Results:** Regression analysis found that I-CAN domain scores and age explained 75% of variance in self-reported hours of direct support needed (n=133) **Conclusions:** The I-CAN directly measures support people need. Standardised support needs assessment can be used to determine individual hours of direct support and funding needs. Holistic approaches to the standardised assessment of support needs can assist in ensuring people have their needs more appropriately met.
Human right to legal capacity: Respecting autonomy and providing support

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Aim: This presentation provides an overview of the right to legal capacity in Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). It also explores the state obligation to provide support for the exercise of legal capacity. It looks at the General Comment on the right to legal capacity from the UNCRPD Committee to examine the requirement to replace substituted decision-making (such as guardianship) with support for the exercise of legal capacity. Method: This paper is a legal analysis based on the text of Article 12 and the accompanying General Comment. Results: This right is often misunderstood or overlooked. It presents challenges to guardianship, mental health law, disability services, and other areas. Conclusions: The right to legal capacity is essential for true inclusion of people with intellectual disabilities. This paper hopes to provide an accessible interpretation of the right and a clear path toward its realisation.

Time use and occupational engagement of people with an intellectual disability in supported independent living

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Aim: This study investigated the daily time use and engagement in everyday activities of people with a mild intellectual disability living in their own homes and receiving outreach support. Method: A case study methodology and mixed methods were utilised to develop an in-depth picture of the six participants’ lives through semi-structured interviews, multiple occupation-focussed assessments and observation of their home environments. Results: The time use profiles of the participants reveal that they spent the majority of their time on their own, in their own homes and participating in personal care activities (including sleeping) and passive leisure. Participants’ engagement in everyday activities is characterised by three main themes: being in a social world, managing independence, and participating. Conclusions: Increased focus on how people with an intellectual disability spend their time, including their participation in meaningful and purposeful occupations, at home and in the wider community, may contribute to greater social connections, and improved quality of life.

Mothers with intellectual disabilities and infant-feeding: An exploration of their decisions

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Aim: Despite recent research focus on prenatal and birth outcomes among mothers with intellectual disabilities (ID), there is little literature that addresses infant-feeding decisions among this population. This study explores experiences of mothers with ID in making and carrying-out infant-feeding decisions. Method: In-depth interviews were conducted with four mothers with ID. Results: Qualitative analysis revealed that infant-feeding decisions can be broken into two elements: making infant-feeding decisions and carrying out infant-feeding decisions. Three sub-themes of making infant-feeding decisions
emerged: being familiar with benefits of breastfeeding, owning the initial decision and preparing for infant-feeding. Two sub-themes of carrying out infant-feeding decisions transpired: facing challenges and receiving support. **Conclusions:** The importance of the prenatal period emerged as a crucial time for the mothers regarding infant-feeding decisions. In this time the mothers expressed feeling the most decision-making power, yet opportunities to prepare for possible challenges were missed. The mothers identified some learning needs and preferences.

**Exploration of intervention plans for parents with intellectual disabilities who receive specialised and child welfare services**

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Aim: Many parents with intellectual disabilities (ID) receive services from specialised agencies and child welfare. As a result many of these families have two separate intervention plans. Little is known about how agencies collaborate to support these families, the ways in which parenting objectives are defined and worked on within specialised and child welfare interventions. This research has two phases; however, phase two will be the focus of this presentation. The aim is to evaluate the content of intervention plans (from both agencies). In particular, to evaluate the way the objectives are operationalised and if there is a link between the objectives in the intervention plans of the two agencies. **Method:** Descriptive statistics and qualitative analysis were used in reviewing 15 intervention plans of parents with ID who received services from the two agencies. **Results:** Generally, the objectives in the two intervention plans were not operationalised and there were few objectives within the separate intervention plans that complemented each other. **Conclusions:** The results of this study have implications for collaboration initiatives in research and clinical practice.

**Recording sleep behaviour via sleep diaries: Feasibility of a smartphone “app” and its equivalence to a paper diary**

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Aim: Smartphone applications (“apps”) are a potentially superior means to record sleep data (compared to paper-based diaries) as smartphones are commonly held near the person at all times, and may be used to prompt timely data entry. The objective of this study was to evaluate a sleep diary app and to explore the user experience. **Method:** Participants were 70 parents of a child 6 to 12 years old with a diagnosis of autism spectrum disorder. Participants were randomised into two groups differentiated by the order in which they used an app and paper-based diary over two weeks. **Results:** The diary formats were found to not yield significantly different data, with most diary variables significantly correlated across formats. Participants reported the two formats to have similar levels of accuracy and convenience. **Conclusions:** Parents found the app-based sleep diary to be an acceptable and convenient means of reporting on their child’s sleep behaviour. While the app yielded equivalent data to a paper-based diary, it had the desirable additional property of enabling researchers to distinguish timely from untimely data entry.
Drug use and healthcare consumption among persons with intellectual disabilities and dementia: A registry study

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**Aim:** To describe drug use and healthcare utilisation among persons with intellectual disabilities (ID) and dementia in comparison to persons with ID only and dementia only. **Method:** From the group of persons with ID (n=7936), 216 individuals with dementia were identified. 81 persons with dementia were identified from a general population sample matched by age and sex. Information on outcomes was collected retrospectively from national registries. Healthcare utilisation was measured as the number of hospital visits and the number of hospitalisations. Drug use was assessed for antipsychotics, benzodiazepine derivatives, and anticholinesterases. **Results:** Persons with ID and dementia had higher healthcare utilisation than persons with ID but without dementia, but similar levels as persons with dementia in the general population sample. They were more likely to use antipsychotics and less likely to use anticholinesterases than persons with dementia but without ID. **Conclusions:** Dementia in persons with ID seems to increase healthcare utilisation and drug use. However, with respect to healthcare utilisation, the levels do not exceed those found among persons with dementia in the general population.
A daughter's perspective

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**Aim:** The aim of this study is to explore the author’s lived experience as a daughter of parents with intellectual disabilities (ID). This personal account collaborates and contrasts with the existing literature involving families headed by people with ID. **Method:** This is an auto-ethnographical study utilizing the author’s retrospective account and vignettes, reflexivity and analysis of these experiences in light of the current research involving non-disabled adult children of parents with ID. **Results:** The study examines and challenges the common negative assumptions held by society that view parents with disabilities as incompetent solely based on their learning difficulty. For this author, her parent’s learning impairment played a rather insignificant role within the relationship. Formal and informal supports served to ameliorate issues typically associated with risk factors within families such as poverty, stigmatisation, and isolation. **Conclusions:** This personal account reflects the fact that families headed by parents with disabilities are as complex and unique as other families. In addition, risks imparted by societal assumptions and social disadvantages can be moderated through loving family relationships and social supports.

Intervention for FASD: How it differs from standard behavioural approaches

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**Aim:** The aim of this research was to investigate health and allied health professionals’ approaches to intervention and management of foetal alcohol spectrum disorder (FASD), and to compare international evidence-based and promising practice models for FASD intervention. **Method:** This research was ethnographic, comprising 20 semi-structured interviews and participant-observation with health and allied health professionals in New Zealand and Canada. The interviews were coded for qualitative thematic analysis, from which the project’s findings were derived. **Results:** This research revealed a gap in effective intervention services for FASD in the New Zealand context, and that standard approaches to behaviour management may be insufficient for children with FASD who have complex needs. **Conclusions:** International promising practice models for FASD intervention employ a neurobehavioural approach, which considers the impact of their primary brain impairment on behaviour. Health and allied health professionals in New Zealand would benefit from further training in evidence-based and promising practice models for FASD intervention.

The complex developmental needs of care leavers involved in the youth justice system in Victoria, Australia

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**Aim:** This study aimed to understand the needs, experiences and good practice with young people leaving state out-of-home care (OHC) who are also involved with the youth justice system. Many such
young people have disabilities of various forms, though these are not always formally diagnosed. **Method:** Individual interviews and focus groups were conducted with 77 key stakeholders in the child welfare and youth justice fields. Additionally, 15 in-depth interviews were held with care leavers aged 18-26 years who had experienced involvement with the Victorian Youth Justice system. **Results:** Findings identified difficulties managing challenging behaviours as a driver for entry into OHC. Ongoing difficulty responding to these needs in OHC contributes to the over-representation of this group in the youth justice system. **Conclusions:** Many aspects of offending behaviour among young people in OHC can be usefully conceptualised as trauma-related, with other developmental deficits as compounding factors. Trauma-informed approaches for preventing and addressing the over-representation of young people in and leaving care in the youth justice system are recommended.

**Early childhood behaviour disorders and mother well-being: Predicting to a decade later**

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**Aim:** To study the trajectory of behaviour disorders in children with intellectual disabilities (ID) or typical cognitive development. Do behaviour disorders and mother distress at child age three years predict behaviour disorders a decade later? **Method:** We studied 114 children with or without ID longitudinally; this report is based on age 3 and age 13 assessments. The outcome was behaviour disorders in adolescence, assessed with Child Behavior Checklist (CBCL) scales: total behaviour problems, ADHD, and anxiety disorders. Predictors included the child behaviour problems at age 3, as both continuous and binary (clinical range vs. not) variables and the mothers’ stress and psychological adjustment, assessed by the Family Impact Questionnaire (Negative Impact scale) and the Symptom Checklist 36. **Results:** CBCL scores at age 3 were highly predictive of CBCL scores a decade later, for children with or without ID. Moreover, mothers’ stress and psychological problems at child age 3 accounted for significant variance in youth CBCL scores a decade later. **Conclusions:** These findings underscore the importance of interventions in early childhood to reduce child behaviour problems and/or to help mothers cope better with stress.

**Opinions of GPs regarding health assessment instruments for people with intellectual disabilities: A qualitative study**

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**Aim:** General practitioners (GPs) provide healthcare to people with intellectual disabilities (ID). Health assessment instruments can support GPs to detect health needs including prevention and health promotion issues in the population. This qualitative study aims to explore GPs’ considerations regarding health assessments instruments for people with ID. **Method:** Four semi-structured focus groups with 23 GPs were conducted. Focus groups were audio-recorded, transcribed verbatim and analysed using a framework approach. This framework and the summaries of views per theme were discussed in the research team. **Results:** GPs addressed three main themes: GPs’ task; usefulness and necessity; and barriers of applying health assessments instruments for people with ID. These assessment instruments
can help GPs to focus on issues that are not common in the general population. GPs are motivated to use the instrument if it provides health gains and is evidence-based. They identify three types of barriers; GP-bound, patient-bound, and organisational-bound. **Conclusions:** GPs consider medical care of people with ID their responsibility. In order to deliver good care they need tools, like health assessment instruments, education and support.

**Health assessment instruments for people with intellectual disabilities: A systematic review**

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**Aim:** People with intellectual disabilities (ID) experience health disparities. Health assessment instruments are a way to address their health problems. The aim of this review was to find the best available health assessment instrument for people with ID. **Method:** Based on an electronic literature search, 25 peer reviewed articles were included. Data were collected on four domains; development, clinimetric properties, content, and effectiveness of the health assessment instrument. **Results:** Eighteen health assessment instruments were distinguished. Limited information was found on development of the instrument as well as on clinimetric properties. The content of the instruments was diverse. Included articles agreed on the effectiveness of the instruments. However, only two instruments tested effectiveness in a randomised controlled trial. Patients with ID, caregivers and GPs generally appreciated the health assessment instruments. The comprehensive health assessment program (CHAP) by Lennox et al. met most criteria, although information on quality issues such as the development, validity and reliability were lacking. **Conclusion:** Although it is an appreciated tool in care for persons with an ID, well-evaluated instruments that apply to all domains are still lacking.

**Substance use among individuals with developmental disabilities in Ontario**

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**Aim:** Previous research has reported that adults with developmental disabilities (DD) experience low rates of substance-related or addictions disorders, but results were based on small sample sizes. The objective of this study was to examine the prevalence of these disorders among adults with DD using a population-based sample. **Method:** We created a cohort of adults with DD using administrative data (n=66,484; ages 18-64) and compared them to a random sample (from the same data source) of those without DD to determine the prevalence of substance-related or addictions disorders and associated co-morbidities. **Results:** The prevalence in adults with DD was higher than in adults without DD; our results were also higher than previously published rates. Persons with DD and substance-related or addictions disorders were more vulnerable to chronic diseases such as asthma and COPD; they were also more likely to be male, and live in the poorest neighbourhoods. **Conclusions:** The higher prevalence in persons with DD compared to persons without DD has important implications for policy and service delivery planning and ultimately, their health and well-being.
Chronic diseases and healthcare utilization in persons with cerebral palsy and intellectual disabilities

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Aim: Adults with cerebral palsy (CP) experience many medical issues and a high need for healthcare support. The occurrence of co-morbid intellectual disabilities (ID) in persons with CP may increase the risk for additional physical health issues. This study compares the prevalence of chronic diseases and indicators of chronic disease management among persons with CP and ID. Method: A cohort of adults with CP with and without ID was created using administrative data (n=14,155; ages 18-64). This sample was then compared to a random sample of those without CP and ID. Results: Individuals with CP with or without ID experience more chronic health conditions than those without P and ID; the disparity was most apparent for low trauma fractures. Persons with CP and ID were 12 times more likely to experience preventable hospitalizations compared to those without CP. Conclusions: The increased risk of chronic health conditions and hospitalizations among persons with CP, with or without ID has important implications for chronic disease prevention, fall prevention, early detection and proper osteoporosis management.

Low trauma fractures and bone mineral density testing in adults with intellectual and developmental disabilities: A population study

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Aim: Individuals with intellectual and developmental disabilities (IDD) are at an increased risk for developing osteoporosis and experiencing low-trauma fractures (LTF); consequently, it is important to monitor bone mineral density (BMD) in this population. The objective of this study was to examine the rates of LTFs and BMD testing among persons with IDD. Method: Using administrative data we examined a cohort of adults with IDD (n= 30,522; ages 40-64) and compared them to a random sample of those without IDD. The number of LTFs and BMD tests were determined for Ontario residents between 2009 and 2010. Results: Adults with IDD had significantly higher rates of LTFs compared to those without IDD; this was most notable among men, and those living in rural neighbourhoods. In addition, we found that high rates of LTFs start at an earlier age. Finally, people with IDD were less likely than individuals without IDD to receive a BMD test. Conclusions: The higher risk of osteoporosis and LTFs and lower levels of BMD testing has important implications related to prevention of fractures and proper management of these conditions among persons with IDD.

Social information processing, impulse, Theory of Mind and interest as social behaviour predictors among children with intellectual and developmental disabilities

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Aim: Social information processing (SIP) is assumed to be hierarchically organized with the first steps being automatic, followed by reflective steps. The purpose of the study was to investigate the
effectiveness and the patterns of SIP among children with intellectual and developmental disabilities (IDD) and to evaluate inclusion of ego control, working memory (WM), Theory of Mind (ToM) and social interest into the model. **Method:** 348 students with IDD, ages 12 to 18 years participated in the study. SIP model was examined using social problems tests. Positive and aggressive behaviors, ToM, WM, social interest and ego control were tested. **Results:** When presented with automatic and reflected SIP steps, aggressive and positive behaviors can be predicted with ego control but not WM as mediators to the reflective components of SIP. **Conclusions:** SIP predicts aggressive behavior and ego control relates to the reflective components of SIP. Students with high ego control effectively execute the reflective steps, while students with low ego control are ineffectively executing the reflective steps. Programs for students with IDD should address the patterns and effectiveness of SIP.

**Can the need for data influence how we teach communication learning?**

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**Aim:** does the need for data influence the manner in which special educators support the communication learning of students with complex intellectual disabilities (ID)? Can communication be learnt by supporting learner-led teaching practices rather than training strategies which promote the performance of communication? **Method:** Communities of practice collectively moderated video footage of learners involved in open-ended social activities underpinned by Intensive Interaction, against the ‘Framework for Recognising Progress’ to identify progress and change. 80% inter-observer agreement was required within the communities of practice to arrive at a judgement of a ‘level of involvement’ which informed teaching for the following year. **Results:** Having established protocols for moderation, sample videos have been shared and viewed and blind interstate comparisons made among teaching teams in Victoria and Queensland. This process of calibration provides collegial professional development opportunities in Intensive Interaction and ensures uniformity of approach across communities of practice. **Conclusions:** Improved learning outcomes for students with complex ID are being supported and clearly identified through the sharing of insights among special educators who have benefitted from mentoring and professional development in Intensive Interaction.

**Parent-child interactions and cerebral palsy: An exploratory study**

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**Aim:** Emotionally available parent-child relationships are supportive of child development. This study investigated links between parent-child emotional availability, child functional abilities and parent distress in a sample of parents and children with cerebral palsy (CP). **Method:** Twenty three mothers and their children with CP participated in this cross-sectional exploratory study. A 20-minute interaction was video-recorded and scored by a blinded coder using the Emotional Availability Scales. Parents also completed the Depression Anxiety Stress Scale, Pediatric Evaluation of Disability Inventory and the Strengths and Difficulties Questionnaire. Correlation analyses were conducted using SPSS. **Results:** Parent depression was negatively associated with all aspects of parent-child emotional availability. Parent anxiety was negatively associated with parent non-hostility and child responsiveness. Parent stress was negatively associated with parent structuring, parent non-hostility, and child responsiveness.
**Conclusions:** Results are consistent with the literature showing a link between parental depression and the parent-child relationship, and extend findings to CP. The importance of routine screening for parental mental health problems in early childhood intervention is highlighted by these findings.

**The impact of training on the beliefs and actions of religious leaders**

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**Aim:** Influencing the attitudes of religious leaders improves the lives of families impacted by disabilities in Kenya and Tanzania. We evaluated the responses of pastors involved in one-day pastor workshops facilitated by a partnering organisation in Kenya. **Method:** The workshops focus on discussions about the theology of disability, healing, and suffering. Success is measured based on observations and interviews with pastors comparing changes in belief and actions before and after training. **Results:** Interviews revealed that prior to training, over 50% of professing Christians were involved in abusive practices with children who have disabilities. Ninety percent of pastors involved in the training influenced communities to include, and provide for, people with disabilities in their communities. **Conclusions:** When spiritual leaders’ beliefs change they positively influence attitudes towards people with disabilities in their communities especially those which impact behaviour and intellect. Our model of advocacy can be applied to other religious leaders to increase inclusion.

**Understanding language development in a community sample: The Early Language in Victoria Study (ELVS)**

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**Aim:** To determine how language develops from infancy through adolescence and why language development is more difficult for some. **Method:** A cohort study commencing in infancy (8–10 months) and continuing through adolescence (13 years) was undertaken. Information was obtained from parents, teachers, direct assessment, and linkage (national academic achievement data). **Results:** Most infants aged 8 to 10 months used a range of communication strategies (eye gazing, making purposeful sounds) and there was rapid increase in social communication (8-12 months). Expressive vocabulary grew dramatically (12-24 months) with children combining words by 24 months. At 4 years, 20% met criteria for low language status, 3.4% had a speech sound disorder and 1.4% had combined speech/language problem. Language development was fluid from infancy into the primary school years. **Conclusions:** Language disorder is a commonly associated with neurodevelopmental disorders and disabilities and adds to a child’s difficulties learning. Understanding how spoken language develops is critical given it underpins a child's learning ability, ability to interact with others, and to establish relationships.

**Individual differences in sign and spoken word use in pre-schoolers with Down syndrome**

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Exercise and autonomic regulation in individuals with Down syndrome: What do we know and where to go

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Aim: Individuals with Down syndrome (DS) experience quite low work capacities when compared to peers without intellectual disabilities. This attenuated work capacity is associated with low maximal heart rates in this population. Data from our group and others demonstrates individuals with DS have altered autonomic function, which is largely responsible for regulating heart rate and blood pressure responses. An overview of current understanding of how autonomic function interplays with work capacity will be provided. Method: Several studies (n=20 to 60 individuals) examining sympathoexcitatory tasks (including isometric handgrip, cold pressor, exercise, and tilt table) to assess non-invasive indices of autonomic function among adults with DS were reviewed. The primary autonomic outcomes analysed included heart rate variability, blood pressure variability and baroreceptor sensitivity. Results: Across all sympathoexcitatory tasks, individuals with DS exhibited attenuated responses with respect to blood pressure and heart rate. Conclusions: Our study suggests physical work capacity in individuals with DS is related to altered autonomic function and provides a possible target of future research.

The role of active support in decision-making

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Aim: This review examined the theoretical underpinnings and findings from a number of studies to illustrate how active support can be instrumental in supporting decision-making for people with intellectual disabilities. Method: Data from three UK studies (n=772) are combined. Quality of support was observed using the Active Support Measure and the Engagement in Meaningful Activities and Relationships measure. Relationships between active support and some of the skills and opportunities that are essential for decision-making were explored. Results: With improved active support,
opportunities and support for choice improves, staff use more appropriate forms of communication and people's own communication is more effective. People are more engaged in a wider range of activities and relationships. **Conclusions:** The enabling relationship and focus on maximising choice and control inherent in active support helps the development of day-to-day decision-making skills and generates knowledge of the individual's likes, dislikes, preferences and previous experiences to inform those who are supporting them to make bigger life decisions.

**Exploring the relationships between active support, practice leadership and staff knowledge and values**

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**Aim:** As part of an ongoing longitudinal study with a national English charity, this paper explores how the expressed knowledge and values of staff relate to both the level of practice leadership and ultimately the quality of support provided for engagement in meaningful activities and relationships.  

**Method:** Structured observations of engagement in meaningful activities, the quality of staff support and the level of practice leadership were collected in 32 services supporting 96 people with intellectual disabilities. Staff (n=103) completed questionnaires focussing on their experiences, attitudes and knowledge. Qualitative data were analysed thematically and then coded to allow exploration of associations with active support and practice leadership.  

**Results:** Findings from the quantitative data will be briefly presented but particular attention will be paid to presenting how staff perceive their role, what they see as skilled support and what they understand by ‘active support’. Whether the views and knowledge of staff are qualitatively different when active support and/or practice leadership is strong will be explored.  

**Conclusions:** Implications for further research as well as for training and support of staff will be discussed.

**Mental and behavioural health of young adults with Down syndrome**

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**Aim:** To characterize the mental and behavioural health of young adults with Down syndrome (DS).  

**Method:** The sample consisted of 86 individuals (mean age (SD) = 33.3 (12.6) years) seen through a specialised DS clinic. Data were collected on demographic variables, medications, mental health, behavioural health, life experiences, stressors, living environment, and employment. Participants were grouped by age: youth 16-25 (n=31), middle-aged 26-49 (n=41); and aging 50+ yrs.(n=14).  

**Results:** Young adults experienced higher rates of negative life events than older adults. Negative life events were associated with mental health concerns, specifically depressed mood, general anxiety, and social avoidance as well as problematic behaviours including irritability and lethargy. There was a steady increase in the use of anxiolytics and mood stabilizers with age.  

**Conclusions:** The significant changes in lifestyle and social relationships that occur during transition years, such as leaving school and starting a job or day program can be particularly impactful on young adults. Without adequate support, these life events may contribute to mental health and behavioural problems.
Dying with epilepsy or dying of epilepsy?: Deaths of people with intellectual disabilities in social care settings in the UK who were living with epilepsy

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Aim: To study the impact of epilepsy on death and dying of adults with intellectual disabilities (ID).  
Method: As part of a larger study, we approached UK service providers for adults with ID supporting 13,199 people. We sent two questionnaires, the VOICES and another designed for this study, to a member of care staff (Carer) requesting more information about the person who died, the death and the setting. Complete data were obtained on 157 deaths over 18 months. Results: 59 of the 157 were said to have epilepsy when they died; though epilepsy was seldom the perceived cause of death. 17% of those with epilepsy, and 22% of those without epilepsy died suddenly or after an illness lasting less than 24 hours. Decedents with epilepsy were significantly younger than other decedents. Detailed analysis will be presented. Conclusions: The rate of epilepsy among decedents was comparable to that seen in living populations of adults with ID. However decedents with epilepsy were younger and often had multiple health problems. Epilepsy appears to be a risk factor for premature but not for unexpected death.

Dying with intellectual disabilities: Death awareness and disclosure among adults with intellectual disabilities in UK social care

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Aim: To examine the extent to which disclosure of a life-limiting condition happens for dying people with intellectual disabilities (ID).  
Method: As part of a larger study, we approached UK service providers for adults with ID supporting 13,199 people. We sent 2 questionnaires, the VOICES and another designed for this study, to a member of care staff (Carer) requesting more information about the person who died, the death and the setting. Data were obtained on 157 deaths over 18 months. Results: Carers had expected 73 of the 157 deaths. Of these, we found 48 concordant responses about whether the person knew they were dying. Ten decedents were aware. Of these, three ‘just knew’. Equal numbers had been informed by doctors and social care staff. Detailed analysis will be presented. Conclusions: Carers in social care settings in the UK responsible for a dying person with ID believed, in the majority of cases, that the person was unaware they were approaching death.

Expecting death?: Expected and unexpected deaths of adults with intellectual disabilities in social care settings in the UK

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Aim: To examine the extent to which the deaths of adults with intellectual disabilities (ID) were expected by paid care staff (carers). To compare this with what is known for the general population.  
Method: As part of a larger study, we approached UK service providers for adults with ID supporting
13,199 people. We sent questionnaires, the VOICES and another designed for this study, to a member of care staff (Carer) requesting more information about the person who died, the death and the setting. Data were obtained on 157 deaths over 18 months. **Results:** Carers had expected 73 of the 157 deaths. Deaths in the general population are more often expected. Detailed analysis will be presented. **Conclusions:** Nearly half all deaths in ID social care settings were unexpected by carers. This relates to age at death and cause of death. Communication between health professionals and carers may be relevant. Further research directions will be discussed.

**Exploring sensory profiles of identical twins with autism spectrum disorder**

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**Aim:** Sensory processing impairments have long been observed in autism spectrum disorder (ASD), but only recently recognised within the core diagnostic criteria. Understanding this construct and its potential association with ASD diagnosis, symptoms, and adaptive functioning is important to inform current practice. This study explores participants’ sensory profiles, and describes sensory functioning similarities and differences across identical twin pairs. **Method:** A case study design was adopted, with a battery of standardised measures administered across five twin pairs concordant and discordant for ASD diagnosis. In addition to direct and parent report measures of core ASD symptoms and adaptive functioning, the Sensory Profile 2 was completed. Variance across raw and standardised scores was explored. **Results:** Results from the Sensory Profile 2 reveal highly variable sensory processing patterns across the sample. Within-twin pair analyses revealed largely discordant sensory profiles, with score agreement ranging between 29-45%. **Conclusions:** Sensory profiles in identical twin pairs with ASD are not concordant, despite similar genetic and early environmental backgrounds. While sensory impairment is now recognised in core ASD diagnostic criteria, the variability in sensory profiles adds to the complexity of diagnosis and phenotype heterogeneity.

**Factors influencing the efforts of women with intellectual disabilities to become successful mothers**

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**Aim:** The topic of motherhood in regards to women with intellectual disabilities (ID) has been avoided by both researchers and service providers in the Czech Republic. Systemic support targeting the needs of these mothers is non-existent. The present study analyses factors influencing the efforts of women with ID to become successful mothers in the Czech Republic. **Method:** A semi-structured interview protocol was used to conduct interviews with 21 mothers with ID. The interviews were analysed using grounded theory. **Results:** The factors influencing the efforts of women with ID to become successful mothers include: their social networks; their knowledge of pregnancy, giving birth, and bringing up a child; their approaches to bringing up a child; their financial situation; their living arrangements; and their independent living skills. **Conclusions:** There is a need for systemic support for mothers with ID, including programs focussed on skills for independent living and bringing up a child.
Dealing with specific cognitive dysfunctions and psychiatric vulnerability in persons with intellectual disabilities

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Aim: To investigate the correlation between specific cognitive dysfunctions or dysfunctional cognitive patterns and the presence of specific psychiatric symptoms or syndromes in people with intellectual disabilities (ID). Method: A sample of 52 individuals with ID consecutively attending a clinic for multidisciplinary evaluation, in Florence, Italy was assessed through the SPAID (Psychiatric Instrument for Adults with Intellectual Disabilities) system, the WAIS III-R (Wechsler Adult Intelligence Scale III - Revised), the TMT (Trial Making Test), and other neuropsychological tools. Psychiatric diagnoses were formulated by expert clinicians in accordance to Diagnostic Criteria-Learning Disability or Diagnostic Manual-ID criteria. The main statistical analyses were the calculation of frequency and correlation indexes. Results: Strong correlations were found between executive frontal functions, autistic traits and impulse control disorder, and between working memory and bipolar disorder. Conclusions: In people with ID the possibility to understand the nature of the relationship between cognitive dysfunction and psychiatric symptoms seems to increase with the degree of specificity in both the cognitive and the psychopathological assessment.

Supported work experience: Job coach and employer assessments of worker performance

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Aim: The Real Opportunities project delivered supported work experience to transitioning young people in nine South Wales areas. This study compares job coach and employer assessments of worker performance and impact on emerging job preferences. Method: Over 24 months, 297 young people (262 with intellectual disabilities and 35 with autism spectrum disorder) achieved supported work placements. Up to three placements were delivered to each, 405 placements in total. Job coaches assessed skills and abilities, work related support needs and job preferences before and after job placement using standard checklists. Employers rated performance in a number of areas after placement using postal questionnaires. Results: Young people reduced support needs and improved work skills over time. Employers reported high satisfaction rates but accounts differed to job coaches. Young people preferred jobs changed over time but did not always reflect placement experiences. Conclusions: Job coaches focusing on key performance areas appears to drive positive employer satisfaction and to focus young people’s employment task choices. Supported work experience with a learning goal can contribute in transition. Implication for practice are discussed.

Dimensions of culture in underperforming and better group homes for people with severe intellectual disabilities

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Aim: Culture is identified as an important variable influencing the quality of life of people with intellectual disabilities in supported accommodation services. We aimed to identify differences in culture between underperforming and better services. Method: In-depth qualitative case studies over an extended period were conducted in five underperforming and three higher performing services using participant observation, interviews and document review. Results: The culture in all services fell along five dimensions; alignment of power holder values, respect for service users, perceived purpose, working practices and orientation to change. Connections between some aspects of culture and good outcomes were evident, e.g. strong alignment of leaders and staff with organisational values in better group homes. However, some aspects of working practices, e.g. strong committed relationships, and perceived purpose, e.g. inclusion in social milieu rather than through engagement may hinder good outcomes in better services. Conclusions: Further study is required to identify if culture differs between better and good group homes. By understanding the nature of culture associated with better quality of life outcomes this study contributes key knowledge to guide service development.

Implementation of active support over time in Australia

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Aim: Research indicates the value of implementing active support in terms of outcomes for those supported, however, doing so is not easy, and little research has explored why. We aimed to identify some of the factors that impact on the implementation of active support over time in supported accommodation services. Method: Data on the quality of active support, staff training and practice leadership were collected through staff questionnaires, observations and manager interviews, for between two and four year across six organisations. Analysis included change over time and the relationships between quality of support, training, practice leadership and other organisational factors. Results: The quality of support improved over time for people who were more able, but not necessarily for people with higher support needs. There was a weak positive correlation between active support and practice leadership scores over time, and the percentage of staff reporting active support training. Conclusions: The importance of recognising the influence of practice leadership and staff training on quality of support and building provision of these into funding schemes is discussed.

Does the model matter?: Comparing outcomes for people with intellectual disabilities in ‘supported living’ and group homes

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Aim: Group homes have been the dominant model of service. The NDIS holds the promise of greater choice about where and how to live through ‘supported living’ which separates housing and support. This study explored quality of life outcomes for a matched sample of people living in group homes or supported living arrangements. Method: Thirty-four people with intellectual disabilities in supported living and seven staff from organisations delivering support participated: 28 people and their support staff in face-to-face surveys and six in more in-depth case studies. Twenty-nine were matched with a sample of group homes residents from an earlier study. Results: People felt moving from their family or
a group home into supported living gave them greater independence and control. Objectively their quality of life was mediocre and similar to people living in group homes. Being younger, strong family support and participation in regular structured activities were associated with better outcomes.

**Conclusions:** The data provides insights into the perceived advantages of supported living, the potential for it to work well and some of the challenges.

**Development of an evidence-based support for a decision-making practice framework to guide decision-making supporters of people with intellectual disabilities**

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**Aim:** Pending law reform about supported decision-making, potential exists to enable people with intellectual disabilities (ID) to participate more in decisions through developing their skills and experience, and increasing the skills and expectations of supporters. As the first stage in developing effective evidence-based training for decision-making supporters we developed and piloted a conceptual practice framework and training package. **Method:** Drawing on prior empirical studies about practice, processes and dilemmas of decision-making support, we conceptualised factors underpinning effective support and trialled training based on these with three staff groups from a service for people with ID. Analyses of session field notes were used to refine the framework. **Results:** The conceptualisation of seven common steps in support for decision-making processes, decision-specific strategies and underpinning support principles of commitment, orchestration and review and reflection resonated with staff involved in training who suggested it helped them understand tasks involved in support. **Conclusions:** More rigorous data is now required to demonstrate the effectiveness of this practice framework and associated training and the impact on the practice of decision-making supporters.

**Models of delivering decision-making support to people with intellectual disabilities in Australia**


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**Aim:** The UNCRPD has generated considerable debate about strategies such as supported decision-making that will enable people with cognitive disabilities to participate more fully in the decisions that affect their own lives. While legal reforms are being explored, several pilot projects have experimented with various models of delivering decision-making support that is based on a rights perspective to people with intellectual disabilities (ID). **Method:** A critical review was conducted of the program documents and evaluations of pilot supported decision-making projects undertaken in Australia from 2010 to 2015. **Results:** The pilots conducted by both statutory and non-statutory bodies are all small, have taken very different approaches to supported decision-making and targeted different sub-groups of people with ID. All projects claim positive outcomes for participants and most have experienced challenges in identifying supporters and the follow through of decisions to action. **Conclusions:** The variable depth and rigor of evaluation and absence of common measures or data on participant
exploring difficult behaviours in young children with tuberous sclerosis complex

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aim: behavioural difficulties, such as self-injury and aggression, are widely reported in tuberous sclerosis complex (tsc). this follow-up study investigated difficult behaviour onset, which may be associated with autism spectrum disorder (asd) and limited verbal ability. method: behavioural data at time one were collected from children 18 months to 4 years of age. caregivers completed behavioural questionnaires and a measure of adaptive functioning. each child completed a cognitive assessment (mullen scales of early learning), a social communication assessment (autism diagnostic observation schedule-2), and a behavioural pain assessment scale. results: of the 17 children seen to date, 11 children were non-verbal (65%), and the majority showed self-injury (n=9; 53%) or physical aggression (n=12; 71%). nine out of 15 children were at risk of, or met the clinical cut-off scores, for asd or autism. conclusions: at time one; some children displayed difficult behaviours, or characteristics that may pre-empt them. it will be of clinical relevance to investigate how these behaviours develop at time two, and which characteristics should be the target of a difficult behaviours early intervention for children with tsc.

profiling the behavioural phenotype of potocki-lupski syndrome

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aim: potocki-lupski syndrome (ptls; dup 17p11.2) is the reciprocal disorder to smith-magenis syndrome (sms; del 17p11.2). whereas sms has a striking behavioural phenotype, ptls, including autism spectrum disorder (asd) prevalence, is less well defined. method: caregivers of individuals with ptls (n = 34; m age = 12.43, sd = 6.78) completed online behavioural questionnaires. individuals with ptls were matched on age and adaptive functioning to individuals with sms and individuals with idiopathic asd from an existing dataset. results: self-injury and property destruction were less common in ptls and asd compared to sms. regarding asd symptomatology, individuals with ptls and sms were both less impaired than individuals with asd on communication and reciprocal social interaction, but did not differ from individuals with asd on restricted, repetitive and stereotyped behaviours. specifically, both individuals with ptls and asd scored higher than individuals with sms on the compulsive behaviour subscale of the repetitive behaviour questionnaire. conclusions: ptls does not appear to be characterised by challenging behaviour, communication deficits or social interaction deficits. however, repetitive behaviours may be characterised specifically by compulsive behaviours in ptls.

positive psychological outcomes among parents of adolescents with asd, with and without id

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Aim: To determine whether dispositional optimism buffers against adverse parent outcomes related to adolescent behaviour disorders. **Method:** Participants were adolescents and their mothers, assessed at youth ages 13 and 15 years. Youth had typical development (TD, n = 88 IQ >84) or autism spectrum disorder (ASD, n = 47, across the IQ spectrum). An earlier study of this sample found ASD group CBCL scores unrelated to IQ. Measures included CBCL scales, parenting stress (Family Impact Questionnaire), and mother’s health and dispositional optimism (Life Orientation Test). **Results:** At age 13, the ASD group scored significantly higher than the TD group on CBCL scales (e.g. total, ADHD, anxiety), though mothers’ optimism did not differ. Predicting mothers’ well-being at age 15 from the age 13 CBCL scores showed optimism to buffer negative relationships. For example, mothers’ stress at 15, while positively related to all child CBCL scales at 13, was also significantly inversely related to optimism assessed at 13. **Conclusions:** While youth with ASD have higher behaviour problems, and their mothers report heightened stress, higher dispositional optimism (positive outlook on life) lessens this relationship.

**Risk and protective factor-based case formulation using the ARMIDILLO instruments**

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**Aim:** the ARMIDILLO-S and G are commonly known as risk assessment tools designed for individuals with intellectual functioning limitations, however that is only part of the usefulness of these instruments. The word ‘manageability’ in the title of these instruments denoted the client’s ability to manage his (or her) dynamic risk and protective factor issues in the context that is being considered for the assessment. This paper describes how these factors can be utilised together in a balanced approach to case formulation that will enhance both intervention and case management. **Method:** The process of case formulation using the ARMIDILLO involves the consideration of risk and protective factors inherent to the individual and their environment to provide an overview of the current issues to guide intervention and management priorities. **Results:** The case profiles show a risk and protective factor-based case formulation enhances client manageability and reduces risk. **Conclusions:** The premise of this paper is that risk and protective factor-based case formulation can enhance client manageability, intervention effectiveness, and case management efficacy.

**Bright-study: Sleep problems and light exposure in older adults with intellectual disabilities**

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**Aim:** Sleep problems are observed in 72% of older adults with intellectual disabilities (ID). Little is known about the severity and cause of sleep problems of this population. Too little or badly timed exposure to (day)light causes a disrupted circadian rhythm. It is hypothesized that inadequate exposure to light might be a reason for the frequent sleep problems in older adults with ID. **Method:** Two studies are presented. The first study compared sleep data (Actiwatch) of two epidemiological studies, the Ha-ID study measuring the severity of sleep problems in 501 older adults with ID and the Rotterdam-study providing data on sleep in 1462 older adults in the general population. The second study measured light exposure (HOBO-dataloggers), sleep and sleep problems (Actiwatch 2) in older adults with ID living in a
healthcare facility. **Results:** Results of both studies are expected in June 2016. **Conclusions:** Insight into the severity and cause of sleep problems in this population is a first step in prevention of these problems.

**Synthesising existing knowledge on the experience of grief for people with intellectual disabilities: Findings from a systematic review**

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**Aim:** Despite increasing research on grief and bereavement in intellectual disabilities (ID), there has yet to be a high level synthesis of the knowledge gained from this research. This project synthesizes research published between 1999 and 2015, with a focus on the experiences of people with ID. **Method:** In line with PRISMA guidelines, a systematic review was developed to search articles included in three commonly used electronic databases (PsycINFO, Cinahl MEDLINE). The search string included variants of ‘intellectual disability’ and grief and bereavement. All abstracts/papers were reviewed by two researchers. **Results:** The search identified 506 abstracts, with 311 eligible for full text screening. Of these papers approximately 65% were identified as relevant to the present study. The most common studies examined individuals’ experiences of other deaths though a small number (based in palliative care) considered the experience of their own approaching death. **Conclusions:** Given the body of knowledge that has been generated in relation to bereavement, this systematic review will allow for key messages to be identified.

**Behaviour problems profiles of young children with autism: Parent and teacher perspectives**

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**Aim:** This study examines separate categories of mental health disorders in young children with autism spectrum disorder (ASD), as assessed by parents and teachers. **Method:** Parents and teachers of 109 children with autism spectrum disorder (M = 4.49 years of age; IQ M = 86.95) completed the Child Behavior Check List. Syndrome scales were subjected to latent class analysis. Children were classified as having either clinically significant or normal levels of problem behaviours. **Results:** Latent class analysis revealed two classes in the parent model: one group of pure withdrawn symptoms and one group of withdrawn behaviours, attention problems, and somatic complaints. In contrast, only one class emerged in the teacher model with an absence of atypical behaviour problems. **Conclusions:** These results suggest that children with ASD in this age range may demonstrate more withdrawn behaviours than externalizing behaviours. Additionally, parents and teachers provide inconsistent reports of co-morbidities. Further analysis will include covariates of autism severity in the model to determine changes in the latent class distribution based on effects of core diagnostic features on problem behaviours.

**Select findings from the National Core Indicators Adult Consumer Survey**
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Aim: Describe selected outcomes measured in the National Core Indicators (NCI) project in the United States of America. NCI is a continuing quality assurance effort and a systematic approach to measure Developmental Disability systems performance and outcomes for service recipients across US states.

Method: The NCI Adult Consumer Survey (ACS) is administered in a face-to-face interview with adults with intellectual and developmental disabilities and people involved in their lives. The survey is administered yearly in participating states to a representative sample of adults receiving one service in addition to case management. Data are aggregated and analysed for state-level reporting. Results: The 2014-15 ACS data cycle represents approximately 26,000 service recipients from 33 states. Analyses presented will include demographic characteristics of the sample, health and employment measures, measures of community integration, and analyses of outcomes by demographic characteristics.

Conclusions: NCI data provide insights regarding service access and outcome to developmental disabilities governmental agencies and other stakeholders, as well as providing useful data to the developmental disabilities research community.

Using National Core Indicators to measure compliance with the articles of the United Nations Convention on the Rights of Persons with Disabilities

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Aim: To assess the application of system level quality of life data collected through the National Core Indicators (NCI) to the measurement of similar domains in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

Method: The NCI Adult Consumer Survey (ACS) has been validated to assess subjective quality of life indicators for people with intellectual and developmental disabilities (IDD). NCI domains and indicators were cross-walked with articles of the UNCRPD. Results: The NCI can be used by countries to monitor progress towards a greater goal of enhanced quality of life for individuals with IDD, as defined by the UNCRPD. Indicators measured in the NCI ACS can be used to monitor a country’s progress towards fulfilling Articles 9, 14, 19, 25, and 27 of the Convention. Next steps will also be discussed. Conclusions: States and nations require a consistent means to monitor the alignment of individual experience in the aggregate with aspirational goals in the UNCRPD.

A systematic review of oral health interventions to reduce disparities between people with intellectual and developmental disabilities and the general population

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Aim: To rigorously examine the evidence for oral health interventions for their potential to improve oral health outcomes and reduce disparities for people with intellectual and developmental disabilities (IDD).

Method: A systematic search of online databases along with grey literature sites was conducted using a search string designed to capture a wide range of interventions in articles published from 1990 to 2013. Over 4,000 titles and abstracts were reviewed, followed by full text review to confirm the population and the presence of an intervention and outcomes resulting in a set of 120 articles which were extracted.
into an online and publicly available systematic review data repository and subsequently analysed.

**Results:** The interventions were categorised into four categories: sedation, education/behaviour, prevention, and access. Only 19% of the articles were randomised controlled trials and 5% were randomised with no control, however the majority included in the review were rated of ‘good’ quality from clinical and biostatistician review. **Conclusions:** There is an emerging body of evidence of successful interventions to reduce disparities and improve oral health outcomes. Future research suggestions will be discussed.

**Perspectives and approaches of inclusive university educators**

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**Aim:** Opportunities for people with intellectual disabilities (ID) to enrol in tertiary education programs are presenting university lecturers with new challenges in addressing the needs of a diverse group of learners. **Method:** Five university lecturers were interviewed who had experience including students with ID in their units of study. The interviews were video-recorded and analysed to explore inclusive tertiary education from the lecturers’ perspective with a focus on five areas: initial concerns, most effective supports provided, benefits, challenges, and impact on teaching practice. Data were analysed using a constant comparative approach. **Results:** University lecturers’ teaching philosophy and previous experience impacted their perceptions related to the inclusion of students with ID and its impact on their teaching practices. Themes emerged related to lecturers’ teaching perspectives and approaches related to the Universal Design for Learning framework. **Conclusions:** Lecturers’ whose teaching philosophy closely align with the principles of Universal Design for Learning are more likely to approach teaching students with ID as being part of a larger continuum of meeting the diversity of student needs.

**Learning together: Collaborating with other university students**

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**Aim:** There is a need to determine student perceptions and outcomes of collaboration involving university students with and without intellectual disabilities (ID). **Method:** Pre and post attitudinal and self-efficacy surveys, observations, post interviews, and student reflection videos and reports were collected and analysed using a mixed methods approach to examine the perceptions of students’ collaborative engagement during small group service-learning projects. Data were collected from students with ID in a post-secondary program and education students in preservice teacher undergraduate programs enrolled at the same university. Control group survey data were collected from university education students enrolled in the same unit of study who did not participate in the collaborative projects. **Results:** The education students participating in the collaborative projects showed statistically significant improved attitudes and self-efficacy from pre to post survey. The qualitative analysis suggests positive learning experiences and outcomes for students with and without ID who engaged in the collaborative projects. **Conclusions:** Collaborative service-learning projects are a promising strategy for promoting positive attitudes toward ID and supporting learning outcomes.
Systematic multidisciplinary medication reviews for older people with intellectual disabilities and polypharmacy in primary care

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Aim: A systematic multidisciplinary medication review in older people with intellectual disabilities (ID) and polypharmacy is recommended, but often not implemented. Explanations are lack of awareness, competence and scientific evidence. If implemented, people with ID are often not actively involved.

Method: 11 trained general practitioners, together with pharmacists and ID physicians conducted the systematic medication review adopted from geriatric healthcare practice in 34 patients with ID and polypharmacy, aged ≥ 35 years. The method consists of five steps: pharmaceutical history with active involvement of patient; identification of potential drug related problems; pharmaceutical intervention plan; informed consent; intervention and follow-up. Qualitative assessment was obtained through semi-structured interviews.

Results: The identified drug-related problems created awareness and evidence for medication reviews in older people with ID. The input of the ID physician was most valued for communication qualities and knowledge on drugs acting on the nervous system. Involvement of the person with ID positively influenced the view of caregivers on active participation. The main barrier was time investment.

Conclusions: The implementation of medication reviews provides valuable benefits.

Dexterity as a marker of neuropsychiatric conditions in adults with 22q11.2 deletion syndrome

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Aim: 22q11.2 deletion syndrome (22q11.2DS) is a common multisystem disorder associated with intellectual disabilities. Prominent features include a one in four risk of developing schizophrenia, and an increased risk of developing early-onset Parkinson’s disease (<50 years). In this study, we systematically assess motor performance in adults with 22q11.2DS, who may also be susceptible to other movement disorders.

Method: 22 adults with 22q11.2DS (mean age 28.9 years; 72.7% female), free of medication that influences dopaminergic neurotransmission, and eleven healthy controls (mean age 28.8 years; 45.5% female) have participated to date. All participants performed an index finger tapping task and the Purdue Pegboard Test.

Results: Adults with 22q11.2DS showed significantly lower finger tapping rates (dominant hand: p<0.01, non-dominant hand: p=0.01) and worse performance on the Purdue Pegboard Test (dominant hand: p<0.001, non-dominant hand: p<0.001, both hands: p<0.001).

Conclusions: These preliminary findings suggest that there are dexterity deficits in adults with 22q11.2DS. The results of this study may help to identify patients at high risk for schizophrenia or Parkinson’s disease, and may contribute to our understanding of the pathogenesis of these disorders.

Why are their physical activity levels so low?: An overview of the literature into the facilitators and barriers to physical activity in people with intellectual disabilities

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Aim: It is generally acknowledged that being physically active is important for people with intellectual disabilities (ID) because of the positive effects on physical and mental health. However, physical activity seems to be a minor part of the support provided to people with ID, especially to those with severe or profound ID. This study provides an overview of the facilitators and barriers to physical activity in people with ID. In addition, differences between direct and proxy reports were explored. Method: A systematic review was conducted using three databases (PsychINFO, ERIC, MEDLINE). All research papers were subjected to narrative analyses. Results: 22 papers investigating facilitators and barriers to physical activity in people with ID were included. Facilitators and barriers were identified in the physical activity itself, the individual with ID, the support offered and in the organisation, resources and environment. A discrepancy between direct and proxy reports was found. Conclusions: Gaps were identified in the literature suggesting the need to identify the facilitators and barriers to physical activity for people with the more severe ID and their direct support persons.

To activate or not to activate: Direct support persons’ experiences in the motor activation of people with profound intellectual and multiple disabilities

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Aim: Motor activation of persons with profound intellectual and multiple disabilities (PIMD) in daily practice is rather limited, notwithstanding the obvious benefit. Given the needs of people with PIMD, direct support persons are to a great extent responsible for including motor activation in their daily work routine. The facilitators and barriers to the motor activation of people with PIMD specifically for direct support persons are as yet unknown. This study explored facilitators and barriers related to motor activation of people with PIMD. Method: Semi-structured interviews (n = 20) were conducted with direct support persons of people with PIMD working in the Netherlands. Interviews were recorded, transcribed verbatim and analysed thematically. Results: Direct support persons underline the motor inactivity in people with PIMD. Preliminary findings suggest that barriers include the high degree of dependency of individuals with PIMD, not knowing what to do or how to motivate colleagues. Conclusions: Barriers perceived by direct support persons need to be taken into account in developing feasible interventions.

Protection and limitation: Experiences of the context that impact the mental health of young persons with intellectual and developmental disabilities

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Aim: To explore subjective mental health and ill-health and how these are related to the family, school and peer-relations in adolescents with intellectual and developmental disabilities (IDD). Results from in-depth interviews were used to explore the validity of self-reports through a questionnaire. Method: 10 students from special education, aged 13 to 17 years answered the Well-being in Special Education Questionnaire and participated in semi-structured interviews. Data were analysed using a mixed methods approach. Results: In both qualitative and quantitative reports the emphasis was mostly on positive emotions and good mental health. Students described the environments of school and family as
inclusive contexts experienced as both protective and limiting. Social interaction with peers was supported within the context of special education, but limited beyond its borders. **Conclusions:** Using well adapted research instruments enables students with IDD to communicate experiences of mental health and how it is related to aspects of their everyday environment.

**The role of practice leadership in active support: Impact of practice leaders’ presence in services**

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**Aim:** Research shows practice leadership to be a factor for successful implementation of active support. We explored differences in staff practice, associated with the presence of a practice leader in a service.

**Method:** Quality of support and engagement for 189 service users with intellectual disabilities from 58 services were collected during a 2-hour observation, using the Engagement in Meaningful Activities and Relationships and the Active Support Measure. The practice leader was present in 19 services (n=59) and absent for 39 (n=111). An observed measure of practice leadership was administered during a second visit to each service. **Results:** When the practice leader was present, levels of engagement (p<0.01) and active support (p<0.001) were statistically higher. Though measured at a different time, observed practice leadership was also higher in services where the practice leader was present during the first observation. **Conclusions:** The level of observed practice leadership and presence of the practice leader appear to be associated with better quality of support. This provides further evidence of the importance of systems for supporting, monitoring, modelling and improving staff practice for effective implementation of active support.

**Social approach and avoidance behaviours: A comparison between Williams syndrome and social anxiety disorder**

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**Aim:** With their contrasting social-behavioural profiles, Williams syndrome (WS) and social anxiety disorder provide a unique opportunity to explore the role of neuropsychological functioning in social approach and avoidance behaviours. This study utilised novel questionnaires and performance-based tasks to explore group differences in approach/avoidance ratings and behaviours; it also considered within-syndrome heterogeneity. **Method:** 60 participants (15 with WS, 15 with social anxiety disorder, 15 neurotypical adults, 15 neurotypical children) completed a range of questionnaire and performance-based measures designed to investigate approach and avoidance. Cross-syndrome differences as well as within-syndrome variation was explored. **Results:** Significant cross-syndrome differences in approach and avoidance were observed, with individuals with WS exhibiting an increased bias towards positive social stimuli and heightened approach behaviours, when compared to individuals with social anxiety disorder. However, interesting similarities in approach ratings were found across groups and there was significant within-syndrome variability. **Conclusions:** Practical and methodological implications of the findings are discussed and an emphasis is placed on the value of cross-syndrome comparisons and of exploring individual variability.
Long-term survival in Western Australian children with intellectual disabilities

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Aim: To calculate long-term survival rates for children with intellectual disabilities (ID) and determine if they had increased mortality risk compared to children without ID. Method: Information from the Midwives Notification System, the IDEA (Intellectual Disability) database, and the Mortality Database was linked for children born in Western Australia from 1983-2010. Children with ID were classified by their level of ID as mild, moderate, or severe. Kaplan-Meier estimates and 95% confidence intervals (CI) were computed by race. Hazard ratios (HR) and 95% CIs were calculated from Cox-Proportional Hazard Regression models after adjusting for potential confounders. Results: Overall 25-year survival for children with ID was 95.1% compared with 99.2% for children without ID. 25-year survival was lower for children with severe ID (76.5%), compared with mild-moderate ID (96.9%). Aboriginal children with ID had similar 25-year survival (95.4%) to non-Aboriginal children with ID (95.1%). After adjusting for covariates, children with ID had an increased risk of mortality (HR=5.6, 95%CI 4.8-6.4) compared to children without ID. Conclusions: Children with ID have lower long-term survival than children without ID.

Supporting participation: Facilitating inclusion of rural Australians aging with intellectual disabilities in research using validated survey tools

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Aim: To determine the feasibility and costs of supporting rural people aging with intellectual disabilities (ID) to complete validated survey tools. Method: Community-based organisations in rural New South Wales identified eligible survey participants, defined as people aged over 59 living in the community either with or without life-long ID. Tools included SF12, Duke Social Support Index (DSSI) and Cummins’ Personal Wellbeing Index. Online and paper-based surveys were completed by the mainstream cohort. A pilot indicated participation by people with ID was only feasible through 1:1 interviews due to language complexity in some tools. Results: Researchers surveyed 70 people with ID from 12 geographically diverse towns, with 164 age-peer surveys independently completed. Costs of survey administration were calculated for each mode. Excluding researcher salaries, the average cost of collecting the rural ID cohort was $101.33 and $11.96 for age-peer paper surveys. Conclusions: Supporting the inclusion of rural people aging with ID in research using validated survey tools is both feasible and desirable. Recommendations include that projects consider the cost and methodological impacts of each mode during design.

Using the National Core Indicators (NCI) to measure the implementation of new federal rules on inclusive service settings in the United States

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Aim: To assess of the application of system level data collected through the National Core Indicators (NCI) to determine state and national performance in meeting the new federal requirements. The new rule mandates that states assess all funded settings and gives states 5 years to bring settings into conformance. Method: An initial crosswalk using NCI domains and indicators and the provisions of the new rule was drafted. The crosswalk was then reviewed by the staff of the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and by the NASDDDS Research Committee comprised of state directors and researchers. Results: The review indicated that of the 27 requirements in the new rule, NCI data was useful for monitoring compliance for 15, partially useful for 9, and not useful for 5. Conclusions: NCI domains and indicators provide a means to assess compliance with significant aspects of system change; specifically change that provides more individual choice, community inclusion, and self-determination.

Benefits of training occupational therapists on low cost assistive technology

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Aim: Occupational therapists (OT) can play critical roles in the lives of individuals with disabilities. They help individuals gain, improve or maintain skills for day-to-day activities and well-being. To accomplish this, an OT seeks a match between the skills and abilities of a person with available assistive technologies (AT). AT may include tools for memory, behaviour management, mobility, hearing, sight, and communication. While AT identification is often a significant part of their jobs, therapists reported having less-than-adequate training and a lack of confidence in delivering services. Low-tech AT devices often are assessed most useful because they tend to be less expensive and easier to obtain. Method: The ‘I Am a Gadget Geek’ pilot trained 187 OT over a two-year period in low-cost AT solutions. Pre/post data were collected to measure perceptions, knowledge and skills on low cost AT recommendation and delivery. Results: Therapists benefited from AT training and felt better prepared to serve their patients. Conclusions: Their increased knowledge and skill can have a benefit for individuals with intellectual and developmental disabilities.

Language development in autism spectrum disorder

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Aim: Language difficulties are common in autism spectrum disorder (ASD). This study described phenotypes, trajectories and outcomes of early language development in ASD in a population-based cohort; and systematically reviewed childhood language outcomes in ASD. Method: Language trajectories in the Early Language in Victoria Study (ELVS, n=1917, n with ASD=50) were mapped at 4, 5 and 7 years. ASD trajectories were compared to language impairment and typical language subgroups. Language outcomes in ASD were also systematically reviewed using a comprehensive database search and well-established methods for prognosis studies. Results: Trajectory data from ELVS demonstrated variability in language outcomes. The systematic review (n=6130) revealed 60 studies of interest. The proportion of verbal individuals with ASD increased over time with 55-91% acquiring verbal language at outcome. Eighty-percent of studies reporting standardised language scores found children with ASD
made gains at a comparable rate to peers without ASD, despite having lower mean scores at baseline. **Conclusions:** Language development in ASD is complex and heterogeneous. Participant and methodological variability and a lack of population-based studies examining language outcomes mean results are difficult to interpret at an individual level.

**The relationship between social support and physical activity for adults with intellectual disabilities**

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**Aim:** Researchers in the health promotion and disability fields have rarely attempted to understand the relationship between physical activity and social support among adults with intellectual disabilities (ID). This study explored the facilitators and barriers to physical activity in the company of others and to develop a more nuanced understanding of social support for adults with ID. **Method:** Seven adults with ID participated in multiple in-depth interviews, participant observation and photovoice over a six-month period to explore their physical activity and social support in their day-to-day lives. **Results:** Among preliminary themes identified through analysis of data collected, two factors were highlighted that facilitated physical activity: formal opportunities for physical activity and social support provided by organisations, and the influence of family when choosing which organisations to engage with. **Conclusions:** The wider social and organisational environment may play an important role in opportunities for adults with ID to be active. In particular, formal supports play a role in the development and support of social networks through formalised physical activity opportunities.

**Retirement as the solution: Retirees with intellectual disabilities share their experience of retirement from mainstream employment**

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**Aim:** Following 30 years of Disability Employment Services in Australia, there are now people with intellectual disabilities (ID) who have retired after a successful working life in mainstream jobs, working alongside co-workers without disability. Part of a larger study exploring the transition to retirement for workers with ID, this paper reports on the process and experience of retirement from the perspective of retirees with ID. **Method:** Semi-structured interviews were undertaken with five retirees with ID previously supported by a Disability Employment Service to participate in the mainstream workforce for over 20 years. Data from interviews and file records were analysed using grounded theory methodology. **Results:** Retirement happened as a solution to problems experienced with health or transport. Retirement decisions were made in conjunction with family and staff from employment and accommodation services, with participants reporting varying levels of self-determination in the process. Participants reported mixed feelings about their current retirement lifestyle. **Conclusions:** There is a need for retirement preparation for this emerging population to support self-determination in retirement–related decisions and individualised support for ongoing participation in the mainstream community once retired.
Caring for adults with intellectual disabilities and type 2 diabetes: The experiences of professionals

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Aim: People with intellectual disabilities (ID) are increasingly presenting with diabetes and require treatment and care to manage their condition from a range of professionals. This study explores the experiences of professionals in providing person-centred diabetes care and support. Method: Qualitative semi-structured interviews were conducted (n=30) with professionals from primary care diabetic services, learning disability services and community support workers, and were thematically analysed. Results: Professionals have limited education, knowledge and skills of the needs of this group and face barriers in relation to communication, capacity and consent to treatment, making adjustments to meet care needs, managing diabetes, and lack networks with other professionals involved in care. ID services lack knowledge about diabetes and of minimising complications. Community support workers play a role in supporting people to access diabetic care and need further education and support. Conclusions: Professionals need joint education and development about type 2 diabetes to share practice and provide better support. Models of collaborative working need to be developed in the future to meet future population needs.

Eye movement desensitisation and reprocessing (EMDR) for DSM 5 post-traumatic stress disorder (PTSD) in adults with intellectual disabilities: A case study review

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Aim: People with intellectual disabilities (ID) may be at a greater risk for exposure to traumatic events and consequently develop post-traumatic stress disorder (PTSD). Although eye movement desensitisation and reprocessing (EMDR) is an established treatment for PTSD in the general population, research involving people with ID is limited. This review aims to critically appraise case studies published in this area, as no controlled investigations are available at present. Method: Nine databases were systematically searched for literature from 1987 to October 2014. Case studies were then reviewed in terms of methods of assessing PTSD and trauma histories, and delivery of EMDR therapy in order to establish the usefulness and acceptability of this intervention for people with ID. Results: Six case studies were identified from peer-reviewed journals describing EMDR therapy for psychological trauma in 14 adults with mild to severe ID. Overall results indicate that EMDR is an acceptable intervention for people with ID. Conclusions: There is now sufficient evidence to conduct a randomised controlled trial to establish its effectiveness in this population.

Findings from the pilot implementation of the Early Response Tool

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Aim: To pilot the use of a Screening Tool and an Early Response Tool (ERT), to provide targeted supports to families at-risk of relinquishing the care of their children with a disability. Method: 11 parents raising a child with a disability completed the full-scale ERT; a desktop audit using the full-scale ERT was rated
for another 30 families and the screening tool was completed for a total of 58 families. Feedback was also sought from the staff who administered the tools. **Results:** Feedback on the measures was positive, with some minor changes proposed to the items. The ERT interview generally took between 1.5 to 3 hours, with practitioners indicating the process supported an in-depth understanding of family strengths and challenges which may lead to a better targeting of supports to meet family needs. **Conclusions:** These findings support the face validity of the ERT measures. Relevant procedural changes to the tools have been implemented to improve their usability for staff and parents. An evaluation of the ERT measures is now required.

### The process of supported decision-making: a Canadian model

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**Aim:** Research was needed to understand the process of how people with intellectual disabilities (ID) are supported with decision-making in the context of legal frameworks that recognise supported decision-making. This study explores the experiences of seven people with ID and their support networks engaging in supported decision-making in Canada. **Method:** A grounded theory analysis, using 100 hours of observation and 34 in-depth interviews, led to the development of a model outlining the supported decision-making process. **Results:** Supported decision-making is complicated and highly individualised. Despite the range of approaches supporters take to providing support, there are common elements that define the supported decision-making process. At the centre is negotiation of need and influence. In the context of support relationships, the way supporters perceive and respond to a person's need for decision support mediates their involvement and influence in the decision-making process. **Conclusions:** A greater understanding of the process of supported decision-making will enable decision supporters to engage in more thoughtful and reflective supported decision-making practice.

### Exploring school spaces and subjectivities through an ableism lens

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**Aim:** Based on the insider perspective of students, the project ‘Inclusive Spaces’ aims to generate knowledge that contributes to foster social cohesion and successful inclusion at mainstream schools. **Method:** Data were gathered through photovoice interviews, conducted with 45 students of so called ‘integration classes’ of secondary schools in Vienna. Data were analysed following a grounded theory approach. Social space theory, ableism and subjectivation were employed as sensitising concepts for reading the data. **Results:** Findings illustrate the impact of educational spatial regimes on students’ subjectivities. Results show how specific spaces in classrooms are structured by ableist discourses and practices of special education needs support teachers. The interlinked discourses are re-cited in other spaces of schools, such as playgrounds and floors, marginalizing students with special education needs and forcing them to embrace an identity as inferior other. **Conclusions:** Teaching all students in one classroom is regarded as key to achieve inclusion. However, results show that teachers need to be aware of their spatial practices and the underlying normative basis, as it affects deeply peer relationships and students’ subjectivities.
Inclusive research on inclusive education? Involving students of ‘integration classes’ in research on their schools

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Aim: This participatory research project aimed to co-construct knowledge of schools spaces with students of so called ‘integration classes’ in Vienna. Method: Within the project, students were taught to conceptualize and conduct quantitative and qualitative research – in a way that tried to respond to the differing abilities of the young researchers. Data were analysed together, using different techniques of visualisation and categorisation of the data. Furthermore, adult and co-researchers developed creative methods together, such as exploring school spaces by playing hide and seek. Results: Researching inclusively with students with different abilities, ethnic backgrounds and class privileges requires a high level of reflexivity and sensitivity as well as time and personal resources. Adapting and creating methods in order to enable all young people to participate in research proved to be a key challenge. Results show that this approach was able to generate valuable insights into the ‘hidden spaces’ of schools and empowered students in their school environments. Conclusions: Inclusive research on inclusive education provides a great potential that should be explored further.

Experiences of healthcare professionals in treating adults with intellectual disabilities and psychological trauma

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Aim: People with intellectual disabilities (ID) who have experienced psychological trauma are receiving support by a range of healthcare professionals following referral to services. This study explores the experiences of healthcare professionals when treating adults with ID and psychological trauma. Method: Semi-structured interviews collected the views of 14 clinicians drawn from a range of professions across four National Health Service boards in Scotland. Interview transcripts were then subject to thematic analysis. Results: Whilst involvement in trauma treatment differed according to professional discipline, all healthcare professionals described a desire to increase multidisciplinary working. Themes were aligned with treatment stages and have been identified as follows; the assessment process, searching for treatment options, providing individualised care, and the challenge of misconceptions. Conclusions: Study findings highlight the need for further professional development so that clinicians are able to identify psychological trauma in people with ID and increase the number of specialist treatment options available.

The effects of linguistic simplification and mediation on the comprehension of adapted (‘easy read’) text by people with intellectual disabilities: A randomised experiment

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Aim: A quasi-experimental 2X2 between subjects factorial design was used to test the effect of linguistically simplified text and literacy mediation on the construction of meaning from ‘easy read’ health-related information. Specifically, the study aimed to answer: What effect does linguistic complexity and literacy mediation have on the reading comprehension of ‘easy read’ information by people with intellectual disabilities (ID)? Method: Sixty adults with ID undertook The Easy Read Task, each allocated to one of four conditions (with and without simplified language/with and without mediation). Analyses of variance (ANOVA) were conducted on the data, testing for main effects of linguistic complexity and mediation on comprehension. Results: Neither linguistic complexity of the text nor mediation independently or combined made a significant difference to the understanding of information. However, when receptive vocabulary was controlled using analysis of covariance (ANCOVA), a significant interaction was present between simplified text and mediation. Conclusions: Constructing meaning needs to extend beyond a consideration of form as found in ‘easy read’ documents to address a better understanding of the relevance of individual capacity for language processing.

Easy Read: simplification or reduction? Critical differences in the discourse of UK Department of Health adapted ‘easy read’ literature for people with intellectual disabilities and their ‘non-easy read’ equivalents

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Aim: This study investigates the critical differences between linguistically simplified documents produced mainly (although not exclusively) for people with intellectual disabilities (ID) commonly known as ‘easy read’, and their ‘non-easy read’ equivalents, both published by the Department of Health in the UK. Method: A systemic functional linguistic framework was used to examine five sets of paired document excerpts, identifying ideological and interactional aspects through referential, interpersonal and textual functions. Results: Common trends in differences between the two sets of data were revealed. Expressions of participant roles and actions denoted a more direct form of communication in the ‘easy read’ versions, along with strong conditionality and clear power differentials. A similar representation of power differential was found to be dominant in the positioning of author and reader, and weaker patterns of cohesion and coherence were evident in the structure of ‘easy read’ texts. Conclusions: The implications of these findings frame a range of possible suggestions for reversing these trends.

The meaning of ‘disability’ in rural Kenya

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Aim: How disability is viewed and understood is variable in low-income countries and may be associated with neglect, mal-treatment and abuse. The aim was to explore the local conceptualisation of disability and associated challenges across communities in a rural part of Kenya. Method: Focus group discussions were conducted with 20 community groups (10 women’s groups; 10 community health worker groups). A topic guide was used to explore participant views. The group discussions were audio-recorded,
uploaded to computer and transcribed. Thematic analysis was carried out. **Results:** Three main themes defined perceived causation of disability: cultural superstitions; the will of God; and organic causes. Cultural superstitions included unacceptable family relations and supernatural visitations. The ‘will of God’ attributed disability to a higher power. Organic causes revealed knowledge of pre-, peri- and post-natal conditions associated with disability. Challenges associated with disability focussed on communication, home economy, the family, knowledge and understanding, personal well-being and physical access. **Conclusions:** The findings were consistent with reports from other low-income countries.

**Prevalence and predictors of osteoporosis risk among older adults with intellectual disabilities in Ireland**

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**Aim:** To describe the objectively measured prevalence of osteoporosis among older adults with intellectual disabilities (ID) and the contributing risk factors. **Method:** The sample was drawn from the Intellectual Disability Supplement to the Irish Longitudinal Study on Aging. Bone quality was measured by quantitative ultrasound. Binary logistic regression analysis was performed to determine the significance of literature supported predictors for poor bone quality. **Results:** In total, 575 participants had ultrasound performed. The prevalence of osteoporosis was 41%. The full model containing all predictors was statistically significant, $X^2 (15, N=329) = 117.86, p<0.0001$ and explained between 30.1% (Cox and Snell R²) and 41.0% (Nagelkerke R²) of the variance. Only six independent variables made a uniquely significant contribution to the model (difficulty mobilising, severe/profound level of ID, history of fracture, older age and antiepileptic medication) with the strongest predictor, mobility difficulty, recording an odds ratio of 3.68. **Conclusions:** There is a need for robust risk assessment and for clinical practitioners to not only consider the obvious risks but also specific concerns for people with ID in order to better target preventative strategies.

**Individual, parent, and social-environmental correlates of caregiving experiences among parents of adults with autism spectrum disorder**

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**Aim:** Parents of adults with autism spectrum disorder (ASD) versus other disabilities experience worse well-being. Thus, it is crucial to identify the individual (e.g., behaviour, intellectual disability status, health), parent (e.g., age, income), and social-environmental (e.g., choice making, community involvement, unmet needs, future planning) correlates of caregiving experiences, including caregiving burden, satisfaction, and self-efficacy, among parents of adults with ASD. **Method:** 130 parents of adults with ASD responded to a survey about caregiving satisfaction, self-efficacy, and burden. Analyses included univariate statistics and hierarchical regressions. **Results:** Greater future planning and community involvement related to more caregiving satisfaction and increased caregiving self-efficacy, respectively. Less choice making of the individual with ASD related to greater caregiving satisfaction and self-efficacy. Maladaptive behaviours and poor health of the individual with ASD related to greater narcissistic tendencies.
caregiving burden. **Conclusions:** Practitioners and policymakers should increase the availability of interventions (e.g., future planning training) which reduce caregiver burden. Longitudinal research about caregivers of adults with ASD to identify other correlates of caregiving satisfaction, burden, and self-efficacy is needed.

**An investigation of the factors that predict the performance of athletes with intellectual disabilities**

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**Aim:** Previous research suggests that IQ alone is not a good predictor of sports performance; however athletes with intellectual disabilities (ID) do not perform at the same level as non-disabled athletes and so compete in the Paralympics. It is hypothesised that one reason for this is the relationship with additional disabilities. **Method:** Health, IQ and performance data were collected for 28 elite, international athletes and 83 regional level athletes with ID. The ICF and WHODAS were administered to provide a rating of range and severity of health impairments and regression was used to explore predictors of sporting performance. **Results:** Total disability scores predicted sporting performance. IQ did not predict performance against a standardised score but did predict category membership. The predictive power of aetiology was explored for athletes with Down syndrome but was found not statistically significant. **Conclusions:** The findings suggest that global IQ is not an important factor in sporting performance, but that its relationship with additional physical disabilities is important. The significance of these findings for the organisation of elite sports for athletes with ID will be discussed.
Activating youth to promote inclusion through sports

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Aim: To understand the impact of student participation in the Special Olympics Unified Strategy through inclusive activities, including sports, and its pathways to positive perceptions and attitudes. Method: A variety of data collection strategies were used. Surveys from 3,380 students with and without intellectual disabilities from 13 United States high schools were obtained, and 228 student and staff interviews were conducted through 11 site visits. Results: 65% of students without disabilities who participated in inclusive sports reported learning they have things in common with their peers with disabilities, and 27% of students without disabilities reported interacting with students with disabilities outside of school. A Generalized Structural Equation Modelling path analysis found that inclusive youth leadership and sports programs create meaningful social interactions between students with and without disabilities. Additionally, 58% of school staff reported reduced bullying. Conclusions: Sports is a key catalyst for social inclusion, as well as attitude and behaviour change. Sports lead to increased interactions, overturn negative attitudes, and increase youth engagement. The combination of these activities can create the tipping point for improved social inclusion among youth.

The relationship between habitual emotion regulation, anxiety, and depression in adolescents and young adults on the autism spectrum

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Aim: Anxiety and depression are among the most common and disabling co-morbid psychiatric conditions in individuals with autism spectrum disorder (ASD). It has been argued that non-autism specific traits might be more important; one such trait is emotion regulation. Emotion regulation strategies such as suppression have been found to be associated with poorer mental health in the general population. This study investigated the relationship between habitual emotion regulation strategies and anxiety and depression symptoms in individuals with ASD over and above age, gender and autism traits. Method: 37 individuals with ASD (12 females; Mean age= 18.59 years, SD=2.37 years) completed the online questionnaires measuring emotion regulation (ERQ), autism symptoms (AQ), anxiety (Cross-D), and depression (PHQ-9). Correlation analyses (Pearson’s r) were conducted using the variables age, gender, AQ score, PHQ-9 score, reappraisal score, and suppression score. Results: Reappraisal was associated with anxiety and depression; suppression was not associated with either. Conclusions: This first study on the relationships between emotion regulation strategies and anxiety and depression in individuals with ASD found cognitive reappraisal to be associated with both anxiety and depression.

A shifting landscape: US legal policy toward parents with intellectual and developmental disabilities after the Gordon case

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Aim: To measure the impact of a 10-year period of concentrated advocacy by the American disability community to secure prohibitions of discrimination against parents with intellectual and developmental disabilities (IDD) and other disabilities by state entities and recognition of this issue from professional, academic and cultural institutions impacting the population. Method: Utilising Boolean analysis of legal, government and academic databases and Altmetric analysis of research dissemination and social media response, we measured four indicators of impact: development in federal and state law/policy, increased development of favourable case law, increase in favourable peer-reviewed articles, and increase in favourable media pieces and social media sharing. Results: Between 2005 and 2015 concentrated advocacy efforts to improve protection and awareness of the right to parent by people with IDD and other disabilities made a significant impact. Conclusions: A combination of proper government funding of NGO advocacy, targeted applied research, knowledge transfer, and multidisciplinary/multi-system collaboration positively impacted the status of parents with IDD in the United States.

"You don’t know until you get there": The positive and negative ‘lived’ experience of parenting an adult child with 22q11.2 deletion syndrome

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Aim: This study explores the subjective interpretations of both positive and negative ‘lived’ experiences of parenting an adult child with 22q11.2 deletion syndrome (22q11DS), a poorly understood condition with challenges for parents. Method: Eight parents (two male, six female) of an adult child with 22q11DS were interviewed. Interpretative phenomenological analysis was used to explore, describe, and interpret the participants’ experiences. Results: Losing ‘I’; Finding ‘self’; overarches six subordinate themes: stigma and a double-edged sword; where is ‘I’; conflicting loss, grief, and guilt; angry advocacy; pragmatic acceptance; and finding authenticity. These themes describe the isolation and stigma seeping into the participants’ lives as they progressively lose their own independence, friendships, and instinctual judgement. Pragmatic re-evaluation allows an authentic and positive psychological shift. Psychological growth is experienced through conscious engagement with empathy, humility, gratitude and pride. Conclusions: This study provides insight into the struggles parents of a child with 22q11DS face and the potential for psychological growth. As this is an unexplored phenomenon within this population, the results can be used to inform hypotheses for future research.

Residents’ voices raise implications for ethics of care on adult psychiatric intellectual disability wards: An intersubjective and relational conceptualisation of care

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Aim: By studying adult psychiatric intellectual disability (ID) care complexities, the research identifies foci for change in delivering ID care services, and reconciles care practices with an Ethics of Care framework. Method: Data were gathered from 10 adult inpatients, 16 nurses as spatiotemporal carers,
and 3 wards as ethnographic participants within 2 Western Cape care sites (120 data collection hours). Participant collaboration underscores an explorative and descriptive methodology. Care interactions were units of analysis during ethnographic data collection on wards. Data (field notes, audio-recordings, transcripts) from free association narrative interviews with nurses and sessions with residents were triangulated with ethnographic data, and examined for common themes. **Results:** Confounding psychiatric ID care factors include staff limitations, lacking ethics of care and nursing training, infantilising care dynamics, gender and race, continuity of care issues, unperformed care activities, and remote controlled care. **Conclusions:** Disabling care dynamics can complicate, but could be addressed by, a relational and intersubjective application of ethical care. To enable a shift away from disabling environments and resultant disability, ID care within an intersubjective and relational frame can be made economically and ethically.

**Can a virtual tour reduce anxiety in young optometry patients with autism spectrum disorder?**

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**Aim:** This study looks at the effect of an interactive preview of visiting the optometrist on the levels of anxiety children with autism spectrum disorder (ASD). It was hypothesised that those who used the online preview would experience less anxiety before their eye-test. This may give the optometrist the opportunity to obtain a more reliable assessment and thus improve service for people with ASD.  

**Method:** 30 boys 4 to 11 years of age were randomly assigned into two equal groups. One group viewed an online interactive video of the examination environment before the appointments. The comparison group received no additional support. On arrival each participant rated their anxiety levels based on a five point Likert scale. **Results:** Levels of anxiety were significantly lower in the interactive video group (p<.05) compared to the comparison group. **Conclusions:** The use of an interactive video could help reduce pre-test anxiety levels in people with ASD by supporting them through familiarity with the examination environment.

**A 50-year study of a population with Down syndrome**

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**Aim:** To follow up a total population sample of infants with Down syndrome who are now 50 years old.  

**Method:** This sample (n=54) was seen first at 6 weeks of age and at several points thereafter. 27 were still available by age 50, all but four of the losses being by deaths. A group of non-disabled infants, matched individually with those with Down syndrome for sex, age and social class, was followed at the same intervals for some years. Every participant was seen in his/her home. General and language abilities were tested. From the age of 30, memory/cognitive deterioration was assessed. Family factors were rated using a semi-structured interview schedule. **Results:** In those with Down syndrome, mean general ability declined rapidly to age 4 years, then slowly declined to 45 years, when some individuals were affected by dementia. Families were seen to be well-adjusted and not unduly stressed. **Conclusions:** The study has provided an unusually extensive overview of the lives of this group in a period in which major changes have occurred in social attitudes and circumstances.
Reducing 1:1 observations through mindfulness-based positive behaviour supports training for caregivers

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Aim: Caregivers are sometimes assigned to 1:1 special observations or staffing for individuals who engage in aggressive behaviours. While this is not treatment, and may violate the individual’s human rights, service providers resort to this practice by policy for the safety of the individuals, peers and staff.

Method: Sixty-seven group home caregivers were randomised into training (n=33) and control (n=34) groups. The treatment group caregivers were assigned to a 7-day intensive mindfulness-based positive behaviour support (MBPBS) training and the control group caregivers were assigned to in-service training as usual. The results were analysed based on intent-to-treat and treatment completes with respect to the use of 1:1 staffing pattern, aggressive behaviours of the individuals, caregiver variables, and the cost of lost days of work due to staff injury. Results: When compared to a control group that did not receive the MBPBS training, the MBPBS-trained caregivers gradually reduced and eliminated the use of 1:1 staffing, the individuals’ aggressive behaviours declined substantially, and there was substantial financial savings to the service providers. Conclusions: The study provides further proof of concept for the effectiveness of MBPBS.

Student-focussed planning for students with autism spectrum disorder: Knowledge, perspectives and experiences

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Aim: Student-focussed transition planning is a well-established evidence-based practice. This study examines the knowledge, skills, beliefs, and experiences with student-focussed transition planning for students with autism spectrum disorder (ASD) from the perspective of students, their parents and teachers in New South Wales (NSW).

Method: An embedded mixed-method design was used to analyse and interpret both qualitative and quantitative data. Questionnaires designed to measure participants’ knowledge in student-focussed transition planning were sent out to 363 NSW government secondary schools (i.e. special and mainstream schools) with support classes. Results: The results indicated that there is a need for professional development on student-focussed planning in mainstream and special schools. Students with ASD and their families need to receive information about why student-focussed transition planning is important, and how they can effectively participate. Conclusions: It is essential to involve students in the transition planning process and to ensure that the goals set for students’ future are based on their strengths, interests, and desires.

Life through others: Boys with intellectual disabilities constructing gendered identities

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**Talk about intellectual disabilities identity and future aspirations: Preliminary findings**

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**Aim:** This study explores identity from the perspective of service users, their non-disabled siblings and carers; and considers what influences the development of dreams and aspiration. **Method:** Separate service user and sibling focus groups were conducted using a variety of triggers. Ideas from these focus groups were used as triggers for a carer focus group. Data were analysed using a grounded theory approach. **Results:** Preliminary analysis offers ideas that will hopefully help to delineate our understanding of intellectual disabilities (ID) identity and future ambition. Data from the sibling and carer group highlight the similarities and differences of lives affected by ID. Further analysis will culminate in an exploratory theoretical framework to influence practice and further research. **Conclusions:** Findings from this pilot study will inform the development of a Managed Innovation Network on Young Adults Living with Learning (Intellectual) Disabilities (YALLiD). This is an interdisciplinary collaboration over three years focussing on ID identity. It is hoped that this will influence both the direction of research and practice in this area.

**A hermeneutic-phenomenological study on the process of meaning construction of persons with profound intellectual and multiple disabilities by telling “Story on the Ceiling”**

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**Aim:** The most common way of storytelling for persons with profound intellectual and multiple disabilities (PIMD) is making the stories concrete in order to be experienced with all their senses. “Story on the Ceiling” (SoC) is a transformation of stories experienced by their senses. Stories experienced by senses and SoC own the same content. SoC are stories made into PowerPoint files and projected on the ceiling. This research focusses on how persons with PIMD experience and develop the meanings of the SoC. **Method:** Data were collected by field/participant observation of storytelling to two pupils with PIMD and in-depth interview with four educators. A hermeneutic-phenomenological approach was used
to describe and analyse the data. **Results:** Pupils with PIMD combine memories of stories experienced with their senses with SoC through music and the figures in the stories. **Conclusions:** After implementing SoC, parents are able to read the original picture books for/with their children at home; this enhances cultural participation of children with PIMD.

**Health Literacy: What does it mean for people with intellectual disabilities?**

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**Aim:** An overview of current definitions and debates within the health literacy field serves to identify health literacy challenges experienced by people with ID, explore approaches to enhancing health literacy for this group, and advocate for more integration between ID and health literacy research.

**Method:** A review of the health literacy literature, focussing on Nutbeam’s (2000) tripartite model, featuring functional, communicative and critical health literacy was conducted. Themes and intervention approaches within ID studies were mapped to this model. **Results:** Most interventions that address health literacy with people with ID focus on functional health literacy using traditional health education frameworks. Research that emphasises self-determination and emancipatory principles can be seen to address communicative and critical health literacy dimensions. **Conclusions:** Health literacy is an important social determinant of health that can help us understand health inequalities experienced by people with ID. Greater mutual awareness and collaboration between ID and health literacy fields would enhance research and practice.

**Adapted written information for people with intellectual disabilities using “Easy Read” formats: A review of the literature**

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**Aim:** Adapted information in accessible “Easy Read” formats is widely promoted as a means to counter inequalities experienced by people with intellectual disabilities (ID). However, questions remain regarding impact and effectiveness. **Method:** We conducted a systematic review of the literature informed by a meta-narrative approach to reflect heterogeneity among studies. We searched health and social science databases for work published between 1995 and 2015 about adapting written information for people with ID. Hand searching yielded publications from the grey literature and diverse research and practice communities. We grouped similar studies according to shared conceptualisations and methodologies. A final synthesis highlighted tensions and conflicting findings within and between groups of studies. **Results:** We included 42 studies presenting varying accounts of the effectiveness of “Easy Read” formats. Four overarching themes encapsulating tensions in the literature: the nature and goals of “Easy Read”; audiences; defining implementation success; social and organisational context. **Conclusions:** “Easy Read” information has been created to address organisational, professional and service user issues. Attention needs to be paid to how it is personalized and employed in real life settings.
'As soon as she was born we wanted to come to the UK': Narratives about migration to the UK of Turkish-speaking families who have a son or daughter with intellectual disabilities

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Aim: Dominant discourses relating to refugees and migrants in host countries can be hostile and shaped by concerns about security and competition for scarce resources. Studies eliciting migrants’ own narratives allow other stories to be heard, highlighting the diversity of migrants’ experiences. However, little is known about the experiences of disabled migrants, and even less about the impact of intellectual disabilities (ID) on stories of migration and resettlement. Method: Interviews took place with five Turkish-speaking families (Turkish, Turkish-Cypriot and Kurdish) with a son or daughter with ID who had migrated to the UK between 5 and 20 years ago. The interviews were subjected to narrative analysis. Results: The family member with ID and hopes for their care and future was a key theme in narratives. Narratives compared barriers to support that families encountered in countries of origin with ‘an idealised UK’. Accounts indicated struggles during initial resettlement and ongoing encounters with UK services. Conclusions: Practitioners need to be sensitive to families’ experience of migration and including traumatic experiences before and during resettlement and their expectations of their new home.

Perspectives of parenting children with intellectual disabilities: Experiences of mothers in Zambia

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Aim: Every culture has challenges of looking after people with disabilities. In Zambia, mothers have always cared for their disabled members. This research investigates the experiences of mothers raising children with intellectual disabilities (ID). Method: This qualitative study used biographical interviews. Twenty mothers of different social backgrounds were recruited using purposive and snowball sampling. Data were analysed using thematic analysis. Results: All mothers, on behalf of their children, navigate through social systems such as the medical system. They also suffer isolation and stigma. Mothers experienced strained relationships, and in some instances, fathers rejected the child with ID, and this often resulted in divorce. Mothers also found it difficult to maintain class and good standing in society. They blamed themselves for the struggles of their children. Conclusions: There is need to involve traditional leaders in rigorous community-based programmes in order to address stigma and discrimination within the cultural context. It is important to understand that caring and rearing of children occurs within a social context.

Parents’ perspectives on pressures and supports across the lifespan in Taiwan

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Aim: In Taiwan, the majority of individuals with intellectual and developmental disabilities (IDD) live at home, oftentimes with parents as primary caregivers; yet there is a lack of understanding of parents’ well-being across the lifespan. This study describes parents’ perspectives on pressures and supports.
**Method:** In Phase I of the mixed-method study, qualitative data from five focus groups and two in-depth interviews (15 families in total) were analysed. In Phase II, the researchers recruited 451 parents who completed a 79-item questionnaire derived from phase I results. **Results:** Parents were more likely to report pressures upon diagnosis and during transitions, and their perceived supports and pressures differ substantially at different life stages. Additionally, the majority of themes centre on the individuals with disabilities instead of parents themselves. Over 75% of participants rated the items with high pressure or perceived support needs confirming the validity of the items. **Conclusions:** To ensure appropriate service delivery, service providers need to explore the needs of parents across the lifespan.

**Life after release from prison: The experience of ex-offenders with intellectual disabilities**

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**Aim:** In the UK, little is known about the experience of ex-prisoners with intellectual disabilities (ID). This exploratory study investigates what life is like for ex-offenders with ID who have left prison. **Method:** Individual semi-structured interviews were conducted with 10 men with ID who had left prison at least 9 months before. The interview explored men’s views of post-prison life, including the opportunities, challenges, and the support from professional services. Interviews were subjected to interpretative phenomenological analysis. **Results:** The upheavals of post-prison lives appeared to be ‘normalised’ by the men with ID. Some had to adopt a ‘hard man’ identity to protect themselves from harm. Hostile relationships with staff were informed by their experiences of restricted, insufficient, and problem-focussed support, whereas a person-centred support was appreciated. Friends and family played an important role in their lives. **Conclusions:** More attention is needed to investigate the type of support offered by professional services. It was clear that an individualised approach was the preferable support style. Further understanding of the men’s life within their social context would benefit their community re-entry.

**School to work transition: A multi-agency national project in Singapore**

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**Aim:** Transition from school to work is challenging for students with disabilities. A national project was designed to prototype a school to work (S2W) transition program for students in special schools in Singapore who were able to work. **Method:** Prototyping is a systems design methodology in which new models are designed, tested, and reworked iteratively to meet the needs of end-users. This approach was adapted in the S2W project. The process involved collaboration between the Ministry of Education, a national job support agency, and five special schools catering to students with intellectual disabilities and autism. A baseline design of the program was first conceptualised, then tested and refined iteratively over a 2-year period. **Results:** The process culminated in a viable, scalable program contextualised to the social and political context in which it is being implemented. Critical processes were specified: transition planning, student profiling, referral, handover, and customised job training pathways. **Conclusions:** By its systematic iterative approach, the process facilitated synergistic
collaborations with deep learning amongst key stakeholders. The S2W prototype will be scaled-up to more schools and students with diverse disabilities.

An evaluation of the school to work transition programme

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Aim: An evaluation of a national project to prototype a school to work (S2W) transition programme for students from five special schools in Singapore who were able to work was conducted to determine the effectiveness of the programme and inform improvements needed for the programme.  
Method: Programme effectiveness was assessed by studying student outcome data from the first cohort of final year students from the five schools. This comprised 30 students aged 18 years with intellectual disability, 11 with co-morbid autism. These students were tracked from the time they were identified, assessed, interviewed, job trained, and finally job placed. Programme improvements occurred through the systematic and iterative nature of the prototyping process, as well as surveys and interviews of key stakeholders including students, parents, and employers.  
Results: 21 of the 30 students (70%) were successfully placed in employment in a range of jobs after one year of post-school job training.  
Conclusions: Survey and interview data informed refinements in key processes of the S2W prototype including student identification and profiling, job matching and training, and setting up structured internships.

Workshop to work: Video case studies of the journey through discovery

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Aim: To evaluate the impact of adapting the Project SEARCH high school transition model to meet the needs of adults with significant disabilities who are seeking to transition from sheltered employment to competitive, integrated employment in the community.  
Method: This qualitative, descriptive study utilised digital video to document the experiences of nine adults with intellectual and developmental disabilities aged 25-45, recruited from a sheltered workshop in Upstate New York, who participated in a year-long employment training program. Individual progress was documented over time using a time series design, paying particular attention to participants’ growing ability to articulate vocational strengths and self-determined career goals.  
Results: Participants demonstrated measurable gains, most notably in self-advocacy, self-confidence and self-awareness of vocational strengths. Program outcomes for employment were consistent with the national outcomes associated with the Project SEARCH high school transition model (>70%).  
Conclusions: The Project SEARCH model, as adapted, shows promise as a feasible and effective work readiness intervention for successfully preparing adults with significant disabilities who are engaged in sheltered workshops to train for and transition to competitive, integrated employment.

Family functioning and quality of life in families of school-age children with autism
Aim: A child with autism would have a special impact on the family's life. It is important to understand this impact. This study examined family functioning and quality of life of families of children with autism.

Method: Using a mixed-methods design, the study compared 17 families of children with autism, aged 6-12 years, with 17 families of non-disabled children of similar age. The parents completed quantitative measures of family functioning, quality of life (QoL), and social support, and were also interviewed via a qualitative questionnaire for their QoL. Results: There were few domains of QoL in which families of children with autism differed from the comparison families. However, the families of children with autism scored less favourably in family functioning and social support. The qualitative data supported the negative quantitative findings in social support. Conclusions: Families of children who have autism experience lower degrees of family functioning and social support. However, consistent with Perry’s ABC-X model of stress, they appear to adapt and maintain their QoL. Implications for providing support for families are identified.

Quality of life and evidence-based practices

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Aim: The call for evidence-based practices (EBP) is increasing in the field of intellectual disabilities (ID) and quality of life research. Despite this widespread advocacy, a number of conceptual issues have to be addressed. The aim of this study was to develop a systematic approach to establishing EBP and to identify its core elements. Method: A six-step systematic approach was developed based on a thorough literature review. The validity of this systematic approach was confirmed through a panel of experts. The same expert panel identified key elements that should provide the basis for a systematic approach. Results: The six-step systematic approach includes defining the practice(s) in question, identifying outcomes and indicators, choosing the right perspective, collecting evidence-gathering strategies, using evaluation standards and translating evidence into practice. Conclusions: The establishment of EBP requires a systematic approach, which includes considering its core elements. All stakeholders should work in partnership to establish and implement such an approach.

History: Four lensmakers

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Aim: To examine development of intellectual disabilities (ID) clinical psychology in Britain post-WWII to 1976. Method: A constructionist historical analysis of the British Psychological Society (BPS) archive of the Division of Clinical Psychology; and of interviews with ID psychologists interviewed for BPS oral archive: Jack Tizard, Peter Mittler, Ann and Alan Clarke and review of their scientific publications. Results: These four’s independence of thought, moral character and creation of new ways to see and respond to ID justifies calling them lensmakers whose new conceptual tools allowed people to see ID differently. Conclusions: Implications of their work: Current clinical psychologists should challenge contemporary denial of ID as a distinct category. Social reform involves political commitment to collaboration; psychologists should renegotiate relationships with psychiatry and parents. History
reveals how a narrow focus on evidence and behaviour allowed emotional life to be dismissed; psychologists should argue for the significance of socio-emotional development to people with ID. Governments should not distract psychologists by commissioning examinations of particular topics; psychologists should do original, strategic research in university-based units with continuity of people and topic.

**Challenging the application of behaviour management strategies in a special education needs school in Perth, Western Australia**

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**Aim:** To gain a greater understanding of the self-identity of adolescents with severe intellectual disabilities (ID), and contribute to a more inclusive theoretical framework for self-determination that can be drawn on to enhance the policy and practice that pervades the lives of people with ID. **Method:** Ethnographic research was used, including ten months of participant observation at a special education needs school, guided conversations with school staff, and parent interviews. **Results:** Students were subject to rigorous hygiene rituals but were still treated as if they were contagious. Behaviour management strategies also reflected the staff concern with contamination through germs, parasites, and challenging behaviours such as aggression. **Conclusions:** There is an overarching belief in the value of these young people and the benefits of their inclusion in society, but underlying assumptions evident in the day-to-day practices of the staff were contrary to this belief. These practices may have implications for the physical and mental health and well-being of the students, and behaviour outcomes that will need to be dealt with at a community level after graduation.

**A planning approach for individuals with complex support needs**

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**Aim:** There is limited evidence about effective planning approaches with people with disability and complex support needs (CSN). Australian research was conducted to guide planning practice in this area. **Method:** Focus groups with 18 people with intellectual disabilities (ID) and 100 paid planners explored CSN planning experiences and barriers. Thematic analysis and action research were used to develop and refine a resource kit for planners to work effectively with people with disability and CSN. **Results:** People with ID need to trust a credible and consistent planner to gain support with decision-making. Planners need time and skills to build trust and harness and strengthen the capacity of a person with CSN. This process includes pre-planning, planning conversations, and plan-to-action. A visual resource kit with explanatory notes and case study was developed. **Conclusions:** The resource kit that was developed can enhance the competencies of planners to engage people with CSN. The resource relies on systems to foster collaborative approaches to individual need. The implications in the Australian disability context are discussed.

**Formal service supports for children of mothers with intellectual disabilities**
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Aim: This study examines the social support role of formal service for children of mothers with intellectual disabilities (ID). Method: Semi-structured interviews and creative methods were used to explore social interactions from the perspective of 7 children (aged 7-11 years) of mothers with ID. Thematic analysis was used to discern patterns in the social worlds of the group. Results: Children who have another supportive adult connected to their home approach social interactions with more optimism and confidence. Formal services staff/volunteers can be an influential relationship for children from homes lacking informal support when their role is enduring and focussed on a child’s unique needs. Two case studies are discussed to explore the nature of children’s relationships with formal services and differences in the influence of these relationships on the social worlds of the children. Conclusions: The findings have implications for policy and practice related to formal services engaged with families headed by mothers with ID. Effective services are family-focussed, they attend to a child’s needs, and create an enduring connection with them via an ongoing relationship with their mother.

Supporting early literacy development through holistic parent-led early intervention

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Aim: Limited literacy learning opportunities have traditionally been recommended for children with Down syndrome (DS). However, more recent research provides evidence that a holistic approach to reading instruction, including a focus on phonological awareness and phonic decoding, is beneficial. Based on Early Intervention Theory of Practice, it was hypothesised that a holistic, parent-led early literacy intervention would yield positive outcomes for early literacy development in children with DS. Method: Effectiveness of a 17-week parent-led early literacy intervention was evaluated through a randomised controlled study involving eight children with DS aged 27-63 months and their parents. Parents implemented the reading intervention incorporating storybook reading and embedded activities targeting phonological awareness and phonic decoding. Results: Comparison of pre- and post-test scores demonstrate significant improvements on measures of phonological awareness, concepts about print, word-reading, reading comprehension and letter-sound knowledge for the experimental, but not the control group participants. Conclusions: While this study is small, the findings provide promising evidence of the effectiveness of holistic parent-led early literacy intervention with children with DS.

Teacher perceptions of using Key Word Sign in early childhood settings

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Aim: Early childhood teacher perceptions of using Key Word Sign (KWS) were examined in order to investigate the implications for communication partner augmentative and alternative communication (AAC) intervention in early childhood settings. Method: 196 pre-service early childhood teachers completed a KWS workshop and developed ideas for implementing AAC in early childhood practice. Participants were required to write an open-ended journal detailing this process. These journal entries formed the data for this study and were analysed in light of a social relational model of disability.
**Results**: 114 Participants reported beliefs that KWS was beneficial for supporting communication development. In implementing KWS, 95 participants recommended its inclusive use within everyday learning experiences. 59 participants identified that using KWS can facilitate inclusive approaches through reducing barriers, ensuring participation of all children, and supporting a sense of belonging. 186 participants reported that engaging with inclusive approaches to using KWS formed a catalyst for fostering openness to inclusion more broadly. **Conclusions**: The findings demonstrate the potential that approaching KWS as a communication partner intervention holds for creating the conditions for inclusion in early childhood settings.

**A doorway into services: Young New Zealanders with disabilities who live away from home**

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**Aim**: To explore ethical concerns and human rights related to out-of-home placement of children with intellectual disabilities in New Zealand. **Method**: A broad analysis of legal and policy documents provide a background to a phenomenological interpretation of interviews with eight young adults who experienced placement in disability support services before 17 years of age. **Results**: The Children, Young Persons and their Family Act 1989 was legislated for children below 17 years being placed out-of-home. Article 23 of the United Nations Convention on the Rights of Persons with Disabilities emphasises the right for children not to be segregated and highlights the importance of children remaining with family wherever possible. The reported experience of the young adults with disabilities raised interesting ethical dimensions. Firstly, relationships with their family remained strong suggesting a shared enduring commitment. Secondly, the young person contributed little to decisions about their placement, however, that service placement tended to remain constant and influential even after they had reached the age of 17 years. **Conclusions**: Being “in relation” was important to the life trajectories of the person but had the potential to constrain their choice of service.

**EEG, volumetric MRI and gait analysis as biomarkers of aging in persons with Down syndrome**

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**Aim**: To identify bio-marker(s) to monitor neurocognitive change associated with aging in persons with Down syndrome (DS). **Method**: Three different studies were conducted - neurophysiological (EEG), neuro-radiological (quantitative analysis of brain MRI) and gait patterns - in 3 different groups of older persons with DS to identify early signs of pathological aging. **Results**: EEG showed a lower amplitude of normalised cortical sources of alpha rhythms in persons with DS than in control subjects (similarly to what happens in Alzheimer's disease). Neuroimaging data of the whole and regional brain volumes and of cortical thickness of older adults with DS showed variations in grey and white matter volumes and in cortical thickness in different anatomical brain regions and these alterations appeared similar to those described in Alzheimer’s disease. The gait pattern study revealed a decrease of walking velocity, reduction of the step length and increment of the step width associated with cognitive decline in older adults with DS. **Conclusions**: Integrating neurophysiological, neuro-radiological and gait data could be useful for an early identification of cases of pathological aging among adults with DS.
Gait patterns variations across aging in adult persons with Down syndrome

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Aim: This study evaluates gait alterations in aging people with Down syndrome (DS). Method: Gait patterns were studied using quantitative 3D multifactorial gait analysis in a group of 45 adults with DS (mean age: 22 years, SD=9) during a 15-year follow-up, and compared with a control group composed of 20 healthy subjects (age range: 20 to 35 years). In persons with DS, clinical examination, cognitive evaluation and brain MRI were also obtained to assess neurological status. Changes in spatio-temporal and kinematic parameters were measured using gait analysis with a mean interval time of two years. Results: Persons with DS showed decreased walking velocity and reduction of step length associated with a significant cognitive decline; as well as a reduction of range of motion of lower limb joints. Conclusions: Gait alterations described in older people with DS were not present in the control group; as these alterations were more evident in subjects developing significant cognitive decline, they can be considered early indicators of pathological aging.

Towards onset prevention of cognition decline in adults with Down syndrome: A pilot randomised controlled trial (The TOP-COG study)

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Aim: Statins (3-hydroxy-3-methylglutaryl coenzyme A reductase inhibitors) may slow brain amyloid β deposition and therefore delay Alzheimer disease onset in adults with Down syndrome (DS). We piloted a trial of simvastatin (a statin). Method: Feasibility/pilot double-blind randomised controlled trial (RCT) of 12 months simvastatin 40mg versus placebo for primary prevention of dementia in adults with DS 50 years and older. Group allocation was stratified by age, apolipoprotein E epsilon4, and cholesterol level. Adults with dementia, or simvastatin contraindications, were excluded. Main outcomes were recruitment and retention rates. Cognitive decline was measured with a battery of tests; secondary measures were adaptive behaviour skills, general health, and quality of life (QoL). Assessments were pre-randomisation and at 12 months. Analysis was on an intention-to-treat basis. Results: 181 (78%) of the likely eligible population were identified and 21 recruited (11.6%), from a 3,135,974 base population. Recruitment was highly labour intensive. 62% completed the full year. Regarding cognitive decline, results favoured the simvastatin group. Cognitive testing was more sensitive than proxy-rated adaptive behaviour, QoL, or general health scores. Conclusion: A full-scale RCT is feasible. It will need 37% UK population coverage to recruit the required 160 participants.

An overview of the development of the Diagnostic Manual – Intellectual Disabilities 2

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Aim: DM-ID was published in 2007. Since then, the American Psychiatric Association has revised its diagnostic criteria with the publication of DSM-5. The aim of this paper is to describe the rationale and process of development of DM-ID2. Method: Expert workgroups were established across each of the main psychiatric diagnostic categories. The groups reviewed the literature in their area, and applied this to the criteria in DSM-5, generating criteria suitable for diagnostic use with people with intellectual disabilities (ID). Results: Particularly for people with more severe ID, psychopathology distorts, requiring interpretations as to how diagnostic criteria should be applied. All diagnostic groups have been updated, resulting in the DM-ID2. Conclusions: The forthcoming DM-ID2 takes account of recent research and diagnostic changes to provide a diagnostic manual tailored for use with people with ID.

A record linkage study of children in Scotland: Obstetric factors and developmental disorders

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Aim: To investigate obstetric factors related to developmental disorders. Method: We linked two Scotland-wide administrative databases at an individual level (the annual school census and the Scottish Morbidity Record maternity database) to provide information on singleton children attending Scottish schools between 2006 and 2011. Results: Of 407,503 children, 7,018 had intellectual disabilities (ID). Extreme preterm delivery (at 24-27 weeks of gestation) was a strong predictor of ID (adjusted OR 11.67, 95% CI 8.46-16.10), with dose relationships across the range of gestation. Similarly, birthweight below the third centile was associated with ID (adjusted OR 2.67, 95% CI 2.41-2.96). Together, gestation and birthweight centile accounted for 26.6% of ID. Obstetric factors were not significantly associated with autism. Month of birth was associated with ID and autism. Conclusions: There are strong links between obstetric factors and ID.

Multiple physical and mental health co-morbidity in adults with intellectual disabilities: A population-based cross-sectional analysis

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Aim: To determine the extent of multi-morbidity experienced by adults with intellectual disabilities (ID) compared with the general population, and associations between co-morbidities, neighbourhood deprivation, and age. Method: Primary healthcare data on 1,424,378 adults registered with 314 practices were used to extract data on ID, 32 physical, and six mental health conditions. Standardised prevalence rates by age-groups, gender, and neighbourhood deprivation were generated. Odds ratio and 95% confidence intervals for the prevalence and number of condition were calculated. Results: 8,014 (0.56%) had ID; they were significantly more likely to have more conditions and only 31.8% had no other conditions compared to 51.6% without ID. No gradient was seen in multi-morbidity extent with increasing neighbourhood deprivation. Co-morbidity increased with age but was highly prevalent at all ages; being similar at age 20-25 to 50-54 year olds in the general population. Conclusions: Multi-morbidity burden is greater and occurs earlier for adults with ID. There is no association with
neighbourhood deprivation; people with ID need focussed services irrespective of where they live, and at a much earlier age than the general population.

**Practice nurse-delivered health checks for adults with intellectual disabilities: A cluster design randomised controlled trial**

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**Aim:** To determine if practice nurse-delivered health checks improve the health of adults with intellectual disabilities (ID). **Method:** A cluster-design, single-blind randomised controlled trial was conducted. General practices were randomised to intervention plus standard care, or standard care only. The intervention was a single health check tailored for the population with ID. The objective was improvement in health, and health care, nine months post-randomisation. The primary outcome was incidence of newly detected health needs being met. Secondary outcomes included extent of health monitoring needs being met, general health ratings, and cost-effectiveness. Analysis was by intention-to-treat. **Results:** 38 practices were recruited and 85 participants randomised to intervention and 67 to standard care. 83 intervention and 66 standard care participants completed the trial. Newly detected health needs were met for 76.4% of intervention, versus 72.6% of standard care group (p=0.085). Health monitoring needs were met for 69.9% versus 56.8% (p=0.0053). Change in EQ-5D health utility scores were better in the intervention group (p=0.015). There were no adverse events. **Conclusions:** The intervention dominated standard care, being both cheaper and more effective, with improvements conducive to longer-term health.

**Post-secondary and higher education: A study of the experiences of people with intellectual disabilities**

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**Aim:** This research explores the lived experiences and investigates the meaning(s) that people with intellectual disabilities (ID) construct of their experience in post-secondary and higher education in the Republic of Ireland. **Method:** Study participants were 27 adults who attended post-secondary or higher level courses. Participants’ narratives of their experiences were captured via audio-taped interviewers and analysed following the interpretive process in Heideggerian hermeneutic phenomenology. **Results:** The findings highlight the transformational role of education. Participants experienced going to post-secondary or higher education as valuable and positive. They described the experience by detailing opportunities such as improving literacy and learning new skills. Their experiences were interpreted as creating conditions that increase their independence and self-belief. The meanings drawn from the experience reflect an understanding of the benefits of inclusion, but also highlight the emerging realities of the limitations caused by having a disability and being dependent on services. **Conclusions:** The methodology used has resulted in a unique method of interpretation which gives a greater insight into the experiences of people with ID. Recommendations are made for research, practice and policy.
Valuing identity: The effects on well-being in older age

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**Aim:** Limited research has examined perceptions of personal identity within the cohort of people aging with intellectual disabilities (ID). The current study assessed how identity contributes to the well-being of older people with ID. **Method:** A mixed-method approach utilising a survey tool (n=450) and semi-structured interviews (n=45) was designed to examine perceptions of quality of life (QoL) held by older people both with and without life-long ID. The survey comprised of demographic questions and validated scales including the Personal Well-being Index (PWI and PWI-ID) and Duke Social Support Index (DSSI) had a 90% response rate. The data were supplemented by interviews with people aging with ID, carers, policy makers, and managers. Data were analysed by thematic analysis and descriptive statistics. **Results:** Three significant factors contribute to individual identity and well-being: life course, activity participation, and social connections. **Conclusions:** Identity is a central component of well-being during aging. A discussion is provided on how the three identified factors can be supported to assist maintenance of identity for individuals aging with ID.

Co-design for community inclusion

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**Aim:** There is a need to understand how co-design, as a research methodology, increases community inclusion, and to develop valid tools to measure this. **Method:** Tailored programs focussed on social inclusion goals were developed with 11 individuals with a disability. The program construction applied the practices of co-design, and was further informed by IABA’s STEP principles, to support inclusion and work transitions. We developed a Community Inclusion Scale (CIS) guided by components of STEP to measure levels of participation in different environments; the type of support the person required; and whether the activity was experiential or developmental. The scale was completed by disability support practitioners who supported the participants; prior to program commencement, then in 3 monthly intervals following implementation. The scales were then compared to ascertain changes in levels of community inclusion. **Results:** The scales completed following implementation demonstrated an increase in community inclusion when compared to the baseline. **Conclusions:** The findings suggest that co-design, an inclusive methodology, increases social inclusion, and that the Community Inclusion Scale is a useful measurement tool.

The complexity of self-determination for people with intellectual disabilities

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**Aim:** Historically people with intellectual disabilities (ID) have often been denied the right to self-determination. Contemporary policy aims to grant this group of people this right yet the empirical data demonstrates that many in this group remain largely subject to the determination of others. This study
examines the experiences of those in an unpaid and paid capacity, supporting individuals with ID to be self-determined. Method: Between two and five semi-structured interviews were undertaken with parents and other members of an individual’s support network. Individuals were also observed during their everyday routines. A grounded theory methodology was utilised to develop a theory about how people were being supported to have their choices and decisions respected and reflected in how they lived their lives. Results: Supporters faced a multitude of issues in their efforts to enable the individual to be self-determined. A case study will be used to illustrate the complexity of these issues. Conclusions: There is a need for recognition in policy of the complexity related to supporting people with ID to be self-determined.

The evolution of inclusive research: A literature review

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Aim: This literature review explores origins of the active involvement of people with intellectual disabilities (ID) in research and its evolution into 'inclusive research'. Method: A systematic literature review was conducted to investigate current national and international literature on inclusive research and ID. Searches across four databases yielded 878 results published from 1967 - 2016. Results: The involvement of people with ID in research has been driven by the disability movement and the principle of the People First movement 'nothing about us, without us'. Emancipatory research models have been increasingly employed enabling people with disabilities to actively participate in the research process as experts by experience rather than as 'objects' of research. Although a number of studies reported the process of inclusive research these consist of reflections done following study completion and from the perspective of the academic researcher. Conclusions: The review identified a gap in the literature: the experiences of the people with ID themselves from being involved in inclusive research initiatives. Further investigation should be explored from this perspective as inclusive research initiatives grow.

Family relationships and support for self-determination: The lived experience of adults with intellectual disabilities

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Aim: Australia has incorporated self-determination principles into current disability policies, focussing on individualised, person-centred support with the expectation that individuals with disability, together with their family, will experience increased choice and control. While the relationship between an individual with disability and their family is frequently referred to, there is limited research on understanding this relationship. This presentation will explore the lived experience of family relationships and support for self-determination from the perspective of adults with intellectual disabilities (ID). Method: Semi-structured interviews with eight adults with ID were conducted on two occasions. An interpretative phenomenological approach to analysis was used to understand the meaning individuals give to their experiences. Results: Emerging themes concerning connection to family, support received, experiences around self-determination, and challenges faced will be presented using participant quotes to illustrate and support the analysis. Conclusions: An understanding of
individuals’ experience of family, and the meaning this has for them, is essential to understanding the context within which increased choice and control is being attempted.

Receptive vocabulary development in individuals with Down syndrome

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Aim: This study investigates the development of receptive language in individuals with Down syndrome (DS) from childhood to mid adulthood and examines the influence of gender, maternal education and nonverbal ability on this development. Method: Scores on the Peabody Picture Vocabulary Test (PPVT) achieved by 205 individuals with DS over 914 occasions provided the data for the study. A subset of this group (n = 162) had also completed the Pattern Analysis subtest of the Stanford-Binet: Fourth edition. Results: Receptive vocabulary increased until approximately 20 years of age when it began to decline. Nonverbal ability was associated with performance on the PPVT; however gender and maternal education were not related to performance. Conclusions: Understanding the contributors to decline in receptive language performance is essential if effective responses are to be provided.
The effect of video-feedback on the communication between people with multiple disabilities and their social partners

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Aim: This study tested the effect of a video-feedback intervention on complex forms of interpersonal communication, such as shared understanding. Method: Interpersonal communication between five children and six adults with dual sensory loss and profound to moderate intellectual disabilities (age range 6-49 years) and their 34 partners was measured before, during and after implementing the intervention. The intervention consisted of education and video-feedback. First, social partners were supported in attuning their behaviours and emotions to the individual with multiple disabilities. Then they were supported in exchanging, negotiation about and sharing meanings. Results: Significant effects on communication were seen in all participants with multiple disabilities and their social partners; e.g. in the sharing of emotions and use of referential communication. More effects were found when social partners were supported in meaning making in addition to attunement. Meaning making support also led to more complex interpersonal communication, such as the sharing of thoughts. Conclusions: Video-feedback appears to be an effective tool to enhance the quality of social interactions and the complexity of interpersonal communication of individuals with multiple disabilities.

The relationship between moral development, distorted cognitions and social problem solving amongst men with intellectual disabilities who have a history of criminal offending

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Aim: This study examines the relationship between moral development, social problem solving ability and distorted cognitions. A secondary aim was to examine the psychometric properties of a revised measure of distorted cognitions called the ‘How I Think Questionnaire – Intellectual Disabilities’ (HIT-IDs). Method: Forty-six men with ID with a history of criminal offending and 51 men with ID without any known history of criminal offending were recruited and invited to complete measures of moral reasoning, social problem solving ability and distorted cognitions. Comparisons were made between the two groups. Results: While both groups of men had developmentally ‘immature’ moral reasoning, the group of offenders were reasoning at a significantly more ‘mature’ developmental level than non-offenders. Offenders endorsed a significantly greater impulsive style of social problem solving, and had significantly higher levels of cognitive distortions. The test re-test reliability of the HIT-IDs was good. Conclusions: The relationship between these constructs has relevance for our understanding of social information processing amongst men with ID.

Is fish consumption during pregnancy safe: 30 years of evidence from the Seychelles Child Development Study

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Aim: This study tested the hypothesis that prenatal exposure to methylmercury (MeHg) from maternal consumption of a high-fish diet is associated with adverse neurodevelopmental outcomes in offspring.
Method: Three birth cohorts from the Republic of Seychelles (where diet contains an average of 11 fish meals per week) are being followed. Prenatal MeHg exposure was measured in all cohorts from maternal hair taken at birth. Maternal nutrient status was measured in cohorts 2 and 3 only. Cohort 1 (n=779 who are now 25 years old) has been evaluated nine times since birth using a comprehensive battery of neurodevelopmental tests. Cohort 2 (n=300 who are now 10 years old) has been evaluated four times since birth and Cohort 3 (n=1522 who are now five years old) is being evaluated for the second time at present. Statistical analyses included adjusted multiple linear regression. Results: No evidence of adverse associations between MeHg and child development has been found. Maternal nutrient status has a beneficial impact on child outcomes. Conclusions: The association between consuming fish during pregnancy and developmental outcomes in offspring is very complicated.

The influence of Real Opportunities Hub Teams on the quality of person-centred planning

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Aim: The Real Opportunities Project implemented evidence-based approaches using Hub Teams to assist people with intellectual disabilities transition from school in Welsh areas. This study looked at whether greater Hub staff input, and an independent development plan format, impacted on the quality of person-centred transition reviews. Method: Records of 213 reviews (2001-2014) were inspected for numbers and categories of people attending meetings; accessibility of language and use of photographs/images; review formats; number and variety of goals; level of goal detail; past goal achievement; and extent of Hub Team facilitation. Inter-rater reliability measures were calculated. Results: Mean number of people attending meetings rose over time (3.8 to 7.0). Percentage of meetings where young people attended rose from 14.3% to 54.2%. Quality of reviews increased from 14.3% having top scores in 2011, to 66.2% in 2014. Reviews using formats proposed in new legislation scored highly. Education or skills were the most common goals. Paid job goals increased but were still relatively rare. Community involvement and relationship goals increased over time. Where Hub staff were involved, more goals were set, they were reviewed more often, and reviews were more consistent with good person-centred planning (PCP) practice. Conclusions: Improvement was attributed to Real Opportunities Hub staff involvement, and their PCP training.

Understanding the mental health care needs of mothers of children with a disability: Informing service need

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Aim: Higher rates of depressive symptoms are found in parents of children with disabilities compared to parents of typically developed children. Service embedded changes are needed to prevent mental ill health. This study investigates the needs, gaps and barriers to supporting mothers' mental health. Method: Interviews with mothers of children aged 0-25 years (mean=10.6) with a disability (n=25) and an online survey (n=294) were conducted. 83% of mothers were between 35 and 54 years of age. The main disability groups were autism spectrum disorder (60%), cerebral palsy (22%), intellectual disability (23%) and developmental delay (20%). A consumer advisory group ensured maximum consumer
involvement. **Results:** Qualitative findings suggest that it is not standard practice to support mothers’ mental health within disability and paediatric health services. Survey data showed 46% experienced clinical depression and anxiety, 76% perceived a need for mental health support, although 42% did not access support. 86% thought it was essential for their child’s health professional to discuss their mental health and 88% felt this was essential at their child’s diagnosis. **Conclusions:** The results inform preventative mental health strategies within health and disability services.

Developing a new service model for children with a disability: What do parents want?

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**Aim:** Yooralla and a team of researchers led by the University of Melbourne are developing and evaluating a cost-effective model of care for children with a disability and their families. This study explores parents’ experiences of accessing services and their recommendations for improving the service model. **Method:** A qualitative study was conducted involving 40 parents of children with a disability. Parents were asked how disability services support their family’s wellbeing and their experiences in accessing services. Transcripts were analysed using a grounded theory approach. **Results:** Parents feel they need to battle, fight and beg for services and feel grateful and lucky when they receive them. Parents feel anxious about the future and conflicted about the best use of funds. Parents want services to be more family-centred and better meet the needs of their children. **Conclusions:** Parents need more support in applying for funding, accessing information and supporting their own and their family’s health and wellbeing. This research will inform organisational redesign within the context of the National Disability Insurance Scheme at a major Victorian disability service.

Measuring the quality of life of children with a disability: Choosing an outcome measure for service providers

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**Aim:** Measurement of quality of life (QoL), defined as an individual ‘assessment of well-being across multiple domains of life’, is an important outcome variable for children and adolescents with a disability. This paper describes the available generic QoL tools for children against criteria identified as important for evaluating services for children with a disability. **Method:** A review of QoL instruments identified in systematic reviews was conducted. Over 30 QoL tools were reviewed using a set of criteria important for service providers, such as domains, consistency with a child rights framework, cost and scoring. **Results:** QoL tools for children varied enormously in terms of their conceptual focus, items and responses. Many tools were deemed not appropriate for children with a disability because they confounded QoL with functioning or illness. **Conclusions:** This research identifies possible outcome measures for service providers that may be useful within the context of the National Disability Insurance Scheme. A new tool to measure the QoL of children with intellectual disabilities is required.
Quality of life for caregivers and youth with disabilities transitioning to secondary school

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Aim: Explore the impact on quality of life for youth and their caregivers during a school transition. Method: A study with youth and their caregivers, using interviewing and surveying techniques was conducted. 15 youth and 17 caregivers, experiencing the transition from primary to secondary school participated. Qualitative and quantitative data analysis using Spearman’s correlations and Mann Whitney U tests, in addition to thematic analysis enabled identification of a range of crucial themes for caregivers at this time. Results: Primary themes identified as vital for caregivers to navigate the process of supporting youth to transition to secondary school well were access to allied health therapies; access to information and clinical assistance to support decision-making; and coordination of tasks were identified as crucial themes for caregivers pre-transition. Youth settled well post transition in the new educational context, however clinical support for developmental growth remained a concern through adolescence. Conclusions: The need for individual therapy during times of emotional and physical growth and development cannot be understated. Youth and their families are disadvantaged by limited access to clinical support during transitional phases.

Using the International Classification of Functioning and the Bridges of Transition frameworks to support youth and their caregivers to transition to secondary school

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Aim: To explore the impact of and determine support needs for youth with intellectual and developmental disabilities (IDD) and their caregivers during a school context transition. Method: A two-year study with youth and their caregivers was conducted. Interviews and surveys of 43 participants, pre and post transition to secondary school, enabled chronicling of the impact of the transition process to the International Classification of Functioning (ICF) and the Bridges of Transition frameworks. Quantitative analysis using Spearman’s correlations and Mann-Whitney tests for between-group comparisons with a thematic analysis of qualitative data were used. Results: The impact of the transition progression clearly translates to both Part 1, functioning and disability, and Part 2, contextual, domains of the ICF at pre and post transition analysis. Additionally, pre transition primary concerns for caregivers strongly associated with the Bridges of Transition framework. Conclusions: Both the ICF and the Bridges of Transition frameworks and the subsequent mapping of the impact of this transition, demonstrate a substantial imperative to utilise these well-established structures when supporting families during transitional life stages.

Communication access for youth with disabilities transitioning to secondary school

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Aim: Explore the impact of transition from primary to secondary school for youth and their families. 
Method: A two-year study with youth and their caregivers was conducted. Interviews and surveys were conducted pre and post transition. Results: Qualitative analysis shows systemic needs appear to outweigh individual communicative necessity. Families were concerned that the communicative strategies being used for the youth in the secondary school were heavily weighted by systemic resource availability. Accessibility to appropriate resources to support individual youth communication across a range of educational placements was challenging, with significant impetus for communicative strategies to be reworked to suit the viability of generic electronic resources available in the educational placement. Conclusions: The abundance of a diversity of electronic resources made available in learning contexts for youth is seemingly overriding the provision of sound alternate and augmentative communication options. Consequently, the communicative capacity of youth is reduced at a critical developmental life stage as well as the capacity of their networks and learning potential.

Training outcomes in positive behaviour supports

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Aim: Positive behaviour supports (PBS) is almost universally accepted as the most effective approach to improving the quality of life of persons with intellectual disabilities and reducing the impact of their challenging behaviour. Method: The present paper reports on the evaluation of the Functional Assessment and Positive Behaviour Intervention training course, delivered by the Centre of Excellence in Clinical Innovation and Behaviour Support across 2014 and 2015. Training evaluation is based on pre and post knowledge and practice translation of plan score using BSPQEII. Results: Analysis indicates continued evidence of significant knowledge gain (pre-test M: 2.36 SD: 1.62 to post-test M: 6.31 SD: 1.37) over the 2014 and 2015 training years. Additionally, the translation to practice of this knowledge demonstrated plan scores (M: 15.56 SD: 3.51) with 47.9% of plans within the ‘Good Plan’ category for quality evaluation, an increase of plan quality since 2012. Conclusions: Endorsement for the current training program is strong with sustained knowledge gain and translation to practice seen across multiple training years. The criticality in continued training in PBS can only improve the implementation.

The development of an ‘easy to use’ version of an evaluation tool to determine the quality of positive behaviour support plans

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Aim: The quality of positive behaviour support plans (PBS) within the context of disability-specific services and the National Disability Insurance Scheme is a fundamental principle for disability supports provision. Well written and implemented plans allow for good disability practice to be envisioned for persons with intellectual disabilities (ID) and their broader networks. Method: An ‘easy read’ tool has been developed to assist families, caregivers and significant others to use in determining plan applicability and that appropriate interventions and strategies have been identified. The tool was tested by scoring training plans with a comparison of scores between the BSPQEII and ‘easy read’ tool. Score comparison and test-retest reliability was conducted. Results: A strong positive correlation was
evidenced on the aggregate score of all domains ($r=0.745, n=90, p<0.01$), with similar results on domain breakdown. The Cronbach alpha coefficient was .717, scoring similarly to the BSPQEII. **Conclusions:** The development of this tool allows for non-clinicians to make judgements on the quality of PBSP that are developed for persons with ID. Further testing of this tool with caregivers, advocates and significant others is required.

**Working together: Findings of an empirical study on multiple perspectives and experiences of parents with intellectual disabilities, professionals and social network members**

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**Aim:** Promoting and hindering factors for a good connection and cooperation between parents with intellectual disabilities (ID), professionals and social network members were explored. **Method:** In a cross-sectional design parents with ID, network members and professionals reported their experiences with support seeking (parents with ID) and giving support (network members and professionals). **Results:** Parents with ID asked for informal support rather than for professional support. A positive working alliance between parents with ID and professionals was associated with a shorter latency to seek professional support. Positive expectancies of professionals towards parents with ID weakened the association between parental adaptive functioning and their support seeking behaviour towards professionals. Social network members reported understanding each other’s perspectives, exchange of tasks and opinions, awareness of the diversity and complexity of both networks as factors promoting cooperation with professionals. **Conclusions:** Positive expectancies towards parenting skills of parents with ID, a good working alliance, and respect for individual characteristics promotes the connection and cooperation of social network members, professionals and parents with ID.

**Stigma and Down syndrome: Social preferences and attributions towards themselves and others by young people with and without Down syndrome**

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**Aim:** Little is known about the impact of stigma on children growing up with intellectual disabilities (ID). This study examines children with Down syndrome (DS)’s awareness of their disability. **Method:** Twenty-eight young people with DS (aged 8-17 years) and a control group of 67 typically developing young people were recruited. Three tasks explored the children’s developing awareness of DS: choice of partner for social activities, sorting photographs of children with and without DS, and attributing positive or negative descriptors to photographs of children with and without DS and to themselves. **Results:** All participants expressed a preference to engage in social activities with typically developing peers and the majority of those with DS identified with typically developing young people. Both sets of children also attributed more positive descriptors to the photographs of the typically developing individuals than to those with DS. Nevertheless most participants remained positive about themselves. **Conclusions:** These findings suggest that children with DS develop an awareness of their disability and related stereotypes from an early age.
Impact of practice leadership management style on staff experience in services for people with intellectual disabilities and challenging behaviour: A further examination and partial replication

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**Aim:** Recent research interest on practice leadership (PL) has suggested that PL is associated with better experiences for staff working with people who show behaviour described as challenging. **Method:** This further examination and partial replication study was a survey of staff self-reported data collected as part of a larger study. Information was collected on PL and staff experiences of: stress, turnover, job satisfaction and positive work experiences. **Results:** The results broadly supported previous findings and demonstrated an association between PL and greater job satisfaction and positive experiences for staff. Results on staff turnover were inconsistent. **Conclusions:** The positive impact of PL on staff experience was further supported by this replication study. Suggestions for further research focus upon the inconsistent results for staff turnover.

Therapy support workers: Building family and community capacity to help rural Aboriginal children with developmental delay transition to school

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**Aim:** Rural Aboriginal children (0-8 years) with developmental delay experience difficulty accessing therapy to support their transition to pre-school/school. A therapy support worker (TSW) service model was trialled using place-based therapy interventions and a community capacity-building approach. **Method:** A rural community organisation in rural New South Wales, Australia employed local mainly Aboriginal women in four communities as TSW to work with 56 children with developmental delay. An evaluation included interviews with 22 stakeholders: family members, pre-school and school staff, outreach therapists. Thematic analysis identified six themes related to what worked well and what were challenges. **Results:** The TSW model was successful due to its grass-roots, community-based focus in which the TSW worked alongside families, early childhood providers and outreach therapists to engage the children and enhance existing services. Challenges to the model included lack of clarity of the TSW role, turnover of outreach therapists, and issues with local coordination of early childhood services. **Conclusions:** This study identified the importance of developing and supporting local, culturally appropriate strategies to enhance the transition to school for rural Aboriginal children with developmental delay.

Lived experience of Microboards

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**Aim:** Microboards are a model of support that can effectively assist people with profound intellectual and multiple disabilities (PIMD) to secure their rights as outlined in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). This presentation illustrates, through stories of lived
experience, how Microboards have been used to do this. **Method:** Three participants who have Microboards from Australia and Canada use a narrative approach with a thematic analysis to identify how community inclusion has been facilitated while respecting their needs and preferences. **Results:** The stories show how Microboards have been used: to enhance the capacity for the person to self-determine; and to advocate for and mobilise available resources for the person to live inclusively in their community. **Conclusions:** Microboards have changed the projected life course of the presenters. Microboards can provide an effective framework through which to support people with PIMD to secure and enact their rights as laid out in the UNCRPD.

**Human rights perspective: Implications for policy and practice**

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**Aim:** This paper explores the relevance of human rights instruments to policy and practice in intellectual disability (ID), in light of those with complex needs who are at risk of significant intersectional discrimination and disadvantage. **Method:** Using qualitative content analysis, this paper examines the concluding observations on the initial report of Australia adopted by the United Nations Committee on the Rights of Persons with Disabilities and maps these to current National Disability Insurance Scheme (NDIS) policy to assess whether the human rights of people with ID and complex support needs are being met. The analysis focuses specifically on issues of significance for this group, such as supported decision-making, use of restricted practices and gender-based violence. **Results:** Analysis highlights the complexity of operationalising support for the human rights of people with ID experiencing compounding forms of discrimination, abuse and vulnerability in their social and systemic interactions and in particular in the operation of Australia’s NDIS. **Conclusions:** Utilising the range of human rights instruments helps to recognise the multiple disadvantages faced by people with ID and complex support needs to be able to live with dignity and respect in the community.

**Inclusive planning for elderly citizens in the community: A process model**

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**Aim:** Although municipal planning for elderly citizens and for citizens with intellectual disabilities (ID) partially follow common objectives, planning processes are often carried out separately. The evaluation of a newly developed model for an inclusive municipal planning for all elderly citizens focuses on selected elements: the function of person-oriented planning objectives, the neighbourhood-centred approach, participatory elements and perceived benefits. **Method:** Model-based planning projects were carried out in an urban and a rural municipality in Germany. In both municipalities, participants in the public events filled out evaluative questionnaires (n=183). 19 expert interviews were conducted with the members of each planning team, service providers and volunteers; and a group discussion was held with eight participants with ID. Questionnaire data were analysed statistically; interview data were subjected to content analysis. **Results:** Conditions for their successful participation of citizens with ID were identified. Their advocacy groups and service providers could be integrated in neighbourhood-oriented networks of cooperation. Planners and service providers favoured the neighbourhood-scaled data
report, but were not used person-oriented planning objectives. **Conclusions:** Key elements of the inclusive planning model were confirmed. Further research should evaluate the medium-term effects of an inclusive planning approach.

**Treatment through contextual support: A conceptual model**

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**Aim:** To gather information about the contextual factors that optimize the quality of life (QoL) of people with intellectual disabilities (ID) and severe challenging behaviour. **Method:** Through a series of Delphi-meetings with professionals (ranging from carers to directors), clients and their representatives, we have identified information about what they consider the most valuable in the contextual support of clients with ID and co-morbid problems. We have used a bottom-up approach first and linked the gathered information to evidence-based practice from literature. **Results:** We have identified eight themes (e.g. relations, knowledge) across five levels of support (from client to society) and reached consensus on all levels of the organisation involved as well as outside the organisation. These themes and levels have been made measurable through statements that can be used as an assessment tool. **Conclusions:** Using a bottom-up approach we have made a model that has formed the basis of an instrument that can be used to gather information on the contextual support of clients.

**Contextual factors influencing the use of restrictive measures**

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**Aim:** This study aims to identify the personal and contextual factors that influence the use of restrictive measures in order to reduce the use of such measures. **Method:** Incident reports (that have to be filled out by law, the so-called BOPZ-law) of 130 clients were analysed. The data has been gathered through a systematic review of the files and a questionnaire filled out by the client’s physician and psychologist. Exploratory statistics using SPSS have been performed. **Results:** We can identify people at risk of restrictive measures, but some risk factors are modifiable. We have found factors that we knew from literature (such as influence of level of functioning, psychiatric illness), but also contextual factors, such as the functioning of the team and the willingness to accept outside consultation. **Conclusions:** Through this analysis we have a better understanding of the factors that influence the use of restrictive measures in people with intellectual disabilities and severe challenging behaviours.

**The Dutch version of the San Martin Scale**

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**Aim:** To validate an instrument that can be used to assess quality of life (QoL) in a broad range of clients (ranging in age, level of functioning and associated problems) to be used in a broader evaluation study. For this purpose we have translated and validated the San Martin Scale (SMS; Verdugo et al.). **Method:**
We have established the preliminary validity and reliability of the SMS for a Dutch population of people with intellectual disabilities (n=60) and serious mental health problems who receive very intensive support. SPSS has been used to analyse the data. **Results:** Preliminary findings of inter-rater reliability (>0.60) are reasonable, internal consistency is good (>0.95). **Conclusions:** The Dutch SMS is a promising instrument to make an objective estimation of the perceived QoL of people of different ages and with different levels of functioning. It is a valuable instrument that needs further development to make it use-worthy in the field of ID in the Netherlands.

**A descriptive literature review of Milieu Teaching studies in Turkey**

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**Aim:** Milieu Teaching (MT) has been studied for years in the United States and in other countries including Turkey. It has been identified as an evidence-based procedure. However, there is no review of the studies conducted in Turkey. The purpose of this research was to describe and discuss the results of studies carried out on the use of Milieu Teaching Strategies with Turkish children, teachers and parents of children with developmental disabilities. **Method:** A descriptive literature review was conducted. Identified studies were categorised according to age, gender, disability group, target group, etc. **Results:** Five studies were identified. All used single-subject designs. The MT strategies were taught to teachers, speech and language therapists, and parents. All participants learned MT strategies and significant improvements were observed in the expressive language skills of the children involved. **Conclusions:** Results showed that MT is a culture-free procedure.

**Human rights, disability and restrictive interventions: Collaborative development of policy and guidance for government schools**

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**Aim:** To describe the historical and political influences on the development of new policy for the oversight of restrictive interventions in an educational jurisdiction primarily for children with intellectual disabilities through a collaborative process across service sectors which promote human rights and contemporary practice. **Method:** A critical-interpretive case study approach was utilised to explore the nature of the impetus for policy change from the perspectives of the education and disability sectors. Conceptual frameworks were applied for the analysis of policy adoption. **Results:** Disparate legislation, the challenge of policy operationalization, concerns made by stakeholders and criticism by public authorities contributed to the development of a collaborative relationship across government departments. This provided the foundation for school policy change and highlighted contextual dissimilarities and commonalities to inform policy implementation. **Conclusions:** While broad human rights legislation exists, their application is complicated by other legislation, barriers to practical application, regulatory differences, cultural variances and service delivery models. Exploration of barriers and facilitators of policy change are necessary for productive regulation of restrictive interventions.
Quality Checking: The gateway to taking control of our lives

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Aim: Quality Checking (QC) was established to ensure persons with disabilities are in control of their lives by having the quality of their support checked. The question we address is how QC is distinctive from professional-led approaches and how such tool empowers the individual. Since 2007, Choice Support employed and trained over 60 people with intellectual disabilities to do QC. Method: A mixed methodology was used; firstly interviews and direct quotes of checkers at work were used. Secondly we conducted both interview visits and evaluation of the impact of the check to providers and people, and we analysed action plans submitted after a visit followed by a revisit. Results: Qualitative analyses of the data revealed that co-production and inclusiveness gives individuals the power to use their experience to shape their own support thereby being in control; and that this peer-support based model is highly effective. Conclusions: This study provides twofold insight on the impact of quality checking firstly for individuals employed as quality checkers and secondly of the impact of the checks on the individuals having their support services checked.

Narratives of home

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Aim: In the United Kingdom (UK) a significant number of people with intellectual disabilities (ID) continue to live in congregate settings as 'patients'. Policy initiatives have a stated aim of transferring people from inpatient settings to a home in the community. This study gathers narrative accounts of the experience of moving from a congregate setting to a home of one's own. Method: Using narrative research, the stories of 6 to 8 individuals are collected. Data is considered both as whole texts, valuing the integrity of the story, and thematically seeking to identify common reflections on the experience of moving to a home of one's own. Results: Findings recount peoples' individual and shared experiences as they move from life as an inpatient to a home of their choosing. The study seeks to relate personal views and perspectives to the UK policy context and rights agenda. Conclusions: This project builds on the established narrative tradition in research with people with ID, and seeks to champion the value of narrative in addressing policy and practice relating to social care in the UK.

Characterising quality of life in children with intellectual disabilities

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Aim: This presentation describes QoL domains in children with disorders that represent a range of intellectual disabilities (ID) and compares them with those represented in generic and disability-specific QoL measures for children. Method: Interviews with parents of 6 to 18 year-old children with Down syndrome (n=17), autism spectrum disorder (n=20), severe cerebral palsy (n=18) and Rett syndrome
(n=21) enabled thematic analysis to identify QoL domains. Domains and domain elements were mapped across the four disorders and against other measures. **Results:** Across disorders, most domains were common whereas some such as “independence and autonomy” applied to specific groups. Domains such as physical health and social connectedness were found in other QoL measures, but for children with ID, there were unique elements in each domain and some new domains such as “routines” were identified. **Conclusions:** These data allow for the construction of a QoL measure for children with ID with modules to address unique elements. This measure will allow clearer identification of support needs.

**From epidemiology to real world outcomes for the management of scoliosis in Rett syndrome**

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**Aim:** Scoliosis occurs commonly in Rett syndrome. This presentation describes multiple methodologies used to investigate its prevalence and clinical management. **Method:** The Delphi technique was used together with consumer consultation to identify clinical management guidelines for scoliosis, and gaps for further research identified. The Australian Rett Syndrome Database then provided the infrastructure for determining the prevalence and trajectory of scoliosis, and for examining relationships between spinal fusion, survival and respiratory health. A broad dissemination plan for findings was identified. **Results:** The clinical management guidelines were developed into a lay booklet for families. Scoliosis occurs in 75% of those with Rett syndrome. Progression of scoliosis is greatest in those with a more severe mutation who are unable to walk. Spinal fusion for severe scoliosis reduces mortality and confers advantages to respiratory health, particularly in those who develop scoliosis when younger than eight years. Dissemination comprises multiple presentation formats including within a clinical ethics framework. **Conclusions:** These findings collectively provide an evidence base for the clinical counselling of individual families to best cater for their needs and wishes.

**Understanding the complexity in complex support needs**

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**Aim:** This paper develops theoretical underpinnings and a conceptual framework for understanding ‘complex support needs’ in the context of people with intellectual disabilities (ID) who experience multiple and compounding disability, disadvantage and discrimination. **Method:** Drawing on current theoretical, policy and practice literature in complexity social science and disability studies, the paper develops a framework to interrogate the nature of ‘complexity’ and of ‘support’ for this group. This understanding is applied to support frameworks embedded in policy and practice through the Australian National Disability Insurance Scheme (NDIS). **Results:** Compartmentalising of individualised funding under the NDIS excludes certain aspects of support, which are fundamental to addressing complex support needs. Most importantly, the relational aspects of support remain poorly recognised and under-funded in the NDIS. **Conclusions:** A framework for recognising and addressing complex support needs in the new era of individualised funding models and marketised disability services is provided.
The health of Scotland’s 5,709 people with autism and intellectual disabilities

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Aim: Little is known about the self-rated health status of people with co-morbid autism and intellectual disabilities (ID) in whole country populations. This paper will present analysis of: self-rated general health status, demographic factors, and prevalence of other disabilities for people with co-morbid autism and ID, as well as people with autism only. Method: We analysed data from Scotland’s Census 2011, and generated descriptive statistics. Results: People with co-morbid autism and ID (n=5,709) comprised 0.1% of the total population of Scotland (n=5,295,403) and 18.0% of the whole population of people with autism in Scotland (n=31,712) across all ages. Only 2,863 (50.1%) people with co-morbid autism and ID rated their health as good or very good, compared with 19,971 (76.8%) of all people with autism only. Conclusions: Health is poorer for people with co-morbid autism and ID than for people with autism only. Further analysis will explore the impact of individual and household characteristics on the health of people with co-morbid autism and ID.

Health-related quality of life and health status of people with intellectual disabilities attending a specialised health service

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Aim: This study measured health-related quality of life (QoL) and health status of people with intellectual disabilities (ID) presenting to a specialised health service, with the aim of using the results to improve health interventions. Method: The EQ-5D-3L, a measure of health-related QoL modified for people with ID was used. Descriptive statistics were used to analyse routinely collected data on health conditions, health risk factors and uptake of preventive health measures. Results: This clinic population had poorer health-related QoL than the general population or other disability population samples. The items relating to pain, anxiety and usual activities were significantly correlated with a simplified visual analogue scale rating overall health. Up to 25% of people had previously undiagnosed health conditions or health risk factors and there was limited uptake of preventive health actions. Conclusions: This population had relatively poor health-related QoL, undiagnosed conditions or inadequately addressed preventive health measures. Specialised health services should work with the primary health sector to reduce these disparities.

Intellectual disability research in New South Wales, Australia

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Aim: To ascertain the range of intellectual disability research being undertaken in New South Wales (NSW); elicit views about the establishment of a minimum dataset; understand the barriers to research; and highlight research gaps. Method: The Research and Development Subcommittee of the NSW Agency Clinical Innovation Intellectual Disability Network conducted an online survey of researchers, clinicians and disability professionals. Snowball sampling was used to contact additional participants.
Research gaps were identified through interviews with some participants. **Results:** There were 105 respondents. Over 80% felt a minimum disability data set was needed for reasons such as identifying unmet needs. Lack of time, funding and difficulties with ethics clearance were important barriers to research. The range of research included studies in aging, falls and mental health. Inclusive research was limited. Research gaps included communication and transition. **Conclusions:** Through dissemination of these results can foster awareness and promote opportunities for research collaborations. A position paper on the minimum dataset has been developed and a progress survey will be conducted in 2016.
Check & Connect: A model for engaging and retaining students with intellectual disabilities in higher education

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**Aim:** In 2010, the Institute on Community Integration (ICI) at the University of Minnesota in collaboration with two Minnesota two-year community and technical colleges implemented a five-year project to establish inclusive and comprehensive services for engaging and retaining students with intellectual disabilities (ID) in post-secondary education. **Method:** Quantitative and qualitative data were obtained from an evidenced-based model of student engagement entitled Check & Connect (C&C). C&C is based on the principles of universal design for learning, person-centred planning, self-determination, and academic and social integration. Developed at ICI in 1990, C&C addresses student persistence, engagement, and successful program completion by providing intrusive mentors. **Results:** 2010-2014 data collected revealed: 65% lived independently (not with family); 110 received diplomas, certificates, or degrees; 31 were working full-time; and 62 were working part-time. C&C coaches check in with students, staff, faculty, and parents on a regular basis and connect students to needed resources and supports to promote a successful and integrated college experience. **Conclusions:** Students were successfully integrated into post-secondary and attained work and independent living skills.

Family quality of life and social support

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**Aim:** Family quality of life (QoL) examines the QoL of the entire family when there is a member with an intellectual and developmental disabilities (IDD). Findings in the field suggest families experience isolation and a lack of social support, but the conceptualisation of social support needs to be expanded in order to explain and explore the phenomenon. **Method:** A multiple case study methodology was employed with six families with a child with IDD. The interviews were guided by a family QoL survey and additional measures related to social support. **Results:** Current family QoL theory was found to be inadequate to explain the nature of the social support required by families and the processes of losing or obtaining support. In addition to findings from the data, the suggested expanded conceptualisation of social support is influenced by social capital, community development theory. **Conclusions:** Results are discussed in terms of future family QoL research, the expansion of research outside of the disability world, and the need to enhance the support for families available within the community.

Visual attention bias to emotional stimuli amongst adults with intellectual disabilities

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**Aim:** The viability of a visual attention task was tested amongst adults with intellectual disabilities (ID). If viable, then it might show the bias in visual attention toward emotional faces found amongst high anxious adult groups in the general population. Attentional training can reduce this bias and symptoms of anxiety. **Method:** Pictures of happy, angry and neutral faces were presented on a screen and
response times (RT) measured in milliseconds. The presence of a bias was determined by the difference between emotional (angry or happy) face RT and neutral face RT. 43 adults with severe, moderate and mild ID attempted the task and anxiety was rated on respondent and informant measures. **Results:** Most participants mastered the task, including some with severe ID but mean difference in RT was not significant for either the low or high anxiety groups. **Conclusions:** The task is viable across levels of ID but it is not clear why a bias is absent in the high anxious group. If methodological problems explain the absence and a bias does exist then attentional training could be trialed.

**Supporting adults with developmental disabilities to access written information**

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**Aim:** The aims are to present proposed elements of a best practice framework to enable written information to be accessible for people with disabilities with limited cognitive or literacy skills. **Method:** The Victorian Electoral Commission (VEC) and Scope have implemented a range of strategies to meet the needs of consumers with low literacy levels. These include producing Easy English resources, providing staff training, developing web accessibility and becoming communication accessible. A critical review of the process and resources through an iterative process of partner collaboration and consumer feedback identified seven elements of best practice. **Results:** A best practice framework has been proposed, incorporating seven key elements involving consumer engagement, process and product. These elements will be presented in relation to a case study from the (VEC). **Conclusions:** Collaborative partnerships with organisations committed to improve access for people with communication disabilities assist in developing our understanding of the constituents of a best practice framework for accessible written information. Further research is needed to support the provision of Easy English.

**Examining the associations between hope, social support, loneliness and depression in mothers of children with autism**

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**Aim:** Mothers of children with autism spectrum disorder (ASD) experience challenges that lead to lower well-being. Studies have found that hope predicts increased positive affect and life satisfaction. The current study examined the role of loneliness and social support as mediators of the association between hope and depression in mothers of children with ASD. **Method:** 94 mothers of a child with ASD (< 18 years old) participated. Mothers completed surveys assessing hope, loneliness, social support, and depression. **Results:** Hope agency and hope pathways were specified as predictors, loneliness and social support were mediators, and depression was the dependent variable. There was an indirect effect of hope agency on depression through loneliness (coefficient = -.42(.15), 95% CI: -.68, -.21). **Conclusions:** This study is the first to identify factors that may explain the association between hope and well-being. The belief that your goals can be met was associated with less loneliness which predicted lower levels of depression. Mothers who are more hopeful about the future may be more likely to draw upon their social support network in order to meet goals.
Capacity building with families: Lessons from one Australian State

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Aim: Capacity building for consumers of disability services is currently being considered in Australia under the National Disability Insurance Scheme’s Information, Linkages and Capacity Building (ILC) framework. This paper explores capacity building undertaken with families of people with intellectual disabilities by the Resourcing Families Capacity Building Project in New South Wales. It examines the opportunities and challenges in supporting families to plan and build a meaningful life for their relative.

Method: 26 families completed qualitative semi-structured interviews at the time of workshops and several months later. Findings were analysed thematically. Results: Families are capable of making significant changes in the lives of their relative within a short timeframe if they are given the skills, and ongoing resources to “dream big” and take action. Conclusions: Successful capacity building with families relies on ongoing resourcing by the ILC of local initiatives which engage families in personal discussion and problem solving. Efforts are also needed to change discriminatory community attitudes and to build the expertise of the disability workforce.

Comparing the developmental trajectory of early social cognition skills between children with Fragile X and Cornelia de Lange syndromes

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Aim: Although individuals with Fragile X (FXS) and Cornelia de Lange (CdLS) syndromes have a heightened likelihood of reaching cut-off scores on assessments of autism spectrum disorder (ASD), fine-grained analysis of ASD-like characteristics highlight their contrasting socio-behavioural profiles. This study compares the developmental sequence of early social cognitive skills that may underpin the socio-behavioural phenotypes in children with FXS and CdLS. Method: Children with FXS (n=22) and CdLS (n=15) participated in the ‘Early Social Cognition Scale’ (Powis, 2014), assessing early social cognition skills that typically emerge in a strict developmental order. Results: The sequence that children with FXS pass these tasks diverges from typical development. Children with FXS develop early abilities, but present an overall deficit in acquiring later abilities despite reaching the developmental age that these abilities typically emerge. Findings from children with CdLS yet to be collected will also be reported. Conclusions: Results suggest there may be an underlying mechanism other than general cognitive ability disrupting social cognitive development in children with FXS. Comparison between CdLS results will confirm whether or not these findings are specific to children with FXS.

Intimate relationships via access to social media and the internet: Research in progress

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Aim: This study explores the lived experience of adults living with intellectual disabilities (ID) and their access to social media as a way of developing intimate relationships and exploring their sexuality

Method: A phenomenological approach is being used to collect data through in-depth, semi-guided,
interviews exploring participants’ experiences of using social media in the development of their sexuality and opportunities to form intimate relationships. **Results:** Preliminary results are consistent with prior research around parental or organisational gatekeeping and the prevention of participants in the study from accessing social media freely. Their desire to be sexual beings or the want to ‘feel sexy’ has not been reported as something they want to do as it is deemed ‘dirty’. However, some participants actively view sexually explicit material to enhance their existing intimate relationships. **Conclusions:** Findings indicate that people living with ID continue to have their human rights denied as they are not allowed to express their sexuality by being ‘gate kept’ in having limited access to social media.

**Transforming group accommodation from block to individualised funding: An exploration in South Australia**

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**Aim:** The aim of this study is to gain further understanding of organisational transformation from block to individualised funding. **Method:** As a qualitative study, the research design was sympathetic to a phenomenological approach in that the data were collected through participant interviews with organisations which had lived experiences of transforming from block funding to individualised funding. **Results:** A number of themes emerged from the data. The key theme is the reciprocal interdependence between the social and developmental needs of organisation and individuals. Additional themes such as presence and participation; relationships; choice and control; dignity and respect; and competence emerged during data analysis and were linked to O'Brien's five service accomplishments (1999) as an indicator of the ability of services to transform and meet the goals of individualised funding. **Conclusions:** Moving from block funding to individualised funding for people living with disability is the first step towards transformational change. The task begins, however, with developing an approach for each person, developed from his or her personal story for the choice of a better life.

**Adapting Lesson Study to support teachers in meeting the needs of complex learners**

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**Aim:** In Lesson Study, groups of teachers collaborate to devise a research question regarding a student. They then design, deliver and evaluate pedagogical approaches to meet the pupil's needs. We utilised an adapted version of this approach as part of professional development of teachers and teaching assistants in a school for children with profound intellectual and multiple disabilities (PIMD). We then evaluated how useful the staff found the process. **Method:** School staff (n=10) participated in action research. Data comprised records of meetings, student profiles and staff interviews. Data were analysed thematically. **Results:** Staff found the Lesson Study process assisted them in developing insight into their students and devising pedagogical approaches to meeting student needs. **Conclusions:** Staff working with the most complex students often work in relative isolation. Lesson Study provided a format for collaboration and mutual support and was effective in contributing to professional development. The process enabled teaching assistants to have a fully participatory role and all participants intend to continue to use the process.
Quality of life indicators for individuals with intellectual disabilities: Extending current practice

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**Aim:** This presentation will review the literature and recommend methods for incorporating aggregate subjective quality of life (QoL) data into larger, more comprehensive strategies for policy and program evaluation. **Method:** Existing measures of QoL were reviewed to create a picture of what we understand to be the social construct of QoL. Using these measures, methods for integrating QoL into larger, more comprehensive policy and service evaluation practices were considered. **Results:** The use of subjective QoL frameworks as a stand-alone evaluation strategy may not be the most suitable conceptual framework for understanding and evaluating the effectiveness of policies and practices. The presentation will highlight more appropriate methods integrating diverse frameworks. **Conclusions:** States and nations require a consistent means to evaluating the effectiveness of publicly funded support. Methods for integrating quality-of-life measurement into larger, comprehensive strategies for this purpose should be considered.

The physical health of British adults with intellectual disabilities: A cross-sectional study

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**Aim:** To add to knowledge about the health of the ‘hidden majority’ of adults with mild intellectual disabilities (ID) who do not use ID services. **Method:** Secondary analysis of data from Understanding Society. We identified 299 participants aged 16 to 49 years (1.1% of the unweighted age-restricted sample) as having ID, and 22,927 as not having ID. Multivariate logistic regression was used to investigate between-group differences adjusting for potential confounding personal characteristics. **Results:** British adults with ID have markedly poorer health than their non-disabled peers on the majority of indicators investigated including self-rated health, multiple morbidity, arthritis, cancer, diabetes, obesity, measured grip strength, measured lung function and polypharmacy. Adjusting for between-group differences in socio-economic disadvantage and neighbourhood quality had a marked impact on risk estimates with the number of statistically significant differences reducing from 13 to 8 and statistically significant attenuation of risk on three indicators. **Conclusions:** The ‘hidden majority’ of adults with primarily mild ID have significantly poorer health than their non-disabled peers. This may, in part, reflect their increased risk of exposure to well established ‘social determinants’ of poorer health.

Challenging behaviours among children at risk of intellectual disabilities in 23 low and middle income countries

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**Aim:** To estimate the prevalence of aggression and problematic peer relationships in 3 to 4 year old children who are not at risk of intellectual disabilities (ID) in low and middle income countries. **Method:** Secondary analysis of Round 4 and 5 UNICEF Multiple Indicator Cluster Surveys from 23 low
and middle income countries (n= 90,179 3-4 year old children). **Results:** Significantly higher rates of problematic peer relations were evident for children at risk of ID in 22 of the 23 countries. Significantly higher rates of aggression were evident for children at risk of ID in only 5 countries. Significantly lower rates of aggression were evident in 12 countries. Lower rates of aggression among children at risk of ID were more common in low income countries (9/11 countries). **Conclusions:** These results stand in stark contrast to evidence from high income countries which suggest that children with ID are at significantly increased risk of ‘challenging behaviours’ when compared to their non-intellectually disabled peers.

**Overweight and obesity among children at risk of intellectual disabilities in 20 low and middle income countries**

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**Aim:** To estimate the prevalence of overweight and obesity in 3 to 4 year old children who are/are not at risk of intellectual disabilities (ID) in low and middle income countries. **Method:** Secondary analysis of Round 4 and 5 UNICEF Multiple Indicator Cluster Surveys (MICS) from 20 low and middle income countries that included a total of 83,597 3 to 4 year old children. **Results:** Few differences in risk of overweight or obesity were apparent between 3 to 4 year old children identified as being at risk/not at risk of ID in 20 low and middle income countries. In the two countries where statistically significant differences were observed, prevalence of overweight/obesity was lower among children at risk of ID. **Conclusions:** These results stand in stark contrast to evidence from high income countries which suggest that children with ID are at significantly increased risk of obesity when compared to their peers without ID.

**Transcranial magnetic stimulation and motor dysfunction in autism spectrum disorder: Novel opportunities for research and intervention**

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**Aim:** Individuals with autism spectrum disorder (ASD) often experience difficulties in motor control. Examining the neurobiology of these difficulties poses several challenges, particularly when approaches are often prohibitively invasive. A novel way of probing the motor system that might be more appropriate for use in ASD involves transcranial magnetic stimulation (TMS). **Method:** Individuals with ASD (n=36; 28 male; mean age: 26 years) underwent TMS to motor cortical regions, and responses were recorded in peripheral muscle via electromyography. In a subsequent study of ASD (n=11), brain responses were recorded via electroencephalography (EEG). **Results:** ANOVA revealed that motor cortical inhibition was reduced among individuals with ASD, but only when early language delay was also present. Applying repetitive TMS to supplementary and primary motor cortices improved neurophysiological (EEG) indicators of movement preparation. **Conclusions:** The current findings indicate that motor problems in ASD may be linked to neurochemical (e.g., GABAergic) impairments, but repetitive TMS holds promise as a potential intervention. Newer TMS techniques used in ASD are furthering our understanding of these motor difficulties, and might indicate abnormal neuroplasticity.
A framework for defining quality of life in children with autism spectrum disorder

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**Aim:** Autism spectrum disorder (ASD) is a common neurodevelopmental disorder characterised by social communication impairments and behavioural challenges. Existing quality of life (QoL) measures for ASD focus on the challenges faced by parents rather than identifying positive aspects of the child’s life quality. This study explored QoL of children with ASD and compared domains with other QoL measures.

**Method:** 19 semi-structured parent interviews were conducted, investigating aspects of their child with ASD’s QoL (6-16 years). Domains emerged through qualitative thematic analysis using grounded theory, and were compared with other parent-report child QoL measures.

**Results:** Ten domains were identified: physical health, behavioural and emotional well-being, comfort and relaxation, communication and expression, social desire, leisure and recreation, the natural environment, flexibility and routines, mastery and achievement, and services and associated outcomes. Existing generic or condition-specific QoL scales did not capture the QoL of children with ASD.

**Conclusions:** Findings support the construction of a parent-report measure for child QoL in ASD that enables more precise assessment of interventions that aim to increase adaptive behaviour and reduce or eliminate difficulties.

Anti-androgenic treatment of sex offenders with intellectual disabilities

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**Aim:** Indication and procedure for anti-androgenic treatment of sex offenders with intellectual disabilities (ID) are presented and critically discussed with respect to benefits and disadvantages of this treatment method.

**Method:** As part of a key date study, all sex offenders with ID were included in this survey. Files were analysed with respect to diagnoses, general treatment strategies, privileges and anti-androgenic treatment.

**Results:** The sample included 33 sex offenders. They all obtained psychotherapeutic treatment. In 21 patients anti-androgenic medication was also prescribed after different lengths of treatment times (1 to 10 years). Indication for anti-androgenic treatment was failure of other treatment methods, precise and individual target parameters and consent of patients. Unaccompanied privileges were granted to 19 of the 21 patients after a reduction of critical incidents and behaviours.

**Conclusions:** Although there is no empirical evidence about the effect of anti-androgenic treatment for sex offenders with ID with respect to time of treatment and success of conditional discharge, this treatment approach showed beneficial effects in numerous patients in our hospital.

Coercive interventions during forensic-psychiatric treatment of patients with intellectual disabilities

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Aim: Physical restraint and seclusion are distressing and indispensable interventions in managing violent behaviour in forensic psychiatric settings. This survey outlines the frequency of these interventions during the period 2000 to 2010 to enable comparisons with strategies in other countries. Method: Files of 80 patients with intellectual disabilities admitted in the time period were analysed with respect to index offence, psychiatric and criminal history, incidents during treatment as well as the nature and frequency of coercive measures applied during hospital treatment. Results: Almost all patients were admitted because of violent offences. 45% of the patients had co-diagnoses of personality or conduct disorders, and two thirds had a criminal history. Frequent incidents during hospital treatment were violence against staff or violence against other patients and non-compliance with rules. Conclusions: Adherence to strict internal standards, repeated staff training in cognitive behavioural treatment strategies and de-escalation reduce the risk of malpractice. However, to prevent physical harm, seclusion remains an important intervention in managing violent incidents during hospital treatment.

Developing a knowledge translation strategy to support effective and tailored services to promote healthy aging in people with intellectual disabilities

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Aim: Health and disability services are ill-equipped to meet the needs of people with intellectual disabilities (ID) with age-related conditions, such as dementia. Effective knowledge translation (KT) strategies for ID aging research are required. This review aims to explore useful KT strategies for this field. Method: A narrative review, using databases (e.g. PubMed), and manual searching was conducted. Search terms included knowledge translation, research-to-practice, aging, dementia, and ID. Included papers focussed on KT or changes in service provision. Analysis focussed on evidence of practice change following specific KT strategies, and applicability to the ID context. Results: There is emerging literature on KT in ID health research, but little specific to aging, or evaluating KT outcomes. KT strategies successful in non-ID aging research could be adapted, including: collaboratively identifying research questions; tailored, targeted messages; measurable targets for practice change; and interpersonal contact. Conclusions: An effective KT strategy can highlight research gaps, maximise the impact of future efforts, and could help bridge the gap between aging and disability.

A critical discourse analysis of community access service policy and practice informed by people with intellectual and developmental disabilities in the United Kingdom and Australia

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Aim: This research explored the extent to which the voices of people with Intellectual and developmental disabilities (IDD) have contributed to Community Access Services (Adult Day Activity Social Services) policy and practice in the United Kingdom and Australia. Method: A critical discourse analysis of publically available Community Access Services extant texts published between 2000 and 2014 in Australia was performed. The written evidence included strategic and operational policies and discussion papers. A comparison of policy discourse and practice in the United Kingdom followed. Results: Five findings relevant to eligibility and equity, design and implementation and evaluation within
policy discourse and practice are presented. The findings contribute to the community inclusion and community participation of people with IDD by focusing on their voices within the policy discourse.

**Conclusions:** These findings add to the understanding of policy in this under-explored area of research and inform the increasing involvement of people with IDD in a co-production process as equal partners in policy development and practice.

The pros and cons of inclusive education for children with profound intellectual and multiple disabilities

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**Aim:** Although children with disabilities have the right to be included into the school system, children with profound intellectual and multiple disabilities (PIMD) are often not included. This study aims to identify factors that contribute to success or failure of inclusive education for children with PIMD.

**Method:** Semi-structured interviews were undertaken with parents, healthcare professionals and teachers involved in the different support and educational systems related to children with PIMD. Interviews were transcribed and analysed thematically. **Results:** Data collection is ongoing. The presentation will give an overview of the themes concerning factors that contribute to the success or failure of the inclusion in education of children with PIMD. **Conclusions:** The knowledge we gain from this study will inform projects targeting the inclusion of children with PIMD and will help to improve the accessibility of education for children with PIMD.

Analysing the practice of effective primary mathematics teachers including students with Down syndrome

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**Aim:** Teaching children with Down syndrome (DS) within a regular primary mathematics class is a highly skilled undertaking. Little is known in the research literature about how teachers do this. Through analysis of a lesson, the aim is to discern features that lead to effective learning in this context. **Method:** Case study methodology was used to analyse a mathematics lesson taught to a year 4 class that includes a student with DS. Lesson observation, field notes, photographs, videos and interviews with the teacher comprise the data used to identify features in effective inclusive mathematics education practice. **Results:** Features include: engagement of the child in all lesson phases; modification of requirements to meet learning goals; opportunities for learners to learn from peers; teacher strategies for monitoring the learning of all students. **Conclusions:** The findings support development of criteria for judging effectiveness of other lessons. With policies around the world specifying inclusive education for all, mechanisms for assisting teachers to undertake this skilled work are needed.
A psychological support to youngsters with intellectual and developmental disabilities as a self-esteem individual and group improvement experience

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Aim: Youngsters with intellectual and developmental disabilities (IDD) face many difficulties in self-esteem, some are stigmatised and not part of any social group. This study examines the impact of psychological support on the personal growth of youngsters with IDD. Method: 18 youngsters with IDD participated in a group using techniques proposed by Carl Rogers, psychotherapist, in the early 60s. Results: Examples will be used to demonstrate how the functional feedback by the psychologist of the emotional contents expressed by the group is highly relevant to growth. Conclusions: By sharing emotions, the need to increase cooperation among the group became fundamental to the success of the educational rehabilitation project, where main activities are based on relationship and socialisation.

Energy expenditure, physical activity and field testing performance in people with intellectual disabilities

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Aim: Individuals with intellectual disabilities (ID), including individuals with Down syndrome (DS) exhibit low levels of physical activity and reduced performance on cardiovascular (CV) fitness field tests. An overview of our current understanding of how physiological differences, such as energy expenditure and muscle strength, interact with objective measures of physical activity and CV field test performance will be provided, with suggestions for future research. Method: Measures of energy expenditure during walking and running and muscle strength, and their influence on physical activity and CV field performance, were evaluated in several studies (35 to 40 participants per study) with repeated measures ANOVA and multiple regression. Results: Individuals with ID have higher energy expenditure during physical activity (15-90%), and lower muscle strength (10-30%), producing higher effort required to be physically active and to perform CV field tests. Conclusions: Our data suggest that the reduced levels of physical activity and CV field test performance are dependent on other physiological variables and this needs to be considered when interpreting and using physical activity and CV field test data in individuals with ID, including individuals with DS.

Vision awareness training for health and social care professionals working with people with intellectual disabilities

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Aim: People with intellectual disabilities (ID) are ten times more likely to have a visual impairment, compared to the wider population. Lack of awareness of their particular vision needs among health and social care professionals can act as a barrier to accessing appropriate care and treatment. Method: Vision awareness training was delivered to 104 professionals over a 12-month period. 90 (87%) completed pre- and post-training questionnaires, using repeat measures, to determine training
outcomes. **Results:** The training was found to significantly increase professionals' knowledge/awareness of the vision needs of people with ID, and their confidence in recognising signs of sight loss and recommending eye test referrals for their clients. **Conclusions:** Vision awareness training addresses a recognised barrier to effective health care delivery for people with ID.

**Investing in knowledge exchange and inclusive research techniques for policy impact of evaluation results**

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**Aim:** Utility is a key principle for effective evaluation design, yet investing in knowledge exchange after the evaluation so that results inform policy change about support to people with intellectual disabilities (ID) is costly. This paper takes the example of a retrospective policy evaluation of closing institutions in New South Wales, which had sensitive critical findings, to examine how the inclusive evaluation design and the activities after the evaluation contributed to policy change. **Method:** Knowledge translation theory is applied to understand the extent of continued effectiveness of an inclusive approach. The translation outputs after the project included confidential and public reports and presentations, media, academic articles and invited discussions. **Results:** The project continues to influence policy change. The government applies the accountability framework to close remaining institutions, to which the researcher with ID contributed and the Disabled People's Organisation promotes. **Conclusions:** If researchers aim to achieve ID policy impact, they must consider and invest in utility during the design, conduct and delivery of the results, as well as continued engagement about the implications for the stakeholders.

**Changes in intellectual and adaptive functioning among adults with Williams syndrome across time**

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**Aim:** A broad age range of participants with Williams syndrome (WS) are often included in research investigations, implying individuals demonstrate consistent cognitive and adaptive development across ages. However, the longitudinal trajectories of intellectual and adaptive functioning have not previously been empirically examined in adults with WS. **Method:** 52 individuals with WS (51.9% male) were assessed with the KBIT-2 between two and seven times (mean age at first assessment=25.4 years, SD=8.6). Parents of 32 individuals with WS completed the VABS-II between two and five times (mean age at first administration=25.8 years, SD=7.3). Multilevel models were used to examine changes in KBIT-2 and VABS-II standard scores over time. **Results:** There were significant individual differences in IQ scores and trajectories. Overall, there were small but statistically significant increases in Composite and Verbal IQ scores over time. Adaptive behaviour scores significantly decreased over time. **Conclusions:** Contrary to the childhood trajectory, intellectual and adaptive functioning do not remain stable in adulthood in individuals with WS. Implications for research and clinical care will be discussed.

**Assessing the risk of online victimisation of adults with Williams syndrome**
Scientific Oral Presentations F

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Aim: Individuals with Williams syndrome (WS) are hyper-social; yet, they also experience social isolation. Thus, individuals with WS may seek social relationships through the Internet and social networking, potentially leading to the risk of online victimisation. This presentation reports social networking use and online vulnerability of individuals with WS. Method: 28 adults with WS (mean age=27.7 years) completed questionnaires about Internet and social networking use and then responded to hypothetical scenarios assessing their likelihood to take social and non-social risks online. Results: Participants with WS frequently used the Internet and visited social networking sites almost daily, with little parental supervision. Responding to scenarios, participants were more likely to agree to engage in socially risky behaviours compared to risky behaviours that were not social in nature (e.g., agreeing to meet an “online friend” in person vs. agreeing to give bank account information). Conclusions: Individuals with WS not only display social vulnerability in the real world but they also display socially vulnerable behaviours online that could also lead to victimisation. Implications for intervention and future research will be discussed.

Do adults with Williams syndrome recognize their own levels of social vulnerability?

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Aim: Specific risks for social vulnerability have been identified for adults with Williams syndrome (WS); yet, it is unknown whether they recognize their own vulnerabilities. This presentation compares parent to self-report ratings of social vulnerability of adults with WS. Method: 28 adults with WS (22 male) and their parents completed the Social Vulnerability Questionnaire (SVQ; Fisher et al., 2012). Average age of adults with WS was 27.7 years (SD= 8.4) and average IQ was 69.11 (15.28). Results: Parents reported higher social vulnerability overall compared to reports by participants with WS (Mann-Whitney U=193, Z=−3.26, p<0.001) and for 5 of 6 domains. Participants with WS reported significantly higher levels of emotional abuse (e.g. being picked on, peers making fun of him/her) than their parents reported.

Conclusions: Adults with WS may lack insight into how certain behaviours they display or how certain dangerous situations could put them at risk for social victimisation; yet, they seem aware of how others treat them. Findings highlight the need for interventions teaching individuals with WS to recognize and respond in risky situations.

High prevalence of diabetes and hypertension among persons with intellectual disabilities, Down syndrome and Asperger syndrome

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Aim: Obesity and lack of physical activity are frequently reported in persons with intellectual disabilities (ID), thus we hypothesise a higher prevalence of diabetes and hypertension in individuals with Down syndrome (DS), other ID and Asperger syndrome compared to the general population. Method: We used data from the central administrative database that is available for Stockholm County, for the years 1998-2014, on all healthcare consultations in primary healthcare, specialist outpatient care and inpatient care.
with at least one recorded diagnosis of diabetes or hypertension. **Results:** Compared to the general population, females with DS or other ID were 2 to 3 times more likely to have diabetes. Males with other ID and females and males with Asperger syndrome were 1.5 to 2 times more likely to have diabetes. Within the DS group, diabetes was more common in girls (age 18 or younger) than boys (2.6% vs 0.3%, $p=0.027$). The prevalence of hypertension was higher in males with Asperger syndrome and other ID. **Conclusions:** There is an urgent need for early diagnosis of diabetes and tailored lifestyle prevention in primary healthcare.

**Assessment of mental health problems and mental well-being in individuals with severe intellectual disabilities: A systematic review**

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**Aim:** This systematic review aims to identify and to evaluate the methodological quality of tools and methods available to assess mental health problems and mental well-being in individuals with severe intellectual disabilities (ID). **Method:** A comprehensive search of the literature identified studies that met the following inclusion criteria: at least 70% participants, or separate reporting of data concerning people with severe ID, development, adaptation or psychometric evaluation of measures aimed at mental health, and minimal description of assessment methods. **Results:** Mental health assessments are presented in terms of scope, methods and feasibility. Data from multiple studies were combined to evaluate a measure's overall reliability, validity and internal consistency. The Characteristics of Assessments Instruments for Psychiatric Disorders in Persons with Intellectual Developmental Disorders (CAPs-IDD) was used to evaluate the methodological quality of and to identify evidence-based assessments. However, many measures did not include a sufficient number of participants with severe ID in their evaluation of the psychometric properties. **Conclusions:** Few measures are available for use with individuals with severe ID and evidence-based assessments for a wider range of mental health problems are currently lacking.

**Psychological and pharmacological interventions for people with severe intellectual disabilities and mental health problems: A systematic review**

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**Aim:** Mental health problems affect people with intellectual disabilities (ID) in rates similar to the non-ID population. This study reviews the evidence concerning the availability and effectiveness of psychological and pharmacological interventions aimed at the prevention and treatment of mental health problems in individuals with severe ID. **Method:** A systematic search of ten databases identified peer-reviewed publications that met the following inclusion criteria: participants with severe ID, delivery of a psychological or pharmacological intervention, and reporting on a quantitative outcome measure of mental health. **Results:** The search yielded over 10,000 articles. Studies eligible for review were subjected to a quality appraisal and risk of bias assessment. Primary outcomes concerned symptom severity and impact of intervention on mental health, as assessed with standardised measures at baseline and post-intervention. Secondary outcomes concerned attrition rates, feasibility of the
intervention, therapy adherence and potential adverse effects. Eligible outcomes were further evaluated using the GRADE approach. **Conclusions:** More primary research is required to establish empirically-validated treatments for mental health problems in individuals with severe ID.

**Transition to adulthood for young people with Down syndrome: Longitudinal research from the Telethon Kids Institute**

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**Aim:** To explore the transition from school to adulthood using population-based and longitudinal data on children and young adults with Down syndrome (DS).  
**Method:** Questionnaires were administered to families participating in the DS ‘Needs Opinions Wishes’ study in 2004 (n=255), 2009 (n=269) and 2011 (n=188). Questionnaires included aspects of health, functioning, daily activities, and family functioning and well-being, as well as information on experiences during and after transition.  
**Results:** The young person’s behaviour and functioning was associated with involvement in post-school employment, which was positively associated with family quality of life. Those who reported better functioning in self-care, community and communication skills were more likely to be in open employment and/or attending technical and further education compared with those attending sheltered employment and/or day recreation programs. In comparison to those young adults attending open employment from 2009 to 2011, those attending day recreation programs were reported to experience worsening in behaviour both in the unadjusted and adjusted models.  
**Conclusions:** This unique longitudinal study provides important findings to guide service provision and policy development to facilitate successful outcomes in adulthood for young people with DS.

**Self-reported quality of life of autistic adults living in Australia compared to non-autistic adults**

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**Aim:** We describe self-reported quality of life (QoL) and its determinants in autistic adults and matched controls living in Australia.  
**Method:** The Australian Longitudinal Study of Adults with Autism and the School Leavers Longitudinal Study collects self-report data from individuals (15 to 18 years) with autism living in Australia. Questionnaires are completed online or via paper copies, recruitment is ongoing. The WHOQOL-BREF, DSM-V anxiety scales, PHQ-9 and the Autism Quotient are included. Regression analysis is used to investigate the relationship between variables.  
**Results:** To date, 115 adults with autism and 46 without have completed questionnaires. Controls reported significantly higher QoL scores across all four subscales; psychological, physical, environment and social relationships. There was no association between age and QoL, except for the environment subscale, where in controls, older age was associated with higher QoL.  
**Conclusions:** This is the first national study exploring self-reported QoL of autistic adults. The results will provide unique insight into QoL and associated factors for people with autism.

**Attitudes of health and social care professionals to the palliative care needs of people with intellectual and developmental disabilities in the United Kingdom, Portugal and Nigeria**
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Aim: To compare the attitudes of health and social care professionals towards death and dying of people with intellectual and developmental disabilities (IDD) across countries. Method: Focus groups were held with medical, nursing and social care professionals in the UK (n=25), Portugal (n=15) and Nigeria (n=8). Results: In the UK, palliative care was reported to be inconsistent; few participants received relevant training and people with IDD were felt to be marginalised from decisions about their end of life care. Staff were concerned about assessment and management of symptoms. In Portugal there was generally little understanding of palliative care and limited discussion regarding death and dying with patients and families; relatives often having unrealistic expectations of treatment. People with IDD were mainly cared for within institutions; homecare was not always successful. In Nigeria people with IDD were viewed as "different" and "difficult to handle" and there were few resources to help in their care. Conclusions: Profound differences in attitudes to palliative care needs of people with IDD exist reflecting societal taboos. Local developments are hindered by deeper cultural attitudes regarding the discussion of diagnosis and care in different countries.

Spirituality in relation to the social networks of individuals with intellectual and developmental disabilities

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Aim: Religious/spiritual communities may provide a conduit to making friendship for people with intellectual and developmental disabilities (IDD). This research explores the significance of spirituality in relation to the social networks of individuals in a faith-based and a non-faith based service. Method: A mixed methods approach was used during six months of voluntary work within each service. Interviews with individuals with IDD (or staff members for those who lacked capacity to consent) as well as the Social Network Guide and Spiritual Belief Inventory-15R were corroborated with field notes and participant observation. Results: Average network size significantly differed with the faith-based group having a higher network size of 78 compared to the non-faith based group (average size=44). Individuals with larger networks reported higher SBI-15R scores. Conclusions: Findings highlight the importance of social, spiritual/religious activities for expanding individuals' social networks.

Conversations about video that contribute to changes in interactions for people with profound intellectual and multiple disabilities

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Aim: Video has been recognised as a useful tool for enhancing communication with people with profound intellectual and multiple disabilities (PIMD). While there has been focus on outcomes of interventions, there has been less attention on the components of intervention that may be pivotal in supporting change. Good videos and well-chosen clips are important; so too, is the conversations that occur during sharing of videos. This study examines the conversation around a video Method: A team of five disability support workers (DSW) for a woman with Down syndrome and dementia participated in
an intervention using video recordings of their interactions. A short conversation between the DSW and a Video Interaction Guidance guide was audio-recorded and analysed to examine the nature of the talk. **Results:** The guide used many strategies to engage the DSW in a process of change, including asking questions to promote reflection, and providing space. **Conclusions:** Video interventions cannot be separated from the conversation that accompanies the video. It is the conversation that supports staff to name, reflect, and see possibilities.

**Parent observations of the language use of preschool children with Down syndrome**

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**Aim:** Children with Down syndrome (DS) present with uneven profiles of pragmatic development. However, effective family-focussed intervention requires both professionals and parents to understand the precise nature of each child’s profile. **Method:** Parents of 26 children completed the Language Use Inventory (O’Neill 2009) and the MacArthur-Bates Communicative Development Inventories. 13 children with DS (mean age 51.15 months; SD=11.65) were pairwise matched on Language Use Inventory Total Score to 13 typically developing (TD) children (mean age 18.62 months; SD=6.76). Total scores ranged from 14 to 136 out of a possible 161. **Results:** While the children with DS have larger vocabularies (mean 216.6 (DS) vs. 164.5 (TD)), those vocabulary gains have been achieved in the face of challenges to teaching and to comprehensibility. Similarly, although both groups use language equally to draw attention to a focus of interest, the children with DS make fewer relevant comments and questions than their TD matches and use language less spontaneously and less relevantly. **Conclusions:** Parents’ contributions to their child’s communication intervention programme can be more effective through precise reflections guided by parent questionnaires.

**What makes inclusive research tick? An explorative, multiple case study in three European countriesmicrobor**

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**Aim:** Inclusive research has been an emergent topic within intellectual and developmental disabilities (IDD) research. Increasing demands for inclusive research require sharing of experiences and, therefore, the aim of this study is to gain insight into: processes of, experiences with, and decision-making power in inclusive research. **Method:** An explorative, multiple case study of four international cases has been conducted by analysing research documents such as research proposals and logbooks (n=12); developing timelines with inclusive research teams existing of co-researchers, academic researchers, and supporters (n=4); and conducting interviews with team members separately (n=21). Data was qualitatively analysed. **Results:** Developing timelines retrospectively was challenging, which indicates reflection should be done iteratively throughout the inclusive process. Participants’ experiences suggested inclusive research was empowering and instructive for people with IDD as well as academic research(ers) and supporters. We will discuss how people with IDD were provided with decision-making
power in the included cases. **Conclusions:** The case studies have identified opportunities for improvement of and reflection on inclusive research.

**Gendered messages in sexuality education: What young men and young women with intellectual disabilities ‘hear’**

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**Aim:** Young people with intellectual disabilities (ID) develop knowledge about sexuality, gender and relationships through formal and informal education and information from families, staff and peers. This research aimed to find out about the quality and focus of this education from the perspective of young people and to understand how it shaped their thinking about gender and sexuality. **Method:** Qualitative research was undertaken with 25 young people in Australia. Gender-specific focus groups were conducted, transcribed and analysed using a constant comparative method of grounded theory. **Results:** Young people expressed an overall negative view of the education and information they received. Gendered messages about male and female sexuality were dominant in the discourses they shared about the quality and focus of this education and information. **Conclusions:** The formal and informal sexuality education and information young people with ID receive is inadequate. It is littered with strong gendered messages. These reinforce ideas that sex is dangerous for young men and something young women should be scared about, leaving young men and young women with little confidence about forming sexual relationships.

**Comparing a coffee can to structured professional and actuarial approaches in predicting risk of general recidivism**

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**Aim:** This presentation explores whether actuarial risk prediction of general recidivism in those with intellectual disabilities (ID) can be improved by using the most reliable items across different tools. **Method:** Six offender risk assessment tools were administered to 139 people with ID who had a history of offending. Tools included the ARMIDILLO-G, HCR-20, CuRV, GRAM, PCL-R and Level of Service Inventory – Revised. Rates of recidivism were followed up after six months. Regression and receiver operating characteristic (ROC) analyses were used to identify the items in tools that best predicted reoffending. The more reliable items were then used to generate new tools and additional tools were generated by selecting items at random. ROC analyses were conducted to assess whether there was a significant difference between tools. **Results:** Tools using items with greatest correlation to offending performed significantly better than tools developed out of items selected at random. **Conclusion:** There is opportunity to develop improved actuarial offender risk assessment tools for people with ID, however it is uncertain whether these tools are any better than those based on structured professional judgement.
Tensions and possibilities of co-producing knowledge of ‘intellectual disability’ with people with intellectual disabilities

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Aim: I address the difficulties and prospects of co-producing knowledge with people with intellectual disabilities (ID) emerging from three inclusive research projects: ‘My Life in the City’ (how people with ID use city space); ‘Re-Imagining Parenting Possibilities’ (experiences and aspirations of parenting for people with ID); and ‘Picture This’ (using photography to represent issues important to people with ID).

Method: Each project employed an inclusive design but varied in terms of how much, at what points, and in which ways people with ID were involved in decision-making and research activities. Results: Three points of tension revealed the complexities/possibilities of inclusive research: time (funding and institutional/caregiver pressures, disability-related time requirements), relationships (nature, duration, unbalanced sharing of information) and control (sharing and/or relinquishing, perceived vulnerability).

Conclusions: Each project had an explicit focus on social change, articulated in the research process and intended outcomes. Tensions highlight the need for ongoing reflection and engagement with people with ID to move towards meaningful inclusion in research.

Intersections between disability, education, employment and homelessness for youth: Challenges and impacts

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Aim: This project focusses on the (typically ignored) intersection of intellectual disability (ID), homelessness, education, and employment among youth in three Canadian cities, exploring experiences of youth navigating these sectors to make visible the prevalence of homeless youth with ID and map referral pathways/blockages between discrete support sectors. Method: A mixed method research design, site-anchored community partnerships, and co-researcher model (site-specific co-researcher teams include academics, agency staff and youth with ID and experiences of homelessness) were used. Data collection included: quantitative intake/program data on youth characteristics; environmental scan mapping referral pathways, gaps, and consequences for youth and agencies, and; key informant interviews with front-line staff and exploratory interviews with youth with ID who have experienced homelessness. Results: Data illuminates eroding social supports, confusing service pathways, gaps in services, wait lists; lack of coordination/integration among discrete sectors; and the consequent limited forms of inclusion offered to insecurely housed youth with ID. Conclusions: Ignoring the intersectionality of social problems, experiences and identities restricts youths’ with ID access to entitlements, supports, and services.

Re-imagining parenting by people with intellectual disabilities: Using forum theatre approaches in data analysis and dissemination

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**Aim:** We discuss the ‘Reimagining Parenting Possibilities’ project: a community-based, participatory research initiative using a co-researcher model to privilege the voices of people with intellectual disabilities (ID). The aim was to explore experiences and aspirations of parenting for/by people with ID. **Method:** Qualitative interviews with key informants and people with ID were conducted in six communities (rural, urban, Aboriginal) across the province of Ontario, Canada. Forum theatre approaches were used in a layered data analysis and dissemination process. **Results:** Initial interpretive analyses of qualitative interviews by co-researchers with and without ID led to the development of three ‘scenes’ that make visible and juxtapose subjugated, dominant, dis/ableist, resistant and other perspectives and raise questions of value, ethics, power and privilege. **Conclusions:** Using forum theatre to engage audiences with these scenes reveals alternative experiences and meanings of ID and parenting/parenthood, leading to deeper analyses and opportunities for initiating dialogue and equipping audiences to re-think parenting possibilities for people with ID.

**Forced marriage of people with intellectual disabilities**

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**Aim:** To explore the burgeoning issue of forced marriage of people with intellectual disabilities (ID) in the United Kingdom, including similarities and differences between forced marriage of people with and without ID. **Method:** Scoping interviews were undertaken with a range of professionals (n=9) with experience of cases of forced marriage of people with ID, including not only health and social care but also police, community development workers and a barrister. This interview data informed an online survey; snowball sampling was used to gain survey responses from 287 professionals about their understandings and experiences of cases of forced marriage amongst people with ID. **Results:** Forced marriage of people with ID shows marked differences to forced marriage of people without ID, in relation to not only age and gender of victims but also the motivations for forcing someone to marry. **Conclusions:** The cultural and social reasons for forcing a person with ID to marry will be discussed, and the possibilities for a new narrative which positions forced marriage as a safeguarding and human rights issue will be explored.

**Onwards transitions from school for young people with intellectual disabilities: A small-scale longitudinal study**

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**Aim:** This study explores the process of transition to adulthood for young people with ID in one English local authority. **Method:** Interviews with key stakeholders in child and adult, education and welfare services; a survey of all young people with ID leaving mainstream or special school in one English local authority in summer 2013; and longitudinal case studies over three years of a subset of the 2013 school leavers with ID were conducted. **Results:** Stakeholders are highly aware of the difficulties faced by young people with ID as they transition from school and children’s service to college and/or adult social care support. However, problems with data sharing; the inaccuracy of key datasets; and the fragmentation of market-driven adult care services militate against effective planning to meet predictable need for adult
services. Case studies over three years illustrate the negative consequences this has for young people with ID and their families. **Conclusions:** Despite attempts to improve the transition from child to adult services for young people with ID, many acute difficulties remain. Ways to improve the current system will be suggested.
Prioritising the voices of people with intellectual disabilities in fieldwork

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Aim: Disability research is undergoing a paradigm shift where people with disabilities are active partners, not just subjects. How can these inclusive research practices be adapted to government evaluation and policy reviews, where they challenge research norms? **Method:** When reviewing the closure of institutions in New South Wales, Australia, the inclusive research team used various research strategies to include people with intellectual disabilities (ID). The methods included designing accessible research tools; using researchers with experience in engaging with participants with complex communication needs; involving a research team member with lived experience (supported by a Disabled Persons Organisation) in the design and analysis; and including trusted persons of participants.

**Results:** A collaborative approach to research that is inclusive and creative privileged the voices of people with ID, which strengthened the content and style of the findings to directly influence policy.

**Conclusions:** Even technical evaluation research can incorporate inclusive practices to improve the policy impact of policy research. Its underlying methodology highlights the pivotal role of inclusion of people with ID in all aspects of the research process.

Models of inclusion in tertiary education

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Aim: The United Nations Convention on the Rights of Person with Disabilities calls for moving from the rhetoric of social inclusion into practice. Article 24 (Education) protects the right of persons with disabilities to education; with a view to realising this right without discrimination through equal opportunity. How can inclusive education be achieved for people with intellectual disabilities (ID) at the tertiary level? **Method:** A review of the international literature on tertiary education for people with ID was undertaken. **Results:** The inclusion of students with ID into tertiary education remains limited, but is gaining interest worldwide. Universities are now shifting paradigms to include people with ID. The literature distinguishes three models of educational opportunities for people with ID at the tertiary level: the fully inclusive, the hybrid and the separate model. **Conclusions:** Separate models run the risk of generating inclusion that is merely locational. Principles of full inclusion need to be informed by a moral perspective, an understanding of the social model of disability, as well as an evidence base on best practice and related outcomes.

United States and New Zealand: Distinct policies, differing disability research

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Aim: A comparison between United States and New Zealand disability legislation was conducted to consider how each country’s distinct philosophical derivation shapes research pertaining to transition from school for students with intellectual and developmental disabilities (IDD). **Method:** Comparative timelines were constructed of each country’s education policies and related features of transition from
school. Meta ethnography (Noblit & Hare, 1988) guided review of seminal empirical studies to ascertain whether the distinct socio-political and philosophical foundations of disability rights in each country have led to qualitatively different research questions, paradigms, and designs. **Results:** Legislative background of transition in the United States established a precedent for research that could be held to a ‘gold standard’. Transition in New Zealand was tied to wider international practices of social development. Research was seen as protecting rights and rectifying political injustices. **Conclusions:** Socio-cultural aspects from each country are used to consider the nature of knowledge in research production. Findings will extend the field of IDD by furthering transition policies with practical implications for examining and shaping international social research.

**Engaging bodies: A classroom-based assessment of movement problem-solving for students with intellectual and developmental disabilities**

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**Aim:** To place students with intellectual and developmental disabilities (IDD) at the centre of their learning, movement learning needs must be taken into account. Teachers are well placed to scaffold learning environments to facilitate maximum physical engagement, however in mainstream settings they are under-resourced for this work, with the result that classrooms are often ‘over-protective spaces’, with reduced motor learning potential. **Method:** Drawing on motor learning theory and a methodology for constructing learning pathways, experienced special educators and school-based therapists collaborated to develop a behaviourally anchored rating scale, describing movements intrinsic to classroom learning, which was trialled by 897 teachers and therapists across 2015, assessing 2300 students with a wide range of IDD. **Results:** A high internal reliability coefficient was returned for this 18-item scale (r² = 0.95), indicating the items are acting consistently together to describe the movement construct. **Conclusions:** A valid and reliable assessment of movement intrinsic to learning can be developed for teacher use, enabling them, in collaboration with school-based therapists, to support motor skill development, and facilitate active learning engagement for students with IDD.

**Spirituality, quality of life, and pathways to community supports**

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**Aim:** To summarise research and practical strategies on the ways that spirituality can be addressed in services and supports for people with intellectual disabilities (ID) and its contribution to quality of life and community supports. **Method:** This presentation will summarise current research in the United States on the role of spirituality in services and supports (Carter, Ault, and others) especially as seen by individuals with disabilities and their families, and practical strategies for addressing spiritual needs and gifts in planning and service delivery. The role of spiritual supports in relation to person-centred planning, quality of life, cultural competence and enhanced community inclusion will be addressed. **Results:** The role and importance of spiritual supports can be seen in theoretical work, quantitative and qualitative research and in a rapidly growing variety of service supports. **Conclusions:** Spirituality is a dimension of support that can be seen in both positive and negative experiences for people with ID and
their families. It requires sensitive approaches, effective community building skills, and long-term commitment.

**Developing a service practice and evaluation model in early childhood intervention**

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**Aim:** In order to address current limitations in the transfer of contemporary conceptual frameworks to practice implementation in early childhood intervention (ECI), we developed a service practice and evaluation model that was continuous, collaborative, and evidence-based. **Method:** Using a participatory action research methodology, 15 practitioners from an Australian ECI service, which supports 150 young children with developmental disabilities and their families, and two external researchers, participated in an iterative process involving data sources such as bi-monthly meetings, staff and family surveys, presentations and observations. **Results:** We identified three models: a conceptual model (key concepts); a service practice model (key practices and child and family outcomes); and an evaluation model (key measures and methodologies). Over a period of five years, these models have been trialled and refined resulting in positive outcomes for children, families and ECI service and its staff. **Conclusions:** The service practice and evaluation model has been effective in implementing evidence-practices in the ‘real world’, providing a blueprint to inform future service and policy development, and evaluation efforts.

**The impact of art making on people using regional disability services**

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**Aim:** To explore the impact of art-making on people using regional disability services as research has shown that art making encourages inclusion, increased brain activity and increased self-esteem. However, art making as a process remains under-researched. It is hypothesised that people with an opportunity to express themselves through art have an outlet to where they may increase their sense of well-being. **Method:** The study included nine participants who use regional disability services to access art making in a group. A case study design was employed using PAR data collection and analysis tools including focus groups, observations, mood questionnaires and art works. Thematic coding tools were utilised for the analysis of the data using NVivo software. **Results:** Preliminary findings demonstrate the multifaceted connections people engaged in art making can experience including connection to the art making process, connection to others and connection to self. **Conclusions:** The results will contribute to our understanding of how art-making impacts self-esteem, social connectivity and community interaction, all of which foster agency and a sense of belonging.

**Indian mealtime habits that may lead to problems with children with cerebral palsy and dysphagia**

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**Aim:** We will outline a range of cultural eating and drinking patterns that impact on children with cerebral palsy (CP) and dysphagia in India, so that these can be taken into account in the culturally appropriate modification of standard mealtime assessment instruments. **Method:** Case study methods will be used to illustrate a range of cultural issues that are common practice at mealtime for all Indian children, posing an increased risk of adverse outcomes. **Results:** When children with CP begin to have solid food, mothers often feed them rice by hand, making a bolus of food and putting it directly into the mouth — avoiding the spillage of food, important if food is a scarce commodity. The common ‘spicy’ foods might be avoided. Thus the child has no practice with chewing or forming a bolus and fewer spicy tastes. Some cultural influence in India may disadvantage children with CP and dysphagia. **Conclusions:** Eating and drinking are influenced by cultural practices that may increase the risk of ill health or death, increased risk of oral sensitivity, choking, and aspiration pneumonia.

**Childhood and adolescent predictors of adult functioning in a sample with Down syndrome**

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**Aim:** Individuals with Down syndrome (DS) tend to have difficulties that restrict their capacity for independent living in adulthood. This 20-year prospective longitudinal study investigated the trajectory of individual (mastery motivation and self-regulation) and contextual (maternal support for autonomy) characteristics, and their predictive associations with measures of adult functioning. **Method:** 25 individuals with DS participated in the first two phases of the study in childhood (aged 4-6 years) and adolescence (11-15 years). Data about adult functioning were obtained for 22 of the young people when they were 24 to 26 years old. Measures in childhood and adolescence included structured tasks, observations and parent reports. Adult measures included the AIR Self-Determination Scale and the Vineland Adaptive Behaviour Scale, Second Edition. **Results:** There were significant associations between the child/adolescent measures of mastery motivation and self-regulation and adult measures of self-determination and adaptive behaviour. Maternal support for autonomy in childhood was unrelated to adult outcomes. **Conclusions:** The findings demonstrate the central and enduring role of mastery motivation and self-regulation for the lives of individuals with DS.

**Diagnosis of disordered attachment behaviour**

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**Aim:** The multifaceted nature of attachment requires a comprehensive approach to the diagnosis of disordered attachment behaviour. The AACAP Practice Parameter describes standard elements and clinical guidelines for this assessment procedure. This study assessed the convergence of structured observations, clinical interviews, and case record reviews for extremes of insufficient care as diagnostic indicators for children at risk. **Method:** Children (n=55) referred for psychiatric consultation with low intellectual functioning (IQ:50–85) participated in the study. The Disturbance of Attachment Interview (DAI) was used to screen for symptoms, and the Clinical Observation of Attachment was used for observing adaptive and maladaptive attachment behaviours. **Results:** Children with extremes of insufficient care (n=12) had a significantly higher total Attachment Behaviour score (mean=24.83,
SD=5.14). Ten children (18%) were diagnosed (DSM-5) with Reactive Attachment Disorder and/or Disinhibited Social Engagement Disorder. The outcomes of the screening interview predicted 75% of the finally determined diagnoses. **Conclusions:** A structured approach to assessment of disordered attachment behaviour yields consistent data, facilitating diagnostic decision-making.

**The sibling experience: Living with Down syndrome or Rett syndrome in the family**

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**Aim:** The aim of our research is to understand the needs of the unaffected siblings of children who have intellectual and developmental disabilities (IDD). Siblings may be disadvantaged when family resources are limited. Our study focussed on parental perceptions on how having a child with IDD in their family affects their other children without disabilities. **Method:** We administered study-specific questionnaires to parents of children with Rett syndrome (RS; n=182) and Down syndrome (DS; n=184) and analysed the data quantitatively using descriptive statistics. **Results:** The majority of parents in both groups described benefits for their children. Parents in both groups thought siblings were disadvantaged in time flexibility and socialisation. Siblings of girls with RS were rated as more disadvantaged than siblings of children with DS. The differences between the two groups may be a consequence of the disability severity and the presence of co-morbidities, behavioural issues and physical impairment. **Conclusions:** Parents of children with RS and DS perceive both advantages and disadvantages for their unaffected children. Detailed data and opinions collected from siblings themselves will complement this research.

**Is the increasing life expectancy of people with Down syndrome starting to plateau?**

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**Aim:** During the 20th century the estimated median life expectancy of people with Down syndrome (DS) rose significantly from nine years of age in the 1920s to 57 years by the year 2000. Using a whole population approach and four linked population-based health datasets, the survival patterns of people with DS born between 1902 and 2009 have been investigated. **Method:** 2,300 cases of DS were sourced from the State Disability Services database, the primary registration point for people with intellectual disabilities in Western Australia, complemented by additional State databases containing codes for DS - Hospitalisations, Death records and the Births Defects register. **Results:** Major improvements in the survival of infants with DS are evident in recent decades, but overall life expectancy appears to have plateaued with only minor improvements observed. **Conclusions:** The findings suggest either a natural upper survival limit for people with DS around 60 years of age, or the impact of health needs later in life which are not being addressed to allow further improvements in survival for the majority of individuals with DS.
A big data view of the health and healthcare of people with intellectual and developmental disabilities from primary care in England

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Aim: To develop regular monitoring of the health and healthcare of people with intellectual and developmental disabilities (IDD), reportable for small areas throughout England. Method: A data collection has been organised to obtain anonymised data from all general practices (GP) in England, covering weight, blood pressure, screening and immunisation status, 14 major health conditions, and management of diabetes, epilepsy and newly diagnosed coronary disease. Data will be reportable for local healthcare administration areas and will directly compare people with and without IDD allowing for age/sex differences. Participation by general practices is voluntary but requires no effort on their part. Results: The paper will cover information governance issues, administrative issues, costs and preliminary findings. Of the four suppliers of GP information systems, one quoted an unrealistic price for first year participation, 74% of practices with the other three types of system have agreed to participate giving a likely first year coverage of at least 46% of the population of England. Conclusions: This approach will allow local monitoring of the complexity and quality of primary care for people with IDD on a national basis.

Psychotropic prescribing by general practitioners for people with intellectual and developmental disabilities in England

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Aim: To describe the extent of current prescribing of psychotropic drugs to adults with intellectual and developmental disabilities (IDD) by general practitioners in England. Method: A population-based descriptive study using a General Practice research database was conducted. Antipsychotic, antidepressant, antimanic, anxiolytic, hypnotic and anti-epileptics prescriptions were studied for all adults identified as having IDD. Periods of hospitalisation were excluded by linkage to national hospital episode statistics. Results: 14,802 patients were followed for an average of 2.3 years. Antipsychotics were being prescribed for 17% of person-years, antidepressants for 16.9%, antimanics for 7.1%, anxiolytics for 4.2%, hypnotics for 2.7% and anti-epileptics for 22.9%. In the case of antipsychotics and antidepressants, these rates far exceed the likely prevalence of conditions recognized as licensed indications. Rates of antipsychotic prescribing rose with age reaching 26.7% at age 65 and older. Conclusions: Some psychotropic drugs are used far more widely than is indicated. The Chief Pharmacist for England has launched a campaign to reduce inappropriate drug use.

Mortality in people with intellectual and developmental disabilities in England

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Aim: To describe the extent and pattern of causes of mortality in the population of people identified as having intellectual and developmental disabilities (IDD) in England. Method: A descriptive study was
undertaken using a research general practice database linked to national mortality data and covering 2.79 million total population including 14,800 identified as having IDD. Deaths over four years (April 2010 to March 2014) were compared to those for the general population in roughly decennial age bands. **Results:** Decennial age-specific death rates were high for people with IDD at all ages, highest in childhood. The standardised mortality ratio associated with IDD was 3.2. Circulatory, respiratory and neoplastic diseases caused the largest numbers of deaths, but excess age-adjusted mortality was greatest for congenital malformations, and diseases of the nervous, and genitourinary systems, mental and behavioural and endocrine disorders. Life expectancy at birth was reduced by 20 years. **Conclusions:** This approach provides good national mortality data, but for England numbers of deaths are too small and the sampling of the database too variable for sensitive monitoring over time or between areas.

**General hospital use by people with intellectual and developmental disabilities**

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**Aim:** To describe the amount and pattern of care in general hospitals used by people with intellectual and developmental disabilities (IDD) in England comparing this to care used by other people. **Method:** A descriptive study was conducted using a research general practice database linked to national hospital admission records (April 2010 to March 2014) and covering 2.79 million total population including 14,800 identified as having IDD. **Results:** Among adults aged 18 to 64 years, people with IDD had 2.3 times as many medical inpatient care episodes as others; corresponding multiples were 1.3 times for surgical and 0.4 times for obstetrics and gynaecology. Durations of stay were longer, and proportions admitted as emergencies greater in all cases. Standardising for age and sex, people with IDD had 4.8 times the expected number of emergency admissions for ambulatory care sensitive conditions (ACSC). **Conclusions:** These findings clarify the likely numbers and location of inpatients in general hospitals where special care adjustments are needed. The ACSC findings have implications for identifying gaps in primary care.

**Function-based interventions for children with autism spectrum disorder in schools**

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**Aim:** Function-based intervention has been shown to be effective in decreasing problem behaviour and increasing appropriate behaviour for students with autism spectrum disorder (ASD), however, there are still a number of gaps in the literature. This study synthesises the research on function-based intervention used in the reduction of problem behaviour for students with ASD in school settings. **Method:** A literature review was conducted for studies published in peer-reviewed journals between 2000 and 2014. 42 studies were included. Characteristics of the participants, assessment, interventions, and studies were analysed. **Results:** Function-based interventions were found to be effective across various target problem behaviours in both inclusive and special education settings. Limited teacher involvement and lack of evaluation of generalisation and maintenance were common across studies. **Conclusions:** A limitation of this review is that published studies are likely to report positive findings, so the results of this review may be positively skewed. Future research agenda should target the collateral
gains, such as social relationships and lifestyle change, as indicators of the effectiveness of behavioural interventions.

**Communication assessment with children and adults with profound intellectual and multiple disabilities: A survey of practice and its challenges**

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**Aim:** Children and adults with profound intellectual and multiple disabilities (PIMD) have communication impairments as one defining characteristic. This project explores decision-making regarding communication assessments for people with PIMD. **Method:** A questionnaire gathering information about the communication assessments used and the rationales underpinning their selection was sent to communication practitioners within the UK. **Results:** The findings revealed that published (100%), self-devised (78%) and in-house (53%) assessments were being used, the latter two more with adults than children. A dearth of appropriate communication assessments for people with PIMD was reported by some practitioners. The PVCS, ACA and Triple C were the most frequently used of the 27 published assessments detailed. Rationales primarily related to utility, detail and applicability to people with PIMD. Supporting evidence was seldom mentioned. **Conclusions:** Great variability in practice and the use of a patchwork of assessments was evident, underpinned by a practice-focused evidence base. Some assessments identified were no longer in print, possibly suggesting that assessment practices were influenced by established practice, which may not have been explicitly reported by practitioners.

**The role of communication in primary healthcare for people with profound intellectual and multiple disabilities**

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**Aim:** People with profound intellectual and multiple disabilities (PIMD) have communication impairments, significant health issues and are often supported by family carers. This study investigates the communication and healthcare of adults with PIMD. Specifically, it explores the impact of communication in healthcare settings on people and their family caregivers. **Method:** This qualitative study employed semi-structured interviews to gather data from a purposive sample of eight family caregivers. Data were analysed using interpretive phenomenological analysis and trustworthiness checks were conducted. **Results:** A significant challenge in addressing the health issues of adults with PIMD is the difficulty carers and healthcare professionals have in identifying and distinguishing behavioural indicators of well-being. This can, in turn, lead to difficulties identifying, treating and managing health issues. The quality of support, communication and the acknowledgement of carer expertise influenced experiences and well-being. **Conclusions:** Despite their increased likelihood of complex health issues, identifying health problems and accessing adequate healthcare and management can still be problematic for people with PIMD. Practice solutions to improve healthcare experiences and access were identified by carers and are provided.
Beyond the limits of inclusion: Students with profound intellectual and multiple disabilities learning in regular classrooms

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Aim: In Germany the ratification of the United Nations Convention on the Rights of Persons with Disabilities led to an increase of inclusive schools, while many special schools were closed. There are no data concerning the educational situation of students with profound intellectual and multiple disabilities (PIMD) in inclusive settings. Method: An online survey containing all federal states in Germany was conducted to determine the number of students with PIMD in inclusive schools. Focus group meetings with teachers were held using appreciative inquiry as a leading principle. Examples of best practice in typical classroom situations were recorded on video. Results: Few schools include students with PIMD in Germany. Short video-sequences will be presented to give an impression of current practice. Conclusions: The establishment of a national/international network of inclusive schools sharing examples of best practice on video could be helpful to create an inclusive school system for all children.

Comparing transition to work for school leavers and those over 30 years of age

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Aim: Over the past decade NOVA Employment has operated a highly effective transition to work (TTW) program for school leavers. In 2014 NOVA also offered Employment Enablement Programs (EEP) for people with intellectual disabilities (ID) over 30 years of age. Similar and differentiating characteristics of NOVA Employment’s successful TTW and EEP are compared. Method: Interviews were conducted with a minimum four staff, six employers, 20 participants and six significant others from the EEP program, representing 40% of EEP participants to date. Statistical analyses compared outcomes of the two programmes. Results: Many EEP trainees had either never been in open employment or had been out of the workforce for more than a decade. The majority of EEP participants also exhibited concomitant mental health barriers. For both groups, by the conclusion of program, the majority had entered open employment and statistical data confirms a 50% higher chance of meaningful (>15hrs per week) participation. Conclusions: The use of strategies developed during the TTW program enabled staff to improve employability for all.

Increasing online conversations for individuals who use augmentative and alternative communication: A peer e-mentoring intervention

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Aim: To investigate whether online peer mentoring is effective for strengthening the participation in online conversations of young people who use Augmentative and Alternative Communication (AAC) methods. Method: Four mentees between 13.33 to 18.24 years (M=16.33; SD= 2.08) and two mentors who all have developmental disabilities and use AAC participated in an online peer mentoring programme. Mentees set their own goals relevant to online social media skills. A mixed methods
approach was used: a single subject experimental design measured changes in participation in online conversations and interviews were conducted to further explore these changes. **Results:** Variability in levels of participation (frequency, duration, words used) in online conversations is evident from visual inspection of the data. Preliminary results from three mentee interviews highlight perceived increases in involvement (i.e., social connections, motivation) and related changes in self-perceptions. **Conclusions:** Preliminary results appear to indicate some strengthening of participation in online conversations following the online peer mentoring programme. The presentation will include maintenance data (6 weeks) after intervention and views of mentees, their parents and mentors.

**How I’m Feeling: The development of a new self-report measure for adolescents with intellectual disabilities**

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**Aim:** Despite high rates of behaviour and emotional problems in adolescents with intellectual disabilities (ID), and elevated rates of anxiety and depression, no self-report measures have been developed specifically for this population. The aim of this research project was to develop and evaluate a new self-report measure, to assess symptoms of anxiety and depression in adolescents with ID. **Method:** Stage 1 consisted of a series of focus groups with parents, adolescents, and professionals in order to evaluate the items for acceptability, readability, and provide feedback on the presentation of the items. Stage 2 involved adolescents aged 12 to 18 years with ID and their parents/carers (n=50). **Results:** Results will be presented in terms of the development of the items of the measure, incorporating the results of the focus groups. Information will also be presented on the reliability (internal consistency, test-retest reliability), concurrent validity, and on the impact of degree of ID on the reliability and validity of the measure. **Conclusions:** The results will be discussed in relation to future research directions and the clinical and research uses of the self-report measure.

**Behaviour and emotional problems in children with developmental disabilities: Results from an Australian public health intervention**

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**Aim:** The high prevalence of behaviour and emotional problems in children with developmental disabilities (DD) has been well established. This project aimed to decrease the rate of behaviour and emotional problems in children with DD. **Method:** The Stepping Stones Triple P parenting programme was made available to the parents of children with DD aged 2 to 12 years, across Queensland and Victoria. Parents completed a range of measures at pre intervention (baseline), post intervention, and at follow-up, assessing child behaviour and emotional problems, parenting style and sense of competence, family functioning, and psychosocial well-being. **Results:** More than 1,000 families have participated in the study to date. Data will be reported on the primary outcome of child behaviour and emotional problems, and the association between outcomes and key variables will be explored. **Conclusions:** The implications of the results in relation to the provision of family-focused interventions at a population level will be discussed.
Association between autism symptoms and child and family functioning in children with attention deficit hyperactivity disorder: A community-based study

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Aim: This study examined the association between autism symptoms and child and family functioning in children with attention deficit hyperactivity disorder (ADHD). Method: 164 children (6 to 10 year olds) attending 43 schools in Melbourne, Australia, who were participating in a longitudinal cohort study, were included. ADHD cases were ascertained using screening and confirmation from a diagnostic interview. Autism symptoms were identified using the Social Communication Questionnaire. A range of child and family outcome measures were used. Results: 23% of children with ADHD had clinically elevated autism symptoms. In adjusted analyses, greater autism symptoms were associated with more peer problems, poorer child and family quality of life (QoL), higher couple conflict, and greater child mental health difficulties. Parents of children with ADHD and clinically elevated symptoms of autism had less self-efficacy and poorer family QoL. Conclusions: Autism symptoms are associated with poorer child and family functioning in children with ADHD. The association between ASD symptoms and poorer family functioning appears to be largely related to co-morbid internalising and externalising symptoms, ADHD severity and socioeconomic status.

Church inclusion audits as a tool to promote inclusion: The case study of indispensability at St Jude’s, Melbourne

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Aim: Religious communities in Australia have generally been slow to promote disability inclusion as reflected by low numbers of people with disability attending church. Inclusion requires a multifaceted approach involving the whole congregation to remove social and physical barriers. Practical materials are available. This case study outlines the approach of a large evangelical Anglican church in Melbourne who utilised materials from the Luke 14 initiative of CBM Australia to promote inclusion. Method: Interviews were conducted with 15 people with disability and all ministry staff at St Jude’s Anglican Church, and an audit of the facilities was undertaken. Thematic analysis was used to assess the attitudinal and physical barriers and also produce various recommendations which were fed back at a staff training day. Results: Physical and attitudinal barriers were identified and avenues to address these were also elicited from staff. A policy was passed, a training day undertaken, building design issues addressed, large print Bibles, accessible standards for presentations and a respite programme initiated. Conclusions: A structured approach to undertaking a disability audit can help promote church disability inclusion.

Healthy dying for people with intellectual disabilities in residential services

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Aim: While disability staff members need further training in end-of-life care, end-of-life choices for people with intellectual disabilities (ID) in residential care, they are constrained by organisational policy and service systems. We have thus developed a sustainable organisational capacity building approach that supports the disability sector to coordinate care of their dying residents. Method: Staff attitudes to providing end-of-life care to residents were explored through a survey (n=141) while focus groups (n=26) elicited experiences. Integrated data analysis identified staff assets, examined 'perceived' and 'actual' barriers to providing care, and explored ways these factors impacted on practice. Results informed organisational capacity building strategy. Results: Opinions, and hence practice, vary widely. Participants who saw dying in medical terms preferred residents to die in hospital. Participants were more willing to provide care at home if they understood dying in social terms and were close to the resident. Staff preferences, not organisational policy, determine where and how a resident dies. Conclusions: Staff willingness to provide end-of-life care is an asset, but organisational reorientation is essential if residents are to have realistic choices about their end-of-life care.

Death and the disability residential home: Mining narratives to enhance practice
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Aim: While researching end of life care for people living in disability residential homes, we encountered memorable stories of deaths. One of these was powerful enough to attract additional funding to investigate further what helps and what hinders care. From the four in-depth stories we examined, we aimed to develop interventions to support residents to die in their own beds, should they choose this setting. Method: Transcriptions of carers' stories were made and analysed for evidence of structural, cultural and practical aspects of care. The project reference group included key stakeholders at local and state levels. Results: We identified policies, practices and attitudes that affected the dying person, fellow residents and care staff. These findings have been formulated into an end of life induction package for staff wishing to support a dying resident, and have also resulted in changes at state-level policy. Conclusions: We suggest that telling and hearing stories from the field - narratives of deaths of individuals in their own surroundings - can prompt advocacy for change.

Comparing staff and self-reports of complicated grief symptoms in adults with intellectual disabilities
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Aim: While previous studies have shown a significant association between parental bereavement and the development of psychopathology in people with intellectual disabilities (ID), little work has been done to accurately assess symptoms of grief, specifically symptoms of complicated grief in this population. Complicated grief has been detailed in the recent publication of DSM 5. This study aims to compare self and proxy reports of the symptoms of complicated grief. Method: A Bereavement History Questionnaire and the Complicated Grief Questionnaire-Intellectual Disability (CGQ-ID) were administered directly to a group of people with mild or moderate ID, who had experienced a parental bereavement within the previous two years of the research interview. Care staff also completed a proxy
symptom report. **Results:** Data have been collected from 30 adults with ID. Comparative analysis highlighted very few correlations between staff and service user reports, with trends in the data suggesting service users had higher reports of symptoms. **Conclusions:** Adults with ID may be reporting higher level of symptoms of complicated grief compared to proxy reports. Complicated grief may be an under-reported cause of distress in adults with ID.

**Family perspectives on the experience of parental bereavement among adults with intellectual disabilities**

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**Aim:** This research explores families’ perspectives of the experiences of parental bereavement for a family member with an intellectual disability (ID). **Method:** Qualitative interviews were conducted with five participants (four females, one male). The family had experienced the death of a parent in the previous 6 to 24 months. Braun and Clarke’s (2006) framework was used to analyse the data. **Results:** Experiences of supporting the family member with ID after the death were varied. Families regularly reported normal grief reactions, including crying and missing the deceased. However some responses were more atypical, with one family member with ID appearing to enter a manic episode, and another showing a delayed response to the bereavement. All family members with ID attended the funeral and all families encouraged openness with the member with ID around the topics of illness and death. **Conclusions:** Families are well positioned to report on the bereavement experiences of members with ID. This research concludes that families recommend a policy of openness and inclusion of members with ID in the bereavement experience. More research needs to be conducted on how families with members with ID can be supported pre and post bereavement.

**Exploring organisational perspectives on the provision of respite services for people with intellectual disabilities in Ireland**

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**Aim:** To gain an understanding of service perspectives on respite care for people with intellectual disabilities (ID) in Ireland. Specific objectives include; generate an understanding of what providers consider respite to be; establish the extent to which current care reflects models identified in the literature; and capture innovative respite practices currently available. **Method:** The study used an online mixed method survey to gather information from organisations offering respite care to people with ID. A sampling frame of suitable organisations was generated and 45 responses were received. **Results:** Responses were received from statutory services (n=11), voluntary agencies (n=21) and other organisations from across the country. Common forms of respite reported were planned respite (n=22) and crisis respite (n=19). A large majority of organisations (n=26) reported that they were not currently able to fully cater to the demand for respite but a minority (n=7) reported they were developing new models of respite. **Conclusions:** The survey findings provide significant insight into organisational
perspectives on respite care, suggesting a high level of unmet need though little discussion of engagement with innovative practices.

Evidence and perspectives from Spain: Findings from research on the Spanish translation of the SIS-A and SIS-C

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Aim: The assessment of support needs has gathered much attention over the last few years in the field of intellectual disabilities, becoming a key aspect for the implementation of individualised support plans. This work is aimed to present findings from research on the Spanish adaptation of the Support Intensity Scale for Adults (SIS-A) and for Children (SIS-C) in Spain. Method: The SIS-C adaptation process (n=814; aged 5-16) was linked to the SIS-A previously conducted (n=885; 16-64 years old). Some extra analyses were also included considering item response theory and comparisons with the ordinary support needs of students without disabilities. Results: Both SIS-A and SIS-C obtained a Cronbach’s alpha > .99; test-retest reliability > .94 and inter-rater reliability > .80. The confirmatory factor analysis showed proof of validity based on the correlational structure of the scale. Some minor problems in the SIS-C discriminant validity were found. Conclusions: Given the lack of instruments to assess support needs in Spain, SIS-A and SIS-C are promising and powerful tools to facilitate the implementation of individualised support plans. However, more research is needed.
An evidence-resistant strain of disablism: Parents and parenting with intellectual impairment

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Aim: The brutal reality is that many parents with intellectual impairment will have their child taken from them by child welfare services. This, despite evidence accumulating since the early 1900s, which shows that most parents with intellectual impairment can meet the needs of their children with appropriate supports. Method: In this paper we revisit some of the earliest (and perhaps forgotten) studies related to parents and parenting with intellectual impairment. In addition, we examine discourse in the media using press clippings dating back 100 years. Using these early studies and media portrayals of parents and parenting with intellectual impairment as our reference point we reflect on the progress, and lack thereof, that has been made in research, policy and practice in this field. Results: Although significant progress has been made in some areas, parents with intellectual impairment are subject to an evidence-resistant strain of disablism. Conclusions: What is the remedy for this disablism? We suggest that intentional (rather than the traditionally passive) knowledge translation strategies are needed to overcome the systemic discrimination that disables parents with intellectual impairment.

Unpacking a falls prevention intervention for adults with intellectual disabilities

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Aim: We evaluated the feasibility and acceptability of a novel physiotherapy intervention to reduce fall risk for adults with intellectual disabilities (ID). Method: 29 adults (13 males, 16 females; age range: 29-71 years, mean: 53 years) with a wide range of ID (mild to profound) who were able to walk independently but had a risk of falling participated. The intervention comprised education on falls prevention, home visits and ongoing support. Three individualised exercises (performed 5 to 10 times as part of daily routine) that challenge balance were taught and monitored. Weekly participation in physical activity was encouraged. At 6-month intervention completion, in-depth interviews explored both participants and support staff perceptions of the intervention. Data were analysed with the general inductive approach. Results: Four themes emerged: ‘understanding the intervention’; ‘routine and reality’; ‘remembering what I have to do’; and ‘what happens beyond the study itself?’. Conclusions: Irrespective of level of ID, appropriate exercises and physical activities were found for all participants. The intervention was acceptable and easily built-in to normal routines. Future research should focus on encouraging long-term exercise self-management.

A multi-centre randomised controlled trial for bright light therapy in adults with intellectual disabilities and depression

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Aim: Current treatment options for adults with intellectual disabilities (ID) and depression are often limited to lifestyle changes and pharmacological treatment. In the general population, bright light therapy (BLT) is an effective intervention for depression. Little is known about its anti-depressant effect
in adults with ID. Our aim is to study the effect of BLT on depression in adults with ID. **Method:** A randomised controlled trial (RCT) with three different study groups was undertaken. BLT is used for a period of 14 days. Depressive symptoms is the primary outcome measure; secondary outcome measures are circadian sleep-wake rhythm and stress. **Results:** Inclusion of the participants is ongoing (started in May 2015). Preliminary results will be presented. **Conclusions:** This is a first multi-centre RCT to evaluate the effect of BLT on depression in adults with ID. Where effective, BLT can become an alternative and/or additional treatment option for people with ID and depressive symptoms.

**The effect of positive parenting experiences on stress and depression in mothers of children with autism spectrum disorder**

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**Aim:** Literature on parenting children with autism spectrum disorder (ASD) has focussed predominantly on negative psychological outcomes, including stress and depression. This study examined whether positive parenting experiences affect the associations among child behaviour problems and self-reported stress and depressive symptoms in mothers of children with ASD. **Method:** The participants, 103 mothers of children with a confirmed ASD diagnosis, completed a questionnaire assessing child behaviour problems, positive parenting experiences, and stress and depressive symptoms. Regression analyses examined whether positive parenting experiences moderated the association between behaviour problems and these negative psychological outcomes. **Results:** There was no association between child behaviour problems and self-reported positive parenting experiences, but we found a strong association between child behaviour problems and negative psychological outcomes in parents, except where parents also reported having high levels of positive parenting experiences. **Conclusions:** Positive parenting experiences can buffer the impact of child behaviour problems on psychological outcomes in parents. This highlights the potential for programs that facilitate the development of positive parenting experiences in addition to addressing the psychological needs of parents and challenging behaviours in their children.

**Outing disability: Inclusion for lesbian, gay, bisexual, transgender, intersex and queer people with intellectual disabilities**

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**Aim:** Lesbian, gay, bisexual, transgender, intersex and queer (LGBTIQ) people with intellectual disabilities (ID) face multiple exclusions to full participation in their communities. This project explored and addressed their unique needs which are largely ignored by disability service providers and LGBTIQ support organisations. **Method:** 19 LGBTIQ people with disability were interviewed and participated in the Outing Disability project. Grounded in a ‘nothing about us without us’ approach, the Outing Disability project explored these barriers and needs. Key to the project was the establishment of a working group of LGBTIQ people with ID who guided and made decisions relating to all aspects of the project. **Results:** The participants’ stories provided a rich understanding of their lived experience with key themes including multi-layered discrimination, restricted opportunities for relationships, social
isolation and exclusion, poor sexual knowledge and lack of access to LGBTIQ information and services. **Conclusions:** LGBTIQ people with ID have unique needs that are currently poorly addressed. Specific programs are required to improve inclusion and access to both disability and LGBTIQ-specific services.

The introduction of Enhanced Milieu Teaching to improve spoken language of students with autism spectrum disorder: An international replication

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**Aim:** The purpose of this study was to determine the feasibility and effectiveness of implementing Enhanced Milieu Teaching (EMT), an evidence-based naturalistic language intervention, in an international context for children with autism spectrum disorder (ASD) and severe communication delays from a diverse and underserved community. Our hypotheses were that children with ASD would increase their spoken language, and the intervention would be implemented with fidelity using a multisite international research team. **Method:** We implemented a multiple-baseline-across-participants design to measure the effectiveness of EMT on increasing language for four school-aged children with ASD residing in Cape Town, South Africa. Participants received 30-minute individual sessions with a speech language pathologist trained in EMT who received fidelity feedback via Skype. A 10-minute segment of each session was transcribed and coded to measure child language outcomes in response to intervention and fidelity of implementation. **Results:** Participants showed an increase on measures of expressive language and the intervention was implemented with high fidelity. **Conclusions:** EMT is an effective intervention for students from diverse language backgrounds and can be implemented in an international context.

A cross-cultural comparison of inclusive education in Japan and Italy: Students’ views on inclusive education

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**Aim:** This study compares students’ views on inclusive education in Japan and Italy. **Method:** Questionnaires about opinions on inclusive education were handed out in each country to 92 Japanese students at one public secondary school, and 159 Italian students at three public secondary schools. **Results:** In Japan, 88 students (95.7%) answered the questionnaire. Of these, 43.2% of students expressed agreement with the Italian system, stating that it would reduce prejudice and discrimination. 8% of these students expressed objection. 48.9% of Japanese students neither agreed nor disagreed, worrying about the difficulties of studying in regular classes for students with disabilities. In Italy, 157 students (98.7%) completed the questionnaire. Of these, 12.7% of students expressed agreement with the Japanese system and 69.4% of students expressed objection, noting that all students should be equal. 17.2% of Italian students neither agreed nor disagreed. **Conclusions:** The difference in value of inclusive education between Japan and Italy probably reflects the cultural, social, and historical contexts of both countries. It can be suggested that Japanese students need more contact with students with disabilities.
A national audit of hospital and primary care services for people with intellectual disabilities in England and Wales

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Aim: A pilot national audit of hospital services in England and Wales was carried out to examine various care parameters for people with intellectual disabilities (ID). Method: An advisory board including people with ID set the standards to be audited by the Royal College of Psychiatrists Centre for Quality Improvement. 12 primary care practices provided data on 794 patients with ID. Nine general hospital and seven mental health trusts contributed 176 case notes. 614 staff and 141 patients and carers were also surveyed. Individual hospital and overall reports were produced and disseminated for local use.

Results: The quality of care for people with ID falls below recommended standards. Areas of further improvement include low uptake of health checks in primary care, unsatisfactory physical health monitoring and health promotion. Identification of people with ID was particularly difficult in secondary care, and ID was not included in mandatory training programmes. Staff indicated they felt unskilled in caring for this patient group. Conclusions: National audits are an invaluable resource which allows for standards comparisons between services. This may lead to ongoing improvements in care and examination of population level data.

EBI-ID: A feasibility study of an extended brief intervention to address alcohol misuse in people with intellectual disabilities

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Aim: To adapt a manualised brief intervention for adults with mild to moderate intellectual disabilities (ID) and alcohol misuse and conduct a feasibility study. Method: The project was carried out in two phases which included an adaptation of the intervention manual (phase 1) and a randomised controlled trial (RCT) to examine feasibility factors such as acceptability of intervention, suitability of outcome measures, primary outcome parameters and willingness to take part in the study (phase 2). A supplementary qualitative study to examine stakeholder opinions of the intervention was also included. The primary outcome was the Alcohol Use Disorders Identification Test (AUDIT) adapted for ID. Secondary outcomes including health-related quality of life were also measured. 30 patients were randomised to the intervention and control arms. Eight participants with ID, the therapist and 12 carers were interviewed. Results: Results will be presented. Conclusions: To our knowledge, this is the first feasibility RCT for an adapted manualised public health intervention to manage alcohol misuse in adults with mild to moderate ID.

The Health Improvement Network: Analysis of psychotropic prescribing patterns for adults with intellectual disabilities and challenging behaviour

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Aim: This study examines prescribing patterns for psychotropic medications using a primary care dataset across the UK (The Health Improvement Network.) Method: An identified subgroup of adults with intellectual disabilities (ID) and matched controls with severe mental illness from the general population were included. Prevalence and incidence of various mental disorders and of challenging behaviour, medication dosage and most prescribed drugs were determined. Side effects reported were also examined and compared with rates in the general population cohort. Results: 9,039 individuals with ID receiving antipsychotic medication (mean age=42 years; SD=16) were identified. 74% had a history of antipsychotic use prior to entering the cohort. Analysis is ongoing. Conclusions: A comprehensive picture of the prevalence of mental disorders and challenging behaviour in primary care, psychotropic medication use and prescribing trends in adults with ID as reported in routinely collected primary care data across the UK will be provided.

Mindfulness-based intervention for parents of adults with intellectual and developmental disabilities: Outcomes from a randomised active treatment controlled trial

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Aim: To compare outcomes for parents of adult children with intellectual and developmental disabilities (IDD) randomly assigned to either a mindfulness-based or support and education focused parent intervention. Method: 50 parents completed baseline questionnaires, with 26 randomly assigned to mindfulness and 24 to support and information. Parent psychopathology was measured by the Depression and Stress subscales from the DASS21, mindfulness was measured by the Five Facets of Mindfulness Questionnaire (FFMQ) and the Bangor Mindful Parenting Scale (BMPS). Results: ANCOVA indicated a significant main effect of group assignment on depression at Time 2 (F (1, 43)=11.99, p=.001), and on stress at Time 2 (F (1, 43)=6.63, p=.04), when adjusting for Time 1 scores. Reductions in distress were in favour of mindfulness. There was no significant main effect of group assignment on the FFMQ or BPMS. Conclusions: Using a robust randomised attention-controlled design, our data suggest a benefit of mindfulness-based intervention for parents of adults with IDD. These are the first more tightly controlled data on the use of mindfulness with parents of adults.

Who’s Challenging Who: A cluster randomised controlled trial to test the effectiveness of a staff training intervention to improve support staff attitudes and empathy towards adults with intellectual disabilities and challenging behaviours

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Aim: To carry out a randomised controlled trial (RCT) to test a new manualised training intervention (Who’s Challenging Who – WCW) designed to change care staff attitudes towards people with challenging behaviour (CB). Method: We plan to deliver a large (118 residential settings, 236 social care staff) cluster RCT of the effectiveness of WCW. We developed WCW from strong user involvement, theory and systematic reviews of background research, and have already carried out a pilot evaluation
which had promising results. WCW is a short training course delivered by a trainer with intellectual
disabilities and CB alongside a trainer without disability. **Results:** We will report on the programme
theory, the pilot study results, and recruitment by summer 2016 to the new RCT study. **Conclusions:** If
effective, WCW will be an important addition to supports for people with CB and offers a direct role for
people with CB to influence staff who support them.

**Ticket to Work: A partnership approach to supporting young people with intellectual disabilities from
school into open employment**

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**Aim:** Ticket to Work (TTW) uses a partnership approach to improve employment outcomes of young
people with intellectual disabilities (ID) in Australia. It involves career development and early contact
with work environments, leading to better long-term social and economic participation. This study
sought to evaluate the programme. **Method:** Participants are young people with ID aged 15 to 19 years.
Interviews with TTW participants, 1 to 3 years after leaving school were conducted and their social and
economic participation compared to data from The Household, Income and Labour Dynamics in
Australia (HILDA). The Survey of Disability Aging and Carers (SDAC), an integration measure that assesses
the current and desired levels of cooperation between the partner organisations, was also completed by
partners. Interviews with the network intermediaries looked at the characteristics of the overall network
using realist evaluation methods. **Results:** Long-term (1 to 3 years post school) economic outcomes were
better for participants. There is a strong desire for more collaboration between stakeholders to achieve
the common vision. **Conclusions:** TTW is delivering economic pathways for young persons with ID.

**Socioeconomic factors and multiple complex needs contributing to offending behaviour for people
with intellectual disabilities**

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**Aim:** To examine the link between socioeconomic factors and complex needs, including substance
abuse, mental health difficulties, and adaptive behaviour deficits in a sample of individuals appearing
before New South Wales (NSW) Local Courts. **Method:** 92 offenders presenting to 9 NSW Local Courts
were assessed for presence of intellectual disabilities (ID), adaptive behaviour deficits, psychiatric
disorders and substance abuse issues, using a number of psychometric instruments. **Results:** More than
10% had IQ scores under 70, whereas 32% had adaptive behaviour scores at the same level. More than
half had a mental health diagnosis and substance abuse issues. More persons with ID abused alcohol
and self-harmed compared with non-disabled counterparts, but no differences in prevalence of
psychiatric disorder were found. Courts in lower socioeconomic areas had higher levels of disability for
all characteristics; there was a significant correlation between Courts’ Socio-Economic Indexes for Areas
(SEIFA) Scale and IQ scores. **Conclusions:** Addressing over-representation of persons with ID in the
criminal justice system must go beyond issues of substance misuse and psychiatric disorder and focus
upon the underlying issues associated with poverty and social injustice.
Offenders with intellectual disabilities: exceptions to the rule in human rights discourse

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Aim: Three studies were conducted to identify how offenders with intellectual disabilities (ID) are constructed via policy, and potential influences on service provision and their rehabilitation. Method: Critical discourse analysis was applied to examine United Nations, Australian national, and Victorian state policy texts (N=13) relevant to both people with disability and offenders more generally. Each policy’s sociohistorical context, themes, use of rhetoric, and ontological, epistemological, and axiological assumptions about people with disability and offenders were evaluated. Results: Both disability and correctional policy emphasise self-actualisation, ‘rehabilitation’, and economic participation as essential for social inclusion and improved outcomes. However, people with ID are constructed as having limited autonomy, agency, and social responsibility, limiting their civil rights. This construction is used to justify soft paternalism in disability policy and hard paternalism in correctional policy. Conclusions: While affording fundamental human rights, the ontological assumptions and rhetoric of human rights discourse constructs people with ID as ‘exceptions to the rule’ of social responsibility and complimentary civil rights, with implications for perceptions regarding rehabilitation through the justice system and allocation of appropriate resources to this end.

Using people’s research voices to change government policy

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Aim: Some disabled persons organisations (DPO) try to use research evidence to persuade government to change policy. Often relevant research is unavailable or does not include the voices of people with intellectual disabilities (ID). This paper examines how advocacy organisations can influence research processes and the policy application of the results, with an example about closing institutions in New South Wales. Method: The DPO supported the researcher with ID to advise about design and analysis of the research, which enabled the inclusive methods. The DPO contribution urged a future focus for the analysis. When the results were published, the DPO joined with other DPOs to advocate that the government adopt the transformative framework in the research for accountability in the closure of the remaining institutions. Results: The collaborative process during and after the research enabled the researcher with ID and the DPO to steer the analytical framework towards a structure that could influence policy change. Conclusions: Including DPO that represent people with ID in research processes can contribute to the feasibility of inclusive methods, where research is useful evidence for systemic advocacy.

Long-term benefits of supported employment for adults with autism spectrum disorder

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Aim: Poor employment outcomes prevail in people with developmental disabilities. Vocational options vary considerably, yet research suggests supported employment programs may lead to better long-term outcomes. This longitudinal study reports on the outcomes of a supported employment program for adults with autism spectrum disorder (ASD). We hypothesised that engagement in the program would lead to improved quality of life (QoL), health and well-being. Method: Participants were 64 adults with ASD; 36 were selected to participate in the employment program. QoL, health and well-being measures were collected at three time-points, for both selected and unselected participants. Analyses included change over time on the questionnaires and between-group factors that might influence initial selection. Results: Participants engaged in the program for six months reported improved social relationships and friendships. No differences in symptomology or daily living skills were identified between selected and non-selected candidates. Adults in the program reported higher levels of job satisfaction than those engaged in other employment activities. Conclusions: Results provide evidence of long-term improvements in QoL, health and well-being for adults with ASD following engagement in a supported employment program.

Collaboration between people with and without intellectual disabilities

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Aim: To examine the capabilities of importance for people with and without intellectual disabilities (ID) to adequately collaborate in order to successfully include the perspective of clients in our collaboration between science and practice. Method: Clients, coaches, policy makers, teachers and researchers were asked which capabilities they consider important for people with and without ID to have to adequately collaborate. Data were collected through focus group, individual interviews, and expert meetings and analysed qualitatively. People with ID participated in data collection and analysis. Results: In addition to the responsibility of people without ID to realise conditions for collaboration, participants indicate the importance of people with and without ID to take responsibility and contribute in line with their ability to achieve an equal (working) relationship. Creating a safe atmosphere and seeking solutions are considered important capabilities both for people with and without ID. Conclusions: To successfully include the perspective of clients in developing practice-based interventions into evidence-based interventions, people with and without ID need to be enabled to adequately work together, e.g., by jointly attending a training and coaching programme.

Too much of a good thing?: Exploring the meaning of statistical significance, population inference and omitted variable bias when using large administrative data samples

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Aim: Linked administrative datasets have become more widely used for intellectual and developmental disabilities research. This paper examines some of the challenges in using such data for research. Method: Three particular challenges are explored: statistical significance, population inference and omitted variable bias. Current statistical solutions to these issues are discussed. Results: First, statistical significance at traditional levels is easily achieved in very large datasets, approaches to combatting this
are discussed. Second, the data in administrative datasets can describe the population under discussion as opposed to inference to the population being drawn from a sample. The implication of this issue is considered. Finally, administrative data are collected for administrative purposes, not to answer specific research questions. The resulting omitted variable bias is explored. **Conclusions:** IDD research has the privilege of having very large administrative datasets to inform its findings. This research aids the IDD population. However, large datasets bring their own challenges to bear and unless these challenges are understood, the findings are much less useful. This paper brings these challenges to light and offers such solutions as currently exist.

**Admissions to psychiatric wards: A comparison of admitted patients with and without intellectual disabilities**

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**Aim:** Using a large linked dataset in New South Wales, Australia, this research explores the interaction between intellectual disabilities (ID) and psychiatric diagnoses in admitted patient care. **Method:** Descriptive statistics and logistic regressions are used to examine the diagnoses made during inpatient stays in psychiatric facilities. **Results:** Compared to those without an ID, patients with ID who are admitted to psychiatric facilities are more likely to be diagnosed with psychotic (OR=1.7; z-score 10.9), personality (OR=1.4; z-score 4.96), or developmental disorders (OR=10.8; z-score 32.9) and less likely to have an organic (OR=0.5; z-score 13.6), bipolar (OR=0.6; z-score 6.7) or depressive disorder (OR=0.5; z-score 10.4). ID patients are more likely to be in a psychiatric ward than the non-ID when there is no psychiatric diagnosis (OR=5.4; z-score 11.0). ID patients are more likely to have an admission pathway from law enforcement than are non-ID patients. **Conclusions:** Using the rich data that is provided by linked administrative databases allows us to take the first steps towards understanding how ID impacts psychiatric care.

**Health documentation in IDD supported accommodation: A conceptual review and proposed consumer informatics model for health information management**

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**Aim:** To determine how documentation in supported accommodation is organized, identify factors impacting on residents’ health documentation, and develop a conceptual model on management of residents’ health information. **Method:** Our review was informed by expert interviews (disability organisations in New South Wales and Australia) and a review of literature, research, policies, procedures, and reports on Disability Deaths in Care. Data from these discussions and documents were analysed to develop a conceptual model for intellectual and developmental disabilities (IDD) health informatics. **Results:** People with IDD have many types of health information stored at several locations (e.g., accommodation, medical, and allied health) with few formal mechanisms for exchange between locations or access to this information. Our findings reflect the fragmentation in health documentation management for adults with IDD in supported accommodation. We will outline a new conceptual model
to guide improved health information management in supported accommodation. **Conclusions:** Health informatics in supported accommodation is complex. Our proposed conceptual model of health consumer informatics will show how future integrated, person-centred health services and e-health records could be contextualised for people with IDD in supported accommodation.

**Social media use by adults with severe communication disabilities: Resilience through experience**

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**Aim:** To investigate social media use by adults with developmental communication disabilities. **Method:** 12 interviews were conducted with adults with lifelong disability and severe communication disabilities, exploring patterns of social media use, motivations, and both positive and negative experiences of social media interactions. **Results:** Participants had been introduced to using social media by friends and family. With years of experience in using Facebook, participants viewed social media as a method to communicate and keep in touch and most had also started to use other platforms including Twitter and Instagram. Participants also experienced and responded to negative events in social media (e.g., of stalking, bullying, harassment) in ways that contained risks of negative impacts associated with the cyber security threats. Major content themes in interviews will be presented and discussed. **Conclusions:** Adults with severe communication disabilities may have years of experience using social media and use multiple platforms for a range of sophisticated purposes. Future research could explore the impact of social media on education, employment, advocacy, and social marking by adults with severe communication disabilities online.

**Health literacy demands of personally-controlled electronic health record systems: A conceptual review to inform the field of intellectual and developmental disabilities**

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**Aim:** This research sought to identify a model of health literacy for reviewing research on personal e-health records, and to review health literacy demands of personally controlled e-health records. **Method:** Health literacy models were compared for characteristics relevant to e-health records, and scientific databases for studies were searched on both health literacy and personal e-health records. **Results:** Hill (2014) Health Literacy Report was selected as providing the most suitable evaluation framework. In total, 70 potentially relevant unique studies were located. Two raters independently excluded studies and 24 studies were included. Evidence mapping on health literacy demands of e-health records will be provided on: characteristics of included studies, relationships influencing health literacy, patient type, carer role, health provider type, service system, environment or society, health information, and technology. **Conclusions:** Personal e-health records place multiple health literacy demands on individuals and services that must be considered in implementation of e-health record systems by people with intellectual and developmental disabilities (IDD), carers, and disability and health service providers. Directions for future IDD research will be discussed.
**Choking risk and repeated hospitalisation: Critical case results**

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**Aim:** To describe the factors leading up to and following choking and hospitalisation in an adult with intellectual and developmental disabilities (IDD) in supported accommodation. **Method:** A critical case inquiry of an adult with cerebral palsy and dysphagia who had been repeatedly hospitalised with choking on food was undertaken. Data sources included interviews with parents and support workers, health record chart and patient safety incident database review. **Results:** Staff responding to choking resulted in reduced asphyxiation risk and ultimate transport to hospital. Incident reporting was important and might form a protective factor against future choking incidents. Data from all sources were in alignment suggesting that choking incidents may be highly salient, the process of incident reporting is important, and the role of direct support workers, family members, and ambulance retrieval staff is vital. **Conclusions:** Residential care workers need to maintain observation of adults with IDD and dysphagia during mealtimes to detect silent choking. Staff need time to reflect upon and report incidents formally and may need support in implementing a cautious approach to mealt ime assistance in subsequent mealt ime situations.

**10 years of psychotropic prescribing in Scotland**

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**Aim:** Studies report high rates of prescribing of psychotropic medications to people with intellectual disabilities (ID), not correlating with reported rates of mental illness. This research analyses trends in the use of psychotropic drugs for adults with ID in Scotland. **Method:** This analysis of psychotropic prescribing trends draws on two sources of data about adults with ID in the same Scottish health board area over 10 years: a large prospective cohort study (n=1023); and electronically extracted primary care records (n=4711). Demographics and health status were analysed to identify potential influencing factors. **Results:** In 2004, antipsychotic drugs were prescribed to 23.2% of adults in the cohort, in 2014/15 this was 19.0% whilst prescribing of antidepressants increased from 11.9% to 25.8% across the same period. **Conclusions:** There have been changes in psychotropic drug prescribing over 10 years however these drugs are still prescribed at higher than expected rates. This study includes data from comprehensive mental health assessments enabling some analysis of the association between rates of mental illness and psychotropic prescribing.

**‘It’s a lonely world out there’: Kew Cottages Parents’ Association and opposition to deinstitutionalisation**

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**Aim:** In 1957, Irene Higgins, Kew Cottages’ first social worker formed the Kew Cottages Parents’ Association (KCPA). This association operated as an auxiliary organisation for Australia’s oldest
institution for people with intellectual disabilities. We explored the history of the KCPA and evaluated its role in shaping Victorian deinstitutionalisation policy. **Method:** A thematic analysis of ten semi-structured oral-history interviews with former association members and documentary sources held in Victorian archives was conducted. **Results:** The KCPA was formed to encourage parents to maintain an interest in their children’s welfare. Initially, it was opposed to the Victorian government’s decision to close the Kew Cottages. The KCPA mobilised opposition to deinstitutionalisation through meetings, publication in the KCPA newsletter and lobbying. **Conclusions:** Between 1999 and 2008, the KCPA played competing roles in the development of deinstitutionalisation policy. Initial opposition to deinstitutionalisation in favour of developing a Centre of Excellence on the site contributed to delay of the closure of Kew Cottages. The campaign was unsuccessful, and Kew closed in 2008, however the KCPA influenced the site’s final redevelopment and retention of a cluster of group homes on site.

**Health conditions and medication use in people with Down syndrome**

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**Aim:** To describe how conditions and medication use among adults with Down syndrome (DS) vary by age and residential setting. **Method:** Data from wave 1 (2009/2010) of the Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA) were gathered using pre-interview questionnaires and face to face interviews with participants and/or caregivers (n=721). 20% had DS (n=144) and provided complete data. The prevalence of conditions and medication use patterns are described. **Results:** The most commonly reported conditions were eye disease (61.8%), thyroid dysfunction (38.2%), constipation (35%) high cholesterol (32.6%), pain (32.1%) and emotional/psychiatric/nervous disorder (25%). Common medications were thyroid hormones (43.8%), laxatives (27.1%), pain relievers (27.1%), and lipid modifying agents (26.4%). Polypharmacy and excessive polypharmacy were more prevalent amongst the older compared to the younger group (37.3% vs 14.3%; 13.4% vs 7.8%) and in those in residential facilities compared to those living independently (7.4% vs 35.2% and 0.0% vs 24.1%). **Conclusions:** Medication use becomes more complex as people with DS age and may pose risks that should be assessed by regular multidisciplinary medication use review especially in residential facilities.

**Complexity of medication use in people with intellectual disabilities**

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**Aim:** People with intellectual disabilities (ID) receive many medicines. To obtain optimal outcomes, the dose, method of administration and other relevant factors must be taken into account so that adherence can be facilitated. **Method:** Medication data (self-report/proxy-report) was drawn from Wave 2 of the Intellectual Disability Supplement to the Irish Longitudinal Study on Aging (IDS-TILDA) - a representative sample of 753 people with ID ≥ 40 years old, randomly selected from the National Intellectual Disability Database. Medication use patterns for 282 residents of care homes were analysed using the Medication Regimen Complexity Index (MRCI). **Results:** 263 people had adequate data for analysis and the mean MRCI was 22.04 +/- 13.09. 27.3% received medicines by ≥ 3 routes of
administration. MRCI did not vary with age or gender whereas 62.7% of those reporting gastro-intestinal disease had an MRCI score ≥ 20. **Conclusions:** The MRCI can be calculated using IDS-TILDA data although the manual process is time-consuming. MRCI could contribute to an estimate of the burden associated with medicines use that must be met by people with ID and their carers.

**The impact of the Confidential Inquiry into premature deaths of people with intellectual disabilities in England**

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**Aim:** The Confidential Inquiry into premature deaths of people with intellectual disabilities (CIPOLD) was conducted in England from 2010-2013. In this paper we review the impact of CIPOLD, and some of the actions at national, regional and local levels that have taken place as a result. **Method:** Formal feedback was requested from professionals about the impact of being involved in a review of a death on their practice. Regional and national level information about impact was obtained from a web-based special interest group, formal reports and documentation. **Results:** A significant impact was made by CIPOLD in terms of national policy and guidance and local action. At the national level, the impact has been with improved data about mortality of people with ID; extension of Annual Health Checks; amendments to inspections of ID services; enhanced guidance on seasonal flu and pneumonia vaccinations; and the introduction of a national ID Mortality Review Programme. **Conclusions:** The recommendations from CIPOLD have been recognised nationally, but have also been powerfully implemented by individuals and groups of practitioners taking them forward in their own spheres of work.

**The effectiveness of a phonological reading program among Hebrew and Arabic speaking children with intellectual and developmental disabilities**

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**Aim:** Arabic speaking children encounter significant difficulties when learning to read and write due to differences between spoken and written language – diglossia. This study investigated the effectiveness of a phonological reading program among Hebrew and Arabic speaking children with intellectual and developmental disabilities (IDD) considering diglossia. **Method:** 60 Arabic and Hebrew speaking children with IDD, ages 7 to 13 years, were selected to one of four groups, based on language and intervention method. Participants received language and functional assessments, letter identification and phonological awareness tests followed by 22 individualised phonology practice sessions and post-intervention evaluations. **Results:** Significant differences in phonological reading (sounding out non words and real words) were found between the two groups that received intervention and the control groups, with no significant differences between the Arabic and the Hebrew speaking groups. **Conclusions:** Since the intervention was effective for both groups with no significant difference due to diglossia, the similarities between the two groups regarding their level of language and developmental difficulties may affected their learning abilities more than the differences resulting from the diglossia.
Routine data research on after-hours health needs of people with intellectual disabilities compared to the general population

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Aim: Knowledge is lacking on how specific health needs of people with intellectual disabilities (ID) are being met in after-hours primary care, which is provided outside the regular practice schedule of physicians. To gain insight in the after-hours health needs of people with ID, the patient, contact and care characteristics are studied. Method: A cross-sectional observational comparative study of people with and without ID was conducted using regional general practitioner cooperative routine data from 2014. People with ID were identified by linking addresses of care provider services to the primary care dataset in Nijmegen, the Netherlands. Variables included patient (age, sex, frequency of contact); contact (type, moment, urgency of contact); and care characteristics (health problems, prescriptions, referrals). Results: Of the total population, 449 were identified as having ID. Differences to the general population were found with regard to frequency and assigned urgency of the contacts and health problems presented. Conclusions: Similarities and differences between the two groups provide insight into the priorities and needs for improving after-hours primary care for people with ID.

Measuring physical fitness and physical activity as an outcome for intervention studies in people with intellectual disabilities: Benefits and pitfalls

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Aim: Improving physical activity and/or physical fitness levels are important goals in the many intervention studies focussed on improving lifestyle and health in people with intellectual disabilities (ID). Using objective measures to evaluate intervention programs has huge benefits, but including valid and reliable measures of physical activity or physical fitness is challenging, not only because of the measurement issues involved in a single execution, but also because they need to be sensitive enough to detect the expected change, and feasible to complete multiple times. Method: Evaluating the existing literature and using a real-life example of a physical activity intervention study in people with ID, the benefits and pitfalls of using objective physical activity and fitness assessments to demonstrate intervention effects are discussed. Results: Sensitivity to change of objective assessments is not always known in the general population, and cannot be assumed for people with ID. Conclusions: With the specific characteristics and intensity of interventions for this group, the choice of assessments needs to be aligned carefully with the expected effects, to capture these intervention effects in the best way possible.

New insights into physiological responses to exercise in people with intellectual disabilities: Translating research in people with Down syndrome to people with intellectual disabilities without Down syndrome

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Aim: This presentation examines autonomic dysfunction in individuals with intellectual disabilities (ID) without Down syndrome. **Method:** A literature review was performed on autonomic functioning in people with ID. A new research study is systematically assessing autonomic function in people with ID (n=10), compared to an age- and gender matched control group (n=10). Heart rate, heart rate variability, breathing, and blood pressure measures are collected during active orthostasis, head up tilt, strength and aerobic exercise. Differences between the groups in steady-state and speed of adaptation to the stimulus will be evaluated with t-tests or Chi-square-tests. **Results:** The review showed that autonomic dysfunction is present in people with ID. Maximal heart rate seems to be lower in people with ID than in the control group. The other preliminary data is currently being analysed. **Conclusions:** Previous research suggests autonomic dysfunction in people with ID, and the preliminary data gives new insights into the extent of this supposed autonomic dysfunction, and its impact on physical activity and fitness levels in people with ID.

**Involving professional caregivers in promoting physical activity: Determinants and strategies**

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**Aim:** The aim of this study was to change the behaviour of professional caregivers towards providing more physical activity support, in order to increase habitual physical activity levels of people with intellectual disabilities (ID). **Method:** Information was collected from professional caregivers of individuals with ID about determinants of physical activity promotion. Using intervention mapping, a multicomponent intervention was designed, with behavioural change strategies applicable to the collected determinants. The intervention was delivered by physical activity specialists and included a health check, demonstrations of activities and coaching of professional caregivers. People with ID were recruited from supported, community-based living facilities. Stages of change, and perceived barriers and facilitators of both people with ID and the professional caregivers were assessed, together with information on daily functioning and objective physical activity, fitness and health measures. **Results:** 115 people with ID and their 39 professional caregivers participated. The largest differences were found for the stage of change and number of perceived barriers of the professional caregivers. **Conclusions:** The intervention demonstrates the effectiveness of a tailored intervention to change the behaviour of professional caregivers.

**Spirituality in the context of people with non-verbal autism**

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**Aim:** Whilst research into autism is increasing, people with non-verbal autism are significantly under-researched. Spirituality is fundamental to all humanness, therefore the spirituality of people with non-verbal autism is worthy of exploration. **Method:** This qualitative research utilised a multi-method, mixed process methodology to undertake a scoping literature review. Four phases of rigorous, comprehensive literature searches were conducted, results tabled and main themes identified. The absence of research on the topic represented a significant gap, prompting two further search phases focussed on non-
academic literature by professionals across relevant fields, and biographies and autobiographies of people with non-verbal autism. **Results:** The only available data was sourced from the final two search phases. Initial results suggest the absence of spoken language may significantly impact personal spiritual experiences, not unlike those achieved through the disciplines practiced by ancient mystics. **Conclusions:** This research forms part of a continuing study so is limited to identifying gaps in the literature and directions for future empirical research. Further investigation into the link between the life context of people with non-verbal autism and their unique spirituality is underway.

**Children of mothers with intellectual disabilities and their peers: Social emotional well-being**

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**Aim:** To identify the social emotional well-being outcomes of children of mothers with and without intellectual disabilities (ID) at 3, 5, and 7 years of age; and examine individual, family and environmental characteristics which influence these outcomes. **Method:** Secondary data analysis of the first four waves of the UK Millennium Cohort Study (MCS) was undertaken. Social emotional well-being was measured from 3 years of age using the Strengths and Difficulties Questionnaire. Individual, family and environmental characteristics known to influence social emotional well-being were recorded at each wave. **Results:** 74 (0.4%) of the 18,189 mothers were identified as having ID. Differences in the social emotional well-being outcomes of children of these mothers and their peers were found. The individual, family and environmental characteristics related to these differences will be reported. **Conclusions:** The results of this study add to the knowledge base on children growing up with a mother with ID. Utilising large representative datasets provides the opportunity to understand these families in relation to their non-disabled peers.

**A parent-to-parent approach to strengthening family relationships after a child is diagnosed with autism spectrum disorder**

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**Aim:** Parents of children with autism spectrum disorder (ASD) face complex parenting challenges that can reduce their well-being and strain family relationships. Yet studies have demonstrated that parent well-being and parent relationship quality are vital to improving parent and child outcomes. This presentation describes the design and delivery of a parent-to-parent (P2P) program to enhance parent self-efficacy and co-parent relationship quality after a child is diagnosed with ASD. **Method:** Parent Navigators is a brief program delivered to co-parents in their homes. The curriculum includes four research-derived content areas: navigating ASD, the parent-child relationship, co-parenting, and parent well-being. Using a pilot randomised controlled trial design (control n=20, treatment n=20) we assessed the acceptability, feasibility, and parent/child outcomes of the program. **Results:** Parents report high levels of satisfaction with the program, and make recommendations for improving its delivery. Modifications were made to training and implementation strategies to better fit with a P2P approach with two parents. **Conclusions:** Using parents to deliver prevention programs is a promising strategy for strengthening families. We discuss unique considerations for designing and delivering similar programs.
Spirituality, nursing and people with intellectual and developmental disabilities

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Aim: To identify how registered nurses apply their competency standards which state that they provide ‘social, cultural, physical and spiritual care’ to clients. Method: A literature search using PubMed/Medline with keywords - spiritual care, intellectual and developmental disability (IDD), nursing assessment' was conducted. Results: The literature (25 papers, 3 books) revealed that registered nurses can correctly assess and assist people who are experiencing spiritual distress, but are not well prepared to assess those with IDD. It illustrates the importance and application of spiritual care and demonstrates that registered nurse who address this in a person-centred way show more purposeful direction in holistic care. Spiritual distress assessment tools are transferrable to many areas of support and care, inclusive of all faiths. Conclusions: This evidence-based application of research is redirecting registered nurses to meet the spiritual needs of clients, and provides a clear and positive bearing on health outcomes. Appropriate application of competency standards including assessment of spiritual distress for our clients must be reviewed thoroughly, with teaching strategies and new tools put in place to support the whole client.

Working with a video-feedback intervention (VIPP-LD): How can parents with intellectual disabilities benefit from it?

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Aim: Parents with intellectual disabilities (ID) are facing many challenges, while fulfilling their parental tasks, causing parenting stress. Parents with ID do benefit from parent support programs. VIPP-LD, a tailored video feedback intervention based on attachment and coercion theory, is focusing on increasing harmonious parent-child interaction and sensitive discipline and might reduce parenting stress. In this study the effects of the VIPP-LD intervention were tested. Method: 85 parents with ID participated in a randomised controlled trial. Parenting stress was measured at pre-test, post-test and follow-up. At the same time observation tasks were conducted for harmonious parent-child interaction and sensitive discipline. Home-visitors rated parents’ easiness to work with, amenability to influence, and cooperation after each home-visit. Results: Parenting stress decreased after follow-up for the total group. Harmonious parent-child interaction increased for parents with low social adaptive parental functioning. No effects were found for sensitive discipline. Rating results of the home-visitors seemed to be mixed. Conclusions: VIPP-LD helps in reducing parenting stress of parents with ID. Parents most in need of support benefit the most from this video-feedback intervention.

The I-CAN v5 as an assessment tool for occupational therapists

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**Scientific Oral Presentations**

**Aim:** Is the I-CAN an appropriate assessment for occupational therapists (OT) to use when evaluating individuals with intellectual disabilities (ID)? I-CAN is a holistic, person-centred, strengths-based standardised support needs assessment. It is proposed that there is a correlation between I-CAN and OT theoretical models. Anecdotal evidence suggests that OT completing support needs assessments often rely on non-standard checklists, observation and clinical reasoning. **Method:** 21 OT working with people with ID completed the 2-day I-CAN facilitator course. A Likert scale survey evaluated the relevance of I-CAN to their discipline, workload, clinical reasoning and compared to current assessment methods. 12 participants of an online OT community of practice answered the same questions to strengthen the sample size. **Results:** >95% of total participants completely or mostly agreed that the I-CAN was relevant to their discipline, workload and clinical reasoning. No significant differences were found between the two groups. Additional reported benefits included the relevance to Australian environments and language, the fit with person-centredness and whole of life supports. **Conclusions:** Initial findings suggest that I-CAN is a clinically relevant tool for OT.

**Arts-based knowledge translation for direct support professionals**

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**Aim:** Do arts-based knowledge translation (ABKT) strategies increase the understanding and uptake of therapy recommendation reports by direct support professionals (DSP) in group homes for adults with intellectual disabilities (ID)? **Method:** Incident reports indicative of poor understanding or application of therapy recommendations were collected for five group homes from two service providers in New South Wales, Australia. 33 DSPs participated in four ABKT workshops to increase participant understanding of therapy recommendations. Based on staff profiles and information requiring translation, ABKT strategies included: keyword collage, visual journaling, photography and mime. Participants completed a workshop feedback survey. Pre- and post-workshop incident report number data were collected for 6 months following the workshops. **Results:** Four of five group homes reported a decrease of 30% or greater in relevant incident reports. Participants reported increased confidence in understanding and following therapy recommendations. Other feedback included the benefits of a safe and fun learning space with added value for staff with language or literacy challenges. **Conclusions:** Initial findings suggest that ABKT strategies are valuable in increasing the uptake and comprehension of therapy recommendations for DSP.

**Pregnancy among women with intellectual disabilities in the United States**

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**Aim:** Understanding how common pregnancy is among women with intellectual disabilities (ID) is important for informing reproductive healthcare. However, very little is known about the proportion of women with ID experiencing pregnancy. We compared pregnancy among women with and without ID or other cognitive disabilities in a nationally representative U.S. survey. **Method:** We analysed 1997-2012 Medical Expenditure Panel Survey data to estimate the proportions of women ages 18 to 44 years who were pregnant during their 2-year panel participation. Family report of cognitive limitations (e.g.,
difficulty making decisions) was the sole variable available for categorizing women as having ID or other cognitive disabilities. **Results:** Our sample consisted of 744 women with ID or other cognitive disabilities and 36,302 with no disabilities. Although a slightly smaller proportion of women with ID or other cognitive disabilities reported a pregnancy (15.3% vs. 16.5%), the difference was not statistically significant. **Conclusions:** Women with ID or other cognitive disabilities are as likely as women with no disabilities to experience pregnancy.

**Do early childhood characteristics predict adult outcome in individuals with autism?**

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**Aim:** To explore childhood factors related to adult outcome in autism. **Method:** 60 individuals diagnosed with autism at mean age of 6 years were reassessed at mean age of 44 years. As children, all participants were of average non-verbal IQ. Assessments included IQ, autism severity and, in adulthood, social functioning, mental health and quality of life. **Results:** Autism symptom severity decreased with age but 25% of the cohort showed significant decline in cognitive functioning. Cognitive decline was associated with very early diagnosis, severe language delay, epilepsy, marked behavioural disturbance. Social outcome in adulthood was rated as poor for 60% of participants; 40% had significant mental health problems. The strongest predictor of overall adult outcome was reciprocal social interaction in childhood. No childhood variables were predictive of adult mental health although adults with the poorest mental health had the poorest social outcomes and more severe current autism symptoms. Despite high levels of need, support services in adulthood were poor. **Conclusions:** Identifying childhood factors related to adult outcomes in autism has important implications for early intervention. Improvements in adult services are also essential.

**Autistic features and emotional/behavioural problems in children with Down syndrome: Impact on parental stress and mental health**

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**Aim:** This study explores the association between autistic features and emotional/behavioural problems in children with Down syndrome (DS), and the impact on parents’ mental health. **Method:** Parents of 485 children with DS (age 5 to 15 years) completed questionnaires of autism symptomatology (Social Communication Questionnaire; SCQ) and emotional/behavioural problems (Strengths and Difficulties Questionnaire). A subgroup of 50 parents also completed measures of emotional stress (Questionnaire on Resources and Stress) and mental health (General Health Questionnaire –12). **Results:** Children with DS scoring above cut-off (SCQ score ≥ 15) for autism spectrum disorder (ASD) had significantly more emotional/behavioural problems than children showing few ASD symptoms (SCQ score ≤10; p<. 001). Further investigation indicated that levels of ASD and emotional/behavioural problems were highly predictive of parental stress and poor mental health. Many of these parents reported difficulties in finding appropriate clinical or educational support. **Conclusions:** Parents of children with DS who show marked autistic features face many challenges that affect their own mental health. However, specialist, professional support for them and their children is limited.
The need for caution in using standardised autism measures with children with genetic conditions such as Down syndrome

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Aim: Recent studies suggest relatively high rates of autism in children with Down syndrome (DS). However, the use of standardised autism diagnostic instruments for children with genetic conditions, such as DS, requires evaluation. Method: 50 children with DS (aged 8-17 years) were assessed on standardised autism measures: the Social Communication Questionnaire (SCQ), a frequently used screening instrument, and the Autism Diagnostic Observation Schedule (ADOS), a detailed observational measure. Adaptive functioning (Vineland) and behavioural difficulties (Developmental Behaviour Checklist) were also assessed. Results: The correlation between the SCQ and ADOS was moderate (r=.59; p<.001). However, among children scoring above autism spectrum disorder cut-off on the SCQ, 32% failed to meet the ADOS threshold; conversely, 24% of children who met ADOS criteria scored below threshold on the SCQ. Discrepancies between SCQ and ADOS were significantly associated with the presence of hearing problems, higher levels of anxiety and disruptive behaviours, and poorer adaptive skills. Conclusions: Whether for clinical or research purposes, scores on autism screening questionnaires should be interpreted with great caution when assessing children with specific genetic disorders. Diagnostic confirmation requires expert clinical assessment post-screening.

Prevalence and modifiable risk factors of diabetes in adults with intellectual disabilities: A three-year follow-up

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Aim: To investigate the prevalence of diabetes in adults with intellectual disabilities (ID) and to identify modifiable risk factors for diabetes. Method: A three-year Longitudinal Health and Intellectual and Developmental Disability Study data (n=1,089) was used for analysis. We collected informant reports data using a mixed mode (web-based and mail-based surveys). Prevalence of diabetes was calculated by gender, age, and ID-related diagnosis. We used a generalised estimating equation (GEE) approach to examine modifiable risk factors (overweight/obesity, physical activity, smoking, dietary habits) for diabetes with adjustments for demographic characteristics (age, gender, ID-related diagnosis) and health factor (hypertension). Results: The prevalence of diabetes differed by age, gender, and ID-related diagnosis, but remained stable over three years. Lower diabetes prevalence was reported by non-health care providers indicating possible under-reporting or under-diagnosis. Overweight/obesity (Adjusted OR=1.89) and smoking (Adjusted OR=1.54) are significant risk factors for developing diabetes in adults with ID. Conclusions: Health promotion targeted in adults with overweight/obesity and smoking is crucial to reduce the risk of developing diabetes in adults with ID.

Quality of primary health care of 5,000 people with intellectual disabilities in Scotland
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**Aim:** This study measures good practice in relation to long-term condition management within primary health care for adults with intellectual disabilities (ID) compared with the general population. **Method:** The electronic patient records of adults with ID (n=5000) registered with participating general practices were extracted and analysed in 2010 (T1) and 2015 (T2) to determine performance on management of long-term conditions according to the Quality and Outcomes Framework indicators. Comparisons at both times were made with the general population from the same health board. **Results:** Adults with ID experienced poorer management of all their long-term conditions according to indicators at T1. Some improvements were reported at T2, including better management of diabetes on two indicators and coronary heart disease on three indicators. **Conclusions:** Effective management of long-term conditions is essential to achieving equal healthcare for people with ID. Although some improvements were found in this study, people with ID still experienced poorer management of their long-term conditions.

**The health of Scotland’s 26,349 people with intellectual disabilities**

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**Aim:** This study analyses and compares reported general health status; reported mental health conditions; and other reported disabilities for people with and without intellectual disabilities (ID). **Method:** Data were drawn from Scotland’s 2011 Census. Descriptive statistics were generated about people with and without ID. Age and gender differences in general health, mental health and other disabilities were analysed. **Results:** We identified 26,349 (0.5%) people with ID from the total Scottish population (n=5,295,403). 15,149 (57.5%) were males and 11,200 females (42.5%). 5,234 were children (0-15 years), and 21,115 (16+ years) adults. Children and adults with ID reported poorer health (47.9% and 40.3%), compared to children and adults in the general population (2.1% and 13.8%). More mental health problems and other disabilities were reported by people with ID across all ages. **Conclusions:** People with ID rated their health less favourably than the general population at all ages. This result corresponds with previous research, suggesting self-rated health is an effective measure of health inequalities in the population of people with ID.

**Development of a scale to measure organisational culture in group homes**

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**Aim:** Organisational culture has been identified as an important influence on the quality of staff support in group homes for people with intellectual disabilities. There is no published and validated instrument to measure dimensions of organisational culture in group homes. The aim of this study was to develop a measure and determine its internal consistency and construct validity. **Method:** The Group Home Culture Scale (GHCS) was developed according to a theory driven approach based on Bigby et al.’s (2012) dimensions of culture. A pool of items was generated from the literature; these were reviewed
Patterns of co-morbidity in older people with intellectual disabilities

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Aim: This paper reports on an ongoing large-scale Australian study with concurrent comparative assessment of prevalence of various co-morbid health conditions in older people with and without intellectual disabilities (ID). Method: Information was elicited using a structured survey form with multimodal methods of delivery across the two population groups of interest. Study sites included metropolitan and rural regions in New South Wales, Australia. Results: Older people with ID were more likely to have select functional and physical impairments (e.g., depression [28% vs 19%] and falls [37% vs 16%]), but both minimal and notable differences among select age-related diseases or health conditions (e.g., equal rates among cardiovascular disorders and greater rates of arthritis [63.1% vs 47%]). Conclusions: It is important to understand differentials in patterns of co-morbidity by biological and systemic issues as well as ascertain variations in access to health services and other social equity issues in tracking functional and health co-morbidities among adults with ID.

Mortality and cause of death in those with intellectual disabilities with and without autism spectrum disorder: An exploration of New South Wales state-based administrative data

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Aim: This study examines mortality rates and cause of death in people with intellectual disabilities (ID) with and without autism spectrum disorder (ASD) in comparison to the general population. Method: Linked administrative data from disability services and mortality registers will be used to derive age-standardised death rates, standardised mortality ratios and comparative mortality figures. Descriptive statistics will be used to explore causes of death. Results: In 2005/06-2011/12 financial years, 73,674 people received disability services and 42,243 of these had ID. Mortality rates and causes of death of 34,746 individuals with ID and 7497 individuals with ID and ASD will be compared to the general population adjusting for age and sex. Deaths recorded during the period of June 2005 - December 2011 for those with ASD with and without ID (n=96) will be presented. Conclusions: This study will provide the most, reliable and current information on mortality and cause of death in individuals with ID, ASD and both.
Hospital encounters of adults with cognitive disability: Report on 10 cases

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Aim: We sought to understand barriers to hospitals responding appropriately to people with cognitive disability (intellectual disability or traumatic brain injury). A further aim was to identify promising ad hoc and systematic processes and practices that enable inclusion and responsiveness. Method: Data were from 10 adults with cognitive disability as they moved from acute care through a metropolitan hospital system. We conducted audits of hospital files, observations, and interviews with participants, their family or paid carers, and hospital staff involved. Results: Participants presented with varied acute care needs, requiring attention within 10 to 30 minutes of reaching hospital. Stays ranged from a few hours to 128 days. We found evidence of barriers previously documented (e.g., diagnostic overshadowing, negative attitudes, poor communication) and failures to implement patient-centred care, as well as ad hoc attempts to accommodate to these patients’ needs. Conclusions: Working with the hospitals is providing the opportunity to build on ad hoc strategies implemented by some hospital staff to make systemic changes. Collaboration across healthcare and disability systems appears key to successfully achieving sustained change.

A scoping review of pathways to dementia diagnosis for people with and without intellectual disabilities

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Aim: A scoping review was conducted to compare pathways to dementia diagnosis across people with and without intellectual disabilities (ID). Method: Two searches were conducted relating to people with dementia, and people with both ID and dementia. Terms for Search 1 captured dementia, care seeking and care pathways. Search 2 added terms for ID and Down syndrome. Searches were of 9 databases from 2000 to April 2015, supplemented by hand searches of studies meeting inclusion criteria: that is, primary studies published in English, addressing dementia diagnosis. A further update is planned for May, 2016. Results: The April 2015 Search 1 yielded 18 studies (eight addressed ethnic minority groups) and Search 2 yielded two studies. The mostly qualitative studies indicated delayed pathways to dementia services, with general practitioners being a usual point of first contact. For both groups, there was evidence of seeking alternative explanations for observed changes, which contributed to delays in diagnosis. Conclusions: There is a need to address the reluctance of healthcare professionals in diagnosing dementia, regardless of whether or not ID is present.
Locating Australia’s new National Disability Insurance Scheme

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**Aim:** This presentation will outline the background to Australia’s National Disability Insurance Scheme (NDIS), and analyse the factors and forces significant in its bipartisan adoption across multiple jurisdictions. **Method:** An initial review of Australia’s social policy history situated the NDIS within Australia’s welfare state and its institutional, governance and political frameworks. A further review of scholarly literature and other sources including media reports, speeches by significant players, government documents, relevant websites, and advocacy material was undertaken to identify the role of key individual and collective players in development and adoption of the NDIS as well as the influences, ideas and factors motivating those players. Critical theory provided the overarching theoretical framework for the analysis. **Results:** Whilst the NDIS has received almost universal support from political parties, the business sector, disability rights and social justice advocates and the broad Australian electorate, divergent ideological and philosophical strands intersected in shaping of the scheme and marshalling of support for it. **Conclusions:** The NDIS is a site of contestation around restructuring of the contemporary Australian welfare state.

A single blind randomised controlled trial of behavioural activation for adults with intellectual disabilities and depression

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**Aim:** Behavioural activation is a psychological therapy that has been shown to be as effective as cognitive behaviour therapy (CBT) in tackling depression. The advantage for adults with intellectual disabilities (ID) is that behavioural activation is less dependent on verbal communication. The question was whether it would be possible to recruit participants to a large-scale, multi-site trial of an individual psychological therapy for people with ID. **Method:** Participants recruited from sites in Scotland, England and Wales using a multipoint recruitment strategy were randomised to behavioural activation or guided self-help, an ethical alternative therapy, and followed-up at four, eight and twelve months post randomisation. **Results:** The target recruitment was for 166 participants and final total achieved was 162. The key challenges to achieving recruitment were not only with identifying individuals who have ID and depression but also in recruiting and training sufficient numbers of therapists to deliver the interventions. **Conclusions:** Successfully recruiting to this trial offers hope for developing the evidence base for using psychological therapies with people who have ID. Lessons were also learned about the considerable challenges to be overcome.

Lessons on intellectual disabilities: Tackling school children's prejudice and ignorance

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**Aim:** To promote positive attitudes towards people with intellectual disabilities (ID), the project set out to develop lessons to be delivered to children in early years of secondary school (12-13 years), and
examine children’s grasp of the materials. **Method:** Seven school lessons were developed based upon three strands of inquiry: a literature review, an overview of current practice and exploring the experiences of adults and young people with ID. To explore the children’s grasp of the materials, 34 school children were interviewed after each lesson was completed in order to examine engagement (pupils’ understanding and recall of the lessons), possible areas of confusion, whether the activities evoked empathy and understanding for peers with ID. **Results:** The pupils demonstrated a good recall of the content and format of the lessons. They also showed a good understanding of the materials and reported few areas of confusion. One of the lessons, concerning bullying, evoked emotional reactions from the children. **Conclusions:** These school lessons show promise as a method for promoting positive attitudes towards peers with ID.

**Experience of raising a child with developmental disability in the context of Asia: A review**

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**Aim:** Misconceptions about the causes of disability and subsequent prejudice and stigma exist among a significant number of people in the Asia. Therefore, families raising a child with a disability encounter different experience compared to the families raising a child without disability. The aim of this paper is to develop a greater understanding of parenting of a child with developmental disability (DD) in the cultural context of Asia. **Method:** This paper adopted content analysis method and the literature was searched utilising A+ Education, ERIC, PsyCINFO and Google Scholar. **Results:** The paper reveals that families raising a child with DD are experiencing high stress, increased financial burden, affiliate and courtesy stigma and negative impact on mothers in terms of additional caregiving role, instability of conjugal relations, giving up of involvement in economic activities, and shrinking kinship and social relationships. **Conclusions:** It is anticipated that this review will provide an in-depth understanding on parenting a child with DD in Asia, which may in turn contribute to improve the quality of life of children with DD, their parents and the family as well.

**Parents’ experiences of collaborating with professionals in the support of their child with profound intellectual and multiple disabilities: A multiple case study**

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**Aim:** To acquire knowledge on the frequency, function and personal experiences of communication between parents and professionals. **Method:** A multiple case-study (n=4) was conducted, in which mothers logged observations every time they had contact with the professionals supporting their children during an uninterrupted twelve-month period. The frequency of contact was logged, along with the professional with whom the parents had contact. The contacts were analysed according to function and subject and the parents’ experiences were labelled and described in a narrative. **Results:** The mean number of contacts a month ranged from 1.9 to 16.7 across the four cases. Most of the contacts were with the child’s direct support persons (DSP) or senior DSP (85.2%); and exchanging information (35.5%) was the most common function of communication. Issues concerning health/physical functioning (28.4%) were the most common subjects discussed. The majority of the mothers’ experiences were
positive. **Conclusions:** The DSPs play a crucial role in all cases. DSPs need training and support from management to fulfil their role, in order to effectively acknowledge parents as partners in the support of children with profound intellectual and multiple disabilities.

**Valenced reactivity and intelligence: Implications for typical intellectual development and autism**

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**Aim:** This research examined the interaction between valence processing and intellectual development in typical development (TD) and autism. It was hypothesised that reactivity to positive and negative valence stimuli would be associated with intelligence and autism symptom severity, potentially accounting for typical and atypical development. **Method:** Participants were 19 TD children and 23 children with ASD, aged 2 to 6 years. Valence processing was assessed using an affective-priming/preferential-looking eye-tracking task. Intelligence was assessed using the Mullen Scales of Early Development. Associations between valence processing and intelligence were examined. **Results:** In TD, valence-processing measures accounted for 53% of variance in verbal intelligence, and 66% of receptive (i.e., non-motoric) nonverbal intelligence. In the autism group, contrasting patterns of atypical valenced reactivity differentiated two distinct subgroups, which offered greater accounting of variability in intelligence and symptom severity than whole-group analyses. In exploratory analyses, contrasting patterns of valenced reactivity (i.e., positive/negative) and intelligence (i.e., verbal/nonverbal) explained more than 71% of variance in autism repetitive behaviours in each subgroup. **Conclusions:** These novel findings suggest that valence processing is intrinsically associated with intelligence and autism.

**Out-of-school care for school age youth with intellectual and developmental disabilities: Do child care providers feel prepared?**

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**Aim:** Research on the challenges faced by child care providers related to including school age children with intellectual and developmental disabilities (IDD) in their settings is largely missing from the literature. **Method:** Focus groups and phone interviews were conducted with 41 child care providers in southern United States. Providers included administrators (directors, assistant directors) of after-school and youth programs, lead and assistant teachers, group home providers, family childcare providers, and other professionals including therapists. Data were analysed qualitatively using a grounded theory approach with the help of Nudist (N6) software. **Results:** Providers reported lack of adequate disability-specific training on how to include children with disabilities in their setting(s). Barriers related to collaborating with parents, school teachers and other professionals also makes inclusion difficult. Providers mention lacking sufficient staff, information on disability resources and financial resources for successful accommodation. **Conclusions:** Although a set of legal, moral, rational and empirical arguments form a basis for inclusive practices, child care providers do not feel prepared for successful inclusion. Supports that providers need to successfully include school age youth with IDD in out-of-school settings will be discussed.
Current perspectives and data on the postsecondary education participation of individuals with intellectual and developmental disabilities in the United States

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Aim: In 2008, the US Congress re-authorised the Higher Education Opportunity Act. This law contained a number of important new provisions to improve access to postsecondary education for students with IDD. The law contained a discretionary grant program entitled ‘Transition Programs for Students with Intellectual and Developmental Disabilities (IDD) into Higher Education’ (TPSID). This presentation reports on the outcomes of these demonstration projects. Method: Over the period 2010-2015, 27 TPSID projects were established in states across the US. The presentation will describe the 27 projects in terms of student characteristics, academic success, inclusive social opportunities in campus activities, student exit outcomes, and career development and employment opportunities achieved. Results: More than 900 students with IDD participated, 40% worked while attending college, most required special mentoring and accommodations, 50% lived in on-campus residence hall, 77% earned one or more credentials, and 47% had a paid job upon program completion. Conclusions: Lessons learned regarding alignment with college and university policies and practices, sustainability, and ongoing limitations and challenges will be presented.

Supporting train travel for people with communication disabilities

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Aim: V/line provides train travel throughout Victoria, Australia and aims to be the first transport provider to be awarded the Communication Access Symbol. People with communication disabilities have reported the need for staff training and communication tools in order to improve their experience of train travel. Method: Communication access assessments at stations and on-line surveys of front line staff were conducted pre and post-intervention. Communication tools were designed and training delivered to staff to facilitate face-to-face interactions with passengers with communication disabilities. Results: Communication Access assessments were conducted at 37 stations across the network. The initial survey data from 111 front line staff identified the tools needed and these were developed in collaboration with station staff. The difference between pre and post-interventions surveys and the communication access assessments will be discussed. Conclusions: V/Line commenced becoming communication accessible in 2012 and will achieve this goal in 2016. Key elements of this process have been a commitment to ongoing staff training and a focus on listening to customer feedback.

Lived experiences of adults with intellectual disabilities using public transport

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Aim: This study explored the lived experiences of adults with ID in relation to public transport in an attempt to better understand the influence public transport may have on feelings of inclusion,
empowerment and quality of life. **Method:** Participants comprising of six adults with ID (2 male, 4 female) and two female disability support workers were recruited from two disability organisations within metropolitan Adelaide, South Australia. They participated in semi-structured interviews, sharing their experiences of transport training, social interactions, and acceptance when using public transport. **Results:** Barriers and facilitators of internalised feelings of citizenship included transport training, relationships with significant others and the inclusiveness of public transport services. Emotional responses of adults with ID to their public transport experiences impacted on feelings of acceptance, empowerment and willingness to participate within the public setting. **Conclusions:** Greater understanding of the practical applications around empowerment for individuals, families and support workers is paramount with future considerations needing to revolve around program development and training.

**Addressing foetal alcohol spectrum disorders in Australia**

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**Aim:** The Alcohol and Pregnancy and FASD Research Group has led foetal alcohol spectrum disorder (FASD) research and policy development for over a decade. Our program of research encompasses four research areas. **Method:** The first involves epidemiology and surveillance of FASD using routinely collected data. The second focusses on prevention and development of the Australian Diagnostic Instrument. The third involves population surveys within Indigenous communities. The fourth focusses on juvenile justice involving screening, diagnosis and workforce development. **Results:** There has been a two-fold increase in FASD case ascertainment. Prevention strategies have included effective television advertisement and midwife training in use of AUDIT-C. The feasibility of the Diagnostic Instrument has been assessed and on-line training developed. Surveys have shown a high rate of FASD but a reduction in prenatal alcohol use. Early information on assessment of FASD in juvenile justice settings has been achieved. **Conclusions:** Our research tackles alcohol use in pregnancy and FASD from several angles and has resulted in promising improvements in FASD prevention and diagnosis, and support for a centre of research excellence.

**Reimagining disability: Towards disability pride**

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**Aim:** This research project considers whether exploring the concepts of ableism and disability pride presents potential for a positive re-imagination of disability. The aim is to offer insights which may help improve the lives of persons with disabilities. **Method:** This project uses a Participatory Action Research methodology. It involves working with a group of seven participants with intellectual and developmental disabilities (IDD) and a co-facilitator with IDD to explore the concepts of ableism and pride. Discourse analysis will be used for the analysis. **Results:** Early results suggest that participants like the idea of disability pride, however complexities around internalised ableism pose a significant challenge to a positive re-imagination of disability. **Conclusions:** This research has highlighted some complex and
uncomfortable issues that need to be addressed to achieve positive change. It is essential that this be
done through ongoing discussion with people with IDD.

From ancient sources to modern practice: Using the scriptures to inform the inclusion of people with
disabilities within Judaism

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Aim: This paper explores how Jewish sacred texts address inclusion with a view to full participation of
Jews with disabilities within the community’s social structures and rituals, in both the private (family)
and the public (community) realms. Method: A midrashic method of interpretation of sacred texts
including the Torah, the T’nach and the Talmud engages in a close reading of the text for the purposes of
discourse analysis. Results: The 613 mitzvot – the commandments relating to how to lead a Jewish life –
are directed at all people including people with disabilities. This paper demonstrates that, when read in
their context, more often than not the texts support inclusion of people with disabilities in all aspects of
Jewish life. Conclusions: A person cannot be said to be included in the community if they have no Jewish
home life, are unable to enter a building, engage in communal worship or access the rituals. Learning
from Jewish sacred texts could improve the inclusion of Jewish people with disabilities.

Development of an inclusive methodological research framework for individuals with Down
syndrome: Social and semiotic approaches and arts-informed research

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Aim: Practice-based video research and visual arts offer opportunities to construct new insights about
the communicative abilities of people with Down syndrome (DS). The tangible nature of the visual data
provides accessibility to their individual narratives. Method: Six months in-situ video observation of the
weekly engagement of a group of six young adults within an arts program of a DS organisation in
Singapore provided the data for this ethnographic case study. Vygotsky's cultural-historical theory
guided the staged approach to social and semiotic data analysis. Results: The social and semiotic tenor
of the communicative details of the participants’ artistic engagement identified their growing ability to
reflect on their experiences. The participants were increasingly able to take control of their narratives
about what mattered to them. Conclusions: This study about visual arts and supported by video
technologies provides new ideas that can reframe inclusive research methodologies. Although care must
be taken with interpretations, the research process illustrates the opportunities for people with
intellectual disabilities as informants in practice-based research.
EMT en Español: Adaptations of caregiver-implemented naturalistic communication intervention for low-income Spanish-speaking families

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Although Hispanic children represent the fastest growing population of young children in the United States, there are currently no evidence-based interventions for young children from Spanish-speaking homes showing delays in their language acquisition. Aim: The main goal of this project was to test the effectiveness of an adapted model of caregiver-implemented Enhanced Milieu Teaching (EMT en Español) intervention. We hypothesised that caregivers would learn to implement language support strategies at criterion levels, they would generalise use of these strategies to untrained routines, and children’s spontaneous vocabulary would increase. Method: Three behaviours related to the main components of caregiver-implemented EMT (matched turns, expansions of language, and milieu teaching prompts) were measured and graphed for visual analysis of the data in a single-subject multiple-baseline across behaviours design. Participants included three 2.5 to 3.5 year olds low-income Hispanic children demonstrating expressive and receptive language delays and their Spanish-speaking caregivers. Results: Caregivers were able to systematically implement language support strategies in home activities. Conclusions: EMT en Español is an effective caregiver-implemented intervention.

Treatment of traumatic stress in people with intellectual disabilities: Preliminary results from a randomised controlled trial on the effectiveness of EMDR for DSM 5 PTSD

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Aim: People with intellectual disabilities (ID) are more likely to experience traumatic life events compared to the general population. Eye Movement Desensitisation and Reprocessing (EMDR) does not require advanced communication skills and therefore it is a suitable intervention for people with ID. Preliminary findings of a pilot trial on the effectiveness of EMDR for DSM 5 PTSD will be presented. Method: A pilot randomised controlled trial with two arms; an active treatment group vs. a waiting list control group was conducted. The primary outcome was post-traumatic stress disorder (PTSD) symptomology as measured by PTSD Checklist for DSM-5 (PCL-5). Results: On the basis of existing limited evidence, we have hypothesised that those on the EMDR arm will present with decreased DSM 5 PTSD symptomology at post-treatment and 3-month follow-up. Data collection and analysis is still ongoing. Conclusions: If EMDR is an efficacious and acceptable treatment for PTSD for people with ID, it can be routinely adopted in clinical practice to alleviate traumatic distress.

Prevalence data and agreement among instruments measuring dementia symptoms in a Swedish sample of elderly persons with intellectual disabilities

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Aim: To gather further data on the prevalence of dementia in elderly persons with intellectual disabilities (ID) as well as to psychometrically evaluate measures in this field. Method: 85 elderly
persons with ID, of which 30 also had Down syndrome (DS), were assessed using three measures for dementia symptoms developed for this population. Participants were also independently assessed for dementia by two expert clinicians. Results: 17.6% (15 participants) of the total sample were judged as having probable dementia according to expert assessment. This proportion was higher among participants with DS but not significantly so. Assessment based on the Dementia Scale for Down Syndrome (DSDS) was most in agreement with expert opinion. Agreement was also substantial between the DSDS and the Adaptive Behaviour Dementia Questionnaire, while results for the Dementia scale for Learning Disorders were mixed. Conclusions: The findings provide further evidence for a substantial prevalence of dementia among elderly persons with ID and indicate that at least some commonly used instruments for making that diagnosis have validity for use in Sweden.

Towards an integrative model of successful parenting of persons with intellectual disabilities

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Aim: A more integrated model for successful parenting is needed to improve diagnosis, treatment and support for parents with intellectual disabilities (ID). This project was undertaken to develop a model that is based on the most recent scientific results, from multiple perspectives, with a large variety of protective and possible risk factors and with a firm theoretical base. Method: With several research projects in the Netherlands with different participants (parents with ID, social network members and professionals) using methods ranging from personal interviews, focus groups, questionnaires, and qualitative observations to randomised controlled trials, various empirical data were collected to build the model. Results: A first presentation of the developed integrated model was presented at a national symposium and the reactions were positive. Conclusions: The developed integrated model seems promising to implement in clinical care and in national and international research as well.

Missing Voices: The views and experiences of children with disabilities and young people living in out-of-home care in Northern Ireland

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Aim: This study examines the over-representation of children with disabilities in out-of-home care in Northern Ireland and explores their views and experiences of growing up in out-of-home care. Method: Case studies of 15 children (9 males, 4 females; aged 4 to 16 years) with a range of disabilities and placement experiences were undertaken. Case files were read, the children, their birth parents, carers and social workers were interviewed. Results: Participants had family-based and residential care placements; however, many experienced repeated placement disruptions which impacted on opportunities for permanence. A lack of appropriate foster care placements also impacted on placement choice. Some participants were not consulted or involved in decisions affecting their lives and there were gaps in service provision across disability, mental health and child care sectors. Conclusions: There is an urgent need to address barriers to permanency for children with disabilities, and to expand the range of specialised foster care available. The views of children with disabilities in out-of-home care should be sought to ensure robust child-centred reviews of their care experiences.
Moving on?: The experiences of young people with disabilities leaving State care in Northern Ireland

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Aim: The overall aim of the study was to examine the needs of care leavers with mental health and/or intellectual disabilities (ID) in Northern Ireland. Method: Case studies of 31 care leavers with mental health and/or ID were undertaken which involved reading their case files, interviewing care leavers up to three times over the course of a year and, where appropriate, interviewing their birth parents and/or carers and social workers. Results: The study found limited efforts to undertake early transition planning and rigid service structures which excluded some care leavers. A range of barriers to education or employment were also identified. Some young people also experienced difficulties in securing appropriate accommodation which impacted on their vulnerability in the community. Relationships with professionals and consistent informal supports were highlighted by young people. Conclusions: Integrated policy and practice is essential to improve care leavers with disabilities’ transitions from child to targeted adult services, with flexible eligibility criteria and extended support well into young adult life. Early transition planning should also be person-centred and mobilise resources from informal networks and formal services.

Supporting people to live self-directed lives in the community: Learning from 54 Irish projects

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Aim: Genio Trust grant-aided 54 projects to support people with disabilities and people with mental health difficulties to move from institutional settings to live self-directed lives in their communities. This paper synthesises the implementation learning across sites. Method: Quantitative and qualitative data were collected from each project on at least three time points through interviews with informants and completion of an anonymous descriptive dataset for beneficiaries. Informants included project leads, managers and front-line staff. Results: Since 2010, 359 people have successfully moved to the community and a further 291 are being supported. The current biggest barrier to people moving is the availability of housing. The factors which have supported effective implementation include: multi-level leadership, the person leading the process, involving families and allies, engaging and consulting with stakeholders, staff skills and training, intentional building of community networks, starting small and modelling change, addressing the challenge of reconfiguration, allowing sufficient time, a focus on outcomes and monitoring progress. Conclusions: A framework to guide implementation of personalised services has been produced for service commissioners and providers.

How to improve the exchange and application of knowledge in the care and support for people with intellectual disabilities?: Results of a systematic review

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**Aim:** The exchange and application of knowledge is a challenge in the care and support for persons with intellectual disabilities (ID). This review examines which factors are enabling/disabling in stimulating the exchange and application of knowledge in the care and support for people with ID. **Method:** A systematic review of the literature was conducted using the databases Pubmed, Psychinfo, Cinahl, Proquest and Business Source Elite for relevant articles published in English or Dutch between January 2000 and December 2015. During the process of selection and analysis two independent reviewers assessed all articles according to PRISMA guidelines. Approximately 20 papers are expected to be included in the analysis. **Results:** The main findings of the thematic analyses will be presented, e.g. enabling/disabling factors on an organisational and on an individual level. In addition, we will share our insights and recommendations for service organisations as well as for researchers and policymakers. **Conclusions:** The results will be useful in improving the exchange and application of knowledge in the care and support for people with ID, which will contribute to enhancing their quality of life.

**Social information processing in Williams syndrome: The challenge of indirect cues**

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**Aim:** Individuals with Williams syndrome (WS) demonstrate high levels of social interest, but their ability to use social information effectively is unclear. This study examined neural mechanisms supporting social information processing in WS. **Method:** 30 young adults with WS completed a visual two-alternative forced-choice task requiring them to identify the preferred ‘gift’ by interpreting the emotional expression and gaze direction of unfamiliar young adult faces. Event-related potentials (ERP) measured associated neural processes. **Results:** Participants with WS correctly identified wanted/unwanted ‘gifts’ when positive and negative facial emotional expressions were paired with the gaze toward the object, but performed at chance level when the correct response required disengaging from the direction of the gaze. ERP revealed faster detection of negative versus positive facial expressions, greater memory for gazed at versus away objects, and increased attention to objects originally presented in locations opposite to the gaze direction. **Conclusions:** Successful social information processing in WS may depend on the ability to interpret indirect cues and shift attention away from the gaze.

**Common physical health conditions and multi-morbidity in adults with intellectual disabilities**

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**Aim:** People with intellectual disabilities (ID) have different health needs and experience greater health inequalities compared to the general population. Gastro-oesophageal reflux disorder, sensory impairments and osteoporosis are thought to be more commonly experienced in people with ID. However, most studies have been small scale or methodologically limited. The aim of this paper is to report the physical health conditions of people with ID. **Method:** The analysis is part of a large prospective, cohort study. The adult population (aged 16 years and over) of people with ID living within one geographical area of Scotland, were recruited. Participants underwent a comprehensive health assessment. Data analysis generated descriptive statistics about the physical ill-health and multi-
morbidity of people with ID. **Results:** 1,023 people with ID took part in the health assessment. 562 (54.9%) males and 461 (45.1%) females aged 43.9 years (16-83). Gastrointestinal conditions were particularly common, and 98% had two or more conditions. Further analysis will be presented. **Conclusions:** Using a robust study design, we have reported the high prevalence of health conditions and multi-morbidities in this population.

**Quality Checkers and organisational person-centredness: An inclusive research approach**

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**Aim:** Current policy reforms emphasising the importance of people with intellectual disabilities (ID) being central to decision making is extending to their involvement in service evaluation. Quality Checkers sees people with ID as experts by experience, where they work in organisations to check the service quality. This paper reports on the use of Quality Checkers by the Inclusive Research Network (IRN) to trial a set of person centredness indicators developed from the perspectives of people with ID, and the use of these indicators to check service quality. **Method:** Semi-structured interviews were conducted with 30 persons with ID from three disability organisations. Thematic analyses of interviews were developed into person-centredness indicators, and used by the IRN to quality check each organisation. **Results:** Inconsistencies between organisational person-centred policy and implementation, and disparities in person-centredness perceptions between services and service users were found. **Conclusions:** The Quality Checker model provides opportunities to develop person-centred policies and practices drawn directly from the input of service users ID. It can provide a useful mechanism with the trends towards individualised funding.

**Collaboration between the disability and aged care sectors: Opportunities and challenges**

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**Aim:** In Australia two productivity reports have led to the concept of individualised funding being embraced by both the aged care and disability sectors. While a person-centred focus is reflected in both policy directions, there is little research conducted on cross-sectorial collaboration to support older individuals with lifelong intellectual disabilities (ID) to age successfully. This paper aims to identify opportunities and challenges for such cross-sectorial collaboration. **Method:** Semi-structured interviews were conducted with 25 senior personnel in the disability and aged care sectors across two Australian states. Thematic analysis of the transcribed interview data was undertaken by three members of the research team. **Results:** Opportunities and challenges at both individual and organisational levels were identified. Individual opportunities included improved options, enhanced social networks; for organisations, adoption of proactive planning approaches, coordinated staff training. Individual challenges included adapting to change, decision-making as an unfamiliar experience; for organisations, confronting bureaucratic boundaries, funding impediments. **Conclusions:** While growth opportunities are evident for each sector, support for individuals in dealing with change and addressing the systemic and political barriers pose impediments to successful cross-sectorial collaboration.
Assessment of job satisfaction in people with intellectual and developmental disabilities: Best practice, current issues and potential for improvement

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Aim: Current research on job satisfaction of people with intellectual and developmental disabilities (IDD) relies on a wide range of research methodologies. Since this heterogeneity of methods is an impediment to research in this domain, the aim of this study is to propose best-practice approaches for the assessment of job satisfaction. Method: Firstly, questionnaires for job satisfaction applied in either organisational-psychology or IDD-specific research were collected and systematically analysed (theory, psychometric properties, IDD-specific questionnaire criteria suggested by Finlay and Lyons, Flesch-Readability-Scores). Secondly, we devised a best-practice questionnaire and conducted a pilot study (n=30 employees with IDD), applying said questionnaire along with two self-devised questionnaires evaluating its feasibility and usefulness. Results: Measures applied in IDD-specific research (n=14) frequently lack psychometric and theoretical foundations. Questionnaires originating from organisational-psychology research (n=65) seldom adhere to requirements relevant for IDD-specific instruments (answer format, item complexity). However, some measures, like the JDI/JIGS, present feasible alternatives to current approaches. Conclusions: Application of specific questionnaires originating from organisational-psychology is feasible and would enhance research quality. Additionally, the knowledge transfer between organisational-psychology and IDD-specific research would be considerably improved.

Inclusion as emergence: Co-creating inclusive spaces in University course settings

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Aim: From 2013/2014 three inclusive University seminars have been carried out at the University of Vienna focusing on advancing our learning on co-creating inclusion in university course settings. Method: The seminars were structured as iterative learning experiments modelled after Theory U, with 12 self-advocates with intellectual disabilities (ID) and 40 Master students participating as co-learners. Data collected from all learners using qualitative approaches (interviews, observations, introspective reflection) led to a “learning history” on what enables and disables inclusive learning environments. Results: A key theme that emerged was inclusion as emergence, with the seminar leading to successful group collaborations (e.g. a group developing a prototype for an empowerment seminar). But even in thoughtfully composed learning environments, inclusion (conceptualised as a group identifying and using all talents to realise a project based on a shared purpose) is not a guaranteed outcome. Conclusions: Instead of seeing inclusion as merely being or doing something together, the research surfaced basic principles that can support the emergence of inclusive outcomes, e.g.: balancing structure and openness, creating opportunities for personal development and welcoming mistakes.
Health promotion for people with intellectual disabilities: An inventory of available nutrition and physical activity initiatives in two service providers

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Aim: Research on healthy lifestyles of people with intellectual disabilities (ID) often focuses on interventions in program settings. As a result, knowledge on initiatives in everyday life settings and the attention for health promotion resources and hindering factors in these is scarce. This study aims to gain insight into the characteristics of health promoting initiatives in the daily life of approximately 2000 people with ID receiving care from two service providers, and the extent of attention for resources and hindering factors in these initiatives. Method: Telephone surveys were conducted among ID service providers' employees to describe characteristics of 47 identified initiatives. Data were analysed using descriptive statistics and the socio-ecological model. Results: Initiatives were mostly led by care professionals and trainees rather than health professionals. Individual factors (e.g. level of disability) received much attention, compared to organisational (e.g. available time and money) and environmental (e.g. norms and values) factors. Conclusions: Health promoting initiatives in everyday life settings could benefit from the use of trained professionals and embedment in organisational and environmental structures.

Health promotion for people with intellectual disabilities: Analysis of involved stakeholders and their perspectives

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Aim: Social support is an important factor in health promotion, even more for people with intellectual disabilities (ID). This study provides an overview of involved stakeholders and their perspectives on health promotion for this group. Method: 29 semi-structured interviews were conducted with key stakeholders regarding their perspectives on the lifestyle of people with ID, experiences with and expectations of health promotion for this group. Data were analysed thematically, focusing on resources and hindering factors within the above-mentioned themes. Results: Interviewees expressed that the lifestyle of people with ID is characterised by a culture in which (often unhealthy) food ‘makes a good day’. Difficulties in changing this culture (e.g. habits, norms and values) and the tension between the low level of independency and autonomy of people with ID make health promotion challenging. Interviewees indicated the need for healthy living to be a normal part of daily life. Conclusions: Social support from various stakeholders is indispensable for health promotion for people with ID; their efforts could be maximised by a culture change and normalising healthy living in daily life.
Sociodemographic, clinical and service utilisation differences among Canadians with autism spectrum disorder and intellectual disabilities across the lifespan

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**Aim:** Individuals with autism spectrum disorder (ASD) have different service needs throughout the lifespan. It is important to tailor services based on an understanding of an individual’s unique cognitive profile, adaptive challenges and life stage. Here, we identify differences in service utilisation patterns and sociodemographic, clinical, and systemic variables between individuals with ASD, with and without intellectual disabilities (ID), across the lifespan. **Method:** An online survey was completed by 3251 caregivers reporting on 3319 family members with ASD across Canada. Participants identified service receipts from a list of 23 services and an ‘other’ category that was recoded as necessary. **Results:** Overall service use was higher in the ASD+ID compared to the ASD-only group. The ASD+ID group received more caregiver-directed services and endorsed more barriers to services. There were no differences in mental health concerns, but there were more physical health concerns in the ASD+ID group. The unique profiles of the preschool, elementary, adolescent and adult age groups will be discussed. **Conclusions:** Understanding how individual and contextual factors function together in these populations will inform policy around service access and resource distribution.

Stepping beyond risk in order to manage recidivism: A strengths-based approach

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**Aim:** Victorian legislation allows for persons with intellectual disabilities to be subject to compulsory treatment under the Disability Act if they present with a significant risk of harm towards others. This study examines the characteristics and treatment needs of this group and proposes a strengths-based conceptual framework for assessment, risk management and treatment. **Method:** Data mapping techniques were used to examine 45 compulsory treatment completers based around accommodation changes prior to, during and after finishing treatment, with information derived from socio-demographic, historical and clinical profiles. **Results:** The study profiled a population whose needs are complex and disparate, revealing two broad groups in the sample, comprising a higher functioning group with more mainstream offender characteristics and the other with higher support needs and a more mainstream disability profile. **Conclusions:** The profile of this sample highlights the importance of placing an emphasis on individualised and comprehensive assessment based within a functional analysis paradigm. A conceptual framework will be presented focusing on enhancing adaptive skills, quality of life and functional based intervention to manage risk and promote behaviour change.

Using Virtual Immersion Therapy to teach offenders with intellectual and developmental disabilities social skills: A modelling study

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Aim: The aim of the study was to model Virtual Immersion Therapy (VIT) as a paradigm to teach social skills to offenders with intellectual and developmental disabilities (IDD). Method: Using a single-case multiple baseline design, 12 men detained in hospital because of criminal offending behaviour were invited to take part in this study. Participants were randomly allocated to either a one, two or three-week baseline condition, followed by either one or two sessions of training, followed by one, two or three-weeks of follow-up. Participants completed measures of empathy, social problem solving and emotion recognition before, during and after the intervention. The primary outcome was the Facial Expression Coding System (FACES). Results: Overall, emotion recognition, the quality of verbal responses, and social problem solving skills significantly improved following intervention, but this was not the case for all 12 participants. For some participants, gains were not maintained at follow-up. Conclusions: The results indicate that a novel VIT paradigm may lead to significant improvements in social skills for some men with IDD who have a history of criminal offending behaviours.

Obstacles to cognitive accessibility by students with intellectual disabilities

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Aim: To identify environmental cognitive components that may become obstacles to learning by students with intellectual disabilities. Method: An ergonomic analysis of cognitive behaviour was conducted among 380 students aged from 5 to 20 years in two contexts of activities such as the use of numbers, reading, etc. They were initially placed under standard conditions to identify factors that place them all in a situation of failure. Then, they were observed under adapted conditions, where obstacles previously identified were eliminated, which allowed 83% of them to succeed. Results: This exploratory research has led us to generate one general obstacle and five more specific and operational factors. The complexity of the prescribed task (supplied materials, instructions to follow, etc.) is the general obstacle. Among the five specific factors, the most critical one is the instability of cognitive elements present in a given task. Conclusions: It is the interaction between the characteristics of these students and environmental cognitive components that systematically places them in failure situations.

The development of life expectancy for people with Down syndrome in Norway between 1969 and 2050

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Aim: Life expectancy for people with Down syndrome (DS) has increased dramatically in the Western world during the 1900s. This study aimed to provide insight into life expectancy for Norwegians with DS from 1969 to 2014 and to project future prevalence for adults with the syndrome until 2050. Method: This registry study estimates the development of life expectancy for people with DS. To calculate age at death we collected data from death certificates. Together with data from Medical Birth Registry we simulated life tables. Results: We will present simulated life tables but preliminary results shows an increase in the age at death for people with DS of nearly 40 years between 1969 and 2014. The future proportion of people with the syndrome older than 40 years of age will increase significantly. Conclusions: It is a dramatic increase in life expectancy, but the preliminary results indicate nearly no
increase in longevity. This change must give consequences for the planning of the care and health promotion of people with DS in the middle and later stage of life.

**Age matters: Variations in long-term supports and services’ settings, costs, and outcomes for children versus adults with intellectual and developmental disabilities**

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**Aim:** To describe age differences in support needs, service use, costs and outcomes for people with intellectual and developmental disabilities (IDD) who receive long-term supports and services (LTSS) in the United States.  

**Method:** Primary analyses use annual and longitudinal data from the RISP study of residential services in the United States regarding utilisation of Medicaid funding authorities, residential setting types, setting sizes, and state versus non-state operated programs. Secondary analyses use the family surveys from the National Core Indicators program.  

**Results:** The proportion of people with IDD living in large state institutions who were children declined from 50% in 1965 to 2.8% by 2013. In 2013, 39% of the people getting LTSS from states were children, as were 24% of Medicaid Waiver recipients, and 7% of people living in ICF/IID facilities. Average annual per person Medicaid expenditures ranged from $19,310 for children living with family members to $153,793 for adults living in ICF/IID. Families of adults were more satisfied with overall services than families of children.  

**Conclusions:** Age is an important covariate in analyses of utilisation, costs and outcomes of LTSS for people with IDD.

**Examining mortality over a decade for people with intellectual disabilities in the United States**

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**Aim:** Mortality surveillance can provide insights into the underlying health and life experience of people with intellectual disabilities (ID). Longitudinal mortality patterns are of particular interest given shifts toward community-based living in recent decades to inform emerging health inequities.  

**Method:** Mortality patterns over a decade (2003–2013) were examined for a large (>25,000) cohort of adults (>17 years) living in the United States receiving a range of disability services.  

**Results:** Top-ranked causes of death in adults with ID showed similarity to the US general population, but with higher cause-specific rates. Alzheimer’s disease and aspiration pneumonia were among causes observed more frequently in adults with ID. Median and mean age at death remained relatively constant (58-63 years). Gastrointestinal conditions increased in frequency, while other conditions (e.g. stroke) were consistently observed at lower rates.  

**Conclusions:** Some differential mortality patterns in adults with ID may be related to disability etiology (e.g. Down syndrome) and challenging to mitigate. However, some causes suggest possible inequities in access to quality healthcare (e.g. cancer screening). Profiles of other causes warrant further study of associated factors (e.g. aspiration pneumonia).

**Parent-assisted social skills training for preschool children with autism spectrum disorder: The UCLA PEERS for Pre-schoolers Program**
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Aim: The purpose of this study was to test the efficacy of a parent-assisted social skills intervention for preschool children with autism spectrum disorder (ASD) using a randomised controlled trial design. Method: 19 children (16 males; 3 females) 4 to 6 years of age (M=4.68; SD=.29) with ASD without intellectual disabilities participated in this study with their parents. Participants were randomly assigned to the 16-week parent-assisted PEERS for Pre-schoolers social skills treatment (TX) or a delayed treatment control group (DTC). Results: A MANOVA revealed that the TX group demonstrated significant increases in social skills and reduced autism symptoms and problem behaviours. Data analysis using Pillai’s trace (V=.98, F(1,14) = 52.27, p=.004) shows a significant effect of treatment on the SSIS (Gresham & Elliot, 2008) and SRS-2 (Constantino, 2012), as well as their subscales (p’s<.05). Secondary analyses showed large inter-individual differences between the two groups (p<.05), and significant decreases in autism symptoms from baseline to post-treatment (p<.01). Conclusions: Findings address a gap in the research literature by demonstrating the benefit of parent social-coaching in early childhood to improve friendship skills for young children with ASD.

Basic motor skills of children with Down syndrome: Construction of motor development curves

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Aim: Young children with Down syndrome (DS) show functional limitation in their development. To evaluate intervention methods, a valid standardisation of the motor development of children with DS is required. The Test of Basic Motor Skills for Children with Down Syndrome (BMS) is a motor measuring instrument developed specifically for children with DS in the first three years of life. Previously however, no motor development curves were available. Method: BMS-data (334 registrations, from 119 participants) were analysed, using non-linear regression. A motor development curve was constructed, based on the BMS. The probability of achieving motor function was predicted. Results: We present a motor development curve and the probability of a child with DS reaching specific motor function, based on the BMS. Conclusions: Our work provides a standardisation of the motor development of children with DS. This will let physiotherapists accurately monitor a child’s individual progress, and allow for better-founded and more goal-oriented utilisation of motor intervention. Additionally it provides an effective tool for providing parents with feedback about their child’s progress.

Stay Connected: The future of inclusive learning support programs for children and young people with disability in the Australian school system

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Aim: A practice review was undertaken which examined how an Australian education support program, Stay Connected, improved educational outcomes for children with intellectual disabilities or autism spectrum disorder. Method: An analysis of existing policy and practice explored the challenges experienced by students with disabilities and supports that help students fulfil their academic potential.
Consultations were conducted with Uniting Stay Connected practitioners and representatives from learning support teams at two schools. **Results:** A number of challenges have risen relating to the future financial viability of the program following Australia’s transition to individualised funding packages, under Australia’s National Disability Insurance Scheme. Concerns include: incompatible transferability of time and resources from block to individual sources of funding, insufficient financial reserves for staffing and resources and incompatible time constraints for those with higher levels of disability to achieve program outcomes. **Conclusions:** Programs like Stay Connected may need to be funded through an additional funding source which recognises the interrelationship between child wellbeing, engagement in education and disability. Uniting recognises the importance of co-design in achieving either transition or the retention of block funding.

**Implementing intensive interaction in a day care setting for people with profound intellectual and multiple disabilities to improve teacher-pupil communication in Taiwan: Using physical support**

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**Aim:** Intensive interaction is used to improve interaction and fundamental communication for people with profound intellectual and multiple disabilities (PIMD) to be active interaction participants. Physical support or touch assistance involves light physical contact to people in order to feel and respond to their possible communication behaviours and increase their participation. This study investigates the communication behaviour between teachers and pupils by examining teacher-pupil interactions, when teachers implemented intensive interaction through physical support. **Method:** Six teacher-pupil dyads participated. Teachers were trained and supported in the use of intensive interaction using physical support. Videos of teacher-pupil interaction were taken before introducing the technique. Following a 15-week period during which the approach was practiced routinely in daily activities, further video recordings were made. Number of turns and initiations of pupils during teachers-pupil interaction were coded and analysed to describe communication behaviour. **Results:** After providing training, physical support, the numbers of interaction turns and initiation behaviours of pupils increased. **Conclusions:** Physical support could be one of the strategies to improve teacher-pupil communication for practitioners when introducing intensive interaction to people with PIMD.

**A journey of empowerment in inclusive research**

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*United Voice, MALAYSIA*  
**Aim:** Inclusive research in Malaysia is scarce. We reflect on our first experiences with inclusive research despite the challenges given to us. **Method:** We were given opportunity to speak and listen to, and contribute to a study as individuals with intellectual and developmental disabilities. We shared our experiences by writing journals, and giving our ideas to the study. We learned to collect data and analyse data through experiential learning. **Results:** As research partners, we learned to reflect and think more. We also learned to discuss and write more. It is a journey of empowerment where we share power whilst producing knowledge as a team. Participating in this research project has enabled us to practice self-advocacy in a proactive manner towards collaborative learning. **Conclusions:** It is an
enriching process. We need to learn and work together as a team. We believe in ‘nothing about us without us’ and our rights to research to promote social change and achieve full inclusion.

A winning solution as peer mediators

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Aim: To explore the learning progress of peer mediation by people with intellectual and developmental disabilities in resolving disputes among their peers. Method: A 90-hour peer mediation training was conducted in 3 phases using experiential learning approach. After which we conducted peer mediation to our members who have conflicts among themselves. We recorded our learning points in our daily journals from training to real setting. We reflected on our own journals and relevant documents, and discussed our learning points in focus group discussions and analysed our data in our review meetings. We reviewed our recorded peer mediation to improve our peer mediation skills. Results: It is a progressive self-emancipation learning process for us as peer mediators. We learned to accept our limitations and work together as a team. Our confidence level was increasing as we learned to manage disputes among our members. Conclusions: It is possible to support our members in resolving their disputes in a systematic and constructive manner. We learned the importance of working interdependently among ourselves as a winning solution.

Improving health advocacy and health outcomes in adolescents with intellectual disabilities

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Aim: Adolescents with intellectual disabilities (ID) experience poorer health than their peers in the general population. We tested whether a health intervention package led to increased health advocacy and improved healthcare for this group. Method: A clustered randomised controlled trial (RCT) was conducted in adolescents with ID in Queensland, Australia. The intervention package consisted of health education, a health diary and health check. Health advocacy was measured by carer questionnaire. Health promotion, disease prevention and case-finding activities were extracted from general practitioner records for one year post-intervention. Results: Carers of 592 adolescents completed the baseline survey. Advocacy and health outcomes were available for 385 (65.0%) and 435 (73.5%) participants respectively. Adolescents allocated to the intervention were more likely to attend the doctor on their own, ask questions and explain their health problems without help. They were more likely to have their vision, hearing, blood pressure and weight checked by the doctor. There were no differences between health intervention and usual care for identification of new diseases. Conclusions: The school-based intervention package improved advocacy and led to increased healthcare activity in adolescents with ID.

The health of adolescents with intellectual disabilities

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Aim: Few studies have reported the prevalence of co-morbid conditions in adolescents with intellectual disabilities (ID). This study investigates the prevalence of co-morbid conditions among adolescents undertaking a health check. Method: Cross-sectional data were obtained from parent/carer-reported information extracted from a health screening tool used in a wider trial of adolescents with ID in Queensland, Australia. Before visiting a general practitioner, the parent or carer completed the first section of this tool to record a complete medical history, after which the general practitioner conducted a thorough medical review. Results: Data were obtained for 176 participants aged 11-19 years at the time of the health check. Parents/carers report high prevalence of many health conditions in adolescents with ID such as constipation (25.6%), sleep problems (24.1%), urinary incontinence (17.6%), epilepsy (24.9%) and known problems with vision (42.3%) and hearing (15.9%). Conclusions: Parents/carers report high levels of co-morbidity in adolescents with ID in their care.

The Autism CHAP: A comprehensive health assessment program for adults on the autism spectrum with intellectual disabilities

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Aim: Adults on the autism spectrum with intellectual disabilities (ID) experience unique health-related needs and difficulties accessing adequate health care. They also exhibit poorer physical and mental health outcomes in comparison to the general population. This project evaluates the feasibility and acceptability of a comprehensive health assessment program (Autism CHAP) for adults on the spectrum with ID. Method: This project is guided by an advisory group including adults on the spectrum. Adults on the spectrum with ID will visit their general practitioner/nurse to complete the Autism CHAP. Up to 35 semi-structured interviews will be conducted with participants including the adults, their support persons and health professionals. Interviews will be digitally recorded, transcribed verbatim and analysed using thematic analysis. Results: Preliminary feedback from advisory group members suggests the Autism CHAP is appropriate and feasible for use with adults on the spectrum with ID. The results of the thematic analysis will be described. Conclusions: The Autism CHAP has the potential to improve health outcomes for adults on the spectrum with ID.

Overview of use of data linkage to understand determinants and outcomes associated with intellectual disabilities

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Aim: Data linkage is the bringing together of specific datasets from different sources using demographic information on individuals within a population. This presentation will provide examples of studies undertaken to investigate determinants and outcomes of intellectual disabilities (ID) and autism. Method: In Western Australia, systematic record linkages between multiple datasets including births, deaths, and hospital morbidity have occurred since 1997. Linkage to our state population database relating to ID and autism also provides an important infrastructure to undertake research in this area.
### Results:
Studies investigating sociodemographic factors, prenatal growth, alcohol exposure, and maternal physical health have identified risk factors associated with ID and autism. An increased risk of hospitalisations from two to ten times and a threefold risk of substantiated child maltreatment have also been demonstrated. **Conclusions:** Linked data studies using population data on ID and autism can help understand the complex multidimensional factors contributing to different outcomes for this particularly vulnerable population. They can also provide valuable information for informing policies and programs for supports and services and potential evaluation of interventions.

### Why we need international rare disease registers to study individual rare disorders associated with intellectual disabilities

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**Aim:** Although individually by definition rare, rare disorders make a significant contribution to childhood morbidity and disability. Many aspects of most rare disorders are poorly understood. These include diagnosis, natural history, life expectancy, and clinical variation and its determinants. **Method:** InterRett, an international register for Rett syndrome (n~2500), now maintained for 12 years, provides a template for other rare disorders such as the CDKL5 disorder and the MECP2 Duplication syndrome.

**Results:** This presentation will highlight outcomes from InterRett involving genotype-phenotype relationships and on breathing and sleep problems, using more recently collected data (n=373). It will also describe the development of an international CDKL5 database and present outcomes relating to the co-morbidities in this disorder (n=167). Finally it will include a description of the trajectory of development and medical co-morbidities in MECP2 Duplication syndrome (n=57), a disorder which involves a duplication of the MECP2 gene. **Conclusions:** This approach to the investigation of rare disorders of childhood using international databases is innovative and comprehensive and involves multiple outcomes important to the child, family and the health sector.

### The relationships between autism or intellectual disability in the child and maternal psychiatric history before or after the birth of the child

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**Aim:** Parental psychiatric history is considered a possible risk factor for autism. The mental health burden of parenting children with disabilities is also considerable. Using data linkage, we aimed to clarify these relationships with respect to the mother. **Method:** Linkage between the Western Australian Midwives Notification System, the Intellectual Disability Database and the Mental Health System provided data on mothers’ psychiatric history (hospitalisations and/or outpatient contacts) before (n=213,656) and after (n = 279,257) the birth of a child with or without autism or intellectual disabilities (ID). Analyses were undertaken using multinomial logistic and negative binomial regression respectively. **Results:** Mothers with a psychiatric history were at increased risk of having a child with either autism or ID. However mothers of children with autism or ID with no psychiatric history prior to the birth of their affected child were also at increased risk of a psychiatric disorder after the birth. **Conclusions:** The
The relationship between maternal psychiatric history and subsequent childhood outcomes is complex and could either be genetic in origin or due to environmental causes such as antenatal maternal anti-depressant use.

The impact of the abnormal behaviour codes (E-Codes) on the Autism Diagnostic Observation Schedule, 2nd Edition (ADOS-2) overall total and comparison scores

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Aim: ADOS-2 E-codes assess behaviours that may interfere with the integrity of test results. However, research has not examined whether E-codes influence test scores. This study evaluated the impact of E-codes on total and comparison scores. Method: 87 children (73% male, mean=51 months) who presented for an autism spectrum disorder (ASD) evaluation at a Midwestern Children’s Hospital were administered tests including the ADOS-2 and measures of socio-emotional behaviour. Results: Greater overactivity (E-Code 1; H=14.53, p<.01) and more aggressive/disruptive behaviour (E-Code 2; H=8.08, p<.05) were related to higher total scores. Increased overactivity was associated with higher comparison scores (H=8.78, p<.05). A positive correlation was found between teacher-reported attention and both total (p<.01) and comparison (p<.05) scores while parent-reported aggression was negatively correlated with total scores (p<.05). Conclusions: Negative behaviour impacts ADOS-2 scores and should be considered before making ASD diagnoses. Although previous research documented ADOS-2 comparison score stability, current results highlight the impact of the E-codes.

Clinical outcomes using the Protective Scale of the Armidilo

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Aim: The Armidilo has two scales: the risk scale and the protective scale. The available research has been confined to the risk scale which appears to predict future incidents with medium to large effect sizes. There have been no publications on the use of the protective scale. This paper is the first to advance the use of this scale. Method: The Armidilo is reported for four individuals with intellectual and developmental disabilities (IDD) who were either moving on from their placement or whose placement was in jeopardy because of new information becoming available or altered policies in the organisation. The Armidilo was completed in the usual fashion for all participants. Results: The risk and protective results show that, for each individual, recommendations could be made that ensured the best outcome. Indeed, for two participants highly restrictive placements were avoided because of the data that emerged on protective factors. Conclusions: The protective scale is a powerful support for the clinician’s case in offenders with IDD. The protective scale should be completed routinely for clinical evaluation.

The relationship between the EZPQ and the five factor model of personality

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Aim: Personality assessments in people with intellectual and developmental disabilities (IDD) have a different perspective from the general population. The former is based on motivational models while the five factor model (FFM) dominates the latter. This study investigates the relationship between the two. Method: The EZPQ assessment for personality in IDD and the informant version of the NEO-PI short form (FFM assessment) were used. Factors in the EZPQ are positive reaction tendency; negative reaction tendency (NRT); expectancy of success (ES); outer directedness; efficacy motivation (EM); obedience (OB); and curiosity/creativity. The NEO-PI assesses the factors of extraversion, neuroticism (N), openness, agreeableness and conscientiousness. Assessments were completed by staff for 52 adults with IDD. Results: Correlations between the FFM and EZPQ were generally consistent with hypotheses as follows: N negatively with EM, ES and OB and positively with NRT (all medium and large effects). Apart from N and NRT all other factors correlated positively or not at all. Conclusions: The FFM mapped on to the EZPQ in an orderly manner suggesting that research on people with IDD is consistent with mainstream research on personality.

Assessing cognitive schemas in people with intellectual disabilities

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Aim: There are assessments for offence-related cognitions related to anger, sexuality, impulsivity etc. in people with intellectual and developmental disabilities (IDD) but there are no assessments that attempt to evaluate the cognitive schemas that underpin these cognitions. We have aimed to develop such an assessment. Method: We gathered the most common schemas from the theoretical literature on offending and developed an assessment around the schemas of ‘the world is hostile’; minimisation and mitigation; egocentric thinking; and blaming others. We developed a 17-item assessment with each item arranged along a Likert scale. It has been used by several experienced clinicians who have given their opinions formally. Results: This assessment was endorsed strongly by clinicians. Responses also informed the nature and presentation of cases with personality disorders, and other difficulties thereby influencing management and treatment. Preliminary factor analysis data generally corresponded with the four assessed schemas. Conclusions: This is the first attempt to develop an assessment for underlying cognitive schemas in people with IDD. Preliminary results and elicited opinion suggests that it is a useful and valid instrument.

Parents with intellectual disabilities in Western Australia

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Aim: To investigate the sociodemographic and perinatal factors for children born to parents with intellectual disabilities (ID) and the child’s subsequent contact with the child protection system. Method: Data from IDEA, Midwives Notification, Birth Registry and Family Connections were linked to identify parents with ID. These were linked with Hospital Morbidity, Mental Health and Child Protection datasets. A control sample matched by year of birth and Aboriginal status of mothers was also extracted for analysis. Results: Among mothers at their primiparous singleton birth, those with ID were more likely to: reside in a socioeconomically disadvantaged area; not be married, be a smoker, have a baby born at
<37 weeks gestation and with lower APGAR score. Parents with ID were more likely to be Aboriginal, to die younger and to have a child in contact with the child protection system. **Conclusions:** Children born to parents with ID are vulnerable to a number of adverse health, developmental, and social outcomes. Policies could address the early intervention needs of these children.

**Parental aspirations regarding employment of young adults with intellectual disabilities**

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**Aim:** This study investigated the current employment circumstances of young adults with intellectual disabilities (ID), their, parents’ aspirations for employment opportunities for their young adult, and expectations of the future. **Method:** 222 parents of 136 male and 86 female young adults with ID living in Queensland, Australia completed a survey which collected information about current circumstances and aspirations for the future. **Results:** Most young adults were not in employment, with the majority who were employed being in segregated settings. Parents reported little preparation for employment had been available to their child. Parents’ preferences were for employment in supported settings and family businesses; however, they had low expectations that employment opportunities would change in either the short or the long term. **Conclusions:** There are substantial disparities between what parents hope for their children and what they expect.

**Children with autism and challenging behaviour: Evaluation of a behavioural intervention**

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**Aim:** The current study evaluates a verbal behaviour intervention programme based on Applied Behavioural Analysis (ABA) that addresses challenging behaviours (CB) in a group of children with autism spectrum disorder (ASD) frequenting the outpatient service “Faroni” (Fondazione Bresciana Assistenza Psicodisabili in Italy). The intervention focused on communication skills, adaptive behaviour and CB reduction. **Method:** The study included 30 children aged 3 to 18 years who received the intervention in public (free) services delivered at school or at home. The sample was divided in three groups on the basis of age and attendance. Learning acquisition, CB reduction and family distress were measured once a year for three years. D Cohen was the statistic used to measure the level of efficacy. **Results:** significant reduction of challenging behaviours and increase in learning goals were found. Different levels of stress reduction were found among parents. **Conclusions:** An intensive intervention proved more effective but adaptations in the services are needed to reduce parental distress.

**Community mobilisation and the sustainability of Healthy Community Initiatives**

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**Aim:** Persons with intellectual disabilities (ID) are often marginalised within mainstream community health systems. Community ownership of Special Olympics` Healthy Communities Initiatives is needed
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with respect to national coverage and sustainability of these initiatives to meet the health needs of persons with ID. **Method:** Individual and group interviews were conducted with key stakeholders involved in Special Olympics’ Healthy Communities Initiatives across seven sites internationally. An inductive thematic content analysis was used to identify emerging high level themes. These themes were then deductively analysed using three theoretical frameworks. **Results:** Three intertwined domains were identified: models of good practice for improved health outcomes; empowering and mobilising local community supports; and forming national alliances for advocacy and lobbying to influence inclusive health policy and practice. **Conclusions:** Cross-sectorial partnerships at local, national and regional levels contribute to sustainability of inclusive health service delivery and social security inclusion of persons with ID.

A multi-method, cross-population comparison of complex social language in two genetically-based conditions with intellectual disabilities: Fragile X syndrome and Down syndrome

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**Aim:** This study examined pragmatic (social) language skills among the two most common genetic causes of intellectual disabilities (ID): fragile X syndrome (FXS; most common inherited etiology) and Down syndrome (DS; most common genetic etiology). **Method:** Participants included school-age children with FXS (66 male, 41 female) and DS (20 male, 23 female), as well as younger typically developing controls of a similar cognitive level (23 male, 24 female). A battery of standardised and semi-naturalistic tasks was applied to capture a range of pragmatic language skills (e.g., handling of communication breakdowns, topic maintenance). **Results:** Controlling for mental age, both clinical groups demonstrated significantly lower pragmatic skills ($p < .05$). In conversation; children with FXS used the most non-contingent language and perseveration. Sex and autism symptomatology impacted symptoms in FXS, with females outperforming males and males with co-morbid autism showing greater impairment across standard and semi-naturalistic tasks ($p < .05$). **Conclusions:** Findings suggest that pragmatic competence is impacted in both of the most common genetic forms of ID but more severely in FXS, where both sex and autism symptomatology further impact symptoms.
The OJKO-project: A longitudinal study on developmental trajectories and patterns of young children with a severe cognitive and motor developmental delay

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Aim: A longitudinal study on the development of young children with severe cognitive and motor disabilities has been started in Belgium and the Netherlands. The aims are to evaluate the general as well as the motor, communicative and social-emotional abilities of these children; to analyse their developmental trajectories and patterns; and to evaluate the effect of child and contextual variables on their developmental trajectories. Method: To date, 30 participants between six months and four years old have been included. Six-monthly assessments of the child’s abilities and of family and contextual variables are realised by means of standardised observations and questionnaires. Results: In this presentation, the study’s design and measurements will be described. We will discuss the expected outcomes of the project, as well as the problems we encountered in data collection and analysis. The limitations and the added value of the project will thereby be addressed. Conclusions: The study’s results will permit the characterisation of the development of young children with a severe cognitive and motor developmental delay and demonstrate the role of family and contextual variables.

The influence of child and contextual factors on early communicative skills of children with a severe cognitive and motor developmental delay

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Aim: Research about the early communicative abilities of young children with a significant cognitive and motor developmental delay is scarce. The primary aim of this study is to determine which child and contextual factors influence the acquisition of early communicative skills within these children. Method: We obtained information on the early communicative abilities of children with a significant cognitive and motor developmental delay using observations, questionnaires and an interview. Communicative profiles were generated by means of the Communication Matrix. Questionnaires and observations of caregiver-child interactions were combined to obtain information about child and contextual factors. Results: The communicative profiles and the correlations with child and contextual factors will be discussed. Preliminary results indicate the diversity of communicative behaviours (e.g. vocalisations, eye contact) these children use in interaction with others. The communicative behaviours are influenced by child as well as by contextual factors. Conclusions: A first step is taken to fill the gap in research on early communicative skills in young children with a significant cognitive and motor developmental delay.

Cardiovascular disease risk factors in older people with intellectual disabilities

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Aim: With increasing longevity in people with intellectual disabilities (ID), age-related diseases, such as cardiovascular disease (CVD) are now the most encountered diseases and causes of death in older people with ID. However, reliable information on cardiovascular disease risk factors (CVRF) was lacking.
This part of the Healthy Aging in ID study provides insight into the prevalence and associations of CVRF and the subsequent development of atherosclerosis in older people with ID. **Method:** Through physical examination, laboratory examination, and use of screening and diagnostic interviews, data were collected from 1050 participants with ID aged >50 years. **Results:** Important CVRF such as peripheral arterial disease, diabetes and obesity (in women), occur more often than in the general population. Others, such as hypertension, metabolic syndrome, obesity (in men) and chronic kidney disease, occur as frequently as in the general population. **Conclusions:** CVRF and CVD are common in people with ID. Related factors are discussed. Professionals in healthcare should be aware of CVRF in ID, and an anticipated preventive health policy should be embedded in care for people with ID.

**Severity and Latino ethnicity in specialty services for children with autism spectrum disorder**

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**Aim:** Latino children with autism spectrum disorder (ASD) in the United States have been found to have lower access to diagnosis and treatment services than White children. However, whether severity impacts service use is unknown. In this study, we examined whether there are ethnic disparities between Latino and White children with ASD in autism-related services, and whether condition severity moderates the relationship between ethnicity and services. **Method:** We analysed data from a supplement to the National Survey of Children with Special Health Care Needs on current use of four specialty services commonly used by children with ASD: behavioural interventions, occupational therapy, social skills training, and sensory integration. The sample included non-Latino White (n=1,063) and Latino (n=120) children with ASD. Regressions were used to determine relationships, adjusting for demographic variables. **Results:** Severity was significantly related to all autism-related services. Latino children with ASD who had severe conditions received fewer autism-related services than White children with similarly severe conditions. **Conclusions:** Future research is needed to investigate factors that contribute to Latino children who have greater severity receiving fewer services than White children.

**Sibling caregivers of people with intellectual and developmental disabilities: Social characteristics and material hardship**

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**Aim:** People with intellectual and developmental disabilities (IDD) are increasingly outliving their parents’ ability to care for them. Consequently, an increasing number of people with IDD are primarily receiving care from adult siblings. We aimed to understand the demographic characteristics and rates of material hardship for sibling caregivers. **Method:** We used data from the 2001, 2004, and 2008 panels of the Survey of Income and Program Participation (SIPP), a nationally representative survey of the US population. We used bivariate analyses to compare sibling caregivers (n=78) to all other working age adults (64,555) on demographic variables, and measures of material hardship and public benefit programme participation. **Results:** Sibling caregiver households were significantly more likely to experience food insecurity (p<.01) and to have low income (p<.01). Sibling caregiver households were
significantly more likely to receive Supplemental Nutrition Assistance Program (SNAP) (p<.001) or Supplemental Security Income (SSI) benefits (p<.01). Sibling caregivers were more likely to be Black (p<.01) and women (p<.01) in contrast to other households. Conclusions: Sibling caregivers need additional supports to alleviate the effects of financial hardship.

Examining the validity of the Spanish ADI-R in a US-based Latino population

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Aim: The use of valid and reliable diagnostic tools for autism spectrum disorder (ASD) is critical, as it is often the pathway to accessing services. Validity studies are needed to ensure that translated versions are culturally equivalent. The current study evaluates the use of the Spanish Autism Diagnostic Interview –Revised (ADI-R) in a US-based Latino population of children with ASD and children with developmental delay (DD). Method: The current study included Spanish-speaking Latino parents of children between 4 and 16 years of age who received a clinical diagnosis of ASD (n = 29) or DD (n = 21). The Spanish version of the ADI-R was administered by trained interviewers. Clinical diagnoses were established through medical records. Results: Analyses of clinical validity found that the Spanish ADI-R had moderate sensitivity (69%) and specificity (76.2%). Social and behaviour domains were significantly different between children with ASD and children with DD. However there were no differences in the communication domains. Conclusions: Overall, the Spanish ADI-R had moderate validity with a US-based Latino population. Further studies are needed to evaluate culturally sensitive tools in identifying ASD.

Self-determination and activity engagement with adults with intellectual disabilities

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Aim: Describe how adults with moderate to severe intellectual disabilities (ID) express self-determination when engaging in meaningful activity. Method: This study was a secondary analysis of data from three phenomenological studies on engagement with adults with ID. Data consisted of 60 observation notes with 36 adults with ID at two adult day programs in the U.S. We used constant comparative data analysis and multiple strategies for trustworthiness to create themes describing how adults with ID demonstrate self-determination while engaged in meaningful activity. Results: Adults with ID expressed self-determination through social interaction and a continuum of involvement. They interacted with their peers and caregivers and approached activities in different ways to create changes in their environment. When individuals demonstrated enthusiastic engagement or complete disengagement with an activity, they demonstrated self-determination clearly. When they were more hesitant and less involved in activities, they needed more support to interpret their self-determination. Conclusions: How adults with ID approach activities and their level of engagement in activities are important mechanisms for expressing self-determination, and this connection is not sufficiently discussed in the ID literature.
Adolescents with intellectual and developmental disabilities who display harmful sexual behaviours: Adaptation of measures

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Aim: A significant proportion of those who commit sexual abuse are young people, below 18 years of age. Compared to adult offenders, there is relatively little research on this cohort. Yet, within specialist services for adolescents with harmful sexual behaviour (HSB), it is thought that up to 40% have intellectual and developmental disabilities (IDD), as well as a variety of mental health difficulties and severe and complex family problems. This research responds to the UK national demand for the adaptation of measures and instruments specifically for adolescents with IDD who display harmful sexual behaviours. Methods: Measures of sexual knowledge, cognitive distortions, attachment, and emotional loneliness were adapted, and adolescents with IDD and harmful sexual behaviours were assessed. In addition normative data for the Resiliency Scales were collected. Results: Over 40 adolescents with HSB were assessed. The validity and reliability of the five measures indicated adequate psychometric properties. Conclusions: This project has provided a set of measures for research into harmful sexual behaviours in adolescents with IDD. Further revisions of measures will be discussed.

Inclusion and socialisation of persons with intellectual disabilities through improvement of their vocational and artistic skills

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Aim: To evaluate a programme for strengthening vocational and artistic skills of persons with intellectual disabilities (ID) to make them more productive and included members of their communities. Method: C.B.R. is a national programme in Sri Lanka. There are 25 districts and 331 administrative divisions in our country. We selected one division in each district and implemented this two-year programme for persons with ID. All 25 programmes participated, and 1036 participants were included. Programme evaluation data were collected. Results: Of the participants, 621 (60%) met the criteria for success. All are now integrated into their communities, and engage in income-generating activities to support themselves and fulfil their lives. Conclusions: Developing and strengthening the innate abilities of persons with ID can enable them to become active ad productive members of their communities. It also supports the dispelling of negative attitudes that are embedded in society.

An investigation of parents’ decision to transfer their children from regular to special schools

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Aim: This goal of this study was to understand the decision-making process of parents who chose to transfer their children from regular to special schools. Method: 80 parents living in Queensland, Australia completed a survey which collected information about the decision to transfer their children from regular to special schools. A factor analysis was undertaken with the survey items relating to: reasons for leaving the regular school; hopes for the special school; the decision-making process; and beliefs about inclusion. Results: Clear factors emerged as underlying dimensions in the decision-making
process of parents. These included components relating to: school work, including support and resourcing; socio-emotional issues, including parental and children’s stress; school culture; the difficulties associated with the decision-making; and beliefs about regular and special schooling.

Conclusions: A number of complex factors were involved in parents’ decision-making including a strong link between the emotional impact of regular schools and parental hopes for learning and belonging in the special school.

Development of the Client Profile Checklist: A screening tool to assess vocational competency in adults with intellectual disabilities

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Aim: There is a need to systematically assess vocational competency of adults with intellectual disabilities (ID). The present study reports the development of the Client Profile Checklist (CPC) as a standardised measure to assess vocational competency of adults with ID. Method: 969 8 to 52 year old trainees with ID from low, medium and high support level vocational training tracks were rated by their training officers on 38 items selected from empirical literature and interviews with clinical staff. Factor analyses, multivariate analyses, ROC analyses and reliability analyses were conducted to examine internal consistency, reliability, validity and factor structure. Results: Factor analyses yielded a 5-factor structure explaining 40.1% of the variance, with internal consistencies of the total and all but one of the subscale items exceeding .70. The CPC total scores significantly differed across the three support levels. Cut-off scores for each track were also identified. In addition, inter-rater and test-retest reliabilities were high at .80 and .92 respectively. Conclusions: The preliminary results suggest that the CPC may be a useful tool to assess vocational competency of adults with ID.

Personal choice, assessed need and future funding: The likely impact of the NDIS on the support available to individuals with intellectual disabilities in Queensland

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Aim: This study examines the aspirations, disability support needs and impact of the forthcoming changes to disability support funding under the National Disability Insurance Scheme (NDIS) in a representative sample of people with intellectual disabilities (ID). Method: Quantitative (amount of funding and type/frequency of support) and qualitative data (goals and aspirations) were collected from 130 individuals in Queensland, Australia using the Instrument for the Classification and Assessment of Support Needs. Results: The most common aspirations of clients included gaining or maintaining employment and undertaking more leisure activities. These aspirations did not consistently map onto the assessed support needs of clients. Initial analysis indicated that even those clients who were able to live relatively independently are likely to receive funding under the NDIS. Conclusions: The task of weaving the pursuit of aspirational goals to the day-to-day support needs of clients is likely to be complicated, and require considerable creativity from service providers. In many cases, the aspirations of clients may not necessarily match their assessed support needs and, as a result, their allocated funding.
Health literacy and patient health information exchange in primary care for people with intellectual disabilities: Views of patients, carers and general practitioners

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Aim: Low health literacy skills in people with intellectual disabilities (ID) negatively influence health information exchange (HIE) with carers and general practitioners (GPs), leading to impairments in recognising and treating health problems. We aimed to provide insight into HIE experiences of people with ID, carers and GPs. Method: Framework analysis of semi-structured interviews and focus groups of people with ID, professional carers, relatives and GPs, on topics related to HIE during and around GP consultation. Results: Major themes, relating to gaps in information pathways included: impaired medical history taking and clinical decision making; and fragile follow-up. Patients’ health literacy skills appeared as an important factor in HIE, alongside factors relating to GP adjustments in communication and planning of consultations and to carers’ roles during and around GP consultations. Conclusions: People with ID experience problems processing and exchanging health information during and around GP consultations. Disregard for the health literacy skills of patients with ID may impact negatively on their opportunities to benefit from healthcare services and health information. GPs can facilitate HIE by adjusting consultations and communication and adequately deploying the patient’s network.

Patient health information exchange in primary care for people with intellectual disabilities: A qualitative study on the general practice care perspective

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Aim: Inadequate health information exchange (HIE) between patients with intellectual disabilities (ID), carers and general practitioners (GPs) leads to impairments in recognizing and treating health problems. This study provides insight into GPs’ and healthcare assistants’ perceived barriers and facilitators of HIE regarding GP consultations for patients with ID. Method: Semi-structured interviews were conducted with GPs (n=19) and healthcare assistants (n=11) on topics related to stages during and around GP consultation, e.g. ‘organising an appointment’ and ‘treatment planning’. Transcripts were coded and analysed using framework analysis. Results: Major themes were: medical history taking and clinical decision making are undermined by inadequate HIE; and fragile follow-up, caused by gaps in the transfer and recording of information. Factors influencing HIE were related to patients’ communication skills; preparing the consultation; fulfilment of professional carers’ roles and responsibilities; relational continuity of care; and GP adjustments in communication and consultations. Conclusions: Findings of this study provide insight into the mechanisms behind inadequate HIE threatening the quality of medical consultations and follow-up, and may help to design interventions to improve HIE for GP patients with ID.
Changes in causative factors among residents of institutions for persons with severe motor and intellectual disabilities in Japan

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Aim: This study examines the influence of medical care on causes of severe motor and intellectual disabilities (SMID) in Japan. Method: Causes of SMID among individuals residing in institutions for persons with SMID in 2007 and 2013 were obtained from reports published by the Japanese association for the welfare of SMID. The reports included causes for 11,000 individuals were analysed. Results: Over the study period, hypoxia/asphyxia, meningitis/encephalitis, microcephaly, low birth weight (small for gestational age), and hyperbilirubinemia decreased; while epilepsy, low birth weight (appropriate for gestational age and large for gestational age), brain injury, chromosomal abnormalities (other than Down syndrome), and encephalopathy increased. Conclusions: Many aetiologies seemed to have been influenced by vaccinations and improved neonatal care. The increased occurrence of brain injury was thought to mirror the growing number of child abuse cases. This analysis of aetiologies can shed light on conditions among individuals with SMID living with family or in hospitals.

Outcomes for the ‘Growing Up With Autism’ programme in New Zealand

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Aim: To evaluate the outcomes of the New Zealand version of ‘Growing Up With Autism’ (GUWA) by examining its impact on adolescent behaviour and parental mental health. Method: GUWA is a 20-week parent training programme for families of adolescents with autism spectrum disorder (ASD). A New Zealand version was developed which is delivered by IDEA Services and funded by the Ministry of Health. Pre and post data were collected for 80 families using the Developmental Behaviour Checklist (DBC) to measure outcomes for adolescents and the GHQ 12 to measure changes in parental mental health. Results: DBC total score and all subscales showed statistically significant reduction, with moderate to large effect sizes for all subscales. A 14.83% reduction in GHQ 12 scores indicated a significant improvement in parental mental health. Conclusions: This paper builds on the evidence from randomised controlled trials demonstrating the programme results in reduction of adolescent behavioural difficulties and improvement in parental mental health. The evidence of effectiveness could be further substantiated by use of a control group.

Five year outcomes for the ‘ASD Plus’ parent training programme

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Aim: To evaluate the 5-year outcomes of ‘ASD Plus’, a parent training programme for families of preschool children with a recent diagnosis of autism spectrum disorder (ASD), and compare outcomes for three different delivery modes: individual family, group and distance learning. Method: ASD Plus is delivered by IDEA Specialist Services and is jointly funded by the Ministries of Health and Education. As New Zealand has a highly dispersed rural population who find it difficult to access services, the
programme was designed to have a high degree of flexibility in method of delivery. Pre-, post- and six-month outcome data have been collected for 202 families. **Results:** Families showed increased ASD-related knowledge, communication skills, behaviour management skills, play skills and coping abilities regardless of programme type. These gains were maintained at 6-month follow-up. Individual programmes were the most effective, followed by group then distance learning. **Conclusions:** The ASD Plus programme is effective in increasing the skills, knowledge and resilience of families who have young children with ASD.

**Co-morbid psychiatric disorders amongst adults with autism spectrum disorder**

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**Aim:** To examine the types of mental health problems experienced by adults with autism spectrum disorder and to investigate the usefulness of two psychiatric screening tools  

**Method:** A mixed methods design comprising of file reviews and psychiatric screening combined with semi-structured interviews was used. Participants were 31 adults who have both ASD and intellectual disabilities (ID), 15 adults who have ASD only, and 23 adults with ID. Two psychiatric screening instruments were completed for all participants: the Reiss Screen for Maladaptive Behaviour and the ASD-Co-morbidity-Adults Scale.  

**Results:** Adults with both ASD and ID experience significantly higher levels of anxiety, depression, behavioural difficulties and ADHD symptoms than the general population. Those with ASD with no ID showed higher levels of anxiety and depression than the general population and had experienced multiple previous psychiatric diagnoses prior to ASD. **Conclusions:** Type and rate of co-morbidity with ASD vary by severity of autism symptoms and degree of ID. Those who have severe ID and/or severe autism symptoms are most likely to experience multiple co-morbidities.

**Peers’ knowledge of autism and attitudes towards their classmates with autism spectrum disorder in inclusive schools: Measuring the effects of an educational intervention**

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**Aim:** The aim of this study was to measure peers’ knowledge, cognitive attitudes and behavioural intentions towards classmates with autism spectrum disorder (ASD) at four time points: before and after a four-session educational intervention for autism, after their contact with students with ASD and three months later. **Method:** 226 children (grades 4-6) completed the Autism Knowledge Questionnaire, the Adjective Checklist and the Shared Activities Questionnaire at each time point and were compared with a no-intervention group (n= 315). The main analysis plan included a 3 (time: pre-test, post-test, after contact, follow-up) x 2 (condition: intervention, non-intervention) mixed design ANOVA. **Results:** As hypothesised, peers’ autism knowledge and their cognitive attitudes were significantly improved after the educational intervention and their contact with the students with ASD. Interestingly, no significant changes were observed in the behavioural intentions of peers towards classmates with ASD at any time point. Notably, the only significant difference between the intervention and the no-intervention group was found in autism knowledge. **Conclusions:** The implications of the findings for raising autism awareness within primary inclusive schools are discussed.
Exploring top down and bottom up anxiety mechanisms in children with autism spectrum disorder

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**Aim:** Anxiety is a highly prevalent co-morbidity in autism spectrum disorder (ASD). Whether anxiety is part of ASD or a distinct co-morbidity and whether top-down or bottom-up anxiety processes are intact is unclear. This research compares parent and child measures of top down anxiety in ASD and explores experimental measures of bottom up cognitive anxiety. **Method:** Children with ASD (Autistic Disorder or Asperger’s Disorder; N=42) and typically developing controls (N=39), aged 7 to 12 years, were compared on the Spence Children’s Anxiety Scale self and parent report and on two experimental cognitive paradigms to measure attentional biases associated with anxiety (computerised dot probe and visual search tasks) using repeated measures ANOVA. **Results:** Children with ASD were poor reporters of their own anxiety but parents reported high levels of anxiety in children with ASD. In contrast, attentional anxiety tasks showed intact bottom up processing similar to typically developing children. **Conclusions:** Findings suggest more basic, bottom up evolutionary mechanisms such as implicit threat detection are intact in ASD, whereas top down anxiety processes, such as the ability to emotionally regulate are impaired.

An investigation into the temporal nature of loneliness in older people with intellectual disabilities

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**Aim:** To investigate both the chronological nature of loneliness in a population of older people with intellectual disabilities (ID) and the variables that predict continual loneliness. **Method:** Responses to a loneliness question were compared for 292 self-reporting participants from the first two waves of IDS-TILDA, Europe’s leading longitudinal study on the aging of people with ID. Logistic regression considered which demographic, quality of life and health variables predicted continual loneliness. **Results:** Continual loneliness was reported for 26% of participants, but over time more participants (19%) progressed from reporting loneliness as compared to those who reported new loneliness (13%). The first regression utilising predictor variables previously reported for aging populations explained 13% of continual loneliness variance and a second regression including more ID-specific variables accounted for 30% of the variance. **Conclusions:** Rates of continual loneliness for people with ID was nearly double those reported in other aging populations but over time more participants moved out of than into loneliness. The regressions suggest that predictors of loneliness are more complex for people with ID than for other populations.

Increasing the visibility of people with intellectual disabilities who are LGBT: A review

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**Aim:** People who identify as lesbian, gay, bisexual and transgender (LGBT) can face many challenges in society including accessing and using healthcare systems. Little is known about the specific health
service needs of people with intellectual disabilities (ID) in relation to these issues. The review explored the ID needs of LGBT people through an examination of relevant studies. **Method:** A search of relevant databases from inception to September 2015 was conducted. Studies were identified that met specific criteria that included: the use of recognised methods, involved people with ID and identified as LGBT. The search yielded 39 papers. Following the application of rigorous inclusion and exclusion criteria 24 papers were included for retrieval. Finally, 10 papers were considered suitable for the review and were thematically analysed. **Results:** Emerging themes were: accessing services, gender and sexual identity, attitudes regarding LGBT status, sexual risk behaviours, supports and interventions. **Conclusions:** The results highlight key gaps in terms of policy, education, research and practice developments.

**Understanding cardiovascular disease risk, prevalence, awareness, and treatment in older adults with intellectual disabilities in Ireland**

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**Aim:** To identify and compare rates of cardiovascular disease risk, prevalence, awareness, and treatment in older adults with intellectual disabilities (ID) as compared to the general Irish population. **Method:** Data were drawn from The Irish Longitudinal Study on Ageing (TILDA) and its Intellectual Disability Supplement (IDS TILDA). **Results:** In older adults with ID, hypertension prevalence was 41.2% (95% CI: 36.33-46.07%) compared to 63.7% (95% CI: 62.3-65.1%) in the general population. Of those with hypertension, 47.8% (95% CI: 40.0-55.5%) were aware, and 68.8% (95% CI: 61.6-76.0%) were on antihypertensive medication, with 70% (95% CI: 61.4-78.6%) of those treated having their blood pressure controlled. This compared to awareness in general population of 54.5% (95% CI: 52.6-56.2%); with 58.9% (95% CI: 57.1-60.4%) on treatment, and 51.6% (95% CI: 49.3-53.9%) having their blood pressure controlled. **Conclusions:** The prevalence of hypertension in older adults with ID was more than 20% lower than that reported for the general Irish population, overall levels of treatment and control was higher in the ID population compared to the general population but levels of awareness were lower.

**A prospective 18-year longitudinal follow-up of dementia in persons with Down syndrome**

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**Aim:** To examine dementia characteristics, age at onset and associated co-morbidities in persons with Down syndrome (DS). **Method:** 77 people with DS aged 35 years and older were followed longitudinally. The diagnosis of dementia was established using the modified International Classification of Diseases, Tenth Revision (ICD-10) criteria and a combination of objective and informant-based tests. **Results:** Over the 18-year period, the average age of diagnosis was 55 years which is in higher range of previously reported estimates (51–56 years); and median survival was 7 years after diagnosis. Persons with dementia in the sample were significantly older than persons without dementia. The presence of dementia was also associated with epilepsy and sensory impairments. **Conclusions:** The previously reported high risk levels for dementia among people with DS was confirmed in these data as was the value of the instruments utilised in tracking decline and helping to confirm diagnosis even in persons with severe intellectual disabilities.
From planning to realisation: Person-centred planning as organisational transformation

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Aim: To understand how a large multi-faceted organisation supporting people with intellectual disabilities (ID) must change in approach and in the organisation of staffing to facilitate genuine implementation of person-centred planning (PCP). Method: Observational, interview and document review data were analysed periodically over a two-year period as a large multi-faceted organisation supporting people with ID worked to respond to the challenges of implementing PCP. Results: A series of lessons were learned from the implementation of training for 259 staff, involvement of 148 family members and the completion with people with ID of 119 plans using PATH. Changes have included development and resourcing of a team to support development of person-centred plans, new approaches to care, greater emphasis on transitions to the community and a re-involvement for many with family members as well as new relationships with friends with and without ID. Conclusions: Genuine PCP within organisations changes not only the lives of people with ID but also the organisations that support them.

Mental health needs of prisoners with intellectual disabilities

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Aim: To determine the extent of co-occurring mental health problems among prisoners with intellectual disabilities (ID). Method: This was a descriptive, cross-sectional study carried out using face-to-face interviews with 240 participants in a prison in South East London, England. Prisoners with ID were identified using the Learning Disability Screening Questionnaire. Mental health problems and suicidality were assessed using the Mini International Neuropsychiatric Interview (MINI). Results: Participants with ID had significantly higher suicidality scores and higher rates of mental health problems with 50% meeting diagnostic criteria for a current psychiatric disorder compared to 17% of prisoners without ID. Conclusions: The results suggest that ID is a risk factor for suicidality and co-occurring mental health problems among prisoners. Therefore improvements in prison health care should include improved recognition of people with ID within a prison setting because of the impact on their mental health.

Trauma- and stressor-related disorders: DM-ID 2

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Aim: Trauma- and stressor-related disorders include disorders in which exposure to a traumatic or stressful event is listed explicitly as a diagnostic criterion. This is a new chapter within DSM-5 and the aim of the presentation is to discuss how DSM-5 criteria for trauma- and stressor-related disorders will be adapted for DM-ID 2. Method: A review of the literature was undertaken since 2002 using key databases namely PsycInfo, Medline, Embase, and CINAHL to identify evidence on reactive attachment disorder, disinhibited social engagement disorder, post-traumatic stress disorder, acute stress disorder
and adjustment disorder in relation to people with intellectual disabilities (ID). **Results:** The evidence is mainly type IV and V with most of the new evidence emerging on posttraumatic stress disorder. The adaption of the criteria for DM-ID 2 will be illustrated by case studies. **Conclusions:** The evidence-based approach of DM-ID 2 for trauma- and stressor-related disorders aims to improve clinical assessment and diagnosis for this under researched area in people with ID.

### Screening for autism spectrum disorder in prison

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**Aim:** To determine the extent of autistic traits among male prisoners. **Method:** This was a descriptive, cross-sectional study carried out using face-to-face interviews with 240 participants in a prison in South East London, England. Prisoners with autistic traits were identified using the AQ-20, AQ-10 and the Autism Diagnostic Observation Schedule (ADOS). **Results:** 39 prisoners had significant autistic traits with the AQ-20 and 12 met the diagnostic criteria using the ADOS. The sensitivity and specificity of the AQ-10 and AQ-20 will be reported. **Conclusions:** The results indicate that screening using a standardised tool as a face-to-face interview can improve identification of prisoners with autistic traits.

### Using the WHO’s ICF as a theoretical framework for the study of social participation for older people with intellectual disabilities

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**Aim:** To examine the application of the Activities & Participation domain of the International Classification of Functioning, Disability and Health (ICF) as a theoretical framework to guide the study of social participation for older people with intellectual disabilities (ID). **Method:** The nine chapters of the Activities & Participation domain provided a theoretical framework. Measures from the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) (n=698) were matched across the nine Activities & Participation domain of the ICF. Bivariate and multivariate analyses explored factors associated with different aspects of social participation. **Results:** A wide range of factors were found to be associated with different aspects of social participation, both personal ability such as level of ID, health, instrumental activities of daily living, communication and literacy, and social factors of residence and social connectedness. **Conclusions:** Use of the ICF framework to study social participation helped illustrate greater complexities in the measurement of social participation.

### Relocating people with intellectual disabilities to new accommodation and support settings: Contrasts between personalised arrangements and group home placements

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**Aim:** Internationally the relocation of people with intellectual disabilities from institutions has brought significant gains to their quality of life although less attention has been paid to differences across the
new settings. **Method:** Three groups of persons who moved either to personalised arrangements (n=29) or to community group homes (n=31) were compared to those who remained in congregated settings awaiting relocation (n=29). Individual interviews were conducted with persons and/or their key workers. **Results:** Persons moving to rented accommodation with personalised support tended to be younger and had fewer support needs than those in group homes. They had greater control and choice in their lives, more community engagement and increased personal relationships compared to residents in group homes. Those remaining in congregated settings fared worst of all. However average staff costs were significantly higher in the latter settings. **Conclusions:** The implications for the future provision of group living arrangements are discussed along with the need for further longitudinal research to assess the sustained impact of personalised arrangements and their funding.

**What is meant by social inclusion through sports?**

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**Aim:** Within sports, the term social inclusion covers the participation of athletes with developmental disabilities both on and off the playing field with their non-disabled peers but it is an elusive concept to measure. The aim of this study was to devise indicators of social inclusion that capture its meaning for players and coaches involved with Special Olympics Unified Sports. **Method:** Following on from reviews of the literature, interviews and focus groups were held with players and coaches. These helped to create a pool of indicators which described the processes involved in promoting social inclusion as well as the outcomes achieved. These indicators were formulated as rating scales for use by Unified Sports players and coaches. **Results:** The reliability and validity of the scales are currently being tested with Unified Sports teams across different sports and from different continents. Initial results suggest the scales show promise as both formative and summative evaluation tools. **Conclusions:** The tools will help sports personnel assess the extent of social inclusion experienced by their athletes with special needs.

**The role of management and support staff as people move from congregated settings**

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**Aim:** This study explores the implications for management and the perceptions of the support provided to people moving to more personalised settings. **Method:** Senior managers in 18 services took part in two focus groups while 16 staff, alongside the people with intellectual disabilities (ID) they supported, were interviewed on two occasions, before and after the move. Thematic content analysis was used to identify the main themes. **Results:** The managers spoke primarily of changed organisational culture from dependency to empowerment and greater emphasis on person-centred practices. When in congregated settings, staff reported steering and supporting people; then they helped them to settle in community group homes; and supported them to increase control over their lives in personalised arrangements in the community. Support staff adopted the role of advocates in which people with ID were seen as human rights holders. **Conclusions:** Implications for staff training, service policy and practices are drawn to guide the necessary transformations demanded by the personalisation of supports.
An international study of obesity and underweight in children and adults with intellectual disabilities

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Aim: The prevalence of obesity is rising world-wide with higher rates reported for persons with intellectual disabilities (ID) in more affluent countries. However obesity rates for these persons in less affluent countries are unknown. The aim was to identify predictors of obesity and underweight in a global sample of over 80,000 youth and adults with ID drawn from 170 countries. Method: Using a standard protocol, body mass index measures based on height and weight were collected at Healthy Athletes screenings at Special Olympics events over a ten-year period and analysed using binary logistic regressions. Results: Higher levels of obesity were found in high income countries – especially in North America – and for females and for adults aged 40 years and over. These rates tended to be higher than those reported for the general population. Rates of underweight were higher in low income countries, in Asia particularly, with children more affected than adults and males more so than females. Conclusions: Contrasting intervention strategies are needed to address the challenges of over and underweight across the globe.

Child welfare process and outcomes for children of parents with intellectual impairment

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Aim: The aim of this study was to determine what, if any, progress has been made in Canada with respect to child welfare processes and outcomes for children of parents with intellectual impairment. Method: The method was secondary data analysis utilising the population-based Canadian Incidence Study of Reported Child Abuse and Neglect (CIS) data repositories. Results: Prevalence and outcomes are more or less unchanged. In the most recent dataset, while parental intellectual impairment was noted in 7.8% of all child maltreatment investigations in Canada, it was noted in 20% of investigations that resulted in child apprehension and 22% of those that resulted in court application and probable permanent out-of-home placement. Parents with intellectual impairment were more likely to be exposed to environmental adversity and this partially explained why their children were more often taken from them. Conclusions: It appears that the all but systematic removal of children from parents with intellectual impairment, and for reasons that are mostly beyond parent control, continues unabated.

The ability of athletes with intellectual disabilities to successfully dual-task a cognitive demand in conjunction with a balance task

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Aim: To assess the dual-tasking abilities of individuals with mild intellectual disabilities (ID) to perform a cognitive and balance task. Method: A sample of 102 athletes with ID and 102 athletes without a disability were recruited. Balance was assessed via a modified Flamingo Balance Test (MFB), while the
Multiple Object Tracking (MOT) system was used to assess perceptual and dynamic attention. All participants performed each test separately, then simultaneously. Statistical methods included multivariate analysis of covariance (MANCOVA) and repeated measures analysis. **Results:** Significant differences were observed between the groups with and without ID for MFB and MOT in the single and dual-task (p<0.001), as well as a significant interaction effect between the groups for MOT single versus dual-task (p<0.05). There was no significant effect found between groups for MFB single versus dual-task (p=0.433). **Conclusions:** There is a difference between athletes with and without ID to perform balance and cognitive tasks separately and together, as well as between the single/dual-task difference of the cognitive task. More research is required with a variety of cognitive and motor components.

**Visiting Earlswood: The asylum travelogue and the shaping of ‘idiocy’**

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**Aim:** This research investigates asylum travelogues - published articles recounting visits to Earlswood Asylum, the National Asylum for Idiots, in Reigate, Surrey - to determine their impact on shaping ideas of idiocy in the 1850s and 60s and on social policy that affected the lives of people identified as ‘idiots’ and ‘imbeciles’. **Method:** The 1850s and 60s saw the publication of many narratives recounting visits to Earlswood (the first large English institution for people identified as ‘idiots’). This presentation uses discourse analysis to anatomise and compare asylum travelogues (by the famous - e.g., Charles Dickens - and the relatively obscure - e.g. Joseph Parkinson and the Reverend Edwin Sidney), identifying dominant rhetorical strategies. **Results:** The asylum travelogues are demonstrated to be the first instance of narratives that will be reproduced in later years to describe the workings of institutions and the character of those incarcerated there. **Conclusions:** Asylum travelogues used similar strategies in describing visits to Earlswood and these were significant in shaping mid- and late-19th century ideas about idiocy and imbecility.

**Ethics of time: Ensuring effective relational communication with NDIS participants who have intellectual disabilities**

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**Aim:** The National Disability Insurance Scheme (NDIS) has been criticised as being insufficiently tuned into the needs of people with intellectual disabilities (ID). Our research project aimed to get an improved understanding of how people with ID experience their disability services now; and what they anticipate they might need or want in the future, following the introduction of the NDIS. **Method:** A systematic randomised sampling strategy was used to recruit Endeavour Foundation research participants residing in the southern district of Brisbane, Logan, Ipswich and Gold Coast. 70 people and their families were interviewed using a mixed methods survey, gathering both quantitative data and qualitative information (personal narratives). **Results:** The interviews were time-intensive, averaging 80 minutes. The interviewers had substantial difficulty communicating with most interviewees. Difficulties included participants’ speech impairments; and the interviewers’ and interviewees’ lack of familiarity with (and/or inability to use) communication aids. **Conclusions:** Effective relational communication
methods to engage people with ID and who are non-verbal, in discussions about their future support have yet to be established. This has significant ethical implications for the NDIS’s processes.

Why does ‘clumsiness’ matter?: Motor impairment, function and emotional behavioural symptoms in autism spectrum disorder

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Aim: Many children with autism spectrum disorder (ASD) experience difficulty with movement. Understanding the nature of the movement variation and associations with other symptoms provides insights into the clinical ASD profile. This study compared motor function of children with ASD with typically developing children (TD) and the relationship with emotional-behavioural symptoms. Method: A prospective cohort study of 23 children with ASD and 22 TD peers was undertaken. Motor impairment tasks and the Movement Assessment Battery for Children-2 evaluated motor proficiency, and the Developmental Behavioural Checklist measured symptoms of emotional/behavioural disturbance. Group differences were assessed with ANOVA and associations with Spearman rho. Results: Children with ASD performed worse than TD peers on manual dexterity, ball skills and balance (p<.05). Higher motor proficiency was significantly associated with less communication disturbance (rho=0.37,) and severity of autistic symptoms (rho=0.33). Conclusions: Motor symptoms are a core element of the clinical profile of ASD. Many children with ASD have impaired motor function that may contribute to activity limitations and participation restrictions. The role of early motor assessment warrants urgent evaluation.

Conducting a feasibility study on cognitive training with adults with Down syndrome: Methodology and lessons learned

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Aim: To assess the feasibility of conducting a cognitive training programme with adults with Down syndrome. Method: In a quasi-experimental mixed factorial with partial crossover design, 46 participants in the BEADS study (Brain Exercises for Adults with Down Syndrome) completed an 8-week cognitive training programme using an Ipad. Participants were aged 30 to 49 years with a mild or moderate level of intellectual disability. The researcher/instructor met with participants 3 times a week. A weekly questionnaire on satisfaction and perceived difficulty was completed as well as a semi-structured interview when the programme ended. Results: Acceptability and usability of the cognitive training programme was high; most participants completed the programme, with number of minutes spent ranging from 450-2000 minutes, which compared favourably with a recommended dosage of 800 minutes (based on previous literature). On the weekly questionnaire, most consistently responded they ‘really enjoyed’ the training programme. Feedback on the length of the programme varied, with some indicating a preference for a longer training period. Conclusions: While additional supports were needed for some participants, all were able to engage in the programme.
Examinaing the relationship between cognitive reserve and levels of executive function: Results from the BEADS study

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Aim: To examine the relationship between level of cognitive reserve and level of executive function in adults with Down syndrome (DS). The cognitive reserve theory posits those with higher levels of education/occupation and higher participation in social activities present with fewer cognitive changes as a result of the neuropathology of Alzheimer’s disease. Executive functioning refers to cognitive processes such as planning, attention and memory. Method: A score on the Cognitive Reserve Index questionnaire was established for 46 individuals with DS aged 30 to 49 years. Assessments of executive function included: Cats and Dogs Stroop, Tower of London, Scrambled Boxed, Spatial Reversal and the Weigl Card Sorting Task. The Behaviour Rating Inventory of Executive Function (BRIEF) was completed by a proxy. Results: Individuals with higher levels of cognitive reserve scored higher on executive function assessments. Conclusions: Preliminary findings suggest that there is a relationship between level of cognitive reserve and scores on executive function assessments.

The impact of cognitive training on executive function scores in adults with Down syndrome: Findings from the BEADS study

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Aim: To examine the effect of cognitive training on executive function scores in adults with Down syndrome (DS) and the factors that may influence this change, including age, IQ and cognitive ability. Method: 46 participants completed the training program, consisting of 20 minutes of training a day, 5 days a week over 8 weeks (800 minutes). A quasi experimental, mixed factorial design was used with a partial crossover. Post-intervention assessments were carried out under blind conditions. Baseline IQ and cognitive ability scores were recorded as were pre and post executive function scores using five assessments and the proxy completed Behaviour Rating Inventory of Executive Function (BRIEF). Results: Scores on most executive function assessments and the BRIEF increased post intervention. No significant changes in executive function scores were noted in the delayed control group. Conclusions: A cognitive training program appears to have a positive impact on level of executive function in adults with DS. A larger more systematic study is recommended.

Educational provision for children with profound intellectual and multiple disabilities: From rights to reality

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Aim: Children with profound intellectual and multiple disabilities (PIMD) had their right to education asserted by order of the High Court of South Africa in 2011. In considering making this right a reality, this paper aims to provide a description of these children and their current educational provision in South
Africa, and to explore the challenges of educational provision for this group. **Method:** A database was created using records and centre visits and analysed with regard to the children, caregivers; and facilities documents relating to the process of educational provision were critically reviewed with regard to feasibility and acceptability of provision to children, families and caregivers. **Results:** The progress toward the realisation to the right to education was evaluated according to the needs of children with PIMD and the responses of civil society and government. **Conclusions:** An inter-sectoral approach that engages with families and communities is required to address the right to education for children who will require lifelong care.

**Strategies for improving access to health within communities**

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**Aim:** The health deficits of persons with intellectual disabilities (ID) are well attested internationally. However access to effective health services remains a global challenge. This study aimed to identify effective strategies to promote improved health through access to services and health promotion activities in seven sites internationally: three states in the USA and in Peru, Malawi, Thailand and Romania. **Method:** Individual or group interviews were conducted with the various stakeholders involved in Special Olympics Healthy Communities Initiatives (n > 400 persons) to obtain their perspectives on the impact that the Initiatives had on them. Thematic content analysis was used to identify the main themes and these were matched against the WHO, Ottawa Charter on health promotion. **Results:** Three core themes were identified: creating supportive environments; reorientation of health services; and developing personal skills. Examples will be provided within each theme. However these were realised to varying extent across the seven sites. **Conclusions:** Locally effective strategies have been identified across high and low income countries. The challenge is to upscale these nationally.

**Can frailty measures be implemented to understand aging in adults with intellectual and developmental disabilities?**

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**Aim:** This study aimed to understand how to improve community care and outcomes of frail adults with intellectual and developmental disabilities (IDD) by developing procedures for identification and prompting action on the part of providers and policy makers. **Method:** A scoping review of the literature explored current knowledge of frailty in the field of IDD. Key informant interviews determined how existing frailty measures are used to assess and monitor frailty among older adults with IDD internationally. **Results:** Most studies identified focussed on frailty as a predictor of outcomes, such as care intensity, sarcopenia, fractures, increased medication use, and mortality. Other studies found associations between frailty and specific risk factors (e.g., poor mobility and functional status). There has been limited uptake of frailty measures. More consideration is needed to ensure the added value of measuring and monitoring frailty is better understood by care providers and policy makers. **Conclusions:**
Future research should focus on validation of frailty measures, as well as the push and pull efforts needed to better integrate such measures into policy and practice.

I’m still here!: Exploring what matters

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Aim: This study explores the lived experience of people with intellectual disabilities (ID) and life-limiting conditions and identifies, from their perspective, factors that strengthen and inhibit advanced care planning. Method: This in-depth qualitative study, involved four participants with ID and their support networks. Participants were interviewed twice during the advanced care planning process. Inductive analysis centred on identifying significant patterns, ideas and themes. Results: There was a high degree of agreement between participants that the following positively influenced advanced care planning: going at my pace; supporting me make my own choices; adapting the process so that it suits me; and, most importantly, continuing to support and plan the life I’m still living. Conclusions: Alongside expert knowledge, the factors that positively contribute to advanced care planning are similar to those required for all forms of person-centred planning. This is encouraging, and suggests that it is realistic and achievable to support advanced care planning, and thereby ensure that people with ID have control and choice over their lives, right to the end.

Why won’t you tell me I’m dying?

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Aim: In this paper the researchers reflect on difficulties recruiting people with intellectual disabilities (ID) and life limiting conditions into a study on advanced care planning. Method: Field notes from the recruitment process were analysed and then critically reviewed against the literature on participation in advanced care planning for the general population. Results: 11 of 18 potential participants were not aware they were dying, and were ineligible to participate in the study. Reasons for not disclosing prognostic information were varied, but largely related to wanting to protect the person, and worry that the person would not cope. There are similarities with elderly adults in the general population. Conclusions: Protectionism continues to limit access for people with ID to decision-making about their lives. In this case it has led to a lack of access to collaborative advanced care planning for those who are dying, and prevented participation in research that might improve people’s lives in the future. There is work to be done on continuing to shift beyond current practices that limit involvement by the person in critical life stages.

Case study of Brazilian families advocating for children with autism

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Aim: Historically, families have been the advocates and catalysts for change in the education of children with disabilities. We conducted a case study of a group of parents who have been catalysts of change in the education of their children with autism spectrum disorder (ASD) in a small community in northeast Brazil. Method: We conducted a semi-structured interview with six parents of children with ASD who founded a specialised education centre in Brazil. We conducted a qualitative analysis of the interviews where we transcribed, translated, and coded the interviews for themes across participants. Results: We found four preliminary main themes: the diagnostic odyssey, parent/family perspective on ASD, the development of a parent group, family advocacy to build capacity and develop a small learning centre, and the growth in their children through the creation of this centre. Conclusions: The results demonstrate the strength and power parents have to advocate for the education of their child with ASD. The interviews reflect how these parents were catalysts in the movement to improve the education and lives of their children.

Teaching financial literacy skills to young adults with intellectual and developmental disabilities using self-directed video prompts

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Aim: For young adults with intellectual and developmental disabilities to have a more independent life, it is critical to have financial literacy skills. We conducted a multiple-probe, single-case design study to look at the use of self-directed video prompting (VP) on an iPad to teach young adults financial literacy skills. Based on prior research in VP, we hypothesised that our participants would be able to acquire these skills. Method: Three students in a post-secondary education program at a private university participated in this study. We measured three financial literacy skills (cheque writing, money management, and depositing money) with percent of correct steps on a task analysis. Results: All three students acquired the three financial literacy skills, using visual analysis we determined that there was an immediate stable level change in the percentage of correct steps from baseline to intervention. On a social validity questionnaire, the students indicated that they liked the intervention. Conclusions: Self-directed VP can be a good intervention to both teach financial literacy skills and to promote independence through the use of socially acceptable technology.

Autism and offending: A systematic review of treatment

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Aim: Theoretical suppositions suggest a potential vulnerability in individuals with autism spectrum disorder (ASD) to offending, and possible barriers to treatment from the features of ASD. A systematic literature review was conducted to identify empirical evidence and examine the effectiveness of treatment programmes for offenders with ASD. Method: Search terms covering ASD, offending and treatment were entered into numerous databases. Research studies meeting specific inclusion/exclusion criteria were included in the review and a mixed methods appraisal tool was used for quality evaluation. Results: A small body of literature on ASD and offending was identified, with very little empirical evidence found. Case studies and case series emphasised the role of ASD in offending,
Adapted sex offender treatment programmes for men with autism spectrum disorder: Clinician and service user views

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Aim: Difficulties with social interaction, social communication and empathy may create barriers to treatment for those few individuals with autism spectrum disorder (ASD) who commit sexual offences. This research explored offender and clinician views of the effectiveness of adapted sex offender treatment programmes (ASOTP) for men with ASD. Method: Semi-structured interviews were conducted with men with ASD who have completed an ASOTP, exploring their views and experience of the treatment. Clinician interviews were also undertaken to ascertain their opinion on the effectiveness of the ASOTP for the individual with ASD. Results: A model was developed, using grounded theory, for the perceived benefits of ASOTP for individuals with ASD. Clinician and offender interviews highlighted whether the treatment needs of men with ASD are met by existing ASOTP. Conclusions: These results provide insight into offender and clinician views of the effectiveness of ASOTP for men with ASD. This work contributes to a much-needed evidence-base into the efficacy of ASOTP for individuals with ASD who sexually offend.

Self-management in people with epilepsy and intellectual disabilities: Unmet needs and the feasibility of a picture booklet intervention

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Aim: As part of the WIELD feasibility study of a picture booklet for epilepsy in people with intellectual disabilities (ID), a nested qualitative study was conducted. The aims were to investigate the impact of epilepsy on people with ID, use of epilepsy information in this group, and views on the acceptability and feasibility of the picture booklet. Method: 15 patients with epilepsy and ID from the WIELD study and/or their carers took part in semi-structured interviews. These were transcribed verbatim, coded, and analysed thematically (dual independent coding for 30% of the transcripts). Results: Patients and carers were largely accepting of epilepsy although they acknowledged that self-management could be difficult and had significant impacts on their lives. Few patients had received accessible information about epilepsy. The use of the picture booklet intervention and the conversations it prompted were perceived to be beneficial, particularly for people with poorly-controlled epilepsy or who were newly diagnosed. Conclusions: People with epilepsy and ID experience significant impacts on their quality of life and have unmet self-management needs, which could be addressed by the picture booklet intervention.
Results from the Family Needs Assessment Study: A multinational perspective

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**Aim:** Families play critical roles in their members’ lives, particularly for families of individuals with intellectual and developmental disabilities (IDD). This presentation reports results from studies in six countries and establishes the Family Needs Assessment (FNA) as an international tool. The FNA is an instrument designed to systematically identify and prioritise needs at the family-unit level. **Method:** 1,986 families participated of which many included a member with IDD. Participants from the United States (n=194), Spain (n=425), Taiwan (n=401), China (n=501), Turkey (n=231), and Colombia (n=252) completed the self-administered FNA. We utilised descriptive statistics to compare response patterns across countries for top ranked FNA items, and explored psychometric properties of the FNA by country in order to examine its utility as a unified international tool. **Results:** Preliminary findings suggest parents across nations consistently rated ‘having access to necessary services’, ‘teaching communications skills’, ‘having education services’, and ‘planning for the future’ as a high support needs. **Conclusions:** Results from these collective studies can be used to advocate for family support nationally and internationally.

Parents’ positive perspectives: Positive psychological indicators of Kurdish parents of children with intellectual and developmental disabilities in Turkey

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**Aim:** This study examines the positive psychological indicators (family quality of life, happiness, life satisfaction, optimism, psychological well-being, and personal well-being) of Kurdish parents of children with intellectual and developmental disabilities (IDD) in Turkey. **Method:** Data were obtained from a convenience sample of 472 Kurdish parents of children with IDD. Six assessment tools were used to collect the data. Family quality of life (QoL) was formulated as a basic indicator of positive psychology. A stepwise multiple regression analysis was run to determine the effects of predictor parameters on family QoL. **Results:** The multiple-regression analysis yielded four regression models. Personal well-being, life satisfaction, optimism, and psychological well-being significantly explained 58% of the total variance in family QoL. Subjective happiness did not predict family QoL. The amount of explained variance, beta score and correlations suggest that personal well-being is the most significant predictor of family QoL reported by parents. **Conclusions:** The study revealed that family indicators as a whole are more predictive of family QoL than subjective happiness in Kurdish parents of children with IDD in Turkey.

Social inclusion in action: Results from sports fields and schools

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**Aim:** To compare and contrast a variety of indicators for social inclusion (e.g. friendship, acceptance, opportunities) on the sports field and in schools, and to examine the role of sports in promoting social interactions and ultimately inclusion. **Method:** A survey for Unified Sports participants with and without intellectual disabilities (ID) was implemented. 1,715 responses from nine countries were collected and analysed. A secondary analysis of a sample of 2,377 students who participated in a school-based Unified Sports program was also conducted. **Results:** Friendships were formed through Unified Sports with 83% of people with ID reporting having more friends without ID, as a result of participation. When asked about their closest friend, 48% of people without ID said their closest friend on their team was someone with ID. In addition, students with and without disabilities who participated in Unified Sports reported more frequent interactions and were more likely to believe that students with ID contribute to their classes. **Conclusions:** Results indicate Unified Sports provides opportunities for improved social inclusion, which is valuable to participants with and without ID.

**‘I am here’: Listening to the lost voices of disability**

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**Aim:** Life-stories that fall beyond the technologies of qualitative research have been ‘explained out’ of the human rights discourse. This paper reports on research aimed at representing the ‘lost voices’ of disability in ways that speak to their right to participatory citizenship. **Method:** An individually responsive research method (IRRM) was developed to support 12 people with high and complex support needs to shape the way they were ‘researched’. Eight different ways of sharing information were offered, adapted (and rejected) within the story telling dyad. Co-created stories were refined and approved alongside an inductive analysis of their collective narrative. **Results:** Together the 12 stories inform of the continuing marginalisation of people with high and complex support needs from places and people necessary to extinguish their invisibility. **Conclusions:** IRRMs offer people ‘chronically short of words’ a response to the challenge of narration and a way to contest their exclusion from the research canon. By humanising the research relationship, co-authors exercised control over the way they were present within a method that accommodated unanticipated epistemologies and new ways to assert the dignity of citizenship within the research enterprise.

**Achieving responsive legal practice and legal processes in New Zealand through research**

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**Aim:** This research aimed to contribute to the development of a legal system more responsive to people with intellectual and developmental disabilities (IDD) in New Zealand. **Method:** 40 individuals with IDD, 15 lawyers and 13 judges participated in qualitative interviews about their specific legal experiences. The interviews were thematically analysed to identify key findings, and to generate recommendations to inform legislation, policy and practice. **Results:** People with IDD, lawyers and judges were found to hold similar views about the strategies that could lead to quality legal representation and appropriate legal decisions. All groups recognised that developing a deeper understanding of a person’s past and current life context was critical to better outcomes for individuals. Demonstrating a commitment to keeping
people informed and involved was highlighted; including the perceived benefit of drawing on the personal knowledge of family and support staff, and the professional skills of communication assistants. **Conclusions:** This research has led to increased education of legal professionals and greater knowledge of how existing New Zealand legislation can be applied to ensure that legal processes are responsive to people with IDD.

**Foetal outcomes among US women with intellectual and developmental disabilities**

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**Aim:** This study examined the deliveries occurring in US women with intellectual and developmental disabilities (IDD) and compared the rates of deliveries complicated by adverse foetal outcomes. **Method:** Data were drawn from the 2008-2011 Nationwide Inpatient Sample of the Health Care and Cost Utilisation Project which is nationally representative of hospital discharges. We compared preterm birth, foetal growth restriction or low birth weight, and stillbirth for women with and without IDD across a variety of demographic characteristics. **Results:** Women with IDD had worse outcomes for all foetal outcomes than the general obstetric population. Namely, women with IDD had about two–fold higher rates of preterm birth, low birth weight, and stillbirth than the general obstetric population. **Conclusions:** Infants born to mothers with IDD are at increased risk of negative foetal outcomes. Targeted interventions are needed to address these deleterious outcomes.

**Antepartum and postpartum hospital utilisation and cost among women with intellectual and developmental disabilities**

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**Aim:** This study used longitudinal data to compare hospital utilisation and costs during pregnancy and one year post-delivery between women and without intellectual and developmental disabilities (IDD). **Method:** Data from the Massachusetts Pregnancy to Early Life Longitudinal Data System (1988-2010) were used. **Results:** Among the 491 women with IDD, 56.4% had an ED visit during pregnancy and 55.6% had an ED visit one year after delivery compared to 24.1% and 21.6% (p<.001) among other women. Among women hospitalised during pregnancy, mean stay among those with IDD was 8.9 days (SD=16.0) compared to 3.9 (SD=6.0) among women without IDD (p<.001). Women with IDD had a mean length of post-delivery hospital stay of 12.3 days (SD=17.6) compared to 4.0 (SD 6.5) for women without IDD. There was no difference in delivery-related hospital stays between the two groups of women. The cost of hospital stay was significantly higher among women with IDD compared to women without IDD. **Conclusions:** The findings highlight a need for expanding access to health care and other support services for women with IDD during pregnancy and at postpartum.

**Family perceptions of the roles of service organisations in the lives of young people with intellectual disabilities**
Aim: This study investigated access, uses and perceptions of service organisations by families with young adults with intellectual disabilities (ID) in regional and metropolitan Queensland. Method: 222 parents of 136 male and 86 female young adults with ID completed a survey which collected information about current circumstances, and aspirations for the future. 30 families were then interviewed once a year for three years as individual case studies. Results: Families used a range of services; however, access to services was not always determined by location. Family understandings of service operations, availability of information and experiences of other parents were strong determinants of usage. Many families expressed concerns about the limited services provided by organisations particularly in relation to independent living, employment and intellectual challenge and were unsure of the impact of the National Disability Insurance Scheme. Conclusions: Many factors contribute to family decisions about accessing and using service organisations that need to be considered by service and other organisations when designing and offering programs for young people with ID and their families.

Developing receptive language abilities of adults with Down syndrome: An Irish case study

Aim: This study investigated changes in receptive language in adults with Down syndrome attending a two-year literacy program at 11 sites in Ireland. Method: Scores on the Peabody Picture Vocabulary Test (PPVT) were collected on three occasions for 99 young adults as they progressed through the program. All of the participants had Down syndrome. Ages ranged from 18 to 55 years and 49% of the participants were female. Results: The analysis revealed a significant increase in PPVT scores across the two years of enrolment in the program. Conclusions: These results provide some indication that ongoing opportunities for literacy learning that are age-appropriate and tailored to the young adults’ needs contribute to the ongoing development of receptive language in young adults with Down syndrome.

Developing language abilities of young adults with intellectual disabilities through an adult literacy program

Aim: This study investigated the development of receptive language and vocabulary in young adults with intellectual disabilities (ID) attending a two-year literacy program. Method: Multiple scores on the Peabody Picture Vocabulary Test (PPVT) and the Burt Word Reading Test (BURT) of 191 students who completed two years in the Latch-On Program were analysed. 48% of the students had Down syndrome, 43% were males, 73% were under 24 years of age. Results: A growth trajectory model accounting for age; disability; gender; maturation and time enabled the analysis of differences between individuals as well as the difference within individuals across the three waves of assessment. Growth trajectories showed an upward trend. While 91.5% of the PPVT scores were attributable to between individual differences 8.5% were attributable to within individual differences. With the Burt Word Reading Test, 93% of the changes in scores were attributable to between individual differences while 7% were
attributable to within individual differences. **Conclusions:** Young adults with ID can continue to develop receptive language and vocabulary as measured by the PPVT and the BURT given appropriate educational opportunities.

**‘I honestly feel like I’m not there or something’: A qualitative study of the experience of intellectual and developmental disability**

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**Aim:** Few qualitative studies exist which explore the experience of stigma and conception of identity among adults with intellectual and developmental disabilities (IDD). Research suggests that self-acceptance and identification with the social category of ‘disabled’ people is integral for developing skills to navigate a world that socially devalues disability. This study aimed to understand how adults with IDD experience disability, stigma, and social interactions. **Method:** 15 adults with IDD were interviewed using qualitative methods. Interviews were analysed independently by two researchers using interpretive phenomenology. **Results:** Three major themes emerged: pressure on participants to behave in a socially normative manner; tendency to produce personal definitions of disability; and consistently limited knowledge of and discomfort around disability terminology. **Conclusions:** Negative self-image and understanding of disability in this study group stemmed from initial confusion surrounding disability terminology, external judgement, and pressure to behave in a socially normative way. Partial, incorrect, or non-existent understanding of disability could pose a serious challenge to individual quality of life, as well as person-centred action and political movement in the broader population.

**Inclusive language: Dutch ground rules for health communication with people with developmental disabilities**

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**Aim:** To assess if people with developmental disabilities (DD) were able to extract better knowledge out of health brochures based on Dutch ground rules instead of regular health brochures. **Method:** 40 people with DD and low literacy capacities were asked to read either a regular health brochure or a translated brochure based on Dutch ground rules. Subsequently, based matched-pair comparisons, the capacity to reproduce facts mentioned in the three brochures was assessed. **Results:** Results suggest that regardless of gender, age or level of DD or literacy, brochures based on Dutch ground rules were better understood. **Conclusions:** People with DD and low health literacy capacities understand health brochures based on Dutch ground rules better than regular health brochures.

**Factors associated with behaviour problems in young children with autism spectrum disorder or global developmental delay**

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**Aim:** Early identification of behaviour problems in young children and a better comprehension of associated factors are important for appropriate intervention and prevention. Few studies have systematically examined characteristics of children with autism spectrum disorders (ASD) or global developmental delay (GDD) which are related to the presence or severity of problem behaviours. **Method:** To date, the sample is composed of 80 children (target of 150) aged between 2 and 7 years and diagnosed with ASD or GDD. Standardised measures were used to assess children’s problem behaviours, adaptive behaviours, intellectual functioning, and severity of autistic behaviours. Descriptive and correlation analyses between problem behaviours and children’s characteristics were performed. **Results:** Children’s mean scores were 92.94 (SD=33.8) for problem behaviours, 68.7 (SD=13.1) for adaptive behaviours, 77.4 (SD=19.6) for intellectual functioning and 27.4 (SD=8.8) for autistic behaviours. Preliminary results indicate that adaptive behaviours are associated with problem behaviours (r= -.40, p < 0.001) but not with others characteristics. **Conclusions:** Services providers must take into account children’s characteristics, particularly adaptive behaviours when planning intervention for problem behaviours.

**Sleep problems and associated health variables in an older Irish population with Down syndrome: Results from the Intellectual Disability Supplement to The Irish Longitudinal study on Ageing (IDS-TILDA)**

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**Aim:** To describe the sleep complaints and associated factors of a national sample of persons with Down syndrome (DS) aged 40 years and over and to compare these to a matched cohort without DS. **Method:** IDS-TILDA is a nationally representative, longitudinal study of persons with intellectual disabilities in Ireland aged 40 and over. Participants and/or their carers were interviewed and data on demographic, health and social variables, including sleep complaints, DS and dementia status were collated. Analyses were conducted to clarify the strength of associations with 4 key sleep variables. **Results:** Of 753 participants, 736 completed the required elements of the interview protocol; 140 reporting a diagnosis of DS, of whom 14 had co-morbid dementia. Analysis indicated factors associated with sleep complaints in those with DS as compared to those without DS and the influence of co-morbid dementia. **Conclusions:** The variables found to influence sleep in persons with DS are similar to those reported for those without DS albeit to differing degrees. Meanwhile optimised management of sleep complaints may benefit from consideration of the variables identified.

**The Diversity Field Officer (DFO) Project: Assisting small and medium businesses to develop disability confidence**

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**Aim:** This 2-year (2015-16) research project explores whether the provision of advice and supports tailored to the needs of small to medium size businesses, increases their confidence regarding employing people with disability (including people with intellectual and developmental disabilities), and
assists in the building of more inclusive workplaces. **Method:** Using an action research approach, 50 small to medium businesses in the Geelong area will be included. Pre and post intervention measures of businesses’ experience employing people with disability, their disability confidence, and their views about the advantages and disadvantages of employing people with disability are obtained. The intervention involves face-to-face advice and support for each business from a Diversity Field Officer (DFO). **Results:** To date, 38 businesses are working with the DFOs. Businesses have developed a broader understanding of disability in all its forms, they have identified key areas needing development such as recruitment processes, disability inclusive culture development, and practical direct contact through work experience, volunteering, job carving, and real jobs. **Conclusions:** This project identifies initiatives and strategies that work for small to medium businesses in building a disability inclusive workforce.

**What is so odd about the gait of children with autism spectrum disorder?**

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**Aim:** To support the diagnosis of autism spectrum disorder (ASD), one of the key motor features listed in DSM-5 is ‘odd gait’. This study utilises three dimensional (3D) gait analysis to quantify the biomechanics of gait to ascertain how children with ASD walk differently. **Method:** This prospective observational cohort study recruited children aged 7-12 years with ASD (27 with Asperger’s disorder, and 23 with high functioning autism), and a typically developing (TD) group (n=24). A 3D motion analysis system recorded full body joint kinematics as children walked at varied speeds. **Results:** Children with ASD walked at comparable speeds to TD children, yet showed subtle differences, such as increased vertical centre of mass displacement ‘bouncy gait’, greater forward trunk tilt and range, and altered timing of ankle motion (all p<0.05). **Conclusions:** The diversity within the ASD population may limit the applicability of joint kinematics in distinguishing the clinically observed ‘odd gait’. Intra-limb coordination patterns which are more sensitive to a limb’s whole trajectory shape rather than isolated events within the gait cycle may better distinguish any altered spatial and temporal characteristics of gait in ASD.

**Life after prison for ex-offenders with intellectual disabilities**

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**Aim:** In the UK, it has been reported that 7% of people in prison have intellectual disabilities (ID). This research explores life after leaving prison for ex-offenders with ID. **Method:** Men screened positive for ID were recruited from prison establishments across the UK. Care managers/probation officers were also asked to participate. Ex-offenders were interviewed one month (T1) and 9 months (T2) after leaving prison, regarding their social networks, service utilisation, quality of life, mood, well-being and offending behaviours. Brief interviews were undertaken with care managers/offender managers. **Results:** Over 80 participants were referred to the project. Of those interviewed at T1, the majority scored as anxious and depressed, 30% had been rearrested at least once and 35% were living in restricted conditions (back in prison or in hospital secure units). Family members formed a key part of men’s social support networks.
Social care and health care input was rare. **Conclusions:** The findings suggest ex-offenders with ID are extremely under-supported upon leaving prison and are at risk of re-offending.

**Linking in and grooving out: Exploring community music participation and social connectedness for young people with disabilities transitioning between school and adult life**

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**Aim:** Young people with disabilities often face challenges with social connectedness when they leave school. We are exploring how a collaborative process of setting up and participating in a community music group may help to address this. **Method:** A participatory action research method is used to establish an ongoing community music group with 5 individuals with intellectual disabilities aged 16 to 30 years in Geelong, Victoria. This is one of the first areas in Australia to implement the National Disability Insurance Scheme. **Results:** Young people have designed the type of music group they wish to participate in, as well as how to evaluate it. The group meets in a youth specific community centre in Geelong where youth from all walks of life come to hang out. Some participants have said that increasing their social connectedness is important, but others say they are just there to make music. **Conclusions:** Participation in community music has shown to improve social networks and feelings of connectedness and this presentation will give a unique insight into how young people with disability gain from the experience.

**Quality of life domains for children with Down syndrome**

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**Aim:** Information is available on aspects of quality of life (QoL) in children with Down syndrome (DS) but there has been no systematic investigation. This qualitative study explored aspects of life that contribute to happiness and well-being in children with DS to identify their domains of QoL. **Method:** Interviews were conducted with 16 parents of 6 to 18 year-old children with DS. Each parent was invited to participate in a recorded telephone interview, which was transcribed and provided to the parent for checking. Inductive thematic analysis was conducted and themes were reviewed with a Community Reference Group. **Results:** Eleven themes emerged: social connectedness & relationships, behaviour & emotion, independence & autonomy, movement & physical activity, communication, routines & predictability, physical health, mastery & achievement, variety of activities, access to services and personal value. **Conclusions:** The themes together reflect how children with DS indicate contentment and happiness in their lives and contribute to understanding how to measure QoL in intellectual disabilities.

**‘Love labour’ and caring for older people with intellectual disabilities within the family home environment**
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Aim: To explore the value of ‘love labour’ within the caring process between family carers and older people with intellectual disabilities (ID) within the family home environment. Method: Within the Irish IDS-TILDA study, a ‘Carer’s Questionnaire’ was completed with 62 carers of older people with ID living within family settings. To build on this data, five qualitative follow-up focus groups and six one-to-one interviews were conducted and analysed. Results: While carer burden was reported across respondents, this was consistently counterbalanced by carers expressing a fundamental love and devotion for the relative they care for. Focus group and interview data confirmed that their caring ‘labour’ was set within a deep emotional context, which they identified as a key driver to long-term quality care within the family home environment. Conclusion: ‘Love Labour’ is a core enabler of quality caring within the family home environment. However it is difficult to measure and problematic to replace should caring move from home to formal service providers.

Questioning the feasibility of the implementation of contemporary policy in Ireland: The narratives of family caregivers supporting older people with intellectual disabilities

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Aim: To examine family caregivers’ perspectives on the contextual applicability and feasibility of implementing Irish contemporary intellectual disability (ID) policy to older people with ID. Method: Framed within a qualitative methodology, 17 family carers of older people with an ID were purposively sampled via the parent population study, IDS TILDA (Intellectual Disability Supplement to The Irish Longitudinal Database on Aging). Data were garnered and thematically analysed from five focus groups and six semi-structured interviews. Results: Family caregiver narratives pervasively highlighted that whilst the ethos informing current policy in Ireland was laudable, its implementation and feasibility in reality was problematic; notably due to inadequate fiscal and community infrastructure. Moreover, sufficient consideration of the contextual realities unique to the older person with ID and their family caregivers was deemed absent. Conclusions: Presently, the content, format and implementation of Irish contemporary policies may detrimentally impact upon sustainable family caregiving capacity in the care of older persons with ID.

Developmental risk factors associated with incarceration in the juvenile justice system

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Aim: Recognition of impairment early in life allows tailored therapeutic interventions and advocacy and may also prevent incarceration. Method: A multidisciplinary team (MDT) measured and determined the bio-psycho-social and neurocognitive profile of 100 incarcerated youth. Youth were considered for possible foetal alcohol spectrum disorder and other disabilities. The multidisciplinary team developed individualised therapeutic strategies for identified strengths and difficulties and liaised with care providers. Results: Developmental pathways associated with incarceration included fractured attachment, lived trauma, interrupted education, accidental injury and substance misuse.
Developmental impairments and disabilities were not commonly recognised among the study participants prior to their early entry into the justice system. Complex biopsychosocial histories and secondary associated adverse behaviours were common. **Conclusions:** Factors and events recurred across the developmental histories among youth participating in the study. Considering and interpreting developmental pathways may alert health professionals to consider assessment of neurocognitive and adaptive strengths and difficulties.

**Prevalence of foetal alcohol spectrum disorder and neurocognitive impairment among incarcerated youth**

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**Aim:** Individuals living with foetal alcohol spectrum disorder (FASD) demonstrate a link between impaired cognitive and adaptive skills and subsequent adverse life outcomes including early contact with the criminal justice system. The aim of this project was to identify possible FASD and other disabilities among incarcerated youth. **Method:** A paediatrician, occupational therapist, speech and language pathologist, neuropsychologist and research officer measured biopsychosocial and neurocognitive strengths and difficulties in 100 incarcerated youth. **Results:** Youth had one or more impaired neurocognitive domains. Several individuals had newly identified intellectual impairment. Many exhibited a positive physical and neurological examination for soft signs. Many had active medical needs. The range and severity of impairments and disabilities will be described. **Conclusions:** Neurocognitive impairment is common among youth engaged in the juvenile justice system although the impairment is not always evident. All youth engaged with justice systems should be referred for multidisciplinary assessment. Neurocognitive disability can be a mitigating factor.

**Mercury and developmental disabilities: 75 years of research**

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**Aim:** To review the evidence that maternal consumption of fish with naturally occurring levels of MeHg harms the foetus. **Method:** MeHg poisoning episodes, epidemiological studies of exposure from seafood consumption, and rationale for fish advisories were reviewed. **Results:** There are two reports of MeHg poisoning from maternal consumption of fish. Both resulted from gross industrial pollution and occurred in Japan over 50 years ago. No cases of poisoning from fish consumption have been reported since. Epidemiological studies of populations consuming seafood that includes sea mammals have reported statistically significant adverse associations of prenatal MeHg exposure with children’s development. Studies of populations consuming seafood not containing sea mammals have not identified consistent adverse associations. **Conclusions:** Consumption of industrially contaminated fish can result in MeHg poisoning. Evidence that MeHg toxicity results from consuming fish with naturally occurring levels of exposure relies on epidemiological studies and is inconclusive. Fish are caloric and nutrient packages and an important source of nutrition and of n-3 polyunsaturated fatty acids essential for brain development.
Cross-sectional study on MeHg exposure and neurological outcomes in a whaling town, Japan

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Aim: This study evaluated MeHg exposure in Taiji and whether there were adverse health consequences to MeHg exposure. Method: 724 residents provided hair samples to assess MeHg exposure, 194 underwent a neurological examination and provided a second hair sample, and 153 also provided plasma samples. Results: The geometric means of hair mercury of the male and female subjects were 9.97 and 6.19 ppm in the first survey and 17.2 and 12.1 ppm in the second. 2.2% and 6.2% had levels higher than 50 ppm (NOAEL for adults set by WHO) at first and second assessments respectively. Since hair mercury levels significantly correlated with daily whale meat intake, Taiji residents were considered to be highly exposed to MeHg by ingesting MeHg-contaminated whale meat. Multivariate regression analysis demonstrated no significant correlations between hair mercury levels and neurological outcomes, whereas some of the findings significantly correlated with age. A significantly positive correlation between plasma mercury and Se levels was observed and the plasma mercury/Se molar ratios of all subjects were <1. Conclusions: Sufficient Se intake might partially explain the absence of adverse effects of MeHg exposure in this study.

Quality of work life in Work Continuance Support B-Type Offices in Japan: Evaluation of the Temil Project

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Aim: In Japan, there are approximately 9,000 Work Continuance Support B-Type offices, a unique system in Japan similar to sheltered workshops, where approximately 100,000 adults with intellectual disabilities work. The Temil Project is a countrywide initiative to enhance decent work and wages. This study evaluates the Temil Project by examining the quality of work life in those offices. Method: This case study is an analysis of interview and questionnaire data from six persons who works there, and also data from published documents about the quality of work life using exploratory factor analysis. Results: The Temil Project focusses on the key factors of quality of work life especially on ‘individual decent work’ by creating the activities to achieve a local community partnership. This results in high quality products, as well as increased confidence and strong emotional attachment to the outcome (products) which encourages workers to take pride in their work. Conclusions: To improve ‘individual decent work’ at B-Type offices, it is important to pay attention to key quality of work life factors and make required adjustments.

Clinical governance: A relevant clinical practice framework to prevent the use of restrictive practices

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Aim: Clinical governance is an important framework to guide quality service provision in the disability service sector. This study explored clinical governance climate from the perspective of allied health professionals (AHPs) working within disability services. Findings are interpreted in relation to restrictive
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practice use. **Method:** 86 AHPs (e.g., psychologists, speech pathologists) completed an online survey containing the Clinical Governance Climate Questionnaire (Freeman, 2003). **Results:** AHPs report that quality improvement initiatives tend to be crisis-driven, with the immediate work pressures taking precedence. Dedicated time for professional development was not available to many of the AHPs, and many AHPs report that hierarchies within multidisciplinary clinical teams were evident. **Conclusions:** Restrictive practice use can be linked to the poor clinical governance climate indicators reported by the AHPs, e.g., a lack of support for AHPs to develop skills and knowledge related to less restrictive evidence-based practices could be fuelling an over reliance on restrictive practice within behaviour support plans. These findings imply that clinical governance is a viable framework to support reduced use of restrictive interventions for people with intellectual disabilities.

**Status of persons with intellectual disabilities in ancient India: A study of Indian epics**

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**Aim:** To systematically study the epics to reveal the status of persons with intellectual disabilities (ID) and to compare with current status. **Method:** As historic research, major epics having terms referring to ID were identified through computer descriptor search. The relevant texts in Sanskrit with English translation were identified and studied in context. The collected information included nomenclature, lifestyle and status of persons with ID in the kingdom. The data were compared to the current status of persons with ID through analysis of literature on practices in ancient times and over the past ten years. **Results:** There is evidence of systematic educational decisions, support for livelihood and respect for the abilities of person with ID. In some instances, they were thought to be a bad omen. Comparison with current practices showed that the close-knit family system now and in ancient times is a strength. **Conclusions:** In the past, the treatment of persons with ID was based on religious beliefs; a rights-based approach and independent living are the focus today.

**Making inclusive quality education a reality for all: Implications for policy development**

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**Aim:** The right to education is enshrined in the Convention on the Rights of the Child. Students with disabilities have the right to education and the education system should be inclusive. Key barriers encountered by students with disabilities and their families in accessing inclusive quality education were explored. **Method:** A review of research and policy explored the challenges faced by students with disabilities and supports which can assist them to remain engaged in education. Practitioners from the Uniting Stay Connected program and representatives from learning support teams at two schools were consulted. **Results:** The issues and solutions raised by practitioners closely aligned with research evidence. Challenges faced for students included repeated suspensions and insufficient support during key transitions. The paper identified systemic barriers which hinder translation of research evidence to policy improvement. **Conclusions:** Policy implications include: addressing high rates of school suspension; strengthening professional development for teachers in working with students with
disability; and better support for children and families through transitions across stages of education such as starting school and the transition from primary to high school.

**Intervention intensity and language intervention for children with Down syndrome: Dose task persistence and phenotypic characteristics**

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**Aim:** Maximising outcomes for learners with Down syndrome (DS) requires an approach that is both effective and efficient. The purpose of this study was to conduct a systematic manipulation of dose, measuring skill acquisition and task persistence during discrete-trial instruction for communication responses in children diagnosed with DS. **Method:** Children with DS were taught expressive and receptive language targets using three manipulations of dose: the number of opportunities, the spacing of opportunities, and the session duration. We measured the effects of dose on skill acquisition and task persistence (off-task behaviour and affect). **Results:** Children acquired targets faster in conditions in which the spacing of opportunities was shorter than conditions in which the spacing was longer. Manipulating dose produced individual differences during the different intensity levels in the two measures of task persistence. The differing effects of dose were greater for phenotypic weaknesses than strengths. **Conclusions:** The results of this study can guide practitioners in developing effective intervention practices for children with DS; high doses of intervention resulted in more efficient acquisition of communication targets.

**Linking transition practices in parent-teacher partnerships to positive outcomes for children**

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**Aim:** The aim was to identify positive practices between parent, teacher and school partners which could be linked to successful transition to school outcomes for children with intellectual disabilities (ID). **Method:** Qualitative interviews with eight parents and their teacher partners in preschool and school over two years of transition were grouped into themes and sets for NVivo matrix enquiries. These explored quality of processes over time, person and place and how they impacted on child developmental outcomes. **Results:** Outcomes for children and parents were strongly linked to family needs, and the presence of shared understanding, teaming and empathy for the emotional dimension of transition between partners. The study discriminated findings on an interpersonal, professional and organisational level, identifying helpful practices to benefit children. **Conclusions:** Parents, teachers and schools need support in understanding the dynamics of partnerships during transition as well as practical strategies which enable them to perform their team roles effectively. This study showed a strong relationship between types of practices and teamwork which related to positive transition outcomes for children and parents.

**The role of mental health, physical health and aggression of adults with developmental disabilities in predicting positive coping and retention in direct care staff**
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**Aim:** To determine the impact that mental and physical health in aggressive adults with developmental disabilities (DD) has on coping and job retention in staff who care for these adults. **Method:** 100 staff completed questionnaires at two time points about themselves and an adult with DD who demonstrates aggression towards them. Time 1 measures include the adult’s demographics, aggression, mental and physical health, and the staff’s demographics, job characteristics, coping, and burnout. Time 2 measures will be collected to measure staff job retention after six months and changes in emotional and coping status. **Results:** Preliminary time 1 results (n=33) show approaching elevated burnout associated with average severity of verbal aggression and below average severity of physical aggression. Poor adult mental health is significantly correlated with negative coping strategies. Poorer physical health is associated with negative coping and burnout. Results from regression and mediation analyses will be presented to show factors associated with job retention at time 2. **Conclusions:** Recommendations will be presented based on findings on how adult health and staff coping skills relate to staff retention.

An evaluation of novel and innovative respite services in intellectual disability services in Ireland

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**Aim:** Alternative models of respite include non-institution community-based services, which aim to support individuals with intellectual disabilities (ID) to develop new skills and gain new experiences. This research compares alternative and traditional forms of respite as delivered within ID settings. **Method:** Participants were people with ID using alternative respite services (n=40), their family carers and respite staff, and a comparative group (n=25) using traditional respite. Quantitative and qualitative techniques included questionnaires that assessed quality of life, process of care and experience of caregiving, as well as semi-structured interviews with project leaders and families. **Results:** Overall, participants showed high levels of self-reported quality of life generally, though staff reports showed more variation. Families generally reported positive experiences of caregiving. The two groups will be compared using inferential statistics. **Conclusions:** The comparative evaluation of different services will allow for variations in outcomes across the two groups to be determined. The results will be discussed in the context of respite provision and implications for practice.

The experience of anxiety in adults with autism: A qualitative analysis

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**Aim:** It is well recognised that anxiety is more common in individuals on the autism spectrum in comparison to the general population. Yet, little is known about the personal experiences of anxiety for adults with autism. This qualitative investigation explores the experiences of anxiety for adults on the autism spectrum. **Method:** Semi-structured interviews were conducted with adults on the autism spectrum. Interviews were digitally recorded and transcribed verbatim. Thematic analysis was used to gain insight into the experiences of anxiety. **Results:** We interviewed 10 adults on the autism spectrum with anxiety, six females and four males. Participants were aged between 23 and 68 years old. Themes
relating to self-awareness, impact of anxiety on the individual and management strategies will be presented. **Conclusions:** The analysis of the qualitative data will provide much needed insight into the experiences of anxiety for adults on the autism spectrum. This information will be used to inform an intervention to improve the health and well-being of Australian adults on the autism spectrum.

**A systematic review and meta-analysis of psychological interventions for adolescents and adults on the autism spectrum with anxiety**

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**Aim:** The presence of a co-occurring anxiety disorder can present challenges above and beyond those already experienced for individuals on the autism spectrum. The aim was to conduct a systematic review and meta-analysis of anxiety intervention programs for adolescents and adults on the autism spectrum.

**Method:** A systematic search of five electronic databases was conducted. Included studies were evaluated in relation to: participants, intervention, dependent variables, results and study quality.

**Results:** The search yielded 13 studies. Interventions were based on cognitive behaviour therapy (CBT) and mindfulness. The studies varied in methods and quality. A meta-analysis conducted with four of the 13 studies demonstrated a reduction in anxiety for adolescents and adults on the autism spectrum (fixed effects model I-V pooled SMD = -0.36; 95%CI, -0.70 to -0.02; p = 0.04).

**Conclusions:** This study is the first to systematically review interventions for adolescents and adults on the autism spectrum with anxiety. Included studies were limited due to a range of methodological problems and these identified limitations could help inform future research to support adults on the autism spectrum with anxiety.

**Story retelling and cognitive ability in school-aged children with cerebral palsy and speech impairment**

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**Aim:** Research on retelling ability and cognition is limited in children with cerebral palsy (CP) and speech impairment. The impact of expressive and receptive language, narrative discourse, memory, theory of mind, and non-verbal cognition on the retelling ability of children with CP and speech impairment were explored. **Method:** 15 speaking children with speech impairment (seven girls, eight boys) (mean age=11 years) with different levels of gross motor and cognitive function participated. Story retelling skills, language abilities, non-verbal cognitive level, theory of mind and memory functions were tested and analysed. **Results:** The children had severe problems with retelling ability corresponding to an age-equivalent of 5.17 to 6.75 years. Language, memory, theory of mind and non-verbal cognitive level varied widely within and among the children. Both expressive and receptive language, and auditory memory correlated significantly with retelling ability. **Conclusions:** It is suggested that retelling ability is dependent on language comprehension and production, and memory functions. To examine retelling ability together with language and cognitive abilities in these children is important in order to provide appropriate support.
Diabetes prevalence and experience amongst people with intellectual disabilities: A systematic review

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Aim: To review the evidence concerning the prevalence of diabetes in people with intellectual disabilities (ID) and their (and their carers’) experience of this condition and treatment. Method: A systematic review identified 22 international papers focussed on prevalence and 5 concerning experiences of diabetes. A narrative synthesis approach was used to amalgamate data from across these studies. Results: Reported prevalence ranged widely from 0.4% to 25% with rates amongst people with ID reported as being higher than those amongst the general population. People with ID were found to have some understanding of their condition but wanted to know more. Carers reported a lack of knowledge and that they did not routinely promote diabetes self-management. Some methodological limitations were noted within the papers reviewed. Conclusions: Further research is needed to determine more accurate diabetes prevalence rates. The participation of people with ID in such research should be encouraged and the potential to adapt diabetes self-management programmes should be explored.

The manifestation of the Swedish disability policies in practice: Using two studies as examples

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Aim: Swedish disability policies increase the possibilities for children with disabilities and their parents to participate in society. This study examines empirical findings of everyday experiences of parents of children with intellectual disabilities (ID) related to Swedish disability policies. Method: Results from two different studies are used as examples of the manifestation of Swedish disability policies in practice: semi-structured interviews with six parents subjected to thematic analysis, and structured interviews with 144 parents and questionnaires from 228 professionals analysed with ANOVA and t-test in SPSS. Results: Parents perceive a lack of information about available support; the process of applying for and managing support consumes time and energy; and children with ID have limited opportunity to participate in planning, decision-making, and evaluation of support. Conclusions: Swedish disability policies increase the opportunity for children with disabilities and their parents to participate in society. However, a lot of work still needs to be done in the implementation of these policies in practice.
Inclusive education in international human rights law: A conceptual examination

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Aim: To interrogate the concept of inclusive education as to enable its efficient implementation for students with intellectual disabilities (ID) in Nigeria. Method: We conducted a literature review of the conceptual analysis of inclusive education using a rights-based approach, and a series of interviews on the extent of inclusiveness without breaching the human rights of others to education. While it is not easy to identify students with ID in Nigeria due to the silent culture, teachers as well as some parents and students with ID were interviewed. Results: While there are existing policies on inclusive education in Nigeria, there are no clear enforcement mechanisms or sufficient skilled educators to ensure inclusion of students with ID. Inclusive education of students with ID enhances the realisation of their right to education. Conclusions: Though inclusive education should be the rule, the concept is still evolving in Nigeria and caution must be taken not to use a ‘one size fits all’ approach in its implementation.

Health for All (except if you have intellectual disabilities?): Examining the extent to which national health policy is equitable

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Aim: To examine national health policies in Ireland and the extent to which they are inclusive of people with intellectual disabilities (ID) and address the health inequalities they experience. Method: A content analysis of four health policies using Equiframe, a human rights approach to policy analysis, was completed. Core concepts of human rights were identified in the policies and calculations made of the extent to which these referred to people with disabilities (including people with ID). Results: Representation of people with ID in health policy core concepts ranged from 0% in one general population policy to just over half (56%) in a policy specifically referring to the needs of people with disabilities. Conclusions: People with ID continue to be excluded from national health policies. Thus, policy implementation in its current form may serve to perpetuate rather than reduce health inequalities that exist for people with ID.

Polypharmacy and the burden of medicines in older adults with intellectual disabilities in Ireland

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Aim: Use of drugs with sedative or anticholinergic effects have been associated with adverse outcomes in older adults. The aim was to examine burden of sedative and anticholinergic medications and functional and cognitive outcomes in older adults with intellectual disabilities (ID). Method: Medication data for those living in residential settings (N=275) was drawn from Wave 2 of IDS-TILDA, a longitudinal study of a representative population of people with ID aged 44 years+ in Ireland. Burden of medications was calculated using the Drug Burden Index (DBI) tool. Results: Of the 275 people, 89% (245) had a DBI score of 1+, a mean (±SD) score of 1.9 (±1.3) (max 6.2), and 41.5% (114) had a DBI score 5+. Anti-epileptics accounted for 26.3% of the cumulative DBI score, antipsychotics for 21.9% and anxiolytics
accounted for 14.5% of the score. There was no significant association identified between scores constipation, sedation or falls. Conclusions: This study presents a novel attempt of estimating cumulative sedative and anticholinergic exposure in older adults with ID and establishes the drug burden was high. The DBI represents a useful tool for medication review.

Children with intellectual disabilities and children with autism in Scottish schools

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Aim: The study aimed to establish a prevalence rate for intellectual disabilities (ID) and autism among pupils in Scotland, and to analyse trends in this rate over time. Method: The Scottish Pupil Census is conducted annually by collecting information electronically from all publicly funded primary, secondary and special schools. Whilst data has been collected since 2002, it is only possible to compare variables relevant to this study from 2008. Analysis across age ranges (4.5–18 years) was undertaken for 2008–2014. Results: ID prevalence increased from 1.3% in 2008 to 2.3% in 2014. Autism prevalence increased from 0.7% to 1.6% over this period. The type of education attended by the majority of pupils with ID changed gradually from special to mainstream primary education between 2008 and 2014. There was a slight increase in pupils attending mainstream secondary education over this period. Conclusions: Reported prevalence of ID and autism among children in Scotland has increased, potentially reflecting improved identification and recording of ID and autism within the education system. Data also suggests a gradual shift from special to mainstream education.

An exploration of the organisational enablers of and barriers to promoting healthy lifestyle behaviours for people with intellectual disabilities

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Aim: The health-related behaviours of people with intellectual disabilities (ID) are strongly influenced by cultural and social factors such as organisational context yet this has rarely been investigated. This study explores the organisational barriers and solutions to the promotion of healthy lifestyle behaviours for this population. Method: Qualitative methodology was used. Focus groups and interviews were undertaken with staff and managers of residential services. Staff job descriptions were also collected from these services. Thematic content analysis was employed. Results: Three overarching themes were identified. The first two themes relate to organisational barriers to promoting health for individuals with ID. These themes focussed on highlighting how administration and routine tasks were prioritised over the promotion of regular physical activity and a healthy diet. The third theme relates to enablers or strategies for implementing health promotion activities. Conclusions: These findings have international implications on how organisations support people with ID to be more aligned with promoting health. They also highlight the need for organisational culture to facilitate knowledge translation and embrace evidence-based health promotion interventions.

Physical assessment in older adults with intellectual disabilities: Results of the HA-ID study
Scientific Oral Presentations

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Aim: Being physical fit is an essential factor in healthy aging, and physical fitness tests can be important tools in the care of the aging population with intellectual disabilities (ID). In the HA-ID study, the feasibility and reliability of eight physical fitness tests have previously been studied for older adults (≥ 50 years) with ID. In the current study, the predictive value of these tests for a decline in daily functioning was assessed. Method: At baseline, an extensive physical fitness assessment was performed in 1,050 older adults. Professional caregivers completed questionnaires regarding daily functioning, both at baseline and at follow-up 3 years later. Multiple linear regression analyses were used to assess the predictive value of physical fitness tests for a decline in daily functioning. Results: Daily functioning significantly declined over the 3-year follow-up period. Most physical fitness tests were significant predictors of both a decline in the ability to perform basic and instrumental activities of daily living and of a decline in mobility. Conclusions: With these, and previous results of the HA-ID study, a physical fitness test battery has been composed of suitable physical fitness tests.

Meanings of gender and disability in the stories of young women with intellectual disabilities

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Aim: Following the work of French philosopher Michel Foucault, dominant discourses establish the ways that women with intellectual disabilities (ID) are constructed. How does this construct influence how they can/not know themselves and be known by others? Method: This research involved six young women with ID aged 18 to 30 years in Victoria, Australia. A qualitative life story approach incorporating photographs and ethnography was used across six research encounters. Results: Gender, relationships and sexuality functioned in the women’s production of self. Family, violence and abuse, sexuality and motherhood were all sites for the production of a gendered identity. To perform their femininity and engage a gendered subjectivity, women with ID utilised several resources and resistance strategies. Intersections with dominant ideas of ID also shaped how the women responded to gendered discourses. Conclusions: Compared with the undesirability of ID discourse, gendered subjectivities were often productive for the women. When other possibilities such as same sex attraction or motherhood do not align with ideas of appropriate gender performances they may be actively forestalled.

Home care service use by adults with intellectual and developmental disabilities over time: The need to understand changes in frailty

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Aim: This study aimed to determine the impact of home care service utilization on frailty in home care users with intellectual and developmental disabilities (IDD) over time. Method: A retrospective, observational, longitudinal study of 5222 adults (18 to 99 years) with IDD in Ontario, Canada was undertaken. Frailty was measured using a 42-item frailty index, which was developed using variables provided by the Resident Assessment Instrument- Home Care. The probability of experiencing a change in frailty status over time will be analysed adjusting for demographic factors and home care services.
Results: At baseline, 69.6% were non-frail, 16.3% pre-frail and 14.1% frail. In the short term (mean=8.3 months; S.D.:1.8), 11.7% of the non-frail worsened, 48.7% of the frail improved while 38.3% of the pre-frail improved and 18.9% worsened. The most common home care services received were health aides and homemaking services. Less than 25% received nursing or therapy services. Analysis is ongoing and will include samples followed beyond a year. Conclusions: The results of this study will provide information to better support persons with IDD living in the community through home care services.

Challenges in measuring adherence to guideline-recommended primary care for adults with intellectual and developmental disabilities using health administrative data

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Aim: This presentation explores the feasibility of using health administrative data to measure adherence to the Canadian consensus guideline recommendation that adults with intellectual and developmental disabilities (IDD) receive an annual comprehensive health assessment. Method: Two observational longitudinal studies were conducted using data for subsets of a broader cohort of over 66,000 adults with IDD in Ontario, Canada. The first study considered two billing codes for annual health examinations and data related to three cancer screens (breast, cervical, colorectal) and compared uptake corresponding to a change in service delivery model. The second study considered the physician billing codes as well as a composite score of the quality of primary care derived from health administrative data to describe change over time. Results: The first study suggests that code shift and workload shift invalidate the use of annual health examination billing codes. Analysis is ongoing for the second study. Conclusions: The combined results of the two studies will provide guidance in how to best measure adherence to guideline-recommended primary care for adults with IDD in Canada and elsewhere using administrative health data.

Barriers and enablers to reducing the use of restrictive practices

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Aim: To highlight factors which inhibit or increase success in reducing restrictive practices at a systemic, organisational and practice level. Method: In 2006, Queensland implemented legislation aimed at increasing reliance on approaches using positive behaviour supports and reducing the use of restrictive practices. In 2014, this legislation was amended to include the mandatory collection of data. The legislation draws upon human rights principles and international evidence in reducing restrictive practices. An analysis of available data and information from focus groups has been used to evaluate what the most successful strategies are for reducing the use of restrictive practices. This data also provides information on the barriers to reducing restrictive practices Results: Practice leadership and development are important as enablers towards reducing restrictive practice. There are common themes in the international literature regarding potential enablers and barriers. Conclusions: A multi-
element framework based on collaborative approaches supported by a legislative driver can be successful in achieving a reduction the use this of restrictive practices.

Exploring data and themes of data in reducing restrictive practices including mechanical restraint, physical restraint, and chemical restraint

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Aim: To explore instances of use in restrictive practices across Queensland. Method: In 2014, the Disability Services Act was amended to require that all instances of use of restrictive practice across the state be reported to government. A database has been developed to enable all instances of use to be tracked and analysis to be undertaken of the data across Queensland. Data is collated centrally, analysed by clinicians and used to provide feedback to the sector in regard to practice issues. Results: The use of data as part of a multi-element approach for reducing restrictive practices appears to have some efficacy. The presentation will explore themes from 18-months of data. Conclusions: Collation and analysis of data is important as part of an evidence-based approach to reducing restrictive practices.

What's next?: The development of self-advocacy in Malaysia

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Aim: Self-advocacy was established in Malaysia since the early 1990s based on People First’s approach. This study aims to empower and realise the potential of individuals with intellectual and developmental disabilities (IDD). Method: A participatory action research was designed to enable the participation of individuals with IDD to develop their leadership and conflict resolution skills underpinning self-advocacy skills. Based on their capacity of learning, individuals with IDD are trained to resolve conflict peacefully. This action research consists of three cycles built around integrated cycles of planning, action, observation and reflection. Data collection includes observations, interviews, documents analysis and records. Results: In the process of conflict resolution, individuals with IDD learn to respect one another as a step to enhance their self-advocacy skills. A new platform for self-advocacy is developed where individuals with IDD are able to be proactive towards restorative justice. Conclusions: Individuals with IDD are able to take control of all aspect of their lives. When services and programmes are enhanced for them to live independently in the community, it leads to the emancipation of self and social empowerment.

Responding to the unmet educational needs of children and young people with disabilities exhibiting behaviours of concern

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Aim: Students with intellectual and developmental disabilities have been shown to have a high level of suspensions from school. Positive behaviour support (PBS) has been suggested as an approach for the
prevention behaviours of concern by replacing them with prosocial behaviours. **Method:** A literature review accessing online databases, PsycInfo and Child Development & Adolescent Studies, examined international research findings regarding amelioration of behaviours of concern. Key words entered included PBS, applied behaviour analysis, person-centredness, schools, strengths-based practice and quality of life. **Results:** Programs which used the principles of PBS were strongly supported when compared to other strategies, and recommended for adoption by services which support children and young people with disabilities in a range of educational and community living settings. **Conclusions:** The paper provides a set of implementation principles to best address educational needs for children and young people with disabilities exhibiting behaviours of concern. The paper also raised important considerations for translating research evidence into practice.

**DSM 5 diagnostic criteria for bipolar and related disorders in persons with intellectual and developmental disabilities**

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**Aim:** To update evidence-based literature pertaining to the diagnosis of bipolar and related disorders in persons with intellectual and developmental disabilities (IDD). **Method:** Utilising an expert consensus model, a NADD expert work group examined changes in the Diagnostic Statistical Manual 5 (DSM 5) and reviewed pertinent evidenced-based literature for persons with IDD. A draft of the review was submitted for peer review and revised. **Results:** A major change has been the introduction of the DSM 5 diagnostic category of disruptive mood dysregulation disorder within the depressive disorders chapter. This new diagnosis is for individuals with onset as children or adolescents who have severe, non-episodic irritability that is developmentally inappropriate. It is hypothesised that this new category will be relevant for persons with IDD. In DSM-IV, these persons were often diagnosed with paediatric mania. The literature review provides evidence of over-diagnosis of bipolar disorders in persons with IDD. **Conclusions:** With the addition of mood dysregulation disorder, there should be greater diagnostic clarity for paediatric bipolar disorder. The review highlights the potential over-diagnosis of bipolar and related for persons with IDD.

**Eye Movement Desensitising and Reprocessing (EMDR) for people with intellectual disabilities with DSM 5 posttraumatic stress disorder: Application and variation of the standard EMDR 8 stage protocol**

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**Aim:** Shapiro has shaped the development of EMDR over the past 25 years with consolidation of the 8 stage protocol to standardise a manualised approach with improved consistency, validity and scientific study. A number of validated variations take account of different symptoms, populations and environments. This paper examines considerations when working with adults who have intellectual disabilities (ID). **Method:** A literature review of EMDR therapy comparing people with ID to other populations applying modifications made in other therapies was undertaken. **Results:** While trauma may be greater in people with ID, therapies have been limited. Practitioners are now expanding their practice to include people with ID. Some of the modifications to the standard protocol relate to developmental
ability affecting conceptual formulation which in turn affects the utility of complex explanations, abstract concepts and detailed discriminant scales of emotions and thoughts. Physical conditions more prevalent in the population further necessitate flexibility with desensitisation methodology. **Conclusions:** Initial results suggest that the amended EMDR protocol is accessible for people with ID and PTSD providing a powerful addition to the range of therapies available.

**Common mealtime difficulties faced by Indian children with cerebral palsy and dysphagia**

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**Aim:** Many problems faced by Indian children with dysphagia at mealtimes are universal but some may be more prominent because of cultural differences regardless of socio-economic status. The aim of the paper is to highlight cultural factors impacting children with cerebral palsy (CP) in India. **Method:** Case studies examined health and safety concerns related to Indian cultural practices at mealtimes. **Results:** Children with CP are usually fed in a lying position using a pouring spoon called a jhinuk. As they are often kept on liquids for a long time, aspiration pneumonia is common. Children do not adjust to food or to different tastes as they are accustomed to a monotonous ‘safe’ diet. Adaptations that Indian parents make when feeding their children with CP and dysphagia, and how these impact on the health and safety of these children will be discussed. **Conclusions:** Indian parents of children with severe CP have little understanding of dysphagia and mealtime practice that optimise health and safety. Education and support is required at all levels of society.

**Examining the social inclusion of children with severe/multiple intellectual and developmental disabilities in school and the community: A descriptive analysis using multiple case studies**

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**Aim:** Although often present in ‘inclusive’ settings, children with severe/multiple intellectual and developmental disabilities (IDD) are at high risk of social exclusion. When they also have autism spectrum disorder (ASD), there are even greater difficulties participating in social interactions and maintaining relationships. These difficulties were examined in this study. **Method:** The parents, teachers and community leaders (e.g., Brownie leader) of 27 children were interviewed to gain their perspectives about the children’s social experiences in school and community settings. Children were also observed in potentially social settings, and information was collected surrounding the types of play, and amount of social interaction with peers and adults, as well as observer ratings. **Results:** 10 cases with data from multiple sources and settings revealed several themes across settings, such as child characteristics, environmental characteristics, integration, accommodation/adaptation, staff resources, communication, and societal awareness/stigma. Agreements and discrepancies in ratings based on the setting and informant were noted. **Conclusions:** These case descriptions and themes provide information surrounding barriers to children’s inclusion, directions for future research in this population, as well as clinical and societal implications.
Examining positive outcomes and associated factors among parents of children with autism spectrum disorder or intellectual disabilities compared to typically developing children

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Aim: Family research is increasingly focussed on potential positive impacts of raising a child with intellectual disabilities (ID) or autism spectrum disorder (ASD), although a clear approach to conceptualisation and measurement of positive impacts has yet to be established. We used Perry’s (2004) model to examine positive and negative outcomes in three groups of families raising a child with ID, ASD, or neither. Method: A brief online survey was completed by over 600 Canadian parents of children aged 3 to 21 years (approximately 200 in each group). Positive and negative outcomes were examined in relation to child characteristics and several resource (e.g., parent’s mental health) and support (e.g., parent’s social participation) factors. Results: Child characteristics (age, adaptive, maladaptive, and diagnosis of ASD) were related to both outcomes, but much more strongly to negative outcomes. Levels of resources and supports were more strongly associated with negative than positive outcomes. Conclusions: Positive outcomes were only weakly related to a range of predictors, suggesting that further work is needed to more fully conceptualise and measure these positive outcomes and associated factors.

Personality profiles and motives for substance use in individuals with mild to borderline intellectual disabilities

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Aim: Risk factors for substance use (disorders) in adolescents and young adults with mild to borderline intellectual disabilities (ID) are understudied. In individuals with an average intelligence it is well established that four personality profiles (i.e., anxiety sensitivity, negative thinking, impulsivity and sensation seeking) are related to elevated risk for substance use (disorders) with related motives for substance use. The present study examines the role of personality profiles and motives for substance use in adolescents and young adults with mild to borderline ID. Method: Over 100 adolescents and young adults (mean age=20.5 years) admitted to care facilities for persons with mild to borderline ID and severe behavioural problem responded to an interactive digital questionnaire using a tablet computer with touchscreen. Associations between IQ, personality profiles, substance use motives and substance use were tested. Results: Preliminary results show that personality profiles identify persons at increased risk for substance use disorders. Conclusions: Implications for substance use interventions in individuals with mild to borderline ID will be discussed.

An examination of the relationship between implicit and explicit attitudes towards people with intellectual disabilities in Singapore

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Aim: This study examined explicit and implicit attitudes, and the relationship between them, towards people with intellectual disabilities (ID) in Singapore. Method: A total of 333 participants recruited from two Singapore universities and the researcher’s network completed the online study, consisting of the Attitudes Toward Intellectual Disability (ATTID) questionnaire and the Single Target Implicit Association Test (ST-IAT). Results: Participants reported overall positive explicit attitudes; these were more negative towards severe ID than mild ID. Participants held overall neutral implicit attitudes, but a large proportion (38.30%) held negative implicit attitudes. Positive implicit attitudes were associated with greater willingness to interact with people with ID, but the level of ID severity did not influence this relationship. Prior contact with people with ID was associated with less discomfort but had little influence on implicit attitudes. Conclusions: Young and educated Singaporeans in this study held neutral to positive attitudes towards people with ID, differing from traditional beliefs. This might reflect a generational shift in attitudes, or positive outcomes of social policies. There should be more opportunities for people with and without ID to interact.

The profile of and subgroups within young children with autism spectrum disorder receiving early intervention in Singapore

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Aim: Young children with developmental disabilities (DD) in Singapore typically receive early intervention in one of the 17 government subsidised early intervention programs under the Early Intervention Program for Infants and Children (EIPIC) funding program. This study, which reports data from the first wave of an ongoing longitudinal study of children in EIPIC programs, seeks to describe the profile and needs of young children with autism spectrum disorder (ASD) receiving EIPIC services in Singapore, and identify subgroups needing support. Method: At least 60 preschool children with ASD preschool attending EIPIC centres in Singapore were recruited. Their developmental profile, behaviour, and functioning were assessed. Information regarding the family and other demographic information were also collected. Results: Interim analyses suggest that children with ASD may be grouped by their level of communicative and behavioural difficulties. Those with greater difficulties tend to have poorer developmental and functional outcomes. The parents of these children also report more symptoms of psychological distress. Conclusions: Children with ASD with greater communicative and behavioural difficulties may require higher intensity of support in early intervention. Their families also require higher levels of support.

Symptoms of depression, anxiety, and stress among parents of young children with developmental disabilities receiving early intervention in Singapore

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Aim: Young children with developmental disabilities (DD) in Singapore typically receive early intervention in one of the 17 government subsidised early intervention programs under the Early Intervention Program for Infants and Children (EIPIC) funding program. This study describes symptoms of depression, anxiety, and stress among parents of young children with DD receiving early intervention
in Singapore in contrast with a normative sample of similar parents in Singapore. **Method:** The Depression Anxiety Stress Scale was administered to parents of over 400 preschool children with DD attending EIPIC centres in Singapore and a normative sample comprising over 1,500 parents of preschool and primary school children. **Results:** Preliminary findings of this study suggest that parents of children with DD exhibit higher levels of depression and stress symptoms than parents of other children in preschools and primary schools. These findings are associated with the level of child support needs as well as the degree to which the family participates in the broader community. **Conclusions:** Parenting a young child with DD might have an impact upon parental mental health.

**Staff attributions about the causes of challenging behaviour in people with profound intellectual and multiple disabilities**

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**Aim:** To determine how staff attribute challenging behaviour in people with profound intellectual and multiple disabilities (PIMD), and analyse how staff attribution and working experience are related. **Method:** 195 staff and people with PIMD participated. Staff filled out the Challenging Behaviour Attribution Scale (CHABA) to explain challenging behaviour in one individual that they supported. To determine which CHABA scale staff attributed the most challenging behaviour to, significant differences in mean scores between the five CHABA scales were analysed. The relationship between the five subscales and the number of years of work experience was calculated using five Pearson’s correlation coefficients. **Results:** The mean score on the biomedical scale differed significantly from the other four models. No significant correlations between the number of years of work experience and the models were found. **Conclusions:** Staff reported the biomedical model as the most plausible explanation for challenging behaviour in people with PIMD. However the mean scores on all models are low. This might indicate that staff found none of the models particularly useful as possible explanations of challenging behaviour in people with PIMD.

**Social, psychological and behavioural functioning in Williams syndrome, Down syndrome and velo-cardio-facial syndrome: A cross-syndrome and individual difference approach**

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**Aim:** Social, psychological and behavioural issues are common in individuals with intellectual disabilities (ID), but not well understood, especially from the perspective of the individuals with ID. The primary aim was to explore the relationship between social, behavioural and mental health issues in Williams syndrome (WS), Down syndrome (DS) and velo-cardio-facial syndrome (VCFS), with a secondary, but important aim of establishing validity of self-report in these ID populations. **Method:** Parent and self-report ratings of social, psychological and behavioural functioning were collected on 60 individuals with WS, DS or VCFS aged 12 years to adulthood. **Results:** Concurrent validity between parent and self-report ratings was established (correlation coefficients as high as 0.85). Significant relations between social, behavioural and mental health functioning were found with some similarities and some differences across groups (e.g., relationships between social functioning and mental health were strongest in WS.
with correlations as high as 0.67). There was within-syndrome variability. **Conclusions:** Self-report measures can be used both clinically and in research on ID populations. Findings also clearly highlight the utility of cross-syndrome comparisons and exploring individual differences.

**Can do or does do?: Fostering awareness of numerosity in children with Down syndrome**

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**Aim:** Research suggests children with Down syndrome (DS) are delayed in the ability to discriminate magnitude, a skill that lies at the foundation of mathematical development. This study arose from a collaboration with a creative team and software designer to develop a game that would support children’s awareness of numerosity. This provided an opportunity to examine responses to magnitude across a range of tasks and raise methodological questions about interpreting the data. **Method:** Eight children with DS aged 5.5 to 9.11 years (mean age=7.25), whose raw scores on the British Picture Vocabulary Scale ranged from 25 to 69, were presented with magnitude discrimination tasks involving a card game and two iterations of an iPad game. **Results:** Group data revealed that presentations varying in ratio of 2v3 in the card game was poor, worse than ratios of 3v4 or 5v6. Performance at an individual level was variable, but only one child performed better with the iPad. **Conclusions:** Aggregating data disguises individual variation. The iPad game was motivating but fostered a number of ‘low level’ response strategies.

**Behavioural and cognitive outcomes in young children of mothers with intellectual disabilities**

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**Aim:** The aims of this study were to examine the behavioural and cognitive outcomes of children of mothers with and without intellectual disabilities (ID) in the United States; and to determine whether behavioural and cognitive outcomes were predicted by mothers’ ID or the contextual factors in which these families live. **Method:** We analysed data from the Fragile Families and Child Wellbeing Study, a nationally representative, longitudinal birth-cohort study, to examine the health outcomes of young U.S. children whose mother have (n=263) and do not have ID (n=1,298). Ordinary least square regression models were estimated, controlling for sociodemographic characteristics. **Results:** Compared to other mothers, mothers with ID were disadvantaged in terms of socioeconomic status, limited support networks, and self-reported health. Moreover, children of mothers with ID had poorer behavioural and cognitive outcomes. However, mothers’ ID did not predict children’s aggressive behaviours unless their family income was below 200% of the federal poverty level. **Conclusions:** Appropriate policies and programs must be developed and implemented to effectively support these families, such as increased financial benefits.

**Health of young children whose mothers have intellectual disabilities**

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Aim: The aims of this study were to examine the health outcomes of children of mothers with and without intellectual disabilities (ID) in the United States; and to determine whether child health outcomes were predicted by mothers’ ID or the contextual factors in which these families live. **Method:** We analysed data from the Fragile Families and Child Wellbeing Study, a nationally representative, longitudinal birth-cohort study, to examine the health outcomes of young U.S. children whose mother have (n=263) and do not have ID (n=1,298). Multivariate logistic regression models were estimated, controlling for sociodemographic characteristics. **Results:** Compared to other mothers, mothers with ID were seriously disadvantaged in terms of socioeconomic status, limited support networks, and had worse self-reported health. However, after controlling for sociodemographic characteristics, mother’s ID was not associated with a child having fair or poor health, asthma, or being overweight or obese. **Conclusions:** This study offers new evidence that young U.S. children of mothers with ID do not have adverse health outcomes in comparison to same-age children of other mothers.

Reproductive cancer treatment hospitalisations of US women with intellectual disabilities

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**Aim:** This descriptive exploratory study sought to determine the relative prevalence of reproductive cancer hospitalisations among US women with and without intellectual disabilities (ID), and to identify the characteristics of women with ID who received such treatment. **Method:** Data were drawn from the 2010 Healthcare Cost and Utilisation Project, which is nationally representative of hospital discharges. We compared hospitalisations for 1,288 women with disabilities and 499,462 women without ID across a variety of demographic characteristics. **Results:** Women with ID who were hospitalised for cancer treatment were significantly younger than women without ID, and were more likely than other women to have public health insurance coverage. Women with ID had longer mean hospital stays, and were much more likely to live in Zip code areas with low median income. Women with ID were more likely to be hospitalised for uterine cancer, and less likely to be hospitalised for cervical cancer than other women. **Conclusions:** Understanding cancer hospitalisations for individuals with ID is an important priority, particularly because of the overwhelming evidence that they receive inadequate healthcare.

Overview of interventions using video feedback to enhance interactions with people who are congenitally deafblind

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**Aim:** Video feedback approaches are becoming increasingly common in interventions aimed at improving interactions and communication with people with complex communication needs. How these approaches are being applied is not well understood. A review of current literature on video feedback interventions with people with severe developmental delays due to congenital deafblindness will be presented. **Method:** A systematic review of literature relating to video feedback interventions aimed at improving social interactions with people with congenital deafblindness was undertaken. The literature was analysed in terms of intervention procedure, setting, participant demographics and outcome.
measures. **Results:** A variety of video feedback interventions are being used with all age groups of people with congenital deafblindness in varied settings and with varied communication partners. Preliminary data reveals positive outcomes including increased affective involvement, more sustained interaction and shared understanding. Issues including sustainability of approaches and their effects were also identified. **Conclusions:** While results of a systematic literature review on video feedback interventions revealed positive outcomes, recommendations for both practice and future research are made.

**Tolerating uncertainty: Perceptions of the future for aging parent-carers and their adult children with intellectual disabilities**

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**Aim:** Improved life expectancy and access to healthcare means that more adults with Intellectual disabilities (ID) are living with aging parents. This study aimed to explore older families’ perceptions of the future. **Method:** Semi-structured interviews were conducted with nine older parent-carers and three adult-children with ID. Data were analysed using a grounded theory approach. **Results:** ‘Tolerating uncertainty’ was the overarching category, which captured participants’ attempts to manage anxieties about the future. It encompassed sub-categories of ‘accepting the parenting role’; ‘facing challenges’; ‘being supported versus being isolated’; ‘positive meaning-making’; ‘re-evaluating as time moves on’; and ‘managing future thinking’. Adult children participants expressed some thoughts and preferences for their future which were in contrast to their parents’ views and wishes. Their opinions provide a unique perspective that has often been neglected in research. **Conclusions:** This research has found commonalities in how families tolerate the uncertainty of the future, but also unique differences that require tailored interventions and a proactive approach from services.

**Exploring dementia and people with intellectual disabilities**

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**Aim:** In recent years, the life expectancy of people with intellectual disabilities (ID) has sharply risen, leading to an increase in dementia. Dementia has serious consequences for the individual and those around them. This presentation discusses a study in progress which explores the experiences of persons with ID and dementia, and their carers. **Method:** Semi-structured interviews were conducted across four participant groups: persons with ID and dementia, family carers, professional carers, and healthcare professionals. Data is being analysed through constructivist grounded theory. Opportunities were taken to collaborate with persons with ID throughout the design of the research to make it more inclusive. **Results:** The challenges of carrying out research with a hard to research population will be discussed, alongside preliminary results across all four groups. **Conclusions:** This study will contribute knowledge to a small field of research, and raise awareness of the benefits and challenges of trying to be inclusive, and the methods used throughout.
Identifying attachment disorders by using the Diagnostic Guideline for Anxiety and Challenging Behaviour

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Aim: People with intellectual disabilities (ID) often have a multitude of problems due to the combination of cognitive impairments, psychiatric disorders (particularly anxiety) and related challenging behaviours (CB). This study evaluates the quality of the psychiatric diagnoses and treatment plans after using the Diagnostic Guideline for Anxiety and CB that was developed to support professionals in their diagnostic tasks. Method: A comparative multiple case study with an experimental (n=29) and control condition (n=30) was conducted, applying deductive analyses of diagnoses and treatment plans. Results: The number of diagnostic statements and planned treatment actions in the experimental group was significantly larger and more differentiated than in the control condition. In the experimental group, the diagnosis of anxiety disorder was identified in 20 persons (pre-test: 4) and attachment disorder in 5 persons (pre-test: 0). Anxiety disorder was identified in 10 persons in the control group (pre-test 6). There was no difference between pre and post tests for attachment disorder. Conclusions: Working with the Diagnostic Guideline for Anxiety and CB leads to improved psychiatric diagnoses and treatment plans compared with care as usual.
Being in two minds: Staff’s perspectives of paperwork in group homes for people with intellectual disabilities

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Aim: Paperwork is an important technology in group homes for people with intellectual disabilities. This study explored frontline staffs' perceptions of paperwork in two Australian group homes. Method: Researchers used a constructivist grounded theory methodology. Data were collected from nine group home staff (1 supervisor and 8 support workers) using semi-structured interviews and observations. Open and focussed coding was used to identify participants' perception of paperwork. Results: Participants described being in two minds about paperwork; considering it a useful yet problematic technology in group homes. They described paperwork as having particular characteristics and used these to evaluate the usefulness of different pieces. Conclusions: Frontline group home staff actively evaluate paperwork technologies in their workplace. Understanding staff perceptions of paperwork might better enable it to be better designed or help better equip staff with meaningful technologies to provide good resident support, rather than paperwork detracting staff from their core work of providing support to residents.

Effects of online mentoring on social media use to enhance social networks of young people with developmental disabilities in rural South Australia

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Aim: Does online mentoring further develop social media skills learnt during home-based intervention and thus enhance social networks? Method: Seven young people with developmental disabilities living in rural South Australia were mentees (mean age=16.58 years). Two young people with disabilities (aged 19 and 23 years) were trained as peer mentors. The four month e-mentoring programme followed a home-based intervention to learn social media skills. The Goal Attainment Scaling was used to develop mentee goals to improve social networking and to measure progress. One-to-one and group support was provided by mentors through online social media. Online conversations were captured. Mentors, mentees and their parents were interviewed before and after the mentoring programme to capture expectations, benefits and challenges. Results: All mentees achieved at least one goal at the expected level, although overall goal attainment was below the expected score (Mean T score=45.57, SD=14.05). Mentees and their parents felt the mentoring programme had enhanced social connections. Conclusions: Online mentoring can complement face-to-face support in developing social media skills and social connectedness of young people with disabilities.

‘It’s helped me connect with more friends’: Impact of social media training on the social networks of rural youth with disabilities

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Aim: Does social media training enhance the social networks of young people with developmental disabilities living in rural communities? **Method:** 17 young people (mean age=16.25 years) with intellectual disabilities (ID) or autism spectrum disorder (ASD) participated. The Goal Attainment Scaling was used to develop personalised goals. Pre and post measures were obtained using the Canadian Occupational Performance Measure (COPM) for performance and satisfaction in aspects of social media use; the Circles of Communication Partners tool mapped the number and type of offline and online communication partners. An individualised home intervention including appropriate assistive technology was provided. Participants and their parents were interviewed post-intervention regarding their views of the benefits and challenges of the intervention. **Results:** Mean self-rated performance and satisfaction with performance on COPM increased post-intervention. Wilcoxon signed ranks showed significant increases in Circle 6 (online communication partners, p=.001). Perceived improvements to speech, literacy, confidence and independence in social media use were reported by parents and participants. **Conclusions:** Individualised training can significantly improve social media skills of young people with disabilities living in rural areas and enhance their social networks.

**Home-based occupational therapy for adults with Down syndrome: A systematic review**

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**Aim:** Adults with Down syndrome (DS) have an increased risk to develop younger onset dementia which may impact on their participation in activities of daily living (ADL). This systematic review aimed to assess whether home-based occupational therapy (OT) maintains or restores the level of performance in ADL in adults with DS. **Method:** A systematic electronic search of databases using DS and OT as keywords was conducted. Studies with a home-based intervention provided or supervised by occupational therapists were included. Two reviewers independently extracted data and evaluated the methodological quality. **Results:** From 1471 titles and abstracts yielded by the searches, only one study fulfilled the inclusion criteria. Findings from a single case study indicated an overall improvement in the level of performance in undisclosed ADL tasks. **Conclusions:** This review underscores the need for more primary studies investigating home-based OT in adults with DS as there is limited data to support the effectiveness of home-based OT to maintain or restore the level of performance in ADL in adults with DS. This research gap can be closed by investigating this topic further in the future.

**Teaching without personal helpers: Exploring classroom interaction of pupils with autism spectrum disorder**

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**Aim:** This study explores the interaction in a special education class with pupils with autism spectrum disorder (ASD) in a Finnish comprehensive school. The aim is to describe what pedagogical consequences emerge, if the teacher and the pupils are interacting through direct communication and interaction in situations, in which pupils’ personal helpers are not present. **Method:** The data consists of video recordings of authentic educational situations in which six pupils with ASD and their teacher are
The interview of the teacher concerning these situations was also available. The data are mainly analysed through applied conversation analysis. **Results:** The interaction increased and was more vivid, and the teacher felt she could better reach the pupils without go-betweens (personal helpers). Interactions with peers also increased. **Conclusions:** The results are intertwined with the activity of the teacher and stress the significance of quality and a pupil-sensitive teaching style (dynamic sensitivity) in the special education context. Dynamic sensitivity draws on the teacher’s personal and professional attributes, teaching experience and tacit knowledge.

**Antipsychotic drug prescription practice in healthcare for people with intellectual disabilities: Treatment policies and monitoring of treatment effects and side-effects**

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**Aim:** This study compares antipsychotics prescription practice of Intellectual Disability (ID) physicians and psychiatrists to existing national and international guidelines in ID medicine. **Method:** A self-designed checklist was used to audit pharmaceutical and medical files of clients of ID service providers in the North of the Netherlands. The checklist was based on available national and international guidelines, and a literature review. **Results:** Antipsychotics were in the majority prescribed for more than one year and for challenging behaviour. In 60%, there was a co-morbid diagnosis of autism. Approximately half of the cases also received non-pharmacological treatment before or during use. Effects on target symptoms were almost never evaluated. In a majority, the type of antipsychotic and dosage changed during treatment. Extrapyramidal and autonomic symptoms were monitored annually in 10-20%, blood counts in 20%, weight in 70%. Prolactin was never evaluated. In 50% discontinuation was considered. **Conclusions:** Most prescriptions of antipsychotics in people with ID were not for psychosis. Monitoring of efficacy and side-effects, and providing non-pharmacological treatments was insufficient. Prescriptions were mostly long-term, although discontinuation was considered in half of the cases.

**Facilitators and barriers in providing appropriate healthcare to people with intellectual disabilities who chronically use antipsychotics**

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**Aim:** The aim of this study was to establish facilitators and barriers in adherence to guidelines and recommendations in prescribing antipsychotics in people with intellectual disabilities (ID) in the Netherlands. **Method:** In-depth interviews with ID-physicians, psychiatrists and behavioural therapists were used to evaluate facilitators and barriers in adherence to guidelines and regulations. These interviews were based on a questionnaire discussing organisational factors (decision-making process, division of responsibilities, logistics, regulations, support of colleagues and supervisor), caregiver attitudes (knowledge, involvement, expectations and ability to change), and facilitating conditions (Electronic Patient Files; and financial, material and administrative support). **Results:** Barriers were limited knowledge of staff and workload. In contrast, the Electronic Patient File facilitated the exchange
between colleagues about the treatment. Overall, collaborations and discussions with colleagues in and outside the organisation were facilitators. **Conclusions:** There is a need for creating more administrative and technological support for reporting on the care provided to people with ID who use antipsychotics. Furthermore, interdisciplinary collaborations with colleagues should be encouraged and further integrated in care provision.

**Mental health difficulties from childhood to early adulthood among those with borderline intellectual functioning: Results from a Finnish birth cohort**

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**Aim:** While existing studies have shown higher rates of mental health difficulties in young adults with borderline intellectual functioning, there is limited longitudinal research examining mental health earlier in life. We compare rates of mental health problems in childhood and adolescence between those with and without borderline intellectual functioning. **Method:** Using subsample data from the Northern Finland Birth Cohort 1986 (NFBC 1986), we compared individuals with borderline intellectual functioning in young adulthood to those without. We compared rates of difficulty at age 7 years (Rutter scale) and at age 16 years (PROD-screen and Youth Self Report) using logistic regression controlling for gender. **Results:** Overall those with borderline intellectual functioning showed broadly similar rates of psychiatric difficulties during childhood and adolescence to those of higher intelligence. However, those with borderline intellectual functioning showed higher odds of antisocial traits in childhood (OR=1.96, 95% CI: 1.11-3.46). **Conclusions:** We showed broad similarity between those with and without borderline intellectual functioning in terms of childhood and adolescent mental health. This suggests differences may arise later or they may not be present in all contexts.

**Online training: Dissemination of an evidence-based intervention for children with autism spectrum disorder and intellectual disabilities across Australia**

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**Aim:** Emotion-based Social Skills Training (EBSST) is an evidence-based intervention which improves emotional competence, social skills and mental health in school-age children with autism spectrum disorder (ASD) and intellectual disabilities (ID). Currently, health, education and disability practitioners are accredited to provide EBSST following 2-day EBSST facilitator training. The current translational research project aimed to facilitate wide-scale, cost-effective uptake and dissemination of EBSST by developing online EBSST facilitator training. **Method:** Participants were 60 school counsellors from New South Wales’ Department of Education schools who completed the EBSST 2-day facilitator training. Knowledge, skills and confidence to complete EBSST were assessed. Health, education and disability practitioners were then surveyed on preferences for models of EBSST training. A sub-set of this group was selected to participate in user testing of EBSST online training. **Results:** EBSST 2-day facilitator training provides ‘gold standard’ training in EBSST implementation. Online training is also a viable option for training EBSST facilitators. **Conclusions:** Translation of EBSST for children with ASD and ID into routine educational and clinical practice can be facilitated by flexible models of facilitator training.
Importance of locus of control in treating the mental health of offenders with intellectual disabilities

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Aim: Research has shown low cognitive ability, low adaptive functioning, childhood trauma history and an externalising self-appraisal could contribute to poor mental health in offenders with intellectual disabilities (ID). This study investigates whether locus of control (LOC), a type of self-appraisal, mediates the relationships between cognitive ability, adaptive functioning and a childhood trauma history with mental illness. Method: 79 offenders with and without ID were recruited from correctional centres in New South Wales and assessed for cognitive ability, adaptive functioning, childhood trauma history, mental health status and LOC. Mediation analyses were conducted between all variables with LOC as mediator and mental health as the outcome variable. Results: LOC mediates the relationship between cognitive ability and adaptive functioning with mental health. LOC partially mediates the relationship between specific types of childhood trauma and mental health. Conclusions: Externalised LOC contributes to a stronger relationship between low cognitive ability, adaptive functioning, childhood trauma and poor mental health. This relationship is more significant for offenders with ID. This indicates psychological interventions internalising LOC could contribute to improved mental health in this vulnerable population.

Bowel cancer screening and people with intellectual disabilities: Establishing principles for good practice initiatives

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Aim: To explore why people with intellectual disabilities (ID) do not access the UK bowel cancer screening programme and to establish principles of good practice. Method: We held a focus group to consult with six people with ID (4 men, 2 women), an advocate and two specialist nurses from a local hospital National Health Service Trust to explore the issues. Data were collected using flip charts and drawings, and thematically analysed. Results: Whilst the primary aim of the co-production meeting was to learn from persons with ID about accessing bowel cancers screening, reciprocal learning was evident. People had a thirst for knowledge around cancer generally and bowel cancer specifically, and whilst they had a number of professionals to address their health questions, they fully maximised this opportunity. Co-production can ensure that research is ‘fit for purpose’. Conclusions: Co-production is the essence of developing good processes and can be the focus of research; it helped to identify the barriers to bowel cancer screening and highlighted a number of principles of good practice.

Loss in the forensic setting: Exploring perceptions from people in a secure environment in the UK

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Aim: Losses associated with living in restricted environments are diverse, yet there is limited empirical research that explores the loss experience of people with intellectual disabilities (ID) living in secure...
forensic environments. The aim of this study was to understand the nature and impact of these losses so that recommendations for future practice in forensic settings could be identified. **Method:** A grounded theory study was designed and conducted to generate a framework about the loss experiences of persons with ID in a low secure environment. Semi-structured interviews with eight persons with ID were conducted. Ethical approval was granted from NHS and University Ethics committees. **Results:** Data analysis revealed a series of critical interactions, primarily involving loss, being heard and identity. Whilst loss was perceived as an everyday occurrence, it was also an historical fact from the past. **Conclusions:** The importance of therapeutic work around loss with people with ID in a low secure environment is not to be underestimated; thoughtful and compassionate approaches to supporting this population in this setting are required.

The development of European consensus norms for palliative care of people with intellectual disabilities: An EAPC White Paper

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**Aim:** To develop consensus norms for palliative care of people with intellectual disabilities (ID) in Europe. **Method:** Following norms agreed by a steering group of 14 experts from nine countries, Delphi methods were used to assess cross-country agreement via an electronic survey; incorporating invitations to provide additional comments to each norm. The norms were accepted if there was sufficient agreement among all respondents (80% or more). **Results:** The draft norms consisted of 52 items in 13 categories, including (for example): equity of access, communication, assessment of needs, symptom management. 80 usable survey responses were received from 17 European countries. There was strong consensus among survey respondents, with none of the items scoring less than 86% agreement. The norms have received approval from the European Association for Palliative Care board of directors. **Conclusions:** The aspirational norms described in this White Paper serve as accepted guidelines for best practice across Europe. Further study is needed to assess the barriers and enablers to achieving these consensus norms throughout Europe.

Drooling in children with cerebral palsy with and without intellectual disabilities

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**Aim:** To compare the prevalence of drooling and the uptake and outcome of saliva control interventions in children with cerebral palsy (CP) with and without concomitant intellectual disabilities (ID). **Method:** Self-report questionnaires on drooling were sent to 522 families via the Victorian Cerebral Palsy Register. Parents/carers reported on excessive drooling after age 4 years for a representative sample of 385 (81%) children with CP aged 7-14 years, saliva control interventions undertaken, and improvements noted. Demographic and clinical information were extracted from the register. **Results:** Children with concomitant ID had a higher frequency of drooling (55% vs 32%), irrespective of gender, motor type and motor topography. One third of families had accessed interventions for drooling but no significant group differences were noted in the uptake of interventions. Two-thirds of children were reported to have
improved following at least one intervention, irrespective of ID. **Conclusions:** Drooling is a common problem experienced by children with CP, particularly those with associated ID. Specific surgical, medical, and behavioural interventions can be helpful in reducing the impact of this often distressing problem.

‘Adults with P Plates’: Conceptualisations of adulthood for young people with intellectual disabilities

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**Aim:** To compare and contrast conceptualisations of adulthood as they apply to young people with intellectual disabilities (ID) and to explore incompatibilities as a possible cause of tension between stakeholders during the transition to adulthood. **Method:** Qualitative research included focus groups and semi-structured interviews with parents, disability support staff and young people with ID. This produced data that was conceptually and thematically analysed using an ongoing iterative process. **Results:** Five major general dimensions were identified: adults are independent beings; adults are rational beings; adults are accepted members of society; adult life offers meaning; and adulthood may be actual (real) or virtual (projected). Each dimension offered potentially incompatible conceptualisations between parents and staff. Young people with ID saw themselves as ‘not quite adults’ but ‘adults with P plates’. **Conclusions:** There is no adequate definition of adulthood for use by families, disability staff and young people with ID, thus tensions exist between stakeholders during transition beyond secondary schooling as a result of different perceptions of these young people as adults or otherwise.

Developmental, adaptive, social and behavioural functioning in young children with Williams syndrome and its relation to family environment

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**Aim:** Increasing emphasis on family-centred approaches to services and supports for families of children with neurodevelopmental disorders has highlighted the importance of accountability for family environment risk factors. The primary aim of the study was to assess the relationship between family environment characteristics and neuropsychological (developmental, adaptive, social and behavioural) functioning in young children with Williams syndrome (WS). **Method:** Parent report ratings and performance-based neuropsychological measures were collected on 24 children with WS (chronological age range=2.2 to 7.7 years, M=4.62, SD=1.59) and 70 typically developing controls (range =2.3 to 7.9 years, M=4.54, SD=1.54). **Results:** In line with predictions, neuropsychological functioning was significantly correlated with family environment characteristics in both WS and controls, although some differences emerged across the two groups. **Conclusions:** Increased participation in social and recreational activities within the family is associated with better neuropsychological functioning in both groups (e.g., executive function and adaptive abilities in WS, and language, psychological, and social abilities in controls).
Emerging behavioural and psychological profile in young children with Williams syndrome

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Aim: This study assessed behavioural and psychological functioning in young children with Williams syndrome (WS). The aims were to profile behavioural and psychological functioning; and investigate the relationship between behavioural and psychological functions with demographic and cognitive variables (gender, chronological age, developmental level and executive function). Method: Parent report ratings and performance-based measures of behavioural, psychological, developmental and executive functioning were collected on 24 children with WS (chronological age range=2.2 to 7.7 years, M=4.62, SD=1.59), and 70 typically developing controls (range=2.3 to 7.9 years, M= 4.54, SD=1.54). Results: In line with predictions, the prevalence of behavioural and psychological difficulties were significantly higher in WS than in controls, but there was individual variation; and gender, chronological age, level of development and extent of executive dysfunction were significantly related to several behavioural and psychological characteristics. Conclusions: Practical and clinical implications of these findings will be discussed, and our findings will also be compared to older children and adults with WS.

A population-based study of cerebral palsy

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Aim: To use a population-based register to describe the epidemiology of cerebral palsy (CP), including trends in prevalence, clinical profiles, and secondary musculoskeletal problems. Method: Active surveillance methods were used to identify 2966 individuals with CP born in Victoria, Australia, between 1983 and 2009. Demographic, perinatal, and clinical data were collected from individual’s medical records. We tabulated and plotted yearly rates and assessed differences in trends between impairment severity groups. A smaller 3-year cohort was used to assess the association between hip displacement and motor function. Results: Following increasing rates of CP during the 1980s, rates declined at all birth gestations from the mid-1990s. Rates were preferentially decreased in subgroups with severe and bilateral CP (p<0.005). A linear relationship was observed between level of gross motor function and presence of hip displacement. Conclusions: CP is the most common physical disability of childhood; intellectual disability is a common co-morbidity. Longitudinal population-based CP registers can provide valuable insight into health service delivery needs, data to support the development of clinical guidelines, and ‘real-world’ evidence for the effectiveness of innovations in perinatal practice.

The epidemiology of intellectual disabilities in cerebral palsy

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Aim: To describe the epidemiology of intellectual disabilities (ID) in people with cerebral palsy (CP). Method: Population-based cross-sectional data for a 1999–2008 birth cohort (n=1141) were used to assess the frequency of ID (IQ<70) and strength of associations between ID and mobility, epilepsy, vision, hearing, communication, and neuroimaging pattern. Survival analysis and assessment of trends
were performed in a 1981-2010 longitudinal cohort (n=3250). **Results:** ID was present in 45% of the cohort and was associated with non-ambulatory status (47% vs 8%), later walking (mean 2.6 vs 1.8 years), hypotonic (8% vs 1%) or dyskinetic (9% vs 5%) CP, a quadriplegic pattern of spasticity (42% vs 5%), epilepsy (52% vs 12%), blindness (8% vs 0%), bilateral deafness (8% vs 1%) non-verbal communication (55% vs 5%), and reduced 30-year survival (97% vs 77%). ID was associated with grey matter injuries (13% vs 6%), malformations (18% vs 6%) and miscellaneous neuroimaging patterns (12% vs 4%). Between 1981 and 2010 there was a gradual decrease in the proportion of the CP cohort with ID. **Conclusions:** ID adds substantially to the overall medical complexity in people with CP.

**Hospital admissions in children with cerebral palsy: Does intellectual disability matter?**

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**Aim:** To understand how intellectual disability (ID) affects the frequency, type and characteristics of hospital admissions in children with cerebral palsy (CP). **Method:** Data pertaining to hospital admissions of a population-based CP cohort were obtained by linking the Victorian CP Register and the Victorian Admitted Episodes Dataset. **Results:** Children with CP (n=1,748) had 11,155 admissions to Victorian hospitals between 2007 and 2014. Overall, 83% of the CP cohort had ≥ 1 admission during this time. After controlling for severity of motor impairment, the proportions of children that had ≥ 1 admission were similar in the groups with and without ID. In groups stratified on motor impairment severity, hospital admissions in those with ID were more likely to be classified as emergency and multiday, compared to admissions in children without ID. Among those with a severe motor impairment, compared to children without ID, a higher proportion of admissions in those with ID were due to respiratory illness (21% vs 14%). **Conclusions:** The type and characteristics of hospital admissions in children with CP vary between children with and without ID.

**Social well-being for persons with autism spectrum disorder receiving assistance allowance**

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**Aim:** The aim of the study was to analyse the experienced social well-being among persons with autism who receive assistance allowance from the Swedish Social Insurance Agency. **Method:** The social well-being outcomes studied were social contacts, whether ‘living as others’, feeling safe, having control over one’s life and good living conditions. Logistic regression was used for the analysis. The population consisted of a survey panel of 2740 persons over 16 years of age receiving assistance allowance in Sweden, of which 479 persons were reported to have an autism spectrum disorder (ASD). **Results:** A strong relationship was found between ASD and social contacts, whether ‘living as others’ and receipt of personal assistance. In multivariate analyses the relationship between ASD and social contacts became stronger for men only. **Conclusion:** Men with ASD seemed to experience better social well-being compared to women, especially when the models were adjusted for other factors. It remains to be studied if personal assistance provided is gender-biased.
Conversation strategies and systems analysis: A tool to identify 'hot spots' in conversations where augmentative and alternative communication is used

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Aim: Identification of communication partners’ conversational strategies in the context of dynamic systems. Method: To highlight what makes the communication partner role easy/tricky, communication partners participated in one or more of the following: survey (demographic, role and future needs data) and recorded conversations between a communication partner and a person with Rett syndrome (RS), Down syndrome (DS) or cerebral palsy (CP). Results: Survey data (n=74) complemented and extended literature findings. Video transcription/data coding of 6 dyadic interactions between a communication partner and someone with RS, DS or CP highlighted the need for a tool identifying more than discourse strategies. Conversation strategies and systems analysis (CSSA), applied by the author and research team, identified a variety of conversation styles which may be specific to disability types and interaction outcome being accelerated (fostered) or distracted (hindered). Some of these elements were identified in the narratives from the 24 communication partners. Conclusions: CSSA proved a valuable tool to identify conversation strategies and systems. Focal points for communication partner training beyond the boundaries of discourse were highlighted.

How is successful aging defined for people with intellectual disabilities?

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Aim: The aims of this study are to define successful aging in ID and to explore areas of successful aging in people with ID. Method: Three areas of successful aging including absence of disease and risk factors; active engagement in life; and intact physical and cognitive functions were examined in people with ID from the Successful Aging in Intellectual Disability sample. Data were collected by survey completed by carers of people with ID over the age of 40 and analysed with descriptive statistics and general linear modelling. Results: 117 individuals with ID were included. High rates of diabetes (17%) and obesity (42%) were observed. The majority of the sample (76.4%) participated in passive leisure activities like watching TV whereas a minority (15%) were physically active on a regular basis. Conclusions: Health promotion programmes tailored to people with ID consisting of exercise and health education are needed to shape more positive attitudes towards exercise and improvements in psychosocial outcomes.

Social Quality Theory: A paradigm for quality assurance in person-centred self-determined disability employment

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Aim: Social Quality Theory (SQT) may provide an evidence-based framework for developing an effective employment outcome measure for people with disabilities seeking employment in a variety of community settings. This study examines existing evidence and determines the gaps in research
concerning the use of SQT as an employment outcome measure. **Method:** A systematic review of peer reviewed journals available online was undertaken using the following key words: disability employment, quality of life (QoL), and SQT. **Results:** 52 relevant papers were identified. SQT measures QoL outcomes in the social domains of socio-economic viability, social cohesion, social inclusion and social empowerment. SQT provides extended quality assurance to current disability employment models leading to possible improved sustainable outcomes. **Conclusions:** SQT is a valid framework for quality assurance of person-centred self-determined employment planning. SQT based outcome measures ensure the client remains central in employment planning and gives primacy to QoL outcomes.

**Sleep disorders and painful health conditions in children with autism spectrum disorder, Smith-Magenis syndrome and Angelman syndrome**

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**Aim:** Sleep disorders are common in individuals with intellectual disabilities (ID). Pain and painful health conditions, whilst often under-identified and under-treated, are also purported to be frequent. There is emerging evidence of a bi-directional relationship between painful health conditions and sleep disorders; this association warrants further investigation. **Method:** Questionnaire data were collected on pain-related behaviour, painful health conditions and sleep quality in children with autism spectrum disorder (ASD), Smith-Magenis syndrome (SMS) and Angelman syndrome (AS). These data were augmented through week-long actigraphy and carer-rated daily pain scores for children with ASD (N=20), SMS (N=20) and AS (N=20). **Results:** Sleep disordered breathing (rs=.53, p=.002) and parasomnias (rs=.36, p=.049) were associated with the presence of painful health conditions in children with AS. Symptoms of gastrointestinal reflux were associated with poorer sleep quality for children with ASD (rs=.58, p=.001), SMS (rs=.63, p=.004) and AS (rs=.37, p=.038). Higher daily pain scores were associated with more disrupted sleep (p<.01). **Conclusions:** Pain and painful health conditions are associated with poor sleep in children with ID. Painful health conditions should be assessed and treated within sleep interventions.

**Understanding the culture of supported accommodation for individuals with severe/profound intellectual disabilities: Preliminary findings from ‘good’ services**

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**Aim:** Bigby et al. (2009, 2012, 2015), have begun to conceptualise the staff culture of group homes for individuals with severe/profound intellectual disabilities (ID). This has only been explored in ‘poor’ and some ‘better’ homes in Australia; as such, there is a need to explore how well the framework applies to services that are delivering good quality of life outcomes. This paper presents the preliminary exploration of staff culture in ‘good’ shared supported accommodation settings. **Method:** Three homes for people with severe/profound ID, where quality of support and outcomes had been confirmed as good through initial structured observations, were recruited from three organisations in the UK. Field notes from participant observations are analysed. **Results:** Preliminary evidence supports Bigby et al.’s framework of informal culture. **Conclusions:** Implications for the remaining observations and interviews
with senior management will be discussed along with preliminary indications of how organisations might be able to develop cultures that promote good outcomes for people with severe/profound ID.

Meanings of sisterhood and developmental disability: Narratives on the intersection of race and disability from African American non-disabled sisters

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Aim: This study is an expansion of work by McGraw & Walker (2007) to better understand how non-disabled sisters understand themselves and their siblings within sociocultural systems that dictate meanings of being a ‘good’ woman and a ‘normal’ person. It focusses primarily on African American women in order to gain an alternative perspective of women from a culturally and racially different population. Method: Nine Black/African American women 18 to 46 years of age participated. Siblings ranged from ages 17 to 32 years. All participants grew up in the south eastern region of the United States. A critical thematic analysis was used. Results: Six themes emerged: beliefs about the sibling; beliefs about the self as a sister; family experiences; intersections of race and disability; closeness of the relationship; and ideas of normality and difference. Conclusions: Sisters serve as major contributors in lives of women with disabilities. Race plays a role in life experiences that may differ from other racial groups; this needs to be considered when providing resources for diverse families.

Does intolerance of uncertainty contribute to insomnia symptoms in young people with autism?

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Aim: Insomnia is a common co-morbid condition in autism; knowledge of factors related to development and maintenance of insomnia will lead to improved interventions. Anxiety, depression, and sensory sensitivity (SS) are reported as associated with insomnia, while recent research indicates that intolerance of uncertainty (IU) mediates the relationship between SS and anxiety. Our aim is to examine if IU also contributes to insomnia. Method: To date, 38 young people (15-24 years) with autism participating in an ongoing longitudinal study have completed standardised sleep, depression, anxiety, SS, and IU questionnaires. Relationships between these scales and sleep were examined using Pearson correlation and then partial correlations, separately controlling for SS and then IU. Results: Sleep was strongly correlated with all measures (all p<.01). Controlling for SS, anxiety and IU were only moderately correlated with sleep (all p<.05); the depression correlation remained strong (p<.001). Controlling for IU, only the depression correlation remained and it was strong (p<.001). Conclusions: IU contributes significantly to insomnia in autism, and may account for relationships between anxiety, SS and insomnia. Implications for early intervention for insomnia are discussed.

Song versus speech with the hard to reach: Investigating interaction approaches with individuals with profound intellectual and multiple disabilities

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Aim: Interaction has an impact on quality of life. Papousek (1991) suggested that the song-like tonal qualities of ‘motherese’ facilitated interaction with infants. The project explores the extent to which song (rather than speech) elicits different response behaviours in interaction with individuals with profound intellectual and multiple disabilities (PIMD). Method: The 10-month study used single subject research methodology (ABAB design); it included five children (mean age=11.4 years) who had PIMD and low social tolerance. Interactions were video-recorded and micro analysed using individual behaviour observation codes. Interactions were presented as event graphs with a written description. Results: Consistent patterns of communicative behaviours were identified. Song was associated with more positive facial expressions (smiles), higher levels of social tolerance (to touch and proximity), and improved communicative responses (eye contact, vocalisations, and coordinated actions). Conclusions: This project supports current practices of singing as an interaction approach (where contextually relevant and suited to individual preferences). It offers an original contribution to the field by demonstrating that song can elicit different behavioural responses from individuals with PIMD.

Inclusive university experience: Perspectives of students with intellectual disabilities and their mentors

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Aim: Participation in university can have positive personal, social, and academic outcomes; however, little is known about outcomes of inclusive university programmes for people with intellectual disabilities (ID). This study investigated expectations and experiences of students with ID participating in an inclusive university programme. Peer mentors’ perceptions of the students’ experience were also explored. Method: Three auditing students and six peer mentors (n=9) participated in semi-structured interviews and questionnaires at two time points throughout one academic semester. Participants provided insight to their experiences of: mentoring relationships, inclusive practices, self-determination, goal attainment, and skill development. Thematic analysis was used to analyse qualitative results. Results: Four major themes and several subthemes were identified by auditing students and mentors including: self-determination (e.g. increased self-confidence/ independence); social development (e.g. enhanced social networks/ adopting university norms); intellectual development (e.g. knowledge of chosen subject); and inclusive practices (e.g. amongst peers and university staff). Conclusions: Students with ID and mentors felt it is possible for people with ID to develop personally, socially, and academically through meaningful involvement in an inclusive university.

Assessment of trauma history and post-traumatic stress disorder in people with intellectual disabilities

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Aim: Awareness for the necessity of research of trauma-related disorders in people with intellectual disabilities (ID) has been rising over the last two decades. Findings show a higher prevalence of abuse in people with ID, indicating a special vulnerability for long-term and multiple abuse. Moreover, post-
traumatic outcomes go beyond those of neurotypical people, making symptoms rather comparable to complex post-traumatic stress disorder (PTSD) than PTSD. Conventional assessment instruments are only partially applicable. There exist different approaches to assess trauma history and PTSD in the ID population. We aim to identify best-practice assessment. **Method:** We are conducting expert-interviews including all relevant stakeholder groups providing care for people with ID by using a Delphi method. Questions refer to the usefulness and feasibility of conventional assessment methods for trauma history, PTSD and complex PTSD, including the ICD-11 Trauma Questionnaire, measures for children and the ID-specific measures IES-ID and TIF. **Results:** This paper will present findings from the Delphi process on assessment methods in the population with ID. **Conclusions:** The research plan for assessment possibilities will be discussed.

**Exploring the association between family functioning and sleep problems in children with autism spectrum disorder: A pilot study**

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**Aim:** Children with autism spectrum disorder (ASD) often experience persistent sleep problems that are associated with a number of negative outcomes both for the child and the family. This study examined the association between sleep problems in children with ASD and family functioning. **Method:** 45 parents of children (6 to 12 years old) with a diagnosis of ASD were included. Parents completed the Children’s Sleep Habits Questionnaire (CSHQ), the Parenting Stress Index Short Form (4th edition) and the Family Adaptability and Cohesion Evaluation Scale (FACES IV). **Results:** Parents reported very high levels of sleep problems, parenting stress, rigid family functioning and low levels of family satisfaction. Rigid family functioning was significantly associated with sleep problems in children with ASD. **Conclusions:** Rigid family functioning may be an adaptive response to the child’s need for routine, predictability and consistency; however, it is also a characteristic feature of the broad autism phenotype. Rigid functioning, therefore, may signal families at greater risk for sleep problems.

**Measuring behaviour problems in young children with autism spectrum disorder and global developmental delay: Data from an adaptation of the Developmental Behavior Checklist- Under 4 (DBC-U4) in a large sample**

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**Aim:** Despite the importance of studying behaviour problems (BPs) in the field of autism spectrum disorder (ASD) and global development delay (GDD), significant challenges remain due to a lack of evaluation tools available and adapted for young children. This study uses an adaptation of the Developmental Behavior Checklist Under-4 (DBC–U4) to evaluate BPs in young children (2 to 7 years) with ASD and/or GDD. **Method:** 561 children (74.15% boys, 25.85% girls; average age=58 months) were included. The presence of BPs in each group was described and exploratory factor analysis used to examine relationships between BPs and different factors. **Results:** ANOVA results (p<0.0001) indicate that children with ASD have more BPs than those with GDD (M=90.8 vs. 56.3), but the group of children with both ASD and GDD has the most frequent and severe BPs (M=100.7). Boys exhibit more BPs than
girls (M=90.2 vs. 76.7; p<0.001). No statistically significant differences were found in terms of ages.

**Conclusions:** A new research project is underway to evaluate the efficacy and the effectiveness of a specific intervention to improve the quality of life of families with children with BPs.

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**New definition of universal accessibility for everyone**

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**Aim:** The concept of universal accessibility is often used, however the definition remains unclear which makes it difficult to apply in the context of product development in the field of intellectual disabilities. The aim of this study was to clarify and provide an operational definition of universal accessibility.

**Method:** A thorough literature review with conducted and content analysis performed on 150 documents using this concept and synonymous terms.

**Results:** We identified 32 different definitions of the concept of universal accessibility, covering a total of eight terminology requirements, while none indicated more than five. This analytical work has led to a new operational definition which covers eight terminology requirements: what is it, applied to what, the goal, in which context, for whom, to do what, how, and why. **Conclusions:** These clarifications are proposed as a framework for product developers and researchers, in particular in universal design for learning. This new definition of universal accessibility is less restrictive and more complete compared to previous definitions.

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**Foetal alcohol spectrum disorder: A problem to solve**


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**Aim:** Foetal alcohol spectrum disorder (FASD) is one of the leading preventable forms of intellectual disabilities. FASD is one hundred percent preventable and is associated with levels of alcohol consumption during pregnancy. Although FASD affects communities worldwide, little is known about the prevalence rates of FASD worldwide. **Method:** We conducted several unmoderated and moderated meta-analyses to report accurate FASD prevalence estimates and differences per country. **Results:** Data revealed that FASD prevalence estimates were available for 10 countries including Australia, Canada, Croatia, Italy, New Zealand, South Africa, and Unites States. Substantial heterogeneity was observed among the reported samples. This variation could partly be explained by geography. **Conclusions:** The results show that alcohol use during pregnancy is an important health problem. A limited amount of data is available on the occurrence of FASD worldwide. It is important to gain more insight related to the global burden of FASD.

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**Detecting intellectual disabilities in a prison population in Trinidad**

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Aim: This paper describes the characteristics of a group of prisoners who were selected to take part in a programme designed to evaluate the impact of a group anger management programme in prisons in Trinidad. Method: Participants were asked to complete various demographic measures, the WASI-2, mental health measures (SCL-90) and anger rating scales (STAXI, PACS and PI). Results: 56 inmates were screened with the WASI-2, the mean IQ for the group was 72.34 and 22 had a recorded IQ of 69 or less (37.5%). All of the respondents reported high levels of mental health problems with their mean ratings on the SCL-90 being closer to inpatient psychiatric groups than non-clinical groups. Conclusions: A score of 69 or less on the WASI-2 is not sufficient for a diagnosis of ID as an evaluation of adaptive behaviour would be required and cultural factors may also influence the results. However, the results suggest that a number of individuals in these prisons may have an undetected ID and that more research is needed to help identify these individuals and provide appropriate support.

Syndromic clusters: Specificity of behavioural equivalents of psychiatric symptoms in people with intellectual disabilities

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Aim: The last decades’ considerable advances of the psychiatric assessment in people with intellectual disabilities (ID) do not include the ability to identify behavioural equivalents of psychiatric symptoms and their relationship with different psychiatric syndromes. The present study evaluates the correlations between behavioural equivalents and DSM-5 syndromic groups of symptoms. Method: An observational cross-sectional analysis was performed for an Italian sample of 843 adults with ID. The total sample was evaluated with the SPAID-G, which is a checklist for behavioural equivalents of the symptoms of the main psychiatric disorders included in DSM-5. Results: Some of the most relevant correlations were found for mood disorders. Psychomotor agitation, disorganised behaviour and distractibility were most pronounced in bipolar patients; for depressed patients, irritability and weight loss had higher correlations than in other diagnostic groups. Conclusions: Although not diagnostically specific, some behavioural equivalents seem to be more strongly related with specific psychiatric disorders. This line of research could improve the definition of the specific expression and clustering of psychiatric symptoms in persons with ID.

Anxiety disorders in Williams syndrome: A meta-analytical review and exploratory caregiver interview

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Aim: The assessment of anxiety in Williams syndrome (WS) typically relies on the use of established psychiatric tools. These measures, designed for the general population, may miss important markers of anxiety associated with the WS behavioural phenotype. This study examines the profile of anxiety in WS. Method: A meta-analysis was conducted in accordance with PRISMA guidelines, and a bottom-up telephone interview was developed and conducted with parents of individuals with WS (n=13, M age=21.92, SD=11.12). Results: The meta-analysis estimated high anxiety disorder prevalence rates, particularly for specific phobias (39%) and generalised anxiety disorder (10%). Compared to individuals with heterogeneous intellectual disabilities (ID), the risk of anxiety for individuals with WS increased four-fold (risk ratio 4.00 [95% CI 2.27 - 7.06]; p<0.0001). The interviews identified triggers and
behaviours associated with anxiety that were not present in the validated assessments. **Conclusions:**
This study highlights an unusual profile of elevated anxiety in WS, and supports the utility of a bottom-up approach for the assessment of anxiety in ID research.

**Same, same but different: The importance of social support for fathers of kids with developmental disabilities**

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**Aim:** Surprisingly few studies explore the impact of raising a child with a disability on fathers. This study investigates the role of familial factors and coping strategies on the well-being and psychological growth of fathers of children diagnosed with neurodevelopmental disorders. **Method:** Participants were male caregivers of children who completed an online survey consisting of questionnaires designed to measure their well-being, psychological growth, coping strategies, and support levels. A correlational design was utilised to explore the variables of interest. **Results:** Adaptive coping strategies were related to increased well-being and psychological growth. The child’s age and perceived behaviour significantly contributed to the father’s level of psychological growth. Fathers’ perceived support was lower than they would like with fathers reporting they would like more practical support and access to a fathers support group. **Conclusions:** To support families of children with developmental disabilities, it is important to identify the specific needs of the parents. Traditionally, most research has focussed on mothers; however, the current study highlights the impact on fathers and suggests that resources such as support groups for fathers would be useful to improve outcomes.

**Mental arithmetic by adolescents with intellectual disabilities**

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**Aim:** To better understand mental arithmetic used by adolescents with intellectual disabilities (ID) to solve addition and subtraction problems in the range 1 to 100. **Method:** 30 adolescents with ID attending a special school in Indonesia were asked to solve addition and subtraction problems mentally during one-to-one video-recorded interviews. The problems included additions up to 10 (4+3, 2+7, 3+6), up to 20 (5+6, 7+5, 7+8, 8+7, 9+4, 9+6), and up to 100 (58+24, 43+19, 37+6, 56+10, 36+22); and subtractions up to 10 (5-2, 8-3, 7-4), up to 20 (13-5, 11-5, 14-7, 20-3) and up to 100 (82-39, 41-24, 31-23, 51-25, 63-8, 56-23.). **Results:** Fingers and gestures play prominent roles for most participants in order to solve the problems successfully. Selected video-clips will be presented during the session to show the various strategies used by the participants. **Conclusions:** Promoting the use of readily available tools such as fingers and gesture may improve the number learning of adolescents with ID.

**Health of people with autism: Findings from Scotland's 2011 Census**

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Aim: Little is known about self-rated health status and demographic factors of people with autism in whole country populations. For the populations with and without autism in the whole of Scotland, this study investigated: self-rated general health status, demographic factors, and the prevalence of self-reported mental health conditions and other disabilities. Method: We analysed Scotland’s Census 2011 self-reported data about people with and without autism, and generated descriptive statistics. Results: 31,712 (0.6%) of all people in Scotland (n=5,295,403) stated they had autism. There were 17,348 (54.7%) children aged 0-15 and 14,364 (45.3%) adults aged 16 and over with autism. Very good or good health was described for 78.1% of children and 64.7% of adults with autism, and for 98.1% of children and 79.0% of adults without autism. 7.6% of children and 23.6% of adults with autism had an additional mental health condition (not including intellectual disabilities) compared with 0.2% of children and 5.2% of adults without autism. Other disabilities were also more common in people with autism. Conclusions: Health is poorer for people with autism than for the population without autism.
Challenging disadvantage in Zambia: People with psychosocial and intellectual disabilities in the criminal justice system

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Aim: This study sought to obtain an understanding of the intersection between disability and criminal justice and, in particular, the extent to which people with psychosocial or intellectual disabilities (ID) might be more adversely affected by their contact with criminal justice services (CJS) than people without such disabilities. Method: Research activities included: a review of national policy and legislation; collation of national criminal justice statistics; a review of international literature; and interviews with over 100 individuals, including senior stakeholders from government and civil society, practitioners from criminal justice and health services, family members of people with psychosocial or ID, and self-advocates – people with psychosocial or ID with direct experience of the CJS. Results: legislation and operational practice draw people with psychosocial or ID into contact with CJS and conspire to keep them in detention for long periods with little hope of review, appeal or release. Conclusions: Ratification of UNCRPD and domestication of its provisions, the new draft Constitution and, in part, the Mental Health Bill have set the scene for change. Recommendations from this study are being pursued by government and civil society organisations.

Relationship between concentrations of docosahexaenoic acid, selenium and mercury in maternal and cord blood

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Aim: Fish is a major source of nutrients such as docosahexaenoic acid (DHA) and selenium (Se) but is also a source of neurotoxicant such as methylmercury (MeHg). This study investigated the relationship between concentrations of DHA, Se and total mercury (Hg) in maternal blood at parturition and in cord blood. Method: Samples were collected from 54 mother-infant pairs in Japan. Results: Median Hg in maternal blood at parturition, and cord blood were 3.79 and 7.26 ng/g, respectively. At parturition, maternal blood Hg concentrations were significantly correlated with maternal DHA (r=0.37) and Se (r=0.32) concentrations. In cord blood, Hg only showed a significant correlation with DHA (r=0.40) but not with Se (r=0.21). Conclusions: The significant positive correlations between Hg vs DHA and Hg vs Se in maternal blood at parturition suggest that the source of Hg, DHA, and Se exposure was primarily from fish consumption. The higher correlation between DHA and Hg in cord blood may indicate higher availability of DHA compared to Se, suggesting DHA may play a more important role than Se in protecting against MeHg toxicity on foetal development.

Patterns of somatic diagnoses in older people with intellectual disabilities: A Swedish 11-year register-based study of inpatient data

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Aim: To investigate patterns of somatic inpatient ICD-10 diagnoses in people with intellectual disabilities (ID) 55 years and older in relation to age over an 11-year period, and to compare these patterns with a general population sample. Method: The study was based on Swedish national registers. The ID group (n=7936) comprised people who were aged 55 or above in 2012. They were age- and sex-matched with people from the general population (n=7936). Data about somatic inpatient diagnoses were collected retrospectively for 2002-2012. Results: In several years, several diagnoses were more common in the ID group, particularly diseases in the nervous system (OR from 2.06 to 31.75), respiratory (OR from 1.78 to 4.08) and genitourinary diseases (OR from 1.59 to 11.50), infections (OR from 1.78 to 4.08) and external causes of morbidity (OR from 1.53 to 4.08). The oldest persons (70+ years) in the ID group had less occurrence of cardiovascular (OR from 0.42 to 0.72), musculoskeletal diseases (OR from 0.32 to 0.53) and tumours (OR from 0.26 to 0.51). Conclusions: Older people with ID are less likely to have some diagnoses but more likely to have others.

Patterns of somatic healthcare utilisation in people with intellectual disabilities: A Swedish 11-year register-based study

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Aim: To explore somatic healthcare utilisation patterns among people with intellectual disabilities (ID) 55 years and older living in Sweden in comparison with the general population. Method: The ID group (n = 7936) comprised people with ID who were 55 years and older in 2012. A general population sample (n = 7936) was age- and sex-matched. The sample was divided into four age groups: <60, 60–64, 65–69 and ≥ 70 years. In- and outpatient data were collected retrospectively from the Swedish National Patient Register (2002-2012). Results: In the three youngest groups, and in most cases in the oldest age groups, people in the ID group had in general higher rates of unplanned in- and outpatient care and longer unplanned lengths of stay. This was seen also for planned in- and outpatient care in the two youngest age groups, but for the two oldest age groups higher rates were found in general population sample. Conclusions: It seems that despite higher rates of unplanned care, people with ID do not receive planned care to the same extent.

Promoting self-reliance in people with intellectual disabilities: Results from a focus group study

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Aim: Promoting the self-reliance of people with intellectual disabilities (ID) is important to reduce the greatly increased demand for care by support staff and family members. In this study, the concept of self-reliance is explored, as well as its (dis)advantages, the requirements for increasing self-reliance, experienced obstacles and possible solutions. Method: Five separate focus groups with either support staff or family members of people with ID were conducted. Different aspects of self-reliance of people with ID were discussed. Verbatim transcripts were analysed qualitatively. Results: Preliminary findings indicate that an increased self-reliance has many advantages for people with ID. In the process of promoting self-reliance, a careful step-by-step tailored approach seems necessary, next to good
communication and agreement between all involved parties, sufficient time, univocal staff support and clients’ intrinsic motivation. **Conclusions:** There is a growing demand for promoting self-reliance in people with ID. Therefore, interventions need to be developed to meet this demand, paying close attention to the clients’ needs, motivation and (dis)abilities, as well as facilitating sufficient opportunities for professional guidance and communication between all people involved.

**Assessing the quality of existing sex education programmes for people with intellectual disabilities: An intervention mapping approach**

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**Aim:** People with intellectual disabilities (ID) face a variety of problems with regard to their sexual health. Several sex education programmes have been developed by professionals with the intention to improve sexual health. An adaptation of the intervention mapping protocol was used in this study to assess the quality of sex education programmes for people with ID that are currently available in the Netherlands. **Method:** A questionnaire based on the steps of the intervention mapping protocol was sent to the developers of 26 existing sex education programmes. 17 questionnaires were filled out. **Results:** Most developers are unable to clearly describe the problem they want to tackle, what the programme intends to achieve and how they are going to achieve the programme goals. Only two programmes seemed to be developed in a systematic way. **Conclusions:** Intervention mapping is a useful tool for clarifying the content of a programme and its development process. It demonstrated that there is a lot of room for improvement regarding the development of sex education programmes for people with ID.

**Exploring the motor development of young children with possible severe to profound cognitive and motor developmental delay by means of a questionnaire**

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**Aim:** Early motor stimulation may be valuable for children with profound intellectual and multiple disabilities (PIMD), however limited knowledge of their typical motor developmental trajectory may be currently restraining the efficacy and specificity of this intervention. Research on young children with possible severe to profound cognitive and motor developmental delays who are expected to meet the criteria of PIMD later on in life, can fill this gap. Therefore, this study aims at exploring the course and (atypical) patterns of motor development in these children. **Method:** We assessed the gross and fine motor skills of 30 children with possible severe to profound cognitive and motor developmental delay (aged 6 to 59 months), using an adapted questionnaire completed by parents and researchers, and video observation of the motor abilities of the children. **Results:** Preliminary results will be presented. **Conclusions:** We expect that an increase in knowledge regarding the course and patterns of motor development can inform research and practice regarding assessment and evaluation of motor skills in persons with PIMD.
The development of cross-cultural quality of life indicators that align with the Articles of the Convention on the Rights of Persons with Disabilities

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**Aim:** To determine objective, cross-cultural indicators for each of the United Nations Convention on the Right of Persons with Disabilities (UNCRPD) Articles that have been aligned in previous studies with one of the eight core quality of life domains (QoL). **Method:** A 3-round Delphi procedure with an international response panel was employed to establish objective indicators for each of the UNCRPD Article/QoL domain pairings. **Results:** 75% agreement among 153 respondents from 12 countries was reached on a minimum of three objective indicators for each UNCRPD Article/QoL domain pairing. **Conclusions:** Objective, cross-cultural indicators are identified that can serve as a basis for both evaluating the current status of the implementation of specific articles of the UNCRPD and for establishing quality improvement techniques.

The Victorian Collaborative Autism Study: A family and community study of the genetics of autism spectrum disorder

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**Aim:** For most patients with autism spectrum disorder (ASD), the cause is not known. About 30% of patients have a known genetic cause and, in some, environmental factors play a role. Relatives of children with ASD may have mild autism traits known as the broader autism phenotype. The Victorian Collaborative Autism Study investigates the genetic causes of ASD and aims to determine the incidence in the Barwon region. **Method:** We recruited patients from Barwon with ASD, together with direct referrals to the study. Patient phenotyping was based on developmental and diagnostic history. A family history of autism traits was obtained. Large families with multiple affected individuals underwent phenotyping with a view to gene discovery. **Results:** 486 children with ASD and their parents were recruited. Two large families with 49 affected individuals with ASD or broader autism phenotype were analysed. Linkage mapping identified an ASD locus in each family. **Conclusions:** Globally there has been an increase in prevalence of individuals diagnosed. Large multiplex family studies are one strategy to identify genes that confer risk for ASD.

A consecutive case review of token systems used to reduce problem behaviour in individuals with developmental delays

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**Aim:** The current paper describes token systems used in a behavioural day-treatment unit for severe problem behaviour (PB) using a consecutive case review spanning three years with the purpose of describing common components of token systems and evaluating the effectiveness of treatment.
packages including token systems. **Method:** The study included 24 individuals with developmental delay who had received a treatment package to reduce PB that had included a token system. Aspects of the token systems and participants were coded. **Results:** Token systems were most frequently employed during demands. The treatment packages resulted in an average reduction in PB of 70.18% (70.83% of participants with reductions greater than 85%). Several commonalities were identified in treatment across participants (e.g., restriction of reinforcers between exchange and initial dense reinforcement schedules). The sample had an over-representation of PB maintained by escape and multiply maintained PB. **Conclusions:** Our findings suggest that token systems may be a beneficial component of treatment for PB. Some common components should be included in all token systems and specific client variables may guide decision related to idiosyncratic components.

**Comparing the outcomes of a functional analysis to the outcomes of the Questions About Behavior Function Scale**

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**Aim:** Identifying the function of challenging behaviour is a key component to developing effective treatment. Functional analysis (FA) is the most effective empirically-based method for identifying the function of challenging behaviour. However, it is not always feasible to conduct a FA due to practicality (e.g., lack of resources or time). Indirect assessment measures, such as questionnaires, may also effectively identify the function of challenging behaviour. **Method:** In the current study, 270 participants were referred to a hospital outpatient clinic for treatment of severe challenging behaviour. An indirect measure, the Questions About Behavioral Function (QABF), and a direct measure, a FA, was completed for each targeted challenging behaviour for all participants. QABF and FA results were compared to assess their level of agreement regarding behavioural function. **Results:** Results show moderate to high agreement between the QABF and FA across functions, with some variation in agreement across behavioural topographies. **Conclusions:** Interpretation of results will focus on the sensitivity and specificity of the measures based on the severity of scores, to aid with determining when more in-depth analyses may be warranted.

**Consequences of frailty in people with intellectual disabilities**

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**Aim:** We evaluated the relation between frailty and deterioration in activities of daily living (ADL), instrumental activities of daily living (IADL), mobility and mortality over a three-year follow-up period. **Method:** This research was part of the HA-ID study where 1050 elderly (50 years and over) with intellectual disabilities (ID) were followed for three years. Frailty was measured with a frailty index (FI). ADL, IADL and mobility were measured with the Barthel index, the Lawton scale and a combination of the Hauser Ambulation Index and the Gross Motor Function Classification Scale, respectively. **Results:** We found a strong relation between frailty and deterioration of ADL, IADL and mobility. Also, frailty was associated with higher risk of death: mortality risk was 2.17 times as great (95% CI=0.95-4.95) for vulnerable individuals (FI: 0.20-0.29) and 19.5 (95% CI=9.13-41.8) times as great for moderately frail
individuals (FL: 0.40-0.49) as for relatively fit individuals (FL<0.20). **Conclusions:** Frailty seems to start earlier and is more severe in people with ID than observed in people in the general population, but consequences on adverse health outcomes are similar.

**Design of a frailty index for people with intellectual disabilities**

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**Aim:** Although there is no strict definition of frailty, it is generally accepted as a state of high vulnerability for adverse health outcomes. Because there is no information on frailty in people with intellectual disabilities (ID), we developed a frailty index (FI) for this specific population. **Method:** Data from the HA-ID study (n=1050) were used. 51 variables were included in the index, including a broad spectrum of objective measurements, informer reports and medical information. An FI score was calculated taking the number of deficits present, divided by 51, resulting in a score between 0 and 1. **Results:** Characteristics of the FI were comparable to FI designed for the general population: skewed distribution, correlation with age and a maximum FI score around 0.7. We found a mean FI score of 0.27, equivalent to the prevalence of 14 out of 51 deficits. The FI score was positively correlated with age and the presence of Down syndrome. More severe ID was associated with higher FI scores. **Conclusions:** Compared to a general population (50+), people with ID accumulate more deficits and this accumulation starts at a much younger age.

**Possible relationships among daytime behaviour, mental health and sleep problems for children with autism spectrum disorder**

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**Aim:** Children with autism spectrum disorder (ASD) experience a wide range of sleep problems. Research demonstrates associations between general sleep problems and challenging daytime behaviours. This study investigated the relationships among general and specific sleep problems and specific daytime behaviour and mental health for children with ASD. **Method:** 510 children diagnosed with ASD (1 to 18 years old) were included. Sleep was evaluated using the Behavioral Evaluation of Disorders of Sleep. Daytime behaviours were evaluated with standardised measures (e.g., Child Behavior Checklist). Stepwise regression analyses determined relationships among sleep and daytime behaviour and mental health. **Results:** Preliminary analyses indicated that sleep problems (i.e. reduced total hours of sleep, disoriented awakening, sensitivity to environmental stimuli, and night screaming) were related to daytime behaviours and mental health (i.e., anxiety/depression, aggression, and lack of attention). **Conclusions:** Relationships among specific sleep problems and daytime behaviour and mental health may have significant influence in treatment choices to address each of these clinically significant issues for children with ASD.

**The challenges of developing national policies on the basis of scientific evidence**
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Aim: To review the development of policies on fish consumption and the role of scientific evidence of methylmercury exposure and child development, and explore the challenges involved, particularly for developing countries, in formulating policies that optimise the benefits of traditional fish diets. Method: A review of population-based studies of methylmercury exposure and child development, and of advisories on the benefits and risks of fish consumption were conducted. Results: Epidemiological studies of methylmercury exposure from traditional diets provide conflicting evidence of adverse effects on child development. Advisories limiting fish consumption are found in some developed countries, but are rare in the developing world. Conclusions: Public health policies should be based on scientific evidence and an understanding of the social and epidemiological characteristics of a population. Developing countries with populations for whom fish is an essential nutritional resource often do not have the capacity to evaluate conflicting scientific evidence obtained from studies elsewhere. The adoption of advisories from developed countries may cause more harm than good.

Citizenship ethics, relationality and social inclusion: A relational approach to ethical disability practice

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Aim: Ruth Lister’s inclusive citizenship theory provides a means of shifting ethical decision making from codified approaches focussed on risk management in disability practice to much more relational and developmental ethical approaches which are focussed on maximising community participation and social inclusion. Method: We have utilised Ruth Lister’s inclusive citizenship to explore ethical approaches to disability practice that focus on displacing paternalism and orienting ethical decision-making towards maximum inclusion. We apply her four principles of inclusive citizenship, justice, recognition, self-determination and solidarity to guide decision-making and practice with an individual with complex disabilities and a history of trauma. Results: We demonstrate through case examples how this approach to ethics and practice transcends risk management which often leads to default paternalism. We demonstrate how it facilitates relational approaches that foster potentiality and development and increases capabilities for participation and the conditions for social inclusion. Conclusions: Lister’s inclusive citizenship translated to ethical disability practice offers profound scope for reshaping disability support towards maximum social inclusion and development of human potential.

Healthy Athletes program second annual data report

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Aim: Special Olympics (SO) Healthy Athletes (HA) program offers health services and information to its 4.5 million athletes in 120 countries. The data collected from the program’s seven disciplines (dentistry, optometry, audiology, podiatry, fitness, sports physicals, and health promotion) form the largest health database in the world on people with intellectual disabilities (ID). An annual report was created to inform researchers about available data and to encourage further research. Method: Descriptive data are used to present differences over time and by demographics. Results: The HA dataset includes over
70,000 observations in each of the health disciplines since 2007. Differences in key health indicators across regions, age groups, gender, and year will be presented. For example, low bone density data from 2014 showed large differences between age groups (22.5% in 20-29 year olds vs. 34.7% in 50-59 year olds). **Conclusions:** There are vast possibilities for research with HA data. This dataset could lead to more research on the health of people with ID.

**Vision improvements resulting from new spectacle corrections at Special Olympics Lions Club International Opening Eyes program**

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**Aim:** Through Special Olympics (SO) Lions Clubs International Opening Eyes (OE) program, SO athletes receive vision assessments, including visual acuity (VA) and refraction. This study aimed to determine what portion of athletes had demonstrated improved vision when provided new spectacle corrections and to what extent their vision improved. **Method:** Data from three 2014 OE programs (n=1344) were analysed. VA improvement of at least 1 line was used as the indicator for improvement. **Results:** 39% of athletes assessed received new spectacle corrections, and an improvement in VA was documented for approximately 99% of those athletes. An analysis of distant right eye vision indicated at least 20% of athletes who received corrections demonstrated >= 2 lines of VA improvement. **Conclusions:** The majority of SO athletes who were provided new corrections experienced an improvement in their distant/near VA. The high rate of improvement highlights the visual needs of this population as well as the effectiveness of the OE program.

**Results from quantitative evaluations across 14 Healthy Communities pilot sites**

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**Aim:** The Healthy Communities initiative has built on Special Olympics’ existing health programme by focusing on local health needs and developing interventions in 14 pilot sites across 9 countries from 2012-2015. The evaluation aimed to track progress and identify successes to sustain and expand the work. **Method:** A global quantitative monitoring and evaluation plan was created to focus on the health and well-being of people with intellectual disabilities (ID), access to healthcare and wellness resources, and local community health capacity. Data were collected from the pilot sites and analysed bi-annually. **Results:** The Healthy Communities initiative had huge reach and impact in its first 3 years. For example, 6,042 family members and 1,940 coaches and teachers were educated to support the health of people with ID. 669 people with ID were trained to become peer health educators, more than 20,000 healthcare professionals and students were trained on how to work with people with ID, and 248 local partnerships were established to help strengthen local programming. **Conclusions:** The evaluation led to continuous improvements throughout the project and an expansion of the initiative.

**Enabling support systems for creating inclusion through sports**
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Aim: To examine the role and impact of the enabling support provided by coaches on the sports field and administrators in schools on the creation of an inclusive and accepting environment for people with and without intellectual disabilities (ID). Method: Eight coach interviews were conducted where coaches discussed ways in which they have promoted social inclusion, the benefits of Unified Sports, and changes they have seen in participants. In addition, 21 Unified Strategy school site visits were conducted to understand how administrators impact social inclusiveness in schools. Results: Coaches mentioned improved confidence, enhanced communication, and improved social inclusion as a result of Unified Sports participation. In schools, teachers encouraged students to be leaders to determine collaboratively how to best implement socially inclusive activities. Conclusions: With the support of the coaches and education leaders to facilitate inclusive activities, there are more opportunities for people with and without ID to learn and grow through sports.

Parents’ perceptions of their role in supporting children with Down syndrome to develop mathematical concepts
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Aim: Many parents of children with Down syndrome (DS) are involved in helping their child learn. However, little is known of the roles they play in the development of mathematics concepts. This study examined perceived parental roles and how these changed during this study. Method: Survey instruments developed from other research were completed by 24 parents (15 mothers; 9 fathers) pre and post an intervention workshop. Parents also completed reflective diaries. The surveys and diaries were analysed according to Cai’s five roles. Results: In some instances, the perceived roles changed following the intervention workshop. The analysis of the diaries provided the parent voice which embellished the quantitative data. The father’s voice, often silent in research of this kind, was heard and contributed to the results. Conclusions: The perceived roles of the parents changed in this study indicating deeper insight into their roles. With support for their roles, parents can make a valuable contribution to the learning of mathematics by their child with DS.

Using risk assessment screening to determine need for dysphagia precautions
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Aim: To describe development, validation and standardisation of the Choking Risk Assessment (CRA) and the Pneumonia Risk Assessment (PRA). Method: A retrospective survey of a cohort of adults with intellectual and developmental disabilities (IDD) was used to determine individual characteristics that were predictive of choking episodes, that required rescue or emergency hospital care, or pneumonia episodes. These data were used as the basis for development of the CRA and the PRA, two assessments for determining level of risk. Results: Standardisation and validation of the CRA and PRA determined screening cut-off scores that maximised sensitivity and specificity for choking and pneumonia risk in this population. Conclusions: Risk assessment is a reliable and valid means for determining choking risk and
pneumonia risk in adults with IDD. Precautions for mitigating specific risks can be applied selectively thereby minimising undue effects on quality of life for those individuals with low risk. Staff, individual and family awareness may be sharpened through use of risk assessment, potentially improving compliance with clinician recommendations.

**Measuring intellectual abilities in children with cerebral palsy**

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Aim: To determine the proportion of children with cerebral palsy (CP) with adequate verbal and motor skills to complete the WPPSI-III, to compare ability on tasks with and without a significant motor component, and to investigate alternative short forms of the WPPSI-III. Method: Participants comprised 78 children with CP (4 to 5 years old). Verbal, Performance, and Full-scale IQ (FSIQ) were determined using the WPPSI-III. Screening for pointing and verbal abilities determined the tests attempted. The impact of speed was investigated by comparing scores on the Block Design subtest with and without an imposed time limit. FSIQ scores from two short forms of the WPPSI-III were compared to the full form.

Results: FSIQ was obtained in 62 (79%) children. Scores on subtests requiring manual ability were depressed relative to other scores. Children performed better using short forms of the WPPSI-III and, for a minority, when time limits were disregarded. Conclusions: Children with CP score relatively poorly on tasks requiring a fine motor response but may increase their FSIQ using short-form estimations comprised of subtests without a significant fine motor component.

**The implementation and effectiveness of progressive resistance training programmes in people with Down syndrome**

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Aim: Muscle strength is important for young people with Down syndrome (DS) as they make the transition to adulthood because their workplace activities typically emphasise physical rather than cognitive skills. Progressive resistance training is a targeted intervention to improve muscle strength. This study involved a review of the evidence of the implementation and effectiveness of progressive resistance training for people with DS. Method: Data on adherence, adverse events and effectiveness from three high quality community-based randomised controlled trials of progressive resistance training with allocation concealment and blinded assessment were combined using descriptive synthesis and meta-analyses. These trials included 111 people with DS (43 female, 68 male; mean age=20 years).

Results: High adherence (92%) and no adverse events demonstrated feasibility and safety. Muscle strength of the arms (mean difference 12kg, 95% CI:6-17kg) and the legs (mean difference 27kg, 95% CI:12-42kg) improved. Physical activity levels and timed stairs climb also improved demonstrating effectiveness. Conclusions: Community-based progressive resistance training is a feasible, safe and effective intervention for young people with DS.

**FitSkills programme for young people with disabilities: Translating evidence into practice**
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Aim: Established in Melbourne in 2014, the FitSkills programme matches a young person with disabilities with a student mentor and the pair exercise together twice a week for 12 weeks at their local gymnasium. Our aim was to evaluate the feasibility of the programme. Method: This prospective cohort study of 20 young people (10 female, 10 male; mean age=18 years) with disability (7 Down syndrome, 7 cerebral palsy, 3 spina bifida, 1 spinal cord injury, 2 autism spectrum disorder) assessed the effect on physical health (muscle strength, walking endurance) using paired t-tests. Descriptive data on attendance, adverse events and subsequent participation in physical activity were also collected. Results: Participants attended 83% of scheduled sessions. There were no major and seven minor (e.g. muscle soreness) adverse events. Participants increased their arm (4kg, 95%CI: 1-8) and leg (46kg, 95%CI: 20-72) strength but not their walking endurance (62m, 95%CI:-11 to 135). Five participants continued exercising at the gym after FitSkills and another five commenced a new physical activity. Conclusions: The FitSkills programme feasibly engages young people with disabilities in physical activity.

Does foot posture and footwear fit influence the level of physical activity of children with Down syndrome?

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Aim: To investigate the association between foot posture, footwear fit and physical activity in children with Down syndrome (DS). Method: A prospective study of 50 children with DS (22 girls, 28 boys; mean age: 10.5 years) was undertaken. Foot posture was assessed using the Arch Index. Footwear fit was assessed by comparing the difference in length and width of shoes with participants’ feet. Physical activity was measured using RT3 accelerometers. Foot deformities were noted. Results: 38 participants had flat feet, five had hallux valgus and six had other toe deformities; the mean Arch Index was 0.29±0.08 indicative of flat feet. Five participants wore footwear that was too short, 30 wore footwear that was too long and 29 wore footwear that was too narrow. 20 children were adherent with wearing an accelerometer. Regression analysis found no association of foot posture or deformity with activity. Footwear fit was negatively associated with activity (p=0.03). Conclusions: These preliminary data suggest poor footwear fit is associated with reduced activity in children with DS. Further research could determine if better footwear fit increases activity in this group.

Measuring social inclusion in children with severe intellectual and developmental disabilities: Development of the GO4KIDDSS Social Inclusion Coding Scheme

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Aim: Children with intellectual and developmental disabilities (IDD) are often integrated into ‘mainstream’ settings with typically developing children but may experience low rates of social inclusion. This study describes the development and implementation of a live observational coding scheme, which allows for the systematic examination of social inclusion experiences of children with IDD in potentially
social situations. **Method:** We developed the GO4KIDS Social Inclusion Observational Coding Scheme in order to code live observations of children with severe IDD at school and in the community. 20 children (aged 6 to 18 years) were observed for 15-30 minutes. Children’s opportunities for interactions and actual interactions with peers and adults were coded. **Results:** Overall, levels of social interaction were low, despite the presence of others. Children’s cognitive, adaptive and social skill levels were positively correlated with the amount of time children spent interacting with peers. **Conclusions:** This measure provides an objective indicator of the social inclusion experiences of children with severe IDD in social settings, and is able to be implemented with live observations where videotaping is not allowed or practicable.

Age-related change in problem behaviours among adults with Williams syndrome

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**Aim:** Little is known about the developmental trajectory of individuals with Williams syndrome (WS), particularly into adulthood. The present study examines changes in behavioural patterns as measured by the Child Behavior Checklist (CBCL) from mid adolescence into middle adulthood. **Method:** 82 individuals with WS (16 to 59 years old) took part in an annual music camp in the United States. Many participants attended the camp over multiple years, allowing for behavioural measurements over time. Behaviours were analysed using the CBCL (2001 version). Of the 82 participants, 46 had data from at least 2 time points, and 27 had data from at least 3 time points. **Results:** Hierarchical linear modelling revealed significant individual differences in overall internalising behaviour, as well as attention problems, aggression social problems, and withdrawn symptoms. Age was significantly related to downward slope in attention problems and somatic problems. **Conclusions:** The findings suggest that certain problem behaviours decline in adulthood among individuals with WS, though significant individual differences remain. Future research is needed to determine reliable predictors of problem behaviour within this population.

Profiles of psychopathology among adults with Williams syndrome

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**Aim:** Although researchers have examined the presence of anxiety and phobias among individuals with Williams syndrome (WS), the rates of other co-morbid psychopathological disorders are unknown, particularly in adulthood. The present study examines reports of various affective disorders and associated symptoms. **Method:** The current sample includes 62 individuals with WS who responded to the Diagnostic Interview of the Schedule for Affective Disorders and Schizophrenia for School-Age Children – Present and Lifetime Version (K-SADS-PL). Based on their interview responses, participants were classified as having definite diagnoses, probable diagnoses, or no diagnoses of various disorders. **Results:** Consistent with previous findings, participants reported a high rate of symptoms of generalised anxiety disorder (40.3% met criteria for a definite diagnosis) and simple phobia (53.2% met criteria for definite diagnosis). Additionally, around one quarter of participants met criteria for a definite diagnosis of major depressive disorder and attention-deficit hyperactivity, respectively. **Conclusions:** The findings
suggest that adults with WS may exhibit at least sub-threshold symptoms for a variety of psychopathological disorders. Implications for research and practice will be discussed.

Preliminary findings from SIS-C international data

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Aim: The Supports Intensity Scale - Children’s Version (SIS-C) was normed in the United States on a sample of 4,015 children and youth with intellectual disabilities (ID) stratified by six age groups (5-6, 7-8, 9-10, 11-12, 13-14, and 15-16 year olds). Smaller SIS-C international samples were collected in several countries and were linked to the original U.S. sample to develop international norms. The purpose of this presentation is to describe the extended international SIS-C norming process. Method: Structural equation modelling (SEM) was used for norming purposes. Six U.S. age groups were included without any constraints in the norm-generating models for the purpose of model stabilisation, and six Spanish age groups were used to test measurement invariance, as well as differences in latent means and variances across age groups. The process was then replicated with data from other countries. Results: International norms could be developed using this process, providing country specific norms for the SIS-C. Conclusions: Professionals can use the SIS-C across countries to meaningfully assess support needs.

Comprehensive health assessment workshop: An evaluation

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Aim: Comprehensive health assessments (CHA) are key preventive measures effective in reducing health disparities for persons with intellectual disabilities (ID). The purpose of the present study was to evaluate the effectiveness of a training programme designed to enhance healthcare providers’ knowledge of persons with ID and the importance of CHA for this population. Method: We compared healthcare providers’ knowledge of health needs and underlying risk factors in persons with ID, before and immediately following training, and after completion of at least two CHA based on the Comprehensive Health Assessment Program (CHAP). Results: Overall, healthcare providers’ of knowledge of health risks and needs of persons with ID increased following training. Healthcare providers also reported that conducting CHA based on the CHAP enabled them to gather a clearer and more complete health history, and direct attention to unmet health and support needs of persons with ID. Conclusions: Ultimately, using structured tools such as the CHAP to conduct CHA should increase clinicians’ willingness to provide ongoing care to this underserved population without increasing the overall consultation and medication costs.

Aging with intellectual and developmental disabilities and dementia in Manitoba

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Aim: This study estimates dementia prevalence in adults with intellectual and developmental disabilities (IDD) in Manitoba (Canada) by age, sex, type of IDD, region of residence, and living arrangements.

Method: Anonymised population-level health and non-health administrative data (1979-2012) were linked to estimate dementia prevalence in persons with IDD living in Manitoba. A history of dementia was established based on the presence of ICD codes. Results: Of the 8,655 adults with IDD identified, 8.1% were diagnosed with dementia - an estimate three times greater than that found for those without IDD (2.6%). More than 40% of adults with IDD who had dementia were aged 18-54 years. Of those with IDD and dementia, 34.7% lived in long-term care facilities. Conclusions: Health and social support services are available to individuals aged 65+ years. Consequently, there may be adults with IDD showing signs of dementia who are not receiving the support that they require. Results of this study will be useful for developing policies and programs to better support those aging with IDD and dementia.

Active citizenship through community living and support: Findings from the DISCIT study

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Aim: This paper draws on a larger study, the main aim of which was to promote and sustain the development of active citizenship through deinstitutionalisation and community living. Method: Across 9 countries, data was drawn from three sources: a review of the research, policy and official statistics; semi-structured interviews with 86 expert informants; and life course interviews with 46 people with intellectual disabilities (ID) from three birth cohorts (c.1950, c.1970 and c.1990)

Results: Despite some positive developments in the living situation of people with disabilities in the past decade, those with ID still experience segregated trajectories and less choice about where to live and who to live with. Issues raised included accessibility of information and the environment, the attitudes and behaviour of other people and lack of appropriate support.

Conclusions: There is still some way to go to see full implementation of Article 19 of the UN Convention on the Rights of Persons with Disabilities in Europe - this is especially true for those with more severe or complex disabilities.

Hospitalisation of adults with intellectual disabilities compared to the general population in Norway

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Aim: Studies have found that adults with intellectual disabilities (ID) are hospitalised more often than the general population (GP). This study investigates hospital admissions among people with ID compared to the GP in Norway. Method: Data from two national register was combined (N_total=1,764,072 and N_ID=7,573) during 2008-2011. Descriptive analyses, Pearson chi-square test, t-tests and standardised incidence ratio analysis were used. Results: People with ID were hospitalised significantly less frequently than the GP (p=0.04), 11% of people with ID and 11.5% of the GP. The length of the average hospital stay was just over 4 days for both groups. Contrary to the GP, adults with ID age 35-60 years were more frequently hospitalised than older people with ID. The most common ICD-10 diagnostic group for hospitalisation among people with ID is injury, poisoning, and certain other consequences of external causes (12.3%), whereas for the GP it is diseases of the circulatory system (13.7%).

Conclusions:
Older adults with ID are less often admitted to hospitals than expected. The results must be interpreted in light of the health-care system in Norway.

**Say Less Show More: An evaluation of visuals to support children with intellectual disabilities in a mainstream health service**

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**Aim:** Many factors contribute to poor health of people with intellectual disabilities (ID). This study was an evaluation of training of clinicians in the use of visuals with children with ID in a New South Wales paediatric emergency department (ED). **Method:** 99 clinicians (doctors and nurses) who underwent training to use visuals completed a structured survey (5 point Likert ratings, and free text) evaluating baseline knowledge and impact of training. 33 clinicians and 41 carers completed surveys to evaluate impact of visuals in ED and recommendations for future use. **Results:** Evaluation of training showed that clinicians learned about ID and were confident to use visuals (more than 80% rated high or very high). Carers felt that visuals were useful for their child (57% high or very high). Clinicians and carers (more than 80% rated high or very high) indicated visuals were easy to use and recommended their use. **Conclusions:** Paediatric ED clinicians can learn to effectively use visuals. Further research to explore impact of visuals in other health contexts is warranted.

**A systems analysis of the factors that lead to the employment of people with intellectual disabilities in Australia**

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**Aim:** An examination of participant experience in the Disability Employment System in Australia. **Method:** Research was undertaken using a multiple perspectives design that resides within the interpretative phenomenological analysis process. Clients (n=30) and employment consultants (n=30) were interviewed using semi-structured interviews in small group settings. Thematic analysis using multiple passes was undertaken to highlight the key issues. **Results:** Whilst the current system purports to be person-centred, the absence of the client voice and lack of evidence-based practices have created a system focussed on compliance-driven outcomes. Whilst consultants attempt to customise employment, the compliance-based nature of the system and the absence of client-focussed outcome measures have undermined these practices. **Conclusions:** The findings highlight shortcomings in a system that gives primacy to compliance over client expectations. The imminent development of a system of individualised funding and customised employment practices offer the possibility of client focussed sustainable career outcomes that support inclusion.

**Stepped care in treatment of sleep problems in individuals with intellectual disabilities**

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**Aim:** Sleep problems in people with intellectual disabilities (ID) is distinctive in causes, clinical presentation and therapy. The physiology of sleep is vulnerable in people with ID. There is a strong relationship between the physiological mechanisms of sleep and the influence of care-dependent daily living, often leading to sleep-challenging circumstances. Above that, typical diseases of sleep appear to be more frequent in people with ID. These two problems have led to practice-based clinical models. In this study these models are validated. **Method:** In a 24-month prospective study, complex sleep problems in 150 patients (aged 5 to 75 years, all levels of ID) are unravelled using questionnaires, actimetry and polysomnography, aiming to validate the existing practice-based diagnostic models. **Results:** An evidence-based clinical model was developed to identify and treat sleep problems in individuals with ID. **Conclusions:** Sleep problems are common in people with ID and have heterogeneous causes. Treatment requires an evidence-based stepped care model; ranging from improving sleep promoting habits to tailor made sleep medicine.

**Theory of Mind and educational setting: The moderating role of a school placement**

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**Aim:** To observe differences in Theory of Mind (ToM) development among children with mild intellectual disabilities (ID), with hearing impairments and without disabilities in different educational settings. Impact of social (i.e. parental up-bringing style, family SES, siblings, class climate), and individual (disability, social skills, academic abilities, integration with school and peers) factors on ToM are tested. **Method:** Over 450 children from primary schools participate in the longitudinal study. Children learn in different classes: special, with less (1-2) or more (3-5) children with disabilities, and without children with disabilities. Parents and teachers assess children’s functioning by completing questionnaires. ToM is assessed with the ToM scale (Peterson et al., 2012), the Faux Pas Recognition Test (Baron-Cohen at al., 1999) and the Children’s Social Understanding Scale (Tahiroglu et al., 2014). Analyses include MANOVA, regression and structural modelling. **Results:** Social as well as individual factors are significant for ToM development. The educational setting can moderate ToM development among children with and without disability. **Conclusions:** School placement is significant for ToM development and should be added to the list of factors influencing ToM development.

**Young people with a disability leaving state care: Findings from a study conducted in Victoria, Australia**

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**Aim:** The aim of this study was to gain an in-depth understanding of the experiences of young people with a range of disabilities (neurodevelopmental and/or mental health) who had exited the state care system in Victoria, Australia. **Method:** In-depth interviews were conducted with 15 young people who identified as having one or more disabilities (e.g. intellectual disability, autism spectrum disorder, attention deficit hyperactivity disorder, physical disability, anxiety, depression, and/or serious behavioural issues). Interviewees were asked about their experiences of being in and leaving state care. **Results:** Overwhelmingly, informants reported a lack of input into key decisions about their lives. Exit
planning was poor to non-existent. Difficulties were experienced with accommodation stability, educational support, and skill development for transitioning to independent living. Few were made aware of leaving-care funding or support services. Some experienced further maltreatment while in care. **Conclusions:** There is an urgent need for more integrated and longer-term leaving-care support for young people with disabilities (to age 25). Mandatory rather than discretionary specialist programs should be provided to address the multiple and complex needs of care leavers with disabilities.

**Texture and preparation of easy-to-eat food for persons with developmental disabilities and dysphagia in Japan**

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**Aim:** Facilities for persons with developmental disabilities serve food in easy-to eat textures. But their names and the ways they are prepared are different among facilities which lead to difficulty in exchanging information. We investigated the preparation and naming of easy-to-eat textures of the food at these facilities. **Method:** We developed a questionnaire about names of easy-to-eat textures and the ways they are prepared showing the photos of servings of rice (n=8), a main dish (n=8) and liquids (n=6), and sent it to 502 facilities in Japan. We analysed the answers across special schools, day care facilities and residential facilities. **Results:** 318 facilities responded. The three most common textures for rice were soft boiled, rice gruel, and pasted with a blender; main dishes were softly cooked and cut with a food processor; and liquids were non-modified, modified like yogurt and modified like honey. Each texture had more than 10 names. Some names were used for four different textures. **Conclusions:** Agreeing on universal names for easy-to-eat textures and their standard preparation, and disseminating them around Japan is necessary.

**Having choice and control: Parenting with intellectual disability under the NDIS**

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**Aim:** Evidence shows that parents with intellectual disabilities (ID) and their children do well when they have access to timely and appropriate support and are socially connected. Nonetheless, many parents with ID lack the informal support and other resources they need. When formal support is not guided by what a parent wants or is mandated by statutory authorities it can lead to mistrust and disengagement. A study will be conducted to explore how the Australian National Disability Insurance Scheme’s (NDIS) promise of choice and control over support can increase the parenting capacity of parents with ID. **Method:** In-depth interviews will be undertaken in 2016 with parents with ID in Sydney, Australia. Participants include parents who are currently accessing the NDIS. Interviews will explore parents’ perceptions of the NDIS as a vehicle to achieving their parenting goals. **Results:** Preliminary findings will be presented. **Conclusions:** The results will provide direction to NDIS planners and providers about how to support parents with ID to engage with the NDIS and take charge of their supports.

**The effectiveness of a running group programme in children with neurological conditions**
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Aim: Children with neurological conditions often suffer physical symptoms that impede acquisition of high-level mobility skills and limit participation. This study hypothesised that a running group programme would improve high-level mobility for such children. Method: 20 children with neurological conditions (intellectual capacity not assessed) were randomised to running or control group. For six weeks, the running group completed a twice weekly running programme while the control group continued usual care. Running group consisted of exercises targeting strength and neuromuscular control needed for running. Assessments were completed before, directly following and eight weeks following the intervention. Raw data were analysed using independent and paired t-tests. Results: The running group’s mean change for high-level mobility (HiMAT) was an improvement of 6.1 (SD=5.2) compared to the control group -0.8 (SD=2.2). Clinically significant improvements were made by seven running group participants and none of the control group participants. Conclusions: Children with a range of neurological conditions can participate in this relatively short, running group programme and make improvements in high-level mobility skills.

Factors related to emergency department service use in people with intellectual disabilities in New South Wales

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Aim: To describe emergency department (ED) use and determine factors associated with ED use in a large cohort (n=51,361) of people with intellectual disabilities (ID) in New South Wales (NSW), Australia. Method: Multiple regression models were used to investigate differences in rates and determinants of ED use in people with ID and the NSW population. Results: 46.4% of people with ID had at least one ED presentation. Rates of ED use in people with ID and in the NSW population were 551 and 283 per person year, respectively. After adjusting for age and sex, people with ID had a higher rate of ED presentation than the NSW population (IRR: 1.58, 95%CI: 1.26-1.98, p <0.001). Compared to people without ID, people with ID had a longer waiting time and were more likely to arrive by ambulance and police. Conclusions: Specific strategies are required to support emergency departments as they work with people with ID. Potential strategies will be discussed.

Causes of death in adults with intellectual disabilities in the disability service system in New South Wales

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Aim: To investigate mortality and its causes in adult disability service recipients with intellectual disabilities (ID) in New South Wales, Australia. Method: We linked administrative data from disability services to mortality data. Our cohort follow-up period was Jul 2005 – Dec 2011. Results: The adult ID cohort experienced 732 (3.8%) deaths with median age at death of 54 (range: 42-64) years. 76% of deaths occurred in people aged < 65 years. Age-standardised mortality ratios were 4.3 in the ID cohort and 1.7 in the non-ID cohort, yielding a comparative mortality figure of 2.5. YPLL75 was 134 per 1000
people in the ID cohort and 48 in the non-ID cohort. Cause of death in people with ID was dominated by neoplasm, circulatory, nervous system, and respiratory related deaths. After recoding causes of death previously attributed to the aetiology of the disability, potentially avoidable deaths accounted for 32.8% of deaths in the ID cohort and 16.7% of deaths in the non-ID cohort. **Conclusions:** Our findings indicate multiple markers of premature mortality and an over-representation of avoidable deaths in people with ID.

**John Locke’s changelings, idiots and the species ‘between Man and beast’**

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**Aim:** This paper seeks to elucidate and clarify the multiple terms Locke used which have been suggested as reference to intellectual disabilities (ID). In particular the paper explores Locke’s proposal that the ‘changelings’ represent an initial species ‘between Man and beast’. **Method:** Historical and philosophical analysis was undertaken. **Results:** Locke’s proposal needs to be understood in the context of his views on ‘essences’ and contemporary religious politics which required Locke to establish a rational explanation for those deemed ‘imperfect’ which did not imply imperfection in the work of God. **Conclusions:** Understanding Locke’s positioning of ‘changelings’ and others arguably associated with ID assists us to understanding such terms in context and to avoid trans-historical or de-contextualised assumptions about ID. It further sheds light on how our constructs, both past and present, are highly contingent, socio-political creations and cautions against essentialist understandings of terms and concept such as ‘intellectual disability’.

**Mapping inclusive employment: A participatory mapping research project**

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**Aim:** There is a need to understand the factors that contribute to positive employment experiences for individuals with intellectual disabilities (ID). **Method:** Using community-based participatory methods, an online mapping database was created to allow stakeholders to upload stories of inclusive employment onto the ‘BC Employment Mapping Tool’. Prior to the map going live, 88 employment stories from British Columbia, Canada were purposively selected and added to the map representing 44 employees with ID, 8 family members, 25 employers, and 11 service providers. Using qualitative methods, we explored, ‘What do the stories about inclusive employment teach us about best practices and inclusive employment for employees with ID?’. **Results:** Content analysis revealed seven thematic findings: the social and relational benefits of employment; the importance of training; the importance of supports and accommodations; the value of having responsibilities; the benefits of work; the value of self-employment; and, factors for success. **Conclusions:** The ‘BC Employment Mapping Tool’ is an innovative approach to share best practices of inclusive employment across stakeholders including policy makers, potential employers, individuals with ID, family members, and service providers.

**Microboards and the realisation of the UNCRPD**
Aim: The paper will highlight specific articles of the UNCRPD and how Microboards can contribute to their realisation. Method: Comparative analysis of the UNCRPD and the Microboard model in theory and practice using current Microboard practice in British Columbia, Canada. The analysis involved comparing the principles of the UNCRPD to those of Microboards and research and grey literature on Microboard practice. Results: The Microboard model can indirectly and directly support the realisation of key articles of the convention, notably: Article 12 - Equal recognition before the law, Article 19 - Living independently and being included in the community, Article 20 - Personal mobility, Article 21 - Freedom of expression and opinion, and access to information, Article 22 - Respect for privacy, Article 23 - Respect for home and the family, Article 24 – Education, Article 25 – Health, Article 26 - Habilitation and rehabilitation, Article 27 - Work and employment, and Article 30 - Participation in cultural life, recreation, leisure and sport. Conclusions: Microboards are an effective means of supporting individuals in line with the UNCRPD.

‘Living a good life’: Quality of life and home share

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Aim: This paper reports research exploring whether moving from a group home to home share resulted in improved quality of life (QoL) for individuals with intellectual disabilities (ID). Method: Using qualitative methods, 32 individuals participated in semi-structured interviews: 17 individuals with ID, 7 home share providers, and 8 family members. In total, these interviews represented the experience of 25 individuals with ID. A combined inductive/deductive analysis informed by the ‘Schalock Quality of Life Framework’ was conducted. Results: The findings from this exploratory study revealed that, overwhelmingly, the participants agreed that the home sharing model was flexible, adaptive, and supported QoL more effectively than group homes. One key theme was the importance of the relationship between the individual with ID and the home share provider. Conclusions: Given that home sharing is the growing residential option across numerous international jurisdictions and little research has been conducted with a specific focus on home share, the findings have important implications for policy and practice. For example, the importance of finding a ‘good match’ for individuals and providers informs the need for careful person-centred planning.

Approaches to doing intellectual disability history

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Aim: To provide a set of guiding principles for historical research on intellectual disabilities (ID). Method: This presentation draws on the authors’ collective analysis of existing historical work in the field and discussions with historians working in the area of ID history to identify common areas of what we perceive as errors in interpretation and analysis or unacknowledged assumptions which frequently underlay historical inquiry in the field. From this, the authors collectively developed a set of principles to guide all historical work in the area. Results: A set of principles are proposed to guide future historical
work on ID and to aide in evaluation existing work. Key aspects of the principles include avoiding trans-historical assumptions about what constitutes ID and ensuring a close reading of both language and context while examining ID in differing historical periods. **Conclusions:** Critical reading of ID history requires a sound set of methodological principles to ensure research supports effective understanding of both our past and present.

**Knowing, planning for and fearing death: Findings from adults with intellectual disabilities and disability staff**

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**Aim:** Adults with intellectual disabilities (ID) are thought to understand less about death, but no comparisons are available to adults without ID. Research involving people with ID is silent on end-of-life planning and fear of death. **Method:** We compared the responses of 39 adults with mild or moderate ID and 40 disability staff on experience of death, understanding the concept of death, knowledge of and self-determination about end-of-life planning, and fear of death. **Results:** Adults with ID (95%) and disability staff (100%) reported that they had experienced the death of other people. We found that adults with ID had a significantly poorer understanding of the concept of death, knew much less about and were less self-determined about end-of-life planning, but reported greater fear of death. **Conclusions:** The poorer understanding and lower levels of self-determination we found suggest that future research should develop and evaluate interventions to increase understanding and self-determination about end of life.

**What if Microboard associations didn’t exist?**

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**Aim:** Microboard associations are integral to establishing effective, sustainable Microboards. Vela Canada has been doing this for 25 years. The aim of this presentation is to outline the work of Microboard associations in Australia and Canada. **Method:** Qualitative inquiry of two Microboard associations in Canada and Australia contributed to a comparative analysis of the types of support provided and the implications of that support. **Results:** Microboard associations provide foundational information and learning opportunities to develop individual Microboards and skilled Microboard members. Embedded in this work is role-modelling and support to uphold Microboard principles – choice, control, and friends. Additionally, Microboard associations are a conduit for information related to evidence-based practice and systemic change. There are impacts for the effectiveness of Microboard associations and individual Microboards in relation to their specific political contexts. **Conclusions:** Microboard associations have a key role in facilitating the uptake of Microboards, promoting the application of foundational principles, and building their capacity for effective practice, consistent with the UNCRPD. The long-term availability of a Microboard association provides a safeguard for the individual, the family, the Microboard, and government funding.
Eternal children?: The use of age in constructing women with intellectual and developmental disabilities that are victims of sexual crimes

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Aim: Individual with intellectual and developmental disabilities (IDD) are often portrayed as childish, assumed to be 'eternal children'. This explorative study examines the intersection between IDD, age and sexuality; investigating professionals' social representations of women with IDD that are in prostitution and have been victims of crime. Method: One group (n=7) and five individual, open interviews were conducted with professionals who meet these women. Data were subjected to discourse analysis. Results: Different conceptions of age were used by the professionals in their descriptions of women with IDD in prostitution. Discussion of vulnerability, although common, was raised in specific contexts that supported both a victim discourse and a discourse of protection. Regarding the victim discourse, reference to physical age served to portray women with IDD as the ideal sexual victim. The protection discourse includes the idea that it is necessary to change the sexual behaviours of these women, including the need for fostering or education. Conclusions: The findings reveal that power relations exists between individuals with and without IDD; those with IDD are assumed to be young, sexual vulnerable and in need of protection.

Swedish parents' perceptions of support in relation to gender and country of origin

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Aim: Parents of children with disability in Sweden have been reported to perceive received support as insufficient. This study compares parents' perceptions of available information, contact with different agencies and how well the received support met the needs of the parent in relation to parents' gender and country of origin. Method: Structured telephone interviews were conducted with 144 parents (47 fathers and 97 mothers) who have children with intellectual and developmental disabilities (IDD). Data were analysed quantitatively. Results: Parents reported a lack of information about available support. It was found that parents born in Sweden had more knowledge of available support and more contacts with different agencies and their needs were more often met than parents born outside Sweden. Parents' perceptions of support and unmet needs also varied depending on the parents' gender, with mothers reporting more need for emotional support than fathers. Conclusion: Information about rights and available support to parents of children with disabilities needs to be improved. When providing support it is critical that professionals consider parents' gender, and country of origin.

Peer-support groups as learning platform for support workers meeting parents with intellectual and developmental disabilities

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Aim: Ongoing, informal and facilitated meetings with colleagues could be a cost-effective method of supporting and educating support workers who work with parents with intellectual and developmental disabilities.
disabilities (IDD). A three-year project implementing a parent education programme for parents with IDD aimed to develop and assess peer support as a learning platform. **Method:** From 2010-2013, the Swedish Parenting Young Children (PYC) implementation project developed peer support groups for 25 participating municipalities. Two research studies explored 31 support workers’ and 5 peer support group facilitators’ perceptions and experiences of peer support. Interviews and questionnaires were used, and data analysed using content analysis and thematic analysis. **Results:** Peer support groups were thought to be beneficial for drawing and maintaining attention towards problems surrounding providing support to these parents, and social support for support workers in this work. Experiences and reflections on how peer support groups can be developed and utilised are discussed. **Conclusions:** Peer support groups seem to be a promising method for supporting and educating support workers who work with parents with IDD.

**The development of the Early Response Tool: A brief history**

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**Aim:** A priority of the Queensland Government is to address the needs of vulnerable families including families of children with a disability at risk of being relinquished into out-of-home care. A service response in line with this priority involves the development of a screening tool and early response tool (ERT) to identify these families’ strengths and challenges and inform the provision of targeted supports. **Method:** A systematic literature review, case study analyses and interviews with families identified the critical factors for families who relinquish the care of their child with a disability into out-of-home care. **Results:** The Screening Tool and Early Response Tool will be described as well as the relevance of an early identification assessment for families of children with disabilities. **Conclusions:** These tools and the service model present a viable and cost-effective service response in line with relevant research, policy and the implementation of the National Disability Insurance Scheme. Future research is needed to establish the content validity of the ERT measures. We also needed to test the application of the tools with families.

**Visual functioning in persons with profound intellectual and multiple disabilities, with specific reference to cerebral visual impairment**

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**Aim:** There is a need for analysis of visual functioning of people with profound intellectual and multiple disabilities (PIMD) in regards to their level of visual functioning due to cerebral visual impairment. **Method:** From 70 case notes of persons with PIMD who attend(ed) two special schools in the Netherlands, data have been collected on visual acuity, field of vision and contrast sensitivity. Medical history, ophthalmological findings, level of development and level of motor functioning were gathered from the files. Data from observations on the use of vision in daily living are used to determine the actual level of visual functioning. After analysis we can expose statistical connections between these data. **Results:** Statistics on the data and the way these inter-relate will be presented. Some video material will illustrate the visual behaviour of this PIMD group. **Conclusions:** Insight in visual functioning
of persons with PIMD in relation to their developmental age, motor functioning and use of vision in daily life is available after analysing 70 cases. The outcome of this analysis will provide practical insight for teachers and carers.

Screening and diagnosing disturbed attachment: Persons with intellectual disabilities

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Aim: Disturbed attachment is noted in 80% of the families in which abuse, neglect and family violence are mentioned. A positive screening for disturbed attachment was found in 42% of children with an IQ between 50 and 85 referred for psychiatric consultation. High prevalence of disturbed attachment may be caused by the impact of the child’s disability on parental distress and the parent-child emotional availability as well as child characteristics. The aim of this study was to find systematic ways of screening and diagnosing disturbed attachment in persons with disabilities. Method: Recent research studies including persons with intellectual disabilities (ID) were reviewed. Results: The practice parameters for assessments of reactive attachment disorder with adapted procedures for persons with ID and diagnostic guideline for anxiety and challenging behaviour are recently reported as ways for screening or diagnosing disturbed attachment. Conclusions: Using a systematic approach to screen and diagnose mental health problems among persons with disabilities contributes to adequate diagnosing.

AFL Auskick and Deakin University: Supporting children of all abilities on the footy field

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Aim: Children with disability participate less in Australian Football League (AFL) Auskick than their typical peers. The AFL-Auskick-Deakin partnership investigates current rates of participation and perceived barriers and benefits. Data will inform what resources delivered in which media are supported by families and coaches to better support children of all abilities to be involved and engaged in AusKick. Method: Parents and coaches involved in AFL Auskick were recruited to participate in an online mixed methods survey or in a focus group. Participants were recruited through social media and local contacts at their local Auskick club. Focus groups were held in both regional and metropolitan locations in Victoria. Results: Survey and focus group results will be presented together with an international review (e.g., ACEing Autism, Chelsea Football Club). Preliminary results from the international review suggest that there are principles of success (coach training, collection of data, balancing centre consistency with autonomy, etc.) identified from existing programmes. Conclusions: Great anecdotal information exists supported by a growing body of evidence supporting the physical, emotional and mental health benefits of sport for children of all abilities.

Women who love: An explorative study on the lived experiences of lesbian and bisexual women with mild intellectual disabilities in the Netherlands

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Aim: Empirical research on homosexuality among people with intellectual disabilities (ID) is limited. Knowledge about personal experiences of lesbian and bisexual women with ID is scarce. This study set out to answer the question: What are the lived experiences of a specific cohort of lesbian and bisexual women with ID in the Netherlands? Method: A qualitative study with semi-structured interviews was conducted with 10 lesbian and bisexual women with a mild ID (average age=33 years). The interviews were audio-taped, typed out verbatim and transcripts were analysed using NVivo10. Results: Participants reported positive and negative experiences. Most participants reported a lack of sexual experiences. They encounter difficulties in finding a partner and are not familiar with the lesbian community. Participants were not openly lesbian or bisexual in all settings; most participants were afraid for negative reactions (at work or in their neighbourhood). They expressed a need for specific sex education. Conclusions: Specific problems make these women vulnerable: their search for a suitable partner, difficulties with being openly lesbian or bisexual, and their needs for specific sex education.

Welcome to Our World: Evaluation of a strengths-based sibling portfolio

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Aim: This research provides a qualitative evaluation of a sibling portfolio, Welcome to Our World, which is completed by sibling pairs and focuses on positive aspects of the sibling relationship. Method: We studied school-aged sibling pairs in which one child has an intellectual disability (ID) or autism. The siblings jointly completed the portfolio, writing answers to questions and decorating pages with drawings, stickers, and ink stamps. The children were videotaped as they worked on the portfolio together. Their mothers were interviewed about their children, the sibling relationship, and what they learned from the sibling portfolio. The maternal interviews and the children’s conversations while completing the portfolio were transcribed. Sibling portfolio content and sibling conversations were thematically coded by the two authors. Results: Siblings easily identified strengths in their relationship and wrote about positive aspects of themselves and their siblings. Sibling themes included strengths of self, strengths of sibling, relationship strengths, and shared activities. Siblings shared similar hopes for their future. Conclusions: The sibling portfolio can be a useful mechanism to communicate siblings’ positive feelings and perceptions to parents and others.

Looking through different windows: How inclusive research can influence policy

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Aim: The end purpose of inclusive research in disability policy is to improve people’s lives through influencing policy. Along the way, people with disability and the people they research with also learn how to do and use research better. What combination of relationships is needed to make that happen? Method: The research team of people with disability, academic researchers, a Disabled Persons Organisation and government officials partnered to review the closure of institutions in New South Wales, which had been a very controversial policy process. The team used participatory methods to organise and conduct the review and apply the results. Results: The research team and government
found new ways of working together that meant that the review results were useful for the government and the community. These included summarising the results into short points, framing them into future action, and using the voices of the people’s stories to demonstrate good practice, as well as what could be improved. **Conclusions:** Planning for inclusive research practice and policy change from the beginning of the project can be useful for the government, researchers and community.

**Students with developmental disabilities in Australia: Parents’ and teachers’ experiences with schooling transitions**

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**Aim:** Students with developmental disabilities (DD) often experience difficulties during schooling transitions. This is due to a number of factors, such as a lack of communication between relevant stakeholders and a lack of information about available options. Although there are a number of scientifically validated models of transitions and evidence-based transition practices, there is limited research available about the transitions of students with DD in Australia, particularly in relation to the use of evidence-based practices in schools. **Method:** The authors interviewed 22 parents and 26 teachers of students with DD, from both special and mainstream government schools in New South Wales, Australia. The interviews were analysed using inductive content analysis. **Results:** While there were some evidence-based transition practices in place, many were missing, particularly in the area of family and student involvement in transition planning. **Conclusions:** More information and teacher training in the area of evidence-based transition practices is necessary.

**Dissecting the Alzheimer’s disease phenotype of Down syndrome**

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**Aim:** Amyloid plaques suggesting neuropathological signs of Alzheimer’s disease (AD) are present in the brains of nearly all individuals with Down syndrome (DS) at the age of 30, but not all show the clinical signs of AD. The London Down syndrome consortium aims to identify protective and risk factors for the AD phenotype in this population. **Method:** We have assessed >400 adults with DS with a variety of cognitive tasks including tests of memory and executive functions (using CANTAB computer tasks) and symptoms of dementia (using CAMDEX-DS). Differences in individual cognitive and clinical profiles are related to genetic and cellular differences to identify predictive phenotypes for AD in DS, and linked with mouse model studies to explore underlying mechanisms. **Results:** The sequence of cognitive decline with aging in DS, and data on clinical differences associated with APOE alleles across the age span will be presented. **Conclusions:** Genetic analysis and detailed cognitive phenotyping will help to delineate the mechanism of AD in DS. Such data may also be used to plan clinical trials to prevent or delay AD in this population.

**Neurocognitive disorders: DM-ID 2**
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**Aim:** Dementia is now named a major neurocognitive disorder (NCD) in the DSM-5, and an attempt has also been made to provide criteria for an earlier stage of the disorder with a new diagnostic category (Mild NCD). The aim is to discuss how these criteria will be adapted for the Diagnostic Manual - Intellectual Disabilities 2 (DM-ID 2).

**Method:** A review of the recent literature was undertaken using key databases to identify evidence on the diagnosis of delirium and NCD (dementia) in individuals with intellectual disabilities (ID). We also reviewed the DSM-5 criteria and made recommendations for interpreting these. This was followed by a project to apply these criteria to case vignettes from more than 100 older adults with Down syndrome (DS) to determine inter-rater reliability and agreement with DSM-IV and ICD-10 criteria for dementia and Alzheimer's disease.

**Results:** Case studies illustrate the adaptation of the criteria for DM-ID 2. We will present data on the reliability and validity of the DSM-5 criteria in individuals with DS.

**Conclusions:** The DM-ID 2 recommendations for the DSM-5 criteria for NCD may improve clinical diagnosis of dementia in people with ID.

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Social support for mothers of children with intellectual disabilities in mainland China

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**Aim:** Chinese mothers of children with intellectual disabilities (ID) have a variety of support needs, but little is known about the support they receive. This study explored mothers’ perceptions of the existing social support for them.

**Method:** 12 mothers of children with ID aged 10 to 13 years were recruited in a special school in Shenzhen, China. The semi-structured interviews lasted 30 minutes to 2 hours. Data were transcribed, translated, and then analysed thematically.

**Results:** Mothers received instrumental, emotional, and informational support from family members, friends and neighbours, special school teachers, and the government. This support was considered helpful for relieving mothers’ physical and mental pressures. However, mothers raised numerous issues regarding this support including family conflicts; few contacts with others beyond family members; discriminations from community members; lack of communication with teachers; and low utilisation of government support.

**Conclusions:** This study highlights the strengths and weaknesses of the existing supports. These findings give practitioners insights into strategies that may enhance the effectiveness of the existing support system for mothers of children with ID.

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Chinese mothers’ perceptions and experience of their children with intellectual disabilities learning at mainstream schools

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**Aim:** Mothers are key decision-makers regarding educational placement for children with intellectual disabilities (ID). This study explored Chinese mothers’ perceptions and the experience of their children being transferred from mainstream schools to special schools.

**Method:** Mothers of children with ID were recruited in a special school in a city in South China. Ten mothers participated in semi-structured interviews. Thematic analysis was used to analyse the data.

**Results:** Mothers considered learning at
mainstream schools beneficial for their children’s behavioural and cognitive development. However, mothers were concerned about their children’s learning difficulties and bullying from other children. The reasons mothers gave for their child returning from mainstream to special schools were: discriminatory responses of teachers and other parents; exclusion of their child from social and academic activities; and their own mental stress due to associated stigma. **Conclusions:** Chinese mothers considered an emphasis on academic performance and an unwelcoming environment to be factors that rejected their children with ID from mainstream schools. Efforts in these areas can potentially increase the chances of mothers placing their children in mainstream schools.

**Human rights of persons with intellectual disabilities in Lithuanian social care institutions**

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**Aim:** To analyse the human rights situation of persons with intellectual disabilities (ID) who are residents of social care institutions particularly focusing on violence in the form of restrictions, seclusion and isolation. **Method:** Semi-structured interviews were conducted during visits to social care homes. In each institution one or two representatives from the administration, all senior social workers and residents who have had plans living independently were interviewed. Interviews were transcribed and coded with a focus on thematic units. **Results:** Residential care institutions are places where persons with ID spend their lives obeying restrictions and surviving violence. The most frequent forms of violence are different types of abuse; placement in the isolation rooms; and restriction on the freedom of movement. **Conclusions:** Violence towards residents of care institutions number more than just a few isolated cases. Analysis demonstrates that the problem is systemic. The tradition of exclusion of persons with ID remains still very strong in Lithuania. The society’s mandate to isolate them in closed social care institutions extends to silent permission to violate other basic human rights.

**Fathers with intellectual disabilities: Experiences as men, as fathers, and of social care in England**

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**Aim:** To better understand the experiences of fathers with intellectual disabilities (ID) as men, as fathers and as recipients of ID services in England. **Method:** In this small scale qualitative study, ten fathers were recruited and interviewed about their lives following a semi-structured format. Practitioners and managers working in English ID services were also interviewed about working with fathers. Data analysis used an abductive interpretive phenomenology. **Results:** Initial hypotheses are: that fatherhood may offer an important opportunity for men with ID to build a meaningful identity as men; that ID services may focus on supporting mothers, but miss opportunities to engage fathers in their parenting role; and that outcomes for children may be improved by better engaging fathers with ID in their role. **Conclusions:** Services for parents with ID are predominantly designed for, delivered to and received by mothers. This study contributes to our understanding of the lives and needs of fathers with ID with implications for service delivery.
Patient journeys: Lived experience of the health system

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Aim: To gather the experiences of people with intellectual disabilities (ID) and their carers of hospitalisation, and to use these to help build a Hospitalisation Toolkit to improve health services.

Method: Using a modified PICKER methodology for surveying patient experience, New South Wales (NSW) Agency for Clinical Innovation Intellectual Disability Health Network conducted in-depth interviews. PICKER methodology uses survey instruments to obtain reports of patient experience and identify areas for improvement. Results: Ten individuals represented people of various ages and locations across NSW. All had ID, or were carers, and had extensive experience in accessing health services. Some consistent themes emerged. People spoke of wanting to improve the system and of some exceptional health staff and services. People interviewed described the complexity of health needs for people with ID. Conclusions: The material gathered provided a rich source of insights, quotes and guidance which was thematically analysed and published and is currently being used to shape improvements and guide health service delivery for people with ID in NSW.

Mainstream health system supports for people with intellectual disabilities in New South Wales

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Aim: To map specialised health supports for people with intellectual disabilities (ID) in local health districts across New South Wales (NSW), to identify awareness of disability by health staff and to gather their thoughts of how to improve health service delivery. Method: The NSW Agency for Clinical Innovation Intellectual Disability Health Network interviewed more than 90 key contacts from local health districts across NSW. Questions covered disability awareness and support, communication methods, routine adjustments, specialised supports and their key characteristics, involvement of staff in disability action planning and suggestions about potential improvements. Results: Although results showed generally low levels of support for people with ID in some areas, there was a high level of motivation amongst clinicians and managers to improve the way they deliver service. Suggestions for improvement fell into ten main themes. Conclusions: The ID Health Network has incorporated these results and its analysis into its development of a toolkit and guidelines to support health services deliver improved health services for people with ID.

ID Co-design Hospitalisation Project

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Aim: Using co-design principles, working with the Agency for Clinical Innovation (ACI) Intellectual Disability Network’s consumers, carers and clinicians to implement changes within the health system, the ACI Patient Experience and Consumer Engagement (PEACE) Team sought to produce better experiences of hospitalisation for people with intellectual disabilities (ID) and carers. Method: Participants attended a masterclass and subsequent coaching in co-design principles. Using participatory
action research, user-centred design, learning theory and narrative-based approaches, the emotional content of healthcare hospital experiences were captured in storytelling. Issues arising were identified at a facilitated solution co-design workshop. The solutions for improvement were then enhanced in small working groups overseen by a local steering group and supported by further coaching. **Results:** Local teams identified needs, solutions and implemented strategies. Key benefits reported include service improvement, strengthened partnerships between patients, families and staff and enhanced experience and satisfaction with health-care. **Conclusions:** Building local capacity to utilise co-design methodology and implementation, improves the patient experience of hospitalisation for people with ID and the carer.

**School achievement of students without disabilities in inclusive classrooms: Results of meta-analysis**

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**Aim:** This study provides an analysis of the effectiveness of inclusive education for students without disabilities. **Method:** Using electronic databases with relevant studies and different configuration of words: inclusive education, effectiveness, co-teaching, achievement, students without disabilities, able students, we identified 94 papers about the school achievement of students without disabilities. 48 studies met our inclusion criteria and were included in the meta-analysis. **Results:** Students who learn in inclusive classrooms have higher achievement than students in regular classrooms (d=0.13). There are variables, which moderate the effectiveness of inclusive education including country (classrooms in USA are the most effective, d=0.14), the absence of children with moderate and severe disabilities in the classroom (d=0.22), the absence of children with behaviour problems in the classroom (d=0.22), co-teaching (d=0.25), inclusion as an experimental implementation (d=0.2), and high school classroom (d=0.27). **Conclusions:** The results show that inclusive education is effective in the case of academic achievement for children without disabilities. The effectiveness is moderated by different factors.
Evaluating and comparing models of training to facilitate future planning by people with intellectual disabilities and their family carers

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Aim: The aim of this ongoing study is to evaluate and compare the effectiveness of two models of future planning training, a Northern Ireland programme for staff and a Scottish programme for family carers, in order to better understand the enablers and barriers to future planning by people with intellectual disabilities (ID) and their family carers. Method: A mixed methods approach was used. Phase 1 was quantitative and included an assessment of the psychological health of Northern Ireland and Scottish family carers at a one-year follow-up. Subsequent Northern Ireland-based phases were qualitative and explored the perspectives of family carers and staff through three focus groups and eight interviews. Qualitative data was analysed using Newell and Burnard’s thematic content analysis framework. Results: The effect on carers’ psychological health, future planning milestones, enablers and barriers to future planning will be presented. Conclusions: A model for effective future planning training will be proposed with consideration of the enablers and barriers to inclusive future planning from a multi-perspective approach.

Assessing the psychometric properties of the Diabetes Illness Perception Questionnaire and the Diabetes Illness Representation Questionnaire for adults with and without ID

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Aim: This study compares the psychometric properties of the Diabetes Illness Perception Questionnaire (DIPQ) and Diabetes Illness Representation Questionnaire (DIRQ) in adults with and without ID. Method: Semi-structured interviews were conducted with 188 adults with ID and compared with 755 adults without ID: both with type 2 diabetes across the UK. Statistical analyses were performed to test the psychometric properties of the DIPQ and DIRQ and to examine if there were any mean differences across samples. Results: The factor structure was found to hold for the DIPQ (participants’ illness coherence score, perception of the duration of their illness and the perception of their ability to affect the course of their diabetes) for both the adults with and without ID. However, the factor structure was found to be poor for both the adults with and without ID for the DIRQ (participants’ perceived seriousness of condition and the perceived impact of diabetes). Conclusions: The DIPQ questionnaire can be used as a secondary outcome measure. Caution must be taken with the DIRQ.

DESMOND-ID: Assessing the quality of life in adults with intellectual disabilities and type 2 diabetes: Psychometric properties of the WHOQOL-BREF

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Aim: The World Health Organization has developed a brief generic questionnaire to assess quality of life (QoL), the WHOQOL-BREF. It has been studied in diverse groups, but not in adults with ID. This study compares the psychometric properties of the questionnaire in adults with type 2 diabetes with and
without ID. **Method:** Semi-structured interviews were conducted with 200 adults with type 2 diabetes and compared with 700 adults without ID with type 2 diabetes across the UK. Statistical analysis was performed to see if there were any differences across the samples. **Results:** Findings are reported across each of the two groups on each of the four broad domains: physical, psychological, social and environmental. **Conclusions:** Comparative research on the similarities and differences in the quality of life among adults with and without ID and type 2 diabetes is required in order to test whether or not QoL in people with ID can be measured reliability with the WHOQOL-BREF items.

**DESMOND-ID: Outcomes of a pilot feasibility study exploring the HbA1c for adults with intellectual disabilities and type 2 diabetes**

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**Aim:** To determine the feasibility of conducting a definitive randomised controlled trial (RCT) of an adapted structured education programme for type 2 diabetes for adults with intellectual disabilities (ID) (DESMOND-ID) targeting HbA1c as its primary outcome measure. **Method:** The study was a two arm individually randomised pilot trial. The DESMOND-ID programme was delivered to 20 participants over 7 weeks at a local health centre. The remaining participants were randomised to the control group. DESMOND-ID was delivered by specially trained educators in each country. Pre/post measures were collected from both cohorts. Focus groups were held with all participants. **Results:** The focus groups indicated that the DESMOND-ID programme could be successfully delivered; with attendance and retention rates of the adults with ID over 90%. Changes to HbA1c, cholesterol, weight and blood pressure will be discussed. **Conclusions:** The results indicate that a definitive RCT could be undertaken and that the DESMOND-ID programme appears promising for adults with ID and their carers.

**Examining the activity participation of young children with intellectual and developmental disabilities**

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**Aim:** Children with intellectual and developmental disabilities (IDD) participate in fewer activities relative to their peers. This study examines participation in this population by focussing on the frequency of participation, types of peers, and barriers to participation. **Method:** 290 Canadian parents of children (age 3 to 8 years) with IDD completed online surveys regarding the frequency of participation in seven activities. When participation did occur, they were asked with whom. When participation did not occur, they were asked about barriers. **Results:** The majority did not participate in most activities. Fewer than 10% participated more than once a week. However, when they did participate, it was often with typically developing (TD) peers. Barriers were child not able, child not interested, and not allowed or invited. Logistical reasons (cost, distance) and unavailability were less common. **Conclusions:** Although it is concerning that this group rarely participates in activities, it is encouraging that when participation does occur, it is with TD peers, an indication of inclusion in social settings. With a better understanding of the barriers, service providers can implement effective intervention strategies to enhance social inclusion.
Predictors of activity participation in children with IDD

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Aim: The purpose of this study was to examine child, family, and community factors as predictors of activity participation for children with IDD. Method: 197 Canadian parents of children (aged 3-21) with severe IDD completed a survey, which included variables relating to the child, family, and community, alongside a measure of activity participation. Hierarchical regression analysis was used to determine the predictors of activity participation. Results: The model significantly accounted for 30% of the variance in activity participation (F (10, 197) = 8.92, p < .01). Greater child adaptive skills, greater parental socialization, and attending integrated school programmes significantly predicted greater activity participation. Conclusions: The proposed model provides a strengths-based perspective, which focuses on children’s skills and the importance of supportive relationships and environments in creating positive outcomes for children with IDD. Furthermore, strategies can be aimed at tackling the factors that are predictive of participation.

Exploring therapeutic interventions to support bereaved adults with intellectual disabilities: A mixed methods study using photovoice

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Aim: This presentation discusses a research study designed to elicit perceptions of support and therapeutic interventions following loss and bereavement. Method: Semi-structured interviews were conducted with 10 adults with intellectual disabilities to identify impact and coping strategies following bereavement. Interviews were facilitated through discussion of participants’ photographs taken after photovoice workshops. Additionally, data were gathered from open-ended questionnaires and focus groups with advocates; focus groups with professional carers; and interviews with family carers, to explore key issues and support needs and their role in supporting bereaved adults at home or in a care setting. Data were analysed using thematic analysis. Results: Preliminary analysis demonstrates limited knowledge of support services and interventions, but highlights the pivotal role of family and friendship networks. Conclusions: Bereavement and loss are difficult concepts for everyone, and participants demonstrated their huge impact on the lives of people with intellectual disabilities. This research demonstrates the social, psychological, and emotional impact of loss and highlights the diverse coping mechanisms employed.

Creative ways of engaging and involving bereaved older adults with intellectual disabilities in research: Developing a photovoice workshop and interviews

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Aim: To critically discuss the use of photovoice as a research tool with adults with intellectual disabilities (ID). Method: Ten bereaved adults with ID (40-65 years of age) participated in a photovoice workshop to learn about the ethical and technical issues of using a camera. This workshop was designed to prepare
participants to take photographs related to loss and discuss them in subsequent semi-structured interviews to identify impact and coping strategies following bereavement. **Results:** The workshop enabled the participants to take and discuss a total of 410 photos related to loss and bereavement. Participants were able to demonstrate their understanding of loss and what helped them to cope after bereavement using photos they had taken. Participants learned a skill for life and got cameras to keep. **Conclusions:** Creative methods like photovoice and clear information can help engage adults with ID in research and enable them to share their viewpoints on sensitive topics.

**Insufficient documentation of participation: A study of contents in implementation plans for adults with profound intellectual disabilities**

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**Aim:** This study investigated what areas, on the basis of International Classification of Functioning, Disability and Health (ICF) were documented in individual implementation plans for adults with profound intellectual disabilities. **Method:** An explorative, descriptive, document analysis of 17 plans was performed. **Results:** Only 163 different ICF category codes were identified mainly in the areas of Activities and Participation (Self-care) and Environmental factors (Personal care providers and personal assistants). Participation was most frequently coded in the areas of Community, social and civic life and Self-care. Personal care providers and personal assistants correlated with Recreation and leisure, Washing body parts and Eating. Plans focused on Self-care and Community, social and civic life while other life areas were seldom, or not at all, documented. **Conclusions:** More focus in documentation of participation in other life areas is needed and it is important that the documentation clearly shows what the person with profound intellectual disability wants, wishes and likes and how he or she wants support to be provided.

**Sensory profiles of people with autism: A comparison with the general population and adults with dyspraxia**

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**Aim:** The two main aims for this study were to investigate the sensory profiles of adults with autism spectrum disorder (ASD) and compare these findings with the sensory profiles of adults with dyspraxia and the general population. **Method:** The Adolescent/Adult Sensory Profile (Brown and Dunn, 2002) was used to measure sensory responses in adults with ASD (n= 32), dyspraxia (without ASD or ADHD co-diagnosis; n=37) and the general population (n=35). Participants were recruited via universities’ email lists and relevant organisations whereas the data on dyspraxia were collected prior to this study. **Results:** There was a significant difference between the three groups. Participants with ASD were more likely to be sensitive to and avoid sensory input. Also, adults with ASD differed significantly on the sensation seeking and sensation avoiding quadrants when compared to adults with dyspraxia. **Conclusions:** Sensory processing difficulties are highly evident in adults with ASD but also in adults with
The role of retail in social exclusion of adults with complex communication needs including those with IDD

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Aim: To review the evidence for the role of the retail sector in the social exclusion or inclusion of adults with or without IDD using Augmentative and Alternative Communication who shop independently.

Method: A systematic literature review was conducted by the first author.

Results: There are few studies into the retail customer experience of adults with disability, and none focusing on adults with complex communication needs. However, interactions with retail customer service staff are a critical factor in the customer experience.

Conclusions: The retail customer experience of people with complex communication needs is under-researched. Although there has been a strong focus in research on instruments of social inclusion for people with disability, there has been less interest in free-market environments such as retail. The legal infrastructure protecting customers with disability has predominantly focused on customers with mobility impairments. Little is known about the customer experience of people with complex communication needs using Augmentative and Alternative Communication, including customers with IDD.

Expressive vocabulary development in children with Down syndrome: A longitudinal study

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Aim: This longitudinal study examines individual differences in the early expressive vocabulary development of young children with Down syndrome (DS) with regard to vocabulary modality, and nature of the vocabulary growth.

Method: Expressive vocabulary growth of 26 children with DS (aged 18 months; 18 boys and 8 girls) was measured over an 18-month period based on monthly administrations of the Lexi questionnaire. Modality of expressive vocabulary (predominant Gestures[G], predominant Speech[S], Gestures + Speech[GS]), and nature of the vocabulary growth (growth without a spurt, growth spurt) were determined.

Results: Children with DS showed a G-profile (31%) or a GS-profile (38%). No S-profile was observed before the age of 30 months. 11% of the children changed from a G-profile to a GS-profile, 6% changed from a GS-profile to an S-profile. With regard to the nature of vocabulary growth, 65% showed growth without a spurt, of which 31% showed only a marginal vocabulary growth. 35% showed a vocabulary growth spurt.

Conclusions: Different vocabulary modality and growth profiles for children with DS were identified, which may provide useful information for language intervention programmes.

Attachment and behaviour/emotional problems in children with autism spectrum disorder

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**Aim:** This study aimed to investigate the association between attachment and behavioural/emotional problems in children with Autism Spectrum Disorder (ASD). **Method:** A mixed-methods cross-sectional design was adopted. Thirty parents of children diagnosed with ASD and thirty parents of children diagnosed with other developmental disabilities completed assessments of child behaviour and emotional problems (DBC), child attachment (CPRS), an autism screening tool (SRS), and an attachment interview (DAI). Children were aged 3.5-12 years. Patterns of attachment and patterns of behaviour and emotional problems will be explored using a series of regression analyses. A qualitative approach will also be used to report findings from the attachment interview conducted with parents. Comparisons between children with and without ASD on attachment and behaviour/emotional problem measures will be explored. **Results:** Preliminary results indicate an association between attachment and behavioural/emotional problems across groups. **Conclusions:** The findings of this study will be discussed and summarised for clinical implications, specifically potential targets for interventions in children with and without ASD who have attachment difficulties.

**An international comparison of a health promotion questionnaire: Use in the UK and Canada**

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*University of Manitoba, CANADA*

**Aim:** The aim was to validate a health promotion questionnaire developed in the UK (Northern Ireland) for use internationally. **Method:** The questionnaire was completed by 248 carers from Northern Ireland and 111 support workers in Canada (Manitoba). A confirmatory factor analysis approach was used to assess the stability of the instrument across populations, particularly in terms of the factor structure and loadings. In addition, Cronbach's alpha coefficients were calculated for the factors in order to assess internal consistency and reliability across the two populations. **Results:** Tool development across different countries needs to consider the use of language such as intellectual disability used in Canada and learning disability in the UK. The large number of items may have influenced the low response rate and therefore the ability to adequately test the tool. **Conclusions:** Validated tools to assess the needs of support staff in terms of their knowledge and understanding of health promotion for this population have been scarce. This presentation will discuss the language variations and details of statistical results of the tool testing.

**Injury reports by carers of people with intellectual disabilities displaying challenging behaviours: A mixed methods study by a unique team**

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**Aim:** The aim of this research is to understand how workplace injury occurrence relates to staff education and training about challenging behaviour, staff perspectives about their use of information and factors most commonly associated with injuries. **Method:** This mixed methods study included three phases: 1) one year of retrospective audit of injuries and programme manager interviews; 2) prospective injury report review and interviews of injured workers; 3) interviews with trainers to determine fit of training to issues faced by workers. **Results:** Themes from interviews from each group and an overview
of the over 200+ injuries were reconciled using the ecological model. One of the main findings was a gap between the two contexts: training of the workers and the practice environment, where it is difficult to ‘translate’ the generic training into more specific everyday use. **Conclusions:** The study provides greater understanding from a variety of stakeholder perspectives of the factors influencing the ability of support workers to use their training to prevent their injuries.

**Knowledge of health promotion: Support workers in two countries**

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**Aim:** The health of people with intellectual disabilities (ID) is often poorer than that of the rest of the population. Preventative screening and health promotion activities are dependent upon the staff who support them. The specific aim of this study is to replicate a study conducted in Northern Ireland to compare results from two countries and consider the contexts of the findings. **Method:** A cross-sectional study using an electronic survey of three organisations’ support workers (n=1000) was conducted. Data cleaning and descriptive analyses were conducted using SPSS. **Results:** The scale scores for Attitudes towards health and knowledge of health promotion were very similar between the two countries, indicating that support workers believe that people with ID can lead healthy and fulfilled lives (>40% strongly agree). There is still a lack of knowledge however about potential health risks, such as risk of death from cancer (>90% disagree or strongly disagree). **Conclusions:** This study could provide the baseline for greater staff training and support of people with ID to improve their health.

**The impact of the Coaching Young Athletes course on programme leaders’ knowledge, confidence and self-efficacy**

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**Aim:** Special Olympics Canada (SOC) was funded by the Public Health Agency of Canada to develop, implement, and resource Active Start and FUNdamentals programmes for 2-6 year old and 7-12 year old children, respectively. The aim of this project was to evaluate the impact of the training on programme leaders’ knowledge and self-efficacy to implement these programmes. **Method:** One-day workshops were conducted in eight provinces. Bandura’s (2006) recommendations were used to develop the perceived self-efficacy questionnaire of task demands based on the key components of the SOC training, specifically: developing children’s physical literacy, goal setting, planning and implementing practices, creating an enjoyable learning environment, and managing risks. Pre- and post-workshop questionnaires were completed by 142 programme leaders (82% women). **Results:** Repeated measures analyses of variance revealed significant increases in participants’ confidence to talk about programme concepts such as physical literacy and confidence to plan, monitor, and implement these programmes. **Conclusions:** These workshops appear to be an effective tool to increase programme leaders’ skills. Research examining the subsequent impact of programmes implemented by the trained leaders on children’s development is needed.
Defining perception-oriented care for elderly people with intellectual disabilities in collaboration with practitioners and other stakeholders

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Aim: Perception-oriented care (POC) is a commonly used practice-based intervention in the Netherlands for elderly people with intellectual disabilities (ID). Our aim is to define POC in collaboration with practitioners and other stakeholders. Method: Existing documents and evidence about POC were selected and content analysis was carried out by three researchers aimed at identifying themes underlying POC. Analysis was conducted inductively and deductively to reach data saturation. Resulting themes were discussed in five semi-structured interviews with stakeholders to clarify or complete themes that were unclear. In addition, three focus groups in which a total of 18 practitioners participated were held to check the consistency of the definition from a practice-based view. Results: Both theory- and practice-oriented perspectives were included in identifying major themes and defining POC for elderly people with ID. Conclusions: The applied method provided valuable insights on first steps in developing perception-oriented care, a practice-based intervention, into an evidence-based intervention in collaboration between theory and practice.

Physical activity and behavioural sleep problems in young people with autism spectrum disorder

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Aim: The current study aimed to investigate levels of physical activity and behavioural sleep problems in children with ASD. Method: Participants aged 4-6 years (n=22) with ASD were recruited from a larger study. Physical activity was measured using a hip-worn actigraph accelerometer worn for one week. Age-appropriate cut-points were used to determine average daily sedentary time (≤25counts.15s⁻¹) and physical activity (≥420 counts.15s⁻¹). Behavioural sleep problems were measured using the Children’s Sleep Habits Questionnaire. Results: The pilot study indicates that there was a negative moderate correlation between sleep onset delay and physical activity (r =-.46, p < 0.05) and a negative moderate correlation between sleep disordered breathing and physical activity(r =-.49, p <0.05). Conclusions: The findings indicate the presence of a relationship between physical activity and sleep in children with ASD. The initial findings shall need to be replicated and expanded on. Such research will set the scene for informing the development of novel interventions that seek to promote healthy outcomes in individuals with ASD.

Can gait differentiate children with ASD from children without ASD? A pilot study

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Aim: From an early age children with ASD show delays in motor development. Gait and motor disturbance may be present prior to social and language difficulties becoming clinically apparent. Our previous analysis of the stability of ASD gait features indicate that children with ASD have more variation
in cadence and stride length. It is hypothesised that gait profiles will differentiate children with and without ASD. **Method:** Participants were recruited from a clinical intervention centre in Melbourne. Children aged 2-3 years with ASD (n=8) and without ASD (n=8) participated in gait testing, using the GaitRite walkway. Spatiotemporal variables from three valid walking trials were examined. Data were analysed using ANOVA. **Results:** Pilot data indicated that 2-3 year old children with ASD showed greater variability for stride length and time. This is consistent with our previous study of 4-6 year olds with ASD. **Conclusions:** Establishing key aspects of motor impairment that distinguish children with and without ASD, and are present during critical motor developmental stages, will help define the difficulties encountered, and open up opportunities for early intervention.

**Functional correlates of sedentary behaviour in children with autism spectrum disorder: A pilot study**

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**Aim:** The current study aimed to investigate the correlates of sedentary behaviour in children with autism spectrum disorder (ASD). **Method:** Participants aged 4-6 years (n=22), with a current ASD diagnosis were recruited from a larger study. Sedentary behaviour was measured using a hip-worn actigraph accelerometer worn for one week. Age-appropriate cut-points were used to determine average daily sedentary time (≤25counts.15s⁻¹). Child, family and environmental correlates were measured via parent questionnaire. **Results:** A moderate positive correlation between sleep problems (r = .48, p=.04) and sedentary behaviour was found. Moderate negative correlations between imaginary play (r = -.50, p=.02), preference for inside activity (r = -.46, p=.03) and sedentary behaviour were found. Contrary to prior research, family and environmental predictors were not associated with sedentary behaviour. **Conclusions:** Sedentary behaviour is associated with a range of functional impairments in children with ASD. Further research to investigate the directions of these relationships is required. Such research will set the scene for informing the development of novel interventions that seek to promote healthy outcomes in individuals with ASD.

**Evidence and perspectives from the US: Creating an annual review protocol to determine the need for SIS-A reassessment**

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**Aim:** The SIS-A is used throughout the world, and many jurisdictions require an annual reassessment. The time devoted to reassessment is a concern in cases where the resulting information is redundant. A protocol was developed to distinguish cases where there is a high likelihood that support needs have not changed from those where there is a possibility that support needs have changed. **Method:** To create the protocol, an online dataset of 129,864 people was analysed using multi-trait multi-method (MTMM) analyses and confirmatory factor analyses. A field test was conducted with 100 individuals with a previous SIS-A assessment. Subjects were administered the protocol and then reassessed using the SIS-A. The protocol’s predictive power was investigated using the Chi-Square goodness of fit test.
**Result**s: Findings showed that the protocol (a subset of 21 SIS-A items and three questions regarding changes in life status) provided a strong predictor. **Conclusion**s: Professionals can use the protocol to determine whether a SIS-A reassessment is warranted.

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**Early outcomes of the Individual Supported Living (ISL) Project for adults with intellectual disabilities**

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**Aim**: This Australian Research Council Linkage Project is evaluating 150 ISL arrangements across Western Australia, New South Wales and Victoria. The presentation discusses preliminary outcomes, describing some major models of ISL and the nature of collaboration between formal and informal supports.  

**Method**: The Project’s third stage, to be completed in 2016, uses the ISL Manual evaluation instrument, developed in earlier Project stages, that consists of 21 attributes. Evaluation also includes outcomes measurement and an interview describing pathways followed in arrangement development. The manual is based on a definition of ISL consistent with UNCRPD Article 16. **Result**s: ISL arrangements include people across the ranges of support needs, adult age, and time in arrangement. Vignettes drawn from the first 50 evaluations completed describe the major types of ISL arrangements and key issues associated with the contributions of formal and informal supports. **Conclusion**s: Both the National Disability Insurance Scheme and UNCRPD espouse the importance of choice and control in living arrangements and people with disability and families seek this. ISL enables adults with ID with appropriate informal and formal support to live in their own homes.

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**Self-advocacy: New roles strengthen self-determination but also resistance**

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**Aim**: This study aimed to further understand the new forms of self-advocacy in Sweden by describing and analyzing the characteristics and organisation of the movement and its activities and by analyzing the meaning for the members and the influence for identifications, self-determination, relations and daily life. **Method**: A national mapping identified more than 60 self-advocacy groups. Case studies of four groups, selected to reflect organisational diversity, were conducted using interviews, focus-groups, observations and document review. **Result**s: Self-advocacy groups can be everything from totally independent to controlled by parents or staff. Despite this, the self-advocacy groups have an important impact on the lives of their members through the value they experience by achieving independence, self-determination and social connections with each other and outsiders. The most independent groups have also mounted resistance to society’s views and treatments of people with ID and the ways of delivering services. **Conclusion**s: Self-advocacy-groups in Sweden are important to their members daily life and are slowly beginning to influence attitudes towards people with ID and traditional ways to offer and organise support and service.
Voices of inclusion: An appreciative inquiry of successful inclusive practices for people with intellectual and developmental disabilities in schools and vocational settings

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Aim: Inclusive education for persons with IDD continues to vary across and within Canadian provinces and territories. The aim here is to highlight successful inclusive practices within educational and vocational settings in Saskatchewan. Method: This multi-stage research project used an appreciative methodological approach to gather and document successful inclusive practices. Semi-structured interviews were conducted with students, parents, teachers, educational assistants, and principals within schools; and employers, employees, job coaches within vocational settings. Following data analysis, a professional photographer visited sites to take pictures of identified successful practices. These will be used in a book of documentary photography to represent the experiences of those directly involved with inclusive education and workplaces. Results: Findings reveal themes that span participant roles and sites: interaction and friendships, teacher/employer commitment, teacher/employer knowledge and skills (especially around differentiation), team work, commitment to problem solving, mutual trust, and principal leadership and commitment to inclusion; finally a common school or workplace vision. Findings will be outlined; implications for practice discussed. Conclusions: This study supports several best practice areas within inclusive instruction.

Measuring the underlying mechanisms of mental health problems in youth with autism spectrum disorder: A role for emotion regulation

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Aim: The purpose of the current study is to examine how components of emotion regulation relate to mental health outcomes in children with ASD. Method: We assessed emotion regulation via child and parent reports, and behavioural observation in 48 children with ASD and at least average intellectual ability. Child psychopathology was assessed through parent and clinical interview measures. Results: Results from Pearson product moment correlations revealed that severity of mental health symptoms was negatively related to parent reports of child emotion regulation ability and to children’s ability to generate emotion regulation strategies in a hypothetical bullying task, and was positively related to parent-reported child emotional lability. Severity of clinician-judged psychopathology was positively related to parent reports of child emotional lability and child reports of emotional suppression. Conclusions: Parent reports of child emotion regulation are consistently related to reports of child mental health problems; child-reported emotion regulation strategies and behavioural observations of child emotion regulation strategies revealed little correlations with child psychopathology. This paper will discuss the challenges with assessment of emotion regulation ability in youth.

The political participation of people with intellectual disabilities: A mapping review

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Aim: The right of people with disabilities to participate in political and public life is enshrined in the UN Convention on the Rights of Persons with Disabilities. Using a broad interpretation of political participation, we aimed to map the research on the participation of people with intellectual disabilities (ID) in political arenas and civil society to identify gaps for further investigation. Method: A systematic search of eight databases was conducted. The relevant research was reviewed and mapped to plot its nature and breadth. Results: The moderate amount of literature can be categorised by the political arena, political activities, and political targets of participation. Research explores participation at both the micro level (i.e. participant characteristics, participatory processes and individual benefits of participation) and the macro level (i.e. issues of access, impact of participation and historical and theoretical contexts of participation). Conclusions: While an emerging body of literature canvasses political and civic participation much remains to be done at the conceptual level, with little investigation of how people with ID actually participate politically or in civil society in Australia.

Is stigma dead and buried: A historical perspective on death, intellectual disability and stigma

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Aim: The meaning of ID as a social identity and how this may have changed over time is examined by studying the relationship between death and disability, and what ID meant in death. Method: This is largely a reflective piece using data and photos obtained over several studies. At the core are 1500 death records from 1918-1940, and interviews from relatives and staff at later periods. Data will be utilised from these studies to examine one crucial question - what does the study of death tell us about what it means to live and die with an ID. Results: The data suggest that the social identity of ID was initially ascribed and marked the individual as 'negatively different'. How people were treated in death confirmed this status. People with ID were buried in exclusive cemeteries in unmarked graves. However, changes can be seen from the 1950’s onwards. The meaning of ID in terms of eulogies and remembrance might now be based on a different narrative but still highlight essential social differences. Conclusions: The relationship between stigma, identity and ID remains worthy of study in the post-institutional era.

Living and dying with Down syndrome in the UK

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Aim: This paper presents new data on the last months of life of people with Down syndrome (DS) living in UK services. Method: Data were obtained from a cross sectional study of the last months of life of people with intellectual disabilities (ID) living in UK services. Core data on deaths in this population were obtained for 240 decedents (48 with DS) and complete data using an ID sensitive and supplemented version of VOICES were obtained for 179 decedents with ID (37 with DS). Results: The average age of death of people with DS was younger than people without DS. Deaths were more likely to be dementia related and less likely to be cancer related than non-DS deaths. Data are still being examined on end of life care outcomes but people with DS were more likely to die at home (61%) than people without DS.
(47%). **Conclusions:** The growing attention to death, dying and ID needs to highlight the heterogeneity of the ID population and the need to focus specifically on the deaths of people with DS.

**Impact of setting and individual characteristics on end of life care outcomes**

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**Aim:** This paper describes and seeks to explain variability in end of life (EoL) care outcomes for people with intellectual disabilities (ID). **Method:** Data were obtained from a cross-sectional study of the last months of life of people with ID living in UK services. Deaths were identified in a living cohort of 13,000 adults over an 18-month period. Core data on deaths in this population were obtained for 240 decedents and complete data using an ID-sensitive and supplemented version of VOICES were obtained for 179 decedents with ID. **Results:** Significant differences in key EoL care outcomes were noted across key individual, death and setting characteristics. 55% of deaths were not expected and therefore did not involve lengthy preparation for death. For expected deaths, people living in smaller and more personalised settings experienced less positive outcomes. Data are still being analysed to examine these differences. **Conclusions:** People living in smaller community-based services may experience poorer outcomes at the end of life. The methodology employed in this study is worthy of replication and findings suggest areas for service development, in particular planning.

**Cancer and end of life care for people with intellectual disabilities**

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**Aim:** This paper examines the end of life events of people with intellectual disabilities (ID) dying with cancer. **Method:** Data were obtained from a cross-sectional study of the last months of life of people with ID living in UK services. Core data on deaths in this population were obtained for 240 decedents and complete data of quality of end of life care (ID sensitive version of VOICES) were obtained for 179 decedents with ID. Core data were obtained for 38 cancer deaths, of which 33 had VOICES data. **Results:** The prevalence of cancer at death was 17% in this population (15% for males and 21% for females). The average age of death of people with cancer was 61.4 years (SD=14.2). End of life care outcomes for people with cancer were better than for people without cancer in terms of some key measures. However, few people with cancer were informed of their dying status. Data are still being analysed. **Conclusions:** People with ID and cancer seemed to experience better care outcomes. However, key areas require further critical study.

**Beyond the last breath**

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**Aim:** This paper shifts the research focus in death, dying and intellectual disability (ID) to the post mortem phase and looks at the events and practices of this period for what they suggest about the
meaning of ID. **Method:** Data were obtained from a cross-sectional study of the last months of life of people with ID living in UK services. Deaths were identified in a living cohort of 13,000 adults over an 18-month period. Data on pre and post mortem events were obtained from key paid carers. Complete data using an ID sensitive and supplemented version of VOICES were obtained for 179 decedents with ID. **Results:** At the moment of death, decedents were with care staff or relatives. However, few (4%) died alone or had another person with ID witness their death. Only 9% had a will. Data are still being analysed on post mortem events and pre-mortem involvement of the decedent in their planning. **Conclusions:** This paper urges that post mortem events are important areas for study and questions for future research raised.

**Death and dying of people with intellectual disabilities in the UK**

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**Aim:** This paper examines the nature, patterns and features of death associated with people with ID living in services in the UK. **Method:** Deaths were identified in a representative living cohort of 13,000 adults over an 18-month period. Core data on deaths in this population were obtained for 240 decedents. **Results:** Death in these ID services was not as prevalent as expected (16 deaths per 1000 residents). However, the living cohort was very much a young one. Death was more prevalent for older age groups. Data on age and gender specific death rates across types of settings will be presented. Just over half of those deaths were expected deaths, and of these two thirds died in the setting. **Conclusions:** ID services are increasingly places for living and dying. Data suggest that although death was not a prevalent feature of services, this will change in the future as the population ages. A focus on quality of care at the end of life is required.

**Quality of life at the end of life in a representative sample of deaths in UK ID services**

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**Aim:** This paper examines the quality of life of decedents with intellectual disabilities (ID) in their last months of life in UK ID services. **Method:** Data were obtained from a cross-sectional study of the last months of life of people with ID living in UK services. Deaths were identified in a living cohort of 13,000 adults over an 18-month period. Core data on deaths in this population were obtained for 240 decedents and complete data of care at the end of life (ID sensitive version of VOICES) were obtained for 179 decedents with ID. **Results:** Data suggest that people with ID who were living in settings typically associated with higher quality of life outcomes (smaller and more personalised) were less likely to have good quality of care at the end of life. Differences were examined in terms of individual and setting characteristics and the latter were much more important in determining quality of care outcomes such as dying in a more appropriate or more preferred setting. **Conclusions:** Data are still being analysed to examine these differences.

**When the institution became a necropolis: Death in an English ID institution (1915-1940)**
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Aim: this paper provides an historical context to recent work on death, dying and intellectual disabilities (ID). Method: Data were obtained from death and burial records from an ID institution in southern England. Five years between 1918 and 1940 were selected for detailed study. In those five years there were 1051 deaths, ranging approximately from 99 to 250 deaths per 1000 residents supported. Data on age, gender, cause of death, disposal and length of admission were obtained for each death. Results: Death was more prevalent, younger and more likely to be preceded by an acute illness than more modern deaths of people with ID. People with ID lived on average 20 years less than people living in ID services today. For almost 60% of institution deaths, death was followed by burial in the institution cemetery in multi occupancy, unmarked graves. Conclusions: Death reaffirmed the outsider and devalued status of people with ID.

Aging and dying with intellectual disabilities: An examination of the impact of aging on death in UK ID services  
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Aim: This paper examines the impact of aging on end of life (EoL) events of people with intellectual disabilities (ID). Method: Data were obtained from a cross-sectional study of the last months of life of people with ID living in UK ID social care settings. Data on the age, gender and living situation of a large cohort (n=13,200) were obtained. Data on 243 decedents using an ID-sensitive and supplemented version of VOICES, a measure of EoL care were obtained. Results: Data will be presented that compares the nature of death for older (aged over 59 years, n=131) and younger (less than 60, n=112) individuals. This will include whether death was expected, cause and place of death, the extent to which people with ID were informed that they were dying, and staff satisfaction with care at the end of life. Conclusions: As people with ID age it is likely that the pattern of mortality within this population will change. It is also more likely that death will become more expected and require service planning and preparation. This paper will outline the challenges for ID services.

Ability of children with ambulatory cerebral palsy to ride a bike: A case control study  
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Aim: Aims were to determine the proportion of children aged 6-15 with ambulatory cerebral palsy (CP) who can ride a bike, the probability of skill acquisition at each age and the median age at skill acquisition, compared to typically developing (TD) children. Method: Parents of 114 children with CP and 87 TD children completed an online survey which included questions related to demographics, riding ability and age at skill acquisition. Chi–square analysis was used to compare proportions. The Kaplan-Meier method was used to compare the probability of skill acquisition at each age. Results: As a group, a lower proportion of children with CP were reported as able to ride independently (36.8%) compared to TD children (87.4%; p<0.001). The probability of skill acquisition was significantly less at each age for children with CP. Children with CP who had learnt to ride, learnt at a later age (CP
median=6.4 TD=5.0; p<0.001). **Conclusions:** Findings suggest ambulant children with CP can learn to ride a bike, however most do not and skill acquisition is delayed.

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**Relationship satisfaction among mothers and fathers of children with autism spectrum disorder**

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**Aim:** The present explores partner relationship in couples raising a child with autism spectrum disorder (ASD). Understanding the spousal/partner dyad is important because of its central role within the family and its potential to affect parent-child and sibling sub-systems. **Method:** 168 couples of children with ASD (mean age: 10 years) reported how satisfied they were with their spousal/partner relationship (Dyadic Adjustment Scale). Multilevel models were fitted to explore whether men and women report different levels of satisfaction with their relationship, and to identify demographic and family characteristics associated with relationship satisfaction. **Results:** Initial findings suggested no significant gender differences in relationship satisfaction scores, accounting for demographic and family characteristics. Depression had a direct, negative, effect on relationship satisfaction that was not moderated by parent gender. The behaviour problems of the child with ASD, but not those of the sibling, were associated with lower levels of relationship satisfaction. **Conclusions:** Analyses are ongoing. We will discuss how findings might inform the development of a more comprehensive theory of partner relationship satisfaction in families raising a child with ASD.

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**Behavioural interventions for sleep problems in people with intellectual disabilities: A systematic review and meta-analysis of single case and group studies**

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**Aim:** Behavioural interventions are frequently used to address sleep problems in people with intellectual disabilities (ID). The current study systematically reviews evidence on the efficacy of behavioural interventions for children and adults with ID and sleep problems. **Method:** Electronic and hand searches identified seven studies for inclusion (n=169). Standardised mean difference effect sizes (d) were calculated for group studies (n=4). Non-overlap effect sizes (Tau-U) were calculated for single case experimental design studies (SCED; n=3). **Results:** A large effect size (weighted d=.923, CI: .705 to 1.151) across group studies indicated large improvements in sleep problems following behavioural intervention. Effect size across SCEDs (weighted Tau-U:.528, CI: .351 to .705) indicated a 53% improvement compared to baseline. Sleep initiation and sleep maintenance problems showed significant improvements post-intervention. Follow-up effects were less consistent across study designs, and suggested that some sleep problems maintain gains better than others. **Conclusions:** Meta-analytic evidence from group and SCEDs can provide complementary information about efficacy. Findings propose that behavioural interventions are a promising evidence-based practice for improving sleep problems in people with ID.
The effectiveness of parent training programmes for families of children with special educational needs: Evidence from a national roll-out in England

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Aim: The study examines whether parent training programmes made available to all families of children at risk of behavioural problems are effective when children have special educational needs (SEN), and whether results are maintained during the phase of sustained implementation by service providers.

Method: There were 708 families with a child with SEN during the national roll-out trial (among 6,143 families), and 453 families with a child with SEN during the sustained implementation phase (among 3,651 families). We will compare SEN and non-SEN families during the trial phase. We will also compare families with a child with SEN during the trial and sustained implementation phases. Results: Analysis is ongoing and we will be reporting on child behaviour problems (Strengths and Difficulties Questionnaire), parenting (Parenting Scale-Adolescent) and parental mental well-being (Warwick Edinburgh Mental Well Being Scale). Conclusions: Findings will be discussed in relation to current policy regarding targeted and universal parent training.

First steps in developing a scientifically-grounded description of the practice-based Triple-C intervention, a method to support people with intellectual disabilities and challenging behaviour

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Aim: Triple-C is a practice-based intervention which is used in the Netherlands to support people with intellectual disabilities (ID) and challenging behaviour. Our aim is defining Triple-C and its possible effects by delineating the intervention’s components and how they inter-relate. Method: A first theoretical framework underlying the intervention was developed based on content analysis of existing theory. Resulting themes were subsequently made explicit in interviewing the founders of Triple-C. Next, we shared the new formulation with practice experts to feedback into the development of the intervention and to be able to inform what approach should be used to robustly evaluate the effectiveness of the intervention. Results: Based on our concrete and comprehensive theoretical framework we were able to define the Triple-C intervention in making its constituting elements and the relations between these elements explicit. Conclusions: Next step in making this theoretical framework scientifically explicit is to examine it by means of focus groups with professionals and interviews with clients and relatives to incorporate their practice based experience, as well as identifying appropriate outcome measures to evaluate the effects of Triple-C.

How well does the NDIS enhance personal quality of life?

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Aim: This paper examines the Australian National Disability Insurance Scheme (NDIS) philosophical congruence with personal lived experience and whether it affirms the dignity of people and enhances quality of life. Method: An interpretive approach was used. Texts examined include accounts of personal
experiences and the practices of business that have emerged. These narratives reveal another side to implementation and the philosophical notion of ‘good’ that underscores the NDIS. **Results:** The NDIS paradigm prioritises ‘person-centred planning’ and ‘self-directed care’ and although these are noble ideals this study revealed possible restrictions to personal flourishing, living a meaningful life and a contribution to higher levels of marginalization and isolation. Reasons for possible limitations will be explored amongst which include focus on individualism, independence rather than interdependency and a low emphasis on social capital. **Conclusions:** If our deepest desires, which are so often confirmed through everyday experiences of mutually valued friendships, of being in love or knowing we are loved, and part of our community are important, the NDIS appears to have minimum impact in these dimensions in peoples’ lives.

**L’Arche: A service provider or a centre for living spirituality?**

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**Aim:** L’Arche was founded in 1964 when three men, one without an intellectual disability (ID), started living together in community. In 2016, L’Arche is an international network of 147 communities where people with and people without ID share life in households through relationships and activities. This paper explores whether L’Arche is primarily orientated towards service provision or a space where people can live out the Gospel in a spirit of poverty and prayer. **Method:** A phenomenological hermeneutic approach is used. The methodology incorporates documentary analysis, results from interviews and the authors’ observations. **Results:** This study revealed how members of L’Arche live out spiritual attitudes and practices and how relevant and congruent they are to the Gospel and a spirit of poverty and prayer. **Conclusions:** The study provided evidence that L’Arche remains faithful to its initial aims of inviting people to live in community to experience mutually transformative relationships in a spirit of interdependence, vulnerability and weakness rather than focusing on management and governance through markets.

**Utilisation and costs of hospital services for patients with intellectual disabilities**

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**Aim:** As health services utilisation, costs and drivers are largely unknown in people with intellectual disabilities (ID), we examine these factors in a large linked administrative dataset. **Method:** Linked administrative data is used to investigate the number and costs of emergency department (ED) presentations and inpatient episodes in New South Wales for people with ID from 2005-06 to 2011-12. Descriptive comparisons are made within people with ID and compared to the general population. Regression analyses explore the drivers of frequency and cost of use of hospital services. **Results:** Compared to the general population, people with ID present to ED twice as often, have higher annual ED costs but no difference in cost per ED presentation, have longer inpatient stays and have twice the admission costs per acute admission. **Conclusions:** Understanding ED and inpatient service profiles of people with ID will help determine how the health system can be better equipped to respond to the
needs of people with ID. The results have substantial potential to shape health policy and practice for people with ID.

Conversation analysis on conversation between individuals who use alternative and augmentative communication and individuals with verbal speech in Taiwan

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Aim: The purpose was to explore the percentages of conversation turns and assigned speaking roles contributed by dyadic conversation participants between individuals with developmental disabilities who use speech-generating devices (SGD) and individuals who use speech. Method: Five individuals with developmental disabilities in Taiwan who use SGD as their primary mode of communication were recruited. Each individual recommended one verbally speaking individual as their familiar conversation partner. Each dyad completed six sessions of conversation, and each session was allowed but not limited to about 20 minutes and video-taped. Frequency and percentages of the contributed conversation turns and speaking roles were computed. Results: The mean percentage of asymmetry of conversations by counting conversation turns was different from that by counting speaking roles. Conclusions: The use of speaking roles can be a better way to evaluate dyadic conversations between individuals with developmental disabilities who use SGDs and verbally speaking partners; it shows how the individuals with disabilities can use their SGDs to “speak” in their dyadic conversation.

Disability, dementia and the environment: Expectations of moving from institutional to community living

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Aim: Whilst there has been an increase in life expectancy of people with disabilities in the past 50 years, little is known about how best to support people with intellectual disabilities (ID) and dementia. We examine the expectations of ten older men with high support needs and possible dementia relocating from a large residential centre (LRC) to community group home living. The perspectives of the men, their families and the staff who support them will be explored in the context of current research on deinstitutionalisation, community living, aging in place, and dementia friendly design. Method: This is an evaluation project which will be completed in 2018. Data collection includes interviews with the residents and family members, focus groups with staff and surveys of management. Results: Preliminary results suggest that residents and family members are satisfied with the care standards in the LRC, but anticipate that the move to community living will result in improved quality of life. Conclusions: Preliminary findings will contribute to the evidence base informing best practice support and accommodation for people with ID who may develop dementia.
Supporting people with intellectual disabilities through communicative performances in musical activities: Towards recovery of self-respect and improved quality of life

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Aim: There is a need to discover unique strategies to connect with the local community for those with communication difficulties. The conflation of utterance, song, and storytelling into instrumental performances is one of the latest innovations that evoke ‘communicative musicality’. Method: We observed Otoasobi, a musical improvisation group comprised of youth with intellectual disabilities (ID), professional musicians, and music and dance therapists in Japan, to investigate factors that contribute to an improved quality of life, including the recovery of self-respect. To understand the factors that contribute to communication-rich activities, we performed a discourse analysis. Results: The analysis of video-recorded data showed how the activity provided an environment that was conducive to participation and a renewed concept of ‘self’ by widening the social network of the participants. Conclusions: Communicative musicality is a viable means towards improving quality of life and the interpretation of communication skills for people with ID.

Choice making in Rett syndrome: A descriptive study using video data

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Aim: To describe the choice making abilities of females with Rett syndrome. Method: Females with Rett syndrome with a pathogenic MECP2 mutation were included. Video clips of choice making interactions of 64 females at a median age of 11.6 years (range 2.3 – 35.6) were analysed. The actions of the females and their communication partners and the location and nature of the interaction were coded. Results: The majority (82.8%, 53/64) made a choice; all but two females used some eye gaze. Just under half (24/53) used one modality to communicate their choice and the remainder used two or more modalities such as eye gaze, body movements, gestures, sounds or language. Of those who made a choice, 50% did so by 8 seconds and 75% did so by 22 seconds, the duration of which did not appear to vary with age. All communication partners used language with 57.8% (37/64) also using gestures and two using language, gestures and symbols. Conclusions: The provision of adequate time allowing for a response and observation for the use of multiple modalities could promote effective choice making.

An exploration of the use of eye gaze and gestures in females with Rett syndrome

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Aim: To investigate the use of eye gaze and gestures for communication in females with Rett syndrome. Method: Caregivers of 151 females with Rett syndrome completed items from the Communication and Symbolic Behavior Scales Developmental Profile Infant-Toddler Checklist. Relationships between the use of eye gaze and gestures to make requests were investigated using logistic regression. The influences of MECP2 mutation type, age and level of motor abilities on the use of eye gaze and gestures were analysed using multivariate linear regression. Results: Eye gaze was used more frequently than gestures
and both predicted the ability to make requests. Females with better gross motor abilities had higher scores for the use of eye gaze and gestures. Women aged 19 years or older had the lowest score for eye gaze. The use of eye gaze did not vary across mutation groups, but those with a C-terminal deletion had the highest scores for gestures. **Conclusions:** Due to the relationships between motor abilities and communication, a multidisciplinary approach considering the contributions of speech-language pathology, physiotherapy and occupational therapy could be beneficial in Rett syndrome.

The development of new evidence-based resources for health professionals who work with adults on the autism spectrum

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**Aim:** The aim of this project is to develop resources that equip adults with an autism spectrum disorder (ASD) to address their health needs and assist health professionals to better understand and respond to those needs. **Method:** We have undertaken a scoping review of online resources for health professionals, a survey of health professionals' training needs (n=78), and interviews (n=10) and focus groups (n=5) with health professionals about improving their interactions with adults with ASD. **Results:** Twenty-one autism-related websites with information for health professionals were reviewed; some provided quality information about adapting physical environments, communication and attitudes when working with adults with ASC. 83% of the health professionals interviewed agreed or strongly agreed that they would like more training specific to adults with ASC, particularly in behaviour management, mental health and communication. Focus groups and qualitative interviews with health professionals revealed strategies that could be incorporated into practice. **Conclusions:** These findings will lead to the creation of useful, useable tools that contribute to real-world improvements in health and wellbeing for a too-often overlooked group.

A multi-year, multi-modal evaluation of psychotropic polypharmacy changes: Comparison of results of functional assessments, direct observations, and staff collected data

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**Aim:** This study’s objective was to determine if, and the extent to which, changes in psychotropic medications altered functional relations between challenging behaviour and the environment for people with intellectual disabilities (ID). **Method:** Enrolled were 10 participants, between the ages of 28-53 years. Nine of these individuals were male and all were Caucasian. Individuals were diagnosed with ID (of varying severity) and comorbid diagnoses (DSM-V) (e.g., autism spectrum disorder, bipolar disorder). Experimental functional analyses (FA), weekly direct observations (analysed using lag sequential analysis), direct-care personnel completed indirect assessments (Questions about Behavior Function form [QABF] and Aberrant Behavior Checklist-Community [ABC-C]), and behavioural data from providers were completed throughout a 2.5 year period. **Results:** Changes in occurrence and frequency of challenging behaviours in FAs were observed across most participants and indirect measures (lag sequential analyses, QABF, personnel collected behavioural data) yielded general correspondence with
these changes. **Conclusions:** These findings suggest continued surveillance of behaviour function is needed when using psychotropic medication, in part, to address challenging behaviour.

**Disruption of the circadian rhythm in adults with intellectual disabilities**

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**Aim:** Building on findings from the Dutch Healthy Ageing and Intellectual Disabilities study (HA-ID), a high number of sleep problems and depression was found. We hypothesise these sleep problems and depression are a result of the disruption of circadian sleep-wake rhythm also demonstrated in this study. Gathering insight in factors influencing the circadian rhythm in individuals with ID is necessary to develop effective prevention and treatment policies for sleep problems and depression. **Method:** As part of the HA-ID study various sub studies were performed. Sleep was assessed using actigraphy in 551 persons with ID. Outcome measures were stability, fragmentation and amplitude of the sleep-wake rhythm. Depression was studied in 990 participants >50 years using self-report and informant-report instruments. **Results:** Sleep problems were found in 72% of the persons with ID and depression in 8%. Sleep-wake rhythm was significantly less stable in persons with ID and showed a larger fragmentation. Implications for further research will be discussed. **Conclusions:** Sleep problems and depression are frequent in individuals with ID and deserve care.

**Promoting physical activity participation among people with profound intellectual and multiple disabilities: An overview of practice-based knowledge**

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**Aim:** Promoting physical activity participation as part of the support of people with profound intellectual and multiple disabilities (PIMD) is important for the functioning of people with PIMD and their participation in daily activities. However, people with PIMD hardly participate in physical activities. Evidence-based interventions specifically designed for, or adapted to, people with PIMD in this field are scarce. To date, practice alone has led to the development and implementation of interventions to promote physical activity participation among people with PIMD. This study investigated and evaluated the use of these interventions. **Method:** A convenience sample of support professionals (n > 30) completed a questionnaire about the physical activity interventions offered in their organisation. Subsequently, they were interviewed to assess the effectiveness of these interventions based on a fixed format. **Results:** An overview of provided interventions and their potential effectiveness will be presented. **Conclusions:** This study will increase our knowledge on the quality and potential of different interventions aimed at physical activity participation among people with PIMD possibly affecting several domains of human functioning.

**Phonemic inventory, phonological error patterns and speech intelligibility of school age children with Down syndrome**
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**Aim:** This study describes the phoneme acquisition, use of phonological error patterns, and speech intelligibility of individuals with Down syndrome and the relationship between these variables. **Method:** Participants were 25 children with Down syndrome (17 girls and 8 boys) aged 5.92 to 13.08 years (M=9.67, SD=2.25) attending primary schools in New Zealand. Phonemic inventories, percent consonants and vowels correct (PCC and PVC), and phonological error patterns were calculated from a single word articulation test. Intelligibility ratings were calculated from a connected speech sample. **Results:** Considerable variability was evident across the group on all measures and no correlation with age was apparent. A developmental progression in speech sound acquisition was evident. All participants used more than one phonological error pattern in their speech. Intelligibility was differently associated with PCC across the group. **Conclusions:** Speech sound development and production present challenges for individuals with Down syndrome that are both widespread and persistent. Qualitative and quantitative measures of speech development and production show both similarities and differences to typically developing speech.

Assessment of substance use (disorder) in individuals with intellectual disability

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**Aim:** Individuals with mild ID are at risk for substance use, however, little is known about its prevalence and determinants. We present results from a validation study and a population study with the newly developed Substance use and misuse in Intellectual Disability Questionnaire (SumID-Q). **Method:** The validation study included 112 participants with ID. Data collected using the SumID-Q were compared with staff report and biomarker analyses of urine, hair and perspiration. The SumID-Q was then used in a sample of 453 participants with ID to assess the prevalence and determinants of substance use. **Results:** In both studies (n=112 and n=453), large proportions of respondents had used tobacco (87% and 82%), alcohol (97% and 92%), cannabis (60% and 47%) or stimulants (21% and 16%). Cannabis use was more prevalent in younger participants. Use of illicit substances was lower in women. Self-reported lifetime smoking, drinking and cannabis use were higher than staff report. Biomarker sampling did not identify more cases compared to self-report or staff-report. **Conclusions:** Substance use in ID can be measured with self-report questionnaires such as the SumID-Q.

A literature review into available scientific knowledge in the support of people with profound intellectual and multiple disabilities

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**Aim:** To analyse recent scientific knowledge related to the support of persons with profound intellectual and multiple disabilities (PIMD) in order to increase their Quality of Life (QoL). **Method:** A literature review was executed (2006-2015) with use of four databases. Studies were categorised into knowledge related to assessment, effectiveness of interventions and general. The studies were also categorised into
the QoL domains: emotional, material and physical well-being, interpersonal relations, personal development, self-determination, social inclusion and rights. **Results:** In total, 90 manuscripts were retrieved. All the domains of QoL were covered except ‘rights’. A total of 53 studies (55.8%) addressed general issues, fewer studies related to assessment (n=13; 13.7%) and to the evaluation of interventions (n=29; 30.5%) were identified. **Conclusions:** Available knowledge about the quality of life of people with PIMD increased dramatically in the last decade. This knowledge needs to be implemented in practice. Science should focus on generating more knowledge in the QoL domains of material and physical well-being, personal development and rights, as well as providing more evidence-based knowledge of the long term effectiveness of interventions implemented.

**Substance use and addiction in intellectual disability: Current status and future directions**

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**Aim:** Knowledge regarding substance use (SU) and substance use disorder in individuals with mild to borderline intellectual disabilities (ID) has increased over the last decade, but is still limited. In this presentation we discuss this body of knowledge in light of new insights from addiction medicine and psychiatry. **Method:** A critical and selective review on SU and SU disorder in ID was published earlier in 2015. **Results:** Data on prevalence and risk factors are fragmented, and instruments for screening and assessment and effective treatment interventions are scarce. Also, scientific developments in other fields are insufficiently incorporated in the care of individuals with ID and SU disorder. **Conclusions:** Recommendations for future research and policy and practice, which may provide a step forward in the care for individuals with ID and SU disorder, will be discussed.

**It’s all between my ears!: Deficiencies in information processing in problematic drinkers with mild to borderline intellectual disabilities**

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**Aim:** Problematic alcohol use has been associated with several neuropsychological disruptions in the reward and information processing system of the brain. The aim of our research project was to study the neuropsychological disruptions in individuals with mild to borderline intellectual disabilities (ID) and study the extent and nature of the influence of IQ on these disruptions. **Method:** Several indirect measures were developed to study both automatic processes (attention selection and allocation, approach/avoidance behaviour, interpretation of environmental cues) and cognitive and executive functioning. Participants were divided into four groups based on severity of alcohol use-related problems and IQ. **Results:** Overall, the results do not support dual process models of addiction. Neither attentional or approach biases nor executive dysfunctions were found in problematic drinkers. IQ did not seem to be a relevant factor in automatic information processing. **Conclusions:** Based on our results, we provide some practical implications that can be translated directly into the day-to-day care of problematic drinkers with and without mild to borderline ID, including the screening, assessment and treatment of substance use disorders.
Parental behaviour towards children with a significant cognitive and motor developmental delay: Relation with children’s interactive engagement and parents’ social resources

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Aim: Family and parenting factors are one of the most striking gaps in the current scientific literature on the development of young children with significant cognitive and motor disabilities. Based on Guralnick’s developmental systems approach, we aim to characterise parental behaviour and its relation to child interactive engagement and parents’ social resources. Method: 20 parents of children with a significant cognitive and motor developmental delay (aged 6 months to 4 years) were video-taped during a 15-minute unstructured play situation and asked to fill out the Parental Behaviour Scale for toddlers. Video fragments were scored using the Child and Maternal Behaviour Rating Scales. Information on perceived social support of parents was gathered through a self-developed questionnaire. Results: The scores on five dimensions of self-reported parenting behaviour (warmth, autonomy support, supervision/safety, discipline, rules/structure) and four dimensions of observed interaction style of the parent (responsivity, affect, achievement orientation, directiveness), will be discussed. Moreover, the relationship of parental behaviour with parents’ social resources (diversity, perceived sufficiency) and children’s interactive behaviour (attention, initiation) will be examined. Conclusions: Conclusions will be formulated based on the results.

Educational quality of life: A merging of student experience, learning and wellbeing for students with intellectual disabilities

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Aim: Students with a disability often experience unfavourable outcomes in education despite international conventions, national laws and local policies. To understand the gap between policy and practice, a new quality of life framework has been developed for education. Method: This is a theoretical paper describing the process of developing a new sub-strand of QoL – educational quality of life, or EQoL. EQoL was developed by analysing factors that influence student experience, noting that the conceptualisation of student experience and QoL are similar. Results: Reviewing different QoL models, EQoL emerged as a model that combined student experience, subjective wellbeing, human needs and policy into an operational model. Conclusions: Understanding influences on EQoL could provide a new way for governments and educational authorities to ensure they meet their obligations under the UNCRPD and facilitate overall school improvement. Student wellbeing and achievement are integral to the EQoL model and identified as the goals of school improvement by The National School Improvement Tool in Australia.

A systematic review of neuropsychiatric comorbidities in persons with both epilepsy and intellectual disabilities

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Aim: We investigated associations between neuropsychiatric disorders, including psychiatric symptoms/disorders and behavioural problems and epilepsy or epilepsy factors in persons with intellectual disabilities (ID), and between neuropsychiatric disorders and ID in persons with epilepsy.
Method: A systematic review of studies published between 1995-2015 in PubMed/MEDLINE, PsycInfo, and ERIC was performed. Neuropsychiatric disorders were either determined by diagnoses or symptom scales. Results: Fifteen studies with acceptable risk of bias were analysed. Neuropsychiatric disorders were studied in relation to epilepsy in nine studies, to epilepsy-related factors in four studies, and to ID in five studies. The presence of epilepsy was not clearly related to neuropsychiatric disorders in persons with ID, although a tendency towards negative mood symptoms was identified. More severe forms of epilepsy and the presence of ID in persons with epilepsy were associated with neuropsychiatric disorders. Conclusions: This study emphasises the relevance of systematic and longitudinal studies of neuropsychiatric disorders in persons with epilepsy and ID according to standardised protocols to acquire further knowledge that can help to improve the quality of care for this population.

Situation specificity of social information processing in adolescents with mild intellectual disabilities with and without aggressive behaviour problems
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Aim: The Social-Information Processing (SIP) model suggests that deviant processing of social situations is related to aggression. These SIP-relations have been found in youth with mild intellectual disabilities (ID) as well. However, these studies only included children 3 to 12 years of old, and studied SIP in ambiguous situations. Adolescents with mild ID and higher intelligence levels, with and without aggression problems were compared across SIP steps and ambiguous versus non-ambiguous situations.
Method: Over 160 adolescents (13 to 17 years old) participated; IQ ranged from 50-120. SIP was assessed by observing videos of social situations that were hostile, accidental, or ambiguous. Aggression was assessed with a CBCL-TRF-YSR composite-score. Results: Different patterns of SIP were found between mild ID, borderline IQ and average IQ groups, and between the aggressive versus non-problematic groups. Situation specificity was found in SIP of adolescents with mild ID. Conclusions: Situation specificity of SIP is discussed. Behavioural interventions for adolescents with mild ID may focus on specific situations and specific SIP deficits.

Mother quality of life or family quality of life? A survey on the quality of life in families with children with intellectual disabilities using home-based support in Flanders
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Aim: Although family quality of life (FQoL) is considered a multidimensional family-level construct, most research asks only mothers about the perceived FQoL. In contrast, we asked the opinion of different
family members regarding the FQoL. We aimed to study similarities and differences between the perspectives of different family members (mothers versus fathers, parents versus children), and considered to which extent using a global FQoL-measure does justice to every member and how we can deal with the opinions of different family members. **Method:** We conducted a survey with 63 participating families, randomly selected by services offering home-based support to families with a child (0–18 years) with an intellectual disability. Both parents (n=97) and youngsters (n=24) filled out the 25-item Beach Center FQoL-scale. **Results:** For FQoL-scores and most subscale scores, variance was seen both within and between families. Role of the family member (parent versus child) and gender of the parent (mother versus father) could not explain the variance within families. **Conclusions:** By asking different family members and comparing their opinions, we contribute to the methodological and conceptual discussions about measuring FQoL.

**The role of the worshipping community in engaging with persons with disabilities through service delivery**

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**Aim:** Wheelchair distributions are important in providing assistive devices to those with multiple disabilities. However, such distributions are typically led from outside the community in a non-participatory approach. We explore the role of worshipping communities in accompanying people with disability and partnering with NGOs to deliver a wheelchair distribution service. **Method:** The study followed the role of the pastors throughout their engagement in a wheelchair distribution service in North India. A series of interviews and surveys were completed to characterise the role of worshipping communities in helping deliver disability services. **Results:** 30 volunteers from 17 churches identified 310 persons with different disabilities requiring mobility aids. Church leaders accompanied those with intellectual disabilities (ID) and mobility difficulties to facilitate their attendance. Data showed improved relationships between churches and those with disability. Pastors expressed a desire for further disability training, especially to enable them to better relate with people with ID. **Conclusions:** The engagement of worshipping communities in this manner moves the impact beyond service delivery and empowerment to opportunities for companionship.

**How do Australian disability support organisations describe the disability support worker position?**

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**Aim:** Role ambiguity is an important predictor of work stress for disability support workers (DSWs). The study was undertaken in an effort to uncover potential sources of role ambiguity for DSWs in Australia. **Method:** A systematic search for publically available position descriptions was conducted, with 162 sourced. These position descriptions were thematically analysed with common descriptors of the DSW role and the skills, attributes and competencies required collated. **Results:** Contradictions in content were revealed, e.g., the role is described as a hands-on support role requiring a wide range of skills prior to entering the role; however minimal education or training requirements are stipulated. The position descriptions also highlight that DSWs work in environments where they are expected to collaborate with
others, but the DSW duties outlined are essentially performed in isolation with minimal supervision. **Conclusions:** These findings could inform improved organisational practices to assist DSWs with their practice, e.g., accurate job descriptions, enhanced induction training. This may reduce role ambiguity, improve worker well-being and in turn, improve the services available to people with intellectual disabilities.

**Can the job demand-control-(support) model explain disability support worker burnout and work engagement?**

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**Aim:** This study examined the utility of the job demand-control-(support) (JDCS) model as an explanation of disability support worker (DSW) burnout and work engagement. This model states that one’s perceived level of work demands, control over their work, and workplace support will influence the development of poor work outcomes. **Method:** 325 DSWs completed an online questionnaire containing measures of workload, job control, supervisor/colleague support, work engagement and burnout. **Results:** Three-way interactions between workload, control and colleague support were uncovered for two of the three burnout components, and one of the three work engagement components. No significant interactions involved supervisor support, and both JDCS hypotheses were supported (high workload, low control and low support related to poorer outcomes; high support and/or control reduces the impact of workload on poor outcomes). **Conclusions:** These findings imply that the JDCS model offers a valid explanation for the development of poor DSW work outcomes. Disability support organisations looking to improve DSW wellbeing should consider interventions or changes to organisational practice that address equitable workload, improved control over one’s workload, and access to desired workplace support.

**Profiling the psychosocial experiences of parents of children with disabilities on factors related to out-of-home care**

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**Aim:** In an effort to aid early identification of parents at risk of seeking out-of-home care for their children with various disabilities (e.g., autism, intellectual disability), this study profiled a sample of parents in accordance to several psychosocial factors reported to be related to why parents seek out-of-home care. **Method:** An online survey containing measures of various parent/child psychosocial factors (e.g., mental health, coping, challenging behaviour, parent hassles) was completed by 273 parents. **Results:** Cluster analysis uncovered four parent groups: relentless (high hassles, mental health and child support needs/behaviour; low competence, poor coping), happy (low hassles, mental health and support needs/behaviour; high competence, good coping), resilient (moderate hassles, support needs/behaviour and competence; low mental health, good coping) and unhappy (low hassles, support needs/behaviour and competence; high mental health, poor coping). **Conclusions:** Psychosocial factors related to out-of-home care can meaningfully distinguish parents raising children with a disability from one another. The relentless parent profile presents with the same characteristics of parents who have
sought out-of-home care in the past, therefore presenting with the greatest risk of seeking care in future.

Can we measure cognitive constructs consistently within and across cultures in low income countries?

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Aim: Consistently measuring intellectual and developmental disabilities across different cultures is not simple. We planned to use adapted tests to determine whether children who had been exposed to acute episodes of malaria in early childhood incurred adverse consequences to their cognitive development. We investigated how cognition was assessed in three low income countries, with constrained health care access, and low literacy levels amongst the adult population. Method: Ten instruments were drawn from previously published materials as well as tests for the study. The instruments were adapted and translated in a systematic way to meet the needs of the three assessment contexts. The instruments were administered by a total of 43 trained assessors to 786 children in Bangladesh, Ghana and Tanzania with a mean age of about 13 years (range: 7-18 years).

Results: Within-group consistency and reliability was adequate in each country. Confirmatory factor analysis showed measurement weights invariance, supporting conceptual equivalence across the three country groups. Conclusions: Adaptation helps testing to be consistent. Comparison between countries in these areas is possible on a common underlying construct by using effect sizes.

Ohio’s statewide consortia: Enhancing employment outcomes through inclusive postsecondary education

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Aim: To determine the effectiveness of inclusive postsecondary education services in enhancing employment outcomes for youth with intellectual disabilities (ID). Method: A comparative analysis of employment outcomes of 50 adults enrolled in college programmes was conducted. Data were obtained from state and national datasets. Variables include employment status, as measured by hourly wage, hours worked per week, and job longevity. Analysis of trends across years was conducted. Results: Adults who completed inclusive postsecondary programmes earned $9.05 per hour and worked 22 hours per week. These outcomes are significantly better than for adults who work in sheltered employment. As of 2014, 83% of college graduates who received inclusive services such as internships in integrated settings were employed, as compared to 31% of high school graduates. Conclusions: By sharing employment outcomes, best practices and successful case studies, participants can replicate services that increase employment for adults with ID.

Quality of life in people with intellectual disabilities in the palliative care phase: A Dutch prospective follow-up study

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**Aim:** We examined QoL over time and its correlations to patient and illness characteristics through the palliative care phase. **Method:** We followed 185 Dutch people with ID whose physicians answered ‘No’ to the question ‘Would you be surprised if this patient died in the next year?’. At baseline, 5 and 10 months, professional caregivers rated three QoL parameters on a 0-10 scale: patient’s comfort, wellbeing and QoL. In addition, we gathered information on relevant characteristics: e.g., activities of daily living, symptoms. **Results:** At baseline, median scores for QoL parameters varied between 6 (wellbeing), and 7 (comfort and QoL). Preliminary results suggest that the QoL parameters did not change much over time. People who died during the follow-up had a lower QoL and were less comfortable at baseline. Our findings suggest that changes in symptom burden (e.g., pain, fatigue) are related to changes in QoL parameters. **Conclusions:** The results generate helpful information in understanding QoL of people with ID in the palliative care phase. Adequate symptom management may help in optimizing QoL.
Worldwide prevalence estimates of parenting with intellectual disability

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Aim: This paper will summarise the extent of previous attempts to measure the prevalence of parenting with intellectual disability (ID) globally, to clarify widely held assumptions about their experiences and living conditions. Method: Using scoping review methods, we located literature on the prevalence of parents with ID by searching bibliographic databases, websites of relevant organisations and reference lists, as well as consultation with experts. Results: The search revealed 42 original studies reported in English that estimated the prevalence of parents with ID in populations. A range of estimates were cited. Challenges associated with the measurement of prevalence of disability in populations, including over-reliance on clinical samples, and definitional differences were identified. Conclusions: The review reveals useful insights into methods to measure prevalence in communities, and contributes to our understanding of the extent of support needs as well as the strengths of these families. This information is invaluable for service planning for governments and community services, and may help to break down widely held stereotypes that these families are inevitably at risk.

What can we learn about prevalence and characteristics of people with disabilities and their families from population and service use data?

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Aim: To describe two studies in Australia using population-level and service use data to estimate prevalence of parents with intellectual disabilities (ID), describe population characteristics and understand service needs. Method: The first study estimated prevalence and described characteristics of parents with disabilities in comparison to non-disabled peers from population surveys and health and social services administrative data. The second identified gaps in supports for caregivers of children with disabilities using data visualisation. Results: Both studies successfully combined data from multiple datasets to answer questions using different analytical approaches. The first study revealed that around 0.4% of parents have an ID and identified a range of disadvantages experienced by these parents compared to other parents in the community. The second study identified gaps in service delivery by comparing data regarding current service locations with population distributions of children with disability. It highlights the importance of question formulation, managing limitations, and analytical methods. Conclusions: Integrating existing available data from different sources creates cost-efficient opportunities to investigate research questions that cannot be answered from clinical populations.

Temper outbursts in Lowe syndrome: Associations with set-shifting and delay of gratification

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Aim: To examine the function of temper outbursts in Lowe syndrome (LS) and associations between these outbursts and difficulties with set-shifting and/or delay of gratification. Method: Twenty individuals with LS aged 6 to 34 years completed two computerised delay of gratification tasks and a
scaled set-shifting task. Parents completed adapted questionnaires measuring severity, duration and frequency of temper outbursts (Challenging Behaviour Questionnaire), the Questions about Behavioural Function scale, and the Vineland Adaptive Behavior Scales-II. **Results:** The majority of individuals with LS (75%) had engaged in temper outbursts in the last month and access to tangible items was the most frequent function (40%). Negative associations were found between outburst score and performance on the delay of gratification tasks ($r = -0.74, p < .001$ & $r = -0.51, p = .03$). These associations remained significant after controlling for adaptive behaviour and communication. Set-shifting score was not associated with outburst score. **Conclusions:** A core deficit in delay of gratification may explain heightened levels of temper outbursts in LS, which may be triggered when individuals with LS are thwarted.

**Microboard research and significance to disability reform in Australia**

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**Aim:** Even with disability reform, people with profound intellectual and multiple disabilities (PIMD) struggle to find effective supports to claim full citizenship and live a good life. Microboards, legally recognised small groups of unpaid people with a close and trusted relationship to a person with PIMD, show promise. This study describes how Microboards are used in Canada and Australia for this purpose, and highlights the relevance of Microboards to the National Disability Insurance Scheme (NDIS) in Australia. **Method:** Qualitative inquiry involving 6 Microboards in British Columbia and Western Australia developed around people with PIMD was undertaken. Thematic analysis was used to interpret the information. **Results:** Microboards develop social capital providing a source of advocacy and political power for people with PIMD to facilitate access to appropriate supports. Microboards acknowledge the natural authority of individuals and their parent carers by supporting self-determination and shifting power into their hands. Outcomes include community participation, independent living, and respect. **Conclusions:** Microboards are a model worthy of attention for people with PIMD to engage with disability reform to secure and enact full citizenship.

**Leaping into the unknown: Futures planning among older parents of adult offspring with intellectual disabilities who live in either supported accommodation or the family home**

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**Aim:** This research investigates older parents’ experiences of supporting adult offspring with intellectual disabilities (ID). We aimed to examine the extent to which parents had engaged in futures planning; the adequacy of their offspring’s current accommodation into the future as well as their opinions on ‘ideal’ models of accommodation and support. **Method:** Participants were recruited via several disability providers in Adelaide, South Australia as well as Carers Australia. Using the theoretical perspective of Phenomenology, we carried out semi-structured in-depth interviews with older parents aged 55+ (n=6 offspring lived in family home and n=6 in supported accommodation). **Results:** Findings show a diverse set of experiences among parents in terms of their needs and concerns about the future care and support of their son or daughter with ID. Unlike previous research, we found that parents are engaged in
futures planning however this places considerable pressure on them in terms of doing ‘the right thing’. **Conclusions:** Older parents need support and guidance around futures planning as increasing numbers of adults with ID are aging both in the community and in supported accommodation.

**Function-based intervention in inclusive school settings: A meta-analysis**

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**Aim:** The purpose of this meta-analysis was to summarise single-case intervention research studies in which students with disabilities, including those with intellectual and developmental disabilities, received function-based interventions within inclusive school settings to address challenging behaviour.

**Method:** A total of 23 studies were identified and systematically reviewed to determine the overall effect of function-based interventions on challenging and appropriate behaviour and whether study characteristics moderated intervention outcomes. In addition, we summarised characteristics of study participants and settings, characteristics of function-based intervention applied within the studies, and quality of the studies. **Results:** Overall, function-based interventions led to improved behaviour in a variety of inclusive school settings. Interventions delivered by classroom teachers and within the context of a whole group instructional arrangement resulted in significant reductions in challenging behaviour and improvements in appropriate behaviour, respectively. **Conclusions:** Results confirm the efficacy of function-based interventions for students with disabilities, while providing additional support for implementation in inclusive school settings. Implications for practice, future research, and limitations will be discussed.

**Family quality of life of Korean families of children with intellectual and developmental disabilities and relationship to family and professional partnerships and service quality**

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**Aim:** There is a growing trend in understanding the similarities and differences of conceptualization and measurement of family quality of life (FQoL) internationally. This study examines the factor structure of FQoL in Korean families and its relationship to family and professional partnerships and perceived service quality. **Method:** The Beach Center Family Quality of Life Scale was administered to 336 Korean families of children with intellectual and developmental disabilities (IDD). Multiple Indicators Multiple Causes (MIMIC) modelling (of structural equation modelling) was used to examine the factor structure of FQoL and similarities and differences on the FQoL domains and items. **Results:** A five factor structure of FQoL emerged from the Korean data which is similar to the factor structure of the Beach Center FQoL Scale. Th FQoL Scale had good psychometric properties in the Korean sample. Family and professional partnerships and perceived service quality affect FQoL of Korean families. **Conclusions:** Korean data reveal a similar factor structure of FQoL and show that perceived service quality and family and professional partnerships are important factors influencing FQoL.
Perceived family well-being of American parents who have young children with and without disabilities: Impact of disability on family quality of life

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Aim: On the basis of conceptual frameworks developed through two central initiatives of family quality of Life (FQoL) research, this study aimed to investigate quality of life of American families who have young children with intellectual and developmental disabilities (IDD) as compared to those without disabilities by using the dataset of the 2011-2012 National Survey of Children’s Health. Method: Parents of 3,412 children with IDD and those of 29,997 children without disabilities completed the survey. 28 survey items related to FQoL were selected for analysis. Multiple Indicators Multiple Causes (MIMIC) modelling was used to examine the factor structure of parents’ perceived family well-being and impact of disability on FQoL and other important demographic variables. Results: Families of young children without disabilities had higher ratings on most of the FQoL domains than those of children with IDD as well as on demographic variables. Conclusions: FQoL domain differences between the two groups suggest families of children with IDD have unique strengths and challenges relevant to achieving better family well-being. The findings have important research and practice implications.

Positive behaviour support: A discipline on the brink of extinction

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Aim: The quality of positive behaviour support plans (PBSP) across Queensland was audited. Method: The Behaviour Support Plan Quality Evaluation guide version II (BSPQEII) was used to quality audit 139 PBSP. Inter-rater reliability using the BSPQEII was established amongst the research team prior to data collection. PBSP reading ease was evaluated using Flesch readability scores. Results: The quality of PBSP was poor (M = 6.53) and statistically lower than Victoria, t (138) = -17.86, p <.001. Mean scores from both states placed PBSP in the ‘weak’ category, indicating they were unlikely to facilitate behaviour change. The statutory regulation of restrictive practices appeared to benefit some quality domains. Readers required 13 years of education to understand PBSP. Conclusions: Reviews of PBSP in Australia have reflected generally poor adherence to the discipline. The statutory approval process influences certain quality domains positively. PBSP in Queensland were not likely to be understood by the direct support workforce. The quality of PBSP across Australia must improve. A failure to respond risks relegating positive behaviour support to a ubiquitous fad which failed to deliver.

Supporting end-of-life care across geographic diversity: What works and what needs to change?

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Aim: There is an emerging need for end-of-life care for people with intellectual disabilities; however, there is limited research that concurrently examines support issues within both rural and metropolitan localities. The aim of the current study was to gain insights from paid carers in both city and country areas of Australia in order to identify facilitators and barriers to the provision of appropriate end-of-life care support. Method: Seven focus groups with a total of 35 participants were conducted in
metropolitan (Sydney and Brisbane) and rural (Armidale, Inverell, Lismore and Warwick) locations using a semi-structured interview guide. All focus group data were independently transcribed, and thematic analysis was undertaken. **Results:** There were seven main themes recognised in the data. These were Training and Staff Support; Health Services; Relationships; Policy and Practice Barriers; Pain and Medication Management; Quality of Life; and Infrastructure. Similarities and differences based upon geographic location were identified. **Conclusions:** The differing end-of-life needs of rural and metropolitan residents are identified. Specific recommendations are made for Australian-based services regarding changes to daily practice that better support people during their end-of-life.

**The relevance of Article 12 of the UNCRPD for people with severe or profound intellectual disability: Is supported decision-making for everyone?**

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**Aim:** Article 12 of the UNCRPD obligates signatory nations to ensure all citizens receive supported decision-making. However, people with severe or profound intellectual disability (ID) are often excluded from this support. This study aimed to identify processes, enablers and barriers to supported decision-making for this population. **Method:** A social constructivist perspective underlies this study. Five people with severe or profound ID and their supporters participated in a six-month supported decision-making intervention. Data from interviews, focus groups, observation, and questionnaires were collected, triangulated, and analysed using an interpretative phenomenological framework. **Results:** Supporter responsiveness to the expression of preference of those they support was found to be important in enabling supported decision-making for people with severe or profound ID. Effective responsiveness was found to be comprised of three dependent and sequential tasks, acknowledging, interpreting, and acting upon a person’s preference expression. Several factors, organised thematically, were found to impact on this responsiveness. **Conclusions:** The findings provide a focus for practice and policy efforts related to supported decision-making for people with severe or profound ID.

**Special Olympics Healthy Communities: Experiences of children and adults with intellectual disabilities in selected districts of Malawi**

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**Aim:** Special Olympics is the only organisation that runs a health promotion programme for children and adults with intellectual disabilities (ID) in Malawi. Yet, the impact of this venture has not been described until now. It was therefore, important to determine the extent to which the Healthy Communities programme has improved the health of the target population. **Method:** This qualitative study took place in Mchinji, Salima and Nkhatabay districts of Malawi. Individual interviews were conducted with 15 young people with ID and focus group discussions with 40 parents, health workers and community leaders across the three districts. A thematic content analysis was used to make sense of the data. **Results:** Young people, their parents and communities are not entirely satisfied with the Healthy Communities programme because it was a once off exercise of health screening for athletes. Communities also need food and income generation. **Conclusions:** The programme is critical for athletes.
Factors associated with long term restrictive intervention use in disability services

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Aim: The Senior Practitioner in Victoria, Australia has monitored the use of restrictive intervention in disability services since 2007. This unique dataset was investigated to examine which client factors were associated with long term use of restrictive interventions from 2008 to 2015. Method: Participants were 1467 adults with an intellectual disability who were reported to be restrained or secluded in accommodation or day disability services from 2008-2015. Sixty-eight per cent of participants were males. Odds ratios were used to determine which factors were associated with people being subjected to restrictive interventions in the years 2008-10 and 2013-15. Results: Type of restrictive intervention (restraint and seclusion) was associated with whether people were reported in both 2008-10 and 2013-15. People with autism were 2 times more likely than people without autism to be subjected to restrictive interventions in 2008-10 as well as 2013-15. Conclusions: The results suggest some types of restrictive interventions may be used over years and specific strategies are required in order to assist services to tailor supports to people with complex and high needs.

Increasing the quality of behaviour support plans: What training works for whom?

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Aim: To compare two levels of training in positive behaviour support planning to determine what level is necessary to improve the quality of behaviour support plans developed by disability professionals in different work roles. Method: Disability professionals working in one of three different roles (house supervisors, authorised programme officers, service managers) completed a 4-day or 4-hour period of training in positive behaviour support planning. The quality of behaviour support plans developed before and after training was compared using a 3 (level of training: 4 hours, 4 days, none) x 3 (work role: house supervisor, authorised programme officer; service manager) repeated measures design to examine the impact of training on work role. Results: Disability professionals who completed the 4-day training produced significantly improved quality behaviour support plans compared to those who completed 4 hours or no training. Professionals within some work roles benefited more. Conclusions: Training in improving the quality of behaviour support plans needs to be tailored to the needs of disability professionals work roles for best outcomes.

Generating behavioural and neurophysiological evidence for mobile technologies in augmentative and alternative communication

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Aim: The proliferation of inexpensive mobile technology has made a strong impact on behavioural interventions in intellectual and developmental disabilities (IDD). Using the example of mobile technology in augmentative and alternative communication, this presentation will discuss two approaches to generate research support. A mobile application was designed for communication training and evaluated for treatment effects. Method: Evidence generation involved single-subject experimental designs to evaluate treatment efficacy through repeated measurement of behaviour and replication across and within participants; and quantitative electroencephalograms to assess improvement in speech and language related symptoms pre- and post-intervention. Results: Single-subject data were collected for 16 participants with severe, non-verbal autism 6 to 23 years old with replications of treatment and generalization effects. Neurophysiological data were obtained for four participants showing resolving anomalies in speech and language symptoms. Conclusions: Comprehensive evidence-generation revealed a fine-grained picture of behavioural and neurophysiological effects to guide clinical practice. Critical app features that enhance skill acquisition include randomization of graphic stimuli, a lock function to prevent self-stimulating behaviours, or access modes for users with motor control difficulties.

Individual factors contributing to the use of mechanical restraint on people with disabilities

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Aim: To investigate the clinical needs of adults with severe and profound disabilities subject to long-term mechanical restraint, and to identify the facilitators and barriers to restraint reduction. Method: A multiple single case study design (n=10) was used. Participants were individually reviewed by physicians, psychologists, speech pathologists, and occupational therapists. Support staff completed questionnaires related to quality of life, behaviours and interventions. Results were analysed quantitatively and qualitatively. Results: Participants consistently presented with complex health and behavioural support needs that had not previously been identified, and which could have contributed to behaviours and the subsequent long-term use of restraints. There was a paucity of information regarding the origin and purpose of the restraints. Formal monitoring, review, and plans to decrease the use of restraint were commonly absent. Conclusions: People with severe and profound disabilities are at high risk of long-term mechanical restraint. Lack of understanding of their clinical and support needs, together with knowledge about, and apprehension concerning, alternatives present as barriers to restraint reduction. Multi-disciplinary assessment and support for staff and families offer a potential solution.

Quality of life and the right support according to people with intellectual disabilities

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Aim: This study examines how persons with intellectual disabilities (ID) experience their quality of life (QoL) and the support of coaches and family members; as well as how coaches and family members view this QoL and their support. Method: The qualitative approach uses an Ethics of Care and the Human Rights of People with Disabilities stance. The study concerns 18 people with ID, living in an institutionalised setting in the Netherlands. 52 people were interviewed: the person, the personal coach.
and a family member. A grounded theory analysis followed. **Results:** The position taken by coaches/family members leads to a complementary position of the person (e.g., dominant versus a submissive position). Many day-to-day and more existential matters are determined for the person by the coach or family member, regardless the amount and type of support needed. **Conclusions:** QoL can be improved by increasing self-determination and life responsibility of the person and by fulfilling the Human Rights of People with Disabilities.

**Improving life environments of elderly people with intellectual disabilities**

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**Aim:** Life environment is a complex aspect of quality of life (QoL) and a challenging issue in the care for older individuals with intellectual disabilities (ID). This study gathered information relevant to developing interventions to improve the life conditions of this group. **Method:** A literature review was conducted on the state-of-art in the field, focusing mainly the following topics: living environment: personalization, simplification, decoration, light, colour; staffs attitudes and engagement: approach, communication, incorporation of biographical knowledge and positive regard; organisation and coaching work processes: organisation of routines and systems, well-being, meaning giving of the day and activities; and methods to improve QoL and care: behavioural, occupational, music and other therapeutic approaches. Several electronic systems, such as Web of Science, Psyinfo, and Pubmed, were searched crossing keywords related to the topics with the words elderly, intellectual disability and dementia. **Results:** Most research shows that general improvement of the environment, interactions with staff, food and activities contribute to QoL. Some research considers more personal preferences. **Conclusions:** Several stimuli and processes need to be taken in account to improve QoL.

**Assessing knowledge, planning for and fear of death**

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**Aim:** Few self-report instruments about dying and death are available for people with intellectual disability (ID). The Dying to Talk project in Sydney, Australia measured knowledge about death, understanding and self-determination of end-of-life planning, and fear of death. This paper reports on the instruments used. **Method:** We describe the use, adaptation, piloting and content of these instruments, including development of a new instrument on end-of-life planning. Participants included 39 adults with ID and 40 adults without ID (disability staff). All were assessed by individual interview on all three instruments. A subsample was scored independently by a second rater. **Results:** Internal consistency and inter-rater agreement were good for each scale. People with ID were willing and able to provide scorable answers for almost all items, with a higher level of non-response on certain fear-of-death items. **Conclusions:** We found the instruments were usable, reliable and valid for people with and without ID. Availability of such instruments will facilitate future research, intervention and practice.
Mainstream, inclusionary and convivial places: Locating encounter between people with and without intellectual disabilities

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Aim: ‘Encounters’ - social interactions between strangers provides a way of thinking beyond binaries of community presence and participation, and are an important aspect of social inclusion for people with intellectual disabilities (ID). We explored the types of places most conducive to convivial encounters between people with and without disability. Method: Four case studies were conducted in the localities where the 26 adult participants with ID lived. Ethnographic observations, as well as a survey and face to face interviews with people with ID, their support workers and neighbours were used to collect data. Results: Convivial encounters where there is a shared temporary identification between strangers with and without ID were rare. They are more likely in ‘mainstream’ places, where people come together with a shared non-competitive purpose, opportunities exist for verbal and non-verbal communication, and there is willingness to make people welcome. Conclusions: The study provides a framework for disability support workers and urban designers to analyse which places are likely to bring cognitively different people together and encourage strangers to move from co presence to conviviality.

Healthy eating: A qualitative inclusive research project exploring the understanding and perspectives of individuals with intellectual disabilities

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Aim: The global acceptance of the benefits of healthy eating underlines the need to explore the perspectives of individuals with intellectual disabilities (ID). Method: We developed six questions about healthy eating that were piloted at a conference for people with ID. A university researcher and a researcher with ID conducted and filmed semi-structured interviews with four participants. All researchers (with and without ID) then contributed to data analysis. Themes identified in each interview were compared across the four sets of data. Results: Participants found the term ‘healthy eating’ difficult. Some could name and recognise healthy foods but had little opportunity to influence their diet. Support staff had some control over access to food and engaging individuals in cooking. Most participants wanted to cook more and have more control over the choice of food. Conclusions: People with ID are interested in eating healthily although few have the opportunity to influence what they eat. Opportunity was determined by where they lived and who supported them.

Who decides: Women with severe and profound intellectual disabilities and mammography

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Aims: Little is known about the support women with severe and profound intellectual disabilities (ID) get in order to attend breast screening. This paper gives some insight into how staff approach mammography in this group of women. Method: Interview data from 23 participants (3 family-carers,
Voting, people with intellectual disabilities and the Scottish referendum

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Aim: Around one in three people with intellectual disabilities (ID) exert their right to vote. To identify factors to enhance voting, this study explored how people with ID were supported to vote during the Scottish Referendum for Independence. Method: Twenty-four people took part in three focus groups including 12 persons with ID, seven family-carers and five paid-carers. Topics included the voting process, facilitators and barriers to voting and the referendum. Thematic analysis was undertaken. Results: Three themes emerged: ‘What are we voting for?’ looked at issues that persons with ID raised in terms of voting and the referendum; ‘Who should I vote for?’ explored the influences that people with ID might be exposed to; while ‘Enhancing voting’ identified how they could be supported to make an informed choice. Conclusions: This study identified that persons with ID have an appetite to take part in political decision making but need help to exercise their right to vote. For this to happen, carers and persons with ID advocated a need for appropriate information.

A review of factors influencing parents' treatment choices for children with autism spectrum disorder

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Aim: Australia’s recently introduced National Disability Insurance Scheme emphasises the role that those with a disability and their families have in making treatment decisions. This reform raises concerns about which treatments parents select for their children with autism spectrum disorder (ASD) and what influences these decisions. The risk is that treatments which are known to be ineffective or potentially harmful are sometimes selected. Therefore, the aim of this review is to identify the factors impacting treatment choice for children with ASD. Method: Qualitative and quantitative studies published after 1994 that reported on factors influencing the selection of conventional, complementary and alternative, or specific treatments were included in a systematic review. Results: The results examine a combination of explicit factors (e.g., parent-reported considerations) and implicit factors (e.g., beliefs about ASD) which provide insight into what influences parents’ treatment decisions. Conclusions: It is important to identify both explicit and implicit factors that influence parents’ treatment decisions for their children with ASD. A better understanding of these factors will inform educational approaches to encourage engagement in best-practice treatments.
The experience of adult children of mothers with intellectual disabilities: A qualitative retrospective study from Poland

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Aim: The aim of study was to give a multifaceted account of the experience of adult children of mothers with intellectual disabilities (ID) in the Polish social context. Specifically, this study examined how grown children refer to their mother’s disability and how this mediated disability is reflected in the formation of their identity and biographies. Method: 23 in-depth interviews with adult children were analysed using Grounded Theory. Results: The central axis of differentiation in the analysed interviews was the availability or unavailability of informal support (with no institutional support). The experience of maternal ID was analysed in the context of four main dimensions emerging from data analysis: realizing the mother’s otherness, the modification of family statuses, parental role negotiation, and the stabilizing role of extended family. Conclusions: The experience of informal support from family members is an important aspect of the context in which the experience of maternal ID takes place; it determines the meaning given to that experience. It also plays an important role in the reorganisation of identity under the influence of difficult life experiences.

Health-related physical fitness of children with moderate to severe intellectual disabilities

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Aim: Physical fitness is an important indicator of health. In this study we investigate the physical fitness of children with moderate to severe intellectual disabilities (ID) by using field-based tests. Method: We selected physical fitness tests based on a review of the literature and input from focus groups. Body weight, height, waist circumference, functional strength measurements and results of the modified six minute walk test were obtained for 131 Dutch children with moderate to severe ID (83 male, age 9.5 ± 4.08 years). A multiple logistic regression analysis was used to study the association between the score on the physical fitness tests and child characteristics (e.g. gender, age, level of ID, physical activity). Results: First outcomes suggest low scores on strength and walk tests. Results of further analyses will be presented. Conclusions: Physical fitness seems to be low in children with moderate to severe ID. This presentation provides new information on the physical fitness of a group that is considered difficult to measure.

Improving health through inclusion and empowerment

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Aim: To engage people with intellectual disabilities (ID) in the development and evaluation of health initiatives. Method: Quantitative data was collected bi-annually from 14 sites involved in Special Olympics’ global Healthy Communities initiative, and qualitative data included interviews with people with ID and other stakeholders across seven sites. Emerging themes from thematic content analysis were compared against theoretical frameworks to answer evaluation questions. Results: Analysis of
quantitative and qualitative data highlighted the importance of people with ID understanding how to be healthy and feeling empowered to make healthy decisions. Another key theme was the importance of including people with ID in all stages of health programming. Quantitative data revealed the inclusion of 560 people with ID in planning and/or implementation of local health initiatives. **Conclusions:** People with ID can act as role models and inspire their peers, families, and community members to change their behaviours.
Supported employment for Chinese persons with intellectual disabilities

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Aim: The aim was to explore feasible models of supported employment for persons with intellectual disabilities (ID) in a Chinese city, and provide evidence-based suggestions on future policies. Method: This research focused on 30 supported employment cases over one year. Twelve job coaches from seven vocational providers were trained in the principles of supported employment. Persons with ID, employers and families rated quality of life and satisfaction from 1 to 5 across 16 indicators including salary, work contents and times, social benefits, working relations, responses towards criticism, and getting along with colleagues. Results: Eleven of the participants signed contracts with companies. Among the 10 who finished the evaluations, most gave scores greater than 4 out of 5; employers scored >4; and families gave social benefits a score of 3. Employers gave the highest scores and were the most satisfied among the three groups. Conclusions: Through supported employment, persons with ID can have employment in a normal working environment in China, which increases their quality of life and the degree of satisfaction among families and employers.

An evaluation of employment outcomes achieved by Transition to Work service providers in Sydney, Australia

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Aim: The Transition to Work (TTW) programme has been implemented in New South Wales (NSW) since 2005 to help school leavers with moderate or high support needs attain employment. This study examined various employment outcomes achieved by 35 TTW service providers in Sydney. Method: TTW outcome data of 1435 school leavers graduated from Sydney high schools between 2007 and 2011 were analysed. About 65% of those school leavers were young people with intellectual disability. Descriptive statistical analysis and Chi-square analysis were performed. Results: There was a constant growth in the number of TTW programme entrants and an overall increase in the employment rate of TTW clients. Many TTW service providers in Sydney served fewer than four clients annually on average. Huge differences were evident in the employment outcome performance of individual TTW service providers. Conclusions: The TTW programme in Sydney allowed more school leavers to achieve employment. However, further research is needed to examine the associations between TTW program features and different employment outcomes to build an optimal TTW programme.

An exploration of school-to-work transition services for adolescents with intellectual disabilities in China

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Aims: Vocational education and transition services for people with disability in China gained currency in the last decade, however systematically planned transition education and services are not usually available for Chinese school leavers with intellectual disabilities (ID). The present study aimed to explore
the delivery of evidence-based practices in school-to-work transition for adolescents with ID in China. **Methods:** 329 transition teachers from 15 institutions across six cities in China were surveyed. Descriptive analysis, Chi-square analysis, ANOVAs and multiple regression were conducted. **Results:** Evidence-based transition practices were at least occasionally implemented; evidence-based transition practices within different categories were implemented at various frequencies; and statistically significant differences existed in the mean scores of transition practices for participating transition teachers in different demographic groups. **Conclusions:** Transition education and associated services in China are in an early stage of development, and signal a need for action to explore effective practices that could address the barriers and promote positive post-school outcomes for Chinese adolescents with ID.

**Surveillance study of the Japanese child development support centres**

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**Aim:** By revision of the Child Welfare Act in 2012, the child development support facilities were reorganised. We investigated the current conditions focusing on medical care in 2014. **Method:** We sent questionnaires to the member facilities of The Council of Development Support Centres, Japan. Topics covered support situations, complications, medical care of children and related challenges. **Results:** Responses were received from 281 centres serving 13,486 children. These included Child Development Support Centres (CDS; n=102), Child Development Support Centres with Medical Services (Medical CDS; n=45), Child development support programs aside from CDS (CDS facilities; n=52), Afterschool Day Programmes (n=43), and others (n=39). Nurses were employed at all Medical CDS, 40% of CDS, and 25% of CDS facilities. Clinics were established at 30% of all facilities. At all facilities, there were many children who required medical care at all facilities. Epilepsy was the most prevalent medical condition seen in children. **Conclusions:** We suggest solutions, such as a support system for children to enable receipt of required medical care, cooperation with clinics, and the employment of nurses.

**The study of rehabilitation needs among children with intellectual and developmental disabilities in China**

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**Aim:** The study aims to identify factors that influence the rehabilitation needs of children with intellectual and developmental disabilities (IDD), and tries to give them early treatment and change their life into better quality. **Method:** Data from The Special Investigation on The Basic Service Status and Demand of The Disabled in China were used to describe the problems seen in children with IDD in China. The sample included 307,131 children with IDD. Logistic regression was used to identify factors (gender, age, census register and the income of family) associated with rehabilitation needs. Difference in needs between normal children and children with IDD was also examined. **Results:** Younger children, children from higher income families, and those who use more services are more likely to have rehabilitation needs. **Conclusions:** Future research should focus on girls and children with IDD in rural areas. The
society and government should pay attention to giving appropriate support and service to children with
IDD.

The impact of self-advocacy in my life in inclusive research

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Aim: Self-advocacy has played an important role in my life, as a young adult with intellectual disabilities (ID). This study aims to share my experience as a self-advocate in an inclusive research. Method: A participatory action research was conducted under a research project in three cycles built around integrated cycles of planning, action, observation and reflection. I was given opportunity to speak and listen through focus group discussions and interviews. Results: It was tough in the beginning because it was my first experience in data collection and analysis even after ten years of learning about self-advocacy. I was encouraged to write about my learning experience as well as expressing my views. The impact of self-advocacy becomes prominent as I learn about myself through my journal writing. I become more confident throughout the study. It is a process of self-emancipation for me. Conclusions: I am confident to take control of all aspect of my life now. I believe we need to learn and work together as a team to achieve better understanding among ourselves.

Investigating racial disparities in age of initial receipt of developmental therapies among a nationally representative sample of children with autism spectrum disorder

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Aim: There is a need to examine the role of a child’s race in access to developmental therapies (e.g., behavioural, speech-language, physical, and occupational) among children with autism spectrum disorder (ASD). We asked the question, what is the relationship between child race/ethnicity and the age of initial receipt of developmental therapy? Method: Using data from the National Survey of Children’s Health (NSCH), 2011-2012 (United States), we used multinomial hierarchical linear modelling to analyse differences in age of initial receipt of developmental therapy (<2 years, 2-3 years, 4-5 years, >5 years) among a nationally representative sample of children with ASD (N=1498) by child race/ethnicity. We controlled for state of residence and key covariates. Results: The analysis suggests mixed results. In most cases, however, compared to white children, children who are black, Hispanic, and multiracial/other have a higher probability of being older when initially receiving developmental therapy. Conclusions: Future research needs to examine the pathways through which children experience delays in receiving developmental therapies.

Does social welfare service experience moderate the effects of caregiving stress on parents’ attitude towards the marriage of children with intellectual disabilities in South Korea?

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**Scientific Oral Presentations**

**Aim:** This study investigates whether the social welfare service experience provided by the Korean Ministry of Health and Welfare can moderate the effects of caregiver stress on parents’ attitude towards marriage of children with intellectual disabilities (ID). **Method:** Data from 739 parents who participated in the 2011 Korean National Survey on Individuals with Developmental Disabilities and their Families were used. Time demands of caring was used as a measure of caregiver stress; the level of social welfare service experience was used as moderator. For parents’ attitudes towards marriage, higher scores reflect negative attitudes. Multiple regression analyses were used. Specifically, interaction effects were tested for moderating effects. **Results:** Parents reporting greater time demands of caring had more negative attitudes towards marriage. Parents who had experience with social welfare were less likely to be influenced by time demands of caring compared to those without, indicating that experience with social welfare moderates the relationship. **Conclusions:** The effect of caregiving stress on parents’ attitudes towards marriage varies by levels of experience with social welfare. Intervention relating to the experience with social welfare in South Korea is necessary.

**Does severity of intellectual and developmental disability predict Mental Health Court decisions about fitness to stand trial?**

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**Aim:** The relationship between intellectual and developmental disability (IDD) severity, comorbid mental illness and being deemed unsound of mind at the time of offence or unfit to stand trial by Court in Australia has yet to be empirically described. **Method:** Two years (2013-2014) of administrative data collected on 96 individuals referred to the Queensland Mental Health Court (MHC) were examined. All individuals underwent a comprehensive psychiatric and cognitive evaluation. The association between IDD severity and MHC decision was assessed using multivariable modified Poisson regression analysis, controlling for demographic, clinical and criminogenic factors. **Results:** Overall, 42 (43.8%) individuals received a diagnosis of either borderline/mild or moderate IDD. Adjusting for covariate effects, a significant positive association was observed between IDD severity and being found unsound or unfit by the MHC (APRR=1.50; 95% CI: 1.07-2.09; p=0.018). However, comorbid mental illness did not predict MHC decision-making. **Conclusions:** Severity of IDD appears to predict being found unsound or unfit for trial, however comorbid mental illness does not. Further research examining how clinical information is related to MHC outcomes for people with IDD is warranted.

**Disability and justice professionals’ perceptions of gaps in the transition out of prison for people with intellectual and developmental disabilities**

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**Aim:** Approximately 1 in every 10 soon-to-be-released prisoners in Australia lives with an intellectual and developmental disability (IDD), yet remarkably little is known about their post-release health and justice-related outcomes. This study aimed to understand the health and social needs during transition out of prison for ex-prisoners with IDD across two Australian states: Queensland and Western Australia. **Method:** A narrative interview schedule was administered to 17 disability- and justice-related service
providers to examine perspectives on where gaps in the transition out of prison exist and what specific steps can be taken to address unmet need. Interviews were manually analysed for key themes. Results: Inadequate life skills, system complexities and combative relationships were identified as crucial gaps to providing comprehensive and effective support during the transition out of prison for ex-prisoners with IDD. For service providers without disability-specific training, a key issue was the lack of formal identification of ex-prisoners with IDD. Conclusions: This arena is complex and our findings indicate that there are clear differences between current policy, service delivery objectives, and actual delivery of services targeted at ex-prisoners with IDD.

Intellectual disability and the ability to self-manage health after release from prison: A prospective cohort study

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Aim: Ex-prisoners who are motivated and feel able to actively participate in the management of their health-related needs have improved health outcomes and are better equipped to address challenges of community re-entry. However, perceived ability to self-manage healthcare after prison release has not been empirically described for ex-prisoners with intellectual disabilities (ID). Method: The Hayes Ability Screening Index (HASI) was administered to 935 prisoners within six weeks of expected release from seven prisons in Queensland, Australia from 2008-2010. Perceived ability to self-manage healthcare was assessed using the Patient Activation Measure (PAM) at baseline, 1, 3, and 6-month follow-up interviews. Adjusting for demographic, clinical, and criminogenic characteristics, the association between ID screening status and ability to self-manage healthcare over six months of community follow-up was assessed using a multilevel mixed-effects linear model. Results: Screening positive on the HASI was negatively associated with PAM score (B=-4.46; 95%CI:-6.05,-2.87; p<0.001) over six months of post-release follow-up. Conclusions: Ex-prisoners screening positive for possible ID report significantly lower levels of perceived ability to self-manage their healthcare after release compared to ex-prisoners without ID. Transitional self-care interventions may be warranted in this marginalised group.

The impact of transition on health and well-being in young people with intellectual disabilities: A qualitative investigation

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Aim: A recently-conducted systematic review revealed a gap in the literature on transition and health and well-being outcomes for young people with intellectual disabilities (ID), highlighting the need for a thorough qualitative investigation. Method: Semi-structured interviews, approximately one hour long, were conducted with around 20 young people with mild to severe ID aged 16 to 24 years, and their families, in order to explore whether transition affects young people’s health and well-being, in what particular ways, and what is useful in supporting a healthy transition. Interviews were transcribed and analysed using NVivo software. Content analysis was conducted, with items coded using a combination of emic and etic categories. Results: Participants engaged well with the interviews, and interesting themes were identified. At the time of writing, key themes include the uncertainty surrounding daytime
activity after leaving school; parents as a key source of support during transition with friends becoming increasingly important, and gender-specific health concerns, such as menstruation and pregnancy.

**Conclusions:** Transition is an impactful time in the lives of young people, and health outcomes need to be better understood.

**Transition and health in young people with intellectual disabilities: Secondary analysis of existing data**

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**Aim:** Transition may be a period of vulnerability for young people with intellectual disabilities (ID), but more evidence is needed on its impact on health outcomes. This study examined this question through secondary analysis of two datasets: the Census Scotland 2011 and the National Longitudinal Transition Study-2 (NLTS2). **Method:** Within the Census 2011, health during transition in people with ID and age- and gender-matched peers without disabilities was compared. Within the NLTS2, parent and youth appraisals of general health were compared. Logistic regression was used to identify predictors of good health across transition. **Results:** In Scotland, the prevalence of people with ID aged 16 to 24 years is 0.66%. Compared with their non-disabled peers, their health is poor: 39.8% rate their health as ‘very good’, compared to 73.5% of people without ID. In the NLTS2, there are 830 people with ID aged 13 to 16 at first wave of data collection. Around one quarter of parents rate their child’s health as ‘excellent’. **Conclusions:** Health during transition is worse for young people with ID than those without.
Effects of thinning positive plus negative reinforcement using chained schedules during treatment of destructive behaviour with functional communication training

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**Aim:** Previous research has supported functional communication training as an effective intervention for reducing problem behaviour across socially mediated functions. Clinicians often programme schedule-thinning procedures to increase the portability of the treatment package. For individuals with escape-maintained problem behaviour, chained schedules have proven effective in increasing task completion and supplemental procedures may ameliorate re-emergence of problem behaviour as the schedule is thinned. The present study evaluated the use of a chained schedule-thinning procedure with and without tangible items (alternative reinforcement) embedded in the negative-reinforcement interval.

**Method:** Two individuals with escape-maintained problem behaviour participated. We compared two treatment conditions, escape-only and escape-to-tangibles, using a single-subject, alternating treatments design with each treatment implemented in a distinct context.

**Results:** Delivering both positive and negative reinforcement within the chained schedule (relative to providing only negative reinforcement) produced larger reductions in destructive behaviour, larger increases in compliance, and facilitated reinforcer-schedule thinning.

**Conclusions:** The current results provided preliminary confirmation that providing positive plus negative reinforcement following completion of the chained schedule would decrease destructive behaviour, increase compliance, and facilitate reinforcer-schedule thinning.

The use of psychotropic medication in the treatment of self-injury

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**Aim:** We evaluated the use of psychotropic medications for 74 individuals on an inpatient unit with self-injurious behaviour (SIB). **Method:** The Treatment Intensity Rating Form (TIRF) is a 10-item scale that includes measures of pharmacological intervention, such as the number of medication trials a patient had over the course of their admission, and the number of medications that were in place at discharge. Medications used to address other medical conditions, illness, or sleep were not included. **Results:** Patients whose SIB was maintained by sensory or automatic reinforcement received significantly more medication trials (p=0.0005). The number of medications at discharge was also greater for patients whose SIB was maintained by sensory/automatic reinforcement, though the disparity in the number of medications was less extreme. Patients whose SIB was maintained by social consequences were more frequently prescribed antipsychotics and anticonvulsant medications than other patients. **Conclusions:** The TIRF may be a useful measurement tool in programme evaluation with regards to the intensity of medication intervention across participant population variables (e.g., functions of problem behaviour).

The role of behavioural flexibility in challenging behaviour

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Aim: Behavioural inflexibility may lead to challenging behaviour in individuals with autism. We examined scores on behavioural flexibility related to adaptive and challenging behaviour. Method: Data were collected from 110 inpatients admitted for the treatment of challenging behaviour. Scores from the Behavior Flexibility Rating Scale (BFRS-R), the Vineland Adaptive Behavior Scale II, and the outcome of a functional analysis of challenging behaviour were correlated for individuals with a diagnosis of autism (n = 17), and those with a diagnosis of autism and intellectual disability (ID; n = 93). Results: There was a significant difference (p < .05) between the BFRS-R total score for the autism and autism and ID groups (18.3 compared to 15.3). Additionally, individuals with autism only were more likely to have challenging behaviour maintained by automatic or sensory reinforcement. Individuals with autism and ID were more likely to have challenging behaviour maintained by access to toys and activities. Surprisingly, high scores the BFRS-R scores were correlated with higher composite scores on the Vineland. Conclusions: Having more adaptive skills does not necessarily lead to greater flexibility in individuals with autism.

Development of an international tool: Family Needs Assessment

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Aim: Better tools are needed to assess and understand families’ needs, particularly families who include a member with intellectual and developmental disabilities (IDD). This research involved the development of the Family Needs Assessment (FNA), an instrument designed to systematically identify and prioritise needs at the family-unit level. Method: A review of the family quality of life (QoL) and family systems literature and a review of existing scales was conducted to develop initial domains/items for the tool. Focus groups and individual interviews (n= 16) were conducted to determine content validity of the FNA tool. Descriptive statistics were conducted in a cross-nation pilot study (n=80).

Results: The multi-step development process resulted in the final version of the FNA which includes 77 items using a five-point likert-type scale to indicate level of need. Domains with the highest mean scores were: Getting Services (3.7); Teaching (3.6), and Recreation (3.5) Conclusions: The development of the FNA was an international, cross-cultural effort to facilitate decision-making processes made jointly by professionals and families of individuals with IDD to achieve better individual and family QoL.
Practical study concerning the development of a support programme for siblings and families of children with profound intellectual and multiple disabilities

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Aim: This study develops and examines the effectiveness of a Family Participation Programme to support siblings of children with profound intellectual and multiple disabilities (PIMD). Method: Participants included seven siblings (6 to 11 years old) and their families. The programme was conducted in seven sessions. Participants engaged in playful movement activities, learning and discussing specific subjects about their family. During sibling activities, each sibling created a portfolio picture book about his/her family. Parents read the book and wrote comments after each session. The siblings completed the questionnaire on negative feelings about their siblings with PIMD (McHale et al. 1986) and the Family Diagnostic Test:FDT (Azuma et al. 2002) before and after the programme. The siblings and their parents were interviewed about themselves and the relationships within the family. Results: Results of Wilcoxon signed-rank test showed that siblings’ concerns regarding the disabilities of their siblings with PIMD significantly decreased. On the FDT, the relationship between the siblings and their parents indicated positive changes. Conclusions: The developed Family Participation Programme to support siblings is effective in altering their negative feelings and in changing parent-child relationships.

Incorporating social-problem solving strategies into individual service plans for individuals with intellectual disabilities

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Aim: Problem behaviours are a public health problem for individuals with intellectual disabilities (ID), often leading to using psychotropic medications for management, to emergency department visits and psychiatric hospitalisations. Evidence indicates that social problem-solving interventions are effective in reducing problem behaviours, however, interventions were largely conducted in clinical and forensic settings. We modified and tailored an existing research-based social problem-solving programme (now called Steps to Effective Problem Solving [STEPS]) as a preventive intervention in the community and piloted the programme with promising results. The aim of this project is assessment of whether skills learned from STEPS can be incorporated into Individual Support Plans (ISP). Method: Sample ISP goals were created utilising frequent scenarios leading to problem behaviours identified during the STEPS pilot and using skills learned in STEPS. With research ethics approval, participants with ID in the STEPS pilot, their residential staff and case managers were interviewed on how they might use STEPS skills learned in planning ISP goals. Results: Scenarios, strategies and sample ISP goals were well-received. Conclusions: Incorporating STEPS skills into ISP may enhance long-term use of the skills.

Mixed methods study phase II: Exploring the facilitators and barriers of screening children for autism in Oman

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Aim: To identify the facilitators and barriers of screening children for autism in the primary healthcare settings, from the perspective of primary health care (PHC) professionals in Oman. Method: The quantitative phase of a mixed methods study is reported. Representatives from 11 Expanded Program of Immunisation focal points (immunisation centres) were recruited from all governorates in Oman to support questionnaire data collection. Representatives attended a full-day workshop to brief them about different aspects about autism, to orient them to the study purpose, and to their role in distributing the survey questionnaires. 572 questionnaires were distributed to proportionate samples of professionals (255 general practitioners and 317 registered nurses), from PHC centres across the Omani governorates. 516 questionnaires were returned. Results: Preliminary results suggest a deficit in knowledge especially among nurses, a lack of public awareness about autism and social stigma which may potentially be challenging barriers to the introduction of screening for autism in Oman. Conclusions: In order to facilitate screening for autism in Oman more public and professional awareness and reducing cultural sensitivity would be needed.

Mixed methods study phase I: Exploring the facilitators and barriers of screening children for autism in Oman

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Aim: To explore relevant barriers and facilitators of screening children for autism in Oman. Method: A qualitative descriptive design was used for this initial phase of mixed methods sequential exploratory (Instrument Development Model) Study. Two focus groups were undertaken with nurses and doctors from the primary healthcare settings in Oman to inform on screening for autism and to develop a survey tool. Results: Both groups were positive about introducing screening for autism, but felt they lacked the knowledge and skills to undertake this. Responses also indicated variable awareness of the referral system, and availability of autism services in Oman. However stigma was raised as a potential barrier. Responses from the focus group were used to inform the development of a survey questionnaire asking about introducing autism screening in Oman. Conclusions: Using questionnaires appeared to be a useful tool to identify barriers and facilitators for screening for autism in Oman. Introduction of screening for autism would necessitate more training and knowledge about autism. Public awareness campaigns to reduce stigma and greater collaboration to provided services.

Family quality of life in Kinshasa, Democratic Republic of the Congo

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Aim: The study of family quality of life (QoL) has gained growing prominence in the field of disability research in the 21st century, with researchers on nearly every continent conceptualising and measuring family QoL. There are relatively few studies exploring family QoL in contexts characterised by poverty, such as in the Democratic Republic of the Congo (DRC). This poster describes an exploration of family QoL among family members of persons with disabilities in the DRC. Method: We conducted four focus groups with family members of persons with disabilities living in Kinshasa, the capital city of the Democratic Republic of the Congo, using a grounded theory approach for analysis. Results: Family QoL is
an important concept to understand and measure in the DRC. In this study, participants often conceptualised family QoL as a family’s ability to ‘solve problems’, and thus, might be highly linked to resilience. **Conclusions:** Continued study of family QoL in the DRC and in other similar African contexts will help to ensure that disability-related programmes and services are as culturally-appropriate, effective, and relevant as possible.

**Barriers to successful employment for individuals with mild intellectual disabilities**

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**Aim:** The focus of this qualitative study was to explore the major barriers to successful employment for individuals with intellectual disabilities (ID). **Method:** Semi-structured interviews were used to explore the perceptions of a sample of eight managers/supervisors of employees with ID regarding the main barriers that face them when trying to successfully gain employment. **Results:** An analysis of the interviews revealed four major factors that impede individuals with ID from successfully gaining employment: work experience, social skills, attitudes towards individuals with ID, and transportation. **Conclusions:** The current study was designed to provide important information to policymakers, officials, educators, and parents regarding the challenges and barriers that face the successful employment of individuals with ID. The study shows the importance of support as well as effective and planned preparation for individuals with ID at school so that they have sufficient qualifications and skills to help them successfully gain employment.

**The effectiveness of interventions for people with intellectual and developmental disabilities with dementia**

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**Aim:** The increased longevity of people with intellectual disabilities (ID) also increases the likelihood of them developing dementia. Although the efficacy of dementia interventions for the general population has been widely researched, little is known about the effectiveness of dementia interventions for people with ID. This systematic review aims to identify the available evidence on interventions for people with ID, and appraise the effectiveness of each intervention to inform current practice, and the direction of future research. **Method:** Two electronic databases were searched: PsycINFO and MEDLINE. A quality assessment was carried out for all studies included in the review. **Results:** 5 non-pharmacological and 9 pharmacological interventions were included. Although favourable results were reported for some non-pharmacological and pharmacological interventions, a firm conclusion on their effectiveness could not be derived as most of the studies lacked the quality needed to assess the efficacy of the interventions. **Conclusions:** Clinicians should be cautious when treating people with ID based studies from the general population. Further research with stronger methodology is needed to assess the efficacy of interventions for people with ID and dementia.

**A review of empirical studies about family quality of life and intellectual disabilities**
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**Aim:** Quality of life (QoL) is a worldwide concept that has been studied in many areas. Given the importance that has been accorded to families, researchers begin to analyse QoL in a family level, also in families with members who have intellectual disabilities (ID). Family QoL has demonstrated much potential in terms of evaluation and intervention with these families. The present work reviews empirical studies of family QoL and ID and explore the main findings. **Method:** The empirical studies were selected in the research databases EbscoHOST and included the concepts of family QoL and ID. **Results:** From a total of 32 studies, 15 essentially used the Family Quality of Life Scale-2006 (FQOLS-2006), 11 used the Beach Center FQOL Survey and 6 used other methods to evaluate family QoL. These studies emphasise the multi-dimensional nature of family QoL evaluated through its domains, as well as some individual and family variables that have impact on family QoL. **Conclusions:** Family QoL offers a positive and comprehensive framework for assessing families of persons with ID.

**Family quality of life in intellectual disability: Perspectives of parents, siblings and persons with ID**

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**Aim:** Although individual quality of life (QoL) is widely studied in the field of intellectual disabilities (ID), family QoL only recently began to be researched. However, some limitations have been highlighted, including the fact that, to date, studies have only considered the perspective of the primary caregiver. This project aims to evaluate the family QoL in families of people with ID, through the perceptions of parents, siblings and the persons with ID. **Method:** In the first phase, focus groups and individual interviews will be used. In the second phase, quantitative methods will be used to validate an assessment instrument of family QoL developed based on the results gathered in the first phase. The results obtained from parents, siblings and persons with ID will be compared. **Results:** Some preliminary results will be presented on the domains of family QoL identified in the first phase of the study. **Conclusions:** It is important to consider the perspectives of different members of the family to know in more depth the family QoL in families of persons with ID.

**Teacher-pupil relationship: Comparison between special and inclusive schools**

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**Aim:** Under inclusive education, most student with intellectual disabilities (ID) are enrolled in regular schools but sometimes parents prefer special schools because they do not want their children to become outsiders in inclusive classes. The teacher and pupil relationship may contribute to this. This study examines the relationship between regular and special education teachers and pupils with ID. **Method:** A case study approach was used. Eight students with ID, their teachers and parents were selected across inclusive and special school settings. Data were collected through observations and interviews. The preliminary analysis was used to continually compare and contrast the findings, to note
any emerging trend, as well as to guide later interviews and observations, clarify findings, and fill information gaps. After all the interviews and observations were completed, data were analysed using content analysis. **Results:** The relationships between students and teachers were good across the two settings. There was no difference between special schools and inclusive schools regarding teacher-pupil relationship of attachment, connectedness, bonding, engagement, caring and closeness. **Conclusions:** Children’s relationships with teachers is an important variable in learning.

**Audiometric threshold measurement in children with intellectual disabilities: Preference of behavioural response mode**

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**Aim:** Clinical threshold measurement is a fundamental diagnostic tool in audiology. This study compared the speed, false alarm rate, and participant preference of different response methods for measuring pure-tone thresholds in children with intellectual disabilities (ID). **Method:** 13 children with ID participated. Response method order was randomly assigned to three different groups. Air-conduction thresholds were measured twice for each response method for each participant in octave intervals between 500 Hz and 2000 Hz. The second threshold measurements were performed on a different day but within two weeks of the initial measurement. **Results:** A significant preference was found for using the verbal response. The groups who were assigned push button or hand raising for response also responded with verbal output and verbal response occurred before the push button but after the raising a hand in the respective group. **Conclusions:** This study supports the use of the verbal response method when measuring auditory thresholds for children with ID with suspected normal hearing.

**Communication modality for children with hearing impairments: Preferences of deaf adults, deaf parents and hearing parents**

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**Aim:** To determine the communication preferences of individuals with hearing impairments and parents of individuals with hearing impairments. **Method:** A questionnaire was completed by 50 adults with hearing impairments as well as parents of children with bilateral profound hearing loss (50 hearing parents and 8 deaf parents). **Results:** The results revealed that hearing and deaf parents have the same desire with respect to communication modality for their child. The desire of both hearing and deaf parents was that their child should speak like hearing children. This was deemed more suitable for the children to progress and to live comfortably in the oral society. However, deaf adults had mixed views on preferences for communication mode. **Conclusions:** The findings of the present study emphasise that awareness should be created among the deaf community, parents of the deaf and significant others about technological advances and rehabilitation strategies for the treatment of hearing impairment. Parents need this information so that they can make rational decisions about the communication modality for their hearing impaired children.
Screening hearing impairment in at-risk infants and children

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Aim: Identification of the aetiology of hearing loss in children facilitates management and provides important prognostic information. This study investigates hearing impairment as co-morbidity so that comprehensive treatment can be facilitated. Method: 612 infants and children with risk indicators for hearing loss and developmental disabilities (DD) including cerebral palsy (CP), intellectual disability, and autistic features were screened for hearing loss. Results: The prevalence of hearing impairment was 8.5% (52 of 612); 13 children were found to have unilateral hearing impairment, and bilateral hearing impairment of various degrees was observed in 39 children. The prevalence of hearing impairment was highest among children diagnosed with Down syndrome, followed by CP, autism, learning disability and ADHD. Conclusions: Hearing impairment is more prevalent in children with DD as compared to general population. The risk factors directly associated with hearing impairment proved to be craniofacial deformities, prematurity, meningitis and duration of mechanical ventilation. Hence, babies with risk indicators should be assessed for the hearing loss so that comprehensive intervention programme can be initiated to facilitate holistic progress in the child.

Stress and depression in parents of children with hearing impairment

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Aim: Depression is a common stress-related response for parents of children with disabilities. Hence, the objective of the study was to determine the levels and detriments of stress and depression in parents of children with disabilities especially with hearing impairment. Hearing impairment of various degrees co-exists with various developmental disabilities. Method: 120 parents (70 mothers and 50 fathers) of children with bilateral profound hearing loss individually responded to two self-report scales duly translated into Hindi: Parental Stress Index (PSI) and Center for Epidemiologic Studies Depression Scale (CESD). Results: Mothers have high stress levels compared to fathers. Compared to other mothers, the mothers of children using hearing aid had lower scores on the PSI. The results on CESD revealed high depression levels in both groups with no significant difference in the mean scores between groups who had children with co-existing cerebral palsy and borderline intelligence. Conclusions: The present study highlights the need for the rehabilitative professionals to focus on creating awareness in masses and on providing family-based counselling and family-based intervention for children with hearing impairment.

Arts is the key to happiness: Parental views around engagement in disability arts

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Aim: This study explores parents’ perceptions of their child’s participation in disability arts. Method: Qualitative research guided by phenomenology explored the views of parents whose children participate in disability arts programmes. The experiences of 13 parents were examined through semi-
guided interviews, focus groups and observations. Parents described insights regarding physical, cognitive and psychosocial development in their child linked to participation in arts. Involvement of a key informant with intellectual disabilities highlighted the importance of people with disabilities being an integral part of research, to be the interviewer rather than the interviewee. Results: Arts participation was reported to have a positive impact on the physical, cognitive and psychosocial development of participants. Synergistic relationships on social, developmental and community levels provided evidence of the changes that parents attributed to engagement with arts. Changes included reported increased confidence, expressions of happiness, increased friendship, cognitive and physical development. Conclusions: Parents are looking for extra-curricular programmes to facilitate leisure experiences and development, without it having to be therapy. This study suggests engagement with the arts offers such outcomes.

**Intersectional perspectives on post-school occupation among young adults with intellectual disabilities in Sweden**

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**Aim:** This study explores and analyses, from an intersectional perspective, the association between parents' country of birth as well as their level of education and their children's type of occupation after graduating from Swedish upper secondary school for pupils with intellectual disabilities (ID).  

**Method:** This is a quantitative study based on three registers (HURPID, LSS, LISA). The analyses are based on logistic regression, interaction analysis and chi-square tests. The sample size was 12,269.  

**Results:** Children of less-educated parents tend to have paid employment and children of highly educated parents tend to participate in disability day programs. Parents’ country of birth and level of education affect the former pupils’ post-school occupation in different ways. The association between parents’ country of birth and former pupils’ occupation is modified by parents’ level of education.  

**Conclusions:** Knowledge and awareness of different background conditions among children graduating from upper secondary school for pupils with ID need to increase.

**A Korean special education teacher’s practical knowledge in math class that uses problem-based learning strategies**

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**Aim:** One of the main challenges of students with intellectual disabilities (ID) is the limited capacity to use problem-based learning (PBL) strategies. The purpose of this study is to explore a Korean special educator’s practical knowledge to fully assist students to use the PBL strategies in math class.  

**Method:** The participants included a researcher who instructed classes, six peer teachers who provided feedback after observing classes, and three students with ID. The data collected from eight classes using an action research were analysed by an inductive method.  

**Results:** Four upper categories emerged: modifications to math classes and PBL strategies, an appropriate class design, ‘my friend, the fraction, in real lives’, and students who lead learning.  

**Conclusions:** Teachers need to modify math classes and PBL strategies to meet students’ educational needs. The class design should consider students’ capacities, limitations,
and the proper amount of activities. Teachers need to employ embedded instruction that uses real-life examples and easy language. Teachers need to facilitate student-directed learning.

Do we take it for granted everyone is connected to and can access the internet?

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Aim: To raise awareness of the needs for people with non-functional literacy when using computers and the internet. Method: This paper reviews implications of research that identifies up to 20% of Australians do not access the internet (10-20% in many Organisation for Economic Co-operation and Development countries). Results: Having access to, is different to being able to meaningfully use, the internet and computers. This is significant as 44% of adult Australians have non-functional literacy. Only small numbers of people are identified as having competent internet skills for problem-based literacy. Conclusions: Access to and connection to the internet is mostly concerned about the hardware, the software and the cost of the internet and computer technology. More attention must be given to the content of websites if access to the internet is to be realised for the many people with intellectual disabilities and others with non-functional literacy.

Family Needs Assessment in Brazil: A pilot study

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Aim: Professionals serving families of individuals with Intellectual and developmental disabilities (IDD) understand the importance of identifying family needs as a key element in improving family quality of life (QoL). We aim to extend the Family Needs Assessment (FNA), an instrument designed to systematically identify and prioritise needs at the family-unit level to the Brazilian population. Method: Our pilot study included 19 families with a person over 18 years-old with IDD living in two states of Brazil. They were administered the Brazilian version of the FNA to indicate level of need across four domains. Results: The domain mean scores were 53.75 for emotional well-being, 56.5 for family interactions, 49.95 for physical and material well-being and 50.0 for education and services. The Cronbach’s alpha and Split-half reliability coefficients were 0.95 and 0.93, respectively. Cronbach’s alpha of the domains was between .82 (emotional well-being) and .90 (physical and material well-being). Conclusions: The results show that the Brazilian FNA is a reliable and valid instrument. Domain mean scores illustrate the areas in which families report the highest level of need.

Development and use of the Key Word Sign Australian Vocabulary

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Aim: To develop a key word sign vocabulary set suitable for the cultural and functional needs of Australian users. A key word sign vocabulary is taught to the communication partners of children and adults with complex communication needs. The selected vocabulary needs to support the development
of communication and language skills. **Method:** Words from refereed vocabulary frequency studies and non-refereed key word sign resources were compiled. The selected words were ranked according to the frequency of use. An expert panel from across Australia rated the vocabulary employing inclusion and exclusion criteria. **Results:** Development of a 600-word vocabulary set comprising 100 core words and 500 fringe words. **Conclusions:** Key Word Sign is used to support early interaction, develop language skills and provides a functional means of communication for individuals with complex communication needs. An iterative process was used to determine the content of the Key Word Sign Australia vocabulary designed for use by communication partners. The 100-word core vocabulary is taught in all introductory Key Word Sign workshops. The total vocabulary is available on the Key Word Sign Australia App.

**Evaluation of treatment of insomnia and behavioural problems in 67 patients with Smith Magenis syndrome**

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**Aim:** Sleep maintenance problems and temper tantrums are a major problem in Smith Magenis syndrome (SMS). Atypical neuroleptics are often prescribed for treatment of disruptive behaviours. We suspected that restoring a normal sleep-wake rhythm could reduce the use of neuroleptics. **Method:** Melatonin levels at admittance and during treatment were measured in 67 patients with SMS. Effects of melatonin treatment on sleep-wake rhythm and behaviour were reviewed, and alternatives to neuroleptics examined. **Results:** For those with high daytime melatonin levels, a normal melatonin dose (1 to 3 mg) can be prescribed (fast or time release), combined with an early morning dose of acebutolol or metoprolol. Most patients with low daytime melatonin levels are slow metabolisers and need a low dose of fast release melatonin (0.1 to 0.3 mg), without blockade of endogenous melatonin. In most cases behavioural problems decreased, but if medication was necessary clonidine and methylphenidate were a good alternative to neuroleptics. Prescribing a ‘normal’ dose to melatonin slow metabolisers resulted in melatonin accumulation and severe deterioration of the sleep-wake rhythm. **Conclusions:** Successful treatment of sleep problems can lead to a decrease of behavioural problems, but the addition of methylphenidate, clonidine or risperidone may be required.

**Family physicians’, family practice residents’ and nurse practitioner students’ attitudes and experiences recommending cancer screening to patients with intellectual disabilities**

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**Aim:** In a mixed methods study, we explored both primary care providers’ attitudes towards recommending cancer screening to people with intellectual disabilities (ID) and providers’ experiences recommending screening. **Method:** A cross-sectional survey, including the Community Living Attitudes Scale-Intellectual Disabilities (CLAS-ID), was completed by 106 family physicians, nurse practitioner students and family practice residents across British Columbia, Canada. Follow-up descriptive, exploratory interviews were conducted with 2 family physicians and 10 family practice residents. **Results:** Participants with negative attitudes were less likely to recommend breast and colorectal cancer
screening to fictional patients. In interviews, limitations related to both patients’ abilities and the physicians’ practice within the healthcare system were frequently discussed as barriers to promoting screening. **Conclusions:** Aspects of participants’ attitudes, and barriers related to family medicine practice structures are related to whether primary care providers promote screening to their patients with ID. The implications for incorporating these findings into routine primary care for people with ID will be discussed, as will the role of the primary care provider in promoting screening to people with ID.

**Attitudes towards caring for a child on the autism spectrum: Long-term well-being outcomes**

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**Aim:** This study investigated carers’ initial motivations and attitudes towards caring for a child on the autism spectrum, and the association between this mind set and future indicators of personal well-being. **Method:** Carers with a son or daughter on the autism spectrum completed a survey containing questions regarding their initial attitudes and perceptions of caring for their child. The survey also included the Personal Wellbeing Index and the Kessler Psychological Distress Scale (K10). Participants’ scores on these validated measures of well-being were investigated in relation to their initial caring motivations. **Results:** Positive attitudes towards caring for a child on the autism spectrum were associated with lower levels of psychological distress, whereas higher distress was associated with an inability to find alternative care arrangements. Having no other family willing to provide care and feeling as though there was no choice in becoming a carer were associated with decreased life satisfaction and increased psychological distress. **Conclusions:** Understanding autism carers’ mind sets towards their caring responsibilities at an early juncture can provide insights into effective education and support strategies as they commence their important long-term roles.

**Autism in the family: More impact than other disabilities**

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**Aim:** This study investigates the personal impact of caring for a family member on the autism spectrum, compared to caring for family members with other disabilities, particularly in relation to conceptualisations of well-being. **Method:** 1,684 carers completed a survey comprising demographic questions, and several validated, self-report measures of well-being, including measures of life satisfaction, psychological distress, positive aspects of caring, and social support. The mean well-being scores of autism carers were compared with those caring for family members with other disabilities. **Results:** In relation to reported positive aspects of caring, there was no difference between autism carers and other disability carers. However, autism carers reported significantly poorer well-being than other disability carers on all other measures of well-being used. **Conclusions:** While caring for a family member on the autism spectrum is associated with significantly poorer well-being indicators than caring for someone with other disabilities, carers also highlight important personal benefits from their caring roles. These positive aspects provide insights into potential avenues of effective support for these carers.
Applying inclusive qualitative research practices with adults with intellectual disabilities: Some reflections

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Aim: Researchers frequently describe the challenges that arise when attempting to capture the views and perspectives of people with intellectual disabilities (ID). Many have endeavoured to develop inclusive research practices that overcome barriers to inclusive research. This study sought to systematically map and implement inclusive qualitative research practices. Method: A systematic review of qualitative research involving people with ID was conducted. Inclusive research practices identified through this review were used in a multi-method qualitative study investigating physical activity and social support, involving seven participants with ID. Results: Some inclusive practices (e.g., responding to participants’ communication abilities) were easier to implement than others. One strategy, closing the research loop, which involved concluding the research in a respectful way, was particularly challenging for the researcher given the time spent building rapport with participants and their support people. Conclusions: The application of inclusive research practices provides an essential foundation for research involving people with ID, however, it offers unique challenges to researchers that must be discussed to progress our field towards one that is inclusive.

Comparison between ADOS-G and ADOS-2 module 4 algorithms in women and men with high functioning autism spectrum disorder

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Aim: Recent studies have found gender differences in age of autism spectrum disorder (ASD) diagnosis and symptom presentation. This study compares the effectiveness of the ADOS-G and ADOS-2 in identifying women and men with ASD. Method: Participants included 28 women and 28 men diagnosed with ASD and no history of intellectual disability. They were assessed with the ADOS-G and gender differences between total scores and ASD classification were examined. ADOS-G scores were converted to ADOS-2 scores to compare total scores and ASD classification across algorithms. Results: Women scored significantly lower than men on both algorithms. On the ADOS-G, a smaller proportion of women (36%) met the cut-off score for ASD than men (71%); on the ADOS-2, a similar pattern was found (women: 25% and men 75%). Conclusions: Women were less likely to meet ASD criteria than men on both ADOS algorithms. While the ADOS-2 improved rates of ASD identification in men, it decreased the sensitivity in women; therefore, females suspected of having ASD may require additional assessment of more nuanced socio-communicative skills (e.g., with same-aged peers).

Local Area Coordination as a model of social prescribing for adults with intellectual disabilities in primary care in Scotland

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Aim: This study examined Local Area Coordination (LAC) as a model of social prescribing to address health inequalities faced by people with intellectual disabilities (ID) in Scotland. Method: Semi-structured interviews exploring the perceptions of the impact of generic- and primary care-based LAC on health and well-being of people with ID were conducted with 14 LAC, 9 persons with ID, 4 carers and 6 primary care health professionals. Results: Key themes identified demonstrate the perceived impact of LAC on the wider determinants of health of people with ID. This included improving personal health and coping practices, social networks, access to services and resources, quality of life and community capacity development. Overall, the service provided by LAC was perceived to be holistic and flexible and to complement current healthcare services leading to positive social and health outcomes. However, LAC’s perceptions of their role in improving health of people with ID varied. Conclusions: Adopting LAC as a model of social prescribing by primary care professionals has the potential to significantly improve health and well-being among persons with ID, by addressing and reducing inequalities with regards to the wider determinants of health.

The Easy Read Project: How does ‘easy read’ contribute to the construction of meaning?

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Aim: To address how effective adapted health-based ‘easy read’ literature is in contributing to the construction of meaning for people with intellectual disabilities. Method: Four studies investigated related areas of ‘easy read’ information and its use. The features in ‘easy read’ and ‘non-easy read’ literature published by the UK Department of Health were surveyed and compared. A quantitative linguistic analysis of text samples from these two document styles then identified critical differences between the linguistic features used. Further systematic qualitative linguistic analysis identified the subtleties conveyed in the discourse of ‘non-easy read’ compared to ‘easy read’ texts. Finally, a 2X2 between subjects randomised experiment tested the effect of linguistic simplification and literacy mediation on the understanding of ‘easy read’ information with 60 participants. Results: Differences were found between text types at feature and linguistic levels while influences of simple text and mediation on understanding raised further questions. Conclusions: Areas for possible improvement in the principles of production were identified and the central importance of the individual capacity for language in constructing meaning was emphasised.

Childhood disabilities in a rural part of Kenya: Pathway to sustainability

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Aim: A series of studies was conducted to investigate support for children with developmental disabilities (DD) and their families in rural Kenya and to establish a way forward offering sustainability. Method: A survey of support available to children (0 to 15 years) and their families was conducted. A second study investigated practices in the health and education sectors to support complex communication needs of children with cerebral palsy and deafness. A third study explored the local conceptualisation of communication. This was followed by a single case series piloting a home-based communication intervention. More recently, a programme has been set up to develop empowering self-
help groups for caregivers of children with DD. **Results:** Resources are inadequate to meet the needs of children with DD. Workforce deficiencies in support staff have led to poor coverage and limited capacities in provision. Home-based intervention offers some new potential. **Conclusions:** Scarce resources and access difficulties present challenges for children with disabilities and their families. Self-help groups may offer opportunities for greater sustainability.

**Promoting disability awareness in rural Kenya**

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**Aim:** People with disabilities are vulnerable to mal-treatment, neglect and abuse in low-income countries. The study’s aim was to engage community groups in a process of reflection, education and positive practice concerning people with disabilities. **Method:** Six adults with developmental disabilities were brought together to develop their personal narratives of living with disability over a series of meetings. They were then supported to tell their stories to 20 community groups (10 women’s groups; 10 community health worker groups). Using a topic guide, focus group discussions were conducted before and after the narrative presentations. The discussions were audio-recorded, uploaded to computer and transcribed. Framework analysis was carried out. **Results:** The values and attitudes espoused by the groups were associated with two key constructs: agency-burden; and human-sub-human. Transformations were observed post narrative presentations, with a greater emphasis on the human construct defined by ‘ability and self-help’ and ‘inclusion and facilitation’; and the agency construct defined by ‘acceptance and rights’ and ‘recognition of pain and difficulties’. **Conclusions:** The power of personal narrative appears to be associated with more positive attitudes and values.

**One size does not fit all: Making reasonable adjustment to facilitate people with intellectual disabilities to engage in objective health assessments**

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**Aim:** To describe techniques employed in designing and engaging people with intellectual disabilities (ID) in physical health assessment measures. **Method:** 708 participants aged 43 years and over, of all levels of ID were invited to take part in a suite of eight objective health measures which included; timed up and go test, height, weight, waist and hip measurement, blood pressure, grip strength and quantitative heel ultrasound. The multiphase approach employed was informed by the emancipatory principles of social engagement, reciprocity, gain and empowerment. The process was pilot tested on a convenience sample of 25 participants prior to the roll out of the main study. **Results:** Specific techniques were developed to address difficulties. Alternate communication, distraction, hand-over-hand techniques, simplified methods of demonstrating and engaging people, and ‘easy read’ materials contributed to 604 participants successfully engaging in the main study. **Conclusions:** Health screening is an imperative first step in improving health. Assessment delivery adaptations will support the promotion of optimum health for people with ID. However one size does not fit all.
The feasibility of using quantitative heel ultrasound to measure bone quality among older adults with intellectual disabilities in Ireland

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**Aim:** The aim of this study was to identify the feasibility of employing a quantitative heel ultrasound (QUS) as an alternative method of identifying the bone health status of older adults with intellectual disabilities (ID). **Method:** 708 participants were invited to complete the QUS. An accessible process and explanatory materials were developed to support the assessment and the Bowen et al., (2009) eight key areas of focus were utilised to guide and examine feasibility of the QUS. **Results:** 575 participants completed successful QUS measurement, 94.8% had both feet measured with 70.6% doing so independently. Positive feedback from participants supported the use of adjusted techniques and ‘easy read’ explanatory information (e.g., “I found the balloons nice and warm; I was ready for the cold ‘cause you told me”). However, 133 participants did not engage in the QUS, with reasons for not engaging including anxiety, challenging behaviour, autism and physical deformity. **Conclusions:** This screening method (QUS) in conjunction with an accessible process and materials is practical, acceptable and suitable for establishing bone health status among people with ID.

Understanding sibling relationships from the perspectives of individuals with intellectual or developmental disabilities

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**Aim:** Little research has examined the perceptions of individuals with intellectual and developmental disabilities (IDD) toward their siblings. Given the reciprocal nature of sibships, it is important to understand the perspectives of individuals with IDD about their sibships. The purpose of this study was to identify the individual, sibling, and family correlates of strong sibships and sibship benefits from the perspective of individuals with IDD. **Method:** 201 individuals with IDD responded to a web-based survey. Descriptive and univariate statistics as well as linear regressions were conducted. **Results:** Individuals with IDD who were employed, and did not report mental or physical health conditions reported significantly more positive sibships. When the sibling provided caregiving support and maternal health was better, individuals with IDD reported more positive sibships. Individuals with IDD with higher incomes and without mental health conditions derived greater sibship benefits. **Conclusions:** Like siblings, individuals with IDD reported some similar (e.g., better health) and different (e.g., employment) correlates of strong sibships. Future research should include sibling dyads as well as parents to better understand the dynamics of sibships.

Advocacy strategies and support needs among Latino families of children with disabilities

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**Aim:** In the United States, parents often struggle to advocate for their children with disabilities to receive school-based services. Latino, Spanish-speaking families especially face barriers to advocacy due
to the language barrier and lack of qualified interpreters. Given these barriers, it is unclear how Latino families advocate for their children. The purpose of this study was to identify effective advocacy strategies and support needs of Latino families of children with disabilities. **Method:** 40 Latino, Spanish-speaking parents of children with disabilities participated in focus groups. Emergent coding and constant comparative analysis were used to code the data. **Results:** Successful strategies included: being informed, recording conversations, and being persistent. Support needs included: qualified interpreters, greater fiscal resources, and parent training. Participants also recommended that professionals be respectful toward Latino families. **Conclusions:** Although they face many barriers, Latino families have successful advocacy strategies to ensure their children receive educational services. Practitioners should consider how to increase unbiased and frequent communication with Latino, Spanish-speaking families of children with disabilities.

**The relationship of IQ to additional disabilities in athletes with intellectual disabilities**

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**Aim:** Epidemiological studies have advanced our understanding of the needs of people with intellectual disabilities (ID); however, there has been little study of the relationship to IQ. This is important when considering people for whom the aetiology of their ID is unknown as additional health problems may be overlooked. This study investigated the relationship between IQ and additional disabilities. **Method:** 111 athletes with ID across 15 nations were recruited at sporting events. The ICF checklist and the WHODAS 2.0 were used to measure a range and severity of health conditions. Previous IQ tests were accessed or the WASI administered. **Results:** Correlational analysis detected a significant negative relationship between total disability scores and IQ scores (\(rs=-.22; 95\% \text{ CI: } -0.39, 0.02; p < .05\)). **Conclusions:** Given this is a relatively active sample it is likely that the levels of additional health impairments might be expected to be higher in the general population of people with ID. This suggests that the health status of people with even mild ID is likely to be compromised and should be appropriately assessed.

**The imitation game: Being an adolescent girl with autism spectrum disorder**

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**Aim:** Recent research within autism has turned its attention towards girls diagnosed on the autism spectrum. Differences in prevalence have been associated with gender-biased assessment approaches and the conceptualisation of autism spectrum disorder (ASD), leading to under-diagnosis and a lack of understanding of this condition in females. This study explores with adolescent girls with ASD how they manage socially and the techniques they use to make and maintain friendships. **Method:** Interpretative phenomenological analysis was used to analyse the data from ten interviews with adolescent girls, exploring the management of their social relationships. Adolescence was chosen as a particularly sensitive period when peer relationships play a significant role in development. **Results:** The girls were extremely motivated to develop and maintain relationships, and used highly developed, learnt techniques to manage their differences, including masking and imitation. However, as social relationships developed through this period, it led to specific challenges particularly around sexuality.
Conclusions: There are gender-specific issues associated with female adolescents with ASD, and these may impact upon the identification and management of ASD during this period.

Research on factors related to challenging behaviour among persons with intellectual disabilities and hearing impairments

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Aim: Challenging behaviour frequently occurs in people with intellectual disabilities (ID). For people with hearing impairments similar findings for the prevalence of challenging behaviour are reported. Risk factors contribute to, and can give comprehension and understanding of, the development of challenging behaviour. This study examines the relationship between challenging behaviour and several internal and external factors. Method: In our study, behaviour of 21 people with both ID and hearing impairments was recorded during a period of one year. A range of external factors was recorded as well. Results: The level of communication, level of social independence and autism spectrum disorder were identified as risk factors. For each subject in our study different external factors like nutrition, staff or conflicts between others were also identified. Conclusions: Communicational skills are essential for experiencing a feeling of (social) independence and will reduce challenging behaviour.

Future research opportunities: Person-making care, intellectual impairment citizenship, and a reclaiming of knowledge in South Africa

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Aim: Socio-political formulations of intellectual impairment create particular spaces for political participation, and also policy environments in which intellectual disabilities (ID) are made to (not) matter. By neglecting these correlations, we perpetuate inadequate responses to assertions of personhood tied to the rights, duties, requirements, and obligations of citizenship made by South Africans with ID. Method: To identify inclusive research opportunities that appropriately advocate these assertions and the needs of South Africans with ID, a literature review following strict criteria covered all scientific and “grey” literature published on ID in South Africa from 1989 to 2015. Results: Claims to human rights, citizenship, knowledge, policy-building, and care design must be drawn from future inclusive ID research. From the review, at least 15 topics on citizenship and 9 on re-claiming knowledge as true experts have been identified for timely policy and knowledge-creating studies. Conclusions: To transform marginalising societal structures and attitudes we must approach ableism with as much criticality as we afford racism and sexism. The onus for its resolution is on us, warranting critical engagement with our own lacking epistemic responsibility and modesty.

The effect of taekwondo training on lower body strength and balance in adults with Down syndrome

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Aim: Research with individuals with Down syndrome (DS) suggests that increasing strength and balance may lead to increases in independence and self-reliance. This study aims to determine whether taekwondo training can improve lower body strength and balance among adults with DS. **Method:** 24 adults with DS aged 20 to 45 years were assigned to either taekwondo classes 2 days/week for 15 weeks (n=17) or a control group (n=7). Strength was measured using a sit to stand test. Static balance assessment relied on a single leg stance test with eyes open and closed, while dynamic balance was measured using a functional reach test. Measurements were taken prior to training, after 5 weeks, after 10 weeks, and after 15 weeks of training. **Results:** A repeated measures MANOVA (p=.05) was used to determine differences between groups over time. There was a significant difference between groups for lower body strength (p=.036). There were no significant differences seen between groups in static or dynamic balance. **Conclusions:** Additional research is needed to determine if other sports could lead to benefits in balance as well as strength.

An organisational approach to safely eliminating the use restrictive practices

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**Aim:** In Victoria, the use of restrictive interventions is regulated by law. This law applies to people with disabilities and behaviours of concern. Yooralla is a disability service provider that has systematically adopted an organisation-wide approach to safely eliminating the use of restrictive interventions.  
**Method:** A mixed methods organisational approach is used. The approach includes independently reviewing the quality of behaviour support plans, the use of RiskMan (management of incident system to monitor and respond to critical incidents), an established committee to oversee practice, and an organisational governance structure. **Results:** The results showed a demonstrable increase in the quality of behaviour support plans, the elimination of routine seclusion and a trend in the reduction of restrictive interventions. **Conclusions:** A comprehensive organisational approach is critical in delivering and maintaining results.

‘Why did children with intellectual and developmental disabilities not go to school?’: A data analysis of possible factors affecting receiving compulsory education in China from personal perspectives

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**Aim:** This study focussed on the differences between children with intellectual and developmental disabilities (IDD) and children with other disabilities to identify factors that may prevent children with IDD from receiving education under the Compulsory Education Law. **Method:** Data about children with disabilities (6 to 17 years old) were obtained from the 2014 National Surveillance Sample Survey on the Disabled in China. Age, sex, disability type, characteristics of guardians, family economic status, community environment, and having a disability certificate were used as independent variables to analyse the distribution of education status using correlations and logistic regression models controlling for accessibility of education. **Results:** Children with IDD were less likely to receive education. The health situations of children, education status of guardians, and community environment may have positive effects while having a disability certificate is negatively correlated with education status. **Conclusions:**
Different measures are required for children with different disabilities. Improving the community environment and increasing awareness of available education among guardians may increase the number of children with IDD who go to school. Children who have disability certificates need particular attention.

**Understanding demographic characteristics of people who access self-directed funding in the United States of America**

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**Aim:** This study aims to identify differences in demographic characteristics between adults with intellectual disabilities (ID) who do and do not receive self-directed disability funding.  
**Method:** Participants who do/do not receive self-directed funding were drawn from the National Core Indicator survey of adults with ID in the United States. This survey collects participant demographic information including age, living situation, disability diagnoses and mental health status, as well as information about the type of disability support funding.  
**Results:** Logistic regression showed the prevalence of self-directed funding was higher in younger age groups and for people who lived with a parent or relative, but lower if the person had a comorbid mental health disorder.  
**Conclusions:** Self-directed funding is not equally available to adult disability service users in the United States. Factors such as living situation and age group influence access to this funding type. Potential policy and practice reasons for this situation are discussed together with approaches to increase access to self-directed funding.

**A Korean special education teacher’s practical knowledge in music class that utilises popular music**

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**Aim:** This study examines a Korean special education teacher’s practical knowledge in music instruction using popular music.  
**Method:** An action research method was applied to this study. The participants included a teacher as a researcher, five peer teachers who observed the classes and provided feedback, and eight students with intellectual disabilities. The data were collected from five classes with five reflective circles, and analysed using an inductive method.  
**Results:** Four upper themes were identified: careful music selections, students showing their interest in study, different purpose of music, and becoming a teacher equipped with knowledge, emotion and will.  
**Conclusions:** Teachers should consider each student’s need, familiarity with music, and the message of the music when selecting the music. Teachers should choose the teaching techniques and modify them to increase students’ interest. Music instruction needs to be a vehicle that improves the students’ quality of life, not to be a subject that causes students stress. Teachers should be experts possessing teaching skills, performance skills, and warm hearts.

**Communicate to connect**

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**Aim:** We hypothesised that client communication, choices and decision-making would improve if we embedded client communication support through enhancing staff’s knowledge, skills, and understanding of augmentative and alternative communication (AAC). **Method:** Four pilot sites, 59 clients, 23 staff were involved. Data about client communication skills and well-being were obtained using the Checklist of Communicative Competencies and the Health of the Nation Outcome Scale – Learning Disabilities (HoNOS–LD). This was an action-research project using each client participant as their own control. Eight communication strategies were selected for implementation: calendar boards (visual schedules); portable calendars; visual choice-making strategies; chat books; who is here boards; personal communication dictionaries; key word sign, and use of simple language. **Results:** Using the HoNOS–LD, 70% of our target group showed an improvement in communication skills on one measure or the other. Of the 23 staff who received training and participated in the pilot, 22 increased their score on the knowledge test. **Conclusions:** Targeted AAC communication training for staff is effective for achieving improved client communication and improving a person’s choice and decision-making ability.

**Measuring group home performance against standards**

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**Aim:** To assess the impact of using a metric audit tool as a framework for measuring eight aspects of service delivery across Sunnyfield’s group homes benchmarked against standards focussed on person-centred practices, measuring personal outcomes, quality of life and safety. **Method:** Compliance to National Disability Standards and New South Wales Standards in Action was measured at baseline and following implementation of the metric audit tool. Data collection involved document review and interviews with staff and clients. **Results:** The audit tool process achieved a 60% increase in compliance in two years across all group homes with all group homes achieving compliance or better against the standards. **Conclusions:** Use of the tool has been a successful catalyst for cultural change. It has resulted in greater understanding of the principles and objectives of the standards and greatly assisted in the professional development of all group home support staff.

The clinical utility of the Glasgow Level of Ability and Development Scale in screening for disorders of intellectual development: A multicentre international study

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**Aim:** To evaluate the clinical utility of the Glasgow Level of Ability and Development Scale (GLADS) screener (a 10-minute 5-item scale for detecting disorders of intellectual development detecting (DID)) within the context of the ICD-11. **Method:** Clinicians from UK, Austria, India, Pakistan, Sudan and Sri Lanka administered the GLADS to 600 adults with DID (18 years+) and a short clinical utility questionnaire. Vineland scores were accessed from case notes. **Results:** Convergent validity between GLADS and the Vineland scale was high with good clinical utility. The data from low and middle income
Breaching orders: Apprehended violence orders a gateway to the criminal justice system for persons with intellectual disabilities

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**Aim:** The project explored how defendants with intellectual disabilities (ID) come to be before the court and how they can be better protected in relation to apprehended violence orders (AVO). **Method:** A search of the Intellectual Disability Rights Service (IDRS) client information database was conducted to identify AVO matters involving a person with ID as the defendant. Files were reviewed to identify recurring issues and outcomes. The data were thematically coded and analysed. Preliminary coding and analysis was shared with the IDRS legal team leading to the refinement of themes. **Results:** Making AVO against people with ID operates as a gateway into the criminal justice, and AVO made against a person with ID may not serve the intended purpose of protecting the person or persons named as in need of protection. Contributing factors included inadequate legislative and procedural frameworks to accommodate people with ID in AVO proceedings; limited understanding of ID by professionals in the justice system; and inadequate referral and diversionary pathways for person with ID subject to AVOs. **Conclusions:** There is a need for law reform in the area of AVO with specific attention paid to defendants with ID.

Methodological issues arising in recruitment and conducting field work with people with intellectual disabilities and their families: Results from the SOPHIE study

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**Aim:** To present the methodological issues arising during the Special Olympics Programmes Health Impact Evaluation (SOPHIE). **Method:** A mixed methods approach was employed using a cross-sectional study design. People with ID (athletes) who take part and do not take part (non-athletes) in Special Olympics were recruited with a family member. The primary aim was to explore whether people who take part are healthier and happier than people who do not take part in Special Olympics. The fieldwork included physical measurements, questionnaires and focus groups. **Results:** 1,908 participants were approached, 292 people took part; this included 146 primary participants (101 athletes and 45 non-athletes) and 146 family members, reflecting a 6.9% participation rate. Reasons for the poor response rate were varied such as having no family member willing or able to participate and family illness. Methodological issues included the length of time taken for data collection and challenging aspects of the fieldwork such as the complexity of the questionnaires. **Conclusions:** Undertaking mixed methods
Finding a shared understanding: A collaborative approach to clinical formulation

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Aim: The aim of this investigation was to measure the impact of an interdisciplinary formulation process on clinical understanding and collaborative practice. It was hypothesised that use of the approach would result in a common language, shared understanding and integrated intervention plans which would ultimately lead to improved client outcomes. Method: The collaborative approach to formulation was applied to 13 cases of children and young people with intellectual disabilities (9 to 18 years old) who presented with significant emotional and behaviour difficulties. On average, nine individuals contributed to each formulation, representing six different disciplines and five agencies. Key outputs were assessed via expert consensus ratings and qualitative feedback from participants post session. Results: The approach reliably harnessed the expertise of the collective, established a shared understanding, generated new insights and empathy, led to greater coordination and integration of support, triggered systemic change and ultimately good quality of life outcomes. Conclusions: The outcomes of this investigation affirmed this interdisciplinary process as a valid means of promoting a shared understanding and a collaborative approach to clinical formulation.

Variations in behaviour function in individuals with intellectual disabilities exposed to psychotropic medications

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Aim: Psychopharmacological and behavioural interventions are used to treat challenging behaviour in individuals with intellectual disabilities (ID), often in combination. However, little is known about the interaction between medication pharmacodynamics and behaviour function. A better understanding of these processes may be important to optimise treatment efficacy. The purpose of the study was to assess the impact of naturally varying dosages of psychotropic medications on behaviour function. Method: Four individuals with ID who engaged in challenging behaviour and were undergoing psychotropic medication changes participated. Medication impact across two topographies for one participant, and three topographies for another participant were assessed, for a total of seven cases. We conducted repeated functional analyses using single-subject experimental designs. Results: Our results suggest that behaviour function remained the same after a change in medication in 14 out of the 21 medication manipulations examined. Conclusions: Medication manipulations may not often induce function-specific changes in challenging behaviour. Moreover, medications rarely produced immediate, sizable and replicable effects on challenging behaviour. Finally, naturally-occurring changes in medication may provide the opportunity for comparisons analogous to parametric, reversal and withdrawal designs.
Can we do better?: Where’s the person in your person-centred practice?

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**Aim:** Assistive technology enables people with disabilities to function in their communities. Customer engagement in assessment and equipment prescription is positively correlated to use and retention. With equipment abandonment being a significant issue, it is timely to question – what does true person-centred practice look like? **Method:** In 2015, Yooralla invited clinicians to attend an interactive forum about complex equipment prescription and customer empowered decision-making. **Results:** The authors found discrepancy in interpretations of person-centred practice. What does it look like? Where’s the power balance? How much should customers be allowed to drive decision-making? What is the clinician’s responsibility? **Conclusions:** Evidence supports person-inclusive interpretations of person-centred practice. Strategies to empower customers to make their own successful choices will be presented.

Intelligence testing and communication disability

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**Aim:** Many children and adults with little or no speech receive IQs well below 50 on the WISC or WAIS. These tests’ verbal scales require speech and their performance scales require manual dexterity. IQs of people with limited speech and impaired fine-motor skills may understate their learning abilities. Assessments which do not require speech or manual dexterity may better reflect their ability. **Method:** Participants were six people with autism spectrum disorder and little or no speech aged from 10 to 20 years who had measured IQs of <50 and who were referred for communication therapy in 2014. Participants were tested using the PPVT, administered in the standard way. Their scores were compared with their previous scores on externally-administered WISC or WAIS tests. **Results:** All six participants scored in the normal range on the PPVT, with scores between 80 and 110. **Conclusions:** We propose to expand the research by incorporating Raven’s Progressive Matrices and recruiting more participants. Current outcomes nonetheless raise significant concerns about IQ testing in this population, with potential flow-on effects for therapy and educational provisions.

Adults with intellectual disabilities: Choice and control within the context of family relationships

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**Aim:** Increased choice and control for people with disabilities and their families is being promoted as a goal of disability policy in Australia. It is important to understand the experience of, and meaning given to, ‘choice and control’ from the perspective of adults with intellectual disabilities (ID). This study identifies key issues associated with these concepts for adults with ID within the context of family relationships. **Method:** Data on choice and control were drawn from semi-structured interviews with eight adults with ID and analysed using an interpretative phenomenological analysis approach. **Results:** Emerging themes concerned with family-imposed limitations to choice and control and the participants’
response to such limitations. The impact of variables including type of decision and family relationship quality will be shown. **Conclusions:** Participants report satisfaction with the level of control they have in their lives despite a strong family influence on, and at times restriction of, their choice-making. Understanding this apparent contradiction is important if adults with ID are to be effectively supported to attain the level of choice and control they desire.

**A multiple perspectives approach on the well-being of students with autism spectrum disorder**

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**Aim:** There is a need to better understand the well-being of students with autism spectrum disorder (ASD). This study examined how student well-being is conceptualised by parents, teachers, and students with ASD themselves as well as to identify the barriers to and assets of the well-being of these students.  
**Method:** To collect data, 17 teachers and nine parents participated in interviews while 12 high school students with ASD were involved in a photovoice project regarding their well-being. Grounded theory approaches were used to analyse the data.  
**Results:** Teachers, parents, and students conceptualised student well-being as a multidimensional construct. Assets of student well-being include teachers, teacher aides, good school facilities, access to visual schedules, and having friends. Barriers to student well-being include inadequate teacher training, difficult and boring lessons, noise in class, and feeling different from peers.  
**Conclusions:** Schools should provide resources to support the well-being of students with ASD.

**Challenging behaviour and organisational drivers**

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**Aim:** We know that hospitalisation is a significant factor in healthcare. More relevant however is the relationship between specific organisational dynamics as housing, staff and company internal logistic systems, and challenging behaviour like aggression, addiction and resisting care. This study attempts to clarify drivers of care organisations in relation to challenging behaviour of people with intellectual and developmental disabilities (IDD).  
**Method:** A case study of an organisation for people with IDD was undertaken. It involved analysis of the relevant drivers and the known research, and their (in)direct impact on clients with challenging behaviour.  
**Results:** The case study identified and clarified three organisational drivers that sustain and contribute significantly to challenging behaviour.  
**Conclusions:** By addressing these drivers we present a fundamental change in perspective for organisations, that of the client.

**Registered nurses supporting people with intellectual disabilities: An exploratory survey examining their role in meeting health needs**

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Aim: People with intellectual disabilities (ID) are at a higher risk of experiencing poorer health than the general population. Registered nurses in intellectual disability (RNID) are ideally positioned to advocate the health needs of people with ID. This study explores the understanding of nurses of their role in health assessment and initiating care actions. Method: An online questionnaire has been developed and is currently being administered to RNID working in the Republic of Ireland. The survey incorporates reflective questioning to obtain their knowledge and understanding of their role in health-related activities. This includes identification of assessment tools available and the supports required for initiating care. Results: Initial findings suggest that numerous factors impact on the role of the RNID in supporting health needs. There can be barriers related to clinical competency, role perceptions, resource availability and interdisciplinary collaboration. Conclusions: This survey creates an opportunity to examine and highlight the key features of the practices and functions of the RNID. It supports the need to improve and advance healthcare services to meet the complex needs of people with ID.

Examining low arousal approaches using a new staff self-report to measure staff perceptions of challenging behaviour

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Aim: Employing low arousal (LA) approaches to provide immediate support for people with intellectual disabilities who present challenging behaviour has face validity. This study examines the statistical properties of a new measure of LA, the Staff Perceptions of Challenging Behaviour (SPCBQ). Method: A self-report questionnaire was administered at a single point to frontline staff in Ireland. The measures included the: SPCBQ, attributions of controllability, mindfulness, self-efficacy, perceived severity of challenging behaviour and use of interventions. Results: The results showed LA is associated with lower attributions of controllability, higher overall mindfulness and the non-reactive facet of mindfulness. LA was not associated with severity of behaviour or self-efficacy. Nurses and one category of restrictive physical intervention ‘walking restraints’ were associated with lower SPCBQ scores. Internal consistency was poor (Cronbach’s alpha .346). Conclusions: These results suggest the SPCBQ has promise as a measure of staff’s perceptions of challenging behaviour. However, the poor internal consistency suggests that further conceptual analysis of LA and how to measure it is required.

A descriptive review of studies carried out on parent-child interaction in children with developmental disabilities in Turkey

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Aim: Quality of parent-child interaction, especially responsive parenting, has been found to be one of the best predictors of engagement and development of children with developmental disabilities (DD). The purpose of this study is to review research about parent-child interaction in children with DD in Turkey. Method: A descriptive literature review was conducted. Twelve descriptive and relational studies were identified. Results: Studies have included both mothers and fathers but most focussed on
mothers. Across studies, parents showed low levels of responsiveness in parenting styles. High levels of directive and teaching-oriented styles were found among parents. **Conclusions:** Results generally parallel the international literature. Improving the quality of parent-child interaction should be a focus while providing early intervention services in Turkey.

**Syntactic impairment in adults with Down syndrome: Evidence from the comprehension of passives**

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**Aim:** Language in Down syndrome (DS) is traditionally described as delayed, with receptive language stronger than expressive. However, experimental studies show significant difficulties in comprehension of complex syntactic structures, such as passives, even by teenagers with DS. **Method:** In order to establish whether this aspect of grammatical knowledge is acquired by adulthood, we tested six adults with DS (mean chronological age: 38 years) on constructions involving actional and psychological verbs using a picture selection task. **Results:** Our participants showed a severely impaired comprehension of sentences including both actional and psychological verbs, significantly worse than the much younger typical controls (mean chronological age: 5 years), matched on non-verbal mental age. Importantly, while control children showed a better comprehension of short actional passives, as has been reported in the literature, our participants with DS showed no such distinction. **Conclusions:** Our results suggest that complex grammatical structures are beyond the grasp of individuals with DS even in adulthood.

**Collage as method in narrative research**

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**Aim:** Our goal was to develop a creative method of data collection under the umbrella of narrative research in order to facilitate the inclusion of people with cogitative impairments in a research project. **Method:** Nine young people with acquired brain injury took part in a narrative project focused on the reconstruction of identity following injury. An inclusive method was devised in conjunction with participants to enable their participation in the project. This four-part method involved the construction of a collage; audio recording the process of making the collage; reflecting on the collage in informal discussion; and audio recording sharing the content of the collage with a parent/relative. **Results:** Using collage as a component of a narrative method enabled the full participation of young people and increased insight and understanding to the abstract and complex subject of identity. **Conclusions:** This method could make a valuable contribution to the development of inclusive approaches to research with people with intellectual disabilities. Seeking alternative means such as this to gather qualitative data can enable a more inclusive approach to research.

**Sleep problems are pervasive in Rett syndrome and the CDKL5 disorder**

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**Scientific POSTER presentations C-E**

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**Aim:** This study examines the types and prevalence of sleep problems in Rett syndrome and the CDKL5 disorder and their associations with genotype. **Method:** Families (n=364) with a child with Rett syndrome (age 2 to 57 years) provided data to the International Rett Syndrome Phenotype Database (InterRett). Families (n=167) with a child with the CDKL5 disorder (age 4 months to 29 years) provided data to the International CDKL5 Disorder Database. Prevalence of sleeping problems and regression models were calculated. **Results:** Sleep problems occurred in the majority (>80%) of each sample, with night laughing more common in Rett syndrome and night waking more common in the CDKL5 disorder. For Rett syndrome, sleep problems were common in those with a p.Arg294* mutation and more likely to be of severe impact, compared with large deletions. Those with severe epilepsy also had more daytime somnolence. In the CDKL5 disorder, males were more likely to have a sleep disorder than females but relationships with genotype were unclear. **Conclusions:** Sleep problems were pervasive and moderated to a certain extent by the type of genetic mutation.

**Health disparities among US racial and ethnic minorities and persons with disabilities**

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**Aim:** Using the public health model of social determinants of health as a framework, comparisons between persons with disabilities and subpopulations (including cognitive disabilities) and racial and ethnic minorities (blacks, Hispanics, Asians, American Indians, and Pacific Islanders) in the United States (US) were conducted. The primary research question is whether persons with disabilities are more or less similar to racial/ethnic minorities in experiencing health disparities. **Method:** A secondary analysis of cross-sectional data from the 2013 Behavioral Risk Factor Surveillance System (BRFSS), a random digit dialled national telephone health survey conducted in the US, was undertaken. Analyses included data for 326,342 working age adults (18-64 years). Using t-tests, social determinants, healthcare system attributes, disease inducing behaviours, and health outcomes were compared between US racial and ethnic minorities and persons with disabilities as a group and disability sub-populations. **Results:** Persons with disabilities experience high rates of disparities compared to racial/ethnic groups. Certain disability sub-populations (including cognitive) contribute more to disparities. **Conclusions:** Persons with disabilities are a health disparity population with significant unmet needs. Public health efforts may need to be customised to specific subpopulations.

**Community Engagement Knowledge Translation Research Project**

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**Aim:** The Community Engagement Knowledge Translation (KT) Research Project is assessing the impact of three technical assistance (TA) levels provided to communities implementing Community Engagement (CE). CE is an evidence-based method to reducing local barriers to healthcare and recreation experienced by persons with intellectual and developmental disabilities (IDD). The project examines whether TA level predicts healthcare and recreation barrier removal, if CE is modified by community implementers, and whether barrier removal increases community participation. **Method:** A
cluster randomised controlled pilot study with equivalent materials design in eight communities in Montana and New Hampshire, USA (four-minimal, two-moderate, two-intensive TA) was undertaken. Barrier identification and removal rates will be compared by TA level. Number and type of CE modifications will be documented. Pre-post changes using a participation measure will be analysed using Wilcoxon-Mann-Whitney U tests. **Results:** Preliminary findings include 21 identified barriers in three communities and significant changes in the CE method. **Conclusions:** KT is important to increase the utilisation of evidence-based research, but communities may change evidence-based methods to meet local needs.

**Hospital admissions for people with intellectual disabilities: Systematic review**

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**Aim:** People with intellectual disabilities (ID) experience poorer health and some studies suggest experiences of suboptimal healthcare management that may lead to more hospital visits. This includes admission for ambulatory care sensitive conditions. The paper summarises the literature on hospital admissions for people with ID. **Method:** Searches were carried out using key words to identify studies which reported on hospital admissions for people with ID. Those studies were then evaluated against specified criteria for inclusion. **Results:** Of 29,613 papers generated by the search, a total of 7 were selected for inclusion. There were more admissions for people with ID than the general population. Papers reported admissions for both ambulatory care sensitive conditions and other medical conditions. As some papers looked at specific medical conditions but not others it was not possible to conclude which conditions most frequently lead to hospital admissions. **Conclusions:** People with ID are admitted to hospital more frequently than the general population, and some admissions are for conditions that should not require hospitalisation (suggesting sub-optimal care). The Scottish Learning Disabilities Observatory is investigating this further.

**Chemical restraint: Perspectives from the coalface**

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**Aim:** Restrictive practices (RP) are controversial and until recently were potentially ‘illegal’ when used across Australia to manage the challenging behaviour (CB) of adults with intellectual disabilities (ID). Queensland enacted legislation in 2006 that manages RP in adults with ID and cognitive disability. This study explored perspectives of chemical restraints (CR) used on adults with ID in Queensland during 2014-2015. **Method:** Statutory decision-makers employed by the Office of the Public Guardian who are involved in the restrictive practice regime participated in a qualitative study. **Results:** Thematic analysis identified a range of issues relevant to ongoing implementation and review of CR. Summarised in a thematic map, key issues include: the negative conceptualisation of CR, relationships with prescribers as ‘defensive, retributive and avoidant’, a systemic lack of evidence-based expertise and knowledge, the role of the delegates of the Public Guardian in illuminating inconvenient truths, and the Positive Behaviour Support Plan as lost in translation. **Conclusions:** Findings from the research are relevant to
Evidence for cognitive content-specificity for depression and anxiety in adults with intellectual disabilities

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Aim: Cognitive models of anxiety and depression have enormous empirical support and underpin cognitive behavioural therapies in the general population. Few studies have investigated of the viability of cognitive models with adults who have intellectual disabilities (ID). Only one has tested Beck’s key concept of cognitive content-specificity for anxiety and depression but ability was not measured or co-varied. Method: 69 adults attending support services and unselected for mental health problems were interviewed using Beck’s paradigm of the Beck Anxiety Inventory (BAI) and Beck Depression Inventory (BDI-II) as well as cognitions checklist – depression (CCL-D) and cognitions checklist – anxiety (CCL-A). Receptive language was assessed on the PPVT-4. Results: Depressive cognitions were the only predictor of depressive symptoms but ability predicted a greater proportion of anxiety symptoms than anxious cognitions. Conclusions: This is the first study to investigate cognitive content-specificity using Beck’s assessment paradigm and to co-vary ability in as sample with ID. The substantial variance in symptoms predicted by depressive cognitions in an unselected sample of adults adds support for the use of cognitive behavioural therapy for depression amongst adults with ID.

Building engagement in a 12 year old girl with autism and challenging behaviour

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Aim: Children with autism can be the most difficult students to engage with typical interventions utilising external motivation. However intrinsic motivation is more likely to lead to sustained generalisation. Researchers hypothesised that a process of ‘enticement’ could effect change in a 12 year old girl who had no systematic functional communication and resisted, through kicking, hitting and self-injury, all adult attempts to engage with her. Method: An observation study was conducted over a period of 28 months. Quantitative analyses of the video data were conducted by volunteers in addition to researchers to ensure reliability of the findings. Results: Indicators of engagement increased alongside a decrease in resistant behaviours. Conclusions: Despite having long-entrenched behaviour at the start of the study, the child-centred practice focussing on building engagement through the MORE approach led to the student being ready to accept adult intervention and therefore to participate in learning opportunities. This offers an alternative method for practitioners which may have greater sustainability and could lead to benefits for the student and staff.

Pneumonia and diarrhoea in young children at risk of intellectual disability in low and middle income countries
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**Aim:** To estimate the prevalence of diarrhoea and possible pneumonia in the previous two weeks among 3 to 4 year old children who are/are not at risk of intellectual disability (ID) in low and middle income (LAMI) countries. **Method:** Secondary analysis of Round 4 and 5 UNICEF Multiple Indicator Cluster Surveys (MICS) from 23 LAMI countries (n=97,554 children) was undertaken. **Results:** Children at risk of ID were significantly more likely to have had diarrhoea in the previous two weeks. This increased risk was eliminated when controlling for the potentially confounding effects of between-group differences in household wealth and maternal education. In contrast, children at risk of ID were significantly less likely to have had possible pneumonia in the previous two weeks. They were, however, significantly less likely to have received help for their illness, a result that was partially attenuated when controlling for the potentially confounding effects of differences in household wealth and maternal education. **Conclusions:** Children at risk of ID in LAMI countries are less likely to receive help for a potentially life threatening illness than their peers.

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**Aging, work, retirement and activities**

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**Aim:** In Norway, there are activity centres and work-places tailored for people with intellectual disabilities (ID). However, the percentage of people with ID in ordinary work in Norway is close to zero. This study aims to increase our knowledge about work participation among older adults with ID and activities offered by municipal services in Norway to aging people with ID. **Method:** This study is based on data from a national survey of all Norwegian municipalities (52% participated). **Results:** There are variations between the municipalities in services provided and lack of work possibilities for aging people with ID. The study also finds that attained retirement (at 67 years) often is the main reason for quitting work-related activities. The municipalities often do not actively engage in establishing more work or activities for older people with ID. **Conclusions:** We need to increase focus on activities for people with ID in later life. We need to work on policies and guidelines in the community to help remain a good quality of life in later life.

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**An exploration of Australian Community Access Services co-produced with, and for, people with intellectual disabilities**

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**Aim:** This research explored Australian Community Access Services relevant to Article 30 of the United Nations Convention on the Rights of Persons with Disabilities (2006) in which people with intellectual and developmental disabilities (IDD) have the same right to take part in cultural life, recreation, leisure and sport as other people do. **Method:** A constructivist grounded theory approach was used involving six data collection methods: memoing, observations, focus groups, face-to-face interviews and questionnaire responses from people with IDD (n=53) and parent(s) and siblings (n=61) in Australia. A critical discourse analysis of Australian Community Access Service extant texts (n=42) including strategic
and operational policies also occurred. **Results:** Four findings contributed to the participation of people with IDD including strategies to enhance choice; access to local community-based services; innovation; and a progressive approach to community inclusion. **Conclusions:** These findings contribute to policy development and professional practice which enhances the development and use of artistic, creative and intellectual abilities for people with IDD, their families and society.

### Contributions of people with intellectual and developmental disabilities to their families

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**Aim:** This research aimed to explore the contributions of people with intellectual and developmental disabilities (IDD) to their families as they participate in Community Access Services (CAS), in Australia.  
**Method:** A constructivist grounded theory approach was used involving six data collection methods: memoing, observations, focus groups, face-to-face interviews and questionnaire responses from people with IDD (n=53) and parent(s) and siblings (n=61) in Australia. Additionally a critical discourse analysis of extant texts (n=42) including strategic and operational policies also occurred. **Results:** Three initial findings are presented including the development of opportunities with and for people with IDD to share their creative visual and performance artistic endeavours, to pursue economic opportunities and support emotional and physical respite for families. Three case studies are presented to illustrate these contributions for families. **Conclusions:** The contributions of people with IDD enhance family well-being and quality of life as CAS are co-produced. The findings also add to policy development and professional practice.

### Sports and recreation co-produced with, and for, people with intellectual and developmental disabilities

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**Aim:** This research explored the contribution of sports and recreation opportunities for people with intellectual and developmental disabilities (IDD) to their quality of life, families and society.  
**Method:** A constructivist grounded theory approach was used involving six data collection methods: memoing, observations, focus groups, face-to-face interviews and questionnaire responses from people with IDD (n=53) and parent(s) and siblings (n=61) in Australia. Additionally a critical discourse analysis of extant texts (n=42) including strategic and operational policies also occurred. **Results:** Three research findings are presented as case studies which contribute to increased recreation skills and knowledge, quality of life and enhanced community participation of people with IDD. **Conclusions:** These findings add to academic research in this under-explored area as sports and recreation opportunities are co-produced with people with IDD.
Independent Monitoring for Quality in Pennsylvania

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Aim: Independent Monitoring for Quality (IM4Q) is a state-wide effort that gathers, analyses and reports information to improve the everyday lives of individuals receiving intellectual disability (ID) services throughout Pennsylvania in the United States. The research objective is to develop a baseline against which future measures can be compared. Method: Local programs conduct face-to-face interviews with the sample drawn from people receiving services from the Commonwealth; family are interviewed by telephone. All interviews are completed by a team that includes a person with a disability or a family member. Results: General findings on the focus of the data collection will be presented, along with findings on employment and people living in a residential situation called ‘lifesharing’. Data show that for those individuals living in ‘lifesharing’ and for those who are employed, outcomes are better than for other groups. Conclusions: Data highlight most effective service models based on participant outcomes.

Measuring the impact of feeding covariates on health-related quality of life in children with autism spectrum disorder

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Aim: The aim of the study was to examine the impact of feeding covariates on the health-related quality of life (HRQoL) in children with autism spectrum disorder (ASD). Method: Data were obtained from a convenience sample of 379 mothers, on behalf of their children with ASD. A stepwise multiple regression analysis was run to determine the effects of predictor parameters (feeding problems, mealtime problems and feeding strategies/practices) on the HRQoL of children with ASD. Results: The multiple regression analysis yielded three regression models. Mealtime problems, parental feeding strategies and feeding problems explained 11% of the total variance in HRQoL. The amount of explained variance, beta score and correlation value suggest that mealtime problems are the most significant predictor of HRQoL of children with ASD. Conclusions: The study provides evidence that feeding problems, mealtime problems and feeding strategies, play a significant and predictive role on HRQoL. Consequently, eliminating feeding and mealtime problems and ameliorating parental feeding strategies/practices may promote the HRQoL of children with ASD.

A case study: A client with Down syndrome and longstanding selective mutism

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Aim: To present the story of an individual’s involvement with Explore and how that improved his quality of life (QoL) by assisting him to resume verbal communication with his mother. Method: An individual was referred to Explore because of a history of being selectively mute. He had not spoken with his mother since his late childhood and was becoming increasingly socially withdrawn. Explore worked with
the individual and his mother to re-establish his communication using a graded exposure hierarchy. Staff at his vocational programme were encouraged to promote his verbal responses using a defocussed communication approach. The number of words used by the individual to communicate directly with his mother was recorded by his mother each day and also recorded during visits by the clinician. **Results:** As a result of this intervention, verbal communication between the individual and his mother was restored. **Conclusions:** An evidence-based approach was utilised to effectively re-establish verbal communication between the individual and his mother. The individual’s relationship with his mother was strengthened and his QoL was clearly improved.

**Health problems, neuroticism and IQ: 40 year follow-up of the Warsaw Study participants**

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**Aim:** This study examines whether low IQ is related to health problems in adulthood. **Method:** The database comes from Phase II of the Warsaw Study (1976) which included 1,000 13-year-olds, whose health was assessed by doctors. In 2015, 230 of them have been followed up (including 39 diagnosed with borderline intellectual functioning). Follow-up data included self-reported health problems and scores on the neuroticism scale. **Results:** Lower WISC IQ was correlated with diseases in childhood ($r=-.36; p< .001$). The correlation between IQ in childhood and adult rating of health problem was $r=-.12$ ($p=.08$). The correlation between subjective health problems and neuroticism was $r=-.14$ ($p=.04$). Persons with borderline intellectual functioning had worse health in childhood ($p=.001$) and in adulthood ($p=.02$), and slightly higher level of neuroticism in comparison to the remaining subjects ($p=.02$). **Conclusions:** IQ seems to be a good indicator of health status in childhood and in adulthood. Persons with borderline intellectual functioning are at greater risk of health problems and of higher neuroticism.

**Employers’ attitudes towards the employment of persons with intellectual and developmental disabilities**

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**Aim:** Despite legal regulations, national and international studies indicate that a high percentage of people with intellectual and developmental disabilities (IDD) are still not employed in the primary labour market. Although there is a body of research on perceived barriers preventing employers from hiring people with disabilities, few studies focussed specifically on people with IDD. Thus, the aim of this study was to explore employer attitudes, perceived barriers and facilitators to hiring people specifically with IDD. **Method:** Qualitative interviews were conducted with human resources managers of 20 companies with more than 150 employees in Vienna. Interview partners also completed a German version of the Community Living Attitude Scale, Mental Retardation Form (CLAS-MR) and estimated abilities of daily living and employment related abilities in persons with IDD. **Results:** Reasons against hiring include lack of applicants with IDD, lack of external support, too specialised jobs, and aspirations to create meaningful jobs instead of merely fulfilling quotas. Governmental incentives are regarded as more
useful than penalties to enhance employment of people with IDD. **Conclusions:** Current measures are insufficient in helping employers hire persons with IDD.

**A pilot intervention study addressing obesity in adults with intellectual disabilities using community-based participatory research strategies**

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**Aim:** A request to develop health promotion programmes for obese adults with intellectual disabilities (ID) was brought to the attention of research faculty by a community service agency. **Method:** Community-based participatory research (CBPR) strategies were used including collaborative development of research question, study design and intervention. The latter was delivered as a team, including service agency staff, consumers and direct service providers (DSP). The study sample consisted of 11 consumers and 4 DSP. Monthly meetings stressed portion control, increased activity, label reading, and healthy nutrition choices. Portion-control dishes (9 inch diameter divided plates, 8 ounce glasses, and smaller snack/cereal bowls) were used in community residences. **Results:** Overall weight change was a 3-pound gain from baseline to programme completion at 7 months. Consumers and DSP described increased activity and healthier food choices. **Conclusions:** Weight loss was not an outcome; yet education and insight into healthier choices were observed. CPBR facilitates study, the finding of solutions to promote optimal health, and development of tailored interventions for significant health issues.

**Improving the food and nutrition intake of people with intellectual disabilities living in group homes in Australia: Scope for programme development**

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**Aim:** The aims of this study were to assess food and nutrition intake of people with intellectual disabilities (ID) living in group homes in an urban area of Australia, and explore decisions of carers related to food provision in group homes. **Method:** Two organisations in Sydney, Australia agreed to participate, and the diets of adults with ID living in group homes were investigated using 3-day weighed food records and photographs (n=33); and carers of the homes were interviewed about food provision practices (n=17). Dietary data were analysed and compared to estimated average requirements (EAR). Interviews were explored for key themes. **Results:** More than 40% of people with ID consumed diets less than EAR for magnesium, calcium, iodine and zinc (men only), with a low consumption of core foods, particularly, vegetables, fruit, wholegrain breads and cereals, and dairy foods. Interviews indicated an understanding about the importance of good nutrition but some confusion about how to provide healthy meals. **Conclusions:** This research suggests the need to develop improved strategies and programs to support provision of healthier foods in group homes.

**Intensive behavioural intervention and the partnership between parents, day care educators and intervention specialists**
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**Aim:** This study explores the elements that facilitate and hinder partnership within the context of behavioural intervention (IBI) provided to children with autism spectrum disorder by intervention specialists at day care centres. **Method:** In the absence of studies on partnership within this context, 20 intervention specialists, 17 parents and 10 educators participated in a focus group. Data were analysed using qualitative and thematic analyses to describe factors that can most effect collaboration. **Results:** Many elements that facilitate and hinder the partnership were listed. All participants stated that having moments to communicate is essential for optimal collaboration. Educators and parents were pleased to collaborate with intervention specialists because they receive strategies adapted for children with special needs. However, several factors hinder these moments. For example, educators and parents are rarely invited to the first meeting between day care and intervention services directors to discuss the process by which the interventions will take place. **Conclusions:** Poor communication can have a considerable impact on the effectiveness of the services. The provided services can be greatly improved if the results of this study are recognised.

**Clothes, fashion and people with intellectual and developmental disabilities**

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**Aim:** Through this action research, individuals with intellectual and developmental disabilities (IDD) explore and reflect on changes in their lives through embodied memories of dress. **Method:** 16 people with IDD and 7 informal carers of a similar age participated in workshops facilitated by staff trained in delivering reminiscence work. Reminiscence memory boxes were provided containing items relating to fashion through the decades. Each participant brought items of clothing which were meaningful to them and talked about them in an informal context. All participants took part equally with carers offering support to individuals with IDD to exhibit their chosen items. **Results:** Four themes were identified: fashion and clothes linked to past positive and negative memories; wider associations made from fashion and clothing; fashion and clothing as an expression of personal identity; and the importance of personal choice of fashion and clothing. **Conclusions:** Clothes and fashion are important to how individuals with IDD perceive themselves, and how quality of life issues (i.e., choice and empowerment) are bound up in tangible items such as clothes. Heritage is helpful for exploring the identities of people with IDD.

**Social inclusion of people with intellectual and developmental disabilities – lost in translation?: Perspectives from Brazil**

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**Aim:** The aim of this pilot study was to map the social lives of 48 adults with intellectual and developmental disabilities (IDD) in Brasília before and after a social inclusion intervention to facilitate the development of their social networks. **Method:** A two-arm, waiting-list pre-post experimental design was utilised with mixed methods including the Social Network Guide (SNG) (Forrester-Jones, 2016
adapted to be culturally sensitive to Brazil) to map the social networks of each individual. A training intervention with staff and family carers and volunteers was facilitated to develop an acceptable social intervention and a semi-structured was administered to them regarding their attitudes around social inclusion and their view concerning the training. Statistical analysis of the SNG data and thematic analysis of qualitative data were conducted. **Results:** Cultural sensitivities and translation issues were encountered. Preliminary baseline social network results reveal that adults with IDD in Brasilia experience similar limited social lives to the British counterparts in terms of network size, membership, density and social support. **Conclusions:** Social inclusion of people with IDD is a world-wide aspiration but systemic and cultural nuances of particular countries need to be considered.

**Spirituality and people with intellectual and developmental disabilities: Staff attitudes and perspectives in relation to spiritual care provision**

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**Aim:** This study explores how support workers in two different services (one faith-based, the other not) provide spiritual care for individuals. **Method:** A mixed methods approach was used during six months of voluntary work within each service. Data from interviews with 42 members of staff (21 in each service) as well as participant observation (informal observations and discussions with staff) and content analysis of policy documents were subjected to thematic analysis to explore how spirituality was embedded within care organisations. Quantitative instruments included the Spiritual Care Competence Scale and the Spiritual Care Perspectives Scale. **Results:** Quantitative analysis (corroborated by more qualitative findings) revealed that staff from the non-faith based service considered service users to have little awareness of spirituality. Staff from the faith-based service were more open to service users’ spirituality and provided more spiritual care for individuals. **Conclusions:** Services need to acknowledge the need for attitudinal change among care staff in relation to spiritual care and the spirituality of people with IDD.

**The effects of word repetition and word diversity on language production for children with profound language impairments**

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**Aim:** Many children with profound expressive and receptive language impairments show deficits in verbal working memory and require more targeted language exposure compared to typically developing children to achieve word learning. Understanding how adult linguistic behaviours affect the early development of language for this population is important to implementing effective interventions. The purpose of this study was to understand how adults’ use of word repetition and word diversity contributes to word learning for children with language impairments. **Method:** We used hierarchical linear modelling of adult utterances during Enhanced Milieu Teaching intervention sessions to measure the relationship between the adult’s use of language and the child’s production of imitated language for preschool children with language impairments. **Results:** Increased adult language was related to an increase in children’s imitated language, while an increase in language diversity was related to a
decrease in children’s imitated language. **Conclusions:** An intervention model that uses targeted vocabulary with repetitive and somewhat limited language models has a positive effect on child language use for children with profound language impairments.

**The experience of alcohol use amongst individuals with intellectual disabilities in Aotearoa/New Zealand**

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**Aim:** The aim of the project was to investigate the experience of alcohol use by people with intellectual disabilities in Aotearoa/New Zealand. **Method:** Ten semi-structured interviews were undertaken to investigate the experience of alcohol use. Participants were selected using purposeful sampling. Working from within a critical realist perspective, interviews were coded and themes identified utilising Braun and Clarke's six stage approach to theme identification. **Results:** Three themes were identified: choices and influences of alcohol use, context and location of use, and drinking behaviour. In making choices about alcohol use participants inhabited a multi-layered social structure which, combined with their disability, constrains their autonomy. Despite these constraints participants were able to exercise valuational agency with respect to their choices about alcohol use. Consumption levels were generally low due to the influence of protective factors, with limited experience of binge drinking or longer term adverse effects of alcohol use. **Conclusions:** Four protective factors mitigated the risk of pathological consumption. These were the participants’ social and support networks, learning from negative experiences, internalisation of rules, and risk aversion.

**An affective re-reading of autism in select fiction**

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**Aim:** With the increase in the number of fictional works about people on the autism spectrum, a slow remapping of cultural geography can be anticipated. This paper explores the contours of affective experience captured in autism fiction of the 20th century and engages with the transference of affect, mainly negative affect that unconsciously maintains the stigma against autism. **Method:** Specific examples from recent British, American, and Indian fiction about autism are taken into consideration. The texts include: Oryx and Crake, The Fifth Child, and Shame; as well as movies and popular fiction that have overtly or implicitly dealt with autism. Literary analysis of the texts relied on Disability Studies, Culture Studies and the theories of affect. **Results:** In the open spaces of the reader’s mind, the affect captured, manipulates notions of autism. Sadly, more negative affect is transferred unconsciously, in spite of the positive intentions of the author. Unconscious transference of affect like shame, disgust and distress can be damaging. **Conclusions:** A significant perspectival shift is possible if positive affect is generated in conjunction with people with autism.

**Assistive technology for supporting participation in employment for individuals with intellectual disabilities**

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**Aim:** The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) implies an increase in participation in employment for individuals with intellectual disabilities (ID). In this process, assistive technology plays an important role. This poster shows results of how a technical assistive system providing cognitive support can promote the participation in the field of employment. **Method:** The study was conducted in a sheltered workshop. Over six weeks, 13 people with ID worked with the support of an assistive system. Quantitative data and qualitative data through participant observation and field interviews were collected. **Results:** The use of the assistive system enabled people with ID to perform work activities. Particularly people with severe limitations who have not previously been able to do such work activities benefitted from the assistive system. Compared to the previous approach, the work load was significantly reduced by using such an assistive system. **Conclusions:** The development and the use of the assistive system followed the requirements of the UNCRPD’s right to work. This kind of assistive system can make a considerable contribution for inclusive employment.

**Elderly people with intellectual disabilities and their health-related everyday life**

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**Aim:** Due to the early and specific signs of aging and an increased morbidity, specific concepts are needed to strengthen the self-determination and competence in dealing with health for elderly people with intellectual disabilities (ID). **Method:** Using a qualitative study design, 31 adults with ID (age >45 years) were interviewed. Interviews focused on the communicative characteristics of the target group. Interview data were evaluated using a reconstructive-hermeneutic method by Kruse to find out how the elderly people with ID construct health in everyday life. **Results:** Elderly people with ID understand healthy living either through their own experience or from information they receive from carers or through television. Health is understood via simple if-then-principles. Complex relationships are therefore not formed. **Conclusions:** Health information for elderly people with ID must be taught using simple if-then-statements. This would allow them to use information for a self-determined healthy lifestyle.

**Transition of persons with developmental disabilities from parental to sibling co-residential care**

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**Aim:** As people with developmental disabilities (DD) age and outlive parents, siblings may become primary caregivers. Data on this growing phenomenon is limited in context of co-residence. This study explored siblings’ post-transitional experiences following this major life change. **Method:** 12 siblings each having transitioned to primary co-residential caregiver of a brother or sister with DD were selected through convenience/snowball sampling. Semi-structured, open-ended interviews were conducted exploring sibling caregivers’ perspectives of well-being, family functioning and other emergent themes post-transition, as well as differences between planned and unplanned transition. Hermeneutic-narrative methodology was used to analyse data. **Results:** Preliminary results shows effect on well-being and family functioning, and reveal meaning sibling caregivers ascribe to their experience. **Conclusions:**
The study outlines directions for future research. Implications for social work practice will be discussed, including understanding sibling co-residential caregivers’ experience. This knowledge can inform treatment interventions, needed supports, and policy interventions to help sibling caregivers adjust to their new role, and create more fluid transitions of brothers and sisters with DD to a sibling’s residence.

**Evaluating alternate residential practice approach for quality of life improvements in adults with intellectual and developmental disabilities**

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**Aim:** Findings on persons with intellectual and developmental disabilities (IDD) in community living show minimal, stagnant quality of life (QoL) improvements. This study provides preliminary baseline data for evaluating alternate residential practice approach and QoL outcomes of community-living residents with IDD. Features of the alternate residential practice approach include: residents as primary decision-makers, non-hierarchical staffing, redesigned personal living space, and congregate, engagement-focussed kitchen, dining room and hearth. **Method:** 40 participants randomly selected, each residing in intermediate care facility (ICF) of which 20 will transition to alternate residence, were included in a two-year longitudinal mixed methods evaluation. Participant observation and QoL IDD scale measures at four follow-up periods (6, 12, 18 and 24 months) will be analysed. **Results:** ICF residents’ QoL at baseline findings will be presented. **Conclusions:** Findings are expected to help social workers reconfigure existing and future residences to improve residents’ QoL outcomes.

**Perspectives of family and school stakeholders on youth with intellectual disabilities transitioning to adulthood**

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**Aim:** This study explores how various family and school stakeholders envisioned the future for youth with intellectual disabilities (ID) in terms of employment, social relationship and other key aspects of growing up; and what they perceived as enablers and challenges to transition to adulthood in Singapore. **Method:** The participants in this study were eight youth with ID, their parents, siblings and school personnel involved in the transition process. We utilised semi-structured interviews and the data were analysed using a grounded theory approach. **Results:** Preliminary findings suggested the following: employment was a key emphasis for family and school stakeholders, school-home collaboration was an important enabler, and the main challenges were the lack of post-school options and collaboration with external adult agencies. **Conclusions:** The findings suggest a clear need for smoother transitioning of support services from school to external adult agencies. Further research is needed on how school, with the involvement of external adult agencies and the community, may support the individuals with ID and their families to achieve their aspirations.

**Gamelan and students with complex needs: Communicating our common pulse**
Scientific POSTER presentations F-G

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Aim: Gamelan comprises percussion instruments from Indonesia. Its communal, egalitarian approach to music-making and the accessibility of the instruments has resulted in its use in inclusive arts and education programmes outside Indonesia. This study explored the impact on interaction and well-being of Gamelan sessions for students with profound and complex needs including hearing loss. Method: 13 students aged 5 to 15 years took part in weekly, 45-minute sessions throughout the school year, each supported by one or two support workers. Sessions were led by three musicians. Data collection included video-recordings, field notes and staff interviews. Results: Video-observations demonstrate increases in engagement, vocalisation, and movements in synchrony. Students reportedly accepted hearing aids more readily and wore them for longer periods in sessions. Students demonstrated increased awareness of, receptivity to, and initiation of musical conversations and music-making more generally. Staff reported gains in their own knowledge. Training was highly rated at 9/10 (n=23 staff). Conclusions: This exploratory study suggests that collective music-making can enhance interaction and well-being in students with complex needs. More systematic evaluation is on-going. Practice implications will be presented.

Anencephaly: Parents’ perspectives on babies without cerebral cortex

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Aim: Anencephaly means the absence of the cerebral cortex. It is the most severe form of intellectual disability. Affected children usually survive only for a few hours or days. An increasing number of parents decide to continue the pregnancy after prenatal diagnosis. There is almost no research on their experiences. Method: Interdisciplinary conferences on anencephaly have been held at the University of Erfurt for more than ten years. Parents of children with anencephaly were included as experts in these meetings. This method of participatory research led to new insights into the parents view. Results: Carrying to term is a trend observable in the international context. Parents consciously use the time to experience togetherness with their unborn child. Major topics relevant to these parents were identified. Conclusions: Dissemination of the parental experience of pregnancy, birth, life and death of a baby with anencephaly is important to inform future parents about an alternative to abortion.

Addressing the assessment challenge in infancy and adolescence: The KidsLife Scale

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Aim: The aim of this research consists in validating a new questionnaire to address the challenge of assessing quality of life-related personal outcomes in children and adolescents with intellectual and developmental disabilities (IDD): the KidsLife Scale. Method: The KidsLife Scale is a 96-item Likert scale questionnaire that is completed by a proxy (e.g., parents, teachers, supports providers). In reference to the person being assessed, the individual needs to: show IDD; be currently receiving supports and services; and be under 21 years old and engaged in the education system. The validation sample was composed of 1,060 persons with IDD from 4 to 21 years old (M=13.51; SD=5.04). Results: The eight
quality of life domains are reliable (Cronbach’s alpha ranging from .78 to .90). Confirmatory factor analysis provides evidence of the great fit to the data of the eight-domain model. Conclusions: The scale provides reliable and valid results related to eight quality of life domains. The utility of this tool for developing evidence-based practices in services and organisations are discussed.

Defining priorities in improving quality of life in children with autism and intellectual disabilities

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Aim: The aim of this study is to identify quality of life in children with intellectual disabilities (ID) and autism spectrum disorder (ASD) to facilitate evidence-based practices. Method: The field-test version of the KidsLife scale was used; it is a 156-item questionnaire that is completed by a third-party respondent (such as staff, proxy, partners, relatives) for people with ID under 21 years of age. This scale was applied to a sample of 275 children from Spain who have ID and ASD and who were users of social and educational services. Results: Significant differences were seen in terms of type of schooling, level of functioning and support needed, as well as the presence of behavioural problems. Conclusion: The implications of the study are discussed and specific recommendations to guide and plan professional practices are provided. Priorities and strategies to improve quality of life-related personal outcomes should be focused on social inclusion, self-determination, and personal development.

How to measure quality of life in people with significant disabilities

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Aim: This research examined the use of the San Martin Scale to measure quality of life (QoL)-related personal outcomes in people with significant intellectual and developmental disabilities (IDD). Method: The San Martin Scale is a 95-item questionnaire that is completed by a proxy (such as staff, partners, relatives). The answer format is a frequency scale with four options. Administration time varies from 20 to 40 minutes. Method: The validation sample was composed of 1770 people from Spain with IDD who showed extensive or pervasive support needs; 8.7% had mild intellectual disability, 28.25% moderate, 41.6% severe, and 21.4%, profound. The age of the participants ranged between 16 and 77 years (M=7.78; SD=1). Results: Reliability, in terms of internal consistency (Cronbach’s alpha), was very good (coefficients ranging from .82 to .93) and validity was shown through confirmatory factor analysis, which suggested the good fit to the data of the eight QoL domains. Conclusions: Given the lack of instruments for this population and the difficulties to measure QoL in those with the greatest supports needs, the San Martin Scale emerges as a useful and powerful tool.

Transition discoveries: Inclusion and empowerment of youth and families in participatory action research

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Aim: To address the dreams and goals of transitioning youth and their families in Pennsylvania. Method: This participatory action research project genuinely includes the ideas, values and understandings of people with disabilities in every stage of the research project: conception, proposal, data gathering, analysis, and writing. To capture the voices of transitioning youth and families, the project did not begin with a prescribed set of shared language and definitions. Results: Data were collected through focus groups which were then coded and analysed to identify a series of salient themes. These themes have then been analysed in comparison to existing research, to establish what works in transition in Pennsylvania, with shared understanding of what this means through the voice of transitioning youth with disabilities and their families, within the interdependent framework of supports and systems. Conclusions: Successes and limitations encountered as we maintained our goal of inclusion and empowerment through participatory action research will be highlighted.

Direct care workers’ experiences of grief and need for support

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Aim: Direct care workers (DCW) care for people with intellectual and developmental disabilities (IDD) across their life spans, and increasingly must negotiate bereavement, as greater numbers of persons with IDD die at older ages and experience prolonged illness. Limited organisational support and inadequate staff coping skills contribute to staff stress regarding bereavement. This may include disenfranchised grief (grief not openly acknowledged by society) as staff are expected to resume work as normal following the death of a person with IDD. In this study, we explore major themes regarding DCWs' grief process and their needs for support. Method: Thematic analysis with Atlas-ti v. 5.0 data management software was conducted to examine data from nine focus groups with 60 DCWs from five community-based organisations. Results: Three themes (DCW grief experiences, DCW support needs, organisational policy and communication) and related subthemes emerged from the data. Conclusions: The study provides insight into staff grief and their social support and organisational needs. The results can inform the development of bereavement training and other organisational supports needed for DCWs caring for seriously-ill persons with IDD.
Recommendations from a specialty consultative rehabilitation clinic for people with intellectual disabilities: What are they?/Do they ever get done?

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Aim: Multidisciplinary rehabilitation clinics are resource-intensive and frequently generate a number of recommendations for the primary care doctor and carer to follow-up. This review examined the common recommendations made by our service and which of these were implemented. Method: 130 consecutive consultations from 01/01/2012 till 13/11/2014 were reviewed for their recommendations. Clinic letters from subsequent appointments were reviewed and family/carers and GP practices were contacted to identify which of the recommendations were completed and what were the barriers to those remaining. Results: Persons with intellectual disabilities who have family members to advocate on their behalf had more recommendations completed. The recommendations that involved our service to complete were more likely to happen. A significant proportion of the health-related recommendations were not implemented. Conclusions: Results have implications for the ongoing role of consultative service models of care. How can our service assist/facilitate? What is our role in ensuring the completion of our recommendations? Can we play more proactive role?

Impact of self-rated social competence on psychological adjustment in adults with autism spectrum disorder

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Aim: Adults with autism spectrum disorder (ASD) often experience problems with social adjustment, and risk developing anxiety and depressive disorders. We compared high-functioning adults with ASD with typical peers on self-reported symptoms of anxiety and depression, and determined the extent to which autistic traits and self-perceptions of social competence were implicated in the development of these symptoms. Method: 97 adults with, and 104 adults without, an ASD diagnosis completed self-report questionnaires which included measures of autistic traits, social competence, and symptoms of anxiety and depression. Bootstrapped moderated-mediation analyses were conducted to determine the strength of relationships among these variables, and the extent to which they varied according to diagnostic status. Results: Diagnosed individuals reported deficits in five assessed domains of social competence. For both groups of participants, social competence was negatively associated with symptoms of anxiety and depression, but mediated the association between autistic traits and these measures of psychological adjustment only in diagnosed individuals. Conclusions: Implications are discussed with reference to social skills training for diagnosed individuals, and the need for cognitive behaviour therapy programmes targeting self-perception of interpersonal competence.

Reasonable accommodation for people with developmental disabilities who want to become nurses

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**Aim:** Since 2016, under the Act for Eliminating Discrimination against People with Disability, Japanese national and private universities are required to make efforts to support and assist students with developmental disabilities (DD). The purpose of this study is to clarify how reasonable accommodations can be provided to students with DD (autism, Asperger syndrome and other DD) in Japanese university nursing programmes. **Method:** A review of the literature concerning nursing university education was conducted. **Results:** The provision of reasonable accommodations for students with DD is increasing. However, how best to accommodate such students in nursing university education has not been reported. **Conclusions:** Further study is needed related to reasonable accommodation; including a fact-finding survey of the present condition and problems related to reasonable accommodation in Japanese nursing education.

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**A comparison of the costs of services for younger and older adults with intellectual disabilities in Northern Ireland**

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**Aim:** The aim of this study is to compare and contrast the costs of services for younger adults (18 to 30 years) with older adults (50 years plus) with intellectual disabilities (ID) in Northern Ireland. **Method:** An adapted version of the Client Service Receipt Inventory (CRSI) was administered to the main carer of the adult with ID, where appropriate the person with ID also aided in the completion of the CRSI. 60 CSRI were completed for older adults with ID and 30 for younger adults with ID. **Results:** Data on receipt and costs of day activity, respite, community/primary care, domiciliary, and other supports and medication for both cohorts will be shared. **Conclusions:** The numbers of older adults with ID utilising social care services in the UK is estimated to rise by 30% by 2030. Meeting the needs of these growing numbers of individuals within current and diminishing healthcare budgets is a priority: planning ahead is fundamental.

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**Towards building an inclusive health system through training community rehabilitation workers: Experiences from South Africa**

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**Aim:** Access to healthcare and rehabilitation remains a challenge for persons with disabilities. The Western Cape Department of Health engaged the University of Cape Town to pilot the training of 33 community rehabilitation workers (CRW) in a Higher Certificate in Disability Practice. The CRW are trained in an interdisciplinary manner to work with people with a variety of disabilities including intellectual disabilities as well as developmental disabilities. This paper synthesises four research projects conducted to generate evidence on CRW building an inclusive health system. **Method:** Focus groups, interviews and questionnaires were conducted. Data were analysed qualitatively against different theories related to each research question. **Results:** Finding related to the perceptions of CRW on the training and challenges, perceptions of rehabilitation therapists to this new cadre of worker, how therapists and CRW can partner in changing health systems, and an evaluation of the training will be presented. Consistent engagement with stakeholders on how to work with and supervise CRW is
needed. **Conclusions:** CRW are a vital member of the primary healthcare team to address the needs of individuals and their families.

**The significance of securing advanced education for persons with intellectual disabilities**

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**Aim:** In Japan, where few advanced educational institutions accept persons with intellectual disabilities (ID), many of them start work after graduating from high school. This study aimed to demonstrate the significance of advanced education. **Method:** A survey was conducted among 200 adults with ID with and without advanced education, and results compared between both groups. The participants attended either ‘Yutaka College’ (educational facilities for post-high school social independence) or ‘Yutaka-no-Sato’ (facilities for post-high school creative and productive activities), both operated by a social welfare corporation. The survey consisted of a 15-item questionnaire asking about self-growth, improvement of interpersonal skills, and improvement of work motivation. **Results:** Those at ‘Yutaka College’ exceeded those at ‘Yutaka-no-Sato’ by 27.4 points in improving work motivation, 15.5 points in improving communication skills, and 15.2 points in learning social manners and rules. **Conclusions:** The survey demonstrated post-high school education is significant. It is necessary to broaden opportunities for advanced education for persons with ID in Japan.

**Relationship of stigma with psychological distress and other variables in adults with mild to moderate intellectual disabilities**

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**Aim:** To investigate the association between self-reported stigma and psychological distress, service use and other factors in adults with mild to moderate intellectual disabilities (ID). **Method:** A survey of adults with mild ID in England was conducted using the Stigma questionnaire by Ali et al. (2008). 229 participants were interviewed. Data were analysed using bivariate analyses and logistic regression as applicable. **Results:** Stigma was significantly associated with psychological distress (measured with CORE-ID), older age and moderate ID but not physical disability. Adults who feel stigmatised seek more contact with statutory services but may not complain about feeling stigmatised. **Conclusions:** This is the first study to examine self-reported stigma in people with mild to moderate ID using a validated instrument. Our findings suggest that it is necessary to develop interventions that can help adults with ID manage psychological distress due to stigma.

**Ensuring better health outcomes for people with intellectual disabilities in the UK**

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**Aim:** Many persons with intellectual disabilities (ID) are not identified as having a disability in health services in the UK and there is a need to ascertain the extent of under-identification to ensure better...
healthcare. **Method:** In three general practitioner (GP) practices in the Liverpool area, a random sample of adult patients were screened by practice nurses, using the Hayes Ability Screening Index; and those who fell below the cut-off score were referred for psychometric assessment. **Results:** Whilst 2% of the UK population is estimated to have ID, the proportion of patients registered with GP practices as having ID is much lower, at approximately 0.4%. The prevalence varies between practices, according to the socio-economic area from which patients are drawn. **Conclusions:** By July 2016, all organisations providing NHS or adult social care are required to follow the Accessible Information Standard, to comply with the duty of making reasonable adjustments for persons with ID. An individual whose ID is not identified by the healthcare service will not receive these adjustments or their annual health check, thus compromising their health status.

**Testing a multisensory narrative assessment for use with children with intellectual and developmental disabilities aged 3 to 5 years**

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**Aim:** Speech and language therapy research supports the use of multi-sensory stories to assess and promote narrative skill development in children with and without intellectual and developmental disabilities (IDD). **Method:** In phase 1, a narrative assessment devised with a written script and multi-sensory objects, was tested with 40 children 3 to 5 years old without IDD and content and grammar scores obtained. In phase 2, the test was administered to 20 children 3 to 5 years old with IDD to determine narrative content and grammar skills. Statistical analyses were undertaken to determine the influence of cognition and age on content and grammar scores. **Results:** The content and grammar scores of the children with IDD revealed narrative skills that were of a younger age group compared to children without IDD. The results revealed a statistically significant influence of cognition on the use of syntactic structures at p<0.05. **Conclusions:** The test has the potential to be used as a narrative assessment tool with children diagnosed with IDD.

**Comparison and structural alignment processes of learning new relational concepts in children with autism spectrum disorder**

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**Aim:** This study examines structural mapping processes that occur during acquisition of new relational concepts among children with disabilities. **Method:** Participants included 24 children (8 to 16 years) with intellectual and developmental disabilities (IDD), 24 children (5 to 8 years) with high functioning autism spectrum disorder (HFASD), and 24 children (5 to 6 years) with typical development (TD) matched in receptive mental language age. Graphic representations were presented in novel spatial configurations with and without comparison to the standards. Children were asked to select from two alternatives (matching item or relational configuration). **Results:** When one standard was available (no comparison), all participants selected concepts by matching to items rather than to relational structures. However, when presented with two standards (with comparison), children with TD and IDD demonstrated significant increase in their tendency for matching based on relational concepts, while participants with
HFASD did not change their preference and continued selection based on item matching. **Conclusions:** Children with IDD and TD benefited from the opportunity to compare during the selection of relational graphic representations, while children with HFASD did not benefit from the process.

**Influence of attitudes of supporters on independence and sociality of children with developmental disorders: Analysis of participant observation records in small-group activities**

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**Aim:** The purpose of the present study was to clarify the influence of attitudes of supporters on independence and sociality of children with developmental disorders in small-group activities. **Method:** Videotaped records of small-group activities were converted into written records. They were analysed by making initial codes, synthesising codes, and creating attitude categories. Three categories were created as supporters’ attitude, and three categories were created as children’s attitude. Frequency of appearance of supporters’ attitude categories shown prior to children’s attitudes was compared using chi-square test of significance. **Results:** Active self-expression among children was more frequent when supporters’ attitudes included sympathy and collaboration. Attitudes of consideration for others and collaboration among children tended to be greater when supporters helped children interact with one another. **Conclusions:** Sympathy and collaboration of supporters’ nourish children’s independence. Supporters’ role as intermediaries between children effectively cultivates children’s sociality.

**The nature of interaction during storytelling between people with profound intellectual and multiple disabilities and caregivers**

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**Aim:** The aim of this study was to explore how caregivers engage people with profound intellectual and multiple disabilities (PIMD) during storytelling. In particular, we were interested in how caregivers could adjust the method of conveying stories and emotion through observing the variety of the dynamics between caregivers and PIMD during storytelling. **Method:** Field observation and video analysis was conducted using a hermeneutic-phenomenological approach. **Results:** Caregivers appeared to rely on the familiarity and dependency that they established with the person with PIMD in their daily life to let the variety of intonation and emotion produced during storytelling transfer the story plot to the PIMD more precisely. Our observations suggested that the persons with PIMD decided how the stories should keep on going, not the caregivers. **Conclusions:** Caregivers and persons with PIMD construct the meanings of the story through the storytelling process together.

**Barriers to inclusion: Investigating education systems within the small island developing states of the Eastern Caribbean**

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Aim: The aim of this study is to explore how disadvantaged students are included within the education systems of the small island developing states of the Eastern Caribbean. The Islands have made strides in achieving international goals of universal primary and secondary education. However, within the global context of inclusion, barriers remain that affect the education of learners with special education needs.

Method: Qualitative interviews were conducted with students, teachers, parents, policy actors and other stakeholders in three islands; St. Kitts, Antigua and St. Lucia between November 2014 and February 2015. Results are being analysed using framework analysis. Results: Barriers to inclusive education were identified as issues of teacher education, curricula development, a lack of resources and funding, negative attitudes, stigma and discrimination as well as the need for communication and awareness within the community. Conclusions: This study highlights the existing barriers within education systems of the Eastern Caribbean that hinder the practice of inclusion. The results have implications for future policy development and practice within the sub-region if states are to meet global targets.

Analysis on quality and outcomes of Korean transition education programmes for adolescents with intellectual and developmental disabilities using the quality indicators of NASET

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Aim: This study investigated the quality and outcomes of Korean transition education programmes for adolescents with intellectual and developmental disabilities to provide implications to improve quality of transition programmes. Method: 51 studies regarding transition education programmes published from 2005 to 2015 in Korea were identified. Transition education programmes addressed in the studies were analysed using modified quality indicators of NASET including 19 indicators in 5 areas (schooling, career preparatory experiences, youth development, family involvement, and connecting activities) to examine the number of indicators covered in each program. Program-targeted transition outcomes were also investigated. Results: Most Korean transition education programmes reflected the quality indicators of career preparatory experiences and youth development areas while only about 20% of programmes considered the indicators of schooling, family involvement and connecting activities areas. With respect to transition outcomes, most programmes targeted career preparation, self-determination and interpersonal relationship. Conclusions: The findings provide researchers and practitioners with several implications for planning high quality transition programmes for adolescents with disabilities.

Parasympathetic regulation eases distress but hinders empathy for pain in autism spectrum disorder

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Aim: Poor parasympathetic regulation may hinder social engagement and empathy, and has been implicated in autism spectrum disorder (ASD). We investigated the extent to which baseline autonomic arousal in ASD facilitates empathy and reduces personal distress for others’ pain. Method: Individuals with varying levels of autism traits, as measured on the Autism Diagnostic Observation Schedule 2 and Autism Spectrum Quotient, participated (N=100, n with ASD=27; ages 14 to 46 years). We measured pre-ejection period (PEP) and skin conductance levels, indicators of sympathetic arousal, and respiratory
sinus arrhythmia (RSA), a measure of parasympathetic arousal, while participants were resting. These measures were correlated with reported distress and empathy on observation of videos of painful or non-painful stimulation. **Results:** Amount of autism traits and baseline sympathetic arousal did not predict self-reported empathy or sympathetic response. Parasympathetic arousal was negatively related to both empathy and distress. **Conclusions:** Our data suggest that empathic arousal and concern is intact in ASD. The findings contradict current theories on parasympathetic regulation; greater parasympathetic regulation at rest predicted decreased distress, but contrary to expectation also predicted decreased empathic concern.

**Children’s School Success+: A framework for inclusive early education**

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**Aim:** The Children’s School Success+ framework was developed as a guide for providing equal access to academic and social content while addressing children’s unique learning needs. The research question addressed was: Can educators implement the framework and in so doing do children including those with delays make meaningful gains in social and academic content? **Method:** A six-step framework was developed through an iterative process with 12 classrooms across 4 early childhood programmes. Data were collected on implementation feasibility through teachers’ documentation of planning steps completed and observation of teachers’ plan implementation. Child impact was assessed for a subgroup of 3 to 4 children in each class through standard measures (e.g., Peabody Picture Vocabulary, Woodcock Johnson Test of Achievement, Social Skills Improvement Rating Scales) and goal attainment scaling on child individual goals **Results:** Teacher data demonstrated that implementation of framework components was feasible. The child impact data demonstrated child gains in academic and social outcomes as well as on individual goals. **Conclusions:** The resulting framework addresses provision of challenging universally designed curriculum content (i.e., literacy, math, science, social-emotional), differentiation, individualisation, and progress monitoring.

**Receipt of contraceptive services among women with intellectual disabilities in the United States**

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**Aim:** Approximately 2% of U.S. women of childbearing age have intellectual disabilities (ID). Yet few empirical data are available on receipt of contraceptive services among women with ID. We therefore conducted a retrospective cohort study of contraception services at a large academic medical centre. **Method:** Women with disabilities (16 to 44 years) were identified by ICD-9 codes anywhere in their medical record indicating presence of ID. We determined what proportion of women with and without ID had a record of diagnoses, procedures, or prescriptions associated with contraception. **Results:** Among women with no disability, 30.9% had received contraceptive services. The proportion was significantly higher for women with ID (44.0%, \( \chi^2=91.01, p<.001 \)). **Conclusions:** Women with ID were more likely to receive contraceptive services than women without disabilities. Greater contraceptive service use may reflect a preference for prescription and long-acting methods rather than over-the-counter contraceptives. Women with ID, their families, and their healthcare providers may also have
greater concerns about pregnancy and childrearing. However, many women with ID may desire future pregnancies, and those desires should be taken into account when considering contraceptive options.

A study on the physical environment of nursery school for children with autism spectrum disorder and children with Down syndrome

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Aim: Nursery school’s physical environment has a significant effect on children and childcare. Daycare centres have been designed for children of typical development. There is little consideration for the physical environment preferences of children with autism spectrum disorder (ASD) and Down syndrome (DS). This study examines the place preferences of children with ASD and DS within daycare settings.

Method: A questionnaire survey was conducted among 35 nursery school teachers. Data analysis considered children’s likes and dislikes regarding places, their reasons, etc. Results: The most frequently mentioned place that children with ASD disliked was a hall because they ‘did not like the sound’ and ‘did not feel comfortable’. Nursery teachers tried to wait for the right moment to invite the child to other places. There were not many places that children with DS disliked. Conclusions: By using places where children with disabilities feel comfortable, the physical environment can be effectively used to help them participate in a group.

Families of children with developmental disabilities: Quality of life, family functioning, and parent-child interaction

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Aim: Despite increasing emphasis on adopting a family-centred approach to early childhood intervention (ECI) programmes, our understanding about family processes is limited. The aim of this study was to explore the relationships among family functioning (FF), family quality of life (FQOL), and parent-child interactions in families of children with developmental disabilities (DD). Method: Families of children with a range of DD aged between 17 and 63 months were recruited from an Australian ECI program. Families completed measures of FF and FQOL. During a home visit, ECI key workers videotaped one 10-minute parent-child interaction session. Parenting behaviour was rated on four domains: affection, responsiveness, encouragement, and teaching. Results: Preliminary results indicated that overall, families were satisfied with their FQOL, had a healthy level of FF, and a high frequency of parent-child interactions. Families with healthy FF had high satisfaction with FQOL and families demonstrating more parent-child interactions reported higher satisfaction with FQOL. When more parent-child interactions were observed, FF increased; but this association was not significant. Conclusions: The current findings highlight the importance of family interactions as ECI programme target areas.

Research on ‘meaningful living’ from the perspective of persons with intellectual and physical disabilities

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Aim: The purpose of this study is to research ‘meaningful living’ from the perspective of persons with intellectual and physical disabilities in Japan. Method: We asked to 30 persons with mild intellectual and mild to severe physical disabilities who use a welfare facility ‘What do you think is meaningful in your own life?’. Results: 56.7% identified meaningful aspects of their lives. What gave meaning was classified into 5 themes: hobbies (e.g. painting, shopping, and sport watching) (20.0% of the total), children and grandchildren (16.7%), rehabilitation (13.3%), company (e.g. friends and others with disabilities) (10.0%), and productive effort (e.g. working and studying) (6.7%). Conclusions: About half the individuals with intellectual and physical disabilities could not identify what gave meaning to their lives. Differences in what people identify as meaningful in their lives probably reflects their life history, family, personality, intellectual ability and physical ability.

Design development of picture cards suitable for adults with autism spectrum disorder  
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Aim: Although the use of picture cards is effective, using cards designed for children for use with adults with autism spectrum disorder (ASD) has the potential to create embarrassment and uneasiness among users and the general public. This study aimed to develop a range of picture card designs for adults and evaluate their suitability. Method: Designs of picture cards were created based on existing picture card (DROPS) for children with ASD. The design approach focussed on using non-childish imagery, stylish colour and realistic expressions. Four new series were developed: replica illustration of DROPS using an adult, stylised illustration of adult, monochromatic pictographs, and a photo-based series. These cards were evaluated using semantic differential method (13-adjectivex5-scalex47 general public). An image profile of each series was created. Results: All new designs were evaluated as more suitable for adults. The series using stylised illustration of adult was evaluated as the most adult. Conclusions: The newly developed picture cards were considered effective in reducing uneasiness.

Time discrimination in children with ASD, ADHD, and co-morbid ASD+ADHD  
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Aim: Overlaps between autism spectrum disorder (ASD) and attention deficit hyperactivity disorder (ADHD) commonly occur. Deficits in cognitive function have been demonstrated in both disorders, yet these impairments have never been directly compared across pure and co-morbid groups using time discrimination task. This study investigates and compares time discrimination in children diagnosed with ASD, ADHD, and co-morbid ASD+ADHD. Method: Time discrimination task was administered to boys (7 to 16 years old) with ASD (n=17), ADHD (n=30), co-morbid ASD+ADHD (n=35), and typically developing controls (TD; n=20). Results: Children with ASD, ADHD, co-morbid ASD+ADHD, and TD showed a trend towards significant difference in time discrimination (p<0.1). The deficits in time discrimination were observed in the combined group of ADHD and co-morbid ASD+ADHD (p<0.05). The significant
correlations between severity of inattentive symptoms and deficits in time discrimination were also observed in the whole sample. **Conclusions:** This study is the first study using a four-group design to compare ability in time discrimination. It could be concluded that the deficit in time discrimination is likely pronounced in children with inattentive symptoms.

**Thyroid function in children with Down syndrome**

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Aim: To study the prevalence of thyroid dysfunction in children with Down syndrome (DS). **Method:** Children who attended the DS clinic, paediatrics ward and general out-patient department in a tertiary care hospital in India during an 18-month period were enrolled in the study. Diagnosis of DS was made from clinical examination using the criteria described by Oster and confirmed by Karyotyping. 80 children were enrolled in the study. **Results:** Classical hypothyroidism with elevated thyroid stimulating hormone (TSH) and decreased T3, T4 were seen only in 2.8% of the 80 children studied. Elevated TSH with normal T3 and T4 was seen in 12.5%. 84.7% had normal thyroid values. **Conclusions:** The results show a lower incidence of hypothyroidism when compared with the published western literature. Subclinical hypothyroidism (with only raised TSH) is more frequently seen. To treat or not to treat, is a debatable question. However, these children should be more frequently followed-up as there can be transient hypothyroidism which will grossly affect their brain development especially in those under the age of 5 years.

**Recurrent respiratory infection and heart disease in children with Down syndrome**

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Aim: To study the incidence and pattern of recurrent respiratory infection and congenital heart disease (CHD) in children with Down syndrome (DS). **Method:** Children who attended the DS in a tertiary care hospital in India during a two-year period were enrolled in the study and a retrospective analysis was done. Diagnosis of DS was made from clinical examination using the criteria described by Oster and confirmed by Karyotyping. **Results:** 88 children were enrolled in the study. 54.5% had recurrent respiratory infection, with acute recurrent upper respiratory infection in 25%, of which 63% were due to rhinopharyngitis. 20.5% had lower respiratory tract infection of which 66.66% had recurrent pneumonia. 36% of the children had CHD, with AV canal defect forming the largest group (37.3%). **Conclusions:** There is a high incidence of recurrent respiratory tract infection, with rhinopharyngitis being the commonest problem. Adequate training in preventive aspects should be initiated, which could probably bring down the incidence. CHD is also high but less when compared to other similar studies. Universal screening with ECHO at birth would probably yield a higher incidence of CHD.

**Preliminary development and evaluation of an adapted dialectical behaviour therapy group for persons with intellectual disabilities**
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Aim: Given recent studies revealing the positive effects of dialectical behaviour therapy (DBT) with individuals with intellectual disabilities (ID), there is a need to empirically evaluate the feasibility and impact of adapted DBT group therapy for this population. Method: Utilising an adapted DBT group therapy model, a revised model was developed for a Canadian community sample of individuals with ID and emotional regulation difficulties and pilot tested. The program consists of weekly 2-hour groups held over a 3-month period. Outcome measures include assessment of emotion regulation, anger control, psychiatric symptoms and a global measure of symptom change. Measures are taken pre, post and at 3-month follow-up. Results: Pilot group revealed improvement in skill development and self-regulation. Conclusions: It is suggested that group participation will assist individuals to identify skills and manage their emotions therefore promoting positive coping and successful community inclusion. A randomised control group design using a treatment group (n=10) and a wait list control group (n=10) is planned.

Finding entry into life worlds of people with a cognitive disability through arts-informed research

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Aim: A principal claim of this study is that the arts create a context for capacity building. A contribution of this study is Vygotsky's cultural-historical theory as the key source to explain artistic engagement as driven by emotions and influenced by the social context. Method: This qualitative ethnographic case study reports the artistic communication of six young adult members of a Down syndrome (DS) organisation in Singapore. Social and semiotic analysis of artworks and artistic engagement investigated the semiotic design features of the individual artworks and matched these with the participants, embodied interactions. Results: The semiotic analysis shows the many communicative and semiotic details of the participants’ artistic engagement. The semiotic design features bring insights into the communicative abilities of the participants. The details of the artworks are part of unique meaning-making practices and show the influences of emotions and group life on the development of self. Conclusions: Social and semiotic approaches bring insights into the communicative abilities of individuals with DS. Learning the social and semiotic nature of artistic language through practice-based research offers an opportunity to build capacity.
A validated conceptual map of health transition research for young people with intellectual disabilities
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Aim: Evidence from research on health transition for young people with intellectual disabilities may poorly match the generic conceptual framework for continuity of care developed by Freeman et al. The study reviewed, appraised and mapped existing health transition research onto the conceptual continuity of care framework to identify the utilisation of existing conceptual frameworks in health transition research. Method: We conducted a scoping study of English language studies on health transitions and used a mapping technique to match research evidence onto the continuity of care framework. We then organised a series of discussion groups (n=3) with an expert panel, utilising nominal group technique, to validate the findings of the mapping exercise. Results: Existing health transition research is poorly matched onto the conceptual framework of continuity of care. This reflects a lack of conceptual and theoretical underpinning of existing health transition research and a poor utilisation of previously funded conceptual research. Conclusions: Health transition research should build on conceptual frameworks such as continuity of care and future research calls should encourage empirical research informed by existing conceptual frameworks.

Evaluation of the cognitive function in middle-aged adults with Down syndrome who have severe intellectual disabilities
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Aim: Evaluation of cognitive function in individuals with Down syndrome (DS) is often ignored after they are grown up. We tried to clarify their function using multimodal methods. Method: The subjects were 17 patients with DS aged 40 to 63 years (49.4±5.6). Full trisomy and mosaics were confirmed in 13 and 4 patients, respectively. They were referred to us for the further evaluation of their condition. We evaluated their cognitive function using neuropsychological, vision, hearing and neurophysiological tests. Results: Their IQ ranged from 16 to 36 (23.1±6.2) by Suzuki-Binet test. One patient could not be tested. Nine patients could write at least part of their names but nobody could answer their ages. Low vision was present in 13 and hearing was impaired in at least 7 patients. Normal Auditory Brainstem Response and Visual Evoked Potential were recorded in 2 and 3 patients, respectively. Mismatch negativity and P300 to tone bursts was normal in 4 and 1 patients. Conclusions: Multimodal examinations revealed diversity of the cognitive function of middle-aged adults with DS. It suggests the need for appropriate individualised instruction.

Decrease of adaptive behaviour in adolescents/young adults with Down syndrome
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Aim: Sudden decline in adaptive levels of daily living can occur in people with Down syndrome (DS) around age 20 who have no specific disease diagnosis. However, their actual condition remains unclear. This study was undertaken to assess such individuals’ actual condition. Method: Interviews were conducted with 27 adolescent/adults with DS who have consulted medical institutions because of a decline in adaptive skills. Results: Reduced conversation/speech, lack of facial expression, loss of interest/concern, sleep problems, and slow movement were found in all participants. It became evident that in patients who were diagnosed with a disorder, stubbornness/persistence, and agitation/panic appeared frequently, whereas in subjects without diagnosis, social withdrawal was frequently observed. Conclusions: The results clarified a difference in the occurrence of symptoms between subjects diagnosed with physical/psychological disorders and subjects without diagnosis. It suggest that some patients are not diagnosed with a specific disorder even though they show a decline in adaptive skills. The symptoms they exhibit are unique.

Memory assessment in intellectual disability and dementia

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Aim: To aid in the development of more robust methods for memory assessment among elderly persons with intellectual disabilities (ID) suspected of developing dementia. Method: 55 elderly persons with mild to severe ID underwent psychometric testing of episodic memory and verbal ability, and they were independently assessed by two experts for the presence of dementia. Caregivers completed the memory subscale of the Dementia Scale for Learning Disorders. Results: Moderate associations were found between test performance and symptom level of memory dysfunction as judged by a caregiver. Persons assessed as dementing by expert opinion performed more poorly than matched controls on the episodic memory tests but not on tests of verbal ability. Conclusions: There is some but not satisfactory agreement between measures of memory dysfunction among persons with ID and suspected dementia. Memory testing does hold promise as a tool for differential diagnosis, however.

Factors explaining job satisfaction of persons with intellectual disabilities

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Aim: It is desirable that work enables people with intellectual disabilities (ID) to flourish and achieve satisfaction, and hence that the work environment fulfils their needs. It remains unclear how characteristics of the work environment contribute to their need fulfilment and job satisfaction. Integrating the job demands-resources model and self-determination theory, this study investigates whether basic psychological needs (autonomy, relatedness, competence) explain the relationship between job characteristics (job demands, job resources) and job satisfaction of people with ID. Method: 129 persons with ID were recruited from a Dutch care organisation. They were interviewed using questionnaires adapted from well-established instruments measuring job characteristics, needs and job satisfaction. Results: Job resources were positively, and job demands negatively associated with basic psychological needs. Basic psychological needs were associated with enhanced job satisfaction, and partially mediated the relationship between job resources and job satisfaction. Conclusions: To
enhance job satisfaction of people with ID, work environments should fulfill their need for autonomy, relatedness and competence. Selection/design of workplaces should therefore focus on enhancing positive, resourceful job characteristics, and diminishing negative, demanding job characteristics.

How to promote social participation?: Preliminary results of a RCT-study testing a mentor support intervention

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Aim: Social participation of adolescents with visual impairments and developmental delays is challenging. In order to participate in society they need to overcome internal and external barriers. This study tests the effects of a mentor support intervention on promoting social participation. Method: The mentor support intervention was developed based on the self-determination theory, Bronfenbrenner’s socioecological theory and the ICF framework. The evaluation used an RCT design consisting of three groups: mentor support where the mentor had impairments; mentor support where the mentor had no impairments; and a control group. 78 mentor-mentee pairs participated in monthly activities regarding leisure activities, education/work and relationships. Pre-post tests and follow-up measurements used standardised questionnaires and open-ended questions. Monthly evaluation forms were also completed by mentees and mentors. Results: A description of the intervention and preliminary pre-test results (N =60) regarding social participation and psychosocial functioning will be presented (e.g., participants reported a low number of friends, low level of peer activities and low well-being). Conclusions: Mentor support seems to be promising in supporting adolescents with impairments towards an active life within society.

Longitudinal change in white matter in preterm infants without magnetic resonance imaging abnormalities: Assessment of serial diffusion tensor imaging and its relationship to neurodevelopmental outcomes

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Aim: Preterm birth is associated with a high prevalence of developmental disabilities. However neurodevelopmental outcomes in preterm infants without abnormalities through conventional brain magnetic resonance (MRI) are unclear. Method: Preterm infants who underwent MRIs clinically at term equivalent age (TEA) and 1 year corrected age (CA) were participated. Of these, 13 infants without MRI abnormalities who performed neurodevelopmental assessment at 3 years CA entered this prospective study. These infants were divided into two groups depending on gestational age (GA): <26 weeks and ≥26 weeks. Tractography was performed to obtain the fractional anisotropy (FA) of several tracts. FA was compared between two groups, and correlations with neurodevelopmental outcomes were assessed. Results: FA of the splenium at TEA was significantly lower in group GA <26 weeks. However, this difference was no longer observed at 1 year CA. There was no correlation between FA of the splenium at TEA and neurodevelopmental assessment scores at 3 years CA. Conclusions: At TEA, FA of the splenium was lower in younger GA infants without MRI abnormalities, but this does not appear to affect subsequent neurodevelopmental outcomes.
Discussion of supported decision-making in Japan

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Aim: To introduce a discussion of supported decision-making (SDM) in Japan and to provide a document for discussing SDM. Method: The study approach consisted of a literature review (books, academic papers, relevant legislation, documents from workshops, lecture notes), and discussions around SDM in Japan. Results: Three preferred approaches to SDM were identified: the approach preferred by legislators, the approach preferred by support workers, and the approach preferred by people with disabilities. Individualised support and support networks are desired by people with disabilities and carers. In Japan, some discussions concerning SDM can focus on the needs and interests of support workers, rather than on those of people with disabilities. Conclusions: The best approach is to provide people with disabilities with individualised support and support networks. People working in, and making policy in, the field of support for people with disabilities should always remember that the subject of SDM is people with disabilities.

Issues and impacts on people with intellectual disabilities having health warning signs and difficulty expressing their symptoms in the community: Case report

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Aim: This case study examines issues resulting from an individual with an intellectual disability (ID) presenting health warning signs and being unable to effectively express his symptoms. Method: An interview with the parent was conducted and analysed using a narrative approach. Results: The case was a 14 year-old male with mild ID who was fairly independent in activities of daily living but who had difficulty to express pain. Two weeks before a school trip, he had diarrhoea and a fever. His family took him to a nearby hospital and he was prescribed medication. No blood test was done. His condition gradually worsened. As his family was very concerned, they took him to the same hospital the next morning where he was diagnosed with appendicitis. After he underwent emergency surgery, he insisted on going on his school trip, despite his unstable condition. Due to stress-related stomach bleeding, he underwent two gastric surgeries within three weeks of the initial surgery. Conclusions: His condition had not only worsened due to the initial inappropriate medical examination, but was further aggravated by stress brought on his difficulty to understand his condition.

The effects of sermons and curriculum activities with graphic organisers on teacher efficacy and understanding of bible knowledge, and participation in worship by persons with autism spectrum disorder

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Aim: The purpose of this study was to examine the effects of sermons and curriculum activities with graphic organisers on understanding of core bible knowledge of people with autism spectrum disorder.
(ASD) and their participation and attitudes in worship along with efficacy of their Sunday school teachers. **Method:** 38 persons with ASD and 34 teachers participated in this study. Sermons and various activities with graphic organisers were provided for the participants in the experimental group for 7 weeks. Pre and post-tests of relevant dependent variables were conducted before and after the intervention for participants in the experimental and control groups, respectively. **Results:** The intervention had a positive influence on understanding of bible knowledge and participation in worship services by persons with ASD. There were also significant differences between the groups in terms of efficacy of their teachers. **Conclusions:** This study provides a number of key implications for future studies related to graphic organisers and meaningful worship services for people with developmental disabilities along with practical ways to increase their participation in religious activities.

**New paths to inclusion: The needed evolution of organisations in disability services**

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**Aim:** UNCRPD heralds a vision for a transformation from institutional to community-based support. The presenter’s habilitation project on the development of disability service organisations aims to link theoretical frameworks on the evolutionary intersection of economy, organisations, consciousness & understandings of persons with intellectual disabilities with qualitative research. **Method:** So far 10 generative interviews with leaders in the disability service sector in Austria and Germany, a two-day dialogue, and one learning journey to an organisational example of evolutionary organisations (Buurtzorg – Netherlands) have been conducted. Data have been analysed based on a grounded theory approach. **Results:** Intermediate results show how different biographically grounded beliefs and worldviews about self, leadership, organisational evolution and its perceived boundaries held by CEOs of disability services affect realised and anticipated levels of individualisation and participation of persons with ID. **Conclusions:** The paper argues that disability services in Western countries following de-institutionalisation have become locked in a transactional and efficiency-based organisational care model which seems unable to deliver the transformational promise of the UNCRPD and that a paradigm shift in understandings of leadership and organisations is needed.

**The HoNOS-LD: Validity and reliability of the French version**

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**Aim:** The aim of this study is to adapt the Health of the Nation Outcome Scales for people with Learning Disabilities (HoNOS-LD) for use among French-speaking adults with intellectual disabilities (ID). **Method:** The adaptation process includes English to French back-to-back translation and the examination of validity and reliability of the translated tool. The final French version was used by a psychiatrist specialised in the assessment of 24 participants presenting ID and co-morbid psychiatric disorders for whom the Aberrant Behavior Checklist (ABC) was also completed. **Results:** The back-to-back translation process highlighted only few differences between the original version and the back translated version. The French version of the HoNOS-LD showed good concurrent validity and internal consistency, considering the small sample size. **Conclusions:** Results suggest that the characteristics of the French
version of the HoNOS-LD are comparable to the original version. Reliability and validity of the French version are also good. Thus, this tool seems to be a useful instrument to monitor globally psychopathology, behaviours and functioning of French-speaking adults with ID.

Efficacy of the Collaborative WISC-IV Feedback with Parents for reducing parental distress

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Aim: Raising a child with developmental disabilities (DD) has been associated with high levels of parental distress. The current study thus addresses the ability of a newly developed Collaborative WISC-IV Feedback with Parents (CFP) to reduce parental distress. Method: 12 parents of youth with DD participated in 1-hour CFP sessions. In addition to understanding and satisfaction ratings, each parents rated the following: general health, parenting efficacy, and coping prior to and 3 months after the session. Results: According to eight parents’ reports, the mean of general health reduced and the mean of parenting efficacy increased. However there was no remarkable change in the coping ratings. All reported high level of satisfaction with and understanding of the CFP sessions. Conclusions: Findings suggest that CFP procedures have some benefits for parents of youth with DD in regard to their general health and parenting efficacy. Additional research is needed with a larger sample to further evaluate the CFP’s benefits.

A Korean middle school special education teacher’s practical knowledge on the career and vocational class that uses role-playing

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Aim: This study examine a Korean middle school special education teacher’s use of role-play in career and vocational instruction. Method: A middle school special education teacher, five experienced peer teachers who observed each instruction, and three students with intellectual disabilities (ID) participated in this action research. Qualitative data obtained from teachers’ discussions and reflections were analysed using an inductive method. Results: Four upper categories were identified: the foundation to facilitate an interesting role-playing, the student-directed learning, maximising students’ learning experiences from the role-playing, and the career and vocational class that focusses students’ independent living. Conclusions: Teachers are encouraged to use a celebrity as a character to initiate the role-play to increase students’ motivation. Role-playing classes should be changed from teacher-oriented activities to learner-focussed activities. Teachers should provide students with multiple opportunities to self-manage their behaviours or learning after each class. The career and vocational class needs to keep focussing on daily living skills and adaptive skills for students’ independent vocational life.

A survey of students with special needs in junior high school martial arts class in Japan

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Aim: Since 2012, martial arts (Budo: Judo, Kendo and Sumo) has been a required subject in junior high school physical education in Japan. The purpose of this study is to clarify the actual situation of the students with special needs in martial arts classes. Method: A survey was carried out in 161 public junior high schools in the X Prefecture of Japan. 151 teachers who taught martial arts in regular classes across 103 public junior high schools participated (response rate: 67%). Results: 42.4% of teachers indicated they included the students from special classes for IDD in their martial arts classes. 48.3% of teachers noted that some of the students they taught from regular classes also showed difficulties in learning (ASD, ADHS, etc.). The main difficulties for students with special needs in martial arts classes were related to understanding of instructions, tying their Budo costume, and distinguishing right and left movements. Conclusions: Martial arts classes include students with diverse special needs. More research is needed to understand how best to accommodate them.

The choice of ethical approaches to care issues for people with disabilities in Taiwan: Policy choices and their consequences

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Aim: This presentation concentrates on understanding the impact of different ethic principles on the formulation of care programme for people with disabilities in Taiwan. Method: The author collected qualitative and quantitative secondary documents related to Taiwan’s care policy for people with disabilities. A policy analysis was conducted using an ethics framework. Results: The preliminary finding is expected to clarify and to anchor state responsibility as either direct (intervention by state to provide welfare service) or indirect (state influence through market regulation to create incentive for private sector to provide service). Conclusions: The author will further examine the results of this finding with an individualistic discourse under Rawlsian tradition, and with caring ethics under relational ontology to gain a broad picture of Taiwan care policy and programme for people with disabilities, especially for people with intellectual and developmental disabilities who are most dependent.

Evaluation of the Metro-Regional Intellectual Disability Network Schoolkit Transition Clinics: Parents and carers’ formative assessment

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Aim: Multidisciplinary school-based transition clinics for students with intellectual and developmental disabilities (IDD) in their final year of school are effective to prepare adolescents and their families for mainstream adult healthcare and post-school options. Method: Special needs schools identify clients for participation in a multidisciplinary clinic with our team, which consist of paediatric and adult medical, allied health professionals and school staff including a transition coordinator. Post-clinic surveys are presented to parents/carers after each appointment examining whether the clinic was useful. We analysed surveys from clinics in the period 1st July 2014 to 30th June 2015 and received a response rate of 48% (11/23) Results: All respondents felt the school transition clinic was useful and the school was the best place to conduct such a clinic. 91% agreed the school clinic was a good way to address concerns and 100% felt it was a unique service. Conclusions: School-based transition clinics are effective in
creating individualised holistic transition plans encompassing medical, personal care, rehabilitation and social and family support that is valuable to the parents/carers of our clients with IDD.

A retrospective analysis of met and unmet needs for adolescents with intellectual and developmental disabilities one year post transition into adult services

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Aim: To identify unmet needs and service gaps arising post-transition into adult system for adolescents with intellectual and developmental disabilities (IDD). Method: We examined met and unmet health/social care needs of adolescents with IDD from our 2014 transition clinic post-transition into adult system using the Needs and Provision Complexity Scale (NPCS). Domains in healthcare, personal care, rehabilitation, social and family support and environment were scored as ‘NPCSNeeds’ based on 2014 clinic records. The extent to which needs were met through service provision and informal care ‘NPCSGets’ was assessed at follow-up. Item difference between NPCSGets and NPCSNeeds was analysed. Results: Significant gaps arise post transition, especially in domains of vocational/educational support, social work and case management, family/carer support/respite needs. Conclusions: A sustainable integrated service referral system for health and social care needs post transition is essential for continuum of care. Future transition clinics will be tailored to better address some of these areas.

Understanding aspiration and associated pneumonia in people with intellectual and developmental disabilities

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Aim: Aspiration and aspiration pneumonia significantly contribute to morbidity, mortality and health service utilisation for people with intellectual and developmental disabilities (IDD). It is estimated that U.S. adults with these disabilities in state disability services have more than 30 times the risk of dying from aspiration pneumonia than the general population. In order to reduce this risk, we sought to better understand contributing factors of aspiration and related pneumonias. Method: A case review tool was developed based upon existing literature and clinical expertise. Retrospective reviews (>300) of deaths and hospitalisations related to aspiration pneumonia in multiple large cohorts of people with IDD (>10,000 people) were conducted. Results: Results indicate a range of contributing factors including co-morbid conditions, medication use, behavioural aspects and connections with sedation and oral health. Underlying risk tends to fall within physical disabilities, behavioural risks, and/or therapeutic-related risks. Conclusions: Findings have important implications for prevention and indicate the need to assess multiple areas of potential risk factors in order to target appropriate preventive efforts and interventions. Translation to preventive strategies will be discussed.

Korean teachers’ experiences on follow-up activities for students with developmental disabilities employed after a post-secondary education program
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Aim: The purpose of this study is to examine special education teachers’ experiences when following-up students with developmental disabilities (DD) who were employed after completing a post-secondary education programme in specialised schools (PEPSS: JeonGongGwa in Korean). Method: Participants included eight special school teachers who were responsible for PEPSS. The data, collected from in-depth interviews, were analysed by the comprehensive analysis procedures based on a pragmatic eclecticism. Results: Three upper categories emerged: becoming an expert in providing follow-up services and managing students, putting the puzzle pieces together (a student, parents, business, and peer teachers), and a rough sketch for successful job maintenance. Conclusions: The difficulties in managing follow-up job services included the unfamiliar tasks that are different from delivering instructions, heavy responsibilities, overburdened duties, etc. Teachers emphasised a need for strong partnerships among parents, business partners, and peer teachers to meet each student’s needs. Factors that lead to the successful job maintenance are associated with a proper job placement, students’ social skills and positive attitudes, systematic information management, and support from professional organisations.

Disability support workers’ perception of music therapy

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Aim: Despite the decent history since 1960s, music therapy is still not acknowledged as an effective therapeutic intervention for adults with disabilities. This paper aims to provide a rationale why music therapy is a reasonable and necessary therapeutic intervention by presenting the evaluation results of music therapy clinical work at an adult day-care centre in Australia. Method: 15 disability support workers who observed clients’ participation in music therapy were asked to complete a questionnaire designed for the evaluation, and 5 were interviewed about their perception of music therapy. Descriptive statistics were used to analyse the survey questionnaire, and the interviews with staff were thematically analysed adopting Braun and Clarke’s (2006) analysis method. Results: Most staff perceived music therapy as beneficial to adults who have disabilities. They reported that music therapy provides opportunities for the clients to express choices of songs and instruments; facilitates positive interactions with peers and staff; and empowers them through community performances. Conclusions: Music therapy work is not entertainment but a therapeutic intervention that promotes the psychosocial well-being and community participation of adults with disabilities.

Effects of a collaboration-based instruction model for self-determination of students with intellectual and developmental disabilities in secondary inclusive education settings

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Aim: This study investigated the effects of a collaboration-based instruction model for self-determination (CIMSD) on enhancing capacity of students with intellectual and developmental disabilities (IDD) and teachers in secondary inclusive education settings. It also examined teachers and
parents’ perceptions of collaboration. **Method:** 27 special education teachers, 30 students with disabilities (15 in the experimental and control groups, respectively), 30 parents of the students, and 29 general education teachers participated in this study. Training and instructional supports were provided for the teachers in the experimental group. Pre- and post-tests were conducted for both groups and analysed. **Results:** CIMSD had a positive influence on promoting self-determination, academic engagement behaviours, and goal-attainment of students with disabilities. It also improved efficacy of special education teachers and attitudes of general education teachers toward inclusive education. There were also positive changes in perception of special and general education teachers, and parents on collaboration with one another. **Conclusions:** This study provides researchers and practitioners with implications and practical tips for promoting self-determination of students with disabilities and collaborative relationships in inclusive education settings.

### An inquiry into impacts of policies promoting inclusive education in Korea

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**Aim:** This study assesses the state of inclusive education in Korea in terms of policies, resources, and practices, explores outcomes and benefits of policies promoting inclusive education, and provides recommendations to strengthen the capacity of the government and other partners in the country to bring about policy reforms and promote programmes that support inclusive education for students with disabilities. **Method:** To investigate participants’ experiences and perceptions about inclusive education, focus group interviews were conducted with four groups, including general education teachers and special education teachers who were supporting students with disabilities in general education schools, parents of students with disabilities attending general education school, and school supervisors. The interviews were transcribed verbatim and analysed using a constant comparative method. **Results:** Five main themes emerged from the data including outcomes and critical success factors of inclusive education, barriers to inclusive education, impacts of and limitations for inclusion policies, and improvement to the policy for inclusive education. **Conclusions:** Based on the results, implications for further studies and practices were discussed.

### Finding their places: Employment and young adults with autism spectrum disorder

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**Aim:** Social interaction and communication are crucial parts of life and support participation in learning, working and living with others. The lack of those skills can have negative effects on obtaining and maintaining a job. Research overwhelmingly demonstrates disappointing employment outcomes for people with autism spectrum disorder (ASD). However, the body of research on best practices for supporting this group based on understanding major challenges they are facing is weak. This study investigates major challenges people with ASD are facing in employment contexts, and identifies strategies for success. **Method:** Semi-structured interviews were conducted with five employees with ASD who assist in office work and their co-workers without disabilities on their experiences and perceptions. The interviews were transcribed verbatim and analysed using content analysis. **Results:**
Three main themes were derived from the data: benefits of employment, major challenges in work life, and ways to find good places. **Conclusions:** Based on the results, implications for further studies and practice regarding supporting adults with ASD at work were discussed.

**Supported decision-making and community living in China: Applying article 12 and article 19 in the lives of persons with intellectual disabilities**

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**Aim:** There is a need to explore how articles 12 and 19 of the United Nations Convention on the Rights of Persons with Disabilities are implemented in practical ways in China. **Method:** Mixed methods will be used. Literature reviews and legal text analysis will be conducted put ahead before examining Chinese legal and policy contexts. **Results:** A number of legal and policy recommendations will be provided. **Conclusions:** Article 12 cannot independently play its role without being combined with other rights, especially article 19 which directs the kind of lives persons with intellectual disabilities should have in the community. Limitations of article 12 and 19 will be pointed out and recommendations provided.

**A self-regulation and impulse control intervention for adults with intellectual disabilities and autism spectrum disorder: A pilot study**

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**Aim:** Cognitive functioning in areas of behavioural self-regulation and impulse control may be related to challenging behaviour in individuals with intellectual disabilities and autism spectrum disorder. Hence, waiting was used as an indicator of self-regulation and impulse control to measure the relationship between waiting and challenging behaviour. The first aim was to teach waiting in an individual setting. The second aim was to teach impulse control within a group setting. **Method:** Four male adults with mild to moderate ID and ASD participated in individual and group Intervention, which included practice waiting through the use of discrete incremental trials. DAS-B scale was used as a pre-post measure. **Results:** All patients achieved significant improvement in waiting and behaviour in the individual intervention but changes were noted in behaviour within group intervention. The possible influence of individual variables and contextual variables are discussed. **Conclusions:** Individual Intervention in a structured setting helped develop self-regulation and impulse control skills. A group setting provides opportunities for learning pro-social skills. Further research could consider incorporating pre-and post-measure of social skills.

**Exploring the role and experiences of young adults with intellectual disabilities participating in a reference committee**

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**Aim:** The research team used a participatory research approach to explore the experiences and roles of two young adults who participated in a research reference committee. **Method:** Two young adults with intellectual disabilities were members of a reference committee for a large research project over a three-year period. Using some question prompts, the young people reflected on their experiences with other members of the research team. They shared their understandings and experiences of the roles, responsibilities and their contributions to the reference group. Together, they prepared a poster to share their experiences and how they were supported. **Results:** These young adults felt validated as contributors to the project. They reported that they had developed their understandings of research and had more confidence in their roles. All members of the research team agreed that the strategies used to support the young people were useful. **Conclusions:** The young adults effectively contributed to the reference group, helping the university researchers to understand their perspectives and develop research instruments, demonstrating how young people can be research consultants if appropriately supported.

The use of the Child and Adolescent Needs and Strengths – Autism Spectrum Profile (CANS-ASP) to measure change in publicly-funded applied behaviour analysis-based services and supports for children and youth with autism spectrum disorder

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**Aim:** Durham Applied Behaviour Analysis (ABA)-Based Services and Supports for Children and Youth with Autism Spectrum Disorder (ASD) provides publicly-funded applied behaviour analysis (ABA) services to children and youth with ASD. Services are provided in 1 of 4 areas of concern: social skills, communication, daily living and behaviour management. The objective was to investigate whether the Child and Adolescent Needs and Strengths – Autism Spectrum Profile (CANS-ASP) is able to detect changes in actionable items following ABA service. **Method:** The CANS-ASP was implemented before and after the short-term intensive service. 832 CANS-ASP assessments have been completed with 270 pre-post assessments providing outcome data. **Results:** A diverse profile of needs was measured by the CANS-ASP, and actionable scores decreased in all areas of service delivery as measured by the CANS indicating a positive effect of the service. **Conclusions:** Preliminary evidence indicates that the children and youth with ASD have diverse needs and strengths when they enter service and this varies by age. In terms of outcome data, within each area of concern (social, communication, daily living, behaviour), children and youth are demonstrating improvements.

Determining equality for youth with disabilities in accessing livelihood opportunities

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**Aim:** Community-based rehabilitation advocates for equal opportunities for persons with disabilities in all aspects of life. This paper presents a participatory research process engaging community rehabilitation and development workers in determining inequalities faced by youth with disabilities (including intellectual disabilities and mental health conditions) and factors that would enable sustainable livelihoods. **Method:** A sequential transformative approach was used to design a
questionnaire to survey youth with and without disabilities across South Africa. The sample comprised 523 (52.9%) youth with disabilities and 466 (47.1%) youth without disabilities (18 to 35 years old).

**Results:** Barriers to education for youth with disabilities were limited financial resources, social exclusion and exclusion by design. The main barriers to employment were poor health, lack of skills and job opportunities and poor social attitudes. Knowledge of available services at the community level was also poor. **Conclusions:** There is a need for more active community services and programmes from the health, education and social sectors of local government, including efficient dissemination of information. Disability integration in curricula across different disciplines at higher education institutions would ensure future graduates are well versed in providing disability-inclusive policies and programmes across all sectors.

**Attachment style in adults with autism spectrum disorder: A case-control study**

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**Aim:** Attachment style, which is expected to be established during childhood, is important in social interaction, emotional regulation and well-being in adulthood. Although assumed to be equally important for people with autism spectrum disorder (ASD), the research on attachment styles in adults with ASD is scarce. **Method:** A sample of 130 people with ASD and 219 without ASD completed Feeney's Attachment Styles Questionnaire and Baron-Cohen's Autism Spectrum Quotient. **Results:** People with ASD had higher scores of avoidance (‘discomfort with closeness’ and ‘relationships as secondary’) and anxiety (‘need for approval’ and ‘preoccupation with relationships’) and lower scores for secure attachment than those without ASD. Degree of autism correlated negatively with secure attachment and positively with insecure attachment factors, irrespectively presence of ASD diagnosis. **Conclusions:** This study shows that people with ASD have lower levels of secure attachment than people without ASD and that degree of autism is related to attachment style also in people without ASD. The question whether insecure attachment (e.g., relationships as secondary) is linked to the attachment process or the symptomatology of ASD will be discussed.

**Susceptibility to emotional contagion in people with autism spectrum disorder**

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**Aim:** Susceptibility to emotional contagion (SEC) is assumed to direct functional behaviours that regulate social interactions. Since deficits in social communication and interaction are central defining features of autism, the present study investigates if and to what extent SEC differs in people with and without autism spectrum disorder (ASD). **Method:** A sample of 130 adults with ASD and 219 without ASD completed Doherty’s Emotional Contagion Scale and Baron-Cohen’s Autism Spectrum Quotient (AQ). **Results:** The ASD-group had lower SEC than the non-ASD group in all five emotions of Doherty’s scale. Social skills was related to higher SEC to positive emotions in both groups, but only to negative emotions among those without ASD. Imagination was unrelated to SEC in ASD but to all emotions in the non-ASD group. **Conclusions:** People with ASD had generally lower SEC, which was mainly related to lack of social
skills and imagination, supporting the hypothesis that deficiencies in social ability and theory of mind are related to social emotional regulation in adults with ASD.
Influence of staff responsivity on key word signing usage in adults with intellectual disabilities

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Aim: Communication partners’ augmentative and alternative communication (AAC) usage can influence AAC usage in individuals with intellectual disabilities (ID). Because researchers have primarily focused on frequency of AAC usage, we examined the influence of responsive key word signing (KWS). Method: 15 adults with a moderate and severe ID (clients) were filmed during a dyadic conversation with two familiar support staff. Clients were divided into two groups: needing KWS encouragement, and spontaneously using KWS. With optimal scaling regression, we examined the relation between these clients’ production of novel signed utterances, and staff KWS usage and imitation. Further analyses account for conversation style and include responsivity rating scales. Results: Preliminary results indicate that spontaneous users produced more novel signed utterances as staff imitated more manual signs than did those needing encouragement. Signed utterance frequency in staff did not influence clients’ KWS usage. Conclusions: KWS imitation has added value over increased KWS exposure as it reinforces clients’ KWS usage. This type of KWS encouragement has an immediate effect on clients who spontaneously use KWS.

Adolescents’ perceptions of their peers with Tourette’s syndrome: An exploratory study

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Aim: The aim of the study was to understand how Tourette’s syndrome (TS) is conceptualised by adolescents and explore how individuals with TS are perceived by their typically developing peers. Method: Free text writing and focus groups were used to elicit the views of 22 year ten students from a secondary school in South East England. Grounded theory was used to develop an analytical framework concerning how school children conceptualise TS. Results: Misconceptions and a lack of familiarity contributed to the participants experiencing conflicting emotions towards peers with TS. An anticipated sense of discomfort was accompanied by feelings of both pity and sympathy towards individuals who they viewed as transcending the boundaries of normalcy. The participants maintained that they would avoid initiating meaningful social relationships while holding feelings of social politeness or even protection towards those with TS. Conclusions: The findings highlight the need and provide directions for developing tailor-made school-based educational interventions about TS targeting typically developing adolescents in order to promote social inclusion.

Keep Safe: Group intervention for young people with intellectual and developmental disabilities and harmful sexual behaviour

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Aim: Between 25% and 35% of all sexually abusive acts are perpetrated by individuals under 18, and it is thought that about a quarter of these perpetrators have intellectual and developmental disabilities (IDD). However, few interventions exist for adolescents with IDD and harmful sexual behaviours. We
have developed an adapted intervention model for adolescents with IDD based on a successful group cognitive behaviour therapy (CBT) model used for adults with harmful sexual behaviours, called SOTSEC-ID (Sex Offender Treatment Services Collaborative-Intellectual Disability). **Method:** This feasibility study developed and delivered this modified group CBT (called Keep Safe) for adolescents with IDD and their parents/carers. The treatment settings included community and residential care services in England. Participants were male, 12 to 17 year olds, with an IQ <70. **Results:** Three sites were set up. Group attendance at community run services has been excellent. Feedback from the facilitator team has been positive. **Conclusions:** A pilot RCT is planned to further test the model.

**The relationship between predicted disability support costs and the assessment methodology used: A comparison of three tools for people with intellectual disabilities**

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**Aim:** The introduction of the National Disability Insurance Scheme (NDIS) in Australia will merge current approaches to funding allocation into a more consistent and equitable method based on individual support needs. This project sought to determine a practical and validated methodology for assessing support needs in people with intellectual disabilities (ID) by examining which measures best fulfil NDIS requirements, how each measure predicts support need, and which are most user-friendly. **Method:** 30 individuals (22 males, 8 females) in Queensland, Australia completed three existing measures of support need, including the Inventory for Client and Agency Planning (ICAP), the Supports Intensity Scale (SIS) and the Instrument for the Classification and Assessment of Support Needs (ICAN). **Results:** Data will summarise the findings, including an analysis of how each measure shows different predictions for primary support needs, and how these differences may affect the nature and degree of funding allocated under the forthcoming NDIS. **Conclusions:** A parsimonious assessment process for people with ID requiring funding under the NDIS will be presented.

**Removing sheltered workshops in Ireland: Next steps for Irish ratification of the UNCRPD**

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**Aim:** This research addresses the current framework of sheltered workshops in Ireland and how the pending ratification of the CRPD will affect employment/rehabilitation policy. It aims prompt new thinking on expectations of ability and disability. **Method:** Explored through the lens of a human rights approach, current employment policy is discussed in light of the UNCRPD. This research assesses the developments in Irish disability policy over the last 30 years and considers the elaboration of the current national Comprehensive Employment Strategy, using critical documentary analysis of secondary resources. The discussion then follows on to deliberate future policy directions inspired by the ideology of the CRPD interweaving this discussion with Wolfensberger’s normalisation theory, along with writers that challenge common perceptions of ability, productivity and human potential. **Results:** The CRPD heralds a paradigm shift and reform of disability services. Its proper implementation requires new philosophical and ethical stances. **Conclusions:** The UNCRPD will have an impact on Ireland’s current
national employment strategy. This will include a higher moral obligation towards people with intellectual and developmental disabilities, valuing their contributions and highlighting potential.

Health and healthcare utilisation of the older population of Ireland: Comparing the population with intellectual disabilities and the general population

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Aim: To compare health and healthcare utilisation of general aging population in Ireland with people aging with intellectual disabilities (ID). Method: Data were drawn from the Irish Longitudinal Study on Ageing (TILDA) and the Intellectual Disability Supplement (IDS)-TILDA. The TILDA sample includes 8,178 individuals aged ≥50 years. The IDS-TILDA sample includes 753 persons with ID aged ≥40. Using age ≥50, 478 persons with ID were matched with TILDA participants on age, gender and geographic location. Both studies gathered self-reported data on physical/mental health, functional limitations and healthcare utilisation. Results: Rates of chronic disease appeared higher for people with ID compared to general population. There were also age-related differences in diabetes and cancer and different rates of engagement between the two groups in activities such as smoking. There was higher utilisation among IDS-TILDA participants for allied health and general practitioner visits. Conclusions: The longitudinal gathering and consideration of the same types of data for people with ID and for the general population offers a better opportunity that the exceptionalism of people with ID will be included in data that informs health planning.

What is community?: A theoretical model of community for people with intellectual disabilities

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Aim: To propose a model of community for people with intellectual disabilities (ID) based on a critical review of the general sociological literature. Method: Keyword searches on Sociological Abstracts from 2000-2013 included community, social inclusion, social cohesion and social capital. Results were filtered and relevant abstracts reviewed; identifying 32 sources for review. Additional emergent texts were included in the review. Results: The review revealed that the concept of community has been a contested concept in sociology. Arguments have centred on spatial, relational, symbolic and recent postmodern understandings of community. However, common elements emerging from these different understandings of community support that interdependent relationships lead to bonding between people and this cultivates the sense of belonging associated with community. Conclusions: Understandings of community based on a dichotomy of institutional and community-based locations potentially overlooks some of the important processes that inform a better experience of community for people with ID.

Quality improvement in the clinical genetic evaluation of patients referred for global developmental delays/intellectual disabilities or autism
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**Aim:** To improve the medical genetic evaluation process for patients referred for global developmental delays and intellectual disabilities (GDD/ID) or autism, by optimising the diagnostic process and improving rate of genetic diagnosis, thus leading to opportunity for improved health outcomes.  
**Method:** Five clinical genetics centres participated in a Learning Collaborative (Institute for Healthcare Improvement), from 1999 to present. This quality improvement (QI) effort was applied to 1,966 consecutive patients. The primary outcome measure is the number with a genetic diagnosis.  
**Results:** 1,329 patients were referred for GDD/ID and 637 for autism. Patients ranged in age from <1 year to 61 years; median age was 8 years. Males comprised 73% of patients referred with autism and 55% with GDD/ID. Diagnoses were established in 50 (8%, range 4-17%) patients with autism and 247 (18%, range 8-29%) patients with GDD/ID. The average number of laboratory, metabolic, and imaging tests per genetic diagnosis was 5.2 (range 0.8 to 11.9).  
**Conclusions:** These data serve to inform practice differences by centre in New England and to generate practice improvement opportunities.  

**Current methods of assessing adaptive behaviour related to motor skills, and exploring their relationship: A review**  
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**Aim:** To outline current methods used to measure motor skill-related adaptive behaviour, and provide an outline of current literature about their relationship. This can inform guidelines for future research in Paralympic classification, as well as support for the implementation of movement pedagogical programmes (i.e. coaching, clinicians) for individuals with intellectual disabilities.  
**Method:** A narrative review approach was used, with a literature search for original articles conducted on databases Medline (1950-2015), Cinahl (1981-2015) and Web of Science (1955-2015) using search terms adaptive behaviour and scale or motor or physical or exercise or movement.  
**Results:** Currently, one assessment tool is used to assess motor skill-related adaptive behaviour, the Vineland Adaptive Behaviour Scales - Motor Skills Domain, which assesses gross and fine motor performance. There are conflicting findings regarding the relationship between motor proficiency and adaptive behaviour.  
**Conclusions:** There is a substantial lack of empirical evidence pertaining to the topic of adaptive behaviour related to motor skills. Further fundamental research is required to understand the link between adaptive behaviour and motor proficiency.  

**Addressing barriers to healthcare for people with intellectual disabilities**  
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**Aim:** Adults with intellectual disabilities (ID) sometimes struggle to have their health needs addressed by mainstream healthcare services. This contributes to the health inequities they experience. This paper aims to identify barriers to use of primary healthcare services and patterns of health service use by this population.  
**Method:** This research project involved a retrospective file review (n=100) of people who
attended a tertiary specialist disability clinical service, and data linkage with local acute health services to identify patterns of health usage. **Results:** Preliminary results demonstrate that most of those reviewed are frequent users of healthcare services, with frequent episodes of care and increased length of stay when admitted to hospital. Many admissions appeared to be preventable. Barriers to healthcare included factors related to the service system, the support network, the healthcare professionals and the consumer. **Conclusions:** Better understanding of barriers to care and patterns of service use by people with ID informs design of services. Targeted interventions are required to support access and use of primary healthcare services by people with ID.

**Evidence and effectiveness of online learning about health for disability support workers**

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**Aim:** Disability support workers (DSW) have little health training, affecting their ability to support access to healthcare for people with disabilities. Online learning provides opportunities for knowledge and skill development convenient to the user and is likely to be useful in training for support workers. This paper summarises the evidence of effectiveness of online learning. **Method:** A systematic literature review was undertaken and two online educational resources about health were developed and evaluated for their utility and effectiveness. Focus groups and interviews were held with staff to identify their comfort, evaluate their learning as well as to identify the factors that made the learning effective. **Results:** Despite initial reluctance, DSW engaged with and enjoyed interactive online learning environments. Accessibility and multimodal delivery were factors that enhanced their learning. Featuring actors with disabilities and DSW in the online content helped make the experience ‘real’. Persistent barriers included lack of access to appropriate technology. **Conclusions:** Online learning principles show promise as a way of enabling access to education on supporting health for people with developmental disabilities for disability support workers.

**Community registered nurses supporting individuals who exhibit challenging behaviours in Wales and Ontario**

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**Aim:** Some community-based individuals with intellectual disabilities (ID) may present with behaviours that challenge and community registered nurses may be involved in their support. This study explores how community-based registered nurses support individuals with ID who exhibit challenging behaviours in Wales and Ontario, Canada. **Method:** Semi-structured interviews were undertaken with 16 participants in Wales and 9 participants in Ontario and these were transcribed and analysed using Charmaz’s approach to grounded theory. **Results:** Two theoretical categories emerged from the analysis: context of role, and nursing practice. The core category was building support for individual, carers and nursing colleagues. **Conclusions:** There are differences between the two settings; such as the Welsh participants having speciality nursing education in learning disabilities, legislation and the recent report ‘Strengthening the Commitment’ whilst Ontario nurses are generalists. The similarities in the role included the definition of challenging behaviours, assessment and implementation of interventions and
working collaboratively in an inter-professional team. No international comparative study has been done looking at the role of the community registered nurse supporting individuals with challenging behaviours.

**Characteristics of students who access transition services**

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**Aim:** Although transition services produce better post-school outcomes for young adults with intellectual and developmental disabilities, we do not know the characteristics of students who receive such services. **Method:** From a U.S. web-based parent survey, we examined students aged 16 to 18 years (n=189). Respondents were mostly White, well-educated, and married mothers. Offspring were mostly males with intellectual disabilities, autism spectrum disorder, or learning disabilities. **Results:** 54% of students received transition services. Only 30% of students in the highest quartile of daily living skills received services, compared to 59% of students with lower daily-living skills, X^2=9.01, p=.003. Students not receiving transition services also had less severe behaviour problems, X^2=6.81, p=.009. A logistic regression revealed that students with (vs. without) problem behaviours were twice as likely, and students with high daily-living skills were 1/3 as likely, to receive transition services. **Conclusions:** All students with disabilities should receive transition services, but only half do. Students who are higher-functioning and with fewer behaviour problems may still benefit from support to improve their post-school outcomes. Results have implications for improving policies and for providing transition services.

**A descriptive study on the work experiences of behaviour support providers**

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**Aim:** As new Board Certified Behavior Analysts (BCBA) enter the field of behaviour analysis, it is crucial to determine where, how, and what populations they are serving. **Method:** We conducted an online survey to determine the potential gaps in behaviour support services. The online survey link was disseminated through behaviour service organisations/associations. **Results:** The 94 participants in the survey were primarily white females with an average age of 36.74 years, who worked for an average of 4.32 years as BCBA in non-rural settings. While most BCBA worked primarily in the top most populated counties, they reported traveling to provide services (76.1%), with a minimum distance of 12.83 miles and maximum of 61.90 miles. On a scale from 1 (never) to 5 (always), participants reported mostly working with younger children with autism, intellectual disability, and developmental delay. **Conclusions:** The results of this descriptive study show that there are different areas, both in population and location, where BCBA can expand in regards to service provision. Service provision gaps still remain in regards to older adults, disabilities beyond intellectual and developmental disabilities, and rural areas.

**A wordless intervention for people with epilepsy and intellectual disabilities: A randomised controlled feasibility trial**
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Aim: This feasibility randomised controlled trial (RCT) explored the acceptability of a definitive trial using a picture booklet to improve quality of life and self-management for people with epilepsy and intellectual disabilities (ID). Method: Patients with epilepsy and ID from one UK site were randomised to receive the picture booklet or usual care. The booklet depicts diagnosis, treatment and management of epilepsy in story-form; participants used this with a researcher and were encouraged to relate the story to their experiences. Data on recruitment and discontinuation rates, demographics, quality of life, seizure severity and control, resource use and booklet use were collected at baseline and 4, 12 and 20 week follow-ups. Results: The target of 40 participants was reached. The 19 control group participants had a mean age of 44.7 years and the 21 intervention group participants had a mean age of 39.0 years. The booklet was received positively and there was an indication of a benefit on epilepsy-related quality of life. Conclusions: The findings confirm the feasibility of a definitive trial which will evaluate the clinical and cost-effectiveness of the intervention.

What are the challenges and facilitators to conducting research with people with intellectual disabilities?: The perspectives of care staff
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Aim: People with intellectual disabilities (ID) are under-represented in health research. Care staff may act as gatekeepers, potentially limiting participation in research that may be beneficial to the potential participants and others. This study explores care staff’s attitudes towards research with people with ID, including perceived barriers and solutions. Method: Focus groups and interviews with eight care staff were transcribed verbatim and analysed using thematic analysis. Results: Care staff felt that research should be inclusive of people with ID. Barriers were identified, mainly to recruitment. Care staff felt organisational policies could prevent them from supporting someone to participate in research. The decision-making process for someone without capacity to consent was viewed as lengthy, complex, and possibly not worth embarking upon. Effective communication and trust-building between the researcher and participant before and during the study were deemed essential. Conclusions: This in-depth understanding of potential challenges perceived by care staff is key to informing the dialogue between research and practice. Researchers need to be aware of existing, or potential, barriers to recruitment in order to design effective recruitment strategies.

Supporting social network development of adults with intellectual or developmental disabilities by support workers from ambulatory services: An inventory of methods, strategies, attitudes and perceptions
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Aim: The purpose of this research project was twofold: to create an inventory of the currently used methods and strategies on social network development in the Flemish ambulatory services for adults
with intellectual and developmental disabilities (IDD), and to investigate the attitudes and perceptions of support workers about bottlenecks and the added value of social network development for adults with IDD, professionals and society. **Method:** A questionnaire in two parts was constructed based on a literature review: a fill-in table with methods and strategies and 10 open ended-questions towards attitudes and perceptions. The questionnaire was reviewed by a steering group. We received questionnaires from 21 ambulatory services. **Results:** Ambulatory services use a wide variety of methods and strategies. These vary not only over services but also over professionals within services. Bottlenecks and the added value of building social networks for adults with IDD, professionals and society are identified. **Conclusions:** Asking services who provide ambulatory support to complete a questionnaire about (strategies for) social network development, enhances discussion of the importance of social network development on quality of life.

**Identification of the autistic spectrum using International Classification of Functioning, Disability and Health - Children & Youth Version (ICF-CY)**

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**Aim:** The ICF-CY developed by WHO offers a method for recording problems manifested in infancy, childhood and adolescence. This study examines how characteristics of autism spectrum disorder (ASD) are identified using the ICF-CY classification. **Method:** The record (38,144 character in Japanese) of an interview with the mother of a 14 year-old boy with ASD was coded using the ICF-CY. For example, ‘He has issues with group behaviour’ was coded as d720 [Complex interpersonal interactions] on the ICF-CY. The frequency of ICF-CY classification codes was expressed by a histogram. **Results:** 961 characteristics were coded into 88 features on ICF-CY. The most common ICF-CY features found in the child with ASD were b156[Perceptual functions] (n=94), e410[Individual attitudes of immediate family members][n=56], b270[sensory functions related to temperature and other stimuli] n=54), b230[Hearing functions] (n=40), b152[Emotional functions] (n=37), d240[Handling responsibilities] (n=37), and e250[Sound] (n=37). **Conclusions:** The range of strengths and support needs of children with ASD can be shown through a histogram using ICF-CY.

**The differential impact of oxytocin receptor genotypes on the risk of autism spectrum disorder and resulting social communication deficits**

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**Aim:** To evaluate the effect of oxytocin receptor (OXTR) single nucleotide polymorphisms on resulting social communication deficits in individuals with a diagnosed autism spectrum disorder (ASD). **Method:** Individuals with ASD who have provided genetic samples to the Autism Spectrum Disorder – Canadian-American Research Consortium (ASD-CARC) research registry were genotyped. Non-verbal subjects were excluded from analysis. The Autism Diagnostic Interview-Revised (ADI-R) was used to classify social communication deficits. The average age at ADI-R administration was 11.6 ± 1.5 (9-19) years old. Simple linear regression was used to determine the effect of OXTR genotypes. **Results:** Results from 193
Caucasians (83% males) indicate that the rs2254298 SNP genotype frequency was 73% GG, 22% GA, and 5% AA. The mean social communication score was 17 ± 4 (3-26) on the ADI-R. After controlling for gender, the GA genotype is significantly associated with higher social communication scores when compared to the GG genotype (Parameter estimate = 1.408, SE = 0.698, p = 0.0448). Conclusions: Ongoing analyses examining the effect of genotypes from three other SNPs (rs2254298, rs1042778 and rs53576), as well as the current SNP with a larger sample, will be presented and discussed.

Reviewing the eligibility criteria of the services for persons with disabilities in Japan using the ICF as a framework

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Aim: In Japan, the opportunity for participation of persons with disabilities is extremely restrictive due to insufficient services. This study examines conceptual issues related to the eligibility criteria for services in Japan using the International Classification of Functioning, Disability and Health (ICF) as a framework. Method: The 80-item eligibility criteria (12 on motor and mobility, 16 on self-care, 6 on sensory functions , 34 on problem behaviour, and 12 on special medical care) were classified in components of ICF (Body Functions and Structures, Activity, Participation, Environmental Factors). Results: Most eligibility criteria items were classified in Body Functions and Structures. Participation included only three items (4%). There were no items coded as Environmental Factors. Conclusions: In older age, the number of individuals with disabilities who need long-term medical care increases in Japan. The service eligibility criteria items should include not only consider the impairments but also the need for participation to improve the quality of life of persons with disabilities.

An infant with sensory processing disorder associated with autism spectrum disorder: The impact on his family members

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Aim: This case study aimed to reveal the difficulties an infant with sensory processing disorder associated with autism spectrum disorder (ASD) confronts and the harsh realities his family members get through. Method: We interviewed a mother of a 15 year-old who had been diagnosed with ASD and had her talk about their daily troubles and struggles when the boy was still an infant (0 to 3 years). We then qualitatively analysed the data in accordance with the KJ method. We acknowledge that the potential for recall bias is a limitation. Results: Hypersensitivity in hearing, sight, taste, smell and touch, along with hyposensitivity in vestibular and pain sensation significantly affected the boy. These had a severe psychological impact on the mother who struggled to give her son the care he needed. Conclusions: We need to make our society more aware of sensory processing disorder associated with ASD, establish a system to share comprehensive information regarding the problem, and provide earlier care interventions to alleviate anxiety among family members.
Comparing measures of ability in adolescents with intellectual disabilities

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**Aim:** Finding the most appropriate intelligence test for adolescents with intellectual disabilities (ID) is challenging due to their limited language, attention, perceptual and motor skills and ability to stay on task. **Method:** This study compared performance of 23 adolescents with ID, with 8 having a co-morbid diagnosis of autism spectrum disorder (ASD), on the Wechsler Intelligence Scale for Children-Fourth Edition (WISC-IV) and three nonverbal IQ tests: the Raven’s Progressive Matrices, the Test of Nonverbal Intelligence-Fourth Edition and the Wechsler Nonverbal Test of Ability. **Results:** The WISC-IV Full Scale IQ scores were highly correlated with total scores from the three nonverbal tests. All the participants with ID attempted more questions on the nonverbal tests than the verbal. Adolescents with ID without ASD achieved higher scores overall than those presenting with ID+ASD. **Conclusions:** The results support the view that short nonverbal tests are likely to give a very similar mental age for cognitive behaviour as the WISC-IV and are more appropriate for assessing adolescents with ID.

Risk factors for unemployment among working-age adults with intellectual and developmental disabilities

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**Aim:** This study explores the individual, family and social factors that prevent people with intellectual and developmental disabilities (IDD) from being employed. **Method:** Data from the National Surveillance Sample Survey on the Disabled in China (2014) were used. Self-care being a prerequisite of employment, the number of people with IDD who could live and work independently at working age was 2,709 (2,038 had complete data). Gender, residence, education level, skill training and other factors were used as independent variables to analyse the distribution of those employed/unemployed using correlations and multivariate Logistic regression. **Results:** 70.6% of working-age people with IDD were unemployed. Female, urban Hukou, low education, no professional skill training, never using a cell phone to access the internet, and low acceptance of community service were associated with higher risk of unemployment after controlling for socio-demographic characteristics. **Conclusions:** Intrinsic, extrinsic and environmental factors should be taken into account to reduce unemployment risk among persons with IDD. Policies should focus more on women, those living in an urban Hukou, and those with low education. We argue that expansion of social service for persons with disabilities is necessary.

The views and experiences of women with intellectual disabilities on sexual relationships

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**Aim:** The sexual lives of people with intellectual disabilities (ID) are often overlooked. This research explores the views and experiences of women with ID on sexual relationships. **Method:** Data were gathered through semi-structured interviews with 16 women with ID. Participants are members of a dating agency of adults with ID. The researcher volunteered within the dating agency to build rapport before interviewing. Data were analysed using thematic analysis. **Results:** Initial findings suggest that most women with ID want to be in a sexual relationship. Some women said they want to get married.
and have a baby. Two women said they just want to enjoy a sexual relationship without getting married or having a baby. Most women interviewed viewed not being in a sexual relationship as frustrating and as a lonely experience. Most distinguished having friends from being in a sexual relationship. **Conclusions:** It is evident from the findings that women with ID are women too. They should enjoy the same sexual rights as other women. Policy makers should listen to their voices.

A narrative review on the play experiences of children with cerebral palsy

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**Aim:** Several factors are known to influence the social interactions of children with developmental disabilities, including physical and communication abilities, environmental factors, and access to assistive technology. The objective of this study was to conduct a narrative review of research specifically examining the play experiences of children with cerebral palsy (CP). **Method:** Research sources included qualitative and quantitative research papers, literature reviews, and meta-analyses. Included papers were required to have a focus on children with CP up to 12 years of age, and on child-initiated or unstructured play. Papers examining play used for therapeutic or rehabilitative purposes (e.g. video games for increasing arm reach or balance) were excluded. Included papers were rated by two authors on both content and quality. **Results:** Preliminary findings reveal a range of potential influences on the play of children with CP, including personal, environmental and impairment-related factors. **Conclusions:** Implications for practice will be provided. The review illustrates the need for more targeted research into this area.

An anxiety intervention program for adults on the autism spectrum: A pilot study

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**Aim:** Co-morbid anxiety disorders in autism are well documented. However, limited evidence exists for anxiety programs for adults on the autism spectrum. In the general population, alternatives to cognitive behaviour therapy, including acceptance and commitment Therapy (ACT), have demonstrated positive results in reducing anxiety symptoms. This study investigates the acceptability and appropriateness of a pilot ACT program for adults with autism and anxiety. **Method:** Participants are five adults aged 18 years or older, with confirmed autism and anxiety. Pre and post measures of anxiety and measures specific to ACT (Quality of Life, Acceptance and Action and Valued Living) were collected as well as participant feedback in relation to the acceptability and appropriateness of the program design and content. **Results:** Findings from the pre and post program assessments and the participant feedback will be presented. **Conclusions:** The results from this pilot program will demonstrate the appropriateness of ACT as a therapeutic approach for adults on the autism spectrum with anxiety.

Comparing the prevalence and nature of victimisation of people with intellectual disabilities and in the community
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Aim: There is considerable concern that people with intellectual disabilities (ID) are more likely to have been victims of crime when compared to the general population. To date, this has been challenging to quantify. This study examines the nature and prevalence of victimisation among people with ID, highlighting the contributing roles of ID, mental illness and gender. Method: This data linkage study drew a large sample of people diagnosed with ID (n=2220), and a representative sample from the general community (n=2085). Samples were linked to data from police, mental health and coronial databases. Odds ratios and log-linear analysis were used to examine differences between groups.

Results: People with ID were at increased risk of victimisation from violent and sexual offences when compared to the community sample. Dual disability further increased this risk. Conclusions: People with ID are victim to a range of offence types, but are particularly vulnerable to violent and sexual crime. Co-morbid mental illness increases this vulnerability. These results highlight the importance of mental health services for people with ID, and systems that provide opportunities for victims to report victimisation.

Discrete trial training and promoting generalisation for children with autism

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Aim: Discrete trial training (DTT) is frequently used with children with autism because it is associated with significant developmental gains. Unfortunately, failure to generalise is common when DTT alone is used. This is problematic because generalisation is required for skills to be functional and useful in natural environments. Method: We reviewed the literature on successful generalisation interventions for children with autism ages 2 to 18 years. We included studies that used generalisation strategies to complement DTT, and studies that did not use DTT but implemented techniques to promote generalisation. We analysed these studies by identifying effective generalisation strategies and comparing outcomes. Results: Several generalisation strategies were found to be effective with children with autism, even during initial skill acquisition. We illustrate our findings with examples from the research literature in which the various generalisation strategies have been applied. Conclusions: Findings of this literature review will be summarised as recommended generalisation practices to accompany DTT or to use as an alternative to DTT to ensure that children with autism acquire skills that are immediately useful in natural environments.

‘She was a human being’: People with intellectual disabilities experiencing professional encounters

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Aim: The aim of this study was to find ways to qualify professional encounters between professionals in social work and people with intellectual disabilities (ID). In a world where you see New Public Management, evidence-based methods and financial cuts, it is likely that values such as understanding, communication and recognition are under pressure – especially if the disability is invisible. Method: A phenomenological investigation was conducted based on life world interviews, observations combined
with document analysis and discourse analysis integrating perspectives of persons with invisible ID as well as professionals. **Results:** In general, attitudes to ID are based on ignorance and distance. Structural obstacles are obvious, but the education of professionals regarding their ability to cope with essential values, dilemmas and ethics is also in focus and needs improvement, e.g. in fulfilling the UN Convention on the Rights of Persons with Disabilities. **Conclusions:** Our way of dealing with otherness underlies a pressure in a modern world. Different ethical approaches should be implemented in practice as well as in education (e.g. integrating recognition, communication and ‘representative’ ethics).

**Meeting the age-related health needs of people with intellectual disabilities: The support needs of residential social care staff**

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**Aim:** As the life expectancy of people with intellectual disabilities (ID) increases, they experience age related health problems. Those living in supported community-based settings are often reliant upon residential social care staff to recognise and meet such needs. However, little is known regarding the support needs of such staff when fulfilling this role. This study sought to address this gap in knowledge.

**Method:** Semi-structured interviews were undertaken with 14 house managers working in community-based supported living schemes in Wales to explore their experiences of supporting staff to meet the age-related health needs of their tenants. The interviews were transcribed and thematically analysed.

**Results:** Five major themes emerged: previous training and experience; training about aging and health; meeting health needs; the consequences of aging; and relationships. **Conclusions:** Residential social care staff may receive training to help them respond to the age-related health problems of their tenants. However, a more proactive approach is needed to promote healthy aging and to ensure early intervention when health problems occur.
Characteristics of figure drawing in school-aged children who may have developmental impairments

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Aim: This study evaluates figure drawing of Japanese school-aged children who may have developmental impairments. Method: The Draw-a-Man Test (DAM test) was completed by 46 school children from a western region of Japan, aged 6 to 11 years (grades 1 to 5) who have difficulties in learning and/or behaviour problems at school. Evaluation of figure drawing was done by using a Quantitative Scoring System (DAM-IQ) standardised in Japan by Kobayashi in 1977. Correlational analyses were performed among drawing scores, DAM Items, DAM-IQ, learning problems and behaviour problems. Results: The average DAM-IQ was 81.9. There were statistically significant correlations between behaviour or learning problems and several DAM items. There was statistically significant correlation between restricted, fixated interests and difference between clothing items and facial parts shown in drawings. Conclusions: These results suggest characteristic figure drawing among children who may have difficulties in learning and/or behaviour problems at school especially with restricted, fixed interests.

Development of leisure activities for children with autism spectrum disorder in collaboration with parents

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Aim: This study attempts to understand how to support parents to develop small group leisure activities for their children with autism spectrum disorder. Method: Interviews were conducted with two mothers whose children joined the activities. Questions included what the mothers were thinking of the continuation of the activities. The interview data were decomposed using the KJ method. Results: The following factors were extracted: the presence of experts, establishment of the process for making parents aware of each other’s children, and future prospects of the activities. The mothers regarded those factors as important. Conclusions: The mothers have become confident in developing the activities. Their confidence was considered to result from the three factors, which contributed to the continuation of the activities.

The role of healthcare financing in access to health screening for older people with and without intellectual disabilities

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Aim: To examine the prevalence and role of healthcare financing in supporting health screening among older people with and without intellectual disabilities (ID). Evidence to date suggests access to health screening checks is lower for people aging with ID compared with the general population. Method: A matched dataset (n=956) of the general older population (The Irish longitudinal study on ageing- TILDA) and the older population with ID (Intellectual Disability Supplement to TILDA) was analysed. Binary
logistic regression examined the predictors of health screening checks for both populations. **Results:** Higher prevalence of health screening overall was found among the ID population, with the exception of access to prostate cancer screening which was higher for the general older population. Having private medical insurance resulted in being 2.4 times (CI 1.2-4.2, p=0.003) more likely to have had a blood test for prostate cancer. **Conclusions:** A targeted public health intervention is needed to increase access to prostate checks for men with ID.

**Systematic review of health service use frameworks: A life course approach for people with intellectual disabilities**

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**Aim:** The aim of the review was to identify the use of health service utilisation frameworks in understanding the barriers and unique challenges experienced by people with intellectual disabilities (ID) in realising appropriate and timely access to care. **Method:** A systematic review of Pub-Med, Cinahl Plus, Emerald, PsycINFO, Web of Knowledge and Scopus was conducted. Data extraction used a framework approach with meta-synthesis to map the identified frameworks to dominant health service utilisation model and life course themes. **Results:** 76 papers met the inclusion criteria and were reviewed, with 20 papers specifying the use of a specific framework. 13 frameworks in total were identified with Andersen’s behavioural framework the most prevalent. **Conclusions:** Frameworks are used less often to guide the analysis of health service utilisation among the population of people with ID as compared to the general population. Limitations in their value when they are used suggest framing studies of health service utilisation within a life course approach may provide a more holistic perspective.

**Tracking change in health service use following a change in living arrangement: Examining the continued role of ID service providers in delivering healthcare**

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**Aim:** To examine the health service use and setting for people with intellectual disabilities (ID) who changed residence in Ireland over a 3-year period. **Method:** Data from the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) were analysed. **Results:** 120 people were confirmed as changing living arrangement between wave 1 and wave 2. Community-based movers continued to rely on ID service providers for specialist health services. Of those who moved to a more community-based setting, 100% received social work services and 80% psychology services from an ID service provider. **Conclusions:** The continued reliance on ID service providers for health services following a move to community living, highlights the need for greater efforts to prepare the mainstream health system to meet the needs of people with ID living in the community.

**Prevalence and types of behaviour that challenges in older adults with intellectual disabilities**

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**Aim:** Behaviour that challenges is a barrier to community integration for adults with intellectual disabilities (ID) and poses management problems for families and service providers. The aim was to identify the prevalence and types of behaviour that challenges in older adults with ID in Ireland.

**Method:** Data were generated from Wave 2 of the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA), a nationally representative sample of 713 persons with ID aged ≥40. Information on the presence of four categories of behaviour that challenges was collected in the pre-interview questionnaire completed by the person with ID and/or a proxy. **Results:** 71.4% (n=487) reported getting angry/frustrated when things did not work out; of those (n=485), screaming was most frequently reported (42.8%), followed by hitting out (33.6%), throwing things (24.7%) and self-injury (18.6%). Of those who reported behaviour that challenges, 60.9% reported a diagnosis of a mental health condition. **Conclusions:** Over half of older adults with ID were reported to have shown at least one type of behaviour that challenges which is likely to be detrimental to quality of life.

**Equality of care at end of life: Love, care and solidarity for older adults with intellectual disabilities in Ireland**

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**Aim:** To develop a clearer picture of the scale and breadth of experiences and challenges faced by people with intellectual disabilities (ID) and carers supporting them at end of life. **Method:** A mixed methods approach was employed, with an emphasis on quantitative analysis, incorporating an embedded qualitative data collection element. Experiences regarding the last year of life were captured through face-to-face interviews with 45 close caregivers interviewed using an adapted version of the Views of Informal Caregivers Evaluation of Services (VOICES) questionnaire. Analysis included descriptive statistical and text analysis presented in the context of Lynch et al.’s (2004) social justice framework. **Results:** Interviews were with caregivers of mostly residential setting dwelling adults (80.4%), who were multi-morbid (87%) with primarily moderate, severe or profound ID (89.1%), and supported by paid caregivers at end of life (95%). Qualitative data highlighted the loving and caring relationships characteristic of long-term carers supporting the last months of life but also inequities in care available. **Conclusions:** Loving, caring and solidarity in relationships supporting people with ID on life’s final journey impacts on access to and quality of care provided.

**Life expectancy of people with intellectual disabilities: A systematic review**

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**Aim:** A systematic review was undertaken to identify the strengths and gaps in the evidence on life expectancy of people with intellectual disabilities (ID) compared to the general population. **Method:** Electronic literature searches of five databases were undertaken using search terms relating to ‘intellectual disability’ and ‘mortality.’ The search was completed in September 2015. Titles, abstracts and full papers were assessed using strict inclusion/exclusion criteria. Study information was extracted, tabulated and reviewed using narrative analysis. **Results:** 32 studies were eligible for review. Mortality
rates were higher in females, and individuals with severe and profound ID. The causes of death identified in the studies analysed revealed a different profile to the general population. People with ID were found to be more likely to die from avoidable causes. However, most studies had methodological limitations. **Conclusions:** People with ID appear to have a shorter life expectancy than the general population. Factors such as gender and level of ID were also reported to impact on life expectancy in this population. However robust comparative data is lacking.

**Paving the way for paeds with needs: Attitudes of healthcare staff in the treatment of children and adolescents with intellectual disabilities**

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**Aim:** This study examines whether the provision of healthcare across the Sydney Children’s Hospital Network is influenced by the skills, knowledge and attitudes of paediatric staff when working with children and adolescents with intellectual disabilities (ID). **Method:** An electronic survey adapted from a previous survey done by Troller et al. for mental healthcare staff was sent to all departments within the Sydney Children’s Hospital Network. **Results:** A total of 160 responses representative of various disciplines and seniority within the network were received. Although staff considered themselves broadly competent in caring for children with ID, they were less confident in specific skills, such as managing associated challenging behaviours during their healthcare encounters. As confidence in skills such as these decreased, the desire for further training increased. **Conclusions:** This study emphasises the importance of providing accessible, high quality professional development resources to further develop these skills within the mainstream paediatric healthcare setting with the potential of improving quality of care and patient experience.

**Gait characteristics of adults with intellectual disabilities**

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**Aim:** Gait is a highly relevant and complex aspect of motor functioning, and it a complex cognitive task. Poorer gait is a predictor for future disability, cognitive impairments, institutionalisation and mortality. In this study, gait characteristics of people with intellectual disabilities (ID) were investigated. **Method:** First, a literature review regarding gait characteristics in people with ID was performed. Second, a cross-sectional study was performed to assess gait characteristics in 31 adults with mild to moderate ID without Down syndrome (DS). Gait was measured with the GAITRite, at comfortable speed and fast speed, and during dual tasking. **Results:** The literature review showed that gait abnormalities are evident in the ID population. However, most studies focussed on syndrome specific ID, mainly DS. Data from the cross-sectional study show gait characteristics of adults with ID without DS. Dual tasking was found to influence gait, which implies the influence of attention demanding tasks on gait in this population. **Conclusions:** This study provides an overview of the gait characteristics of people with ID and provides directions for further research on this important aspect of motor function.
Annual health exams for adults with intellectual and developmental disabilities: The perspective of caregivers

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Aim: To explore the utility of an intervention to increase uptake of the Annual Health Exam (AHE) among adults with intellectual and developmental disabilities (IDD). Method: Accessible information packages about the AHE were mailed to 39,868 adults with IDD in Ontario, Canada. They or their caregivers were asked to contact the researchers to provide their views about the AHE and whether they intended to book one. Results: 85 caregivers completed surveys for 127 adults with IDD, and 91% viewed AHEs as important. Two reported that the adults in their care did not have a physician. Among the other 83 caregivers, 53% reported that they made, or planned to make, an appointment for those in their care (n=45 adults with IDD) after receiving the package; 34% had scheduled an appointment prior to receiving the package (n=68 adults with IDD). Conclusions: In this sample, the intervention prompted half the caregivers to make an appointment for an AHE. Given the need to enhance primary care and health equity for adults with IDD, interventions such as this deserve further study.

Booking and attending annual health exams: The perspective of adults with intellectual and developmental disabilities

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Aim: In Canada, an annual health exam (AHE) is recommended for persons with intellectual and developmental disabilities (IDD). The purpose of this study was to gain knowledge about the experiences of adults with IDD when booking and attending AHE. Method: A convenience sample of 13 adults with IDD participated in this study. Participants completed semi-structured in-person interviews regarding their experiences booking and attending the appointment. Interviews were transcribed verbatim and coded line by line using thematic analysis. Matrices were developed to further analyse the data. Results: Various combinations of informational, instrumental and emotional supports were identified by participants. Some supports are provided or expected from informal supports (family members) while others are provided or expected of formal supports (receptionists, nurses, doctors). Conclusions: Individuals with IDD form a heterogeneous population. They have different needs and require varying levels of support. Patient-centred care, in which caregivers and physicians adapt to an individual’s needs and preferences, is crucial to support adults with IDD in accessing the AHE.

Importance of and intention to book the annual health exam: The perspective of adults with intellectual and developmental disabilities

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Aim: To explore the utility of an intervention to increase uptake of the Annual Health Exam (AHE) among adults with intellectual and developmental disabilities (IDD). Method: Accessible information packages
about the AHE were mailed to 39,868 adults with IDD in Ontario, Canada. They or their caregivers were asked to contact the researchers to provide their views about the AHE and whether they intended to book one. **Results:** 85 adults with IDD participated. 88.2% (n=75) thought it was important to attend an AHE. 94% (n=80) of participants had a doctor. 30% (n=24) of these individuals had booked an AHE, 25% (n=20) intended to book one, and 45% (n=36) did not intend to book an appointment. Reasons for not booking included attending an AHE too recently, visiting the doctor frequently, being busy, or physician refusal. **Conclusions:** Information mailed to adults with IDD may increase knowledge and awareness about the AHE. However, promoting this preventive care opportunity to adults with IDD and their primary caregivers remains a challenge.

**Are people with intellectual and developmental disabilities who lack capacity to consent at risk of being excluded from research?: Ethical implications of the UK Mental Capacity Act 2005**

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**Aim:** This study investigates the ways in which people with intellectual and developmental disabilities (IDD) who lack capacity to consent are at risk of being excluded from research. **Method:** A retrospective review and content analysis of research ethics applications concerning people with IDD who lack capacity to consent, over a three-year period was undertaken. In-depth interviews with six researchers regarding their decisions to exclude people with IDD from their samples were also conducted. **Results:** Consideration of the ethical approval process appears to affect sampling decisions. **Conclusions:** Improved knowledge and skills in navigating research ethics and integrity is likely to increase confidence to include participants who lack capacity to consent in research projects.

**Capacity assessment in adults with intellectual disabilities: Education needs analysis to inform professional development**

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**Aim:** Capacity legislation for adults with intellectual disabilities (ID) has been increasingly adopted internationally over the past 15 years to safeguard this vulnerable group. This pilot investigation explores the knowledge, confidence in application with corresponding educational needs, and preferences of non-specialist health carers working within primary care. **Method:** Following a review of the literature, one area of Scotland was chosen, where an online survey of primary care practitioners took place. Training, knowledge, confidence and learning preferences were considered. **Results:** Examples of current knowledge, learning needs and preferences for learning will be presented from a pilot study to inform development of a professional course that traverses the status quo to statutory guidance. **Conclusions:** Despite statutory powers aiming to protect adults with ID existing for the past 15 years in Scotland, educational needs are not being fully addressed by medical education. This creates an opportunity to develop a professional development course to improve the confidence and quality of capacity assessments that are aligned with statutory legislation and guidance.
Comparative outcomes of NDIS planning using a standardised measure of support needs

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Aim: To examine the benefit the I-CAN (Instrument for the Classification and Assessment of Support Needs) provides for people living with disabilities as they transition into the National Disability Insurance Scheme in Canberra, Australia Capital Territory (ACT). Koomarri is currently the only service provider using the I-CAN in the ACT, one of the first Australian States or Territories to implement the National Disability Insurance Scheme (NDIS) for all residents living with disabilities. Method: The outcomes of people who have transitioned to the NDIS with the support of an I-CAN assessment are being compared to a control group. To ascertain if the tool secured greater results in meeting their support requirements and increased funding allocation quantitative and qualitative data are being gathered; including surveys, interviews with NDIS staff, verbal feedback from participants, their families and service providers and comparative data on funding allocations. Results: Initial results suggest better outcomes for people who approach the NDIS planning session with a completed I-CAN assessment. Conclusions: Koomarri is offering I-CAN assessments to all people supported prior to NDIS planning to ensure better outcomes.

‘Take it personal!’: A pilot study of a selective intervention for substance use and co-morbid behavioural problems in adolescents with mild to borderline intellectual disabilities

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Aim: Evidence-based interventions for adolescents with mild to borderline intellectual disabilities (ID) are lacking. Therefore ‘Take it personal!’ was developed and adapted to the needs of these adolescents. The programme consists of four interventions that address four personality profiles: anxiety sensitivity, negative thinking, impulsivity, and sensation seeking. The aim of this pilot study is to test the feasibility and user experience, and to explore the effectiveness of the intervention in reducing substance use. Method: Participants were adolescents (14 to 21 years old) with mild to borderline ID admitted to treatment facilities in the Netherlands. Inclusion criteria were previous substance use and personality risk for substance use. Feasibility and user experience were tested in a pilot study with six adolescents. Measures on substance use were collected in 25 participants (pre- and post-test). Results: Descriptive analyses show that the feasibility and user experience of ‘Take it personal!’ were evaluated as very positive. Preliminary results showed a decrease in substance use in almost all participants. Conclusions: ‘Take it personal!’ appears to be a promising substance use intervention for adolescents with mild to borderline ID.

Making a difference together: A health toolkit to promote access to healthcare

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Aim: People with intellectual disabilities (ID) often have worse health than other members of the population, but have difficulty accessing healthcare. This study involved the development and evaluation of a bespoke toolkit to facilitate better health access for people with ID. Method: A participatory action research framework was used to work with people with ID, families, clinicians and
academics across the West Midlands (UK). The project was funded by the West Midlands Education Council, and pre and post evaluation surveys used to review its usage. **Results:** The toolkit’s 40 components support healthcare professionals when caring for people with ID in hospital and community settings. Resources include booklets, leaflets, workbook, films, Power Points and a communication app. **Conclusions:** Toolkits need to be accessible, portable, flexible and cost-effective in order to maximise their true potential and a collaborative approach to toolkit development is crucial throughout to ensure they remain ‘fit for purpose’.

**Dying to talk: Exploring dying and death**

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**Aim:** Adults with intellectual disabilities (ID) often lack opportunities to discuss their end-of-life concerns and wishes, particularly regarding their own death. **Method:** Focus groups were conducted with people with ID (3 groups) and disability staff (3 groups). Audio recordings were transcribed and analysed to identify key themes, comparing the two groups on experiences, knowledge and concerns about dying and death. **Results:** Both groups reported experiencing the death of others and spoke about grief, rituals and remembrances. People with ID demonstrated limited understanding of the choices surrounding dying and death, and of the inevitability of death. People with ID wanted to talk about death. Staff had concerns about talking about death with clients, which contributed significantly to avoidance of the topic. **Conclusions:** Problems for people with ID about end-of-life knowledge, planning and self-determination provide clear evidence of the need for intervention. Disability staff may need support and training to engage in constructive and supportive conversations with clients about end-of-life.

**Conversations using augmentative and alternative communication: More than just ‘talk’**

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**Aim:** This study aims to show the dynamic interplay of strategies and systems used by communication partners. **Method:** The second phase of a three phase, qualitative study analysed six dyadic conversations between communication partners in Queensland and a person with Down syndrome, Rett syndrome or cerebral palsy. Conversations were filmed and transcribed using conversation strategies and systems analysis (CSSA). This tool was informed by the augmentative and alternative communication (AAC) literature and provided a richer framework than conventional discourse analysis techniques. **Results:** Specific styles of conversation were identified and linked to five dynamic systems: the disability, language, relationships, culture, and environment. Layering of data enables CSSA to be considered as an interdisciplinary tool not confined to linguists. **Conclusions:** Conversation is more than an exchange of ‘talk’. The literature proposes that communication partners be trained in their role as integral components of an AAC system. CSSA has the potential to secure a means to identify interaction hotspots where this training can be directed.
Conversation Strategies and Systems Analysis: A tool to identify hot spots in conversations with people who have Down syndrome

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Aim: The primary aim of a three stage study was to investigate the conversation strategies used by communication assistants for people with complex communication needs. A secondary aim became to develop a tool which could respond to the data across interaction dynamics of language, disability, relationship, culture and environment. Method: Survey, ethnographic and narrative data were collected from 110 participants made up of communication partners for someone with Down syndrome (DS), Rett syndrome or cerebral palsy to inform a qualitative methodology with descriptive statistics. 25 people from the DS cohort are reported in the presentation. Results: Conventional tools e.g. discourse and interactional analysis proved inadequate in identifying dynamic system connectivity. Consequently, Conversational Strategies and Systems Analysis (CSSA) was developed. This tool informed the identification of conversation strategies that appeared in particular genotypes and particular styles of conversation. Styles of conversation reflected asymmetry through structures that included monologic, constrained, rounded and processional. Conclusions: CSSA may be a valuable tool that can be used in a multi-disciplinary context to target intervention and training.

Enhanced employment outcomes for people with intellectual disabilities

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Aim: This study investigated enhanced employment outcomes that affect quality of employment for individuals with disabilities supported by the NOVA Disability Employment Service (DES) over and above the Star Ratings Key Performance Indicators of efficiency and effectiveness, and the key factors that contribute to attaining these outcomes. Method: A mixed method design was chosen to enable qualitative and quantitative data collection of outcomes and processes involving a rapid review of literature, desktop review and interviews with key stakeholders. Results: Employment outcomes considered most important to the various stakeholders were identified as well the key processes that contributed to the attainment of these outcomes. The value of a staff incentive scheme for job placements over and above the department funded performance indicators was also assessed for effectiveness and value. Conclusions: A range of employment outcomes are valued by jobseekers with disabilities and the employment personnel who support them, over and above those of mere job placement.

Developmental Educators: Disability professionals supporting people with intellectual disabilities in the community

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Aim: Australia’s National Disability Insurance Scheme (NDIS) will see individuals with intellectual disabilities (ID) self-managing funds for professional services, such as those rendered by university
qualified disability specialists (Developmental Educators; DE). DE are allied health disability professionals with multi-disciplinary, holistic, and person-centred approaches to supporting individual learning and development across the lifespan. This study investigated the skill set, roles, responsibilities, perceived recognition and careers of DE. **Method:** An online survey was completed by 121 DE. Descriptive statistics and content analysis were used to analyse quantitative and qualitative data. **Results:** The skills and values that DE reported contributing to the lives of people with ID include: positive behaviour support, functional/social skill development, lifelong support, person-centred focus, and passion for social justice. DE reported that people with disabilities, caregivers/families, and other professionals are unfamiliar with their skill set. **Conclusions:** DE possess a multitude of skills to support quality of life of people with ID; however, further evidence about quality and variability of service provided by DE is needed from other stakeholders such as recipients of DE services.

**Psychometric properties of the Developmental Behavior Checklist Under-4 (DBC-U4) in a large French-speaking sample**

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**Aim:** There is an important need for evaluation tools tailored to early intervention programmes in autism spectrum disorder (ASD) and global development delay (GDD), especially in regard of their impacts on problems behaviours. This challenge is particularly true in non-English speaking populations, where there is an important lack of evaluation tools available for young children. **Method:** We developed and tested the French version of the Developmental Behaviour Checklist Under-4 (DBC-U4). The sample consists of 516 children (73.4 % boys, aged 2 to 7 years; Mean age=52 months) diagnosed with ASD or GDD, registered in 13 of the 17 rehabilitation centres in Quebec, a French province of Canada. **Results:** The factor structure and Cronbach alpha for each subscale of this new version will be presented. Differences between sex, age range and diagnosis will also be reported. **Conclusions:** The DBC-U4 French version will be used in specialised services, among other evaluation tools, to screen for problem behaviours in young children and to plan for more individualised interventions.

**Inclusive education for students with autism: A review of stakeholder perspectives**

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**Aim:** Students with autism are increasingly being educated in mainstream schools. They have extraordinary potential to excel and yet outcomes are poor with high rates of co-morbid mental health problems, suspension and exclusion compared to typical students and other diverse learners. What are the facilitators and barriers to success at school? **Method:** A review of research into the attitudes of key stakeholders (educators, parents, people with autism) to inclusion of students with autism was conducted. **Results:** Key themes emerged: attitudes to inclusion, characteristics of autism and social communication in particular, interaction with the school environment, and consequent student problem behaviour. Level of knowledge and understanding of staff is the primary issue with all stakeholders identifying the need for more training. Other support needs identified included the need for structural support, resources and funding. Parents identified the need for a collaborative approach. **Conclusions:**
Findings highlight the need to translate theory into practice at a system, school, class and individual level to increase capacity in schools to provide effective educational programmes for students with autism and other diverse learners.

**Current understanding of good practice in early intervention for children with autism and their families**

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**Aim:** Increasing numbers of very young children are being identified with autism and many programmes and interventions are now available. However, there is ongoing debate about what constitutes good practice in early intervention for children with autism and their families. **Method:** Systematic reviews, evidence-based guidelines, key publications and reports were reviewed. Key messages were synthesised. **Results:** An underpinning principle identified is that parents/carers of children with autism should be supported during the early intervention years using a family-centred approach. Effective supports are evidence-based, of sufficient intensity and fidelity, include evaluation and regular review, incorporate individual planning taking account of each child’s strengths and difficulties, age and stage of development, and family capacity and preferences. Early intervention should focus on social communication development, enhancing learning and participation and minimising behaviours that challenge. Environmental modification, capitalising on strengths and opportunities and support for transitions should be included. **Conclusions:** The trend towards earlier diagnosis and merging of behavioural and developmental approaches to autism early intervention has resulted in important changes in the way we do business in the autism early intervention space.

**Arrangements of everyday mobility-focussed participation**

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**Aim:** The aim is to explore how young people attending their last years in Swedish upper secondary special school describe their mobility-focussed participation. In Sweden, people with disabilities travel less than people without disabilities and international research shows that lack of accessible transportation is an important barrier to inclusion in society among people with intellectual disabilities (ID). **Method:** Study participants were pupils (>18 years old) attending their last years in Swedish upper secondary special school - a school for pupils who have been assessed to have ID. A qualitative approach with semi-structured interviews was used; some interviews were supported by photographs taken by the pupils beforehand. **Results:** Results will be presented. **Conclusions:** Implications will be discussed.

**Co-morbid health conditions in people with autism spectrum disorder: A systematic review of systematic reviews and meta-analyses**

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**Aim:** Research on co-morbid health conditions experienced by people with autism spectrum disorder (ASD) is underdeveloped. This study aimed to systematically review existing systematic reviews and meta-analyses in order to identify evidence on the physical and mental health needs of people with ASD.  

**Method:** A literature search was conducted through PsycINFO, Scopus, CINAHL, Medline, and Cochrane databases and was limited to systematic reviews and meta-analyses published between 2005 and 2015. The following search terms were used: ‘autis*' OR ‘pervasive developmental disorder' OR ‘Asperger*' OR ‘ASD'.  

**Results:** Out of 3,035 results, 243 articles were identified as potentially relevant and chosen for further review; 20 articles met the inclusion criteria. These focussed on mental health conditions (n=8), physical and genetic conditions (n=7), epilepsy (n=3), gender differences in health needs (n=1) and health problems in aging populations (n=1).  

**Conclusions:** Individuals with ASD experience a variety of co-morbid health problems, and frequently more than one condition co-occurs with autism. Whilst evidence exists regarding prevalence of co-morbidities, significant heterogeneity of studies and inconsistent reporting impact on the quality of systematic reviews and meta-analyses in this field.

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**Attentional bias towards positive and negative images amongst offenders and non-offenders with intellectual disabilities**

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**Aim:** The aim of the study was to examine attentional bias towards positive and negative images amongst men with intellectual disabilities (ID), some of whom had a history of criminal offending. A secondary aim was to explore the relationship between attentional bias, empathy and distorted cognitions.  

**Method:** 46 men with ID with a history of criminal offending and 51 men with ID without any known history of criminal offending were recruited and invited to complete a dot-probe paradigm using images, as well as measures of distorted cognitions and empathy. Comparisons were made between the two groups.  

**Results:** Non-offenders had a significant attentional bias away from negative images, while offenders had a small attentional bias towards negative images. There was a significant positive relationship between distorted cognitions and an attentional bias towards negative images. There was a significant negative relationship between empathy and an attentional bias towards negative images.  

**Conclusions:** The results indicate that men with ID who have a history of criminal offending may allocate attention when processing information differently than those who no such history.

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**Survey of community-dwelling people with severe motor and intellectual disabilities in Aichi prefecture, Japan**

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**Aim:** In Japan, there are approximately ~40,000 persons with severe motor and intellectual disabilities (SMID); about 70% of those who require medical support live with their family in the community. The number of persons with SMID is increasing in Japan, and their conditions are more severe and medically dependent. To improve access to community services for persons with SMID, a survey was conducted by Aichi prefecture.  

**Method:** Of the 1,474 persons with SMID living at home or group homes in Aichi prefecture (excluding those institutionalised), 985 responded to the mailed questionnaires (response rate: 68.8%) regarding medical care.  

**Results:** Suction was necessary in 25.3% of cases, tracheostomy in 10.1%, ventilator support in 5.9%, tube feeding including gastrostomy in 26.8%, and gastrostomy in
19.4%. Ventilator support was necessary in 16.7% patients aged <7 years, 7.4% aged 7-17 years, and 3.9% aged >18 years. **Conclusions:** Medical intervention is more frequently needed in younger persons with SMID. For many medically dependent persons with SMID and their families, enriching visiting care services by nurses and doctors, day care services, and respite services is necessary.

**Preliminary evaluation of a tailored goal-directed self-management training programme for people with intellectual disabilities**

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**Aim:** To help people with intellectual disabilities (ID) lead an independent life and to reduce their demand for care and its related costs, it is important to promote their self-management. This study aims to evaluate the effectiveness of a tailored goal-directed self-management training programme for people with ID. **Method:** Adult clients with ID will enter a weekly training programme guided by support staff, where they can work on self-selected training goals. Questionnaires addressing self-reliance, behaviour, quality of life and self-worth will be collected 3-6 months before the training programme, at the start of the programme and 3, 6, 9 and 12 months after the start. Within-subjects analyses will be conducted. **Results:** The training programme has recently started. The evaluation of its effectiveness is still in progress. **Conclusions:** The results of this study will show whether the tailored goal-directed self-management training programme will increase the self-reliance of people with ID, with secondary improvements in behaviour, quality of life and self-worth.

**Preliminary findings on the effectiveness of staff training to promote self-management in people with intellectual disabilities**

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**Aim:** For people with intellectual disabilities (ID) it has become increasingly difficult to lead an independent life within our growingly complex society. It was hypothesised that training for support staff to support self-management of people with ID would improve self-reliance and simultaneously reduce problem behaviours. **Method:** A training programme focussed on the promotion of self-management was provided to support staff of adult clients with ID living within a residential setting. The control group consisted of clients with ID whose support staff was not trained. Effectiveness of the training was assessed with questionnaires addressing self-reliance and behaviour filled in before the training and after 3 and 6 months. **Results:** Analyses of covariance showed there are no significant differences between the groups in self-reliance and behaviour three months after the training. **Conclusions:** Six-month results will be discussed, in addition to their implications for promoting self-management in people with ID.

**Improvement of self-determination in young persons with intellectual disabilities**
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Aim: It is important to equip youngsters with intellectual disabilities (ID) with relevant competencies corresponding with their opportunities and learning style. We investigated how self-determination, as a result of this policy, has developed. Method: In a longitudinal research project (2011–2015), skills of 96 youngsters aged 10 to 23 years were measured three times by INVRA (INventarisatie Van Redzaamheid Aspecten, Inventory of Self-determination Aspects). In between, an assessment of the degree of the implementation of the support method OEB (Op Eigen Benen, On Your Own Legs) was made. We used a single-group pre-test/post-test design. Results: Development of skills results from a combination of gender, age and environment. Girls achieved considerably higher scores on skills than boys. The effect of OEB is assumed but could not be proven statistically. Conclusion: The results of INVRA are being used to connect support closer to the individual needs and goals. Also, the awareness of the importance of stimulating competencies by support workers was improved. Management became more aware of the need to complete the chain of support.

Psychometric properties of the Proxy-Reported Activities-Specific Balance Confidence Scale (ABC-P) among individuals with intellectual disabilities

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Aim: Fear of falling impairs mobility and independence among individuals with intellectual disabilities (ID). The lack of studies addressing proxy-reported fear of falling is often attributed to the unavailability of valid and reliable assessment tools specific to individuals with ID. Method: We assessed the validity and reliability of the Proxy-Reported Activities-Specific Balance Confidence Scale (ABC-P) for determining balance issues related to the fear of falling among individuals with ID attending an employment development centre at Movement for the Intellectually Disabled of Singapore (MINDS). Training officers of 42 participants assessed fear of falling using ABC-P. Therapist-assessed balance using Berg Balance Scale, functional mobility using the Timed Up and Go Test, functional independence using the modified Barthel Index and Lawton's Score of Instrumental Activities of Daily Living were recorded. Results: Good concurrent validity was observed between ABC-P and participants’ balance (r=0.316; p=0.021). ABC-P had excellent validity for predicting falls (r=−0.72; p=0.0001) among individuals with ID. The inter-rater (icc=0.973) and test-retest reliabilities (icc=0.976) between training officers were excellent. Conclusions: ABC-P is a valid and reliable tool for assessing the fear of falling among individuals with ID.

The impact of financial support on life satisfaction of elderly persons with intellectual disabilities

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Aim: Life satisfaction among elderly persons with intellectual disabilities (ID) has become a major issue of concern in the rapidly aging and developing Chinese society. This study examines the impact of intergenerational financial support and its correlation to the satisfaction level of elderly persons with ID. Method: Data from the Second National Sample Survey on Disability in China were analysed to examine
the impact of support on life satisfaction among elderly persons (60 years and older) with ID in Eastern, Central and Western China. **Results:** In the most developed region (Eastern China) and the most economically backward area (Western China), financial support has had positive influence on elderly persons with ID. The degree of life satisfaction among those who have received financial support from their children is significantly higher than those who have not. However, the developmental level of Central China in comparison to that of Eastern and Western China, and the relationship between financial support and life satisfaction were not clear. **Conclusions:** These findings indicate that there is a different impact of intergenerational financial support in different region.

The employment conditions and demands for people with intellectual and developmental disabilities in China

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**Aim:** In order to help people with intellectual and developmental disabilities (IDD) get out of poverty, we focus on discussing their employment rates, working types, the reasons for unemployment and the ways of improving their employment situation through welfare policies. **Method:** The sample size of our investigation was 1,897,200 people with disabilities, surveyed by National General Investigation of the Situation and Needs of the Disabled People in 2015. We used descriptive analysis to explore the distribution and relationship among sex, age, economic level, education level, employment situation and welfare security. **Results:** The unemployment rate of people with IDD reached 84% in China. The main causes of unemployment are loss of capacity to work and being unskilled. Main sources of livelihood are support from family members and social welfare. **Conclusions:** In China, the employment rate of people with IDD is low, especially for women. In solving the employment problems, the government should continue playing the leading role and emphasise the function of social and non-profit organisations to offer suitable jobs to certain groups.

Through the window: What can we learn about a person’s communication from a ten-minute video clip?

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**Aim:** For people with severe intellectual disabilities (ID) and communication impairments, assessing communication in naturalistic environments is essential but challenging. Caregivers have first-hand knowledge about the person’s communication but may over interpret the behaviours as having intent or of being symbolic. This study will investigate the use of a Model of Observational Screening for the Analysis of Interaction and Communication (MOSAIC) to analyse communication of young children with Down syndrome. **Method:** Parents of children with DS recorded video of themselves interacting with their child as part of another study. These will provide 20 clips per child recorded over a 3-month period. Speech therapy student used MOSAIC to analysed ten-minute video clips of 12 children with DS interacting with their parents. **Results:** Results will include student feedback and interrater reliability. **Conclusions:** Implications of findings will be discussed.
Uptake of the annual health exam among adults with intellectual and developmental disabilities from 2003 to 2015 in Ontario, Canada

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**Aim:** Over the past decade, annual health exams (HE) have been de-emphasised for the general population but emphasised for adults with intellectual and developmental disabilities (IDD). This study compares the proportion of adults with and without IDD who received a HE annually from 2003 to 2015.

**Method:** Using administrative health data, the proportion of adults (18-64 years old) with IDD who received a HE each year was compared to the proportion in a propensity score matched sample of the general population. Negative binomial regression controlling for age and including an offset term equal to cohort size was used to determine the effect of time. **Results:** Adults with IDD were 15% (95% C.I.: 14-17) more likely to have a HE than the general population. There was a 2.5% (95% C.I.: 2.3-2.7) decrease in the likelihood for both groups to have a HE over time, after controlling for age. **Conclusions:** Despite efforts to improve the uptake of HE in adults with IDD, during this period the proportion of adults with IDD receiving an HE decreased. This trend matches what was seen in the general population.

Developing social skills and Theory of Mind among preschool children with autism spectrum disorder

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**Aim:** This study compares the effectiveness of two programmes for developing social skills and Theory of Mind (ToM) among preschool children with autism spectrum disorder (ASD): “Play Time/Social Time” (PT/ST) with behavioural basis, and a cognitive programme “I Can Problem Solve” (ICPS). **Method:** 52 children from inclusive preschools were assigned to 3 groups: PT/ST (n=14), ICPS (n=12), and control (n=26). Children’s ages were similar across the three groups. Children’s social skills and ToM were examined three times: before the start, after 30 days and after 60 days. The data were analysed with structural modelling. **Results:** Children in the experimental groups developed social skills faster than children in the control group. The programmes are similarly effective in developing social skills and ToM. The PT/ST and control groups did not differ in ToM development, but positive changes were seen in the ICPS group. **Conclusions:** The programmes are effective in developing social skills. Moreover, even if the changes are not significant, there are positive results in the case of ToM tasks, even though developing ToM was not the main aim of the programmes.

Yield of diagnostic exome sequencing in 100 individuals with both epilepsy and an intellectual disability

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**Aim:** The genetic contribution to intellectual disabilities (ID) and epilepsy has undergone a revolution in the past decade. This study assesses the value of diagnostic exome sequencing (WES) in a cohort of
individuals with previously unexplained ID and epilepsy. **Method:** We enrolled 100 individuals with both epilepsy and (borderline) ID (IQ ≤ 85) with unknown cause. They were all evaluated by a clinical geneticist and a (paediatric) neurologist at our combined outpatient clinic. WES was requested in all individuals who remained undiagnosed by specific DNA diagnostic tests and genome-wide chromosomal analysis. **Results:** Preliminary analysis of the WES results in a subset of 47 patients resulted in a (likely) diagnosis in 23% and an unknown or possible pathogenic variant in 32%. **Conclusions:** These numbers illustrate the potentially high diagnostic yield of WES for this specific population. We will discuss the value of diagnostic WES in care and counselling of patients and their families. Insight in genetic aetiology may lead to a greater understanding of co-morbidities, prognosis, and may guide treatment choices.

**Against the law: Volunteers supporting people with intellectual disabilities in the criminal justice system**

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**Aim:** The Criminal Justice Support Network (CJSN) provides support persons and advocacy for people with intellectual disabilities (ID) who come into contact with the criminal justice system. CJSN provides supports in police stations and courts across New South Wales 24 hours a day all year around. In 2014-2015 CJSN provided 1648 supports to 510 clients. These supports were mainly undertaken by volunteers, many of whom have been volunteering with CJSN for over five years. This study aims to understand what draws people to volunteer with CJSN and moreover what holds and sustains them. **Method:** The study involves an online survey and follow-up phone interviews with volunteers, an audit of volunteer recruitment strategies, selection and training and ongoing support mechanisms. Interviews will also be conducted with the CJSN staff. **Results:** Preliminary findings will be presented. **Conclusions:** The findings will provide useful guidance to organisations wishing to establish a programme to support for people with ID in the criminal justice system using volunteers.

**Have efforts to positively influence the public opinion been worthwhile?: A follow up on the effect of different portrayals of people with IDD in non-profit organisation fundraising campaigns**

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**Aim:** Earlier findings concerning the impact of stereotypical representation of people with intellectual and developmental disabilities (IDD) in non-profit-organisation (NPO) fundraising campaigns suggest that advertisements can influence attitudes towards people with IDD. As attitudes are sensitive to change over time and since there have been ongoing efforts to positively influence the public opinion on IDD, it is crucial to determine whether these findings are still applicable. **Method:** Six fictional advertisements systematically varying visual and semantical representations of people with IDD were used. Participants were shown one of six advertisements while completing a questionnaire measuring willingness to donate and expectations concerning the abilities of people with IDD. Attitudes towards people with IDD were assessed using the Mental Retardation Attitude Inventory-Revision in its German version. A proposed sample of 415 participants was recruited online. **Results:** Preliminary results indicate differences in the influence of semantical representations on donations. Other than concerning
private rights, attitudes have not changed significantly. Influences of semantical representations on expectations of abilities of people with IDD were found. **Conclusions:** Implications will be discussed.

**Mental health and behavioural problems in children and adolescents with Down syndrome and intellectual disabilities attending special schools in Singapore: A cross sectional survey**

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**Aim:** The aim of the study was to identify the prevalence of challenging behaviours or psychiatric problems in children with Down syndrome and moderate to severe intellectual disabilities (ID) attending four special schools in Singapore.  
**Method:** Data were collected for 64 children aged 7 to 18 years using the Nisonger Child Behaviour Rating forms (parent and teacher) and ADAMS (Anxiety, Depression and Mood scale) which were completed by parents and the child’s teacher. The data was analysed using SPSS.  
**Results:** Hyperactive behaviour was correlated with hyperactive disorder and self-isolated behaviour with social avoidance. Parents reported more problematic behaviours than teachers. Hyperactivity, social anxiety and depressed mood were the most common problems reported by teachers and parents.  
**Conclusions:** The results indicate that hyperactivity, social avoidance and depressed mood are more prevalent in children with Down syndrome and moderate to severe ID. First of its kind in Singapore, this study highlights that increasing the awareness and early intervention can enhance the quality of life of these children.

**The portrayal of persons with intellectual disabilities in children’s literature**

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**Aim:** Children's literature can be a powerful tool in education and identity construction. The images and stories one is subjected to during early childhood can help bring an understanding of oneself as well as other people. The focus of this project is intellectual disabilities (ID) in children's literature with a special interest in picture books for the younger ages. One of the main questions is if these portrayals contain any stereotypes or outdated imagery that in turn could influence how people with ID are perceived and treated in society.  
**Method:** Using a Foucauldian discourse analysis, a selection of picture books was studied in order to gain an understanding of how these works of fiction portray people with ID.  
**Results:** The preliminary results show both positive and accurate portrayals as well as some significant differences when compared to picture books without any characters that have ID.  
**Conclusions:** The different roles available for the intended audience to identify with and how the selected books differ in some ways from mainstream children’s literature will be discussed.

**Sexuality in support plans for people with intellectual disabilities in the Netherlands**

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**Aim:** This study explores if and how attention is paid to the sexuality of people with intellectual disabilities (ID) in their individual support plan (ISP). The research question is: In what way is there attention to sexual health and sexual rights of people with ID in ISP in the Netherlands? **Method:** 184 ISP were examined (93 men and 91 women; average age=43 years), coded and analysed. **Results:** The plans showed a low score on sexual goals; a low score on sexual abuse (lower than the literature indicates); hardly any treatment for sexual abuse or trauma; the use of contraceptives without being sexually active but for secondary goals (menstrual or behavioural problems); sexually deviant behaviour; unwanted sexually-oriented behaviour, and a low score on sexual education. **Conclusions:** More attention to sexual health of people with ID is required in ISP. We recommend support for people with ID to realize their sexual rights.

**Perceptions of family well-being as held by families which include children with autism: A multiple perspectives approach**

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**Aim:** To understand the perceptions of family well-being for families that include children with autism. To explore how they engage with each other as a family, their quality of life and the family’s interpretations of their everyday lived experiences. **Method:** Six families were involved in a series of in-depth, semi-structured interviews. The interviews were conducted over a six-month period for each family. Children, aged 5 to 17 years, were involved in the interviews, including the children with autism. This was followed by two family group interviews. **Results:** Six families described their everyday life experiences, including the child with autism. This revealed possible bidirectional pathways of family’s relationships, resilience, challenges and the unique and diverse ways in which families adapt when there is a child with autism. **Conclusions:** The findings from this study illustrate how each family’s experience is unique, multifaceted and diverse in how they engage as family and their perceptions of family well-being. This will influence our understanding of family-centred practices and collaborative relationships between families, health professionals and policy makers.

**Relocating people with intellectual disabilities into the community: Process and outcomes in Japan**

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**Aim:** This study examines the outcomes of relocation into the community and makes recommendations for future activities. **Method:** 38 community homes for a total of 157 persons with intellectual disabilities (ID) have been established. A survey reviewed their daily activities, financial situation, degree of satisfaction and aspirations. **Results:** 12.7% are engaged in ordinary work, 68.8% in supported employment 68.8%. All utilise day care services. They have a monthly income between 5,000 yen and 150,000 yen. The future focus should be on helping identify opportunities for people to take part in a variety of cultural, artistic, sporting and other leisure activities on weekends and holidays. **Conclusions:** Following relocation, people had stable and secure lives but, to be more fulfilled, they need support to use their spare time meaningfully.
An investigation of maternal lived experience in raising a child with autism spectrum disorder in China

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**Aim:** Chinese mothers are usually confronted with various challenges when raising a child with autism spectrum disorder (ASD). Although priorities have been placed on education and rehabilitation services for children with ASD in China in recent years, systematic support and services are not readily available for children with ASD and their families. The present study explores the lived experience of Chinese mothers with a child who has ASD. **Methods:** Semi-structured in-depth interviews were conducted with six Chinese mothers who have a child with ASD. All interviews were audio-recorded and transcribed. The interview data were thematically analysed using a combined data-driven and theory-driven approach. **Results:** Primary lived experience for mothers who have a child with ASD include: children’s behavioural problems, social exclusion, and lack of quality policy and financial support system. **Conclusions:** It is recommended that the Chinese government and professionals make changes to provide services, interventions and supports to mothers and families who have a child with ASD.

Social skills intervention to combat bullying among children with intellectual disabilities

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**Aim:** This study aims to combat bullying through social skills intervention among children with intellectual disabilities (ID). **Method:** Preliminary pre-intervention screening of bullying was done by the administration of survey instruments. The sample consists of 40 students from upper primary classes. A 10-session intervention programme specially developed for children with disabilities including communication skills, listening skills, assertiveness and self-control was administered over the period of three months. The survey instruments were used immediately after the completion of intervention and three months after the intervention. The data collected were analysed using correlation and t tests for pre-, post- and follow-up comparisons. **Results:** Statistical analysis confirmed the efficacy of the intervention as social skills training significantly reduced bullying and victimisation. **Conclusions:** The social skills-based intervention to combat bullying is a useful tool for the management of bullying among children with disabilities.

An evaluation of occupational therapy using sensory integration to improve academic skills of school age children with autism

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**Aim:** People with autism often present with difficulty processing and integrating sensory information, they are restricted in their interest, and have repetitive and stereotypical behaviour which has an impact on their adaptive behaviours and participation in daily activities. We examined the effectiveness of a 10-week programme of intensive occupational therapy using a sensory integrative approach (OT–SI) for increasing academic skills in school age children with autism. **Method:** Social participation, self-
stimulatory behaviours and attention during a fine motor task were observed in 67 children diagnosed with autism before and after the intervention. \textbf{Results:} Paired t-test statistic confirmed that all of the participants in this study improved their academic skills in social participation and attention, and had fewer self-stimulation behaviours post-intervention. \textbf{Conclusions:} Occupational therapy using sensory integration is effective to improve academic skill in school age children with autism. However, occupational therapists should promote continuity of care, including Sensory Integration Summer Camp and use of an individual activity book to empower parents to continue the programme in order to achieve sustainable changes in adaptive behaviours and participation in preschool children with autism.

**Trends in adult patients with autism spectrum disorders admitted to psychiatric units**

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\textbf{Aim:} Adults with autism spectrum disorder (ASD) are younger, less likely to have psychotic disorders and have longer lengths of stay than other psychiatric patients. Staff of one psychiatric unit in a large medical centre report increasing numbers of patients with ASD over time. This study aims to determine if numbers of psychiatric patients with ASD have increased, and describe psychiatric patients with ASD.

\textbf{Method:} De-identified data of patients with ASD admitted from 8/1/2013 to 9/1/2015 to the adult psychiatric unit were analysed. \textbf{Results:} A trend for increasing numbers is likely; of 21 admissions, 62\% were in year two. The age range of patients was 18 to 45 years (mean=23.6 years); 62\% were male; 76\% were Caucasian and 24\% Black/African American. The mean length of stay was 10.3 days (range: 2.1-25.1); 52.4\% were admitted for aggression/agitation/change in behaviour; 28.6\% for suicidal ideation or attempts. 16 had 1:1 assistants related to impulsiveness, risk for self-harm, and/or risk for falls.

\textbf{Conclusions:} Recommendations will be made regarding need for additional staff resources and training in the care of psychiatric patients with ASD.

**Study of sexuality education for children with intellectual disabilities**

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\textbf{Aim:} This study examines the specifics of romantic behaviour in students with intellectual disabilities (ID) and the homeroom teachers’ feelings and reactions upon hearing about or witnessing romantic behaviour in students. \textbf{Method:} A questionnaire was given to 370 classroom teachers of special schools. The survey was conducted in March 2014 by mail. The questions were about whether or not the homeroom teachers had heard of or observed any romantic behaviour from the students in their grade level within the past year, and the homeroom teachers’ feelings and reactions. \textbf{Results:} We obtained responses from 285 (77.0\%) homeroom teachers and analysed data pertaining to 279 of these respondents. Romantic behaviours heard of or observed by homeroom teachers primarily included moving nearer to the object of affection (71.3\%), and exhibitions of shyness (50.2\%). With respect to observing or hearing of students moving nearer, 43.2\% of homeroom teachers answered they sympathised with the budding feelings of the students, and thought they displayed behaviour appropriate to their level of development. \textbf{Conclusions:} Upon observing various romantic behaviours by students, most homeroom teachers experienced positive feelings.
Discussion of how to effectively support mothers in health examinations for toddlers

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Aim: For screening infants’ development, health examinations are provided free for 18-month and three-year old toddlers throughout Japan, so nearly all the subjects have undertaken them. There was the case where a 15 year-old boy who had passed the toddlers’ health examinations with no problem was later diagnosed with ASD. Based on this case, our study aimed to discuss the considerations in administering the toddlers’ health examinations to make the health screening system more effective.

Method: In an interview, the boy’s mother was asked about his developmental problem and the specialists’ responses in the previous screening examinations. The data were qualitatively analysed using the KJ method.

Results: The interview revealed that the mother had brought her son’s symptoms of suspected developmental disability to the attention of the specialists, who had concluded him to be normal because no problem had turned up in the checklist.

Conclusions: The screening examinations should not only focus on the checklist, but also carefully consider symptoms reported by mothers.

Participation for adults with profound intellectual disabilities: Perceptions of managers and staff

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Aim: What participation in everyday life is for adults with profound intellectual disabilities is an unexplored field. The aim was therefore to elucidate and describe conceptions of participation of managers and support staff who work in group homes or as personal assistance to adults with profound ID.

Method: Phenomenographic analysis of interviews with 10 managers and 17 staff in social care was undertaken.

Results: Preliminary result show that there were many different conceptions of participation in the organisation. Participation for adults with profound ID was conceptualised as: to do things, to be present, to choose, to affect or to decide; it was often connected to the individual’s abilities or degree of impairment. The staff’s knowledge about the person with profound ID, lack of definition of participation and having enough time contributed to the conceptualisation.

Conclusions: It is difficult for staff to facilitate participation for adults with profound ID when there is no common definition of what participation is. It is also difficult to work towards the same goals.

Does Signposts benefit caregivers of children with moderate to severe intellectual disabilities?

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Aim: Signposts, an evidence-based parenting programme, targets caregivers of children with intellectual disabilities (ID) or developmental delay who have behavioural difficulties. This research is the first preliminary study in Singapore to examine the effectiveness of Signposts with caregivers of younger (7 to 12 years old) and older (13 to 16 years old) children with moderate to severe ID.

Method: 20 caregivers completed pre- and post-programme self-report measures on parenting competency,
perceived challenges in managing their child’s behaviour, and their child’s strengths and difficulties.

**Results:** Paired-sample t-tests and independent-sample t-tests were conducted to compare pre- and post-programme scores within and between age groups respectively. Caregivers of younger children perceived a significant decrease in their challenges with managing their child’s behaviours and in their child’s level of negative conduct problems. Caregivers of older children perceived a significant decrease in their child’s hyperactivity level. Changes in scores were similar for caregivers in both the younger and older groups. **Conclusions:** Caregivers of younger and older children benefitted from Signposts, with a relatively better outcome for caregivers of younger children.

**A study about the circumstances of the married lives of people with intellectual disabilities in Japan**

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**Aim:** After the approval of the UN Convention on the Rights of Persons with Disabilities (CRPD), the States’ Parties should guarantee the rights of marriage and family lives for people with disabilities. Especially for people with intellectual disabilities (ID), these rights could be easily infringed upon. Studies about parents with ID have become more vigorous in western countries. Since Japan ratified the CRPD in 2014, there is a need to understand the circumstances of the married lives of people with ID in Japan and create a support system for them. **Method:** Based on previous research, a questionnaire survey about number and circumstances of couples with ID was given to 323 Employment and Livelihood Support Centres for Persons with Disabilities in Japan. **Results:** Although incomplete, the results suggest the number of couples with ID is increasing in Japan. Supporters struggle to help their clients, because supports to couples and parents are not part of their responsibilities. **Conclusions:** Supporting married couples with ID should be regarded as a significant part of work duties. Adequate guidelines for such support are needed.

**Analysing transitions: The clinical profile of former child psychiatry patients progressing on to the care of the first specialised, multidisciplinary adult neurodevelopmental service in Southeast Asia, based in Singapore**

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**Aim:** The Adult Neurodevelopmental Service at the Institute of Mental Health, Singapore is the first dedicated multidisciplinary service for adults with neurodevelopmental disorders and psychiatric co-morbidities in Southeast Asia. This study analyses the clinical profile of child psychiatry patients who have progressed on to this adult service. **Method:** The electronic records of 50 such patients seen in 2015 were analysed in relation to socio-demographics, diagnosis and psychiatric co-morbidities, pharmacotherapy, functioning and illness severity scores. **Results:** All patients except 3 (6%) were seen as outpatients. 41 (82%) were male with a mean age of 21.1 years (SD±2.68). 32 (64%) had autism spectrum disorder, 28 (56%) had intellectual disability and 8 (16%) had attention-deficit/hyperactivity disorder. Co-morbid psychiatric disorders included anxiety disorders (24%), mood disorders (14%), and psychotic disorders (8%). Risperidone and fluoxetine were the most commonly used antipsychotics and antidepressants respectively. The mean initial clinical global impression score was 4.05 (SD±0.87) and
the mean global assessment scale score was 53.78 (SD±9.42) in patients who were assessed.

**Conclusions:** Analysing the profile of these patients will be beneficial in striving towards evolving the service to meet their specific needs.

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**Applied behaviour analysis intervention on challenging behaviour in individuals with severe intellectual disabilities**

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**Aim:** The purpose of this study was to assess the effectiveness of an applied behaviour analysis intervention on challenging behaviour in individuals with severe intellectual disabilities (ID). **Method:** Subjects were four individuals with severe ID showing challenging behaviours. We performed functional analysis on all subjects for two weeks before the intervention, and intervened with each subject based on the results of the functional analyses. The duration of a course of the intervention was four weeks, and we intervened with each subject for three courses. We assessed the effectiveness of the intervention by the average number of challenging behaviours per week and scores on the aberrant behaviour checklist. **Results:** Three of the four cases showed decrease in challenging behaviours during the intervention period, but in one case the behaviour deteriorated. After the intervention period, all cases showed a decrease in challenging behaviours compared to the baseline. However for maintenance of effectiveness, continuous intervention was needed in two cases. **Conclusions:** The applied behaviour analysis intervention was effective in reducing challenging behaviour in most individuals with severe ID.

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**Impact of the Great East Japan Earthquake on intellectual ability in 7 year-old children**

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**Aim:** To assess the neurodevelopmental effects of the Great East Japan Earthquake in resident children. **Method:** The disaster on March 11, 2011 caused severe damage to the Sanriku coastal area, where we had been conducting a birth cohort study since 2003. It occurred in the middle of our 7 year-old examination. Our participants were divided into two groups: 123 children finished the examination in the pre-disaster period, and 289 did in the post-disaster period. At the time of 7 year-old examination, we administered the Wechsler Intelligence Scale for Children-Third Edition (WISC-III). **Results:** Verbal IQ of the WISC-III, at 7 years of age was significantly lower in the post-disaster group than in the pre-disaster group. However, there were no significant differences in performance IQ and full-scale IQ between the two groups. **Conclusions:** Since many schools were used as primary refuges after the disaster, the deficits in verbal IQ may have been due to the interrupted schooling. Therefore, the educational environment for children should be restored as soon as possible, when an enormous disaster occurs.

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**The assessment of quality of life people with intellectual disabilities in Denmark**

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**Scientific POSTER presentations S-U**

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**Aim:** The purpose of this study was to examine the characteristics of quality of life (QOL) of people with intellectual disabilities (ID) in Denmark using the Personal Outcomes Scale (POS). **Method:** 102 people with ID participated in interviews using the self-report version of the POS in Danish, and 76 professionals were separately involved in the report of others version of the POS in English. Data were analysed statistically to confirm the consistency between self-report and report of others versions of the POS, and relationships between eight domains and personal and environmental factors. **Results:** Self-report ratings were significantly higher than ratings based on reports of others in the total scores and three domains. Personal outcomes were significantly impacted by day arrangements, living arrangements, age and ID levels. For example, people with ID at school showed higher scores in the personal development domain than those with ID in day centres. **Conclusions:** These findings were consistent with previous studies that self-ratings were higher on several domains, and highlight the need to understand personal outcomes from various perspectives.

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**The contribution of work to daily physical activity among adults in supported employment**

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**Aim:** Work is a potential motivating factor for physical activity as well as a context where physical activity occurs. We hypothesised that participants would meet the Canadian physical activity guideline of 60-minutes of moderate-to-vigorous physical activity (MVPA) per day. Further we hypothesised that participants would be more active at work than when they were not at work. **Method:** Physical activity intensity levels of ten adults with intellectual disabilities (ID) in supported employment were examined using accelerometers over eight consecutive days. Cohen’s effect sizes (d) were used to compare work and non-work physical activity levels. **Results:** Nine participants (90%) met the Canadian daily MVPA guideline. Comparing work versus non-work time, participants spent 20% vs. 55% in sedentary behaviour (d=2.9), 62% vs. 37% in light-intensity physical activity (d=1.1), and 20% vs. 7% in MVPA (d=0.6). **Conclusions:** The medium to large effect sizes indicate that work had a substantial impact on participants’ physical activity levels in comparison to other daily activities. These findings illustrate that in addition to the many other social, financial, and psychological benefits of work, there are important physical health-behaviour benefits.

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**Development and introduction of communication passports in an acute adult intellectual disability unit in a tertiary psychiatric hospital in Singapore**

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**Aim:** Adults with intellectual disabilities (ID) may present with multiple and complex needs. A holistic account of each individual in terms of their needs, likes and dislikes and behavioural issues may help patients and their caregivers in communicating with each other and understanding their needs. We describe development and introduction of a communication passport in an acute adult ID inpatient unit. **Method:** A team was formed to develop a communication passport through literature review, focus group discussions and liaison with caregivers and patients. We amended the content based on feedback
from stakeholders. **Results:** The final format of the communication passport consisted of a 12-page document encompassing multiple aspects including communication and behavioural issues. The initial feedbacks from caregivers of patients who have been discharged from the inpatient unit indicate that this has been particularly beneficial for them in communicating with the patient and understanding their challenging behaviours. **Conclusions:** Communication passports tailored to individual patient’s needs and difficulties may be beneficial.

**Examining executive function in young children with autism spectrum disorder**

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**Aim:** Executive function (EF) deficits in individuals with autism spectrum disorder (ASD) have been documented. However, few studies investigated the association between EF and other child characteristics such as intellectual functioning, adaptive behaviours and severity of autistic behaviour. Early identification of EF deficits in young children should help to better intervene and to limit long-term deficits. This study examined EF in a large sample of young children at the onset of receiving early behavioural intervention in a public rehabilitation centre. **Method:** The sample consisted of 277 children (79.8% boys aged between 22 and 65 months, mean age=45.2 months) diagnosed with ASD. Descriptive analysis, correlations and multivariate analyses between EF and other child’s characteristics, were conducted. **Results:** Young children with ASD exhibited deficits in EF. These deficits were associated with autistic and adaptive behaviours. Given the heterogeneity of autistic profiles, these preliminary data could allow identification of patterns among the sample. **Conclusions:** Results suggest that EF should be taken into account in order to better plan and maximise effects on individualised interventions.

**Clinicians’ perspective on the usefulness and usability of sexual knowledge assessment tools for people with intellectual disabilities**

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**Aim:** Many people with intellectual disabilities (ID) have limited sexual knowledge. Several assessment tools have been developed to assess the sexual knowledge of people with ID. This study examined clinicians’ perspective on the usefulness and usability of these tools. **Method:** This research uses a constructionist grounded theory approach. Semi-structured qualitative interviews were conducted with clinicians who use sexual knowledge assessment tools. To provide a context for clinicians’ comments about these tools, a content analysis of several sexual knowledge assessment tools was also performed. **Results:** Clinicians found sexual knowledge assessment tools useful in that they provided a framework to enable them to assess sexual knowledge. However, they also identified several shortcomings such as not having enough pictures, use of complex language and not being practical enough to use with people with ID. **Conclusions:** Given the identified shortcomings of the current tools, there is scope for the development of new sexual knowledge assessment tools or refinement of the existing tools.
Strengths- and deficits-based perspectives in autism spectrum disorder: A 10-year literature review of intervention and non-intervention studies

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Aim: It is important for research on autism spectrum disorder (ASD) to balance the traditional deficits-based studies with a greater focus on strengths, as seen more recently in research and practice in intellectual disabilities (ID). This study compares the strengths- and deficits-based perspectives in intervention and non-intervention studies of individuals with ASD, over a 10-year period. Method: We randomly reviewed 1155 articles from five prominent ASD journals from 2004 to 2014. Adapting an existing coding scheme (Shogren et al., 2006), we selected articles focussed on well-being for strengths, deficits or mixed perspectives. Results: To date, 37% (n=422) of the articles have been scored. Of the articles focussing on well-being (n=157), 47% were intervention studies. Intervention studies were more likely to have a mixed perspective, and non-intervention studies were more likely to have a deficits perspective (p < .001). Trends over the 10-year period will be reported. Conclusions: Our findings will reveal trends in the strengths and deficits perspectives of intervention and non-intervention studies in the ASD literature.

The evaluation of a person-centred profile for children with intellectual disabilities during a health care encounter

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Aim: To evaluate the efficacy of the Person-Centred Profile (PDP) in improving the experience of patients with intellectual disabilities during a healthcare encounter through telephone interviews or self-completed forms with carers and healthcare staff. Method: A 9-item questionnaire was developed to elicit qualitative and quantitative data from healthcare staff and families of children with ID who had a recent healthcare encounter with the use of the PDP. Results: Healthcare staff found that the PDP helped in preparing for the child’s admission by contributing to an improved understanding of the child’s communication level, behaviour and care needs. Parents were unable to comment specifically because it was uncertain to them if healthcare staff actually used the information within the PDP. Conclusions: Healthcare staff found the PDP useful in terms of improved patient care. Advanced provision of patient information in a concise document with a planned patient journey and communication strategy potentially leads to a more streamlined patient journey. More research is needed with its application in a variety of context and settings.

Ballet Burst: An intervention study to improve health and fitness in people with intellectual disabilities

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**Aim:** A high percentage of inactivity and low levels of health outcomes are reported for people with intellectual disabilities (ID). The aim of the current study was to investigate whether ballet would improve the weight, balance, self-esteem and overall quality of life of people with ID via identifying differences between the intervention and the control group. **Method:** A pilot randomised control trial was conducted with participants being assigned to either a ballet intervention group (n=15) or a control group (n=16). The intervention group received one-hour weekly ballet sessions for 26 weeks. Body mass index, waist and hip circumference was obtained for all participants. Balance was assessed via the Timed Up and Go test as well as the Berg Balance Scale. Self-esteem and quality of life were assessed via the adapted Rosenberg Self-Esteem Scale and Cummins’ Comprehensive Quality of Life Scale respectively. **Results:** No differences were found between the intervention and control group; however, an improvement in balance was shown for the intervention group. **Conclusions:** The study needs to be replicated with increased power and objective assessment tools.

**Describing sleep quality in children with Angelman syndrome and Smith-Magenis syndrome**

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**Aim:** Both children with Angelman syndrome (AS) and Smith-Magenis syndrome (SMS) are reported to experience sleep problems, but studies lack standardisation of assessment for comparison between these two groups. **Method:** Sleep quality was assessed using the Modified Simonds and Parraga sleep questionnaire and seven days of actigraphy. Actigraphy data will be compared for 20 children with SMS, 20 children with AS and 40 aged-matched typically developing (TD) children. **Results:** The questionnaire data revealed significant differences between all three groups in the following order of severity; SMS>AS>TD, for both sleep disordered breathing and daytime sleepiness scores. Differences in night waking scores followed a different pattern; SMS=AS>TD, and no significant differences were found for sleep onset latency between the three groups. Children with SMS had significantly earlier bedtimes (7:30 pm versus 8:00 pm, U=125 p=0.005, r=-0.41) and wake up times (5:00 am versus 6:45 am, U=52, p<.001, r=-0.68) than children with AS. Actigraphy data is expected to corroborate these findings. **Conclusions:** Differential patterns of sleep problems exist for children with SMS and AS.

**Navigating ever-changing seas: Aging with intellectual disability**

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**Aim:** To explore aging and future planning in a hidden population of people with intellectual disabilities (ID) and those nominated as family carers. **Method:** The qualitative design for this study was based on Charmaz’s Constructivist Grounded Theory. Non-probability and snowball sampling recruited people with ID aged 40 years or older and their nominated family carer. The constant comparison of data between and across cohorts informed data analysis. **Results:** 19 people with ID and 28 family members participated in this study and data revealed the long-term nature of caregiving. Internal and external factors were found to influence the roles of caregiving and receiving. Concepts of aging and decision-making were found to be dynamic across the lifespan; critical features of this inter-generational arrangement identified the complexity of these caregiving relationships. **Conclusions:** Navigating ever-
changing seas is the emergent theoretical model that resulted from this study. It illustrates both the dynamics and the caregiving implications for people with ID, family carers and health and disability service systems.

**The effect of familiarity of conversation participants on speaking roles contributed by individuals who use augmentative and alternative communication and individuals who use speech in Taiwan**

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**Aim:** The purpose was to determine the effect of familiarity of conversation participants on contributed speaking roles to dyadic conversation between individuals with developmental disabilities (DD) who use speech-generating devices (SGD) and individuals who use verbal speech. **Method:** Five individuals with DD (16 years and older) were recruited. They all used speech-generating devices (SGDs) as their primary mode of communication. Each individual completed six sessions of 20-minute conversation with a familiar conversation participant and an unfamiliar conversation participant, respectively. 60 sessions of conversations were analysed. Frequency and percentages of the contributed speaking roles were computed. **Results:** Asymmetries of contributed speaking roles exist in both familiar and unfamiliar dyadic conversation between individuals who use SGDs and those who use verbal speech. In addition, the mean percentage of the asymmetries of contributed speaking roles in familiar conversation dyads was significantly different from those in unfamiliar conversation dyads. **Conclusions:** In order to get co-construction and then achieve communication goals during a dyadic conversation, the individuals who use verbal speech might actively lead the conversation when the individuals who use SGDs passively play their conversation roles.

**Assessing cognition in interaction: A dynamic assessment approach to evaluate persons with multiple and sensory disabilities**

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**Aim:** The aim of this study was to find ways to observe and analyse elements of cognition in individuals usually considered as difficult or impossible to assess using psychological tools or instruments. **Method:** A qualitative study with 2-3 children having severe/profound intellectual and multiple (including sensory) disabilities was conducted. To find out how cognition is manifested in interaction, a dynamic assessment procedure was developed including individually modified Bayley Scales III (including modification of the equipment to emphasise tactual modality and stimuli attractiveness), and evaluation of environmental factors and the quality of interaction. Video recordings of assessment situations were analysed through theories of bodily tactile modality and information processing view on cognition, by coding non-linguistic elements of interaction. **Results:** The interactional dimension is essential to observe cognitive capacity. Modification of assessment equipment and procedure will be presented. **Conclusions:** There are suitable and non-suitable ways to accommodate the equipment, procedure and interaction. Cognition is manifested in individual ways of which certain common factors can be observed through precise video analysis.
Premier Practice Improvement Framework: A multi-modal learning and work practice support framework for non-practitioners providing behaviour support services in the disability sector

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**Aims:** Sometimes people with intellectual disabilities (ID) need behaviour support services to help them maintain their quality of life. It is important that the people providing this support are knowledgeable and skilled in the provision of positive behaviour support. The Premier Practice Improvement Framework (PIF) is a multi-modal professional development framework designed to develop knowledge and skills in positive behaviour support within the disability sector. This study evaluated the Premier PIF.

**Method:** 280 non-practitioners from a variety of non-government and government organisations have completed the Premier PIF. Pre-post participant knowledge and confidence data will be presented to highlight learning outcomes. **Results:** Preliminary findings suggest that the multi-modal design of Premier PIF met participants’ learning needs and has contributed to changes in confidence and work practices in positive behaviour support. **Conclusion:** Premier PIF provides a professional development and work practice support solution for non-practitioners involved in the provision of positive behaviour support services. This is of particular importance given there are currently no formal qualifications or peak professional bodies in behaviour support.

Family leadership development: A means of social change

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**Aim:** This study examines how families have taken opportunities through a formal leadership series to develop their leadership abilities and act collectively. **Method:** In this qualitative participatory research, a cross-section from 500 families (including siblings, parents with intellectual disabilities and grandparents) participated in this 15-year study through interviews, reflecting on actions taken both individually and collectively. **Results:** Applying the concept of normative pathways across major life domains, progress was measured in terms of improvements in the quality of inclusion, including substantive outcomes in access to inclusive post-secondary education, individualised funding and competitive employment. Collective action has led to the development of six new locally-based rural, urban and First Nations family advocacy organisations committed to inclusion. **Conclusions:** Inclusion Alberta’s Family Leadership Series has demonstrated value at the individual family level through personal actions but equally important, it has created a talented pool of knowledgeable families with the demonstrated capacity for action, enabling cross-generational change and organisational growth.

The oral health and dental needs of adults on the autism spectrum

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**Aim:** In Australia, little is known about the oral health and dental needs of adults with autism spectrum disorders (ASD) including potential barriers to dental care. The aim of this project was to describe the oral health and dental needs of adults with ASD in an Australian context. **Method:** An online survey
collected data on oral health and dental problems, dental care routines and experiences with dental professionals. 16 surveys were completed; 12 by the adult with ASC, of which one had intellectual disability, and four by a substitute decision-maker for an adult with intellectual disability. Descriptive statistics were used to describe the participants and their responses. **Results:** Almost all participants (14/16) reported disliking one or more of the following during a visit with a dental professional: drilling, bright lights, having someone put instruments in their mouth, smells, loud sounds and leaning back in the dentist’s chair. 4/16 required a general anaesthetic during treatment. **Conclusions:** This research highlights key barriers to oral health and dental care for adults with ASD that need to be addressed by dental professionals.

**Trial on investigating the relationship between direct perception and intellectual functioning in individuals with intellectual disabilities by using a dynamic touch task**

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**Aim:** Purpose was to investigate whether direct perception, thought to be a primitive perceptual system, could be kept within individuals with intellectual disabilities (ID) regardless of their level of intellectual functioning. **Method:** 17 individuals with ID and 21 without participated. Wearing an eye mask, participants were handed a bar, returned it to the experimenter, and then were asked to look and select the bar from nine choices. Percentage of correct answers (PCA) and absolute error (AE), defined as the average of the difference between the length of handed and selected bars, were calculated. Group (with ID and without) * length (short, middle, long) ANOVA for PCA and AE were conducted. **Results:** There were significant main effects of only length on PCA (F=26.148, p < .001, short > long > middle), and of both group and length on AE (F=5.640, p < .05, with > without; F=20.922, p < .001, middle > long > short). **Conclusions:** Direct perception might be kept in individuals with ID, but it is less accurate when details are to be specified.
Accuracy of WISC-III and WAIS-IV short forms in patients with epilepsy with and without intellectual disabilities

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Aim: This study examines the reliability and validity of WISC-III and WAIS-IV short forms in patients with epilepsy with and without intellectual disabilities (ID; FSIQ<70). A global estimate of intelligence is particularly useful for reassessing, screening, and research purposes, and reduces the burden of full-length assessment, especially in patients with ID. Method: Subjects were patients with epilepsy including 228 children (18% with ID) and 201 adults (23% with ID) who completed a WISC-III or WAIS-IV. The accuracy of short forms was analysed via correlation analyses, paired t-tests, and frequency analyses, for the groups FSIQ<70 and FSIQ>=70. Results: Estimated IQs correlated strongly with the actual FSIQ (rs=.76–.97). For children but not adults, the short form with best psychometric properties included a different subtest combination for those FSIQ<70 compared to FSIQ>=70. The actual FSIQ (within +/-5 points) was correctly identified in 79% and 73% of children and 80% and 76% adults, respectively. Conclusions: Short forms are appropriate to obtain an accurate estimate of intelligence for those with and without ID, although the choice of subtests should be adjusted to the presumed performance of children where possible.

Executive function, social information processing, and aggressive behaviour in youth with mild to borderline intellectual disabilities

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Aim: Executive function (EF) and social-information processing (SIP) have been studied separately as underlying factors of aggression in youth with mild to borderline intellectual disabilities (ID). However, cumulative or mediating mechanisms of EF and SIP associated with aggression remain unclear. This study adds to the knowledge of social-cognitive factors that may provide core aspects for guidance and behavioural interventions, specifically for youth with mild to borderline ID. Method: Over 160 children (8 to 12 years) and over 160 adolescents (13 to 17 years) participated. Their IQ ranged from 50 to 120. Digital performance tasks/games assessed EF. Videos of social situations measured SIP. T-scores of Child-Behavior-Check-List, Teacher-Report-Form, and Youth-Self-Report were used to assess aggression. Results: Relations between several EF, especially working memory, SIP steps, and aggression were found for both children and adolescents, with and without mild to borderline ID. Differences in pathways and further results are forthcoming. Conclusions: Indications are found for cumulative and mediating mechanisms of the social-cognitive factors EF and SIP towards aggression. Differences between age- and IQ-groups, and implications for behavioural interventions are discussed.

Implementing service-wide positive behaviour support: A case study

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Aim: The aim of this study was to reduce challenging behaviour and improve quality of life (QoL) through use of a service-wide, positive behaviour support intervention to improve the quality of social care support. Method: In a supported living setting for two adults with intellectual disabilities (ID), one of whom displayed high rates of challenging behaviour, we assessed quality of support, agreed planned improvements and supported staff to achieve the improvements. Results: 163 standards for improvement were set across eight areas of social care. The service achieved 92% of the standards in nine months. The staff team won an award for excellence, experienced reductions in stress and increases in job satisfaction. Both individuals with ID experienced significant QoL improvements. The individual with high rates of challenging behaviour’s Aberrant Behaviour Checklist score reduced from 67 to 14 post-intervention and 7 at follow-up 18 months later. Conclusions: The findings are promising and strongly suggest that future research on challenging behaviour should continue to investigate its prevention through intervention in the system of supports surrounding individuals at risk of developing or continuing to display challenging behaviour.

Quality of life: Listening to adults with intellectual disabilities in Chile

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Aim: This study examines how young people with intellectual disabilities (ID) in the V Region of Chile perceive their quality of life (QoL). Method: A quantitative observational design was used. The INICO-FEAPS Scale about QoL self-report version (Verdugo, Gomez Arias, Santamaria, Clavero & Tamarit, 2013) was administered to a convenience sample of 16 young people with ID. The participants’ ages ranged between 17 and 26 years; 75% were male. Results: The QoL dimensions of self-determination and rights obtained the lowest scores and the dimensions of personal development and physical well-being had the highest values. Conclusions: The perceptions of young people about their QoL can inform priority areas of support. This is consistent with the rights approach that considers the person as the main actor of his life thereby challenging current professional practice.

Self-perceptions of people with intellectual disabilities about their quality of life: A preliminary analysis of the dimensions of self-determination and rights

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Aim: We hypothesised that people with intellectual disabilities (ID) have low scores on self-determination and rights due to the lack of attention to their felt needs. Our goal was to describe the perceptions of adults with Down syndrome (DS) regarding their rights and opportunities for self-determination. Method: Four adults with DS were interviewed using the INICO-FEAPS Scale Quality of Life (Schalock & Verdugo, 2013). We used the ATLAS T 7 software to analyse the transcripts of the four interviews. This analysis consisted of a cyclical process of three activities: data reduction, interpretation and removing emerging reflections. Results: The adults interviewed perceive that others tell them what to do. They report that environments make it difficult for them to have opportunities to decide for themselves. As for the dimension of rights, they constantly refer to the right to freedom and mutual respect. Conclusions: It is important to address self-perceptions to identify the felt needs without
interference from third parties. In general, while recognizing the existence of rights, adults with ID may not perceive that they have rights.

**Constructing and evaluating the Grief-Cube**

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**Aim:** Researchers have acknowledged that adequate grief support enhances the quality of life of people with intellectual disabilities (ID). The aim of this research is to construct and evaluate a tool that enables staff to support people with ID during a grief process. **Method:** Based on current research and theories of grief and loss in the general population and in people with ID, a tool was designed called the Grief-Cube. The Grief-Cube covers six dimensions of the grief process and grief support. The comprehensibility and usability of the tool was assessed in two focus groups consisting of four professionals each. An advisory group consisting of professionals, people with ID and their relatives discussed the tool and its content. **Results:** The participants found the Grief-Cube to be an appropriate and accessible tool for learning more about grief and grief support of people with ID. **Conclusions:** The Grief-Cube is a potentially suitable tool for staff members to provide high quality grief support. In the next phase, the optimal way of use will be studied and its consequences evaluated.

**Self-determination in adolescents with intellectual disabilities: A confirmatory factor analysis of the ARC-INICO scale**

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**Aim:** The aim of this study is to analyse the internal structure of a new assessment tool developed in Spain (ARC-INICO Scale) to assess self-determination in adolescents with intellectual disabilities (ID) according to the Functional Self-determination Model. Self-determination is considered a right frequently demanded by people with ID; however, there are few tools to assess and promote self-determination. **Method:** The process of developing and validating this new instrument has been completed after an exhaustive review procedure and with the collaboration of different entities, professionals, and users. The sample of validation consisted of 279 young people with ID (aged between 11 and 19 years). **Results:** The Scale and its four sections (autonomy, self-regulation, empowerment and self-realisation) are reliable. Confirmatory factor analysis shows proof of validity based on the internal structure of the Scale, and confirms the correct fit of the proposed hierarchical structure. **Conclusions:** This tool provides reliable and valid information about self-determination and its domains. Its use may be useful in designing intervention strategies to improve self-determined behaviours and promote transition to adulthood.

**‘I feel in control of my life’: Exploring innovative forms of support through co-operative research**

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Aim: Nowadays, it is no longer possible for healthcare workers to regularly visit people with intellectual disabilities (ID) living independently. Therefore, Philadelphia Care Foundation started one-to-one support with specially trained professionals through a video-chatting program called Digicontact. This co-operative research evaluates whether Digicontact can improve life. Method: A researcher and a co-researcher with ID worked together on this study. The co-researcher interviewed 21 Digicontact users. Both researchers analysed and coded the interviews separately. Results: Firstly, participants are satisfied with Digicontact: it's easily accessible, good for a chat, practical advice and useful in case of emergency due to the 24/7 availability. Staff are more focussed on support than on troubleshooting and appear to stimulate self-sufficiency. Most participants use Digicontact in combination with a meeting point nearby where healthcare workers are available. Some participants are dissatisfied when the system/internet fails. Secondly, this research in co-operation was a satisfying learning experience. Conclusions: For people with ID living independently, Digicontact seems a good support in combination with a meeting point. Co-operative design is advisable when research concerns life of people with ID.

Identifying people with intellectual disabilities who may need palliative care: The development of a tool for practice

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Aim: Healthcare professionals are in need of support in identifying people with intellectual disabilities (ID) who may need palliative care. We aimed to develop a tool for this purpose. Method: With a survey for physicians about their last patient with ID with a non-sudden death and interviews with professionals regarding identifying palliative care needs, we were able to generate relevant items for the tool. These were subsequently prioritised in focus groups. The resulting preliminary tool was tested in a prospective follow-up study among 185 Dutch people with ID. At baseline, 5 and 10 months, professionals completed the tool and provided information on relevant health parameters. Results: The preliminary tool includes 39 questions, which can be answered either by the physician or by the professional caregiver with ‘yes’, ‘no’, or ‘don't know’. Preliminary results from the follow-up study suggest that the tool is considered feasible. People who died during follow-up had a higher score on the tool at baseline. Conclusions: The tool generates important information that may help professionals to identify and discuss those people with ID that may benefit from palliative care.

Patient and illness characteristics related to whether or not people with intellectual disabilities will die

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Aim: Mortality in people with intellectual disabilities (ID) is an important domain receiving increasing attention in research and practice. We explored which patient and illness characteristics are related to whether or not people with ID will die. Method: We followed 185 Dutch people with ID for 12 months. They were included if their principal physician indicated they would not be surprised if they died in the next year. Patient and illness characteristics were collected through surveys from physicians and professional caregivers, and by review of medical records. Results: After 12 months, 20% of the people...
had died. Preliminary results suggest that these people had a lower quality of life at baseline and had shown a greater overall decline in the past months. Furthermore, these people were more dependent in activities of daily living and were more often in need of symptom management (e.g., fatigue, dysphagia and dyspnoea). **Conclusions:** The results generate important information in the understanding of mortality of people with ID. Early awareness of people with ID nearing end-of-life helps to attain the highest quality of death and dying.

**Perceptions of healthcare professionals on identification of the need for palliative care in people with intellectual disabilities: An interview-based study**

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**Aim:** Healthcare professionals are increasingly confronted with people with intellectual disabilities (ID) in need for palliative care. We explored how this need is recognised in practice. **Method:** Semi-structured interviews with 10 physicians and 13 professional caregivers for people with ID in the Netherlands were conducted. **Results:** Identification of people in need for palliative care mostly results from a process in which multiple signs (e.g., changes in characteristic behaviour or functional decline) from different information sources converge and lead to a growing awareness. The process is influenced by the presence, stage and prognosis of diseases, professional-patient interaction, and interaction of physicians with professional caregivers as providers of contextual information. **Conclusions:** The interviews provide insights in when and how the need for palliative care is recognised in people with ID. These insights contain useful information for practice that may help to identify the need for palliative care in a timely fashion. Early provision of palliative care in the disease trajectories facilitates healthcare professionals to achieve the highest quality of life and dying for people with ID.

**Perceptions of physicians on recognition of people with intellectual disabilities nearing end-of-life: A retrospective survey**

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**Aim:** Little is known about when healthcare professionals recognise people with intellectual disabilities (ID) nearing end-of-life. We explored when and based on which signs physicians recognised that a patient with ID would die in the foreseeable future. **Method:** 97 Dutch ID-physicians and general practitioners completed a comprehensive retrospective survey about their last patient with ID with a non-sudden death. **Results:** In more than 20% of all cases physicians did not foresee death until the last week of life. The physician did not discuss the start of the palliative care phase until the last week in 30% of all cases. We found 40 different signs that lead to physicians foreseeing death. Physician-professional caregivers interaction is important in noticing and interpreting signs, as these are not only medical signs, but also include characteristic changes in behaviour and functional decline. **Conclusions:** Results suggest that physicians’ recognition of death in the foreseeable future is a challenge in patients with ID. Continuous interaction of physicians with providers of contextual information is needed for a timely awareness of patients’ death in the future.
Functional communication training and augmentative and alternative communication: A meta-analysis

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Aim: The purpose of this meta-analysis was to summarise single-case intervention research studies in which individuals utilising augmentative and alternative communication (AAC), including those with intellectual and developmental disabilities, received functional communication training (FCT) to address challenging behaviour. Method: Single-case intervention studies were identified and systematically reviewed to determine the overall effect of FCT on challenging and appropriate behaviour (e.g., AAC-based replacement behaviour) and whether study characteristics, including the specific training procedures employed (e.g., least-to-most prompting, time delay) moderated intervention outcomes. In addition, we summarised characteristics of study participants and settings, characteristics of FCT intervention applied within the studies, and quality of the studies. Results: Data collection is ongoing. Conclusions: Implications for practice will be discussed.

Poverty issue of people with disabilities and their rights to live: The challenge to citizenship rights concept

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Aim: People with disabilities have higher risk of falling into poverty than people without disabilities. Because disability and poverty are inextricably linked, poverty can never be eradicated until people with disabilities enjoy equal rights with people without disabilities. Method: We conducted a thematic analysis of papers identified through the Social Science Citation Index (SSCI). Using the keywords disability, poverty and rights, 138 papers published from 2010 to 2015 were identified. The main analysis, based on framework of right-based approach to human needs by Dean (2010), focussed on 11 papers. Results: These papers point out that people with disabilities living in poverty lack participation rights; namely related to employment, social activities and access to social environments. The claims-based rights of people with disabilities implies that that concept of passive-client-citizen transfers to active participating citizen thereby improving their subsistent rights. Conclusions: An examination of equal rights and how to include people with disabilities in society is important for them to have better life and get out of poverty.

The use of the Welsh Routes for Learning Assessment for learners with profound intellectual and multiple disabilities

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Aim: Routes for Learning is an assessment for learners with profound intellectual and multiple disabilities (PIMD) which was developed in Wales. It has been widely adopted by schools for learners with PIMD. This project aims to identify the numbers of UK schools using it, the reasons they have adopted it, and their perceptions of its advantages and disadvantages. Method: All schools for learners
with PIMD in the UK will be identified through use of relevant databases, and invited to take part in a brief questionnaire about their use of Routes for Learning. Returned surveys will be analysed using SPSS.

**Results:** Findings reported will include numbers of schools using Routes for Learning, schools’ rationale for adopting or deciding not to adopt it; perceived advantages and disadvantages of Routes for Learning as an assessment for learners with PIMD. **Conclusions:** The research will identify modifications to Routes for Learning which would make it easier to use, training which might help schools to use it more successfully, and potentially contribute to knowledge of any of the assessment items which cause particular difficulties.

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**Pain management during end-of-life care: Support for individuals with intellectual disabilities**

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**Aim:** Examining the provision of end-of-life care for individuals with intellectual disabilities (ID) is a relatively new research area, with limited investigation of how such support is provided. The aim of this study was to identify aspects of current end-of-life care practices considered by carers to be unsatisfactory. **Method:** Focus groups with a total of 35 participants were conducted in two capital cities and four rural centres in New South Wales and Queensland, Australia. A semi-structured guide was used, with one specific focus being on pain management issues. All focus group data were independently transcribed, and thematic analysis was undertaken. **Results:** The participants identified problems with pain management for people with ID. These issues included failure to recognise the need for any pain management, poor identification of pain, limited monitoring of pain, communication problems and inappropriate review of treatments. **Conclusions:** Specific recommendations are made for Australian-based health and community services that support individuals with ID during end-of-life. These recommendations are premised on explicit changes to daily practice that better meet the pain management needs of individuals during their end-of-life.

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**What influences women to not participate in breast screening?**

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**Aim:** Breast screening in Britain is free yet up-take of this service is often poor in women with intellectual disabilities (ID). Reasons suggested are numerous including poor knowledge, pain and difficulty travelling to the centre. This study explores what influences their decision to attend. **Method:** 12 semi-structured interviews and three focussed observations were undertaken with women with ID to explore what influenced them to participate in breast screening and their experience of having mammography. Data were analysed thematically using a blended framework. **Results:** Pain and previous poor treatment in hospital were reasons for non-participation in breast screening. Awareness about breast screening varied, however those who had previous breast problems were more knowledgeable. Paid carers played a key role, as means of support, information and a potential influence in determining participation in breast screening. **Conclusions:** Equality of access existed but an inequality in the preparation and delivery of the service which was dependent on a complex range of issues and relationships. Key to participation was preparation with the paid carer facilitating discussions.
Preparing Adult Nursing students to be better equipped to work with people with intellectual disabilities and those who support them

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Aim: The care of people with intellectual disabilities (ID) in hospitals has been consistently documented as poor. This study explores one way to raise awareness of people with ID in Adult Nursing students.

Method: Two higher education institutions hosted a two-day event consisting of lectures and discussions involving academics, health and social care service providers, service users, carers and practitioners in the field on intellectual disability. Year 1 Adult Nursing students (n=48) from one university with only Adult Nursing provision and Year 1 Learning Disability (ID) nursing students (n=45) from a second University were asked to evaluate the days. Results: 51 students completed the evaluation. Students reported increased knowledge of social care services and the role of the ID Nurse. Despite this, Adult Nurses felt the content was not always relevant to them.

Conclusions: Exposure to services for persons with ID can increase awareness for hospital staff not trained in ID. Although this event increased confidence, it relied on dedicated staff with an interest in the area as well as special funding.

What do health and social care staff want and need in terms of training in discussing death and dying?

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Aim: To explore what people who support people with intellectual disabilities (ID) need in terms of training/support to help with end-of-life care. Method: Four workshops were undertaken half for final year pre-registration learning disability nurses as well as NHS and third sector learning disability nurses in order to help understand what is currently provided, what is needed and if there is an appetite for training in this area. Using a scenario and discussion based learning format it is hoped that this will empower nurses to think more deeply and enhance confidence about discussing bereavement at an earlier stage. Data from evaluation forms were analyses thematically and using descriptive statistics.

Results: Total of 71 participants booked places but only 55 participants attended. Evaluations from 47 participants gave an 85.5% response rate. Participants wanted more training in this area especially on breaking bad news and discussing loss, end-of-life care/bereavement issues with people with ID.

Conclusions: Our findings support the evidence that end-of-life care is poor and that there is limited training available in this area.

Supporting the transition to adulthood for youth with intellectual disabilities through intergenerational mentoring at Men’s Sheds: A pilot study

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Aim: Design, pilot and evaluate the feasibility and appropriateness of a transition to work mentoring intervention at Australian community-based Men’s Sheds for youth with intellectual disabilities (ID).

Method: We trained older males (n=12) who were members of a Men’s Shed to mentor youth with ID (n=5) over a 10-week period. Mentors and mentees worked together on shared construction projects at the shed. Measures included social, vocational and well-being outcomes plus individual interviews with mentees and mentors about the appropriateness of the mentoring intervention. Results: Using a realistic evaluation framework, we identified a range of positive outcomes. Mentors offered graded support based on mentee strengths leading to a noted increase in mentee skills, confidence and social competence. Mentees found that the non-school setting made them feel special and enabled them to mix with others. Not all outcome measures were feasible due to communication deficits and perceptions that some measures (e.g., depression) were intrusive. Conclusions: With the right amount of training and support, community-based mentors are willing to provide targeted support to youth with ID offering an increase in skills, confidence and competence.

Children with intellectual disabilities, with or without Down syndrome, have lower peak oxygen uptake than typically developing children

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Aim: Peak oxygen uptake (VO₂peak) is the most widely used indicator of cardiorespiratory fitness. The purpose of this study was to investigate the VO₂peak in children with intellectual disabilities (ID) with or without Down syndrome (DS), and compare their values to typically developing (TD) children. Method: We performed a cross-sectional regression analysis in 210 untrained American and Spanish children aged 8 to 17 years, with and without ID. VO₂peak was determined with a graded exercise test on a treadmill using indirect calorimetry. Multivariate linear regression analyses were performed to determine the association of having ID, or DS (as independent variables) with VO₂peak (as dependent variables), controlling for sex, age, body mass index (BMI) and peak heart rate (HRpeak). Results: In the final model, group (ID, DS, TD), sex, BMI, and HRpeak were significantly contributing to VO₂peak (adjusted R²=62%). Conclusions: This study indicates that having ID, with or without DS, is associated with lower VO₂peak values, controlling for age, sex, BMI and HRpeak.

Prediction of maximum heart rate in children with intellectual disabilities

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Aim: Maximum heart rate (HRmax) is often used as the basis of exercise prescription. Several formulas use age to predict HRmax, but it is unknown how well these formulas predict HRmax in children with intellectual disabilities (ID). Method: In this study, we compared the model fit of three formulas to predict actual HRmax obtained during a maximal exercise test in 210 American and Spanish children with and without intellectual disabilities (ID) and/or Down syndrome (DS) (aged 8 to 17 years). Goodness of fit was studied using R-square statistics, for the whole group and the subgroups (ID, DS and no ID). Moreover, multivariate linear regression analysis was performed to determine the best fitting model to the sample. Results: The goodness of fit for the whole sample ranged from 7-44%, for the subgroups 0-
8%. In the newly developed best fitting model, age was not a significant contributor, only having ID or DS was a contributing factor (R²=45%). **Conclusions:** The studied formulas predicting HRmax with age are not suitable for children with or without ID.

**Support for a child with autism’s picky eating habits: The relationship between support type and original checklist**

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**Aim:** Some children with autism have picky eating habits. We examined the improvement of this through 3 types of special lunchtime diets and nutritional consulting (type1: changing food into favourite textures, tastes, and colours, type2: cutting food into favourite shapes, and recipes, type3: offering favourite food while encouraging inexperienced food). We made an original checklist for determining the most appropriate type of support and examined the relationship between the checklist and support type. **Method:** 45 parents of children with picky eating habits filled out the checklist upon entering the facility. We compared the result of the support type and the type determined by the checklist. **Results:** 95% of the children improved. The concordance between the checklist and best support was 75% for type1, 45.4% for type2, and 61.5% for type3. **Conclusions:** the checklist would be a good screening method for determining the type of support likely to be effective.

**The effects of tablet-based SDLMI intervention on academic engagement and problem behaviours of elementary school students with severe intellectual disabilities**

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**Aim:** This study examined the effects of tablet-based Self-Determined Learning Model of Instruction (SDLMI) intervention including visual aids for choice options on academic engagements and problem behaviours. **Method:** The participants were three students with severe intellectual disabilities (ID) in a special education classroom at an elementary school. The tablet-based SDLMI intervention including visual aids for choice options was implemented by the researcher for each student in the special education classroom during lunch time or after-school class. The multiple probe baseline across subjects design was applied to this study, including baseline, intervention, generalisation, and maintenance periods. **Results:** During the intervention, the positive academic engagement behaviours that the three students had chosen as their own goals were more frequently observed and their problem behaviours were less observed in Korean language class compared to those of the baseline period. These positive changes were also observed in math class and maintained after the intervention. **Conclusions:** This study provides researchers and practitioners with evidence that the tablet-based SDLMI intervention using visual materials is effective to improve behaviours of students with severe ID.

**Does perceived social support moderate the effects of caregiving stress on life satisfaction of siblings of people with intellectual disabilities in South Korea?**
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**Aim:** This study investigates whether perceived social support in siblings caring for people with intellectual disabilities (ID) can moderate the effects of caregiving stress on life satisfaction. **Method:** The sample includes 130 siblings of people with ID who participated in the Korean National Survey on Individuals with Developmental Disabilities and their Families in 2011. Time demands of caring (TDC) and caregiving stress (CS) were independent variables; perceived social support was used as moderator. Socio-demographic variables were controlled. Multiple regression analyses were used to address the research objective. **Results:** Siblings with higher levels of caregiving stress presented lower levels of life satisfaction, but those reporting higher levels of perceived social support presented higher levels of life satisfaction. Siblings with lower levels of perceived social support were more likely to be influenced by TDC compared to those with higher levels, indicating perceived social support moderates the relationship. **Conclusions:** The effect of TDC on life satisfaction varied by levels of perceived social support. Intervention aimed at improving perceived social support among siblings of persons with ID in South Korea is necessary.

**Constructing adulthood: Describing the goal-directed actions of young people with intellectual disabilities and their parents as the young persons move to adulthood**

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**Aim:** This study examines the transition to adulthood of young adults with intellectual disabilities (ID) as implemented in the joint actions between youth and their parents. Goal-directed actions in which the parent and young adult engage are identified, and ‘joint projects’ inferred to gain understanding of the strategies used when co-constructing and jointly shaping the youth’s move to adulthood. **Method:** The qualitative action-project method was employed in order to describe the parent-youth project. Parent and young adult dyads (n=9) were videotaped as they were discussing the youth’s transition to adulthood, followed by a self-confrontation interview asking about underlying cognitions and emotions during their discussion, and a closing feedback meeting offering the participants a narration of their observed joint actions and goals. **Results:** Preliminary joint projects include fostering independence, planning for the future, and improving social life. Differences and similarities of participants’ goals and strategies are discussed. **Conclusions:** Findings suggest that the goal-directed actions implemented by the parent and young adult provide critical insight in how both parties navigate and shape the young adult’s transition to adulthood.

**What is the impact of transition on health and well-being in young people with intellectual disabilities? A systematic review**

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**Aim:** A range of experiences, including health, independent living, and employment may be poorer in the population with intellectual disabilities (ID) than those without disabilities. As transition is a period
of vulnerability, it may be a risk period for poor health in young people with ID. We could find no existing synthesis of research on this topic: this review aimed to redress that gap. **Method:** PRISMA/MOOSE guidelines were followed. Six databases were electronically searched and reference lists, key journals and grey literature were hand searched. A second reviewer rated 10% of titles and abstracts to check agreement. **Results:** 11 articles met the inclusion criteria. The results were mixed and in places contradictory, indicating that, while there are multiple health and well-being issues present in this population during transition, including sexual health, obesity, and social conflict, parents rate their child’s quality of life positively, and more highly than young people rate their own health. Several studies had methodological limitations. **Conclusions:** This review reveals a gap in the literature on transition and health, and indicates a need for future work in this area.

**Research-supported practices for promoting employment outcomes**

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**Aim:** Successful and gainful employment is an essential part of quality of life (QoL) outcomes for individuals with intellectual and developmental disabilities (IDD). There is a need to review the literature to identify research supported practices in the transition to employment. **Method:** We conducted comprehensive reviews of the research literature on transition to employment from 1980 to 2014. The review process included development of search terms, identification of databases and other resources for the search, exporting identified abstracts to Refworks for screening, screening of abstracts, development and application of inclusion and exclusion criteria, and identification of research supported practices in the transition to employment. **Results:** A total of 3,423 abstracts were screened; 447 articles were reviewed, 333 of which met the inclusion criteria. The top three topics include vocational rehabilitation (100 articles), intervention/training (94 articles), and school vocational programming (63 articles). Key research on each topic in each decade has been identified. **Conclusions:** A set of transition to employment practices have empirical support and can be implemented in schools worldwide to help promote QoL outcomes for individuals with IDD.

**Community participation of adults with IDD in China**

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**Aim:** This study describes and analyses the community participation of adults with intellectual and developmental disabilities (IDD) in China. **Method:** We summarised the participating frequency in community activities (including public affairs, cultural activities, physical exercises and other social activities) among adults with IDD within one year. The data is from the Monitoring Survey on The Disabled in China in 2013 (n=2,003 with IDD). We mainly used the logistic stepwise regression model, and add independent variables into the model step by step in the following order: demographic characteristics, social economical characteristics. **Results:** Residence, gender, age, marital status, education level, household income and work experience have varying degrees of influence on the community participation of adults with IDD. **Conclusions:** Residence has the most significant impact on community participation; that is to say, adults with IDD who live in urban areas take part in community
activities more frequently. Besides, as the household income increases, the enthusiasm for attending community activities will also be heightened.