

# Abstracts of papers and posters from the IASSIDD 2016 conference relating to people with profound intellectual and multiple disabilities (and a few extras)

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*Compiled by Sheridan Forster*

2016 IASSIDD WORLD CONGRESS August 14-19, Melbourne, Australia

Abstracts organised alphabetical by first author

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B. Hemsley (bronwyn.hemsley@newcastle.edu.au)*, J. Steel, A. Georgiou, S. Hill, S. Balandin .....	13
T.-Y. Ho (assistentz.ncc@gmail.com)*, Y.-H. Chuang, C.- H. Yeh, Y.-T. Hsieh .....	14
S. Jansen (Suzanne.Jansen@sheerenloo.nl)* .....	14
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J. Lee (jy2712@hotmail.com)* .....	15
B. Maes (bea.maes@ppw.kuleuven.be)* .....	16
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J. Mckenzie (judith.mckenzie@uct.ac.za)* .....	17
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I. Rämä (irene.rama@helsinki.fi)*, E. Kontu, R. Pirttimaa .....	19
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A. Smidt (andy.smidt@sydney.edu.au)* .....	22
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A. Taheri (azint@yorku.ca)*, A. Perry, P. Minnes .....	23
L. Talman (lena.talman@mdh.se)*, C. Gustafsson, J. Stier, J. Wilder .....	23
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E. Tuomi (emmi.tuomi@rinnekoti.fi)*, A. Laitila.....	24
A. Urbanowicz (a.urbanowicz@uq.edu.au)*, J. Downs, S. Girdler, N. Ciccone, H. Leonard .....	24
L. van Alphen (h.j.m.van.alphen@rug.nl)*, A. Waninge, A. van der Putten .....	25
A. van der Putten (a.a.j.van.der.putten@rug.nl)*, A. Ter Haar, B. Maes, C. Vlaskamp .....	25
I. Van keer (ines.vankeer@ppw.kuleuven.be)*, K. Van Leeuwen, C. Vlaskamp, B. Maes .....	26
E. Walker (ellen.walker@postgrad.curtin.edu.au)*, M. Walker .....	26
J. Watson (joanne.watson@deakin.edu.au)*, E. Wilson .....	26
K. White (ktwhite90@gmail.com)* .....	27
D. Willis (d.willis2@napier.ac.uk)* .....	27

## Practical study concerning the development of a support programme for siblings and families of children with profound intellectual and multiple disabilities

M. Abe ([abe.mihoko@k.hokkyodai.ac.jp](mailto:abe.mihoko@k.hokkyodai.ac.jp))\*

*\*Hokkaido University of Education, JAPAN*

**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.

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

M. Barber ([drmarkbarber@hotmail.com](mailto:drmarkbarber@hotmail.com))\*

*\*Bayside Special Developmental School, AUSTRALIA*

**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.

## Dealing with specific cognitive dysfunctions and psychiatric vulnerability in persons with intellectual disabilities

M. Bertelli ([mbertelli@crea-sansebastiano.org](mailto:mbertelli@crea-sansebastiano.org))\*, D. Scuticchio, M. Rossi

*\*San Sebastiano Foundation, ITALY*

**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.

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

C. Bigby (c.bigby@latrobe.edu.au)\*, J. Beadle-Brown

*\*La Trobe University, AUSTRALIA*

**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.

## 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

L. Bossink (l.w.m.bossink@rug.nl)\*, A. van der Putten, C. Vlaskamp

*\*University of Groningen, THE NETHERLANDS*

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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

L. Bossink (l.w.m.bossink@rug.nl)\*, A. van der Putten, A. Waninge, C. Vlaskamp

*\*University of Groningen, THE NETHERLANDS*

**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.

## 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

S. Buell (s.buell@uea.ac.uk)\*, G. Pounds, K. Bunning, P. Langdon

*\*University of East Anglia, UNITED KINGDOM*

**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.

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

E. Burke (eburke1@tcd.ie)\*, P. McCallion, R. Carroll, J. Walsh, M. McCarron

*\*Trinity College Dublin, IRELAND*

**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  $R^2$ ) and 41.0% (Nagelkerke  $R^2$ ) 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.

## The effect of video-feedback on the communication between people with multiple disabilities and their social partners

S. Damen (s.damen@rug.nl)\*

*\*Royal Dutch Kentalis, THE NETHERLANDS*

**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.

## Lived experience of Microboards

E. Dickenson (jaquiemills@gmail.com)\*, B.-A. Robertson

*\*Blazing Condor Soul Explosions Inc., AUSTRALIA*

**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.

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

A. Emerson (anne.emerson@nottingham.ac.uk)\*, J. Dearden

*\*University of Nottingham, UNITED KINGDOM*

**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.

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

S. Everaarts ([s.everaarts@rug.nl](mailto:s.everaarts@rug.nl))\*, A. De Boer, A. van der Putten

*\*University of Groningen, THE NETHERLANDS*

**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.

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

S. Flynn ([S.Flynn.1@warwick.ac.uk](mailto:S.Flynn.1@warwick.ac.uk))\*, R. Hastings, CRG Severe Learning Disabilities, L. Vereenoghe

*\*University of Warwick, UNITED KINGDOM*

**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

S. Flynn ([S.Flynn.1@warwick.ac.uk](mailto:S.Flynn.1@warwick.ac.uk))\*, R. Hastings, CRG Severe Learning Disabilities, L. Vereenoghe

*\*University of Warwick, UNITED KINGDOM*

**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.

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

S. Forster ([sheridan.forster@monash.edu](mailto:sheridan.forster@monash.edu))\*

*\*Video Interaction Guidance, AUSTRALIA*

**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.

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

I. Ghosh ([indranilg2014@gmail.com](mailto:indranilg2014@gmail.com))\*, S. Balandin

*\*Indian Institute of Cerebral Palsy, INDIA*

**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.

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

J. Goldbart (j.goldbart@mmu.ac.uk)\*, D. Chadwick, S. Buell

*\*Manchester Metropolitan University, UNITED KINGDOM*

**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-focussed 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.

## Gamelan and students with complex needs: Communicating our common pulse

J. Goldbart (j.goldbart@mmu.ac.uk)\*, R. Swindells

*\*Manchester Metropolitan University, UNITED KINGDOM*

**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.

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

J. Goldbart (j.goldbart@mmu.ac.uk)\*, D. Chadwick, J. Jolliffe, A. Traynor, J. Barker, J. Holt

*\*Manchester Metropolitan University, UNITED KINGDOM*

**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.

## Anencephaly: Parents' perspectives on babies without cerebral cortex

H. Goll ([harald.goll@uni-erfurt.de](mailto:harald.goll@uni-erfurt.de))\*, M. Jaquier

*\*University of Erfurt, GERMANY*

**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.

## Beyond the limits of inclusion: Students with profound intellectual and multiple disabilities learning in regular classrooms

H. Goll ([harald.goll@uni-erfurt.de](mailto:harald.goll@uni-erfurt.de))\*

*\*University of Erfurt, GERMANY*

**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.

## Choking risk and repeated hospitalisation: Critical case results

B. Hemsley ([bronwyn.hemsley@newcastle.edu.au](mailto:bronwyn.hemsley@newcastle.edu.au))\*, J. Steel, A. Georgiou, S. Hill, S. Balandin

*\*University of Newcastle, AUSTRALIA*

**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 mealtime assistance in subsequent mealtime situations.

## The nature of interaction during storytelling between people with profound intellectual and multiple disabilities and caregivers

T.-Y. Ho ([assistentz.ncc@gmail.com](mailto:assistentz.ncc@gmail.com))\*, Y.-H. Chuang, C.-H. Yeh, Y.-T. Hsieh

*\*Kaohsiung Medical University, TAIWAN*

**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.

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

S. Jansen ([Suzanne.Jansen@sheerenloo.nl](mailto:Suzanne.Jansen@sheerenloo.nl))\*

*\*'s Heeren Loo Zorggroep, THE NETHERLANDS*

**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.

## Evaluation of the cognitive function in middle-aged adults with Down syndrome who have severe intellectual disabilities

M. Kaga ([kaga@ncnp.go.jp](mailto:kaga@ncnp.go.jp))\*, M. Inagaki, S. Oana

*\*Tokyo Metropolitan Tobu Medical Centre, National Institute of Mental Health & National Centre of Neurology and Psychiatry, JAPAN*

**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 ( $49.4 \pm 5.6$ ). 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 ( $23.1 \pm 6.2$ ) 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.

## 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

H.-C. Lee ([m1088@mail.maria.org.tw](mailto:m1088@mail.maria.org.tw))\*, H. Ho, I.-H. Lai, Y.-L. Hsieh

*\*Maria Social Welfare Foundation, TAIWAN*

**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.

## Disability support workers' perception of music therapy

J. Lee ([jy2712@hotmail.com](mailto:jy2712@hotmail.com))\*

*\*The University of Melbourne, AUSTRALIA*

**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.

## The OJKO-project: A longitudinal study on developmental trajectories and patterns of young children with a severe cognitive and motor developmental delay

B. Maes ([bea.maes@ppw.kuleuven.be](mailto:bea.maes@ppw.kuleuven.be))\*

*\*KU Leuven, BELGIUM*

**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

B. Maes ([bea.maes@ppw.kuleuven.be](mailto:bea.maes@ppw.kuleuven.be))\*, S. Colla, A. van der Putten

*\*KU Leuven, BELGIUM*

**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.

## Influence of staff responsivity on key word signing usage in adults with intellectual disabilities

B. Maes ([bea.maes@ppw.kuleuven.be](mailto:bea.maes@ppw.kuleuven.be))\*, E. Rombouts, I. Zink

*\*University of Leuven, BELGIUM*

**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.

## Changes in causative factors among residents of institutions for persons with severe motor and intellectual disabilities in Japan

T. Matsubasa ([ktpwk175@jcom.zaq.ne.jp](mailto:ktpwk175@jcom.zaq.ne.jp))\*, S. Kimiya

*\*Kumamoto University Hospital, JAPAN*

**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.

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

J. McKenzie ([judith.mckenzie@uct.ac.za](mailto:judith.mckenzie@uct.ac.za))\*

*\*University of Cape Town, SOUTH AFRICA*

**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.

## Common mealtime difficulties faced by Indian children with cerebral palsy and dysphagia

S. Paul ([swaruppaul1971@gmail.com](mailto:swaruppaul1971@gmail.com))\*, S. Balandin

*\*The Indian Institute of Cerebral Palsy, INDIA*

**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

A. Perry (perry@yorku.ca)\*, R. Shine, O. Weiss, P. Minnes

*\*York University, CANADA*

**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.

## Staff attributions about the causes of challenging behaviour in people with profound intellectual and multiple disabilities

P. Poppes (p.poppes@rug.nl)\*, A. van der Putten, A. ten Brug, C. Vlaskamp

*\*'s Heerenloo Zorggroep & University of Groningen, THE NETHERLANDS*

**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.

## Overview of interventions using video feedback to enhance interactions with people who are congenitally deafblind

M. Prain ([merryprain@gmail.com](mailto:merryprain@gmail.com))\*, S. Damen

*\*Able Australia, AUSTRALIA*

**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.

## Teaching without personal helpers: Exploring classroom interaction of pupils with autism spectrum disorder

I. Rämä ([irene.rama@helsinki.fi](mailto:irene.rama@helsinki.fi))\*, E. Kontu, R. Pirttimaa

*\*University of Helsinki, FINLAND*

**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 present. 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.

## Conversation strategies and systems analysis: A tool to identify 'hot spots' in conversations where augmentative and alternative communication is used

J. Remington-Gurney ([Janeremingtongurney@gmail.com](mailto:Janeremingtongurney@gmail.com))\*, J. Clapton

*\*Griffith University, AUSTRALIA*

**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.

## Understanding the culture of supported accommodation for individuals with severe/profound intellectual disabilities: Preliminary findings from 'good' services

L. Richardson (l.j.richardson-29@kent.ac.uk)\*, J. Beadle-Brown, C. Bigby, J. Bradshaw

*\*University of Kent, UNITED KINGDOM & La Trobe University, AUSTRALIA*

**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.

## Song versus speech with the hard to reach: Investigating interaction approaches with individuals with profound intellectual and multiple disabilities

R. Ridgway (r.a.ridgway@durham.ac.uk)\* *\*Durham University, UNITED KINGDOM*

**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.

## Survey of community-dwelling people with severe motor and intellectual disabilities in Aichi prefecture, Japan

H. Sakurako (sakurako@inst-hsc.jp)\*, M. Kiyokuni

*\*Aichi Human Service Center, JAPAN*

**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.

## Exploring the motor development of young children with possible severe to profound cognitive and motor developmental delay by means of a questionnaire

G. Schalen (g.h.schalen@rug.nl)\*, A. van der Putten, L. Visser, B. Maes, C. Vlaskamp

\*University of Groningen, THE NETHERLANDS

**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.

## Using risk assessment screening to determine need for dysphagia precautions

J. Sheppard (jjsheppard38@gmail.com)\*, B. Hemsley, S. Balandin

\*Columbia University, USA

**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 social inclusion in children with severe intellectual and developmental disabilities: Development of the GO4KIDDs Social Inclusion Coding Scheme

R. Shine ([rsshine@yorku.ca](mailto:rsshine@yorku.ca))\*, A. Perry, J. Bebko, P. Minnes, B. Ncube

*\*York University, CANADA*

**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 GO4KIDDs 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.

## Through the window: What can we learn about a person’s communication from a ten-minute video clip?

A. Smidt ([andy.smidt@sydney.edu.au](mailto:andy.smidt@sydney.edu.au))\*

*\*University of Sydney, AUSTRALIA*

**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.

## Texture and preparation of easy-to-eat food for persons with developmental disabilities and dysphagia in Japan

S. Sone ([sone-jes@umin.ac.jp](mailto:sone-jes@umin.ac.jp))\*, M. Mizukami, K. Asano, J. Fujitani, S. Hironaka, A. Kojo, T. Suzuki, I. Takehara

*\*Tokyo Metropolitan Higashiyamato Medical Center for Multiple/Developmental Disabilities, JAPAN*

**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.

## Visual functioning in persons with profound intellectual and multiple disabilities, with specific reference to cerebral visual impairment

M. Steendam ([mariekesteendam@visio.org](mailto:mariekesteendam@visio.org))\*, M. Wallroth

*\*Royal Dutch Visio, THE NETHERLANDS*

**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.

## Predictors of activity participation in children with IDD

A. Taheri ([azint@yorku.ca](mailto:azint@yorku.ca))\*, A. Perry, P. Minnes

*\*York University, CANADA*

**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.

## Insufficient documentation of participation: A study of contents in implementation plans for adults with profound intellectual disabilities

L. Talman ([lana.talman@mdh.se](mailto:lana.talman@mdh.se))\*, C. Gustafsson, J. Stier, J. Wilder

*\*Malardalen University, SWEDEN*

**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.

## Participation for adults with profound intellectual disabilities: Perceptions of managers and staff

L. Talman ([lena.talman@mdh.se](mailto:lena.talman@mdh.se))\*, J. Wilder, J. Stier, C. Gustafsson

*\*Malardalen University, SWEDEN*

**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.

## Assessing cognition in interaction: A dynamic assessment approach to evaluate persons with multiple and sensory disabilities

E. Tuomi ([emmi.tuomi@rinnekoti.fi](mailto:emmi.tuomi@rinnekoti.fi))\*, A. Laitila

*\*University of Eastern Finland, FINLAND*

**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.

## An exploration of the use of eye gaze and gestures in females with Rett syndrome

A. Urbanowicz ([a.urbanowicz@uq.edu.au](mailto:a.urbanowicz@uq.edu.au))\*, J. Downs, S. Girdler, N. Ciccone, H. Leonard

*\*Telethon Kids Institute, Edith Cowan University & University of Queensland, AUSTRALIA*

**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.

## Promoting physical activity participation among people with profound intellectual and multiple disabilities: An overview of practice-based knowledge

L. van Alphen ([h.j.m.van.alphen@rug.nl](mailto:h.j.m.van.alphen@rug.nl))\*, A. Waninge, A. van der Putten

*\*University of Groningen, THE NETHERLANDS*

**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.

## A literature review into available scientific knowledge in the support of people with profound intellectual and multiple disabilities

A. van der Putten ([a.a.j.van.der.putten@rug.nl](mailto:a.a.j.van.der.putten@rug.nl))\*, A. Ter Haar, B. Maes, C. Vlaskamp

*\*University of Groningen, THE NETHERLANDS*

**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.

## Parental behaviour towards children with a significant cognitive and motor developmental delay: Relation with children's interactive engagement and parents' social resources

I. Van keer ([ines.vankeer@ppw.kuleuven.be](mailto:ines.vankeer@ppw.kuleuven.be))\*, K. Van Leeuwen, C. Vlaskamp, B. Maes

*\*Catholic University of Leuven, BELGIUM*

**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.

## Microboard research and significance to disability reform in Australia

E. Walker ([ellen.walker@postgrad.curtin.edu.au](mailto:ellen.walker@postgrad.curtin.edu.au))\*, M. Walker

*\*Curtin University, AUSTRALIA*

**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.

## The relevance of Article 12 of the UNCRPD for people with severe or profound intellectual disability: Is supported decision-making for everyone?

J. Watson ([joanne.watson@deakin.edu.au](mailto:joanne.watson@deakin.edu.au))\*, E. Wilson

*\*Deakin University, AUSTRALIA*

**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.

## Individual factors contributing to the use of mechanical restraint on people with disabilities

K. White (ktwhite90@gmail.com)\*

*\*Deakin University, AUSTRALIA*

**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.

## Who decides: Women with severe and profound intellectual disabilities and mammography

D. Willis (d.willis2@napier.ac.uk)\*

*\*Edinburgh Napier University, UNITED KINGDOM*

**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, 10 paid-carers, 10 allied-professionals) were interrogated to identify those who worked with women with severe and profound ID. Data extracted were analysed thematically to identify how decisions about breast screening were managed. **Results:** Findings identified that due to the difficulties of gaining consent, the decision whether to participate was made by those who supported the women. These decisions also debated the need for sedation and whether the procedure was in the woman's best interest. **Conclusions:** Due to multiple health problems, decisions about attending breast screening were often based on a hierarchy of need and a debate about whether mammography was necessary.