



# FAMILIES SUPPORTING A CHILD WITH INTELLECTUAL OR DEVELOPMENTAL DISABILITIES: THE CURRENT STATE OF KNOWLEDGE

## FAMILIES SPECIAL INTEREST RESEARCH GROUP OF IASSID

### SUMMARY

This IASSID *Position Paper* provides a concise authoritative summary of: (1) existing scientific knowledge regarding the situation, challenges and well-being of families that include a child with intellectual and/or developmental disabilities; and (2) priorities for future research. IASSID ([www.iassid.org](http://www.iassid.org)) is the leading global organisation for researchers and research centres that seek to improve the understanding of and improve the lives of people with intellectual or developmental disabilities, their families and those who support them. The paper and the recommendations it contains have been developed through an iterative process led by IASSID's Families Special Interest Research Group (SIRG). During this process, all members of the Families SIRG and all members of IASSID's ruling Council have had opportunity to comment on drafts of this paper. The final *Position Paper* was adopted by the Council of IASSID on 9<sup>th</sup> July 2012.

### INTRODUCTION

This IASSID *Position Paper* provides a concise authoritative summary of: (1) existing scientific knowledge regarding the situation, challenges and well-being of families that include a child with intellectual and/or developmental disabilities; and (2) priorities for future research. We use the term intellectual and/or developmental disability to refer to people who either have an intellectual disability (a general impairment in cognitive functioning that is acquired during childhood and is commonly associated with impaired adaptive behaviours, World Health Organization, 1996) or a pervasive developmental disorder (e.g., autism). We use the term families to refer to all forms of family grouping (nuclear and extended) across the life course of the child with intellectual and/or developmental disabilities. While some children with intellectual and/or developmental disability will have a parent or parents with intellectual and/or developmental disability our focus is on the families of children (including adult children with intellectual and/or developmental disability. A recent IASSID position paper has addressed the situation of parents with intellectual disability (IASSID Special Interest Research Group on Parents and Parenting with Intellectual Disabilities, 2008).



It should be kept in mind throughout reading this position paper that *existing scientific knowledge* is not representative of the global situation of families supporting a child with intellectual or developmental disabilities. The vast majority of research in this area, and in relation to intellectual and/or developmental disability more generally, has been undertaken in English speaking high income countries (Emerson, Fujiura, & Hatton, 2007; Emerson, McConkey, Walsh, & Felce, 2008). As such, it privileges the situation of people in those countries; a pattern of inequity that is repeated across many areas of health and social research (Global Forum for Health Research, 2004).

Nevertheless, we consider it important at this stage in the development of this field to attempt to concisely summarise what is (and what is not) known. In undertaking this task we restricted judgements of 'what we know' to findings that have been replicated across time and/or settings from peer-reviewed publications of well-constructed research studies. In the final section of this position paper we turn to our recommendations for future priorities for research in this area. These will inevitably focus on issues and contexts about which the existing scientific evidence has very little to say (e.g., the situation of families supporting children with intellectual and/or developmental disability in low and middle income countries) and on emerging issues in the field.

## BACKGROUND

It has been estimated that 1-2% of the world's population have intellectual disabilities, with higher prevalence rates reported among children and adolescents and in lower income countries (Maulik, Mascarenhas, Mathers, Dua, & Saxena, 2011). The median prevalence for pervasive developmental disorders (which include autism and Asperger's syndrome) has been estimated at 6.2/1000 (Elsabbagh et al., 2012). Between 40-67% of children with pervasive developmental disorders also have intellectual disability (Baird et al., 2006; Chakrabarti & Fombonne, 2005). Given the current global fertility rate of 2.5 (Unicef, 2011), this suggests that between 1 in 50 and 1 in 20 families with children in the world include a child with intellectual disabilities. Ninety per cent of the world's children aged 0-14 live in low or middle income countries (World Bank, 2012).

International human rights conventions recognise the right of children to family life in the community (United Nations, 1989, 2006). In the vast majority of instances, children with intellectual disability are cared for by their parents who (along with other family members) serve as their most constant and life-long caregivers. They play a critical role in shaping the development and life experiences of their children with intellectual and/or developmental disability. In many contexts family involvement extends over the life span of parents, with siblings and extended family members taking on caring roles, especially when parents are no longer able to.



These conventions also require Member States of the UN to make every effort to ensure that when a family cannot care for a child, alternative arrangements are made either with the child's extended family or in substitute family settings in the community (United Nations, 2006, 2011). The continuing reliance in some countries on institutional provision for a minority of children with intellectual and/or developmental disability is a source of major concern (Council of Europe, 2008; United Nations, 2011; World Health Organisation Regional Office for Europe, 2010).

While families supporting children with intellectual and/or developmental disabilities are first and foremost families, they may in some cultures differ from families who do not include a child with disabilities in some important ways. These include: increased risk of exposure to socio-economic disadvantage; exposure to disability-related discrimination; coping with exceptional and prolonged caring tasks; complex interactions with disability services; and continuing to provide support into later childhood, adolescence and adulthood. Many of these differences are also shared by families supporting a child with other types of disabilities and are likely to vary as a function of social/cultural context and the nature/severity of the child's impairment. The general and specific challenges faced by families are addressed in more detail in the following section.

This *Position Paper* recognises the great diversity worldwide in the definition and nature of 'family' in relation to such issues as: family structure (e.g., one and two-parent headed families, child headed families, extended families); cultural beliefs and practices; and the availability of formal and informal support for families supporting a child with intellectual and/or developmental disability. We also recognise that families are dynamic systems changing in role and structure across their life course and in response to changing external contexts shaped by broader political, cultural, social and economic contexts.

## WHAT WE KNOW: FAMILY WELL-BEING

The majority of research in this area has focused on the well-being of individual family members, especially mothers. More recently, however, there has been growing interest in the conceptualisation and measurement of family quality of life (Brown, Schalock, & Brown, 2009; Hu, Summers, Turnbull, & Zuna, 2011; Samuel, Rillotta, & Brown, 2012; Zuna, Summers, Turnbull, & Hu, 2010) and of family dynamics (Llewellyn et al., 2010).



## MOTHERS

In general, mothers of children with intellectual disabilities report greater parenting demands than parents of non-disabled children, increased stress levels and poorer physical and psychological health (Blacher, Neece, & Packowski, 2005; Gerstein, Crnic, Blacher, & Baker, 2009; Miodrag & Hodapp, 2010; Olsson & Hwang, 2002; Saloviita, Italinna, & Leinonen, 2003; Singer, 2006). It should be noted, however, that in most studies the majority of mothers of children with intellectual disabilities report normative levels of well-being (Baker, Blacher, & Olsson, 2005; Glidden & Jobe, 2006; Glidden & Schoolcraft, 2003; Olsson, Larsman, & Hwang, 2008) and also report positive aspects of parenting their child with intellectual disabilities (Blacher & Baker, 2007; Green, 2007; Hastings & Taunt, 2002; Scorgie & Sobsey, 2000; Ylvén, Björck-Akesson, & Grandlund, 2006).

## FATHERS

Less attention has been paid to the well-being of fathers. The available evidence suggests that the association between parenting a child with intellectual disability and lower well-being is much less pronounced among fathers and fathers typically report lower levels of psychological distress than their spouses (Emerson et al., 2010; Gerstein et al., 2009; MacDonald & Hastings, 2010; Olsson & Hwang, 2001; Saloviita et al., 2003).

## SIBLINGS

As parents grow older, siblings may become carers (Heller & Arnold, 2010; Hodapp, Glidden, & Kaiser, 2005; Stoneman, 2005). Both benefits and disadvantages to siblings of children with intellectual disabilities have been reported in the literature (Blacher & Begum, 2011; Heller & Arnold, 2010; Hodapp et al., 2005; Mulroy, Robertson, Aiberti, Leonard, & Bower, 2008; Rossiter & Sharpe, 2001; Stoneman, 2005). Overall, it appears that siblings of children with intellectual and/or developmental disability are at minimal (if any) risk of psychosocial problems (Dew, Balandin, & Llewellyn, 2008; Heller & Arnold, 2010; Rossiter & Sharpe, 2001).

## PARENTAL SEPARATION AND DIVORCE

The available evidence suggests slightly higher rates of parental separation or divorce among families with a child with disabilities (Hartley et al., 2010; Hatton, Emerson, Graham, Blacher, & Llewellyn, 2010; Risdal & Singer, 2004), although not all studies have replicated these findings (Bengtsson, Hansen, & Røgeskov, 2011; Lundebj & Tøssebro, 2008; Urbano & Hodapp, 2007).



## WHAT WE KNOW: FACTORS ASSOCIATED WITH VARIATION IN FAMILY WELL-BEING

### CHILD CHARACTERISTICS

One of the most replicated findings in family research is that parental well-being is lower when children exhibit more maladaptive behaviour (Glidden, 2012). Results from different investigators and samples have demonstrated that it is child behavior problems, rather than intellectual disabilities *per se*, that are associated with lower levels of parental well-being (Nalavany, Glidden, & Ryan, 2009; Totsika, Hastings, Emerson, Berridge, & Lancaster, 2011) and sibling well-being (Hastings, 2007; Neece, Baker, & Blacher, 2010).

Research on behavioral phenotypes (Dykens & Hodapp, 2001; Dykens, Hodapp, & Finucane, 2000) has focused on individual differences as a function of diagnosis. An outgrowth of this work is the finding that the association between child disability and parental well-being is much less pronounced among parents of children with Down syndrome than among parents of children with other diagnoses (Corrice & Glidden, 2009; Urbano & Hodapp, 2007), especially autism (Esbensen, Bishop, Seltzer, Greenberg, & Taylor, 2010). Investigators relate this finding to the higher level of adaptive behavior exhibited by individuals with Down syndrome and widely documented higher prevalence of behavior problems among children with autism (Hartley, Sikora, & McCoy, 2008; Totsika, Hastings, Emerson, Lancaster, & Berridge, 2011).

### PARENTAL CHARACTERISTICS

The quality of evidence relating to parental characteristics associated with their well-being is currently relatively poor. Longitudinal research designs, allowing some understanding of causality, are rare, and systematic and quantitative reviews of research studies have not yet been published. A considerable difficulty in reviewing this evidence also relates to the wide variety of measures used and the lack of consistency of measurement across research groups and studies. What follows is a tentative summary of themes from existing published research derived from a consensus process.

For both mothers and fathers, a variety of personality factors and coping strategies have been reported to be related to parental well-being (Baker et al., 2005; Glidden, Billings, & Jobe, 2006; Glidden & Natcher, 2009; Hassall & Rose, 2005; MacDonald, Hastings, & Fitzsimons, 2010; Nachshen & Minnes, 2005; Oelofsen & Richardson, 2006; Olsson, 2008; Olsson et al., 2008; Paczkowski & Baker, 2008; Van der Veek, Kraaij, & Garnefski, 2009). The majority of parents with children with intellectual disabilities employ a variety of coping strategies to deal with the demands facing them (Glidden & Natcher, 2009; Lee, 2009). A larger repertoire of and greater use of coping strategies are related to increased well-being (Taanila, Syrjälä, Kokkonen, &



Järvelin, 2002). Mothers tend to use coping strategies more frequently than fathers, possibly as a consequence of mothers taking more responsibility for child care (Saloviita et al., 2003). The use of active or problem-focused coping strategies which emphasize efforts to seek social support, actively solve the problem, and positive reappraisal, appear to be recorded more frequently than other strategies and to be associated with more positive parental well-being (Glidden et al., 2006; Kim, Greenberg, Seltzer, & Krauss, 2003; Paczkowski & Baker, 2008; Van der Veek et al., 2009).

There is some evidence to suggest that stress processing abilities (coping) may be linked to personality factors which in turn are related to levels of well-being in parents of children with intellectual disabilities (Baker et al., 2005; Glidden et al., 2006; Glidden & Natcher, 2009; Glidden & Schoolcraft, 2003; Hassall & Rose, 2005; Hastings, 2002; Oelofsen & Richardson, 2006; Olsson et al., 2008; Ylvén et al., 2006). Personality seems to be a better predictor of adaptation for mothers, whereas coping strategies have been found to predict more variance for fathers (Glidden & Natcher, 2009).

The limited literature on parents who adapt and cope effectively suggests that optimism, hope, positive reframing of thoughts and attitudes about their circumstances may be important for adaptive parental coping (Baker et al., 2005; Hastings & Brown, 2002; Hastings & Taunt, 2002; Kausar, Jeven, & Sobsey, 2003; MacDonald et al., 2010). There is also some evidence of cultural variation. For example, in the US Latino families are more positive toward their children with intellectual disability; an effect that has been demonstrated across ages, level of intellectual disability and over time (Blacher & Baker, 2007; Blacher, Begum, Marcoulides, & Baker, in press; Blacher & Begum, 2011; Blacher & McIntyre, 2006).

Parents who themselves have intellectual disability (or borderline intellectual disability) face particular challenges in accessing the knowledge, resources and support that contribute to effective parenting (IASSID Special Interest Research Group on Parents and Parenting with Intellectual Disabilities, 2008; McConnell, Matthews, Llewellyn, Mildon, & Hindmarsh, 2008).

## CONTEXTUAL FACTORS

Overall, families supporting a child with intellectual disability are more likely than other families to be exposed to poverty and a range of associated environmental adversities, though the strength of this relationship will vary with the severity and cause of intellectual disability (Emerson, 2007, in press; Emerson & Hatton, 2010; Olsson & Hwang, 2008; Parish, Seltzer, Greenburg, & Floyd, 2004; Simkiss, Blackburn, Mukoro, Read, & Spencer, 2011; Zheng et al., 2012). A number of recent large-scale population-based studies have suggested that the poorer well-being of families supporting a child with intellectual disability may be attributable in large part to their increased rates of exposure to poverty associated environmental adversities



(Emerson, 2012; Emerson & Hatton, 2010; Olsson & Hwang, 2008). Divorce rates are likely to vary with context such as general divorce rates and also provision of supports. Recent Scandinavian studies show results diverging from the English-American literature, with similar and even lower divorce rates among families with disabled children (Bengtsson et al., 2011; Lundeby & Tøssebro, 2008).

People with intellectual disabilities are frequently a low priority in government planning and policy development. Governments may fail to provide essential services to people with intellectual disabilities and their families in such areas as education and employment thereby perpetuating the devaluation of persons with intellectual disabilities, as well as the stigma, exclusion, and shame associated with the disability (Adnams, 2010; World Health Organization, 2007; World Health Organization and the World Bank, 2011). Less than 50% of low or middle income countries report providing any support to families of children with intellectual and/or developmental disability in such areas as respite care, in-home support or advocacy (World Health Organization, 2007).

## WHAT WE KNOW: INTERVENTIONS/SUPPORTS FOR FAMILIES

Despite the large research literature on families of individuals with intellectual disabilities, published research focused on evaluation of interventions and supports for family members is limited. Especially in high income countries, considerable support services are provided for families. However, there are few examples of good quality research evaluations of various support models.

In general, there have been three types of interventions or supports for families that have been subject to research evaluation: (1) training for parents designed to improve their parenting skills; (2) psychological interventions for parents designed to reduce distress; and (3) supports designed to help the family as a whole or focused on family members other than parents.

### PARENTING SKILLS INTERVENTION

In common with the general research literature on parents of children with behaviour problems, most parenting skills training in the field of intellectual disability and autism uses behavioural methods. The focus is typically on skills for managing difficult behaviour as well as skills for building more positive child behaviours. Such interventions may also be combined with elements of stress management skills for parents themselves. Both the *Incredible Years* and *Triple P* parenting training interventions, considered as evidence-based outside of the disability field (National Institute for Health and Clinical Excellence & Social Care Institute for Excellence, 2006), have been tested and show positive results in terms of reduction in child behaviour problems in families of young children with intellectual disability and/or autism (McIntyre,



2008a, 2008b; Whittingham, Sofronoff, Sheffield, & Sanders, 2009). A systematic review of parent training interventions in the field of autism also concluded that there is good evidence generally of positive outcomes (Matson, Mahan, & LoVullo, 2009). A Cochrane review (Diggle, McConachie, & Randle, 2003) and recent randomized controlled trial evidence (Dawson et al., 2010) in the field of autism support the contention that parents can be successfully trained to deliver interventions for their children focused on communication and social skills. A meta-analysis of the secondary effects of behavioural parent training on parental psychological distress also concluded that these interventions have a positive but small secondary effect (Singer, Ethridge, & Aldana, 2007; Singer et al., 1999).

Training groups of parents may also be a cost-effective and practical method for offering intervention for families, and focused on outcomes for children with intellectual disability or autism, in low and middle income countries (Einfeld et al., 2012; Hastings, Robertson, & Yasamy, 2012; Robertson, Emerson, Hatton, & Yasamy, 2012). However, the quality of evidence in these settings is currently poor.

#### PSYCHOLOGICAL INTERVENTION FOR PARENTS

Singer et al. (2007) carried out a systematic review and meta-analysis of the impact of various interventions on parental distress (depression and related variables) even when the primary focus of the intervention may not have been stress reduction (i.e., behavioural parent training). Seventeen studies were included in the review, and results showed that cognitive behavioural interventions (CBT), behavioural parent training, and multi-component interventions all reduced parental distress. Larger reductions in distress were found for multi-component interventions (e.g., parent training, plus CBT, plus case management and/or respite care). However, only five studies included comparison against an active control intervention or an attention control condition. Given the lack of resources available to support families in several contexts (e.g., rural communities, low and middle income countries), parent-to-parent support models (parents trained to offer psychological/counselling support to other parents) are especially interesting. In a randomized waiting list control design effectiveness study (i.e., focused on support groups already established), Singer et al. (1999) found that those parents receiving support reported increased family strength and more progress towards meeting their current needs.

#### WHOLE FAMILY AND EXTENDED FAMILY MEMBER INTERVENTIONS

Individuals with a disability are part of a wider intergenerational family system including siblings, grandparents and other extended family members. Despite recognition that, on average, siblings may possibly be mildly negatively affected when they have a brother or sister with intellectual disability or autism (Rossiter & Sharpe, 2001), and that grandparents offer





significant support to families (Mitchell, 2007), interventions to support other family members' well-being have rarely been evaluated and certainly only with poor quality research designs.

Research reviews that examined one or more supports assessed at the family level (Dunst, Trivette, & Hamby, 2007; Gabovitch & Curtin, 2009; Kyzar, Turnbull, Summers, & Gómez, in press) conclude: (a) family-centered care may improve parental self-efficacy, supportive family partnerships with professionals, and child functioning; and (b) although designed to support families as a whole, family level outcomes were rarely measured for these interventions. High quality evidence (for example, in the form of good quality randomized controlled trials) was rare and difficult to evaluate in the context of these reviews.

In terms of respite care alone as an intervention model, systematic reviews have revealed poor research designs (none with a quality level higher than well-designed controlled studies that did not include random assignment) across the field of disability/healthcare needs as a whole (Robertson et al., 2011; Strunk, 2010). A tentative conclusion was that “respite care appears to result in reductions in psychological distress in parents of children with developmental disabilities” (Strunk, 2010). However, no quantitative analysis was performed and so the clinical significance of any potential gains is unknown. Again, although potentially designed to be a support to families, outcomes have typically been measured for parents only.

## SHAPING THE FUTURE: WHERE DO WE GO FROM HERE?

Families raising children with intellectual or developmental disabilities tend to face challenges above and beyond those faced by families raising ‘typically developing’ children. These challenges may relate to factors ranging from the increased rates of problem behaviours shown by children with intellectual and/or developmental disability and the high prevalence of autism amongst children with intellectual disability, to increased risk of exposure to poverty, stigma, and social exclusion. For many families, and especially families in low and middle income countries, these challenges will be exacerbated by the absence of effective and appropriate services and supports.

There are many ways to carry the research agenda in this area forward. The following list has been generated by IASSID’s Families SIRG and is intended to both summarize and stimulate the field. It should be considered within the context of other recent attempts to identify research priorities for children with intellectual disability and people with intellectual and/or developmental disability more generally (Emerson, Barron, et al., 2012).

## TAKING A GLOBAL PERSPECTIVE

In the introduction to this position paper we stressed that *existing scientific knowledge* is unrepresentative of the global situation of families supporting a child with intellectual or



developmental disabilities, privileging the situation of families in English speaking high income countries (Emerson et al., 2007; Emerson et al., 2008). Given that only 10% of the world's children live in these countries, there is a clear and compelling need for the intellectual and/or developmental disability research community to adopt a more global perspective. We need to know the extent to which the knowledge derived from the existing literature can be generalised to the situation of families living in the rest of the world. While some of this knowledge (e.g., the poorer well-being of families supporting a child with intellectual and/or developmental disability) may generalise (Ajuwon & Brown, 2012; D'Antonio & Shin, 2009; Ryu, 2009; Wang, 2009), there will certainly be many exceptions. Most importantly, we need to begin to build an evidence-base on what works in supporting families in diverse economic and cultural contexts (Emerson, Yasamy, & Saxena, 2012; Tomlinson et al., under review; World Health Organization and the World Bank, 2011).

#### BUILDING THE EVIDENCE BASE

In many areas the quality of evidence relating to families supporting a child with intellectual and/or developmental disability is currently relatively poor. Longitudinal research designs or well constructed randomized controlled trials, two approaches which allow some understanding of causality, are rare. Few studies are based on sizable representative samples of families. Systematic and quantitative reviews of research studies have yet to be published in many areas. A wide variety of measures are often to measure the same constructs. In short, we need better science. Research involving randomized controlled trials is appropriate for treatment and intervention studies, but there are many contributions of correlation-based research for building an evidence base. There is a pressing need for greater investment in undertaking systematic and comprehensive reviews, including, but not limited to meta-analyses. In addition, more attention needs to be paid to: (1) measurement and the selection of instruments for outcome variables that could be considered as a 'gold standard' for constructs of interest; (2) the extent to which evidence can be generalized across different children (e.g., children with intellectual disability with or without autism), families (e.g., single and dual parent families) and contexts (e.g., wealthy and poor families).

#### CONSIDER CONTEXTUAL FACTORS

As we noted in the introduction, families supporting children with intellectual and/or developmental disabilities differ in some cultures from other families in some important ways that relate to the families broader social context (e.g., increased risk of exposure to socio-economic disadvantage; exposure to disability-related discrimination; complex interactions with disability services). Relatively little attention has been paid to the impact that these and other contextual factors (e.g., overall levels of social inequality) may have on family well-being or the effectiveness of interventions and supports. For example, the impact of highly populated



urban settings on children needs to be understood in the lives of families raising a child with intellectual and/or developmental disability as does the influence of rurality on these families (Unicef, 2012). In addition, the study of families needs to extend beyond the home or place of residence. Research efforts should also target the relationship of family members to the school, the community, to the place of employment and possibly residence of the individual with intellectual disabilities. These contexts will change, but the family remains as a potential support to the individual throughout his or her lifespan.

#### TAKING A LONGITUDINAL PERSPECTIVE

Although potentially costly in both effort and resources, following families through time provides us with invaluable information that cannot be gained via one-time cross-sectional methods. We need more comprehensive and extended longitudinal studies of families. Greater exploitation of existing general longitudinal child development studies may, at times, provide a highly cost-effective option for undertaking longitudinal research (Emerson, 2012).

#### BROADEN THE CONCEPT OF FAMILIES

We know that worldwide, family structures extend beyond the nuclear family. The roles of siblings, fathers, extended family and alternative caregivers (other than mothers) in raising individuals with intellectual disabilities need to be documented, and economically feasible interventions utilizing their involvement developed. Future reviews of Family Quality of Life could add another dimension to our knowledge and understanding of families. Attention also needs to be paid to the possible intersection between parental and child disability and effective supports across the generations (Read, Blackburn, & Spencer, 2012).

#### CHALLENGING BEHAVIORS

Challenging behaviors continue to be – well – challenging, to family members and other caregivers. While applied behavior management and medication treatments have come a long way, the field still begs more easily exportable and translated interventions. This is an area where research evidence may not easily translate to low and middle income countries. Evidence-based treatments in high income countries are relatively expensive and rely on highly trained practitioners. Such finance and infrastructure are unlikely to be available elsewhere in the world.

#### BETTER USE OF TECHNOLOGY

The internet is perhaps the most exciting resource for bringing education, social support and to some extent intervention to families around the world. To date, it has served to connect families and provide much social support and information (Blacher & Baker, 2002; Hasman &



Zafron, 2010), but the future holds much promise for efforts in telemedicine (Kobak et al., 2011).

There is much to be done to broaden our knowledge base of families and intellectual disability, perhaps heeding Bertrand Russell's adage, "Science may set limits to knowledge, but should not set limits to imagination." With better funding from agencies that recognize the importance of family context and international collaborative efforts, we may be better able to support and intervene with all families supporting an individual with intellectual disabilities, regardless of their location, socioeconomic circumstances or access to research.

## REFERENCES

- Adnams, C. M. (2010). Perspectives of intellectual disability in South Africa: Epidemiology, policy, services for children and adults. *Current Opinion in Psychiatry*, 23, 436-440.
- Ajuwon, P. M., & Brown, I. (2012). Family quality of life in Nigeria. *Journal of Intellectual Disability Research*, 56, 61-70.
- Baird, G., Simonoff, E., Pickles, A., Chandler, S., Loucas, T., Meldrum, D., & Charman, T. (2006). Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP). *Lancet*, 368, 210-215.
- Baker, B. L., Blacher, J., & Olsson, M. B. (2005). Preschool children with and without developmental delay: Behavioural problems, parents' optimism and well being. *Journal of Intellectual Disability Research*, 49, 575-590.
- Bengtsson, S., Hansen, H., & Røgeskov, M. (2011). Børn med en funktionsnedsættelse og deres familier [Children with disabilities and their families]. Report 11:09. Copenhagen: Danish National Centre for Social Research.
- Blacher, J., & Baker, B. L. (2007). Positive impact of intellectual disability on families. *American Journal on Mental Retardation*, 114(5), 330-348.
- Blacher, J., & Baker, B. L. (Eds.). (2002). *The Best of AAMR: Families and Mental Retardation: A Collection of Notable AAMR Journal Articles Across the 20th Century*. Washington DC: American Association on Mental Retardation.
- Blacher, J., Begum, G., Marcoulides, G., & Baker, B. L. (in press). Longitudinal perspectives of child positive impact on families: Relationship to disability and culture. *American Journal of Intellectual and Developmental Disabilities*.
- Blacher, J., & Begum, G. F. (2011). Sibling relationship quality and adjustment: Considerations of family, genetics, cultural expectations and disability types. In R. Hodapp (Ed.), *International Review of Research in Developmental Disability*, Volume 41 (pp. 163-197). Chennai, India: Elsevier.
- Blacher, J., & McIntyre, L. L. (2006). Syndrome specificity and behavioural disorders in young adults with intellectual disability: cultural differences in family impact. *Journal of Intellectual Disability Research*, 50(3), 184-198.
- Blacher, J., Neece, C., & Packowski, E. (2005). Families and intellectual Disability. *Current Opinion in Psychiatry*, 18, 507-513.
- Brown, R. I., Schalock, R. L., & Brown, I. (2009). Quality of life: Its application to persons with intellectual disabilities and their families - Introduction and overview. *Journal of Policy and Practice in Intellectual Disabilities*, 6, 2-6.
- Chakrabarti, S., & Fombonne, E. (2005). Pervasive Developmental Disorders in preschool children: Confirmation of high prevalence. *American Journal of Psychiatry*, 162, 1133-1141.



- Corrice, A. M., & Glidden, L. M. (2009). The Down syndrome advantage: Fact or fiction? *American Journal on Intellectual and Developmental Disabilities, 114*, 254-268.
- Council of Europe. (2008). Recommendations and guidelines to promote community living for children with disabilities and deinstitutionalization, as well as to help families to take care of their disabled child at home. (Adopted 31. December 2007). Strasbourg.
- D'Antonio, E., & Shin, J. Y. (2009). Families of children with intellectual disabilities in Vietnam: Emerging themes. In R. M. Hodapp (Ed.), *International review of research in mental retardation, Vol. 38* (pp. 93-123). San Diego, CA: Academic Press/Elsevier.
- Dawson, G., Rogers, S., Munson, J., Smith, M., Winter, J., Greenson, J., . . . Varley, J. (2010). Randomized, controlled trial of an intervention for toddlers with autism: The Early Start Denver Model. *Pediatrics, 125*, 17-23.
- Dew, A., Balandin, S., & Llewellyn, G. (2008). The psychosocial impact on siblings of people with lifelong physical disability: A review of the literature. *Journal of Developmental & Physical Disability, 2*, 485-507.
- Diggle, T., McConachie, H. R., & Randle, V. R. (2003). Parent-mediated early intervention for young children with autism spectrum disorder. *Cochrane Database of Systematic Reviews*.
- Dunst, C. J., Trivette, C. M., & Hamby, D. W. (2007). Meta-analysis of family-centered helping practices research. *Mental Retardation and Developmental Disabilities Research Reviews, 13*(4), 370-378. doi: 10.1002/mrdd.20176
- Dykens, E. M., & Hodapp, R. M. (2001). Research in mental retardation: Toward an etiological approach. *Journal of Child Psychology and Psychiatry, 42*(1), 49-71.
- Dykens, E. M., Hodapp, R. M., & Finucane, B. M. (2000). *Genetics and mental retardation syndromes: A new look at behavior and interventions*. Baltimore: Paul H. Brookes Publishing.
- Einfeld, S., Stancliffe, R., Gray, K., Sofronoff, K., Emerson, E., & Yasamy, M. T. (2012). Interventions provided by parents for children with intellectual disabilities in low and middle income countries. *Journal of Applied Research in Intellectual Disabilities, 25*, 135-142.
- Elsabbagh, M., Divan, G., Koh, Y., Kim, Y. S., Kauchali, S., Marcín, C., . . . Fombonne, E. (2012). Global prevalence of Autism and other Pervasive Developmental Disorders. *Autism Research, 5*, 160–179.
- Emerson, E. (2007). Poverty and people with intellectual disability. *Mental Retardation and Developmental Disabilities Research Reviews, 13*, 107-113.
- Emerson, E. (2012). Understanding disabled childhoods: What can we learn from population-based studies? *Children & Society 26*, 214-222.
- Emerson, E. (in press). Commentary: Childhood Exposure to Environmental Adversity and the Well-Being of People with Intellectual Disabilities. *Journal of Intellectual Disabilities Research*.
- Emerson, E., Barron, D. A., Blacher, J., Brehmer, B., Clinch, S., Davidson, P. W., . . . Weber, G. (2012). *Better Health, Better Lives: Research Priorities*. Copenhagen: WHO European Regional Office.
- Emerson, E., Fujiura, G. T., & Hatton, C. (2007). International perspectives. In S. L. Odom, R. H. Horner, M. Snell & J. Blacher (Eds.), *Handbook on Developmental Disabilities*. New York: Guilford Press.
- Emerson, E., & Hatton, C. (2010). Socio-economic position, poverty and family research. In L. M. Glidden & M. M. Seltzer (Eds.), *On Families: International Review of Research on Mental Retardation*. New York: Academic Press.
- Emerson, E., McConkey, R., Walsh, P., & Felce, D. (2008). Intellectual disability in a global context. *Journal of Policy and Practice in Intellectual Disability, 5*(2), 79-80.
- Emerson, E., McCulloch, A., Graham, H., Blacher, J., Llewellyn, G., & Hatton, C. (2010). The mental health of parents of young children with and without developmental delays *American Journal on Intellectual and Developmental Disability, 115*, 30-42.



- Emerson, E., Yasamy, M. T., & Saxena, S. (2012). Scaling up support for children with developmental disorders in low and middle income countries. *Journal of Applied Research in Intellectual Disabilities*(25), 96-98.
- Esbensen, A. J., Bishop, S., Seltzer, M. M., Greenberg, J. S., & Taylor, J. L. (2010). Comparisons between individuals with autism spectrum disorders and individuals with Down syndrome in adulthood. *American Journal on Intellectual and Developmental Disabilities*, 115, 277-290.
- Gabovitch, E. M., & Curtin, C. (2009). Family-centered care for children with autism spectrum disorders: A review. *Marriage & Family Review*, 45, 469-498.
- Gerstein, E. D., Crnic, K. A., Blacher, J., & Baker, B. L. (2009). Resilience and the course of daily parenting stress in families of young children with intellectual disabilities. *Journal of Intellectual Disability Research*, 53, 981-997.
- Glidden, L. M. (2012). Family well-being and children with intellectual disability. In J. A. Burack, R. M. Hodapp, G. Iarocci & E. Zigler (Eds.), *The Oxford handbook of intellectual disability and development* (pp. 303-317). Oxford, UK: Oxford University.
- Glidden, L. M., Billings, F. J., & Jobe, B. M. (2006). Personality, coping style and well-being of parents rearing children with developmental disabilities. *Journal of Intellectual Disability Research*, 50(12), 949-962.
- Glidden, L. M., & Jobe, B. (2006). The longitudinal course of depression in adoptive and birth mothers of children with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 3, 139-142.
- Glidden, L. M., & Natcher, A. (2009). Coping strategy use, personality and adjustment of parents rearing children with developmental disabilities. *Journal of Intellectual Disability Research*, 998-1013.
- Glidden, L. M., & Schoolcraft, S. A. (2003). Depression: its trajectory and correlates in mothers rearing children with intellectual disability. *Journal of Intellectual Disability Research*, 47, 250-263.
- Global Forum for Health Research. (2004). The 10/90 Report on Health Research. Geneva, Switzerland: Global Forum for Health Research.
- Green, S. E. (2007). "We're tired, not sad": Benefits and burdens of mothering a child with a disability. *Social Science & Medicine*, 64, 150-163.
- Hartley, S. L., Barker, E. T., Seltzer, M., Floyd, F., Greenberg, J., Orsmond, G., & Bolt, D. (2010). The relative risk and timing of divorce in families of children with an autism spectrum disorder. *Journal of Family Psychology*, 24, 449-457.
- Hartley, S. L., Sikora, D. M., & McCoy, R. (2008). Prevalence and risk factors of maladaptive behaviours in young children with autistic disorders *Journal of Intellectual Disability Research*, 52, 819-829.
- Hasman, L., & Zafron, M. L. (2010). An analysis of online resources for parents, siblings, and other caregivers of adults with intellectual disabilities. *Journal of Consumer Health on the Internet*, 14, 33-41.
- Hassall, R., & Rose, J. (2005). Parental cognitions and adaptation to the demands of caring for a child with intellectual disability: A review of the literature and implications for clinical interventions. *Behavioural and Cognitive Psychotherapy*, 33, 71-.
- Hastings, R. P. (2002). Parental stress and behaviour problems in children with developmental disability. *Journal of Intellectual & Developmental Disability*, 27, 149-160.
- Hastings, R. P. (2007). Longitudinal relationships between sibling behavioral adjustment and behavior problems of children with developmental disabilities. *Journal of Autism and Developmental Disorders*, 37, 1485-1492.
- Hastings, R. P., & Brown, T. (2002). Coping strategies and the impact of challenging behaviours on special educators' burnout. *Mental Retardation*, 40, 148-156.



- Hastings, R. P., Robertson, J., & Yasamy, M. T. (2012). Interventions for children with pervasive developmental disorders in low and middle income countries. *Journal of Applied Research in Intellectual Disability, 25*, 119-134.
- Hastings, R. P., & Taunt, H. M. (2002). Positive perception in families of children with developmental disabilities. *American Journal on Mental Retardation, 107*, 116-127.
- Hatton, C., Emerson, E., Graham, H., Blacher, J., & Llewellyn, G. (2010). Changes in family composition and marital status in families with a young child with cognitive delay. *Journal of Applied Research in Intellectual Disabilities, 23*, 14-26.
- Heller, T., & Arnold, C. (2010). Siblings of adults with developmental disabilities: Psychosocial outcomes, relationships, and future planning. *Journal of Policy and Practice in Intellectual Disabilities, 7*, 16-25.
- Hodapp, R., Glidden, L., & Kaiser, A. (2005). Siblings of persons with disabilities: Toward a research agenda. *Mental Retardation, 43*, 334-338.
- Hu, X., Summers, J. A., Turnbull, A., & Zuna, N. (2011). The quantitative measurement of family quality of life: A review of available instruments *Journal of Intellectual Disabilities Research, 55*, 1098-1114.
- IASSID Special Interest Research Group on Parents and Parenting with Intellectual Disabilities. (2008). Parents labelled with Intellectual Disability: Position of the IASSID SIRG on Parents and Parenting with Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities, 21*, 296-307.
- Kausar, S., Jeven, R. F., & Sobsey, D. (2003). Hope in families of Children with developmental disabilities. *Journal on Developmental Disabilities, 10*, 35-46.
- Kim, H. W., Greenberg, J. S., Seltzer, M. M., & Krauss, M. W. (2003). The role of coping in maintaining the psychological well-being of mothers of adults with intellectual disability and mental illness. *Journal of Intellectual Disability Research, 47*, 313-327.
- Kobak, K. A., Stone, W. L., Wallace, E., Warren, Z., Swanson, A., & Robson, K. (2011). A web-based tutorial for parents of young children with autism: Results from a pilot study. *Telemedicine Journal and E-Health: The Official Journal of the American Telemedicine Association, 17*, 804-808.
- Kyzar, K. B., Turnbull, A. P., Summers, J. A., & Gómez, V. (in press). The relationship of family support to family outcomes: A synthesis of findings from research. *Research and Practice for Persons with Severe Disabilities*.
- Lee, G. K. (2009). Parents of children with high functioning autism: How well do they cope and adjust? *Journal of Developmental and Physical Disabilities, 21*, 93-114.
- Llewellyn, G., Bundy, A., Mayes, R., McConnell, D., Emerson, E., & Brentnall, J. (2010). Development and psychometric properties of The Family Life Interview. *Journal of Applied Research in Intellectual Disabilities, 23*, 52-62.
- Lundeby, H., & Tøssebro, J. (2008). Family structure in Norwegian families with children with disabilities. *Journal of Applied Research in Intellectual Disabilities, 21*, 246-256.
- MacDonald, E. E., & Hastings, R. P. (2010). Fathers of children with developmental disabilities. In M. E. Lamb (Ed.), *The Role of the Father in Child Development, 5th Edition* (pp. 486-516). Chichester: Wiley.
- MacDonald, E. E., Hastings, R. P., & Fitzsimons, E. (2010). Psychological Acceptance Mediates the Impact of the Behaviour Problems of Children with Intellectual Disability on Fathers' Psychological Adjustment. *Journal of Applied Research in Intellectual Disabilities, 23*, 27-37.
- Matson, J. L., Mahan, S., & LoVullo, S. V. (2009). Parent training: A review of methods for children with developmental disabilities. *Research in Developmental Disabilities, 30*, 961-968.



- Maulik, P. K., Mascarenhas, M. N., Mathers, C. D., Dua, T., & Saxena, S. (2011). Prevalence of intellectual disability: A meta-analysis of population-based studies *Research in Developmental Disabilities*, 32, 419-436.
- McConnell, D., Matthews, J., Llewellyn, G., Mildon, R., & Hindmarsh, G. (2008). "Healthy start." A national strategy for parents with intellectual disabilities and their children. *Journal of Policy & Practice in Intellectual Disabilities*, 5, 194-202.
- McIntyre, L. L. (2008a). Adapting Webster-Stratton's Incredible Years parent training programme for children with developmental delay: Findings from a treatment group only study. *Journal of Intellectual Disability Research*, 52(12), 1176-1192.
- McIntyre, L. L. (2008b). Parent training for young children with developmental disabilities: Randomized controlled trial. *American Journal of Mental Retardation*, 113, 356-368.
- Miodrag, N., & Hodapp, R. (2010). Chronic stress and health among parents of children with intellectual and developmental disabilities. *Current Opinion in Psychiatry*, 23, 407-411.
- Mitchell, W. (2007). The role of grandparents in intergenerational support for families with disabled children: A review of the literature. *Child and Family Social Work*, 12, 94-101.
- Mulroy, S., Robertson, L., Aiberti, K., Leonard, H., & Bower, C. (2008). The impact of having a sibling with an intellectual disability: Parental perspectives in two disorders. *Journal of Intellectual Disability Research*, 52(3), 216-229.
- Nachshen, J. S., & Minnes, P. (2005). Empowerment in parents of school-aged children with and without developmental disabilities. *Journal of Intellectual Disability Research*, 49, 889-904.
- Nalavany, B. A., Glidden, L. M., & Ryan, S. D. (2009). Parental satisfaction in the adoption of children with learning disorders: The role of behavior problems. *Family Relations*, 58, 621-633.
- National Institute for Health and Clinical Excellence, & Social Care Institute for Excellence. (2006). Parent-training/education programmes in the management of children with conduct disorders. London: National Institute for Health and Clinical Excellence.
- Neece, C. L., Baker, B. L., & Blacher, J. (2010). Impact on siblings of children with intellectual disability: The role of child behavior problems. *American Journal of Intellectual and Developmental Disabilities*, 115, 291-306. .
- Oelofsen, N., & Richardson, P. (2006). Sense of coherence and parenting stress in mothers and fathers of preschool children with developmental disability. *Journal of Intellectual & Developmental Disability*, 31, 1-12.
- Olsson, M. B. (2008). Understanding individual differences in adaptation in parents of children with intellectual disabilities: a risk and resilience perspective. In L. M. Glidden (Ed.), *International review of research in mental retardation*, 36 (pp. 281-315). Burlington: Academic Press.
- Olsson, M. B., & Hwang, C. P. (2001). Depression in mothers and fathers of children with intellectual disability. *Journal of Intellectual Disability Research*, 45(6), 535-543.
- Olsson, M. B., & Hwang, C. P. (2002). Sense of coherence in parents of children with different developmental disabilities. *Journal of Intellectual Disability Research*, 46, 548-559.
- Olsson, M. B., & Hwang, C. P. (2008). Socioeconomic and psychological variables as risk and protective factors for parental well-being in families of children with intellectual disabilities. *Journal of Intellectual Disability Research*, 52(12), 1102-1113.
- Olsson, M. B., Larsman, P., & Hwang, C. P. (2008). The relation between risk, sense of coherence and well-being in parents of children with and without intellectual disabilities. *Journal of Policy and Practice in Intellectual Disability*, 5, 227-236.
- Paczkowski, E., & Baker, B. (2008). Parenting children with developmental delays: The role of positive beliefs. *Journal of Mental Health Research in Intellectual Disabilities*, 1, 156-175.





- Parish, S. L., Seltzer, M. M., Greenburg, J. S., & Floyd, F. (2004). Economic implications of caregiving at midlife: Comparing parents with and without children who have developmental disabilities. *Mental Retardation, 42*(6), 413-426.
- Read, J., Blackburn, C., & Spencer, N. (2012). Disabled children and their families: A decade of policy change. *Children & Society, 26*, 223-333.
- Risdal, D., & Singer, G. H. (2004). Marital adjustment in parents of children with disabilities: A historical review and meta-analysis. *Research & Practice for Persons with Severe Disabilities, 29*(2), 95-103.
- Robertson, J., Emerson, E., Hatton, C., & Yasamy, M. T. (2012). The efficacy of community-based rehabilitation for children with or at significant risk of intellectual disabilities in low and middle income countries : a review. *Journal of Applied Research in Intellectual Disabilities, 25*, 143-154.
- Robertson, J., Hatton, C., Wells, E., Collins, M., Langer, S., Welch, V., & Emerson, E. (2011). The Impacts of short break provision on families with a disabled child: an international literature review. *Health & Social Care in the Community, 19*, 337-371.
- Rossiter, L., & Sharpe, D. (2001). The siblings of individuals with mental retardation: A quantitative integration of the literature. *Journal of Child and Family Studies, 10*, 65-84.
- Ryu, S. Y. (2009). Special education and social services in Korea: Past, present, and future. In R. M. Hodapp (Ed.), *International review of research in mental retardation, Vol. 38*, (pp. 125-146). San Diego, CA: Academic Press/Elsevier.
- Saloviita, T., Italinna, M., & Leinonen, E. (2003). Explaining the parental stress of fathers and mothers caring for a child with intellectual disability: a double ABCX model. *Journal of Intellectual Disability Research, 47*, 300-312.
- Samuel, P. S., Rillotta, F., & Brown, I. (2012). Review: The development of family quality of life concepts and measures. *Journal of Intellectual Disability Research, 56*, 1-16.
- Scorgie, K., & Sobsey, D. (2000). Transformational outcomes associated with parenting children who have disabilities. *Mental Retardation, 38*, 195-206.
- Simkiss, D. E., Blackburn, C., Mukoro, F. O., Read, J., & Spencer, N. (2011). Childhood disability and socio-economic circumstance sin low and middle income countries: systematic review. *BMC Pediatrics, 11*, 1471-2431.
- Singer, G. H. S. (2006). Meta-analysis of comparative studies of depression in mothers of children with and without developmental disabilities. *American Journal on Mental Retardation, 111*(3), 155-169.
- Singer, G. H. S., Ethridge, B. L., & Aldana, S. I. (2007). Primary and secondary effects of parenting and stress management interventions for parents of children with developmental disabilities: a meta-analysis. *Mental Retardation and Developmental Disabilities Research Reviews, 13*, 357-367.
- Singer, G. H. S., Marquis, J., Powers, L. K., Blanchard, L., Divenere, N., Santelli, B., . . . Sharp, M. (1999). A multi-site evaluation of Parent to Parent programs for parents of children with disabilities. *Journal of Early Intervention, 22*, 217-229.
- Stoneman, Z. (2005). Siblings of children with disabilities: Research themes. *Mental Retardation, 43*, 339-350.
- Strunk, J. A. (2010). Respite care for families of special needs children: A systematic review. *Journal of Developmental and Physical Disabilities, 22*, 615-630.
- Taanila, A., Syrjälä, L., Kokkonen, J., & Järvelin, M. R. (2002). Coping in parents with physically and/or intellectually disabled children. *Child: Care, Health and Development, 28*, 73-86.
- Tomlinson, M., Yasamy, M. T., Emerson, E., Officer, A., Richler, D., & Saxena, S. (under review). Setting research priorities for intellectual disabilities and autism: A priority setting exercise.



- Totsika, V., Hastings, R. P., Emerson, E., Berridge, D. M., & Lancaster, G. A. (2011). Behavior problems at five years of age and maternal mental health in autism and intellectual disability. *Journal of Abnormal Child Psychology*, *39*, 1137-1147.
- Totsika, V., Hastings, R. P., Emerson, E., Lancaster, G. A., & Berridge, D. M. (2011). A population-based investigation of behavioural and emotional problems and maternal mental health: Associations with autism spectrum disorder and intellectual disability. *Journal of Child Psychology & Psychiatry and Allied Disciplines* *52*, 91-99.
- Unicef. (2011). *The State of the World's Children 2011: Adolescence - An Age of Opportunity*. New York: UNICEF.
- Unicef. (2012). *The State of the World's Children: Children in an Urban World*. New York: Unicef.
- United Nations. (1989). *Convention on the Rights of the Child*. New York, NY: United Nations.
- United Nations. (2006). *Convention on the Rights of Persons with Disabilities*. New York: United Nations.
- United Nations. (2011). *Status of the Convention on the Rights of the Child: Report of the Secretary-General*. New York: United Nations.
- Urbano, R. C., & Hodapp, R. M. (2007). Divorce in families of children with Down syndrome: A population-based study. *American Journal on Mental Retardation*, *112*(4), 261-274.
- Van der Veek, S., Kraaij, V., & Garnefski, N. (2009). Cognitive coping strategies and stress in parents of children with Down syndrome: A prospective study. *Intellectual and Developmental Disabilities*, *47*, 295-306.
- Wang, P. (2009). Persevering in the face of hardship: Families of individuals with developmental disabilities in the people's Republic of China. In R. M. Hodapp (Ed.), *International review of research in mental retardation*, Vol. 38 (pp. 69-92). San Diego, CA: Academic Press/Elsevier.
- Whittingham, K., Sofronoff, K., Sheffield, J. K., & Sanders, M. R. (2009). Stepping Stones Triple P: A randomized controlled trial with parents of a child diagnosed with an Autism Spectrum Disorder. *Journal of Abnormal Child Psychology*, *37*, 469-480.
- World Bank. (2012). *World Development Report 2012: Gender Equality and Development*. Washington: World Bank.
- World Health Organisation Regional Office for Europe. (2010). *European Declaration on the Health of Children and Young People with Intellectual Disabilities and their Families*. Copenhagen: World Health Organisation Regional Office for Europe.
- World Health Organization. (1996). *ICD-10 Guide for Mental Retardation*. Geneva: World Health Organization.
- World Health Organization. (2007). *Atlas: Global Resources for Persons with Intellectual Disabilities 2007*. Geneva: World Health Organization.
- World Health Organization and the World Bank. (2011). *World Report on Disability*. Geneva: World Health Organization.
- Ylvén, R., Björck-Akesson, E., & Grandlund, G. M. (2006). Literature review of positive functioning in families with children with a disability. *Journal of Policy and Practice in Intellectual Disabilities*, *3*, 253-270.
- Zheng, X., Chen, R., Li, N., Du, W., Pei, L., Zhang, J., . . . Yang, R. (2012). Socioeconomic status and children with intellectual disability in China. *Journal of Intellectual Disabilities Research*, *56*, 212-220.
- Zuna, N., Summers, J. A., Turnbull, A., & Hu, X. (2010). Theorizing about family quality of life. In R. Kober (Ed.), *Enhancing the Quality of Life of People with Intellectual Disability* (pp. 241-278). Dordrecht: Springer.