Journal of Applied Research in Intellectual Disabilities 2008, **21**, 296–307

Parents labelled with Intellectual Disability: Position of the IASSID SIRG on Parents and Parenting with Intellectual Disabilities

IASSID Special Interest Research Group on Parents and Parenting with Intellectual Disabilities

Accepted for publication *14 March 2008*

Background On August 5th, 2006, the third meeting of the International Association for the Scientific Study of Intellectual Disabilities (IASSID) Special Interest Research Group (SIRG) on Parents and Parenting with Intellectual Disabilities was convened in Maastricht, The Netherlands, coinciding with the 2nd International Congress of IASSID-Europe. The SIRG Parents and Parenting with Intellectual Disabilities membership includes scholars from a number of countries including the United States, Canada, England, Germany, The Netherlands, Sweden, Denmark, Iceland, Japan, Australia and New Zealand. These scholars come from a range of academic and professional disciplines, including sociology, psychology, education, nursing, social work and occupational therapy.

Method This position paper developed by the Parenting SIRG brings into sharp relief the UN Convention on the Rights of Persons with Disabilities adopted by the General Assembly in December 2006. The convention affirms the right of persons with disabilities to marry and found a family (Article 23, (1)(a)). Further, states parties are bound to 'take effective action and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships…' (Article 23 (1)), and '…render appropriate assistance to persons with disabilities in the performance of their child-rearing responsibilities' (Article 23 (2)).

Results This position paper synthesizes messages from research about the challenges that parents labelled with intellectual disability face, and how they can be assisted in their parenting role.

Keywords: capacity building, intellectual disability, learning difficulties, parenting, parents

Position Précis

There is now over five decades of research that demonstrates that many parents with intellectual disability will succeed while others will struggle and lose custody of their children. As a group, parents labelled with intellectual disability face predictable but regrettable challenges. These include poverty, prejudice, and limited access to the resources that most other parents can take for granted, including for example, respect, moral support, information, good guidance and practical assistance. This paper strengthens the case for doing more to translate the principles of normalization and anti-discrimination and the findings from empirical research into policy and practice to support parents labelled with intellectual disability and their children.

Introduction

In one of the first scientific studies in the field, Mickelson (1947) investigated the adequacy of care and outcomes for 300 children of 'feeble-minded' parents. Over fifty years later, there are now more than 400 refereed journal articles in the field (abstracts available at http://www.healthystart.net.au). Although researchers have employed somewhat diverse systems for classifying and labelling people with intellectual disability, in line with the practice in their country of origin, the findings from this body of literature are remarkably consistent. This position paper begins by addressing the question 'who are parents labelled with intellectual disability?' This is followed by a brief discussion of challenges or barriers that parents labelled with intellectual disability typically face. We then present findings about the capacity of

10.1111/j.1468-3148.2008.00435.x

parents labelled with intellectual disability to raise children and the outcomes for their children. Findings from intervention studies are reviewed with some promising developments described briefly. This paper concludes with recommendations for policy and practice.

Who are parents labelled with intellectual disability?

Most parents labelled with intellectual disability have mild to borderline cognitive limitations. In high-income countries, where almost all of the research on the topic has been conducted, these parents fall into one of three groups. Firstly, there are those who, previously institutionalized, now live in the community and have had children. Then there are parents who, although never institutionalized, have received services for people labelled with intellectual disability more or less continuously for most of their lives. Third, there are those whom Edgerton (2001) refers to as the hidden majority. These are parents who, when at school were usually labelled as 'slow', having developmental delay, learning difficulties or intellectual disabilities. On leaving school, they live in the community with few if provided any specialized supports. It is only when they become parents that their general cognitive ability is questioned again. Historically, these three groups have been 'pooled' together for the purposes of research, with potential between-group differences remaining under-explored.

Several factors make it difficult to estimate the number of parents labelled with intellectual disability. These include the lack of a common definition of intellectual disability, variable population screening and diagnostic practices, inconsistent record-keeping, and the invisibility of many parents to official agencies. Consequently, mothers and fathers labelled with intellectual disability constitute a hidden population whose size is hard to estimate (Booth *et al.* 2005a). There is evidence; however, that referral of parents labelled with intellectual disability and their children for social and protective services is rising steadily in developed countries. Most health and social welfare practitioners, such as health visitors and midwives, community nurses, community disability team personnel and child welfare officers now have parents labelled with intellectual disability on their caseloads (Genders 1998; English 2000; McConnell *et al.* 2000a, 2000b; Guinea 2001).

Barriers to participation in the parenting role

People labelled with intellectual disability now enjoy a historically unprecedented opportunity to become parents, yet significant barriers persist. One barrier is continuing opposition from others to their child-bearing. Llewellyn (1994) for example reported that the announcement of pregnancy was often met with disbelief or dismay from family, friends and the community more broadly. Similarly, Booth & Booth (1995) observed that becoming pregnant was often viewed by others as a mistake never to be repeated rather than an event to be celebrated. More recently, Mayes *et al.* (2006) also found that women labelled with intellectual disability encounter significant opposition to their child-bearing. This opposition may take the form of pressure to have an abortion (Booth & Booth 1995; Sigurjonsdottir & Traustadottir 2000; Mayes *et al.* 2006). Opposition often intensifies once the child is born. Some parents labelled with intellectual disability are not allowed to take their child home from the birthing centre or hospital. Others face ongoing scrutiny and live with an ever-present fear that 'the welfare is coming' to take their child away. All too often that fear is realized. The separation of children from parents labelled with intellectual disability is discussed below.

Parents labelled with intellectual disability often lack the resources that most other parents count on, for example, safe and suitable housing, and an adequate subsistence base. Although the level of income support and accommodation assistance for parents labelled with intellectual disability varies from country to country, most are impoverished relative to other parents in their community. Poverty is a significant barrier to good parenting. Good health is another vital resource for parenting. Mickelson (1947) found that poor mental health was prevalent in a sample of ninety 'feeble-minded' mothers, and was a primary influence on the quality of care given to their children. More than 50 years later, Llewellyn *et al.* (2003a, 2003b, 2003c) investigated the self-reported mental health status of 50 mothers with intellectual disabilities using the MOS SF-36 health survey and found that they reported significantly poorer mental health than their similarly socio-economically disadvantaged peers. Overall, parents labelled with intellectual disability, as a group, report higher levels of stress, depression and generally poorer mental health than their peers (Mickelson 1947; Tymchuk 1994; Feldman *et al.* 1997; Llewellyn *et al.* 2003a, 2003b, 2003c). Further research is needed to identify the processes underlying these health inequalities. A number of conditions may contribute including higher exposure to poverty, stigma and social exclusion, and, limited access to health promoting services.

> 'Parents labelled with intellectual disability, as a group, report higher levels of stress, depression and generally poorer mental health than their non-labelled peers'

Parents labelled with intellectual disability also lack access to the learning opportunities and support that other parents can take for granted. Most other parents have positive parenting role models, but this is not the case for many parents labelled with intellectual disability, particularly those who have grown up in institutions or in out-of-home care. Most other parents can access popular literature and educational materials on pregnancy and parenthood. Parents labelled with intellectual disability have great difficulty sourcing, understanding and applying this information. Most other parents have a network of people to whom they can turn for reassurance, practical help and guidance. Research into the support networks of parents with intellectual disabilities has found that, on average, they have smaller support networks compared to other parents in the community, and they report lower levels of perceived social support (Llewellyn *et al.* 1999; Feldman *et al.* 2002; Llewellyn & McConnell 2002; Stenfert Kroese *et al.* 2002).

> 'Parents with intellectual disabilities tend to have smaller support networks compared to other parents in the community, and they report lower levels of perceived social support'

Further, while most other parents can access formal or professional services when needed, these services are rarely equipped to support parents labelled with intellectual disability (Goodringe 2000; Tarleton *et al.* 2006). Health and human service professionals often lack time, training (knowledge & skills) and material resources (e.g. evidence-based parenting programs) to work effectively with these parents (McConnell *et al.* 1997). Centre-based and/or group-based parent training programs in the community often exclude parents labelled with intellectual disability because they are not able to accommodate their special learning needs. Even those services that are more welcoming may inadvertently disadvantage parents labelled with intellectual disability by being time-limited when these parents need flexible support, varying in intensity, over a longer time (McConnell *et al.* 1997; Tarleton *et al.* 2006).

> 'Parents labelled with intellectual disability need flexible support, varying in intensity, and over a longer time'

Capacity of parents labelled with intellectual disability to raise their children

With respect to parenting capacity, above an IQ of 60 parental intelligence (IQ) is not systematically correlated with parenting capacity or child outcomes. Researchers have employed a variety of research designs and methods to assess adequacy of parental care. Early research employed review of welfare records and professional (third-party) observation and opinion (e.g. Ainsworth *et al.* 1945; Mickelson 1947; Mattinson 1970; Scally 1973; Berry & Shapiro 1975; Floor *et al.* 1975). Subsequent research used more systematic methods including standardized measures and behavioral checklists (e.g. Feldman *et al.* 1985, 1986; Keltner 1992, 1994; McConnell *et al.* 2003; Tymchuk 1990a, 1990b). This body of research demonstrates that few generalizations can be made about the parenting abilities of parents labelled with intellectual disability. Professionals must therefore regard each parent as an individual rather than as a member of a category (Budd & Greenspan 1984; Taylor 1994).

> 'Professionals must regard each parent as an individual rather than as a member of a category'

There is little robust data to explain why some parents labelled with intellectual disability 'succeed' while others struggle. That said several factors are thought to offer some parents a general advantage. One factor is informal and formal social support, although how parents think about the support they receive is critical to support being helpful (e.g. Tucker & Johnson 1989; Tymchuk 1992; Aunos *et al.* 2004). Tucker & Johnson (1989) observed that support which is competence-promoting helps parents to learn and achieve by themselves. Support, however, can also be competence-inhibiting when others criticize or 'do-for' the parents, thus undermining the parent's confidence and denying them opportunities to learn. Another factor is the absence of co-morbidity, including mental illness and physical disability (e.g. Mickelson 1947; McGaw *et al.* 2007). Other factors believed to contribute to a general advantage profile include no personal history of maltreatment or childhood trauma, positive parenting role model/s, a supportive and healthy partner, an intelligence quotient above 60, fewer children, and children without special needs (Andron & Tymchuk 1987; Tymchuk 1992; Feldman 2002; McGaw *et al.* 2007).

The frequently seen focus on individual parent knowledge and skills as the determinant of parenting capacity, has been called into question by social-ecological theories of child development which promotes parenting as a social rather than a solo activity (Booth & Booth 2000). These theories, in contrast to assuming that only parents affect child outcomes, propose that many people and circumstances influence childrens' life chances (Llewellyn & McConnell 2004). This social-ecological conceptualization regards parenting as the work of many to meet the needs of a child for preservation (physical care needs), nurturance (emotional and intellectual needs) and socialization (learning to 'fit-in' to society). From this perspective, parenting capacity is a quality of the child's environment or social milieu rather than a quality possessed by any one individual (i.e. a mother or father). A social-ecological assessment of parenting capacity considers the complex interplay between children and their parents, home and community environments, and family and human service systems (Feldman 2002; McConnell & Llewellyn 2005).

> 'Social-ecological assessment of parenting capacity considers the complex interplay between children and their parents, home and community environments, and family and human service systems'

Outcomes for children of parents labelled with intellectual disability

There are two distinct periods of research into outcomes for children of parents labelled with intellectual disability. Pre-1980s research discredited the earlier eugenic fear that if people labelled with intellectual disability were allowed to 'breed', they would infect the human gene pool by reproducing 'imbeciles' in untold numbers. Research findings demonstrated that people labelled with intellectual typically do not produce a higher than average number of children and that, on average, their children have significantly higher IQs and most have IQs above 70 (and within one standard deviation of the mean) (Penrose 1938; Mickelson 1947; Brandon 1957; Shaw & Wright 1960; Reed & Reed 1965; Laxova *et al.* 1973; Scally 1973). Brandon (1957) assessed the intellectual status of 108 children of 73 'certified mental defectives' mothers (mean IQ~73.5) who were former patients at the Fountain Hospital in London, UK. Various measures of intelligence were employed and four statistical methods were used to synthesize the results. These four methods produced mean IQ scores ranging from 91.2 to 94.5. Only 3.7% of the children were identified as 'mentally defective'. In another early study, Ainsworth *et al.* (1945) followed up 50 women (mean IQ~68.2) who were former residents of the Wayne County Training School in Detroit, USA. These 50 women had 115 living children between them, aged 7 years and 4 months on average. This study assessed the general behaviour and social maturation of the children. The general behaviour of 94% of these children was rated as 'fair' or 'no problem' on the basis of their mothers' descriptions. In addition, the children were assessed using an abbreviated version of the Vineland Social Maturity Scale. On this measure, 89% of the children were graded as developing in accord with or above age expectations.

> 'People labelled with intellectual typically do not produce a higher than average number of children and … most have IQs above 70 and within one standard deviation of the mean'

From the 1980s onwards, researchers have expanded the range of child outcomes examined. A major limitation is that most of the studies are conducted with mothers who attend clinics, which introduces a clinical population bias to the findings. That said, the research as a whole suggests that children of parents labelled with intellectual disability, as a group, are at risk for poor development outcomes. In the USA, for example, Keltner *et al.* (1999) examined the developmental status of 70 two-year old children, 38 born to low-income mothers with intellectual 'limitations' (IQ < 75) and 32 born to low-income mothers without such limitations matched for age, race and the number of viable pregnancies. Using the Bayley Scales for Infant Development, 42% of the children of parents with intellectual limitations and 12% of children in the comparison group were assessed as developmentally delayed. In Canada, Feldman & Walton-Allen (1997) looked at outcomes for children 6–12 years of age. Twenty-seven children of mothers with 'mental retardation' (IQ < 70) were compared with 25 children of mothers without mental retardation, recruited from the same low-income neighbourhoods, on measures of intelligence, academic achievement and child behaviour. Although the outcomes for the children of mothers with mental retardation were diverse with many exhibiting no problems, on average, their performance on measures of IQ, reading, spelling and math was poorer than the comparison group, and more behaviour problems were observed.

Qualitative methods have been used to investigate life experiences and outcomes for children of parents labelled with intellectual disability. In Denmark, Faureholm (2006) interviewed 20 young adult-children of mothers with intellectual disability. Overall, these young people recounted stressful childhoods. They recalled at times being bullied, ostracized and rejected by other children, attributed in part to the stigma of having a mother with disability. Despite the difficult circumstances of their growing-up, most of the young people discovered an underlying personal strength that enabled them to overcome this experience, and all but one maintained a close and warm relationship with their parents. In England, Booth & Booth (2000) also interviewed adult-children of parents with 'learning difficulties'. The majority recalled happy, if not necessarily carefree, childhoods. Only three regarded their childhoods as wholly unhappy. Significantly, most (24 of 30) of the interviewees expressed positive feelings of love and affection towards their parents with learning difficulties. All of the adult-children maintained close contact with their parents and most said that they were particularly close to their mothers. Those who had been removed by child welfare authorities had subsequently re-established and maintained contact with their surviving parents. In both studies, family bonds endured despite time and circumstance intervening. This led Booth & Booth (2000) to observe, '(t)he general conclusion seems to be the obvious one: people love their parents despite and not because of who they are' (p. 28).

Research is only just beginning into the factors that predict child outcomes and in particular to determine which children fare better and under what circumstances. For example, Feldman & Walton-Allen (1997) have reported an association between maternal social support and child outcomes. Feldman *et al.* (2002) found an association between social support and maternal stress, and in turn, Aunos *et al.* (2004) report significant correlations between maternal stress, parenting style and child behaviour problems. Another small sample study has drawn attention to the potential influence of pregnancy and birth outcomes. McConnell *et al.* (2003) investigated the developmental status of 37 pre-school aged children of mothers with intellectual disability. Between one-third and one-half of these children demonstrated delay of at least 3 months in one or more developmental domains. The relationships between developmental status and selected child, maternal and home/environment characteristics were examined. Only pregnancy and birth outcomes explained the observed variation.

Child welfare intervention and family outcomes

Parents with intellectual disability are more likely than any other group of parents to have their children removed by child welfare authorities and permanently placed away from their home (Booth *et al.* 2005a, 2005b). In the United States, analysis of the 1994/5 National Health Interview Survey data identified 430, 257 adults with mental retardation and/or developmental disabilities (MR/DD) who had a living child (28% of all adults with MR/DD in non-institutional settings) (Larson *et al.* 2001). Of these, 219 357 (51%) had a child who lived with them. Although child separation is only one possible reason why 49% of the identified parents with MR/DD were not living with their child/ren, this figure is consistent with earlier reports from the United States by Accardo & Whitman (1990) in St Louis, and the New York State Commission on Quality of Care for the Mentally Disabled (1993) on the proportion of children removed from parents labelled with intellectual disability/mental retardation. In England, the first national survey of adults with 'learning difficulties' found that 48% of parents with cognitive limitations interviewed were not living with their children (Emerson *et al.* 2005). Again, others factors, such as children growing up and leaving home may contribute to this figure, but a similar figure was earlier reported by Nicholson (1997) who found that 48% of children of parents with cognitive limitations in his Nottinghamshire study had been adopted, fostered or placed with kin. Studies in other European countries, including Denmark, Sweden, Norway, Germany and Belgium, report figures ranging from 30% to 45% of children permanently placed away from their family home (Gillberg & Geijer-Karlsson 1983; Van Hove & en Wellens 1995; Faureholm 1996; Mørch *et al.* 1997; Pixa-Kettner 1998). In Australia and New Zealand respectively, Bowden (1994) and Mirfin-Veitch *et al.* (1999) report similar figures of 30% and 45%.

A substantial proportion of all matters in children's welfare courts appear to feature parents labelled with intellectual disability. In the USA, Taylor *et al.* (1991) examined 206 consecutive cases before the Boston Juvenile Court. In approximately 15% of cases, one or both parents were identified as parents with intellectual impairment (IQ < 79). Llewellyn *et al.* (2003a, 2003b, 2003c) reviewed 407 consecutive Children's Court cases in Sydney, Australia, and found that parents labelled with intellectual disability featured in 9% of cases initiated by the child welfare authority. And in England, Booth *et al.* (2005a, 2005b) reviewed 437 cases involving public law applications by local authorities under the

Children Act 1989, and found that parents labelled with intellectual disability featured in 22.1% of these cases. All three studies found that children of parents labelled with intellectual disability were more likely than any other group, including children of parents with mental illness and/or drug and alcohol issues, to be permanently placed away from their family home.

When a child's welfare is at stake, child separation is a necessary last resort. However, there is evidence that the separation of children from parents labelled with intellectual disability is often based on two prejudicial and empirically invalid assumptions. These have been documented by legal scholars and disability researchers in several countries including Australia, the United States, England and Iceland. In the first assumption, parental intellectual disability PER SE is mistakenly taken for *prima facie* evidence of parental incapacity or risk of harm to the child. In some instances, this is sanctioned or 'legitimized' by state statute. Lightfoot & Laliberte (2006) in their recent audit of USA state statutes, found that 32 US states still include parental intellectual or developmental disability (mental deficiency is the most frequently used synonym) in their grounds for the termination of parental rights. In other countries, states and jurisdictions, this false assumption is legitimized by the routine use of IQ assessment as a proxy measure of parenting capacity. In New South Wales, Australia, for instance, McConnell *et al.* (2000a) found that standardized measures of IQ were the most common assessment tools used by court appointed 'experts' in their assessment of parenting capacity. The assumption of incapacity leads to two likely outcomes. One is when the risk of harm is imputed despite there being no evidence of parental deficiencies. The other is when any perceived parenting deficiencies are automatically attributed to the parent's intellectual disability without due consideration of other relevant factors, such as poverty, ill-health and/or limited social supports.

The second assumption is of irremediable deficiency in the parent such that any parental incapacity cannot be overcome or corrected. This occurs when any parenting deficiencies are thought to be part of an irreversible 'condition' of intellectual disability. This leads to the assumption that no matter what interventions are undertaken it is unlikely that parents are able to change. In this situation, the state authority 'naturally' holds little hope of improving the child's situation, resulting in the permanent placement of the child away from their family home (Booth *et al.* 2006; McConnell *et al.* 2006). Both the assumption of parental intellectual disability as indisputable evidence of risk of harm to a child and the assumption of parenting deficiencies being irreversible are incorrect and invalid.

Teaching and supporting parents labelled with intellectual disability

A consistent research finding is that many parents labelled with intellectual disability can learn, apply new knowledge and maintain new skills (Budd & Greenspan 1985; Tymchuk 1990a, 1990b; Tymchuk & Feldman 1991; Feldman 1994). Maurice Feldman in Canada, Alexander Tymchuk in the USA, and Susan McGaw in England pioneered the use of applied behavioral methods in teaching skills to parents labelled with intellectual disability. Their studies and others since, including a randomized controlled trial (Llewellyn *et al.* 2003a, 2003b, 2003c), have demonstrated positive parent skill gains through appropriate training in childcare such as bathing, changing nappies and cleaning baby bottles (e.g. Feldman *et al.* 1992); child health and home safety (e.g. Tymchuk *et al.* 1990a, 1990b, 1990c; Tymchuk *et al.* 1992; Llewellyn *et al.* 2003a, 2003b, 2003c); parent–child interaction and play (e.g. Feldman *et al.* 1986, 1989; Keltner *et al.* 1995); decision making (e.g. Tymchuk *et al.* 1988); responding to common problematic parenting and social situations (e.g. Fantuzzo *et al.* 1986); and, menu planning and grocery shopping (Sarber *et al.* 1983).

> 'Parents labelled with intellectual disability acquire parenting knowledge and skills when appropriate teaching methods are used'

Successful parent education programs for parents labelled with intellectual disability contain certain attributes. The program needs to be individually tailored to the parent's learning needs; it should address topics of interest to the parent, where there is a high degree of motivation to learn; the skills need to be taught in the environment in which they are to be applied; and, all training needs to be systematic and concrete. Training must also incorporate modelling and simplified verbal and visual techniques and allow opportunities for practice with feedback and positive reinforcement. Periodic maintenance training sessions may be required and more self-directed approaches may also be effective (Feldman & Case 1999).

Strengthening social relationships

Over the last decade intervention studies have begun to address other challenges to successful parenting including the social isolation of parents labelled with intellectual disability. In Sheffield, England, Booth & Booth (2003) prospectively evaluated the Supported Learning Project (SLP), a group-based intervention designed to enhance the support networks of mothers with 'learning difficulties' and foster their self-advocacy skills. Reported outcomes for the 31 participating mothers included greater personal and practical skills, greater sense of control over their lives, a better self-image and more confidence in their own abilities, greater assertiveness; more awareness of their own needs and how to get help, and a larger support network. McGaw *et al.* (2002) report similar findings from their evaluation of a group intervention for parents with mild intellectual disabilities, conducted in Cornwall, England. In this study, 12 parents were assigned to an experimental parent group and 10 were assigned to a control group. A cognitive-behavioural approach was employed to teaching topics that were intended to raise social awareness, enhance inter-personal communications and listening in relationships. Major findings included significantly improved self-concept, improved relationships with partners, new friends, and increased confidence in accessing resources for themselves.

> 'Group programs can strengthen the social relationships and self-esteem of parents labelled with intellectual disability'

Cultural and cross country limitations of current knowledge

Research about parents and parenting with intellectual disability comes primarily from high-income countries. While it would be expected that in middle and low-income countries there are parents labelled as parents with intellectual disability, concerns about their parenting do not seem to have attracted attention in service delivery, in policy formulation or among researchers. This may be attributed in part to how intellectual disability is understood in particular social settings and cultures. In part, it may be due to the more pressing concerns of people who present with severe health, daily life, accommodation or employment needs.

With few exceptions, the body of research is also drawn from the dominant socio-cultural group within each country. In some instances, parents from another culture group or indigenous parents may be included in larger population group studies. As yet, there are very few studies that address the needs of parents labelled as parents with intellectual disability from a minority cultural group within any one high-income country. This is a gap in our understanding which requires urgent and dedicated attention.

Promising developments

The IASSID SIRG on Parents and Parenting with Intellectual Disability strongly emphasizes the need for a concerted international effort to mobilize knowledge from research for policy and practice. There are several recent positive developments. These developments include interventions that target change at organizational and institutional levels of social organization, in addition to the well tested interventions with parents and their families. One example is the Disability and Parental Rights Legislative Change Project, initiated at the University of Minnesota as a collaborative project in the College of Education and Human Development between the School of Social Work and the Institute on Community Integration (see http://ssw.che.umn.edu/cascw/parentdisability.html). The overall goal of the project is to assist interested parties in eliminating discriminatory statutes from legislation including statutes that equate parental intellectual disability with parental incapacity or risk of harm to the child.

Another example is the development of a statutory code of practice and good practice guidelines on working with parents with learning disability in the United Kingdom. The Duty to Promote Disability Equality: Statutory Code of Practice (2006) (Disability Rights Commission 2006) places a duty on all public authorities, when carrying out their function, to have due regard to the need to promote equality of opportunity between disabled persons and other persons; eliminate discrimination that is unlawful; eliminate harassment of disabled persons that is related to their disabilities; promote positive attitudes towards disabled persons; encourage participation by disabled persons in public life; and, to take steps to take account of disabled persons' disabilities. The Good Practice Guidance on Working with Parents with a Learning Disability (2006) issued by the Department of Health & Department for Education & Skills (2007) is aimed at improving practice across children and adult services, including greater collaboration between workers in these departments when supporting parents with learning disability, so that the children of parents with a learning disability can live in a positive and supportive environment that meets their needs and reduces the risk of separation from their birth families.

A third example comes from Australia where the Parenting Research Centre (http://www.parentingrc.org.au) and the University of Sydney based Australian Family and Disability Studies Research Collaboration (http://www.afdsrc.org) have come together as the Australian Supported Parenting Consortium to implement and evaluate an Australia-wide capacity building initiative, funded by the Australian Government. This initiative aims to build systems capacity, including the commitment, knowledge, skills and material resources needed to support parents with intellectual disability and promote a healthy start to life for their young children. The *Healthy Start* initiative (http://www.healthystart.net.au) involves the development of local leaders and practitioner networks and dissemination of knowledge and innovation to support research-informed practice. At the heart of the initiative is the establishment of local cross-disciplinary and inter-sectoral practitioner networks. These networks are designed to translate knowledge from research into practice and to bring this together with knowledge of the local community as a basis for planning and coordinating local, research-informed service development.

The now substantive body of research on parents and parenting with intellectual disability demonstrates that many people labelled with intellectual disability are able to raise children. The opportunity to do so is often limited by enduring prejudice and unequal access to resources, in particular by scarce and inappropriate professional support and services. Equity demands that governments and human service agencies translate the findings from research into policy and practice to support people labelled with intellectual disability as parents as now required by the UN Convention of the Rights of Persons with Disabilities (United Nations 2006).

This position paper concludes by highlighting the significant barriers to people with intellectual disability being successful parents in high-income countries at this time. The IASSID SIRG on Parents and Parenting with Intellectual Disability presents 11 recommendations aimed at overcoming these barriers to achieve greater equity and more opportunities for parents labelled with intellectual disability and their children. Recommendation 12 addresses the need for research to advance knowledge about parents and parenting with intellectual disability in low and middle income countries.

Recommendations

Problem 1.

Statutes and 'expert opinion' give legitimacy to the widespread, prejudicial and empirically invalid assumption that parents labelled with intellectual disability do not have the capacity to raise children

Recommendation 1. Governments should revise child welfare statutes that equate parental intellectual disability with parental incapacity or risk of harm to the child

Recommendation 2. Professionals should stop using standardized assessments of parental intelligence (IQ) as a proxy measure of parenting capacity

Recommendation 3. The assessment of parenting capacity should incorporate valid methods that directly evaluate parenting knowledge and skills, and consider the role of ecological factors that may impede or support positive outcomes

Problem 2.

Parents labelled with intellectual disability lack access to resources that most other parents take for granted such as safe and suitable housing, employment and/or an adequate subsistence base, and good health and quality health care

Recommendation 4. Governments should invest in prevention focusing first on meeting the basic survival and maintenance needs of these socially vulnerable families

Recommendation 5. Health authorities should implement universal psychosocial screening in antenatal care, and provide information and support to vulnerable mothers on the basis of need not diagnosis

Problem 3.

Policy preferences and/or funding constraints that exclude parents labelled with intellectual disability from mainstream services, or limit agencies to providing centre-based and/or time-limited support services are discriminatory.

Recommendation 6. Governments should develop and/or enforce service standards that require mainstream services to include parents labelled with intellectual disability and to accommodate their special needs

Recommendation 7. Governments should fund mainstream agencies to deliver home-based learning and support services that are evidence based, tailored to individual needs, and build on the strengths of each parent and family

Recommendation 8. Service providers should provide flexible support to families over the long term, recognizing that the intensity of support required increases and decreases as children develop and circumstances change

Problem 4.

Uni-disciplinary and one dimensional models of service provision do not give due consideration to the broad range of factors that may impact children and families including socio-economic and other disadvantages such as poor parent health

Recommendation 9. Health, social and other community service authorities should promote trans-disciplinary and cross-sector collaboration, for example, by establishing trans-disciplinary and cross-sector networks at the local community level

Problem 5.

Parents labelled with intellectual disability are often consigned to the 'too hard basket' by health and social service professionals who are ill-equipped both in knowledge and skill to assess and provide confident and competent support to parents labelled with intellectual disability

Recommendation 10. Professional bodies, health and social service authorities should ensure that professionals are taught and implement evidence-based methods and non-discriminatory practices to work with parents labelled with intellectual disability

Recommendation 11. Governments should fund and support the wide dissemination of evidence-based programs and resources for parents labelled with intellectual disability

Problem 6

Little research attention has been paid to parents and parenting with intellectual disability in low and middle income countries

Recommendation 12. The International Association for the Scientific Study of Intellectual Disability, in partnership with member organizations, should foster cross-national research partnerships, and develop strategies to stimulate research about parents and parenting with intellectual disability in low and middle income countries

Acknowledgement

Paper prepared and presented by IASSID SIRG Parents and Parenting with Intellectual Disabilities coordinated by Dr David McConnell, Deputy Chair.

Correspondence

Any correspondence should be directed to David McConnell, Associate Professor, Department of Occupational Therapy, Faculty of Rehabilitation Medicine, University of Alberta, Edmonton T6G 2G4, Alberta, Canada (e-mail: David.McConnell@ualberta.ca).

References

Accardo P. J. & Whitman B. Y. (1990) Review. Children of mentally retarded parents. *American Journal of Diseases of Children* **144**, 69–70.

Ainsworth M. H., Wagner E. A. & Strauss A. A. (1945) Children of our children. *American Journal of Mental Deficiency* **49**, 277–289.

Andron L. & Tymchuk A. J. (1987) Parents who are mentally retarded. In: *Mental Handicap and Sexuality: Issues and Perspectives* (ed A. Craft), pp. 238–262. D.J. Costello, Turnbridge Wells.

Aunos M., Goupil G. & Feldman M. A. (2004) Mothers with an intellectual disability who do and not have custody of their children. *Journal on Developmental Disabilities* **10**, 65–79.

Berry J. D. & Shapiro A. (1975) Married mentally handicapped patients in the community. *Proceedings of Royal Society of Medicine* **68**, 795–798.

Booth T. & Booth W. (1995) Unto us a child is born: The trials and rewards of parenthood for people with learning difficulties. *Australia and New Zealand Journal of Developmental Disabilities* **20**, 25–39.

Booth T. & Booth W. (2000) Against the odds: Growing up with parents who have learning difficulties. *Mental Retardation* **38**, 1–14.

Booth T. & Booth W. (2003) Self advocacy and supported learning for mothers with learning difficulties. *Journal of Learning Disabilities* **7**, 165–193.

Booth T., Booth W. & McConnell D. (2005a) The prevalence and outcomes of care proceedings involving parents with learning difficulties in the family courts. *Journal of Intellectual Disability Research* **18**, 7–17.

Booth T., Booth W. & McConnell D. (2005b) Care proceedings and parents with learning difficulties: Comparative prevalence and outcomes in an English and Australian Court sample. *Child and Family Social Work* **10**, 353–360.

Booth T., McConnell D. & Booth W. (2006) Temporal discrimination and parents with learning difficulties in the child protection system. *British Journal of Social Work* **36**(6), 997–1015.

Bowden K. (1994) Parents with intellectual disability. *CAFHS Forum* **2**(4), 19–24.

Brandon M. W. G. (1957) The intellectual and social status of children of mental defectives. *Journal of Mental Science* **103**, 710–738.

Budd K. & Greenspan S. (1984) Mentally retarded mothers. In: *Behaviour Modification With Women* (Ed E. A. Blelchman), pp. 477–506. Guildford Press, New York.

Budd K. & Greenspan S. (1985) Parameters of successful and unsuccessful interventions with parents who are mentally retarded. *Mental Retardation* **23**, 269–273.

Department of Health & Department for Education & Skills. (2007) Good Practice Guidance on Working with Parents with a Learning Disability. Available at: http://www.valuingpeople.org.uk (accessed on 15 September 2007).

Disability Rights Commission. (2006) The duty to promote disability equality: Statutory code of practice. Available at: http://www.drc.org.uk (accessed on 11 September 2007).

Edgerton R. B. (2001) The hidden majority of individuals with mental retardation and developmental disabilities. In: *The Forgotten Generation: The Status and Challenges of Adults With Mild Cognitive Limitations* (eds A. J. Tymchuk, C. K. Lakin & R. Luckasson), pp. 3–19. Paul H Brookes, Baltimore.

Emerson E., Malam S., Davies I. & Spencer K. (2005) Adults with learning difficulties in England 2003/4. Available at: http://www.ic.nhs/pubs/learndiff2004 (accessed on 9 July 2007).

English S. (2000) Parents in partnership. *Learning Disability Practice* **3**, 14–18.

Fantuzzo J. W., Wray L., Hall R., Goins C. & Azar S. (1986) Parent and social-skills training for mentally retarded mothers identified as child maltreaters. *American Journal of Mental Deficiency* **91**(2), 135–140.

Faureholm J. (1996) *From Lifetime Client to Fellow Citizen*. Paper presented at the Parenting with Intellectual Disability conference, Snekkerstein, Denmark.

Faureholm J. (2006) *''You Have to Fight'' - About Childhood and Adolescence of Children With Parents, who Have Intellectual Disabilities*. PhD thesis. University of Education, The Danish.

Feldman M. A. (1994) Parenting education for parents with intellectual disabilities: A review of outcome studies. *Research in Developmental Disabilities* **15**, 299–332.

Feldman M. A. (2002) Parents with intellectual disabilities and their children: Impediments and supports. In: *Ethical Issues in Sexuality of People With Developmental Disabilities* (eds D. Griffiths & P. Federoff), pp. 255–292. NADD Press, Kingston.

Feldman M. A. & Case L. (1999) Teaching child-care and safety skills to parents with intellectual disabilities via self-learning. *Journal of Intellectual and Developmental Disability* **24**, 27–44.

Feldman M. A. & Walton-Allen N. (1997) Effects of maternal mental retardation and poverty on intellectual, academic, and behavioral status of school-age children. *American Journal on Mental Retardation* **101**, 352–364.

Feldman M. A., Case L., Towns F. & Betel J. (1985) Parent education project I: Development and nurturance of children of mentally retarded parents. *American Journal of Mental Deficiency* **90**, 253–258.

Feldman M. A., Towns F., Betel J., Case L., Rincover A. & Rubino C. (1986) Parent Education Project II: Increasing stimulating interactions of developmentally handicapped mothers. *Journal of Applied Behavior Analysis* **19**, 23–37.

Feldman M. A., Case L., Rincover A., Towns F. & Betel J. (1989) Parent education project III: Increasing affection and responsivity in developmentally handicapped mothers: Component analysis, generalization, and effects on child language. *Journal of Applied Behavior Analysis* **22**, 211–222.

Feldman M. A., Case L. & Sparks B. (1992) Effectiveness of a child-care training program for parents at-risk for child neglect. *Canadian Journal of Behavioural Science* **24**, 14–28.

Feldman M. A., Léger M. & Walton-Allen N. (1997) Stress in mothers with intellectual disabilities. *Journal of Child and Family Studies* **6**, 471–485.

Feldman M. A., Varghese J., Ramsay J. & Rajska D. (2002) Relationship between social support, stress and mother-child interactions in mothers with intellectual disabilities. *Journal of Applied Research in Intellectual Disability* **15**, 314–323.

Floor L., Baxter D., Rosen M. & Zisfein L. (1975) A survey of marriages among previously institutionalized retardates. *Mental Retardation*, **13**, 33–37.

Genders N. (1998) *The Role of the Community Nurse (Learning Disability): Parenting by People With Learning Disabilities*. The Maternity Alliance, London.

Gillberg C. & Geijer-Karlsson M. (1983) Children born to mentally retarded women: A 1–21 year follow-up study of 41 cases. *Psychological Medicine* **13**, 891–894.

Goodringe S. (2000) *A Jigsaw of Services: Inspection of Service to Support Disabled Adults in Their Parenting Role*. DH, London.

Guinea S. (2001) Parents with a learning disability and their views on support received: A preliminary study. *Journal of Learning Disabilities* **5**, 43–56.

Keltner B. (1992) Care giving by mothers with mental retardation. *Family Community Health* **15**, 10–18.

Keltner B. (1994) Home environments of mothers with mental retardation. *Mental Retardation* **32**, 123–127.

Keltner B., Finn D. & Shearer D. (1995) Effects of family intervention on maternal-child interaction for mothers with developmental disabilities. *Family Community Health* **17**, 35–49.

Keltner B., Wise L. & Taylor G. (1999) Mothers with intellectual limitations and their 2-year-old children's developmental outcomes. *Journal of Intellectual and Developmental Disability* **24**, 45–57.

Larson S., Lakin K., Anderson L. & Kwak N. (2001) Characteristics of and service use by persons with MR/DD living in their own homes or with family members: NHIS-D Analysis. *MR/DD Data Brief* **3**, 1–12.

Laxova R., Gilderdale S. & Ridler M. A. C. (1973) An aetiological study of fifty-three female patients from a subnormality hospital and of their offspring. *Journal of Mental Deficiency Research* **17**, 193–226.

Lightfoot E. & Laliberte T. (2006) The inclusion of diosability as grounds for termination of parental rights in state codes. *Policy Research Brief*, **17**. Available at: http://ici.umn.edu/products/newsletters.html#policy (accessed on 21 August 2007).

Llewellyn G. (1994) *Intellectual Disability and Parenting: A Shared Experience*. PhD Thesis, University of Sydney, Sydney.

Llewellyn G. & McConnell D. (2002) Mothers with learning difficulties and their support networks. *Journal of Intellectual Disability Research* **46**, 17–34.

Llewellyn G. & McConnell D. (2004) Mothering capacity and social milieu. In: *Mothering Occupations: Challenge, Agency and Participation* (eds S. Esdail & J. Olsen), pp. 174–192. FA Davis, Philadephia.

Llewellyn G., McConnell D., Cant R. & Westbrook M. (1999) Support networks of mothers with an intellectual disability: an exploratory study. *Journal of Intellectual & Developmental Disability* **24**, 7–26.

Llewellyn G., McConnell D. & Ferronato L. (2003a) Prevalence and outcomes for parents with disabilities and their children in an Australian court sample. *Child Abuse and Neglect* **27**, 235–251.

Llewellyn G., McConnell D., Honey A., Mayes R. & Russo D. (2003b) Promoting health and home safety for children of parents with intellectual disability: A randomised controlled trial. *Research in Developmental Disabilities* **24**, 405–431.

Llewellyn G., McConnell D. & Mayes R. (2003c) Health of mothers with intellectual limitations. *Australian and New Zealand Journal of Public Health* **27**, 17–19.

Mattinson J. (1970) *Marriage and Mental Handicap*. Duckworth, London.

Mayes R., Llewellyn G. & McConnell D. (2006) Misconception: The experience of pregnancy for women with intellectual disabilities. *Scandinavian Journal of Disability Research* **8**, 120–131.

McConnell D. & Llewellyn G. (2005) Social inequality, the deviant parent and child protection practice. *Australian Journal of Social Issues* **40**, 553–566.

McConnell D., Llewellyn G. & Bye R. (1997) Providing services for parents with intellectual disabilities: parent needs and service constraints. *Journal of Intellectual and Developmental Disability* **22**, 5–17.

McConnell D., Llewellyn G. & Ferronato L. (2000a) *Parents With a Disability and the NSW Children's Court*. University of Sydney, Sydney.

McConnell D., Llewellyn G. & Ferronato L. (2000b) Disability and decision-making in Australian care proceedings. *International Journal of Law, Policy and the Family* **16**, 270–299.

McConnell D., Llewellyn G., Mayes R., Russo D. & Honey A. (2003) Developmental profiles of children born to mothers with intellectual disability. *Journal of Intellectual & Developmental Disability* **28**, 122–134.

McConnell D., Llewellyn G. & Ferronato L. (2006) Context contingent decision-making in child protection practice. *International Journal of Social Welfare* **15**, 230–239.

McGaw S., Ball K. & Clark A. (2002) The effect of group intervention on the relationships of parents with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities* **15**, 354–366.

McGaw S., Shaw T. & Beckley K. (2007) Prevalence of psychopathology across a service population of parents with intellectual disabilities and their children. *Journal of Policy and Practice in Intellectual Disabilities* **4**, 11–22.

Mickelson P. (1947) The feeble-minded parent: A study of 90 family cases. *American Journal of Mental Deficiency* **51**, 644–653.

Mirfin-Veitch B., Bray A., Williams S., Clarkson J. & Belton A. (1999) Supporting parents with intellectual disabilities. *New Zealand Journal of Disability Studies* **6**, 60–74.

Mørch W. -T., Jens S. & Andersgard A. (1997) Mentally retarded persons as parents: prevalence and the situation of their children. *Scandinavian Journal of Psychology* **38**, 343–348.

New York State Commission on Quality of Care for the Mentally Disabled (1993) *Parenting With Special Needs: Parents who are Mentally Retarded and Their Children*. New York State Commission on Quality of Care for the Mentally Disabled, Albany.

Nicholson J. (1997) *Parents With Learning Disabilities: A Survey of Current Services in the Mansfield and Ashfield Areas*. Central Nottinghamshire Healthcare Trust, Mansfield.

Penrose L. S. (1938) *A Clinical and Genetic Study of 1,280 Cases of Mental Defect. The Colchester Survey. MRC Special Report Series 229*. HMSO, London.

Pixa-Kettner U. (1998) Parents with intellectual disability in Germany: Results of a nation-wide study. *Journal of Applied Research in Intellectual Disabilities* **11**, 355–364.

Reed E. W. & Reed S. C. (1965) *Mental Retardation: A Family Study*. Saunders, Philadelphia.

Sarber R. E., Halasz M. M., Messmer M. C., Bickett A. D. & Lutzker J. R. (1983) Teaching menu planning and grocery shopping skills to a mentally retarded mother. *Mental Retardation* **21**, 101–106.

Scally B. G. (1973) Marriage and mental handicap: Some observations in Northern Ireland. In: *Human Sexuality and the Mentally Retarded* (eds F. F. de la Cruz & G. D. la Veck), pp. 186–194. Brunner/Mazel, New York.

Shaw C. H. & Wright C. H. (1960) The married mental defective. A follow up study. *The Lancet* **30**, 273–274.

Sigurjonsdottir H. B. & Traustadottir R. (2000) Motherhood, family life and community care. In: *Women With Intellectual Disabilities* (eds R. Traustadottir & K. Johnson). Jessica Kingsley, London.

Stenfert Kroese B., Hussein H., Clifford C. & Ahmed N. (2002) Social support networks and psychological wellbeing of mothers with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities* **15**, 324–340.

Tarleton B., Ward L. & Howarth J. (2006) *Finding the Right Support.* A Review of the Issues and Positive Practice in Supporting Parents With Learning Difficulties and Their Children. The Baring Foundation, London.

Taylor S. J. (1994) Children's division is coming to take pictures. Family life and parenting in a family with disabilities. In: *The Variety of Community Experience: Qualitative Studies of Family and Community Life* (eds S. J. Taylor, R. Bogdan & Z. M. Lutfiyya), pp. 23–45. Paul H. Brookes, Baltimore.

Taylor C. G., Norman D., Murphy J., Jellinek M., Quinn D., Poitrast F. & Goshko M. (1991) Diagnosed intellectual and emotional impairment among parents who seriously mistreat their children: Prevalence, type, and outcome in a court sample. *Child Abuse & Neglect* **15**, 389–401.

Tucker M. B. & Johnson O. (1989) Competence promoting versus competence inhibiting social support for mentally retarded mothers. *Human Organization* **48**, 95–107.

Tymchuk A. J. (1990a) Parents with mental retardation: A national strategy. *Journal of Disability Policy Studies* **1**, 43–56.

Tymchuk A. (1990b) Assessing emergency responses of people with mental handicaps: An assessment instrument. *Mental Handicap* **18**, 136–142.

Tymchuk A. J. (1992) Predicting adequacy of parenting by people with mental retardation. *Child Abuse & Neglect* **16**, 165–178.

Tymchuk A. J. (1994) Depression symptomatology in mothers with mild intellectual disability: An exploratory study. *Australia and New Zealand Journal of Developmental Disabilities* **19**, 111–119.

Tymchuk A. & Feldman M. A. (1991) Parents with mental retardation and their children: Review of research relevant to professional practice. *Canadian Psychology* **32**, 486–494.

Tymchuk A., Andron L. & Rahbar B. (1988) Effective decision-making/problem solving training with mothers who have mental retardation. *American Journal on Mental Retardation* **92**, 510–516.

Tymchuk A. J., Hamada D., Andron L. & Anderson S. (1990a) Home safety training with mothers who are mentally retarded. *Education and Training in Mental Retardation* **25**, 142–149.

Tymchuk A. J., Hamada D., Andron L. & Anderson S. (1990b) Emergency training for mothers with mental retardation. *Child and Family Behavior Therapy* **12**, 31–47.

Tymchuk A. J., Yakota A. & Rahbar B. (1990c) Decision-making abilities of mothers with mental retardation. *Research in Developmental Disabilities* **11**, 97–109.

Tymchuk A., Andron L. & Hagelstein M. (1992) Training mothers with mental retardation to discuss home safety and emergencies with their children. *Journal of Developmental and Physical Disabilities* **4**, 151–165.

United Nations. (2006) Convention on the rights of persons with disabilities. Available at: http://www.un.org/esa/socdev/enable/rights/convtexte.htm#convtext (accessed on 15 September 2007).

Van Hove G. & en Wellens V. (1995) Ouders met een mentale handicap: realitet en begeleiding. *Orthopedagogische Reeks Gent* **5**, 4–7.