

## Parental intellectual disability and child protection: Key issues

Alister Lamont & Leah Bromfield

A high proportion of families with a parent with an intellectual disability will come to the attention of child protection and support agencies due to allegations that a child has been or is at risk of abuse or neglect (James, 2004). However, prejudice and lack of understanding have contributed to these heightened rates. In this paper, we examine parental intellectual disability and the common risk factors associated with child abuse and neglect to understand if and why parents with intellectual disability are at heightened risk of abusing or neglecting their children.

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Parents with intellectual disabilities represent a modest number of all parents in Australia (estimate 1–2%). However, they are over-represented in child protection and legal proceedings (Booth, Booth, & McConnell, 2005; McConnell, Llewellyn, & Ferronato, 2000). For example, in Victorian child protection cases first investigated in 1996–97, cases in which a parent had an intellectual disability were almost twice as likely to be substantiated, and more than three times more likely to be re-substantiated than cases where parents did not have an intellectual disability (Allen Consulting Group, 2003). In 2007–08, parental intellectual disability was a characteristic in 12.5% of cases reviewed by the Victorian Child Death Review Committee (2008). In reviewing 285 court files in two children's courts in New South Wales, McConnell and colleagues (2000) found that 8.8% of cases featured a parent with an intellectual disability. This over-representation is a characteristic in other jurisdictions and internationally. For example, a UK study of data collected in 2000, found that 15.1% of child protection cases before two English family courts featured a parent with learning difficulties (Booth et al., 2005). Research suggests factors contributing to the over-representation of parents with intellectual disability in child protection include discrimination, prejudice and a lack of support services (Booth & Booth, 2005; McConnell et al., 2000; Mildon, Matthews, & Gavidia-Payne, 2003).



## Australian Government

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This paper discusses the key issues associated with parental intellectual disability and child protection, including:

- definitions of intellectual disability;
- whether there is a link between parental competence and intellectual disability;
- risk factors for abuse and neglect and whether or not parents with an intellectual disability experience higher rates of these problems; and
- the role of support services in assisting parents with intellectual disability.

## Defining intellectual disability

Currently there is no generally accepted definition of what constitutes an intellectual disability. Inconsistent terminology is a feature of the research, as “intellectual disability”, “mental retardation”, “developmental disabilities”, “learning disabilities” and “learning difficulties” are all common terms used to describe a person with below average intellectual functioning (Mildon et al., 2003). The term “intellectual disability” is used for the purpose of this paper. However, when reporting study findings the terminology used by the researchers is retained.

In Australia, and in most Western countries, a person with an IQ (intelligence quotient) less than 70 is usually deemed to have an intellectual disability. People scoring an IQ in the borderline range of 70 to 80 may also have intellectual limitations (McGaw & Newman, 2005). IQ testing is unable to assess the way individuals adapt to their environment and therefore further assessments are based on adaptive behaviour. Limitations in skills affecting an individual's ability to live in the community including communication, self-care, safety-awareness and the capacity for self-direction are other indicators for identifying intellectual impairments (NSW Department of Community Services, 2007). It is important to note that intellectual limitations vary from individual to individual and therefore assessments of parental skills must be taken on a case-by-case basis.

Cognitive limitations vary from individual to individual. There are no uniform impacts and each case must be assessed individually.

An alternate definition is that intellectual disability “refers to the need for specific training or skills that most people acquire incidentally and that enable individuals to live in the community without supervision” (Dever, 1990, cited in Mildon et al., 2003, p. 1). The implication of this definition is that a solution-focus—rather than a deficit-focus—is needed to identify what services, if any, people with intellectual disabilities require to participate fully in the community (Mildon et al., 2003).

## Prevalence of parents with an intellectual disability in Australia

There are no up-to-date national statistics indicating the number of parents with intellectual disabilities in Australia. The most recent data available, which provided statistics of children living with a parent with all types of disabilities (physical and mental), are over 10 years old. These data show that there were 843,700 children living with a parent with a disability in 1998, equating to 18% of all children in Australia. Of those children, 92,807 were living with a parent whose main condition was described as a mental or behavioural disorder, which incorporates psychoses and neuroses as well as intellectual disorders (Australian Bureau of Statistics, 2000). The best available estimate, produced by the NSW Department of Community Services (2007), was that 1–2% of families with children aged between 0–17 years of age include at least one parent with an intellectual disability.

Although it is difficult to determine the exact numbers of parents with an intellectual disability, it is generally acknowledged throughout the research literature that the numbers are increasing (Bernard, 2007; Feldman, Leger, & Walton-Allen, 1997; McConnell et al., 2006; Pixa-Kettner, 2008). Reasons for this include better opportunities for community living, the banning of involuntary sterilisation and repeal of anti-discrimination laws (Feldman et al., 1997; McConnell & Llewellyn, 2002).

While there are no reliable data, the best available evidence suggests parents with intellectual disabilities represent a modest number of all parents in Australia (estimated at 1–2% of all families in Australia) and that they are over-represented in child protection and legal proceedings.

## Research reviewed

A literature search was conducted for relevant primary research on parental intellectual disability and parental characteristics, and family court case outcomes. Search terms used included “intellectual disability and parents”, “parental intellectual disability and child protection or child abuse and/or neglect”, “parents with learning difficulties” and “mental retardation and parents”.<sup>1</sup> Twenty-five primary studies were identified, which were categorised into the areas: parental characteristics (17 studies) and child protection case outcomes (8 studies). A further 7 studies were identified that related to the outcomes of children of parents with intellectual disability, which were not included in this review as the focus was on parental capacity. A synopsis of each is shown in Tables 1–2.

<sup>1</sup> The specified search terms were used to identify primary research studies published in English between 1997 and December 2008 in the following databases: Australian Family and Society Abstracts, PsychINFO, Australian Education Index, Healthy Start, Social Care Online, PubMed and Child Development and Adolescent Studies.

**Table 1: Parental characteristics**

Research objective	Method	Sample	Relevant findings
<b>Mothering with intellectual disabilities: Relationships between social support, health and well-being, parenting and child behaviour outcomes</b> (Aunos, Feldman, & Goupil, 2008)			
Canadian study Examined the relationship between social support, psychological wellbeing, parenting style and child problem behaviours.	Parent survey. Quantitative analysis including: descriptive statistics, <i>t</i> -tests, correlations and linear regression. Data was compared with population norms.	<i>N</i> = 32 mothers who were identified by welfare agencies offering services to adults with an intellectual disability.	After controlling for maternal parenting stress, parenting styles were not associated significantly with child problem behaviours. There was a direct relationship between parent stress and child behaviour.
<b>Stress in mothers with intellectual disabilities</b> (Feldman, Leger, & Walton-Allen, 1997)			
Canadian study Examined the stress levels in parents with intellectual disabilities as a potential contributor to parenting problems.	Survey questionnaire and face-to-face interviews. Quantitative analysis including demographic statistics, <i>z</i> -tests and hierarchical regression. Data was compared with a "normative" sample.	<i>N</i> = 82 mothers diagnosed to be intellectually disabled receiving specialised services. <i>N</i> = 600 in normative sample.	Mothers with intellectual disability experienced significantly higher parenting stress than the parents in the normative sample. They were also significantly more likely to experience stress associated with life experiences, having a school age child and living in a crowded environment.
<b>Relationships between social support, stress and mother-child interactions in mothers with intellectual disabilities</b> (Feldman, Varghese, Ramsay, & Rajska, 2002)			
Canadian study Investigated relationships between social support and stress in mothers with intellectual disabilities.	Survey questionnaire in face-to-face interviews. Sample data transformed for analysis. Quantitative analysis including demographic statistics, <i>z</i> -tests and cross tabulations. Data was compared with a Parenting Stress Index "normative" sample.	<i>N</i> = 30 mothers with intellectual disabilities (based on diagnostic assessments) recruited from social service agencies. <i>N</i> = 600 in normative sample.	Mothers with intellectual disability were found to experience significantly higher levels of parenting stress than the normative sample and their stress was significantly related to having low levels of social support.
<b>Mothers with learning difficulties and their support networks</b> (Llewellyn & McConnell, 2002)			
Australian study Identified the views of mothers with learning difficulties about types of support they receive.	Survey questionnaires in three studies over a 4-year period. Quantitative analysis including one-way ANOVA with Bonferroni contrasts, Mann-Whitney <i>u</i> -tests and cross tabulations comparing mothers living in different household arrangements.	<i>N</i> = 70 mothers with learning difficulties identified by social service agencies, grouped into five groups according to their household living arrangements (e.g., Group 1 featured mothers living alone with their children).	A majority of mothers felt that most of their support came from family members, but they have low levels of support from friends and neighbours and inconsistent support from service providers.
<b>Health of mothers with intellectual limitations</b> (Llewellyn, McConnell, & Mayes, 2003)			
Australian study Investigated the health status of mothers with intellectual limitations.	Self-reported health survey. Quantitative analysis with descriptive statistics that compared data with general Australian population.	<i>N</i> = 50 mothers with intellectual limitations referred by social welfare agencies in Western Sydney.	Self-reported maternal health of mothers with intellectual limitations was significantly worse than women's health in the Australian population (derived from the Australian Bureau of Statistics National Health Survey, 1995).
<b>Active negotiation: Mothers with intellectual disabilities creating their social support networks</b> (Mayes, Llewellyn, & McConnell, 2008)			
Australian study Explored the nature of support provided to mothers with intellectual disabilities.	Semi-structured face-to-face interviews with a qualitative thematic analysis.	<i>N</i> = 17 expectant mothers with intellectual disabilities (12 recruited through their first prenatal clinic appointment).	Some mothers with intellectual disabilities have a capacity to build social connections with people and prefer people who provide practical support without taking over their role as a mother.

Research objective	Method	Sample	Relevant findings
<b>Prevalence of psychopathology across a service population of parents with intellectual disabilities and their children</b> (McGaw, Shaw, & Beckley, 2007)			
UK study Investigated incidence of childhood trauma and psychopathology across a population of parents with intellectual disability.	Survey questionnaire. Quantitative analysis including descriptive statistics, cross tabulations and chi-squared tests. No comparison group was used.	<i>N</i> = 49 parents with intellectual disabilities referred by a UK-based parenting service and 58 children.	79.6% of parents had experienced maltreatment as children. There was a significant relationship between parents' own experience of childhood trauma and their child being registered for maltreatment. Significant associations also found between parent psychopathology and mental and cognitive problems in children.
<b>"Parenting with support": The views and experiences of parents with intellectual disabilities</b> (Tarleton & Ward, 2007)			
UK study Described examples of "positive practice" in supporting parents with intellectual disabilities.	One-on-one interviews and focus groups. Qualitative thematic analysis.	<i>N</i> = 30 parents with intellectual disabilities (17 located through case study visit and 13 via a voluntary organisation providing parenting support).	All of the parents were positive about the ongoing support they were receiving from services. Parents themselves recognised that they need this support and that support should be "all the way through" parenting. Parents with intellectual disability can parent adequately if given support.
<b>Service delivery to parents with an intellectual disability: Family centred or professionally centred?</b> (Wade, Mildon, & Matthews, 2007)			
Australian study Examined the importance of family-centred practice in service delivery to parents with intellectual disability.	One-on-one interviews. Data analysis included logistic regression analyses and chi-square tests to test associations between variables.	<i>N</i> = 32 parents had an intellectual disability who were receiving support services.	Parents preferred services with family-centred practices and preferred help from services that was participatory in style, such as assistance with transport.
<b>Parenting by persons with intellectual disability: An explorative study in the Netherlands</b> (Willems, de Vries, Isarin, & Reinders, 2007)			
Netherlands study To investigate the prevalence of "successful parenthood" by persons with intellectual disabilities.	Mixed methodology. Survey questionnaire using quantitative descriptive analysis and semi-structured interviews with a qualitative thematic analysis.	<i>N</i> = 37 parents from 34 families were interviewed having been identified as having an IQ below 70.	51% of cases analysed were regarded by caregivers as not being good enough parents, 16% were doubtful and 33% were seen as good enough. A range of factors predicted quality of parenting, including following advice, quality of social networks and being accepted in a local community.
<b>Social support networks and psychological well-being of mothers with intellectual disabilities</b> (Kroese, Hussein, Clifford, & Ahmed, 1999)			
UK study Investigated the impact of social support networks of mothers with intellectual disabilities on their psychological wellbeing.	Mixed methodology. Three survey questionnaires using Spearman correlations and quantitative descriptive analysis. Semi-structured interviews with a qualitative thematic analysis.	<i>N</i> = 15 mothers with intellectual disabilities identified by social services.	Mothers who reported having more people in their social support network have more positive psychological wellbeing. Perceived helpfulness of contacts and having recent contact with helpful people was associated with better self-esteem.
<b>Perception of service needs by parents with intellectual disability, their significant others and their service workers</b> (Llewellyn, McConnell & Bye, 1998)			
Australian study Reported the views of parents with intellectual disability, their "significant others" and service workers on parents' service needs on 20 items incorporating child care, social and community living and domestic skills.	Mixed methodology. Survey questionnaire using quantitative analysis of Spearman correlations, descriptive statistics and one way ANOVA analysis. Thematic analysis was used for open-ended questions in the survey.	<i>N</i> = 47 parents with intellectual disabilities identified by social service agencies. <i>N</i> = 15 significant others and 26 services workers.	Parents with intellectual disability identified that their greatest unmet needs were help with understanding child development and increasing community participation (work options, making friends, knowing what services were available).

**Table 1: Parental characteristics (continued)**

Research objective	Method	Sample	Relevant findings
<b>Follow up study on parenting with intellectual disability in Germany (Pixa-Kettner, 1999)</b>			
German study Examined the experiences/ challenge of parents with intellectual disability raising their children.	Descriptive follow-up of small sample of parents from previous study (Pixa-Kettner, 1998). One on one interviews. Qualitative thematic analysis.	<i>N</i> = 5 parents with intellectual disability (3 mothers and 2 couples).	Problems identified by parents included financial problems, marital conflicts and disciplinary problems with children.
<b>Parents with intellectual disability in Germany: Results of a nation-wide study (Pixa-Kettner, 1998)</b>			
German Study Examined the prevalence rates of parents with intellectual disability in a German nationwide survey questionnaire. Also investigated examples of parenthood by interviewing mothers, fathers and adult children.	Mixed methodology. Quantitative analysis using descriptive statistics. One-on-one interviews with qualitative thematic analysis.	<i>N</i> = 700 service providers who could identify adults with intellectual disability who had become parents. <i>N</i> = 30 interview participants (12 mothers, 10 couples, 4 fathers and 4 grown up children).	969 parents with intellectual disability were identified. High levels of psychosocial stress were found in the qualitative sample group. Many participants experienced trauma during their own childhood. Parents who remained together had a greater likelihood of not being separated from their child. Most were positive about their role as parents.
<b>Parenting with intellectual disability in Germany: Results of a new nationwide study (Pixa-Kettner, 2008)</b>			
German study Examined the prevalence rates of parents with intellectual disability in a German nationwide survey questionnaire.	Survey questionnaire. Quantitative analysis using descriptive statistics.	<i>N</i> = 701 service providers who could identify adults with intellectual disability who had become parents.	An increase of more the 40% was found both in the number of people with an intellectual disability becoming parents and the number of children born from the previous study in 1998.
<b>Parenting perceptions and social supports of mothers with cognitive disabilities (Ehlers-Flint, 2002)</b>			
US study Examined a range of parenting perceptions and experiences of mothers with intellectual difficulties.	Survey questionnaire. Quantitative analysis including descriptive statistics, Pearson correlations and <i>t</i> -tests.	<i>N</i> = 20 mothers with mild to moderate cognitive disabilities recruited from community agencies.	Mother's views of parenting were quite positive. Mothers also perceived more support than interfering from their social networks. Social isolation and financial difficulties were common challenges.
<b>Misconception: The experience of pregnancy for women with intellectual disabilities (Mayes, Llewellyn, &amp; McConnell, 2006)</b>			
Australian study Reported experiences of becoming a mother for women with intellectual disabilities.	One-on-one semi-structured interviews. Qualitative thematic analysis.	<i>N</i> = 17 women recruited during their first antenatal clinic appointment. The study mainly focused on the stories of three participants.	By experiencing their pregnant bodies, the women began to understand themselves as mothers. The women actively made decisions regarding how their baby would be cared for and they trusted others in these decisions.



**Table 2: Child protection case outcomes**

Research objective	Method	Sample	Relevant findings
<b>The Prevalence and Outcomes of Care Proceedings Involving Parents with Learning Difficulties in The Family Courts</b> (Booth, Booth, & McConnell, 2005)			
UK study Identified the numbers of parents with learning difficulties coming before the family courts and results of court proceedings.	Case file review of court records, social services case files and one-on-one interviews. Quantitative analysis including descriptive statistics and correlation tests comparing families with and without a parent with an intellectual disability.	<i>N</i> = 437 care applications initiated for the courts in four local authorities in England.	15.1% of cases featured a parent with learning difficulties. Parents with learning difficulties were found to be disproportionately represented in care proceedings and their children were more likely to be removed from the family home.
<b>Parents with a disability and the NSW Children's Court</b> (McConnell, Llewellyn, & Ferronato, 2000)			
Australian study Detailed prevalence and outcomes data for parents with intellectual disabilities in statutory child protection proceedings.	Case file review of care proceedings initiated over a 9-month period between 1998–99. Quantitative analysis including descriptive statistics, correlation tests and one-way ANOVA with Bonferroni contrasts comparing outcomes of five distinct groups.	<i>N</i> = 285 court files at two children's courts in New South Wales.	8.8% of cases featured a parent with an intellectual disability and a disproportionately large number of children of parents with intellectual disabilities were removed from the primary carer.
<b>Mothers, intellectual disability and child protection: Characteristics of a court sample</b> (Glaun & Brown, 1999)			
Australian study Identified the main concerns presented in case assessments in a Children's Court in families with a mother with an intellectual disability.	Case file review of case assessments in the Victorian Children's Court Clinic between July 1996 and December 1997. Quantitative analysis of descriptive statistics. No comparison group was used.	<i>N</i> = 12 court case notes and records of families before the Children's Court Clinic with a mother with an intellectual disability.	Predominantly neglect rather than abuse was alleged. Mothers frequently had a history of deprivation, neglect or sexual abuse in their own childhoods. A high prevalence of co-morbidity, such as drug-abuse, psychiatric or medical disorder was identified.
<b>Disability and decision-making in Australian care proceedings</b> (McConnell, Llewellyn & Ferronato, 2002)			
Australian study Examined the court process and decision-making in the New South Wales Children's Court in Sydney, Australia of families with a parent with an intellectual disability.	Mixed methodology. Case file reviews, one-on-one and group interviews and court proceeding observations were conducted. Quantitative descriptive statistics and qualitative thematic analysis.	<i>N</i> = 285 court files in Children's Courts in News South Wales	The over-representation of parents with intellectual disability in care proceedings was found to be due to enduring beliefs about parental incapacity, poorly resourced legal representatives, lack of suitable support services and the diagnostic-prognostic rationality of decision making.

**Table 2: Child protection case outcomes (continued)**

Research objective	Method	Sample	Relevant findings
<b>Parents with learning difficulties, care proceedings and the family courts: threshold decision and the moral matrix</b> (Booth, Booth & McConnell, 2004)			
UK study Investigated how social services and the courts handle child protection cases involving parents with learning difficulties	Mixed methodology. Case file reviews of court proceedings in Leeds and Sheffield in the year 2000. One-on-one interviews with a thematic analysis.	<i>N</i> = 437 case files. <i>N</i> = 20 households where at least one parents had learning difficulties. <i>N</i> = 31 professionals experienced in working with parents with learning difficulties.	Only 10.2 % of children of parents with learning difficulties in the court sample returned home. Difficulties/problems identified in family proceedings involving parents with learning difficulties could be traced back to the disability, yet no accounts were taken of parents special needs for support.
<b>Parents with learning difficulties in the child protection system. Experiences and perspectives</b> (Booth & Booth, 2005)			
UK study Documented views and feelings of parents with learning difficulties ongoing through care proceedings	One-on-one interviews. Qualitative thematic analysis.	<i>N</i> = 22 parents with learning difficulties (18 mothers and 4 fathers) involved in care proceedings and contacted through health social services	A recurring theme throughout parents accounts was that they lacked appropriate support to ensure their interests were properly represented in assessments and court proceedings
<b>Care proceedings and parents with learning difficulties: Comparative prevalence and outcomes in an English and Australian court sample</b> (Booth, Booth & McConnell, 2005)			
Australian/UK study Presented and compared findings of the court studies in Australia and England, of care proceedings involving parents with learning difficulties.	Case file comparison. Quantitative analysis including descriptive statistics and cross-tabulations.	<i>N</i> = 285 court files in Children's Courts in News South Wales. <i>N</i> = 437 court files in four local authorities, England.	Cases of parents with leaning difficulties were more prevalent in England than Australia and were more likely to result in children being placed in out-of-home care.
<b>Parental intellectual disability and children's needs: Family experiences and effective practice</b> (Cleaver & Nicholson, 2007)			
UK study Compared assessments for children who lived with a parent with learning disabilities with children who did not. Identified factors that encouraged or hindered the involvement of parents with learning disabilities in the assessment process.	Mixed methodology. Review of social work case files— compared parents who had learning disabilities with parents who did not. Qualitative study of one-on-one interviews with a thematic analysis. Follow up studies of case file reviews and one-on-one interviews three years after referral.	<i>N</i> = 228 social work case files (76 cases of children living with a parent with learning disabilities and 152 where children did not). <i>N</i> = 23 parents with learning disabilities and their social workers and 42 parents without learning disabilities participated in one-on-one interviews.	In many cases social workers reported that the parent's learning disability was an obstacle to their involvement in the assessment process. Families where a parent had learning disabilities were frequently experiencing poverty and living in inadequate housing. Of children who were removed from the family home, there was no evidence that the learning disability in itself was the reason children were removed.



### Box 1: What is the quality of the evidence-base in the primary studies identified?

Of the 25 studies reviewed, 13 were quantitative studies, 5 were qualitative and 7 used a mixed methodology. Much of the research in each country was conducted by a single group of researchers. For example, Llewellyn and McConnell contributed to the bulk of research in Australia.

The quality of the primary research was mixed and were prone to several common methodological limitations:

- only 3 studies used a comparison group and 4 compared sample data from general population norms;
- several studies did not include detailed descriptions of their methodology;
- parent samples mainly included mothers with intellectual disabilities, excluding fathers;
- samples were recruited through support agencies—this means studies may present an inaccurate picture of the broader population of parents with intellectual disability;
- studies predominantly relied on small sample sizes; and
- research implications were further complicated by definitional issues as inconsistencies occur due to the varying degrees of intellectual disability and differences in definitions of parenting competency (Dowdney & Skuse, 1993).

Overall, the quality of the evidence base means that many of the findings can not be generalised to the wider population of parents with an intellectual disability.

## Does parental intellectual disability increase the risk of abuse or neglect?

### Assessing parental capacity

Assessing minimal parental competence is a significant issue in the child protection system as there are no agreed definitions of adequate parenting and parental competence. Abuse and neglect are conceptualised as a continuum that ranges from positive parenting behaviour through to fatal abuse or neglect (Zigler & Hall, 1989). While agreement can be reached about behaviours at either end of the continuum, there is no agreed threshold for when an act becomes abusive or neglectful (Mash & Wolfe, 1991). Attempts to define concepts that are situated around this threshold (such as adequate parenting, minimal parenting competence, and “good enough” care) are extremely difficult and open to debate (NSW Department of Community Services, 2005a). Assessing parental competence of any parent is difficult as standards are inconsistent (NSW Department of Community Services, 2005a). However, assessing the capacity of parents with intellectual disability is even more complex (McConnell & Llewellyn, 1998).

Information provided to service professionals on conducting assessments for parents with an intellectual disability is usually limited (McConnell & Llewellyn, 1998). There is evidence of inappropriate use of assessment tools, an over reliance on IQ testing (instead of directly assessing parenting skills/knowledge) and a preoccupation with the parents’ intellectual disability as the reason for any difficulty in parenting (Australian Family and Disability Studies Research Collaboration, 2008). Assessments have also been criticised for being heavily focused on risks that tend

to categorise, diagnose and label parents without identifying strengths or protective factors (Mildon et al., 2003). Further research is required on how to effectively develop assessment frameworks that specifically address the needs of parents with intellectual disabilities (Bernard, 2007).

## Intellectual disability and neglect

A common perception is that parental intellectual disability affects parenting capacity to the extent that parents with intellectual disability are unable to provide adequate care for their children. In the following section we examine what evidence exists regarding parental intellectual disability and neglect.

Neglect of a child refers to the persistent failure to meet a child's basic developmental needs. Key factors of neglect acknowledged in the literature highlight how it is a passive rather than an active form of abuse; it is chronic in nature; and neglectful families often face multiple problems (NSW Department of Community Services, 2005b). Neglectful parents are characterised by having poor problem solving skills, a lack of understanding of human relationships, particularly parent-child relationships, a lack of knowledge of child development and an inability to engage positively with their children (Sullivan, 2000). Neglect from parents with intellectual disability can be associated with a lack of support services and/or of knowledge regarding health care and child safety (James, 2004).

Child neglect is identified as the most common type of maltreatment in care and protection court proceedings regarding families with a parent with an intellectual disability in Australia and internationally (Booth, Booth, & McConnell, 2004, 2005; Glaun & Brown, 1999). However, research suggests that in some cases, the evidence of child neglect is based mainly on the parent's intellectual limitations without considering other risk and protective factors (Booth et al., 2005). This suggests that the evidence of child neglect brought before the court system is often poor and based solely on the presence of the parent's intellectual disability (Booth et al., 2004, 2005; McConnell & Llewellyn, 2002). Booth and colleagues (2004) concluded that parents with intellectual disability meet with a presumption of incompetence that too easily leads to their child being deemed to be at risk of harm.

Some parents with intellectual disability may neglect their child, but it is not clear whether children of parents with intellectual disability are at greater risk than other children—particularly given the variation in the degree of intellectual disability and the impact it may have on children's safety and wellbeing.

## Physical abuse, sexual abuse and witnessing domestic violence

Research into child sexual abuse suggests that perpetrators create opportunities in which they can offend, select situations in which they believe they are least likely to be detected and target those children most vulnerable to victimisation (Irenyi, Bromfield, Beyer, & Higgins, 2006). Children of parents with an intellectual disability may be more vulnerable to predatory perpetrators of child physical and sexual abuse. In Booth and Booth's (1998) study of 30 adults raised by parents with intellectual disabilities, over half gave accounts of both physical and sexual abuse, most of which was perpetrated by the mother's partner. On the evidence available it appears that parents with intellectual disability may be more vulnerable to predatory perpetrators targeting them or their children, placing children at heightened risk of sexual and physical abuse and of witnessing domestic violence (Booth & Booth, 1998; Tymchuk, 1992).

As with neglect, some parents with an intellectual disability may physically or sexually abuse their children, however, little is known on whether the risk is higher or lower than that for other parents in the community.

## Are parents with an intellectual disability more likely to experience problems and stressors associated with child abuse and neglect?

Intellectual disability per se is a poor indicator of parental capacity (Mildon et al., 2003; NSW Department of Community Services, 2007). There are many other factors that will influence a parent with an intellectual disability's capacity to provide adequate care to their children. The problems associated with parental intellectual disability may be compounded by other problems that make parenting difficult, such as poverty, unemployment, social isolation, stress, and relationship difficulties.

Broad factors commonly associated with child abuse and neglect include:

- social isolation;
- parental stress;
- parents with past histories of being abused or neglected as children;
- demographic characteristics such as parental income, education, and employment status;
- parental physical and mental health problems;
- children with physical or mental health problems, behavioural problems or disability;
- parental substance abuse; and
- domestic/family violence (Cleaver, Unell, & Aldgate, 1999; Feldman et al., 2002).

Risk occurs on a continuum from no risk to high risk. Every child has some risk of experiencing abuse or neglect, but for most it is very low. Some factors increase children's risk (risk factors) and some reduce children's risk (protective factors). This reflects a probability approach to risk, in which "risk" is value neutral. However in modern society the term "risk" has taken on a negative connotation, is value-laden and implies heightened risk (e.g., groups are referred to as "at risk" rather than "high risk") (Kemshall, 2002).

We now examine whether the available research indicates that parents with intellectual disability are more likely to experience risk factors associated with the occurrence of child abuse and/or neglect. The experience of these factors does not mean that parents are at high risk of abusing their children—the problem might increase the risk, but could be counter-balanced by other protective factors. Even where the risk is high, it does not mean that parents definitely will abuse or neglect their children. However, identification of risk factors is valuable as it may help to determine the support needs of parents with intellectual disabilities, or situations where the risk of children's safety and wellbeing is unacceptable high.

### Social isolation

Several research studies identified that parents with intellectual disabilities experience higher levels of social isolation (Ehlers-Flint, 2002; Llewellyn & McConnell, 2002; Willems, de Vries, Isarin & Reinders, 2007). In their study of 70 mothers with intellectual disability, Llewellyn and McConnell (2002) found that a majority had few supportive friends or neighbours and most were socially isolated from their local communities. They also found that support mainly came from their families and that if such support broke down, mothers were particularly vulnerable. In Canada, Feldman and colleagues (2002) found similar results in relation to higher rates of so-

cial isolation on a study of 30 intellectually disabled mothers, however support was identified as mainly coming from support workers rather than family. Research into child abuse and neglect has reported social isolation as common for parents involved with child protection (DePanfilis & Zuravin, 1999; Kotch, Browne, Dufort, & Winsor, 1999).

Evidence indicates that parents with intellectual disability are more prone to social isolation than other groups of parents, which may increase the risk of child abuse and neglect. However, in a study of 17 mothers with intellectual disability, Mayes and colleagues (2008) found that nine of the mothers strategically negotiated new support networks prior to their baby's birth and the remaining eight mothers already had support networks in place, suggesting that many mothers are pro-active in seeking additional support.

## Parental stress

Parents with intellectual disabilities have been found to frequently experience very high stress levels. High stress in parents with an intellectual disability can be a result of other stressors such as a history of abuse, low socio-economic status, stigmatisation, a history of failure, unemployment, lack of support and social isolation (Feldman et al., 1997). Aunos and colleagues (2008) determined that high levels of maternal parenting stress were associated with less positive and more hostile parenting styles. In a study of 82 mothers with intellectual disabilities, Feldman and colleagues (1997) found that the mothers endured clinically significant levels of stress and that maternal stress increased when the child reached school age. Maternal stress may disrupt optimal parenting practices and can be associated with a lack of warmth and responsiveness (Feldman et al., 2002).

## Parents with past histories of being abused or neglected as children

Broader research into child abuse and neglect has often found an association between parental histories of abuse and neglect and a parent's propensity to abuse or neglect their own children (NSW Department of Community Services, 2005b). Research has found that parents with intellectual disabilities report having experienced high rates of physical and sexual abuse during their own childhood (Dowdney & Skuse, 1993). In a study by Llewellyn and colleagues (2003), half the mothers disclosed a history of physical abuse and almost half (46%) reported being victims of sexual abuse. McGaw and colleagues (2007) found in their study on the prevalence of psychopathology in parents with intellectual disabilities that 79.6% of the sample had experienced abuse or neglect of some form during their childhood. This suggests that parents with intellectual disability are more likely than other groups of parents to have a past history of child abuse and neglect.

## Socio-economic status

The research showed that parents with intellectual disability were much more likely to experience socio-economic hardships (Cleaver & Nicholson, 2007; Ehlers-Flint, 2002; Feldman & Walton-Allen, 1997; Llewellyn & McConnell, 2002; McConnell et al., 2006). Unemployment and inadequate housing may contribute to the low socio-economic status of many parents with intellectual disability (NSW Department of Community Services, 2007). Focusing support services on socio-economic disadvantage may help to reduce risks of abuse and neglect in families with a parent with an intellectual disability.

## Mental health problems

Several research studies have identified a high prevalence of mental illness in adults with intellectual disability (Cleaver & Nicholson, 2007; Costello & Bouras, 2006; Hudson & Chan, 2002; McGaw & Newman, 2005). Research suggests that mental disorders are experienced by people with intellectual disability at a prevalence rate two to three times higher than the general population (McGaw et al., 2007). In a study by McGaw and colleagues (2007), 45% of parents with intellectual disabilities were identified with symptoms of a mental disorder. In a literature review of mental illness and intellectual disability, Hudson and Chan (2002) found evidence of depression, anxiety, bipolar disorder, personality disorder, psychosis and schizophrenia. Research consistently indicates that children of parents with mental health problems are at increased risk of abuse and neglect (Cowling, 2004; Williams & Cowling, 2008).

## Health problems

Mothers with intellectual disabilities may experience significant health problems that could interfere with their parenting capacity. Llewellyn and colleagues (2003) assessed and compared the health status of 50 women with intellectual disabilities with the general population of women in Australia. Using the 36-item Short Form Health Survey (SF-36), the study found that mothers with intellectual disabilities possessed significantly poorer health on all subscales compared with the general population (Llewellyn et al., 2003). In a further cohort study examining the pre- and post-pregnancy outcomes of 878 mothers, McConnell and colleagues (2008) found that mothers with intellectual disability experienced an unusually high rate of pre-eclampsia (a form of toxemia in pregnancy characterised by hypertension and fluid retention) and almost double the amount of pre-term births. Providing sufficient care may prove difficult when the health of a primary caregiver is poor, particularly if the caregiver is restricted to staying in bed and/or mobility is a problem.

## Children's characteristics

Research into risks for child abuse and neglect in the general community have shown that specific characteristics of the child may heighten their risk (Irenyi et al., 2006). There is limited recent research investigating the intersection between child characteristics and parental intellectual disability. Feldman and colleagues (1997) found that the age of the child contributed to parenting stress for mothers with intellectual disability, who reported significantly higher stress if they had school-aged children than mothers of infant/toddler and pre-school children. Older research has suggested that parents with intellectual disabilities may struggle to cope if their children have complex medical and educational needs (Gilberg & Geiger-Karlsson, 1993). However, without a comparison group it is not possible to say if parents with intellectual disability struggle more or less than other parents.

## Other risk factors for abuse and neglect

It is worth noting that two of the most common risk factors for child abuse and neglect in the general population—domestic violence and parental substance abuse—were rarely mentioned in the literature as having an association with parental intellectual disability. Studies by Cleaver and Nicholson (2007) and Glaun and Brown (1999) did find some associations between parental intellectual disability and substance abuse and/or domestic violence, however, with small sample sizes these findings can not be generalised to the wider population of parents with an intellectual

disability. This suggests that on the evidence available we do not know whether parents with intellectual disabilities experience these problems at higher rates than the general population.

Intellectual disability per se is a poor indicator of risk for abuse and neglect. Each case must be assessed individually with consideration for the risk *and* the protective factors.

## Assisting parents with intellectual disabilities

### Issues for support services

Many parents with intellectual disabilities will be able to provide sufficient and supportive care to their children, however others will need additional support and training. The capacity for the service system to accommodate the support needs of such parents is a critical step in trying to reduce the over-representation of parents with intellectual disability in the child protection system. The high rate of parents with intellectual disability involved in the child protection system suggests that there is a significant gap in effective services for parents with intellectual disability (Llewellyn, McConnell, & Bye, 1998; Mildon et al., 2003). Research indicates that services rarely meet the needs of families with a parent with an intellectual disability and that child protection practitioners fall into a focus on deficits at the expense of recognising strengths and competencies in parental capacity (NSW Department of Community Services, 2007; Kroese, Hussein, Clifford, & Ahmed, 2002). Support workers have reported feeling ill-equipped in their knowledge and skill base to meet the demands of parents with intellectual disabilities (Llewellyn, Bye, & McConnell, 1997; McConnell et al., 2006).

Research suggests that to improve service delivery for parents with intellectual disability, interventions should be family-centred and focused on family and parental strengths (NSW Department of Community Services, 2007; Wade et al., 2007). In a family-centred approach, the family's needs and wants determine aspects of service delivery, as opposed to a professional-centred approach, in which professionals make decisions about the needs of the family. In a study assessing whether family-centred practices benefited parents with intellectual disability, Wade and colleagues (2007) examined qualitative interview responses from 32 parents with intellectual disability. Findings indicated that parents identified more family-centred practices as useful compared to professional-centred practices. Participant statements that reflected useful family-centred practices included “strategies to assist with child’s behaviour”, “to be listened to more often” and “taxi vouchers for people with a disability for transport to appointment”. Aspects of services that were deemed to be unhelpful were reflected in participant statements such as “services too far away”, “very demanding and forceful”, “they ask too many questions” and “transport—lack of transport”, which were all deemed to be aspects of professional-centred practice. Tarleton and Ward (2007) sought the opinion of 30 mothers with intellectual disabilities on examples of positive practice. They found that mothers stressed the importance of being respected, listened to and not judged. These findings further support family-centred and solution-focused interventions in which parents are meaningfully involved in decision-making. In delivering family-centred services, practitioners working with parents with intellectual disability need to demonstrate respect for families, reinforce positive qualities, work toward parent-driven goals, teach skills in the setting in which they will be needed (e.g., in the home), and provide services for the long-term (Wade et al., 2007).

A second major finding in the study by Wade and colleagues (2007) was that useful elements of family-centred practices were more likely to be participatory rather than relational. Parents in



the study were more likely to identify participatory practices such as providing transport, home-based service delivery, and specific skill development as being more helpful than relational practices such as having a friendly service provider (Wade et al., 2007). This demonstrates that service accessibility is a key component to service delivery.

A further intervention recommendation identified in the literature was to focus on performance rather than knowledge-based programs (McGaw & Newman, 2005; Mildon et al., 2003). Previous research has indicated that training that focuses predominantly on building parents' knowledge may influence their verbal behaviour and understanding, however it does not, by itself, transfer to performance ability (Mildon et al., 2003). In the study by Tarleton and Ward (2007), parents indicated that a variety of support should be available, including life skills training and a 24-hour help line. Parents in the study identified that learning practical skills such as healthy eating, shopping, getting children ready for school, dealing with paperwork and attending meetings at school were all important aspects of skills training (Tarleton & Ward, 2007). This highlights the importance of behavioural-based interventions to assist parents with intellectual disabilities to acquire the skills they need to enhance their parenting capacity (i.e., a focus on performance rather than knowledge-based programs). Wade and colleagues (2007) concluded that service delivery for parents with intellectual disability should focus on practices that encourage skill development to enhance a family's ability to independently meet their needs.

### Box 2: Healthy Start

A positive development to better improve services in Australia was the establishment of Healthy Start in 2005. Funded by the Australian Government, Healthy Start is an initiative of the Australian Supported Parenting Consortium, comprising the Australian Family and Disability Studies Research Collaboration of the University of Sydney and the Parenting Research Centre. The main aim of Healthy Start is to build the capacity of practitioners and service providers to better meet the needs of families with a parent with an intellectual disability by supporting the use of evidence-based practice and programs (McConnell, Llewellyn, Matthews, Mildon, & Hindmarsh, 2008). An evaluation of the initiative indicated that it had been positive for building the capacity of support services for parents with intellectual disability; and that parenting programs provided as part of the initiative were effective in enhancing parenting skills (Healthy Start, 2008a, 2008b, 2008c).

## Key messages and implications

### The evidence base

There were no large-scale population studies that identified the prevalence of parents with an intellectual disability. In addition, national child protection statistics do not include the characteristics of parents who come to the attention of child protection services. The lack of data makes it difficult to assess the size of the population of parents with intellectual disabilities and the extent to which children of parents with intellectual disability are over-represented in child protection services.

Despite using very broad inclusion criteria, there was a limited body of primary research studies that specifically investigated the impact of parental intellectual disability on parenting and its association with other problems (e.g., socio-economic disadvantage, stress). The issue of parental intellectual disability and child protection services has also been neglected in research, which is concerning given the over-representation of parental intellectual disability in child protection services.

Of the primary research that has been conducted in this area, very few studies used comparison groups, they relied on small sample sizes (indicative of difficulties identifying and recruiting parents with intellectual disability) and much of the research has been conducted by a small number of research consortiums.

Far more research is therefore needed to help build the evidence base, particularly robust, large-scale studies with comparison groups. There is also a need to specify learning difficulties and/or intellectual disability as a distinct category in large-scale population based surveys to help ascertain the prevalence of these issues.

## Why are children of parents with intellectual disability over-represented in care and protection proceedings?

Parents with intellectual disability represent a small number of parents in Australia, however, on the evidence available, they are over-represented in child protection services and legal proceedings. In this paper, we have explored whether this over-representation is a true indication that children of parents with intellectual disability are at heightened risk of abuse and neglect. We have identified three issues that appear to be contributing to the over-representation of children of parents with an intellectual disability in child protection services and legal proceedings.

- Parental intellectual disability may adversely impact parenting. We know that some parents with intellectual disability may neglect or physically abuse their children, yet little is known regarding whether the risk is higher or lower than the risk for other parents in the community. Parents with intellectual disability may also be more vulnerable to perpetrators of physical and sexual assaults targeting them or their children, which can heighten the risk of children experiencing sexual and physical abuse and of witnessing domestic violence.
- Intellectual disability can contribute to parents experiencing other problems and stressors, which are associated with an increased risk of child abuse and neglect, such as social isolation, parental stress, past histories of abuse and neglect, poverty, and physical and mental health problems. However, it is worth noting that there was little evidence that parents with intellectual disability experienced substance misuse or domestic violence—the two most common reasons for referral to child protection services—at higher rates than other parents in the community.
- Intellectual disability is likely to adversely impact parenting. The extent to which intellectual disability impacts parenting will vary dependent on the nature and extent of the disability, the other stressors the parent experiences and availability of support. However, there is a substantial difference in the question “could parenting be enhanced” to the question “is parenting inadequate to the extent that state intervention is required to protect the child?” Prejudicial and incorrect beliefs that any parent with an intellectual disability will be unable to provide adequate care contributes to over-representation of children of parents with intellectual disability in referrals to child protection, within child protection services and in care and protection legal proceedings. There is evidence in practice of inappropriate use of assessment tools in practice, an over reliance on IQ testing (instead of directly assessing parenting skills/

knowledge) and a preoccupation with the parents intellectual disability as the reason for any difficulty in parenting (Australian Family and Disability Studies Research Collaboration, 2008).

What this means is that the diagnosis of intellectual disability is a poor indicator of risk for child abuse and neglect. Parents with an intellectual disability are not a homogenous group. Cognitive limitations vary from individual to individual and IQ testing fails to reflect the way in which individuals adapt to their environments or their social functioning. It is important for each case featuring a parent with an intellectual disability be assessed individually with consideration given to the risk and the protective factors. When concerns regarding parental capacity are raised, practitioners making assessments, need to focus on how the parent's intellectual disability or learning difficulty is affecting their parenting and whether they are experiencing other stressors that may increase the risk of children experiencing abuse or neglect.

This also points to an urgent need for evidence-informed information and training to be provided to practitioners that focus on practical issues, tips and guidance for conducting assessments and providing interventions for parents with an intellectual disability (McConnell & Llewellyn, 1998).

When concerns regarding parental capacity are raised, practitioners making assessments, need to focus on how the parent's intellectual disability or learning difficulty is affecting their parenting.

## Providing support services

Where intellectual disability is negatively impacting parenting and/or contributing to other problems that affect the ability to parent effectively (e.g., social isolation, socio-economic disadvantage or parental stress), parental capacity can be enhanced with appropriate support services. Early provision of such services may help to prevent the over-representation of parents with intellectual disability in the child protection system. Research suggests that optimal services for parents with an intellectual disability are:

- family-centred;
- provided over the long-term;
- focused on strengths rather than deficits;
- home based;
- feature participatory rather than relational elements of practice; and
- performance rather than knowledge based.

## Conclusion

Services for parents with intellectual disability are improving (e.g., reduced systemic prejudice achieved through equal opportunity and anti-discrimination laws). However, work is still needed in identifying, preventing, and compensating for factors that promote the reoccurrence of child development and parental problems in families with a parent with an intellectual disability (Feldman & Walton-Allen, 1997). Further research is needed that focuses on how the child protection system can better accommodate the needs of parents with intellectual disability so that their children are provided with the best care and protection. Particular attention should be directed at making assessments, establishing case plans and agreed parent actions, and identifying appropriate support services and interventions for parents with intellectual disabilities involved in the child protection system.

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- Mental health practitioner
- Nursing professional
- Other health professional (e.g. specialists, health trainer/administrator)
- Police officer
- Other legal professional (e.g. court services professional, victim support services, other specialist lawyer)
- Media professional (e.g. journalist, editor, public relations)
- Politician
- Librarian
- Student
- Community member
- Other (please specify) \_\_\_\_\_

**In your role, do you specifically target:**

- Aboriginal and Torres Strait Islander communities  Yes  No
- Culturally and linguistically diverse communities  Yes  No

**Are you employed by a peak body, advocacy or lobby group (e.g., CAFWAA, NAPCAN, AFCA)?**

- Yes  No

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