

## LITERATURE REVIEW

# Children of parents with intellectual disability: Facing poor outcomes or faring okay?

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### Abstract

**Background** Children of parents with intellectual disability are assumed to be at risk of poor outcomes but a comprehensive review of the literature has not previously been undertaken.

**Method** A database and reference search from March 2010 to March 2011 resulted in 26 studies for review.

**Results** Two groups of studies were identified. The first investigated an association between parental intellectual disability and child outcomes where there was significant disadvantage. Some findings suggest low parental intellectual capacity can negatively impact child outcomes, but others indicate child development approaches population norms. A second, small group of studies explored narrative accounts of childhood to find that social exclusion, bullying, and stigma are commonplace. Removal from parental care emerged as a significant risk for this group of children.

**Conclusions** Studies focusing on child development represent 85% of the literature but reach no consensus about likely developmental or behavioural outcomes. Children studied usually come from clinical populations or other high-risk groups, and are typically young children.

**Keywords:** *child outcomes, parental intellectual disability, child development*

### Introduction

Despite a substantial body of literature about parents with intellectual disability dating back to the 1940s (Mickelson, 1947), there is surprisingly little known about the lives of their children. People with intellectual disability (ID) have consistently been regarded as less than competent adults; when a woman with an ID becomes pregnant, it is not uncommon for her to encounter negative responses and for termination of the pregnancy or adoption of the baby to be proposed, or for another family member to raise the child (Mayes, Llewellyn, & McConnell, 2006). Set against this negative view there is a growing body of literature which demonstrates that people with ID can and do become competent parents (IAS-SID SIRC on Parents and Parenting with Intellectual Disabilities, 2008; Llewellyn, McConnell, & Ferronato, 2003). Parenting interventions that are specific, structured, and set in familiar environments with opportunities for practising newly learnt

skills and behaviours have recorded good outcomes, although "gold standard" research designs remain unusual in this literature (Coren, Hutchfield, Thomae, & Gustafsson, 2010; Wade, Llewellyn, & Matthews, 2008).

One of the frequently cited reasons for undertaking parenting interventions is the assumption that the children of parents with ID will inevitably be at risk of poor developmental outcomes or maltreatment (Booth & Booth, 2000; Wade, Llewellyn, & Matthews, 2008). Parenting interventions are typically conducted with families headed by parents with ID who have come to the attention of welfare and family support services, meaning they already exhibit parenting difficulties and a host of parental vulnerabilities (Feldman, 2002; Hewitt, 2007). Thus, to learn from the literature about the parenting interventions used for children of parents with ID presents some difficulties. An alternative way to consider the lives of these children is to examine

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studies that address children who are severely disadvantaged from any cause (e.g., Ramey & Campbell, 1984; Weikart, Deloria, Lawser, & Wegerink, 1970). A third way is to identify studies that examine the lives of these children in their own right. That is, exploring their experiences as a child growing up with a parent (typically a mother) with ID.

In this review of the literature we utilise all three approaches to gain as full an understanding as possible of the current state of knowledge about the lives of children of parents with ID. We are mindful that Feldman (2002), a long-time contributor to the literature on parents with ID, writing in a review chapter on child outcomes, concluded that many children of parents with ID are at risk for developmental, academic, behavioural, and social adjustment problems. Not surprisingly, he called for research to focus on the impact on a child being raised by a parent or parents with ID and, specifically, the variables that affect parental competency. This review is a first step towards meeting this goal.

Currently, it is challenging for policymakers and service providers to fashion policy and/or service responses to address the needs of children in these families. It is critical to establish just what impact, negative or otherwise, flows from having a parent with an ID before designing policies and services to meet an unexamined and unknown need. What is clear—and sobering—is that the children of parents with ID are as likely as not to be raised by someone other than their parent with ID (McConnell, Feldman, Aunos, & Prasad, 2010). Studies from several continents concur that approximately 40–60% of these children will be removed from their parents' care. This increases the urgency for a critical review of research on the lives of children of parents with ID to differentiate influences that may stem from parental ID from contextual factors related to, for instance, the significant socioeconomic disadvantage and social exclusion experienced by people with ID (Emerson, 2007).

This review builds upon earlier reviews by Feldman (2002) and Hewitt (2007), conducted for somewhat different purposes. Feldman (2002) reviewed studies that included developmental outcomes and the efficacy of early education for children and parent training interventions for parents with ID. With a different aim and scope, not surprisingly only five studies are common to the current review and that by Feldman (2002). Hewitt (2007) examined the parental and social factors that place the children of parents with ID at risk of abuse and neglect. In contrast, the current review offers a comprehensive examination of existing evidence about the lives of children of parents with ID.

## Method

A search of the Cochrane Database of Systematic Review revealed no meta-analyses or systematic reviews on this topic by March 2011. (A Campbell Systematic Review limited to parenting training support for parents with ID was published in December 2010.) An analytic review of Medline(r), ERIC, psychINFO, psychCRITIQUE, and Proquest (Central) was then undertaken. Search terms used were: parents, mothers, parenting or parental *together with* intellectual disabilities, learning difficulties, learning disabilities, cognitive limitations, intellectual limitations, mental retardation, low maternal IQ or low IQ *together with* children, child outcomes or child development. This search strategy yielded 94 studies of which 82 were excluded because they were about children with ID or parents with ID only or, after examination, were found to be solely concerned with parenting, services, or the advocacy needs of parents with ID. Of the remaining 12 studies, one was excluded after being identified as a literature review (Feldman, 2002). Another review (Hewitt, 2007), found in the references of an excluded study (Ward & Tarleton, 2007), was also excluded. Eleven studies<sup>1</sup> were found to meet the criterion for inclusion by addressing child outcomes. A further 15 studies about children of parents with ID were identified from the reference lists of the initial 11 studies, resulting in a total of 26 studies for this review (see Table 1 for a summary of these studies).

### *Child protection proceedings and children of parents with ID*

Children of parents with ID face a serious risk of removal from parental care. Of the 26 studies, three were primarily concerned with child protection court files and three with case files from human service agencies.

### *Child protection court files*

In the US, Taylor et al. (1991) used court records to review 206 cases of serious child maltreatment before the Boston Juvenile Court over a 2-year period in order to determine the prevalence of parental emotional disturbance or low IQ, and to compare child outcomes based on parental characteristics. Boys and girls were equally represented in these 206 cases and children were, on average, 4 years old. Placement decisions had been made for the majority (83%) of cases, and 69% of children had been removed from parental care. Court investigators were asked to complete a questionnaire which ranked the degree of

Table 1. Studies about children of parents with intellectual disability (ID)

Year	Author	N	Focus <sup>a</sup>	Age	Sample	Design	Purpose	Measures	Label used <sup>b</sup>	Mother features	Child features
1983	Gillberg & Geijer-Karlsson	40	Yes	1-21 years	Clinical (disability services)	Medical and psychiatric records review	Examine outcomes for children of mothers with ID	Nil	Mental retardation	Low IQ, low SES, childhood deprivation, high proportion single mothers	35% ID; 85% social and behaviour problems
1984	Ramey & Campbell	111	No	Newborn	Community (prenatal clinic) and clinical (social services)	Randomised control trial (5 years)	To determine if educational day care improves IQ and academic outcomes for children at risk of educational disadvantage	Bayley Scales of Infant Development; Stanford-Binet Intelligence Scale; McCarthy Scales	Mental retardation	"High risk" = young, African American, single parent, extreme poverty, low educational attainment, overcrowded housing	Healthy and free from diagnosed disabilities
1985	O'Neill	19	Yes	Unknown	Community (school)	Cross-sectional	Determinants of behavioural and emotional adjustment for children of mothers with ID	Rorschach & Thematic Apperception Test; interviews; school records	Mental retardation	Low IQ, high proportion single mothers	Normal range IQ
1986	Seagull & Scheurer	64	Yes	Unknown	Clinical (child welfare services)	Child protection records review	Review placement outcomes for children of mothers with ID who were neglected/abused	Nil	Mental retardation	Low IQ, low SES, 75% childhood deprivation/abuse, couple status unknown	Unknown
1988	Garber	40	No	Newborn	Community (infant health clinics)	Intervention (alternate assignment) (5 years)	Improve academic performance/prevent learning difficulties.	Gesell Schedules; WISC IQ; Stanford Binet	Mental retardation	Maternal IQ < 75, low SES, African American, high proportion single mothers	Study group: 9 boys, 11 girls; healthy, no gross pathologies detected
1989	Nichols	4	Yes	8-9 years	Clinical (social services)	Case studies	Assess self-esteem of children of mothers with ID	Roberts Apperception Test; Piers-Harris Self-Concept Scale; Coopersmith Self-Esteem Inventory	Mental retardation	Low IQ	Normal range IQ; 2 girls, 2 boys

(Continued)

Table 1. (Continued)

Year	Author	N	Focus <sup>a</sup>	Age	Sample	Design	Purpose	Measures	Label used <sup>b</sup>	Mother features	Child features
1991	Taylor et al.	206	Yes	4 years (mean)	Child protection	Court records review	Prevalence of parental low IQ/ mental illness in maltreatment cases	Questionnaire to determine level of risk	Intellectual impairments	84% psychiatric disorders, high proportion (76%) single mothers	67% from "minority" backgrounds
1993	Feldman et al.	28	No	5 months-2 years	Clinical (social and health services)	Randomised control trial (48 weeks)	Improve language development by improving mother-child interactions	Bayley Scales (plus observation)	Mental retardation	Caucasian, low SES, couple status unknown	16 boys, 12 girls; 30% with developmental delay; no disabilities
1995	Keltner et al.	40	No	1-3 years	Health clinics and child protection agencies	Randomised control trial (1 year)	Improve mother-child interactions	Slossen Intelligence Test - Revised; Nursing Child Assessment Teaching Scale	Intellectual limitations	IQ < 85 (mean 59); 60% African American; low SES, > 50% single parents	At risk of developmental delay
1996	Bowling & Keltner	62	Yes	2 years	Community (infant health clinic)	Medical records review	Examine differences in child health indicators of children of mothers with and without ID	Bayley Scales	Intellectual limitations	Maternal IQ < 70, most single mothers and African American	43% of the children with mothers with ID had IQ < 70; more likely to be delayed in speech and socialisation
1997	Ronai	1	Yes	Adult	N/A	Autobiography	Account of childhood with a mother with ID		Mental retardation	Mother with ID, estranged from husband	Unknown
1997	Feldman & Walton-Allen	52	Yes	6-12 years	Clinical (disability services)	Concurrent correlation	Examine relationship between poverty, maternal IQ and child outcomes	HOME; child behaviour checklist; WISC-R & WRAT-R	Mental retardation	Maternal IQ < 70, low SES, Caucasian, high proportion single mothers	No known disabilities; mother with ID: 19 boys, 8 girls; comparison: 12 boys, 13 girls
1997	Mørch et al.	65	Yes	1-17 years	Population (national survey)	Medical records	Determine prevalence of parents with ID; examine child outcomes	Einstein Parent Screening Instrument; child developmental profile	Mental retardation	Maternal IQ < 70; 49 single mothers and 16 couples with ID	43% learning or developmental issues; 39% removed from parental care

1998/ 2000 <sup>c</sup>	Booth & Booth	30	Yes	Adult	Clinical (social services)	Narrative case studies	Lives of adult children with parents with ID	N/A	Learning difficulties	26 mothers with ID; 4 fathers with ID, all low SES, 9 couples and 7 deceased parents	16 men, 14 women; 50% learning disabilities
1999	Giaun & Brown	17	No	5 months-6 years	Child protection	Court records review	Compare parent and child factors in child protection cases with mothers with ID	Nil	Intellectual disabilities	Maternal IQ < 70; 59% developmental problems including 29% developmental delay; 18% physical ill-health homeless Most young, low SES, African American, single mothers	11 Caucasian, 1 Maori; 75% history of sexual abuse and deprivation; 2/3 isolated, 1/3 homeless High % of children of mothers with ID—cerebral palsy & developmental delay compared to other group 18 boys, 18 girls. No ID or behaviour problems
1999	Keltner et al.	70	Yes	2 years	Community (antenatal)	Concurrent correlation	Compare impact of maternal IQ and poverty on child development	Slosson IQ Test; Vineland Adaptive Behavior; Bayley Scales	Intellectual limitations		
2002	Perkins et al.	36	Yes	9-17 years	Clinical (disability services)	Cross-sectional	Examine effect of maternal style and ID stigma on child self-esteem, identity	Multiple measures of self-esteem and attachment	Developmental disabilities	Mother with ID, low SES	18 boys, 18 girls. No ID or behaviour problems
2003	Llewellyn et al.	469	No	5 years (mean)	Child protection	Court files	Prevalence of parents with disabilities in court proceedings		Intellectual disabilities	53% single mothers with ID; no single fathers with ID	Unknown
2003	McConnell et al.	37	Yes	<5 years	Clinical (social services)	Concurrent correlations	Relationship between child development and maternal/ home variables	Developmental Profile II; Kaufman; Neale Analysis; SF-36; HOME	Intellectual disability	45 parents with ID including 40 mothers (23 with partners) and 5 fathers; English speaking, low SES	20 girls, 17 boys; high incidence of organic pathology,
2005	Trasvadóttir, & Sigurðsdóttir	3	Yes	Adult	Convenience (known to researchers)	Narrative case studies	Life history of adult children of mothers with ID	N/A	Intellectual disabilities	Low IQ, 2 sexually assaulted; institutionalised; all fathers unknown	2 grew up in rural areas; 1 woman with ID

(Continued)

Table 1. (Continued)

Year	Author	N	Focus <sup>a</sup>	Age	Sample	Design	Purpose	Measures	Label used <sup>b</sup>	Mother features	Child features
2005	Booth et al.	828	No	<1 month-16 years	Child protection	Court records review	Prevalence of ID in court proceedings	N/A	Learning difficulties	59 mothers and 21 fathers with ID (14 couples)	Most with an English background, 1:3 impairment/disability
2007	McGaw et al.	58	No	5-17 years	Clinical (disability services)	Concurrent correlations	Effect of childhood trauma/psychopathology of parent with ID on child behaviour, mental health	Parent Assessment Manual; Childhood Trauma Questionnaire; Psychiatric Assessment Schedule; Devereux Scales	Intellectual disabilities	Low IQ, low SES, 50% partners with history of violence/prison, 19 parent couples, 10 single mothers	31 boys, 27 girls, 12 with learning difficulties
2007	Cleaver & Nicholson	228	No	<17 years	Clinical (social services)	Case records	Effectiveness of social service interventions for parents with ID	Nil	Learning disabilities	76 with ID: more likely to be disadvantaged than comparison group. Both groups: +80% mother = primary carer	Similar % of boys and girls, 23 children with developmental disability; 12 chronic illness
2008	McConnell et al.	57	Yes	Newborn	Community (antenatal)	Medical records	Prevalence of adverse birth outcomes	Nil	Intellectual disabilities and learning difficulties	Mothers with ID (and comparison group)	Higher rates of low birth weight, admissions to ICU, special care nursery
2008	Aunos et al.	32	No	2-13 years	Clinical (disability services)	Concurrent correlations	Maternal social support, health/wellbeing on child behaviour	SF-36; Parenting Stress Index; HOME; child behaviour checklist	Intellectual disabilities	Low SES, no other characteristics known	Good health, 2 with developmental disability, 16 boys, 16 girls
2010	Faureholm	23	Yes	8-22 years	Clinical-known to disability services	Narrative case studies	Childhoods of children with mothers with ID	N/A	Intellectual disabilities	Mothers with ID, no other characteristics known	11 boys, 12 girls, 7 with mild ID

Note. <sup>a</sup>Focus of research was primarily the children of parents with intellectual disabilities (not their parents or a different child group). <sup>b</sup>To describe parental intellectual disability. <sup>c</sup>Booth and Booth (1998) and (2000) report on the same study.

risk facing children; children's case records, including any medical and psychiatric reports available, were also reviewed. A determination on the emotional state and intellectual ability of parents was based on documented evidence of diagnosed psychiatric disorders and IQ test results. Half the parents (51%) had a diagnosed intellectual or emotional impairment and another 17% showed probable evidence of a diagnosis. In 15% of cases, at least one parent had an intellectual disability. No diagnosis significantly predicted mistreatment type. Parents with ID were found to be less likely to have had prior court involvement and more likely to have accepted court-ordered services. Nevertheless, their children were almost as likely to be removed (75%) as the children of substance-abusing parents (81%) and more likely than other emotionally disordered or non-diagnosed parents.

A decade later in Australia, Llewellyn et al. (2003) reported on a review of court records in 285 consecutive child protection cases initiated by the Department of Community Services and appearing before two NSW Children's Courts during a 9-month period in 2000. The cases involved 469 children with a mean age of 5 years. Almost a third (29.5%) of parents had disabilities, including 8.8% of parents with ID. Given population prevalence of parents with ID is estimated to be less than 1% in Australia (McConnell & Llewellyn, 2000), the court sample indicated an over-representation of this group of parents. All families were more socioeconomically disadvantaged than the general population<sup>2</sup> but no between-group differences were identified in terms of relative socioeconomic disadvantage. A statistically significant association was found between parental disability type and placement outcome. A disproportionately large number of wardship orders and out-of-home orders were made for the children of parents with ID, with more than half (61%) of these children removed from their parents' care. The authors suggest that court pessimism about the capacity of parents with ID to overcome their parenting difficulties may be one factor leading to the high prevalence of child removal.

In the UK, Booth, Booth, and McConnell (2005) reported on their review of applications initiated by local authorities in family proceedings and county courts in two cities during 2000. This sample consisted of 828 children representing 437 care applications. Fifteen percent of parents had a confirmed diagnosis of ID, with the files of a further 5% showing evidence of likely borderline intelligence. There were 127 children whose parents had ID and 56 children whose parents were considered likely to have a low IQ. Their ages ranged from less than a month to

16 years, with an average age of 4 years. Almost all children (90%) were Caucasian and a third presented with some impairment or disability—3 times the rate in the overall sample. Neglect was the leading professional concern prompting a care application in the case of children of parents with ID, with almost a third of children considered "at risk" of neglect and over 60% alleged to have been neglected. The study found that only 10% of children were returned home to their parents with ID and over 40% were adopted. One in five children who were adopted were under one month old. A statistically significant association was found between parental ID and court orders, and this was likely due to the high rate of adoption of newborns. Children of parents with ID were more than twice as likely to be under a month old compared with other children when proceedings were initiated.

#### *Case files from human service agencies*

Earlier in Sweden, Gillberg and Geijer-Karlsson (1983) had reviewed the case files of children known to a registration agency for services for people with ID (BPSMR) and related files from the Child and Youth Psychiatric Departments. Case file data were supplemented with interviews with social workers, psychologists, and psychiatrists in an unspecified number of cases. This study found that almost half the children were removed from parental care, including 10% placed in foster care at birth and 34% placed in care following substantiated cases of abuse or neglect. A further three children were registered for abuse or neglect concerns. One third of children had ID and these children were significantly more likely to be placed in foster care than children without ID. Almost all mothers came from severely disadvantaged backgrounds; half had experienced childhood trauma and one third had been institutionalised. The authors estimated that BPSMR registration was undertaken by two thirds of people with ID in Sweden but it was not known whether there were differences in family or personal characteristics between those registered to receive services and those who were not.

In the US, Seagull and Scheurer (1986) conducted a case file review to examine the placement outcomes of 64 children of parents with ID reported to child protection authorities up to 7 years earlier. The children were referred to an assessment service for "difficult cases" and included cases where at least one parent had an ID (IQ score below 74). Twenty mothers fitted this criterion and of the 18 fathers for whom diagnosis was available, seven had an ID. The study found that three quarters of the mothers had



chaotic and abusive backgrounds and almost half (40%) spontaneously disclosed a history of sexual assault by family or friends. Children were removed at a rate of 87.5%. All the 12.5% of children who remained with their parent received daily support from extended family or another parent without ID.

In Victoria, Australia, Glaun and Brown (1999) used Children's Court Clinic (CCC) records to identify the factors that may have contributed to the breakdown of parenting care by mothers with ID alleged to have abused or neglected their children. The CCC, which assesses families in child protection matters before Victorian children's courts, yielded a sample of 656 families between January 1996 and June 1997. This sample included 12 mothers with a formal diagnosis of ID (IQ under 70 and adaptive deficits) and their 17 children, aged between 5 months and 6 years. The majority of cases involved neglect and in only one case was the mother the alleged perpetrator of abuse. Three quarters of the mothers had experienced severe deprivation and sexual abuse during their own childhoods, two thirds were estranged or received no practical help from family, and almost half were single parents. All relied on welfare payments and four mothers did not have stable housing. Overall maternal physical and mental health was poor, with nine mothers having a medical or a psychiatric condition and four having substance abuse issues. Information was available for nine fathers, four of whom had ID and three had substance abuse issues and multiple health problems. More than half (59%) the children presented with developmental problems, including 29% with developmental delay and another 18% having medical problems including cerebral palsy, epilepsy, and sensory disability.

Each of the above studies based on child protection court files or case files from human service agencies suggests a particularly disadvantaged group of parents—typically mothers—for whom ID is one of many characteristics, such as poor socioeconomic circumstances, severely troubled childhoods, and associated emotional disturbance or mental health difficulties, that are known to influence child outcomes.

#### *Studies with a primary focus on child outcomes*

Eleven studies were found that specifically addressed the cognitive, behavioural, or social development of children with parents with ID. The studies are examined chronologically as research assumptions, methods utilised, and research focus and questions have changed somewhat from the early 1960s to the present day.

#### *1960s*

In 1966 a longitudinal treatment intervention commenced in Milwaukee, Wisconsin, USA, with the healthy newborns of 40 African American mothers with an IQ below 75, indicating low maternal intelligence, who came from socioeconomically disadvantaged backgrounds (Garber & Hodge, 1989). Babies were alternately assigned to either a treatment or control group and 17 of the 35 children who completed the 5-year intervention attended a full-time, centre-based intensive educational program. The program focused on cognitive, language, and social skills and the mothers received vocational training, adult education, and assistance to find employment. The children's IQ was regularly tested during the intervention and until adolescence. No IQ difference was documented between the groups at commencement; however, by 18 months old, those who received the intervention consistently scored higher than the comparison group (Garber, 1988). While IQ scores fell gradually after the intervention ended and the IQ of control group children improved during the first years of school (Garber, 1988; Garber & Hodge, 1989), a statistically significant difference of 22 IQ points remained between the two groups. While these results are instructive, the study has been criticised for its small sample size without random allocation and the possibility that teaching to the test determined the child outcomes (Feldman, 2002; Zigler & Hodapp, 1986).

#### *1980s*

In the US, O'Neill (1985) used school records to identify a sample of 19 children from 12 families with average or above average IQ whose mothers were known to have ID. Using open-ended interviews to explore outcomes for children, she found that children were as likely as not to be well adjusted if their mother had ID. She identified four patterns of adjustment, two of which involved role reversal with the mother, and together accounted for half the children's behaviour. The first type, considered to result in positive adjustment, occurred when children became their mother's "right hand" and used the responsibility positively. It was equally likely, however, that the children would rebel against parental demands. This rebellion formed a second pattern that potentially resulted in anti-authoritarian behaviour. The third pattern, normal adjustment, was found in 25% of children and the likelihood of this occurring was increased if the child had support from another adult without ID. The fourth pattern, labelled "pseudo-retardation," was likely in children who mimicked



the behaviour of their mother. Children with above average IQ were likely to either rebel or to display normal adjustment. The design of this study poses at least two difficulties. The first is that there were no independent measures of child behaviour. Second, without information on child and family characteristics, it was not possible to determine the influence of other factors, such as the mental health of mothers or family socioeconomic circumstances.

In Oregon, US, Nichols (1989) conducted an exploratory study on the effect of maternal ID on the self-esteem of four primary school children with normal IQ whose parents were known to services for parents with ID. The case study design included interviews and observation of parenting style and standardised measures of maternal and child self-esteem. All four families experienced multiple contextual difficulties including financial hardship, maternal mental illness or substance abuse, family violence and child sexual abuse by non-related men who had been living with them. The researcher determined that the parents of two of the children were critical, neglectful, controlling, or overprotective, although the children did not perceive their parents in this way. Both of these children recorded higher self-esteem scores than children whose parents were regarded as providing more positive parenting. Three children had low self-esteem and all four exhibited anxiety, depression, and aggression. No association was found between the level of maternal self-esteem and that of the child, and there was inconsistency in the children's scores on different self-esteem measures. Nichols (1989) determined that the finding of self-esteem scores falling within normal range was not reliable and likely to be due to socially desirable responses, and thus gave higher weighting to her observations and interviews. As a small case study, the findings must be interpreted with caution.

### 1990s

By the 1990s, greater interest had developed about the influence of socioeconomic circumstances on child development and, when these resources were lacking, the implications for child maltreatment. Accordingly, researchers studying parents with ID began to take into account the socioeconomic background of the families they were studying. In Ontario, Canada, Feldman and Walton-Allen (1997) examined the association between poverty, parental ID, and child development. This study compared the developmental and behavioural profiles of 27 primary school children of mothers with ID and 25 children whose mothers had average IQ. The mothers with ID were recruited from disability services

and the comparison group was recruited through community centres located in the same area. Child intelligence and behaviour, home environment, and maternal social support were measured. Children of mothers with ID were found to be intellectually and academically disadvantaged compared to those in the comparison group. More than 60% in the study group had an IQ below 85 and over half received special education services, compared with 12% of the comparison group. Children of average IQ with mothers with ID themselves were likely to have at least one behavioural disorder or learning disability and 25% had multiple behaviour problems compared with no children in the comparison group. Analysis of child characteristics indicated that boys were at significantly higher risk of poor behavioural outcomes than girls. There was a significant disparity between the numbers of boys (19) and girls (8) in the sample, which may explain this finding; however, a post-hoc analysis using an equal number of randomly selected boys and girls found that the gender difference in behavioural outcomes remained. Caution needs to be applied to child behaviour results based solely on maternal reports. Interestingly, the mothers with ID—especially those with sons—reported significantly greater social isolation than comparison group mothers. It is possible that their level of isolation affected how they regarded their child's behaviour.

In Norway, Mørch, Skår, and Andersgård (1997) conducted a nationwide survey of public health practitioners to determine the prevalence of children born to parents with ID. They identified 126 children under 16 years of age, or a prevalence of one in every 2,000 families. Following the survey, public health nurse assessment records were examined to analyse outcomes for 65 children of parents with ID. The study found that more than a third of children had been taken into care, two thirds before their first birthday, and proceedings were underway with another 22 children, representing over half of those still living with their parent. Twenty-six cases of neglect were recorded including under-stimulation and inability to control children's behaviour and one case of sexual abuse where the perpetrator was unknown. More than two thirds of children were removed in the absence of evidence of inadequate care but where likely future risk was identified. Almost half (43%) of the children were found to have learning disabilities ranging from literacy issues to intellectual disability and autism; 40% of children had reading and writing problems only. Of those with learning difficulties, more than two thirds had problems in motor, language, or psychosocial development. The presence of learning difficulties

was found to be unrelated to whether a child lived with their parent with ID or with foster or adoptive parents. The authors concluded that an association between parental ID and child learning difficulties is likely to exist.

#### *Post 2000*

In the US state of New York, Perkins, Holburn, Deaux, Flory, and Vietze (2002) examined the effect of stigma associated with having a mother with ID on child self-esteem. In this study, maternal attachment style, caregiver style, and perception of maternal stigma and self-esteem were measured with 38 school-aged children, none of whom had ID. Stigma related to maternal ID was found to negatively affect the quality of the mother-child relationship. Those children who were less affected by stigma were more securely attached to their mothers. Overall, children were found to have moderately secure attachments to their mothers and tended to perceive maternal caregiving as either ambivalent or warm. Children with an avoidant, anxious, or ambivalent attachment to their mother were significantly more likely to have low self-esteem. Older children were less likely to perceive their mother's caregiving as warm than younger children. Damage to self-esteem was avoided by children seeing themselves in terms of other identities (such as sibling or friend) which were unaffected by stigma. A gender difference in perceptions of maternal warmth was identified, with girls more likely than boys to perceive their mothers as warm caregivers.

McConnell, Llewellyn, Mayes, Russo, and Honey (2003) examined the developmental status of 37 children aged less than five years whose parents with ID were participating in an Australian randomised controlled trial of a parenting intervention. This study utilised standardised measures and structured interviews. The findings demonstrated that the developmental status of the children as a group did not differ significantly from general population norms, however, there was substantial individual variation. On average, children showed global delays in development of at least one month. Delays were especially notable in physical and communication areas where delays of more than 3 months were identified in over half of the children. A striking finding was that almost half the children had one or more conditions characterised for this study as "organic" or pre-existing, such as attention deficit hyperactive disorder, megaloccephaly, or epilepsy, conditions requiring ongoing specialist medical care, or had mothers who had experienced pregnancy or birth-related complications. Premature birth occurred in

28% of cases and 22% of children had low birth weight. No association was found between child pathology and the IQ or general health of their mothers or between the presence of an organic condition and the home environment. There was no association established between child developmental status and characteristics of the mother or the home environment, but a significant association was established between the presence of organic pathology and the presence of developmental delay in children. This finding suggests that children with existing medical conditions may be particularly vulnerable to developmental delay irrespective of parental intellectual profile or the level of stimulation provided at home.

In the UK, McGaw, Shaw and Beckley (2007) examined the relationship between parental mental health and history of childhood abuse for parents with ID and children's behavioural outcomes. Forty-nine parents with a confirmed diagnosis of ID who were known to a parenting service and their 58 children took part in this study. The study used a range of independent measures, all of which relied on parental reports, on parental mental health, parenting style, parental childhood trauma, and child mental health. Most parents had experienced abuse or neglect during their own childhood and almost half had some form of psychopathology, usually depression or anxiety. Twenty percent of children in the study had ID and more than half the children had current or past child protection registration. Child protection registration was more likely when parents reported emotional abuse in their own childhood. Child emotional disturbances were identified at a rate of two in five children. Multiple behavioural problems, including conduct disorders, poor attention span, anxiety, and acute problems were identified. However, the rate of parental agreement about child behavioural problems was low—just six of the 19 couples agreed—and mothers tended to rate their children's behaviour more severely than fathers. It is not clear why this difference was found; for example, depression did not explain the difference in how parents rated their child's behaviour.

Also in the UK, Cleaver and Nicholson (2007) examined the effectiveness of service interventions for parents with ID and their children. This entailed a review of 228 referrals to Children's Social Care across England in 2000–2001, including 76 cases where parents had ID and 152 matched cases where there was no parental ID. Families headed by parents with ID were found to be 5 times more likely to be identified with multiple issues across child development, parenting capacity and family/environmental domains, and were more likely to be referred because of child protection concerns. Referrals were more

likely to result in an assessment being undertaken if families were headed by a parent with ID. Two thirds of families were headed by a single parent with ID; four out of five such families had multiple children, a third having at least four children and almost half were found to be caring for at least one child with learning or physical disability. A pattern of developmental and behavioural problems was identified among children of parents with ID but almost half the cases had been closed after initial assessment, suggesting that insufficient support had been provided. Where developmental needs were identified at initial assessment, emotional and behavioural problems were identified at much higher rates (80%) for children whose parents had ID than the comparison group (57%). However the actual number of children identified with developmental problems was small, at 21 and 8, respectively. Seventeen percent of children had been removed from the care of their parent with ID for at least a year, and two children had been adopted. In a third of the cases where children remained in the care of a parent with ID, another adult without ID also lived with them. A standout finding in this study is the large number of children per parent and the presence of disability for at least half of the children. Large family size can overtax the coping resources of parents with ID (Dowdney & Skuse, 1993) as can having a child with a disability (Booth & Booth, 1994). This study points to the need for ongoing services to support families headed by parents with ID assessed as having multiple, complex needs. The study also indicates that children in families headed by parents with ID are at elevated risk of poor outcomes compared to other families requiring clinical assessment.

In Australia, McConnell, Mayes, and Llewellyn (2008) used a prospective cohort design to analyse the birth outcomes of 57 babies born to mothers with ID in a sample of over 1000 expectant women. The mothers were identified during prenatal clinic visits and their medical records were compared to those of the other new mothers attending over the same time period. The study found that mothers with ID experienced unusually high rates of pre-eclampsia and their babies were more likely to have low birth weight and to be admitted to neonatal care units than other newborns. No other significant pregnancy-related differences were identified between mothers with ID and the mothers without disability. The findings supported those of the earlier study (McConnell et al., 2003) and suggest a disproportionate risk of adverse pregnancy and birth outcomes for mothers with ID and their children. The use of a cohort design with a non-clinical population, which is unusual in this literature, increases the utility of the findings from this study.

In Canada, Aunos, Feldman, and Goupil (2008) examined the relationship between maternal psychological wellbeing and behavioural outcomes for 32 children aged from 2 to 13 years who had mothers with ID receiving disability services in Quebec. The study included equal numbers of boys and girls, although they were not evenly distributed across age groups. Semistructured interviews involved a range of independent measures of maternal health, social support, parenting stress and style, quality of the home, and child behaviour. Mothers generally provided a normative home environment in terms of emotional responsiveness, acceptance of the child and organisation of the physical environment; however, they provided significantly below average levels of interaction and stimulation if their child was younger than 3 or older than 6 years. Maternal parenting stress was found to be significantly and directly associated with maternal reports of child problem behaviours. Behavioural problems were more common among school-aged children than preschoolers, with 10 of the 27 school-aged children receiving special education and early intervention services such as speech therapy, psychology, or occupational therapy. Almost three quarters of the mothers received regular support, usually from family members. The majority of children did not have significant behavioural problems, with only six (18%) children, four girls and two boys, scoring at the clinical level. The authors caution that reliance on maternal reports of child behaviour can be problematic, particularly as it is impossible to determine whether child problem behaviours cause parenting stress, resulting in more hostile parenting, or whether stressed mothers perceive greater behavioural problems in their children. The authors further suggest that the mothers with ID may have greater difficulty providing academically stimulating environments for children as they grow older which may contribute to their behavioural problems.

#### *Studies where children are the secondary focus*

Four studies were found where the outcomes about children were secondary to the main research focus. In the first study, commencing in 1972, the focus was on parental socioeconomic status; in the remaining three, the primary focus was parent training.

In 1972, the Abecedarian Project (Ramey & Campbell, 1984) commenced in North Carolina, USA. The project aim was to prevent developmental delay and improve academic outcomes for children from "high risk" families. Families with healthy newborns were recruited through prenatal clinics and Department of Social Services registers and most were headed by a young, single, African American female living in

poverty. The average maternal IQ was 85, with 13 mothers with an IQ below 70. Fifty-seven children were randomly assigned to a treatment group. These children attended full-time centre-based educational day care until they started school. Another 54 children entered the control group, which received nutritional supplements and episodic contact only. The study found that the educational preschool program had a positive effect on IQ from the first year of testing. By 4 years old, the control group children were 6 times more likely than those receiving the educational intervention to record IQ scores under 85. Significant differences in IQ scores were evident through to 6 years of age, and children in the treatment group maintained scores close to the national average. For the first 3 years of school, half of the treatment group were randomly assigned to a further treatment, the K-2 early education support program, and received educational support and advocacy. The results of this further study (Ramey & Campbell, 1987) demonstrated that early full-time centre-based educational intervention supplemented by educational assistance in the early grades was the most effective intervention. The Abecedarian Project followed children throughout their school years, and while large IQ gains were not sustained by the treatment group children, they were less likely to be retained in a grade or to be placed in special education than children in the control group throughout school (Ramey & Ramey, 2004). As an additional feature of this study, the results for the children of mothers with ID were analysed separately. The results for the 13 children whose mothers had ID, six of whom were assigned to the treatment group, were examined at 5 years (Martin, Ramey, & Ramey, 1990). All six children who received the education intervention scored within the normal IQ range, while all but one child in the control group scored either in the borderline or intellectual disability range. Average IQ in the treatment group was 22 points higher than that of the control. The authors conclude that the children of mothers with ID benefitted more from early education intervention than the other children. Although the numbers of children of mothers with ID was small, randomised group assignment increases the validity of these findings.

#### 1990s

Two decades later in Canada, Feldman, Sparks, and Case (1993) conducted a training intervention for mothers with ID to promote language development in their infants. This involved 28 mothers with ID from low socioeconomic backgrounds whose children were assessed as being at risk of developmental

delay due to insufficient stimulation at home. The main purpose of the study was to improve the parenting skills of the mothers. Child outcomes data were collected pre- and post-intervention. Upon entering the intervention, 16 children scored below average on the Bayley Scales of Infant Development (Bayley, 1969). Mothers who entered the treatment group received, on average, a 45-week individualised home-based training program. Mother-child behaviours including vocalisation, praise, affection, and imitation were monitored during home observations. Mothers were able to learn most interaction methods, including praise, imitation, and physical affection, and their children were found to have greater vocalisations than the control group. Eight mothers in the treatment group maintained improvements, except in the areas of physical affection and talking to their child. Significant improvements were found in several child language measures including frequency of vocalisations, verbalisations, initiation of words, and performance on standardised language tests. Child vocalisations continued to increase; however, treatment effect is likely to have been obscured by the effect of natural child maturation. Follow-up data presented some difficulties with substantial variability from 13-82 weeks, with six mothers from the treatment group not taking part.

In the south of the US, Bowling and Keltner (1996) examined the health profiles of children with parents with ID. The study used secondary data from a longitudinal study about parenting skills of parents with ID, which also examined child development. Sixty-two of the 100 families who took part in the study had a child still attending a community health clinic at 2 years of age. Of these, there were 35 mothers with ID and 27 mothers of average IQ who were matched for age, race, and numbers of viable pregnancies. Growth charts were used to evaluate length, weight, and head circumference of children. Health records were used to obtain information about referrals, immunisation, diagnoses, and appointments. The study found that the mean growth parameters for both groups of children were within normal range with no statistical between-group differences identified. However, there were three children diagnosed with failure to thrive, all of whom were the children of mothers with ID. Developmental problems related to speech and socialisation were reported more frequently in the records of the children whose mothers had ID. Of the 50 children born to mothers with ID, almost half (43%) scored below 70 on the Bayley Scales of Infant Development (Bayley, 1969). This was more than 4 times the rate of scores below 70 in children born to mothers without ID.

In a later study, again in the south of the US, Keltner, Wise, and Taylor (1999) compared the effects of low socioeconomic status and maternal ID on the development of 2-year-old children in a matched community study of 38 mothers with ID and 32 mothers with an IQ above 85. A significant difference was found between the cognitive, social, language, and motor skills of the two groups of children. Developmental delay occurred in 42% of children whose mothers had ID compared to 12% of children with mothers with an average IQ. The authors noted that for all children there was an exceptionally high incidence (1 in 7) of cerebral palsy compared to population estimates of 1 in 500. For children of mothers with ID the incidence of cerebral palsy was 87%, significantly higher than the 13% for children of mothers without disability. This finding may help to explain the disproportionately high incidence of developmental delay found in several studies among the children of mothers with ID.

#### *Studies about children's experiences*

To date, only four studies have examined the child's experience of having a parent with ID. Of these, three are retrospective accounts from adults looking back at their childhood, including one that contains a series of autobiographical vignettes. The fourth study is the only one located that follows children over time from childhood and on into adolescence.

#### *Retrospective accounts*

Booth and Booth (1998, 2000) used a narrative approach to examine the lives of 30 adult children of parents with ID identified through the social service records of their parents. Four out of five had a mother with ID and half had ID themselves. The authors used in-depth interviews to explore family life, perceptions of parental ID, and experiences of social exclusion. The majority of adults interviewed in this study regarded their childhoods as happy, with their extended family, particularly grandparents, providing stability. Several adults recalled the death of a grandparent as being traumatic and a trigger for rebellion. All but one adult maintained regular contact with their (living) parent with an ID. Many of the adult children without ID, however, expressed ambivalence about their parent with ID. Two sisters reflected on being both protective toward their mother and frustrated that she was not more capable and emotionally available. In this study, adult children with ID had fewer behavioural problems and more positive feelings toward their parent with an ID than was the case for adult

children who had average IQ. According to the study authors, the all too common experience of stigma, social exclusion, and bullying because of parental ID was more responsible for undermining parent-child relationships than parenting per se. This stigma of parental ID appeared to have a greater impact on children with average or above IQ who usually had poor academic records, few friends, and problems with authority figures.

Two publications represent the findings from this study. In the first publication (Booth & Booth, 1998) the authors compared the life stories of two men to demonstrate the variability of life experiences and the place of parental ID among other factors influencing children's lives and outcomes. While both men were raised by a single mother with ID in similar circumstances, and both enjoyed family support and a close relationship with their mother, their adult paths diverged with one man becoming a well-adjusted and successful family man and the other unemployed, depressed, and socially isolated. In the second publication, Booth and Booth (2000) report on child wellbeing in terms of interpersonal relationships. The authors note that eight people had lonely and friendless childhoods, nine had many friends, and the remainder fell into the middle category or moved from one to another over time. All but one of the friendless children had an ID, suggesting that peer relations cannot be explained simply in terms of parent characteristics.

In Iceland, Traustadóttir, and Sigurjónsdóttir (2005) took a life history approach to explore the childhood of three adults, two women and a man, whose mothers had ID. All had grown up with extended family in rural towns and two of the mothers had been placed in institutions while their children were young. This study highlights the important role that support from extended family can play. One young girl was brought up believing her aunt to be her mother. While she and her mother went on to develop a close relationship, once told her mother's true identity she had difficulty adjusting to the stigma of parental ID and referred to her mother's "mental instability." The male participant recalled the anguish of his mother being taken away when he was 10 years old and the joy of re-establishing contact. The account of the third participant in this study, who herself has an ID and continues to live with her now frail mother, is notable for the absence of any mention of childhood stigma, bullying, or trauma.

In the last of the narrative studies, an autobiographical reflection on her childhood with her mother with an ID by an academic author, Ronai (1997) describes sexual abuse, social isolation, and



stigma, and the absence of extended family support. Despite having regular contact, and even living with her grandmother at times, she describes the support received from extended family as negligible. Her account deals with the stigma that she experienced from her mother's ID and also the strategies she used to overcome this, such as hiding her mother's identity so that her schoolmates' parents might consider her a suitable playmate.

#### *Growing up with a parent with ID*

A Danish study, a summary of which was recently published in English (Faureholm, 2010), is the first to provide a longitudinal perspective from childhood to early adulthood of growing up with a mother with ID. The study involved 23 children who were interviewed first when they were 8–12-years-old and again a decade later when the children, now young adults, reflected on their upbringing and relationship with their mothers. All the children lived with their mothers until they started school, although six were permanently placed outside the family home during childhood. The children reported that they became aware their mothers were different when they started school. This was triggered by being ostracised for having poor hygiene and because they could not get help with homework from their mothers. Recognition of these differences by other children often resulted in stigma and peer rejection. Stigma was particularly acute for the seven children with ID. Some children experienced ambivalent feelings toward their mothers that oscillated from love to irritation. This was more common during adolescence when they began to question their upbringing and the reasons for their frequent social exclusion. Despite this, unconditional maternal love was identified as providing security in the face of social difficulties, and the children in this study rarely spoke negatively about their mothers. The author noted that younger children were more likely than older children to have positive feelings about their extended family; adolescents often felt that their relatives were unsupportive and condescending.

This study presents a compelling example of the positive role that peer relationships can play; in this case, in the "after-school" residential program in Denmark. After-school, a residential education and personal development program, which is available to all Danish school leavers, was attended by almost half the adolescents in this study. The author suggests that after-school provided an opportunity for children with low self-esteem to develop a positive self-image and healthy peer relationships. Importantly, the study reports that half the children completed all

compulsory schooling and none were known to have been involved in crime or substance abuse, a concern often expressed by child protection authorities presenting their views on the risky, uncertain future of children of parents with ID.

#### **Discussion**

Perhaps not surprisingly, the findings from the studies analysed for this review suggest that some children of parents with ID fare well and others are at risk of less than ideal outcomes. A well-established outcome is that if a child of a parent or parents with ID encounters the child protection system they are at significant risk of being removed from the care of their parent(s) with ID (Booth et al., 2005; Llewellyn et al., 2003; Taylor et al., 1991). Overall, the studies demonstrate that disadvantage and social isolation contribute to a heightened risk of child maltreatment and the relative influence of parental ID per se cannot easily be disentangled from these other social factors. Several of the earlier studies associate parenting deficits (Bowling & Keltner, 1996; Feldman et al., 1993; Keltner, Finn, & Shearer, 1995; Keltner et al., 1999) or poverty (Garber, 1988; Ramey & Campbell, 1984) with poor cognitive outcomes. Evidence from more recent studies suggests that higher-risk pregnancies and birth complications may also contribute to poorer child outcomes (McConnell et al., 2003; McConnell et al., 2008). In three of six studies conducted with children not already identified as having developmental delay, most scored close to population developmental norms across the developmental domains (Aunos et al., 2008; McConnell et al., 2003; McGaw et al., 2007). The literature is currently limited primarily to children under 5 years (Bowling & Keltner, 1996; Feldman et al., 1993; Keltner et al., 1995; Keltner et al., 1999; McConnell et al., 2003; McConnell et al., 2008). Only three studies (Feldman & Walton-Allen, 1997; McGaw et al., 2007; Perkins et al., 2002) addressed developmental outcomes for school-aged children, and all but one of the narrative accounts were conducted with adult children. Gender differences have been somewhat neglected. Only three studies (Aunos et al., 2008; Feldman & Walton-Allen, 1997; Perkins et al., 2002) have examined gender differences in child outcomes. Feldman and Walton-Allen (1997) found that behavioural problems were more common among boys than girls. Aunos et al. (2008) found no difference in behavioural patterns based on gender. In a study by Perkins et al. (2002), boys were found to be less likely to perceive their mother as a warm caregiver, a state that was associated with lower self-esteem. This

limited information on gender differences in child outcomes is also reflected in the paucity of studies that examine gender differences in parents, primarily because fathers with ID are rarely included at all. At this time, it is not possible to draw any conclusions on the effect of parental or child gender on child outcomes; and both ought to be fully explored in future research.

The outstanding finding from studies in which adult children reflect upon their childhood or children recount their life experiences is their experience of social exclusion and stigma. This comes from the three narrative studies (Booth & Booth, 1998; Faureholm, 2010; Ronai, 1997) and is supported by the findings from the study addressing stigma by Perkins et al. (2002). Although the long-term consequences of stigma and social exclusion are yet to be understood, Booth and Booth (1998) suggest that stigma and social exclusion can lead to poor educational, psychological, and behavioural outcomes and damage self-esteem. While an association between maternal ID, stigma, and low self-esteem was established in the cross-sectional study by Perkins et al. (2002), most children had a secure maternal attachment which was found to protect their self-esteem. There is inconclusive evidence about which children might be at greatest risk of stigma. Booth and Booth (1998) found that children with average or above-average IQ were more affected by stigma which, in turn, resulted in poorer academic outcomes and behavioural issues. This supports the association between IQ and academic and behavioural problems found by Feldman and Walton-Allen (1997) and O'Neill (1985). In contrast, the children with ID in Faureholm's (2010) study were especially subject to bullying and peer rejection. No association was found between this and their close relationship with their mother with ID or stigma and a resultant outcome of behavioural difficulties. Findings from the study by Faureholm (2010) suggest that the effect of stigma earlier in childhood may be mediated by participation in a structured program later in adolescence such as "after-school." The role that support such as this may play in compensating for the effects of stigma on self-esteem warrants closer examination.

Two studies (Aunos et al., 2008; Feldman & Walton-Allen, 1997) found an association between maternal stress and social isolation and behavioural problems in children. A third study (McGaw et al., 2007) found a positive association between parental mental illness and behavioural problems in children. Sole reliance on parental reports to measure the behaviour of children in each of these studies introduces possible bias in that stressed or depressed parents may judge their children's behaviour more

harshly than others. Human service agency reviews demonstrate emotional and behavioural problems for children, as in the studies by Cleaver and Nicholson (2007), Gillberg and Geijer-Karlsson (1983), and Mørch et al. (1997); however, these findings need to be interpreted cautiously as they come from data collected for another purpose—namely, the clinical assessments and care plans of children identified *because* they are already experiencing difficulties or are at risk of poor outcomes. The community study conducted by O'Neill (1985) suggested that rebellion, poor socialisation, and "pseudo-retardation" were common outcomes; however, half of the 19 children in this study were regarded as being positively adjusted, including those given almost "adult" responsibilities, offering contradictory findings that are similar to the inconclusive findings on the long-term effects of stigma. One study only has established a positive association between above average IQ and behavioural problems (Feldman & Walton-Allen, 1997) but this result has not been tested in subsequent studies, although Aunos et al. (2008) suggest that older children may be more likely than younger children to develop behavioural problems. Perhaps not surprisingly, children of parents with ID who themselves experienced childhood neglect or abuse, have mental illness, or misuse drugs or alcohol are at greater risk of neglect and—more rarely—abuse (Gillberg & Geijer-Karlsson, 1983; Glaun & Brown, 1999; McGaw et al., 2007; Seagull & Scheurer, 1986).

### Limitations

The first limitation in this review of studies on children of parents with ID is the studies available for review. In many of the studies, parents and their children are drawn from those already identified in clinical or court populations, therefore including only families already under stress or children considered at risk of harm. Only six of the 26 studies available were conducted with community samples, five of which sampled parents and their children associated with health clinics. A number of limitations result from these sampling approaches: studies include mainly mothers, there is a high rate of single mothers, and study samples are skewed toward parents already experiencing crises or dealing with multiple issues. Sampling difficulty besets all researchers on this topic: identifying a community sample of parents with ID is an enormous challenge for many reasons, not least of which is the fact that they are estimated to make up just 1% of the parent population (McConnell et al., 2008) and are often at pains to avoid being labelled "intellectually



disabled" due to the stigma this term carries (Edgerton, 1967). Parents often fear that participation in research could lead to unwelcome scrutiny of their parenting, which may result in their children being removed (IASSID SIRG on Parents and Parenting with Intellectual Disability, 2008). A related limitation is the tendency of studies to have small samples and mostly without a suitable comparison group. This means that findings are limited to within-parent group data such that the current understanding of the lives of children of parents with ID compared to other children remains quite limited. The state of knowledge about fathers with ID is more severely limited. No study to date addresses fathers solely, and in studies where fathers are included, gender analysis has not been undertaken.

A second limitation is that only studies published in English could be included in the review, which, as in the case of Faureholm (2010), means that often only a summary is available. A second difficulty related to language and discourse is that definitions of intellectual disability have changed over time, which makes it challenging to compare findings from studies conducted in the 1970s with studies conducted more recently. Studies from several decades ago used standardised IQ measures to select samples (e.g., Feldman et al., 1993; Garber, 1988; Ramey & Campbell, 1984) or, in the case of court reviews, only included those with a confirmed diagnosis of intellectual disability. This, as Llewellyn et al. (2003) and others have observed, is likely to underestimate prevalence. Today, with IQ testing less frequently employed, many parents with ID may not have had an IQ test. Indeed, it is well established that IQ alone is unreliable for predicting parental capacity (IASSID SIRG on Parents and Parenting with Intellectual Disability, 2008; Tymchuk, 2001; Tymchuk & Andron, 1990). Today, a social systems definition (Mercer, 1973) is often used to determine samples of parents as this definition acknowledges that many adults with ID are not, or do not wish to be, identified as having an intellectual disability. The social systems definition includes those who attended special schools or classes, receive a disability allowance or consider themselves or are regarded by service providers as a "slow learner." The studies reviewed for this paper have variously described parents as having intellectual disability, cognitive or intellectual limitations, developmental disability, learning difficulty, intellectual impairments, or mental retardation. These terms are not always used synonymously, suggesting that aggregating the findings from these studies ought not to be done, or if done, be undertaken with a great deal of caution.

## Conclusion

From the 26 studies reviewed here, there are several conclusions that can be drawn. First, researchers have been preoccupied with examining parenting competence or conducting parenting interventions, with outcomes for children typically measured or observed as a secondary interest rather than a primary focus. That said, the child variables most frequently assessed are cognitive development, child health, and behaviours with some attention given to physical safety. Research using longitudinal, population-based data to investigate how these children compare to their peers and to understand their development over time would contribute greatly to our knowledge about the likely long-term outcomes for children with parents with ID. This type of research is long overdue. Second, there is no consensus in the findings from the studies reviewed about whether having a parent with ID inevitably results in poor child outcomes. Some studies suggest these children will be disadvantaged by their parent's low intellectual capacity; others suggest that once other factors are taken into account, such as heightened risk in pregnancy and poor birth outcomes, poverty and troubled parental childhoods, and social isolation and stigma, child development approaches population norms. However, and third, as most studies have been conducted with children under 5 years, the tentative findings from this literature are limited primarily to a young group of children. Of the few (four) studies that examine the lives of children beyond adolescence, all but one are retrospective accounts, the findings from which are more challenging to interpret given the passage of time. Importantly, however, the narrative studies confirm that children of parents with ID experience normal feelings of love and connection toward their parents, to the extent that those removed from their parents' care seek to re-establish and maintain their family relationships despite difficulties encountered in doing so. Fourth, a finding which emerges strongly from the qualitative studies included in this review, is that social exclusion, bullying, and stigma are likely to be common experiences for children growing up in families headed by a parent or parents with ID. The long-term consequences for academic, social, and behavioural outcomes of social exclusion, bullying, and stigma for this group of children have yet to be explored. Indeed, the social world of children of parents with ID is an under-researched area and only the study by Faureholm (2010) provides a child's perspective of childhood. The children's perspective on

their lives warrants attention. These children are born to a population of parents about whom many negative stereotypes exist. It is vital that they are not overlooked or labelled with similar stereotypes as their parents. Perhaps most worrying is the continuing risk that they be regarded as uniformly in need of protection from harm.

### Author note

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### Notes

1. One study, Booth and Booth (2000), "Against the Odds: Growing Up With Parents Who Have Learning Difficulties," reports on the findings of research which is dealt with in more detail in Booth and Booth (1998), "Growing Up With Parents Who Have Learning Difficulties." The latter reference is primarily used but both are referred to in the review and included in Table 1.
2. Based on the Index of Relative Socio-Economic Disadvantage (Australian Bureau of Statistics, 1998).

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