



Picture: Rhonda Milner

Parental Disability and the Threat of Child Removal

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Families headed by parents with disabilities may be seriously disadvantaged as a consequence of an uneven spread of expertise among service providers. This paper discusses the situation of parents with intellectual disability in care and protection proceedings.

Families where one or both parents have a disability are among the most vulnerable and isolated in the community. Many service providers faced with the challenge of meeting the needs of this particular parent group feel ill equipped to do so (Llewellyn, McConnell and Bye 1995; McConnell, Llewellyn and Bye 1997). Some have expertise in family support and/or child protection but lack knowledge about parental disability. Others have expertise in disability but have limited knowledge about family support or child protection strategies. Families headed by parents with disabilities are potentially disadvantaged by this uneven spread of expertise.

Over the last ten years we have had the opportunity to talk with around 100 parents with intellectual disability (Llewellyn 1995; Llewellyn, McConnell, and Bye 1998; Llewellyn, McConnell and Bye 1995; McConnell, Llewellyn and Bye 1997). A considerable number of these parents have spoken of living under constant scrutiny and their fear that 'the welfare' might take their children away. This is not a new or exclusively Australian phenomenon. Researchers in the United States and the United Kingdom have reported similar findings (Andron and Tymchuk 1987; Booth and Booth 1993).

Responding to these parents' concerns, the specific focus of this article is, first, to review the literature on the involvement of parents with intellectual disability in care and protection proceedings and, second, to propose several measures to ensure parents with intellectual disability are no longer subject to prejudicial treatment in care and protection proceedings.



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Legal and Research Literature

Are the fears of these parents justified? High rates of notification (reports of child abuse or neglect) and child removal suggest so. For example, in the United Kingdom, Shaw and Wright (1960) found that in a sample of 197 parents with intellectual disability, nearly one-third were known to the National Society for the Prevention of Cruelty to Children. A study conducted in Sweden found that of 40 children born to mothers with intellectual disability 18 were

in foster homes, and there were reports of neglect for another three children (Gillberg and Geijer-Karlsson 1983). In the United States, Accardo and Whitman (1990) reviewed hospital records and found that of 226 children born to 76 families headed by a parent with intellectual disability 103 (45.5 per cent) had been removed.

Two Australian studies present a similar picture. A study conducted in South Australia identified 77 parents with intellectual disabilities that were known to have 116 children; of these, it was estimated that one-third had been taken into care (Bowden 1994). In New South Wales, a survey conducted by the Family Support Services Association found that among their clients, parents with identified cognitive limitations were almost twice as likely as non-disabled parents to have involvement with the NSW Department of Community Services in matters of child protection (personal communication, M. Spencer, Family Support Services Association, April 1998).

It may be easy to conclude that high rates of notification and child removal indicate that parenting failure is all but inevitable.

However, reviews of court proceedings involving parents with intellectual disability suggest a different conclusion. Legal commentators have documented that parents with intellectual disability are subject to prejudicial treatment from child protection agencies and courts (Galliher 1973; Haavik and Meninger 1981; Hayman 1990; Hertz 1979; Levesque 1996). In brief, Hayman (1990: 1203) noted that 'each mentally retarded parent faces the substantial likelihood that, by legal prescription, she will soon no longer be'. Furthermore, Levesque (1996: 105) asserted that 'the rights of mentally retarded parents are, in practice, being terminated when States present evidence which, if used against non-disabled parents, would not be enough to sever the parental relationship'.

There are cases cited in the legal literature in which child removal has been ordered without evidence of abuse or neglect. Typically, but not exclusively, these cases involved child removal at the time, or within days of a child's birth. In some cases cited, courts have ordered child removal when evidence of possible neglect was refuted or when the disabled parent was shown to be providing adequate care. In other cases, evidence of neglect or abuse was established yet support services were not provided before the child was removed.

One North American study reports prevalence data about parents with disabilities from a court sample. Taylor and colleagues (1991) examined 206 cases of child maltreatment before the courts in Boston in 1985–86. In 31 cases, (approximately 15 per cent of the total sample), either one or both parents had a diagnosis of intellectual impairment (IQ < 79). Judicial outcome was significantly linked to parent diagnosis. The histories of parents with intellectual impairment revealed less prior court involvement and greater acceptance of court ordered services than any other group, yet their children were removed nearly as often as substance abusing parents, and more often than emotionally disordered or non-diagnosed parents.

As yet we do not know whether parents with intellectual disability in Australian care and protection proceedings are subject to discriminatory treatment. However, we should take the international trends quite seriously. In Australia, we share a common tradition with the United States and the United Kingdom in our treatment and institutionalisation of people with intellectual disability. Moreover, community stereotypes of people with intellectual disability are as pervasive here as they are in other western nations. For example, people with intellectual disability are frequently regarded as 'eternal children' who do not ever mature sexually, socially or emotionally. Consequently, they are perceived to be dependent and therefore incapable of raising children. Such beliefs distort our perceptions of the ability of people with intellectual disability, in particular, their potential ability as parents.

Australian child protection legislation leaves child protection agencies and the courts to determine what constitutes child neglect, child abuse or the likelihood of child maltreatment. In this context, mistaken beliefs about parents with intellectual disability may potentially influence decisions about parents' current or future parenting competencies.

Discriminatory Treatment

What factors may influence discriminatory treatment of parents with intellectual disability? Six potential factors are discussed below.

A presumption of inevitable neglect or abuse

The scrutiny under which these parents live and the removal of children without evidence of abuse or neglect reflects an expectation of failure, or a presumption of inevitable neglect or abuse. Members of the general public, child protection workers, legal representatives, and magistrates may make such presumptions.

A presumption that parenting deficiencies are irremediable

When evidence of neglect or abuse is established, but no support services are provided before removing the child, the presumption may be that parenting deficiencies are irremediable. Children's Court magistrates acknowledge that in many cases potential outcomes are constrained by the level of resources available in the community to support families (Coates 1998; Llewellyn and McConnell, research in progress). In other words, custody or wardship may be ordered when it is judged that a parent with intellectual disability requires a level of support that cannot be provided or sustained.

A mistake of false attribution

Booth and Booth (1993) suggest that parents with intellectual disability are subject to a mistake of false attribution. That is to say, parent's difficulties are attributed to their disability when their difficulties derive more from poverty, poor housing, social isolation, harassment, and the lack of appropriate support services. These circumstances are likely to be viewed as confirming parental inadequacy, rather than as social constraints that precipitate parenting difficulties.

Parents with intellectual disability are vulnerable

From investigation of a notification through to a court order, parents with intellectual disability are at a distinct disadvantage. In the first instance, they may fail to understand the implications of how they present to child protection workers. Perceiving they are under threat, some parents may

respond in anger and be uncooperative. When court proceedings are instigated, parents may fail to understand the significance of the action brought against them and its potential implications (Haavik and Menninger 1981). Parents with intellectual disability may have difficulty instructing their solicitors, performing well under cross-examination or understanding the content of court orders or other decisions concerning the future of their children.

Child protection agencies and legal representatives may not appreciate the need to provide explanations in language that parents can comprehend. Alternatively, they may not have the skill or time required to help parents with intellectual disability articulate their wishes and respond to 'evidence' filed in court.

Inadequate legal services

In an Australian study, Keyzer, Carney and Tait (1997) report that legal services for parents with intellectual disability may be inadequate. Their findings suggest that in terms of both resources and training, legal services are poorly equipped to represent parents with intellectual disability. Prior to court, parents with intellectual disability are rarely advised to seek legal representation nor provided with the details of solicitors who may be able to help. Further, these authors note that few parents with intellectual disability will satisfy



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the criteria of a 'reasonable chance of success' to meet the merit test for Legal Aid in applications for rescission or variation of a court order.

Perceived disadvantage of inter-dependent parenting

Parents with intellectual disability may be penalised for getting help with their parenting from significant others. Yet, in many societies, extended family interdependence and shared child care are normal practice. However, in western societies autonomous and independent nuclear families are the perceived ideal. Reflecting this, parenting independence may be the standard against which parents are judged. For many parents with intellectual disability total independence in parenting is problematic.

Children's grandparents, for example, may play an important role in child rearing. Our research demonstrates that some parents with intellectual disability may belong to extensive, inter-dependent networks of family and friends that provide reciprocal support (Llewellyn, McConnell, Cant and Westbrook, in press).

Hayman (1990) cites one case in which a child was removed despite evidence that the child's needs were being met within a relationship that included a mother with intellectual disability and a non-disabled grandmother. The judge is quoted as saying: 'The test must be whether the parent, ultimately standing alone, is capable of mastering and can effectively demonstrate the ability to utilise . . . parenting skills' (in re S.R.J. 1985, cited in Hayman 1990, p.1253).

This focus on parents 'standing alone' is both ironic and unjust in relation to parents with intellectual disability. Their families, like all families, may need ongoing support as children's needs change over time. Where this support is available and accepted, either from family, friends or professionals, it can hardly be said that their children are 'in need of care'. Moreover, throughout their lives, parents with intellectual disability may have been socialised to be more inter-dependent. In homes or institutions, little may have been expected of children, youth and young adults with intellectual disability. The irony is that having been socialised to be dependent, as parents, they are penalised for their dependency.

Likelihood of Child Neglect or Abuse

Is there any foundation for presuming that parents with intellectual disability will inevitably neglect or abuse their children? The answer to this question is no. Regardless of how parenting adequacy is defined, virtually all studies report that a significant proportion of parents

with intellectual disability provide a level of care acceptable by community standards (see reviews by Booth and Booth 1993; Dowdney and Skuse 1993; Llewellyn 1990). Even the earlier studies of previously institutionalised parents suggest that most parents with intellectual disability provide adequate care. As far back as 1947, Mickelson found that only 26 per cent of a sample of 90 families (where one or both parents had previously been institutionalised) provided unsatisfactory care.

This is not to say that all parents with intellectual disability will be able to parent satisfactorily. However, to assume that neglect or abuse is inevitable is to ignore the fact that a consistent majority of parents with intellectual disability provide adequate care.

Research studies to date have only included samples of parents for whom support needs were already identified – that is, those referred to service agencies and/or with histories of institutionalisation. Parents with intellectual disability who do not come into contact with service agencies are not represented. The research literature is therefore biased toward those parents likely to have greater difficulties.

Whether 'intellectual disability' per se increases the likelihood of child neglect and abuse is another question – to which there is no simple answer. A number of so called 'risk factors' are often present in the lives of parents with intellectual disability. These include poverty, unemployment, social isolation and low self-esteem. It is difficult to separate out the effects of intellectual disability from such risk factors. However, most researchers suggest that intellectual disability per se is unlikely to increase risk, and that parenting difficulties arise from social constraints. This conclusion is supported by studies which have consistently found that IQ – a measure on a standardised intelligence test – is a poor predictor of parenting competence (Andron and Tymchuk 1987, Booth and Booth 1993). The ability of a parent to provide 'good enough' child care cannot be predicted on the basis of IQ alone.

The literature suggests two tentative conclusions. First, parents with intellectual disability appear to be no more likely than other socio-economically disadvantaged parents to abuse their children. Second, child neglect is more often encountered than abuse, but where neglect does occur, it is attributable to the parents' lack of experience, parenting training and appropriate supports (Tymchuk 1990; Tymchuk and Andron 1990).

Acquiring Parenting Skills

Is there any foundation for presuming that parenting deficiencies, when identified, are irremediable?

The answer to this question is no. The assumption that parenting deficiencies cannot be improved comes from an often cited study by Seagull and Sheurer (1986) who suggest that most parents with intellectual disability will not benefit from services due to their cognitive limitations. This conclusion was at best speculative, and is not supported by the weight of research that demonstrates that parents with intellectual disability can acquire and generalise parenting skills and 'unlearn' negative behaviours (see review of parenting education for parents with intellectual disability by Feldman 1994).

The most recent findings on parent education have emerged from two projects: Project Parenting, based at the University of California at Los Angeles and the Parent Education Project at Surry Place Centre in Toronto, Canada. These programs report significant results in training parents with intellectual disability in several parenting activities including child care (Feldman et al. 1992),

home safety and emergencies (Tymchuk, et al. 1990), parent-child interactions (Feldman et al. 1989), and decision-making (Tymchuk, Andron and Rahbar 1988).

Our research team at the University of Sydney is currently conducting a randomised controlled trial of a home learning program designed for parents with cognitive limitations which is concerned with child health and safety. The Commonwealth Department of Health and Family Services and the New South Wales Ageing and Disability Department, under the federal Best Practice Parenting Education Initiative, funds this study, The NSW Parent-Child Health and Wellbeing Project. The results of this study will be available early in the year 2000.

Most intervention studies to date, including our own, have as their focus parents' knowledge and skills. Clearly these are important. However, child outcomes are not solely a function of the parent's skills or lack thereof (Booth and Booth 1997). On the positive side, the support given by others, such as a grandmother, may compensate for limited parental skill. On the negative side, social isolation, poverty and other socio-economic constraints may undermine parental ability. Parents and their parenting must therefore be viewed in their family and community context, not simply as individuals in isolation. Support for parents must reach beyond skills training to address the environmental pressures that weigh heavily on families headed by parents with intellectual disability.

Need for Adequate Support Services

Child protection practice is appropriately committed to children's best interests. The best interests of children are generally served by preserving and supporting their families whenever possible. Furthermore, federal and state legislation specifically prohibits discrimination on the basis of a disability in the provision of a service, including child protection (Australian Disability Services Legislation 1986; NSW Disability Services Act 1993).

It is therefore incumbent on family support providers, child protection agencies and courts to ensure that parents with intellectual disability are not inadvertently subject to prejudicial and discriminatory practice. To this end, several steps could be taken.

- Child protection workers need to be aware of negative community attitudes towards people with intellectual disability and anticipate increased reports of child abuse and neglect. It has not been all that long since people with intellectual disability were institutionalised and the idea of them becoming parents may still be a little too radical for some members of the community to accept.
- Child protection workers and other professionals who come into contact with parents with intellectual disability in matters of child protection need to reflect on their own beliefs and challenge their

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own presumptions and those of their co-workers. Attitude change must start from within agencies and attention should be given to raising awareness of the special needs of parents with intellectual disability in child protection agencies, with legal personnel and among magistrates.

- Professionals should ensure that parents with intellectual disability understand the nature and purpose of any decisions that affect their families. In determining an action plan, parents with intellectual disability should be consulted, particularly as they are more likely to be motivated to cooperate if they have taken part in setting goals. Parents should be offered the assistance of an independent advocate who can reinforce information given and ensure that their wishes and views are heard. Efforts should also be made to ensure that the legal process is explained to parents by Legal Aid prior to court action.
- Parental skills and abilities need to be assessed in context, with due consideration given to parents' social support and the social constraints under which they live. As we have noted elsewhere: 'Families can no longer be examined from an "ideal" family, single point of reference. Families have to be understood as they are, and as they perceive themselves to be.' (Llewellyn 1995: 361)
- Agencies should advocate actively for adequate and appropriate support services to address the needs of both parents and children. Far greater emphasis needs to be given to prevention and support than to monitoring and surveillance. With this focus, parents' fears may be diminished, and they can be encouraged to seek support without fear of 'the welfare' taking their children away.

Conclusion

There is considerable evidence in the literature to suggest that parents with intellectual disability receive prejudicial and discriminatory treatment in matters of child protection. False presumptions, inadequate legal representation, parents' vulnerability, and culturally biased views on what constitutes family and parenting competence are among the factors accounting for this.

To investigate empirically the situation of parents with intellectual disability in Australia, we are currently conducting a prevalence and outcomes study about parents with disabilities in the New South Wales Children's Court. This study, funded by the Law Foundation of New South Wales, aims to determine whether parents with disabilities (intellectual, psychiatric, physical or sensory) and their children are disproportionately represented in care proceedings, and whether outcomes (court orders) for these families are different from the outcomes for parents without disabilities. In addition, we are investigating the

factors that influence court decisions and whether court processes and procedures disadvantage parents with disabilities.

To redress the current situation of presumed discriminatory treatment of parents with intellectual disability, workers in the field and the community at large need to become better informed about these parents, and to challenge their own often stereotyped beliefs.

Parents with intellectual disability deserve to be approached in a spirit of optimism and to be actively involved in plans concerning themselves and their children. An advocacy service is needed for parents involved in care proceedings with adequately trained and resourced solicitors to ensure these vulnerable families are fairly represented.

If adopted, such measures would ensure a more equitable and brighter future for parents with intellectual disability and their children.

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