

Parents with an Intellectual Disability: Common problems

Eddie Gallagher, Mar 2001

We have little idea how many parents with an intellectual disability there are in the population. A recent New Zealand study estimated that 1 family in 400 has a parent with an intellectual disability.¹ It is assumed by many writers that the numbers are increasing due to less institutionalisation and sterilisation of the intellectually disabled². However it is difficult to be sure as definitions vary and change with time³ and only a minority of eligible people come to the notice of agencies or researchers.

Most parents with an intellectual disability (well over 90%) are mildly rather than moderately disabled⁴. With parents who have a **mild** intellectual disability the available evidence suggests that the intellectual disability generally does **not** have a significant **direct** effect on parenting unless mediated through other problems, which may be related or coincidental. A number of studies have suggested that quality of parenting is not related to IQ (at least in the mild range of intellectual disability).⁵ The majority of adults with IQs in the mild range of intellectual disability do not use disability services once they leave school⁶. This probably also applies to those who become parents. Although some of these (and we don't know how many) are undoubtedly in contact with welfare or child protection services, many appear to be parenting adequately⁷. Thus intelligence in the range of mild intellectual disability is not *by itself* a risk factor for inadequate parenting. This is not to say that it will not complicate things when other problems are present (as they often are). It is also clear that those individuals who receive services or are registered as intellectually disabled are a highly selected sub-group from within those with IQs within this range.

On the other hand with the very small number of parents who have an IQ well below 60 there **does** appear to be a relationship between poor parenting and IQ⁸. Though the evidence is slim, "moderate" intellectual disability alone probably **is** a risk factor for inadequate parenting, unless there are extremely good supports in place. However, even for this very small group of parents, it should not be assumed that "inadequate parenting" necessarily implies maltreatment.

For intellectually disabled parents (either moderately disabled or mildly disabled with other problems) the risk to children is much more the possibility of neglect rather than of deliberate physical abuse.⁹

"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." McConnel & Llewellyn, 1998, p35

A recent study of the N.S.W. Children's Court found that even for those parents with a disability who actually appear before the children's court "Abuse, either alleged or substantiated was rare."¹⁰ A similar Court sample from Victoria also found that "even when there was an allegation of abuse, in only one case was this attributed directly to the mother."¹¹

This has also been my own experience. What is remarkable is that there is so little actual abuse substantiated given the many risk factors common in these families and the intense scrutiny that these parents are often under.

Many workers have beliefs about the disabled which presume poor parenting. The NSW Court study noted workers negative attitudes. "As 'eternal children' people with intellectual

disability are thought never to mature sexually, socially or emotionally. Consequently they are perceived to be dependent and therefore incapable of taking responsibility for their children."¹²

Parents' rights and children's rights

Much of the literature on this subject shows an obvious bias, either towards parents or towards children. Many writers support the rights of parents with an intellectual disability to have children, and bring them up. Their focus is the injustice and prejudice that these parents suffer. This focus sometimes leads to an over-optimistic viewpoint and to the harmful effects on children being minimised. On the other hand a small number of writers have focussed on the harmful effect on children in such a way that they give the impression that such effects are inevitable and incurable.¹³

Professionals working with families where a parent has an intellectual disability also often tend towards similar biases, often, but not invariably, depending on whether they are employed to work with the disabled or to work with children. It is important that we strive for balance, neither romanticising parents (and minimising the difficulties which children may face), in an attempt to counter negative prejudices, nor making prejudiced assumptions that all individuals in a category are similar. Parents with an intellectual disability not only vary greatly in ability but in every other way that individuals can vary: personality, culture, motivation, interests, morals, etc. etc.

"It would undoubtedly be wrong to assume incompetence, but it would be equally wrong to accept different standards for the welfare of certain children." Schofield, 1996, p92.

Mild intellectual disability should probably be thought of as a factor similar to poverty. Families in poverty are more likely to have problems of many types, some of which substantially increase the risk of abuse or neglect. However, we do not consider poverty alone as indicating an inability to parent properly or as a justification for prejudice and discrimination. The same should apply to mild intellectual disability, though correlations with other problems will be higher than for poverty alone. Unfortunately, far too often the focus is almost exclusively on the intellectual disability with other social and personality factors ignored or played down.

People with **mild** intellectual disabilities tend only to be handicapped in literate, industrial societies and generally only when they also have other problems, medical, psychiatric or social. As measures are so imprecise and definitions have changed many times, whether someone is given the label is very much a lottery¹⁴.

"Even when they have shown deficits, examination of distributions of performance shows overlap with normal samples and some problems may be related as strongly to socio-economic status as intellectual level." Azar, et, al 1995, p 609

"Good enough" parenting?

It would be difficult to disagree with a plea for fair treatment for parents with a disability. However, confusion arises over the question of whether or not we should make allowances for the disabled and accept what in some cases may be seen as sub-standard parenting. Stated baldly like this it seems obvious that we cannot, and should not, condone sub-standard parenting which is harmful to children even when it results from well-meaning incompetence rather than maliciousness. However, when considering passive neglect rather than active child abuse it becomes quite difficult to be clear about what the long-term consequences are for children. Research on the long-term effects of neglect is very thin on the ground and we

really do not know which aspects of a pattern of neglect seriously effect children's development¹⁵. A very dirty house does have health implications for children (as well as social implications) but are these any more severe than having a parent who smokes? Lax safety standards increases the statistical risk of accidents but so does spending a lot of time in the car or living on a farm. Lack of physical affection is certainly a cause for concern but the amount and type of physical affection shown to children varies greatly within different cultural groups (even within the English speaking world)¹⁶ so who is to say what is acceptable or unacceptable.

Appeals to act "in the best interest of the child" often beg many questions. In judging anyone's "best interest" we make judgements about current happiness and safety and balance this against guesses about future outcomes: developmental, social and psychological. We should be clear that these really are *guesses* as neither our theories nor our assessment tools are sophisticated enough to make any useful predictions about individual cases.

There is tremendous scope for our individual, and professional, values and prejudices to come into play in the highly emotional and contentious area of parenting by the intellectually disabled. This makes it imperative that we are at least clear in our own minds what our values and prejudices are. Otherwise we cannot take them into account, cannot compensate for them, and honest communication becomes difficult or impossible.

We must beware of imposing culturally inappropriate (usually middle-class) standards on families. We should only **insist** on *good enough* parenting rather than demand what we (we personally, organisationally or societally) see as the ideal.

On the other hand, with cooperative parents and sufficient resources we can and should aim for the best possible outcomes for children and families and **not** settle for "good-enough".

Some positives

- Parents with an intellectual disability are often very keen and enthusiastic about being parents. The parental role often gives them a sense of normality and purpose. It may be the first positive status they have enjoyed.
- Although most intellectually disabled adults have difficulty explaining their feelings, and a few may appear easily distracted and emotionally shallow, there seems little doubt that parents with an intellectual disability love their children just as much as other parents.¹⁷ However, the idea that they are **more** loving and affectionate than others is a myth.
- Attachment problems (unless these are defined in a very broad way) do not appear to be any more common than in comparable families without an intellectual disability.
- On the whole they do not have large families¹⁸. **Most** have realistic ideas about how many children they can cope with¹⁹.
- They do not appear to physically abuse their children any more than parents in similar social situations (i.e. taking into account poverty, social supports, etc)²⁰.
- Some parents show remarkable resiliency and tenacity despite burdens that would floor most of us.
- Their children tend not to be intellectually disabled unless subjected to a deprived environment ("regression to the mean" makes the majority of children more intelligent than parents with an intellectual disability).²¹
- They are often very accepting of children with an intellectual disability.

- Some children appear to survive and flourish.²²
- Many studies have shown that they have the ability to improve their parenting with training or support²³

Problems sometimes associated with parental intellectual disability

The following problems are **more common** for parents with an intellectual disability, at least those known to services. This list is based mainly on the research evidence and to a lesser extent on my own professional experience.

- ◆ Intellectually disabled adults have often been restricted in life experience generally and often have had little opportunity to practice decision-making²⁴
- ◆ Socialised to be dependent, i.e. not encouraged to be independent or assertive.²⁵ This is doubly so for disabled women in our society.
- ◆ Some have lacked the opportunity to acquire general social skills because of over-protection, institutionalisation, segregation or discrimination.
- ◆ Often had little opportunity to care for children – less likely to be given babies to hold, not used for baby-sitting, their friends are less likely to have children.
- ◆ Other people less likely to have discussed intimacy, marriage, relationships, sexuality and parenting with them as children or adults – it has usually been assumed that they will not marry or have children.²⁶
- ◆ May have lost touch with extended family²⁷ or are part of a multi-problem family²⁸ (which may be causally related to their intellectual disability).
- ◆ Much more likely to have had abusive or troubled childhoods.²⁹
- ◆ Often suffered abuse as adults: more likely to be the victims of domestic violence³⁰ and sexual assault.³¹
- ◆ Often lack social supports and friends³², or may be accepted by socially stigmatised friends (eg individuals or groups with criminal tendencies, psychiatric problems, substance abuse, etc).
- ◆ Highly likely to be in poverty³³ and more often in inadequate housing.
- ◆ Discriminated against and stigmatised, both individually and organisationally.³⁴
- ◆ Live with the (realistic) fear that their children will be taken away from them.³⁵
- ◆ Low self-esteem is endemic³⁶ and long-term depression common.³⁷
- ◆ They frequently live with the expectation of failure and feelings of inadequacy.
- ◆ Higher than average rates of emotional and personality problems³⁸ and stress.³⁹
- ◆ More likely to be sole parents.⁴⁰
- ◆ When married are more likely to be in unsupportive relationships⁴¹ or have partners who have some kind of disability or psychiatric problems⁴².
- ◆ Often closely monitored by professionals and family⁴³, which can be confidence destroying and stressful: may become somewhat paranoid and defensive⁴⁴.
- ◆ Poor problem solving ability⁴⁵: in household management, dealing with children's problem behaviour and safety issues.

- ◆ Restricted communication abilities and passivity may mean that parents do not adequately stimulate their children: amplifying or creating developmental delays⁴⁶.
- ◆ Lack of praise for their children appears to be a common problem⁴⁷.
- ◆ May not play with children in a helpful way: may either become too self-absorbed in play activities or may be oversensitive about appearing childish⁴⁸.
- ◆ Flexibility is a key element of good parenting - this can be very difficult for parents with an intellectual disability⁴⁹.
- ◆ Effective discipline often requires judgement and a balanced approach⁵⁰, eg. some parents with an intellectual disability give in to their children's demands and tantrums much more frequently than normal.
- ◆ Difficulty in establishing routines is a common problem.
- ◆ Their children are more likely to have disabilities themselves⁵¹. This is partly genetic but appears to be mainly environmental.
- ◆ Sexual abuse of their children more common than in general population – sometimes deliberately targeted by paedophiles⁵².
- ◆ Children become able to out-argue and out-smart parents at a fairly early age.
- ◆ Children may take on too much responsibility at an early age (for themselves, for sibs and for parents)⁵³.
- ◆ Older children often become embarrassed by parents or their home. They may be teased by peers.
- ◆ For many of the above reasons children more often have behaviour problems⁵⁴

This is undoubtedly a depressing list! However, it is **very** important to bear in mind that we are talking about correlations. Some of the correlations are worryingly high but **none** of these problems are inevitable. We must remember that health and welfare agencies are **much** more likely to come into contact with those families who do have a number of these problems.⁵⁵ Statistically it can be shown that there are **many times** more parents with IQs below 70 in the general population than are known to services⁵⁶. We must beware of overgeneralising from a small, unrepresentative sample. Those agencies whose focus is on child protection or family welfare obviously see only those cases where things are going wrong. Less obviously, agencies working specifically with the disabled only see a small percentage of those with mild intellectual disabilities and who they see is **heavily** biased towards those with additional problems.

Too often this bias in research and in our professional experience is unacknowledged. Though referring to a specific study the following is true of all the research in this area: *“This bias towards couples with problems has been unavoidable. It has implications when we look at the results, for if many couples can, for the most part, maintain themselves in spite of difficulties, there is reason for a degree of professional optimism.”* Craft & Craft, 1979.

It is also important to recognise that most of the problems listed above can be overcome with training or support. As stated earlier (but worth repeating for emphasis) numerous research projects have shown that parents with an intellectual disability can improve their parenting with training.⁵⁷ Given the high rates of behaviour problems and learning difficulties in their

children and high rates of child removal, long term support and training for this group of people is **essential** not only on moral grounds but also makes good economic sense.

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NOTES

¹ Mirfin-Veitch et al, 1999.

² Although this assumption is common in the literature there is virtually no evidence to back it up and it seems unlikely that more than a small minority of mildly intellectually disabled individual were ever sterilised or institutionalised. "Though a number of sterilizations were performed [in the USA in the first half of the 20th century]... the vast majority of mentally retarded persons, whether in the community or in the institution, did not undergo this indignity." Scheerenberger, 1983, p191

³ Wen, 1997.

⁴ **Mild intellectual disability is usually defined as an IQ of 55 to 70 (2 to 3 standard deviations below the mean) and moderate intellectual disability as 40 to 55 (3 to 4 standard deviations below mean). Less than 1 in 10 of parents known to services have moderate intellectual disabilities: and this is clearly a great overestimation of the ratio of mild to moderate in the population as a whole.**

⁵ Borgman, 1969; Mickelson, 1947; Dowdney & Skuse, 1992; Feldman & Walton-Allen, 1997; Rosenberg & McTate, 1982; Shaw & Wright, 1960; Zetlin, Weisner & Gallimore, 1985; Polansky, Saix & Shallin, 1973. **"Clinical reports, unpublished papers and professional communications... support the finding that, above 60, the IQ of the parent is a poor predictor of ultimate parenting success."** Andron & Tymchuk, 1987, p243 **"the research evidence is consistent and persuasive. There is no clear relationship between parental competency and intelligence"** Booth & Booth, 1993, p 463

⁶ eg Ross et al (1985); **"research suggests that many graduates of educable mentally retarded classes more or less 'disappear' into the normal population after they leave school"** Koegel & Edgerton, 1984.

⁷ Scally, 1973. **There are no reliable demographic statistics on this.**

⁸ **Clinical evidence seems to support this but the empirical evidence is very weak, mainly because such parents are rare: Shaw & Wright, 1960; Borgman, 1969; Mickelson, 1947. Note the age of these much-quoted studies! It is of interest that Mickelson rated 3 of 10 mothers with IQs below 50 as giving "satisfactory" care to their children.**

⁹ McConnel & Llewellyn 1998, p35; Tymchuk & Andron, 1990; Tymchuk, 1992; McConnell, Llewellyn & Ferronato (2000). **This is also strongly supported by my clinical experience.**

¹⁰ McConnell, Llewellyn & Ferronato (2000), p 84.

¹¹ Glaun & Brown, 1999, p 98

¹² McConnell, Llewellyn & Ferronato (2000), p 83

¹³ eg. Whitman & Accardo, 1989; Seagull & Scheurer, 1986.

¹⁴ **The word "handicap" appropriately comes from "hand-in-cap" which was a lottery game.**

¹⁵ Stevenson (1998)

¹⁶ **Parenting indicators "may not be meaningful across diverse groups... Family transactions within some cultural groups, for example, are not characterized by overt shows of affection."** Azar et al, 1995, p 611.

¹⁷ Eg. Brandon, 1957.

¹⁸ Eg Floor et al, 1975; Andron & Tymchuk, 1987; Craft & Craft, 1979; Kollberg, 1989; Ross et al, 1985.

¹⁹ Espe-Sherwindt & Crable, 1992; Whitman et al, 1989.

²⁰ **In my experience lack of discipline is a much more common issue than harsh discipline.**

²¹ Tymchuk et al, 1987; Reed & Reed, 1965.

²² Booth & Booth, 1999

²³ Budd & Greenspan, 1985; Feldman et al, 1985; 1986; 1992; Fantuzzo et al, 1986; Tymchuk et al, 1988; Whitman & Accardo 1990; Wolf et al, 1982

²⁴ Llewellyn, 1997

²⁵ Llewellyn, 1997; Andron & Tymchuk, 1987, p247

²⁶ Andron & Tymchuk, 1987, p247

²⁷ Booth & Booth 1993; Andron & Tymchuk, 1987, p 250.

²⁸ **Strongly supported by clinical experience, lots of indirect evidence from research, but little direct evidence because of problems with definition and reliability of evidence;** Heighway, 1992.

²⁹ Gillberg, & Geijer-Karlsson, 1983; Ray & Rubenstein, 1994; Seagull & Scheurer, 1986; Gath, 1988; Booth & Booth, 1998; Office of the Status of Women, 1993; Glaun & Brown, 1999; Collins & Coker, 2000; **Hard**

(1987) estimated that sexual abuse is 4 times higher among those with intellectual disabilities generally than the general public.

³⁰ Tymchuck & Andron, 1990

³¹ Seagull & Scheurer, 1986. McCarthy, 1999.

³² **“Many people with learning difficulties experience emotionally barren lives starved of friendship, intimacy and solace...”** Booth & Booth, 1994; Booth & Booth, 1995, p35; Llewellyn et al. 1999; Feldman & Walton-Allen, 1997; Andron & Tymchuk, 1987: **“Their poverty as well as their sense of being different leads to severe social isolation.”** p254

³³ Llewellyn et al., 1999; Booth & Booth, 1993; Andron & Tymchuk, 1987; Hatton, 1998.

³⁴ Booth & Booth, 1998; Hertz, 1979; Levesque, 1996; McConnel & Llewellyn 1998; Matava 1994; Dowdney & Skuse, 1992; Feldman, 1992; McConnel, 2001; **Andron & Tymchuk, 1987: “they have experienced condescending attitudes, patronisation, distrust and outright dislike from various agencies.”** p256

³⁵ McConnel, 2000; Hayman, 1990; Levesque, 1996; **“many of the mothers live in fear of losing custody of their children and are afraid of strangers who might report them to Child Protective Services”**

Sigurjonsdottir & Traustadottir, 2000, p 259.

³⁶ Llewellyn, 1997; Tymchuk, 1991.

³⁷ Andron & Tymchuk, 1987, p254; Tymchuk, 1994; McGaw, 2000; Collins & Coker, 2000.

³⁸ Sundram, Stack & Benjamin, 1993; McGaw & Beckley, 2000

³⁹ Feldman et al, 1997

⁴⁰ Rosenberg & McTate, 1982; Whitman & Accardo, 1990; **In various studies “the proportion of single parents has ranged from 37% to 92%”** Dowdney & Skuse, 1992, p35

⁴¹ Wayne & Fine, 1986. **Mickelson (1947) noted “there seemed to be an extremely high correlation between harmonious marital relationships and adequate child care.”** P 651.

⁴² Glaun & Brown, 1999; **Eg. In Craft & Craft’s 1979 study only 11 partners of a sample of 50 partners had no overt disability.**

⁴³ Llewellyn, 1997, p254.

⁴⁴ Andron & Tymchuk, 1987, p249

⁴⁵ Tymchuk, Andron & Rahbar, 1988; Lynch & Bakley, 1989.

⁴⁶ Booth, & Booth 1993; Feldman & Walton-Allen, 1997; McGaw & Sturney 1993; Martin et al. 1990; Rolfe, 1990; Budd & Greenspan, 1984.; Keltner, 1994; Keltner, Finn & Shearer, 1995; **Keltner, 1992: “Rarely did any mother [with an I.D.] say anything at all when feeding her baby... Eye contact with the baby during the feeding was also unusual.”** P 16

⁴⁷ Feldman, 1986; Tymchuk & Andron, 1992.

⁴⁸ Andron & Tymchuk, 1987, p 254

⁴⁹ Booth & Booth, 1993.

⁵⁰ Booth & Booth, 1993.

⁵¹ Mitchelson, 1945; Morch, Skar & Andersgard 1997; Ray & Rubenstein, 1994; Accardo & Whitman, 1990; Shaw & Wright, 1960; Glaun & Brown, 1999; Reed & Reed, 1965. **Estimates vary widely! Craft & Craft (1979) state that estimates have ranged from 2.5% to 93%! Probably a third to a half of families with parents with an intellectual disability (known to services) have one or more children with a disability.**

⁵² McCarthy, 1999. **Also supported by my clinical experience.**

⁵³ **Booth & Booth, 1998 argue from their study of adult children that this problem is frequently exaggerated and the term “parentified” is overused.**

⁵⁴ Feldman & Walton-Allen, 1997; LeClare & Kowalewski, 1994; McGaw & Beckley, 2000; O’Neil, 1985. **A Swedish study, with a more representative sample than most, concluded that “only a small minority of the 41 children were possibly ‘well adjusted’.”** Gillberg & Geijer-Karlsson, 1983.

⁵⁵ **“It must be realised that retarded parents who are coping adequately may never come to the attention of either researchers or the service delivery system. Research may therefore be based primarily on the ‘problem’ population.”** Tucker & Johnstone, 1989.

⁵⁶ Richardson & Koller, 1992. **Roughly one person in 200 has an IQ between 65 and 70. Few of these are disabled as adults and most probably become parents.**

⁵⁷ See note 21

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