

Parental Intellectual Disability/ Learning Difficulties Vulnerability

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Parental intellectual disability/learning difficulties

Description and context

Definition of intellectual disability/learning difficulties

There is inconsistency and ambiguity in the use of terms to describe people with below average intellectual functioning. Different countries use different terms. The term 'learning disability' is used in the United Kingdom (UK), while 'intellectual disability' is used in Australia, Canada and some countries in Europe. 'Cognitive disability' is also used in some jurisdictions in different countries. In each jurisdiction there is a set of criteria to assess intellectual disability or learning difficulties.

In Australia, people with limitations in intelligence (measured as having an intelligence quotient (IQ) of less than 70) and significant limitation in the skills needed to live and work in the community are considered to have an intellectual disability. Such skills include communication, social skills, self-care, safety-awareness and capacity for self-direction. These limitations are evident before a person turns 18 years old (BIGBY, FYFFE AND OZANNE, 2007).

While this was the case in the past, there is a tendency now to move away from classifying an intellectual disability into 'mild',

'moderate', 'severe' or 'profound', based upon certain IQ ranges as these classifications have limited utility and can sometimes be misleading.

Some people may not meet the criteria for having an intellectual disability but may still show cognitive and learning difficulties which present challenges for their functioning on a daily basis and in particular with their parenting.

In this practice resource, the terms **intellectual disability** and **learning difficulties** will be used interchangeably.

In most cases the cause of a person's intellectual disability is not known. Some identifiable causes include: hereditary factors; chromosome abnormalities, such as in Down Syndrome; brain damage before or at birth; brain damage after birth but before age 18 due to illness or accident; malnutrition or other deprivation in early childhood. (SEE [BETTER HEALTH VICTORIA](#)).

People with an intellectual disability can have more difficulty than others in understanding ideas, solving problems, maintaining attention and concentrating, remembering and learning new things but with appropriate supports and targeted skills-based training, they **can** learn and **can** apply adequate parenting skills.

The severity and the consequences of intellectual disability will vary from person to person.

It is important to recognise that an intellectual disability is not a mental illness or a physical sickness which can be 'cured', though people with an intellectual disability can benefit from appropriate educational programs. Nor is an intellectual disability necessarily accompanied by a physical disability or obvious from a person's appearance.

People often confuse having an intellectual disability with acquired brain injury. These are two different conditions. Acquired brain injury is classified as a physical disability and can result from a number of causes, including head trauma, hypoxia, infection, tumour, substance abuse, degenerative neurological disease and stroke. People with a brain injury may have difficulty controlling, coordinating and communicating their thoughts and actions but they usually retain their intellectual abilities. (SEE [BETTER HEALTH CHANNEL](#))

Prevalence of people with an intellectual disability/learning difficulties

The Australian Bureau of Statistics estimates that almost one per cent of the Australian population have an intellectual disability needing assistance in self-care, mobility and verbal communication (WEN, 1997).

Approximately one to two per cent of families with children between 0-17 years have at least one parent with learning difficulties (ABS, 2000).



NSW Department of
Community Services

✎ While parents with an intellectual disability in Australia, the United States (US) and United Kingdom (UK) have been found to be 15 to 50 times more likely than other parents to have their children removed and placed in care, this is rarely because of allegations of abuse and mostly due to increased risk of harm due to neglect (BIGBY, FYFFE & OZANNE 2007).

✎ International research shows high rates (40-60 per cent) of child removal from the family home when a parent has a learning difficulty (BOOTH & BOOTH, 1996).

✎ Research in NSW and Victoria has shown that parents with learning difficulties are disproportionately represented in child protection services and care proceedings (McCONNELL, LLEWELLYN & FERRONATO, 2000; SWAIN ET AL 2002).

✎ Some of the reasons why parents with intellectual disabilities may be over-represented include living conditions (i.e. poverty, unemployment, etc.); the role of prejudices beliefs, perceptions and expectations (McCONNELL ET AL 2000); and the significant gaps in support services (BOOTH, 2000).

✎ Many parents with a learning difficulty live with the constant fear that contact with welfare and disability services will result in the removal of their children (McCONNELL ET AL 1997).

Legislation

Legislation has been enacted in Australia to ensure that the presence of a disability should not prevent a person from participating equitably in the activities of the broader community.

Federal Government Legislation

The Federal *Disability Discrimination Act 1992 (DDA)* provides protection for everyone in Australia against discrimination based on disability. Disability discrimination happens when people with a disability are treated less fairly than people without a disability. It also occurs when people are treated less fairly because they are relatives, friends, carers, co-workers or associates of a person with a disability (See *A Brief Guide to the DDA* published by the Human Rights and Equal Opportunity Commission).

State Government Legislation

The *NSW Anti-Discrimination Act 1977* parallels the DDA in many ways, but includes many other grounds for discrimination including sex, age, and race. Where the *NSW Anti-Discrimination Act 1997* differs from the DDA, the Federal legislation over-rides the State legislation.

The *NSW Disability Services Act 1993 (DSA)* sets out the ways in which funded services for people with disabilities must be delivered so as to ensure equity. The DSA also requires all Government agencies to prepare Disability Action Plans that detail the barriers faced by people with disabilities

in dealing with the agency or in gaining employment with the agency and strategies to remove the barriers.

The *NSW Government Disability Policy Framework* requires State Government agencies that offer community services to adjust their programs to ensure access for people with disabilities.

Key learnings from current evidence based research

Most research on parents with an intellectual disability has focused on the deficits e.g. the obstacles to effective parenting they must overcome, the failings in their parenting, and the problems observed in their children, while ignoring the positive aspects or competencies (BOOTH & BOOTH 1993). This has contributed to perceptions in the community and amongst professionals that people with an intellectual disability cannot be good parents. There are many myths widely held about people with an intellectual disability. Some examples of these can be found in the *NSW Council for Intellectual Disability* website.

An extensive body of research now shows that having an intellectual disability does not cause poor parenting and it does not necessarily lead to neglect and abuse (BOOTH & BOOTH 1993, DOWDNEY & SKUSE 1993, FELDMAN 1994, BOOTH 2000, LLEWELLYN, ET AL 2003). Nevertheless, parents with an intellectual disability may have difficulties ensuring adequate child care, and health and safety

for their children (FELDMAN, CASE & SPARKS 1992 TYMCHUK, HAMADA, ANDRON & ANDERSON 1990) and may experience difficulties solving problems (TYMCHUK, YOKOTA & RAHBAR 1990). Some implications for the Brighter Futures program are that Brighter Futures workers will need to assist parents with an intellectual disability to provide child care, and to develop skills that enable the parent to ensure the health and safety of their children.

Research also shows that people with an intellectual disability may experienced cognitive limitations which may include maintaining attention and concentrating over long periods of time, learning and remembering information and using it appropriately, problem solving, communicating both receptively and expressively (particularly reading and writing), choosing between different types of information, and displaying appropriate social skills (LUCKASSON ET AL 2002).

These cognitive limitations vary from person to person and reflect many different biological and environmental factors. People with learning difficulties differ greatly in their intellectual ability and adaptive social skills. The implications for Brighter Futures workers are that they treat each person as a unique individual.

Also, Brighter Futures workers need to tailor their methods of supporting parents to develop parenting skills to suit the learning needs of each family. Some parents with intellectual

disabilities have difficulty adapting skills they have learnt in line with the changing needs of the developing child. Parents' learning difficulties may result in limitations with regard to correctly recognising a child's cues and responding to the child (HEALTHY START).

Competent parenting includes adapting to the changing requirements and circumstances of the child and involves perceptiveness, responsiveness and flexibility. However, some parents with learning disabilities are limited in thinking in terms of relationships or abstractions (KILLEN 1994). The Healthy Start program proposes a set of practice principles to meet the support needs of parents with an intellectual disability.

Impact of intellectual disability on parenting capacity

There are a number of factors that can affect parental capacity for people with an intellectual disability.

Parents with an intellectual disability are more likely to face specific problems that make the task of child rearing more difficult. These include:

- poor physical health
- poverty, unemployment, inadequate housing, unsafe neighbourhoods
- relationship difficulties, high stress, poor treatment throughout life, depression, low self-esteem
- little exposure to positive parenting role models

- difficulty sourcing, understanding and applying information
- isolation and limited informal advice, practical and emotional support from friends and family
- few formal services and supports that accommodate their learning needs. (BOOTH & BOOTH 1993 FELDMAN 1997, KELLEY, SIKKA & VENKATESAN 1997, KIRSHBAUM 2000).

Many of these factors have been shown to be associated with negative child and parenting outcomes (HOPS ET AL 1987, WEBSTER-STRATTON 1998). Experiencing several of these factors at one time can increase levels of risk of neglect or abuse for children.

The level of a parent's intellectual ability may have little relationship to their parenting ability. How mothers manage their parenting role is influenced by their mental maturity and stability including having a positive and realistic picture of oneself, feeling valued as an individual, and feeling that she is an asset to her children (LLEWELLYN 1997).

Parents with an intellectual disability often do not seek assistance from formal support providers because they fear that they will be judged as poor parents and that their children will be removed from their care. These fears are understandable as the view that people with intellectual disabilities are unfit to parent is still evident in the service system that supports children and families (McCONNELL ET AL 1997).

The beliefs, perceptions and expectations of health and welfare practitioners about the nature of disability and the learning process influence the way practitioners work with families.

- It is easy to fall into a focus on deficits at the expense of recognising strengths and competencies. An assumption that a parent does not have the capacity to learn tends to lead to the practitioner providing fewer opportunities for the parent to participate in programs which promote development of parental competence. Lack of learning opportunities can result in a parent becoming less competent over time. This then justifies and reinforces practitioners' pessimism about the parent's potential for development, and so the cycle goes on.
- If health and welfare practitioners take a positive approach to the parent's capacity to learn appropriate parenting skills, this will directly affect the nature of the supports that are provided by the practitioner. Once practitioners start to recognise strengths in a parent with a learning difficulty, they will develop positive expectations about the parents' ability to learn and do new things (BOOTH 2000).

The most common support need reported by parents with an intellectual disability is for assistance in providing appropriate child care and understanding child development.

For example:

- how to engage and stimulate a child
- how to discipline a child and set boundaries
- how to attend to a child's hygiene and safety
- what to do when there is a medical emergency

Parents have also reported needing assistance in the community participation area; knowing what community services are available and how to access them; developing self esteem and assertiveness skills; meeting people and making friends; and advocating on behalf of themselves and their children. This is because typically many parents are isolated and without friendships or peer group support (LLEWELLYN & McCONNELL 2002).

Impact of parental intellectual disability on the child

Research on the effects on children of having a parent with a learning disability is scarce. The available literature focuses almost exclusively on whether people with a learning disability can be provided with adequate support, and can learn sufficient skills to allow them to be 'good enough' parents. The subjective experience of these children has been

recorded in only one study that was found (BOOTH & BOOTH 2000).

Booth and Booth (2000) conducted a retrospective study examining the childhood experiences of 30 individuals whose parents had a learning disability. They compared 15 adult children who themselves had a learning disability with 15 adult children whose IQ was in the normal range. Only four of the 30 children left school with any qualifications, 15 had experienced persistent bullying and 13 had regularly skipped school. Generally, children without a learning disability showed a pattern of persistent under-achieving, truancy, problems with learning and clashes with teachers, dropping out of school and subsequent unemployment. Children with a learning disability showed a broadly similar picture, but with fewer behavior problems at school.

Brighter Futures workers should be mindful of the possible effects of having a parent with a learning disability on the child:

- Isolation – The high degree of social isolation experienced by most parents with intellectual disability affects children. An unusually high proportion of these parents are estranged not only from their immediate family but also receive very little, if any, support from extended family, neighbours or other community members (LLEWELLYN 1995).

When parents are socially isolated so are their children.

Opportunities for children to develop friends may be very limited. Parents may not know other parents with children of the same age. Families may live in neighbourhoods that are intolerant or inhospitable. Children may be reluctant to invite friends home due to the stigma associated with their parent's disability.

- Psychological difficulties – Limited research has been conducted on the specific psychological consequences of having a parent with a learning disability. Some studies have shown that children often feel stigmatised by certain characteristics and behaviors of their parents, particularly those who are noticeably different from other parents (PERKINS ET AL 2002). Stigma may be more obvious if the children themselves do not have a learning disability. The mother may respond to her child's needs in an atypical manner, which tends to become especially difficult if the child is more intelligent than the mother (WHITMAN & ACCARDO, 1990). The child may react or interact with the mother in a way that reflects the emotional confusion created by this perception. An ultimate consequence may be that the child has less positive feelings about his/herself.

Evidence based practice principles

Some practice principles arising from the available research are:

- The most appropriate approach to working with parents with an intellectual disability for Brighter Futures workers to take is one that formally recognises the parent's intellectual disability and acknowledges their resource and support needs, rather than one that is deficit and diagnosis-focused. This model fits well with the Brighter Futures program model as it takes a holistic approach that considers a person's strengths and the needs of family members across four areas: (1) parent's intellectual functioning and adaptive skills, (2) psychological and emotional considerations, (3) physical and health needs, and (4) environmental considerations such as living situations, work, and education issues (LLEWELLYN 1995 LLEWELLYN 1997 SPENCER 2001).
 - Given that other factors, than the intellectual disability itself, have been found to impact parenting ability, Brighter Futures workers should take a holistic view of parent and family needs and not simply on the parent's intellectual disability as the reason for any difficulty in parenting.
 - When role modelling to teach parenting skills to parents with learning difficulties, it is important not to undermine already vulnerable parental self-esteem, and to avoid encouraging the baby to be drawn to the Brighter Futures caseworker during home-based intervention. It is better for the caseworker to facilitate and reinforce the positive aspects of the parent-child relationship (KIRSHBAUM 2000).
- Healthy Start is an Australian national strategy to support parents with an intellectual disability and promote a healthy start to life for their young children by enabling them to create a safer, more supportive environment for their children. Healthy Start has been adopted as the initiative to inform working with parents with an intellectual difficulty in Brighter Futures.
- Healthy Start suggests the following practice principles to meet the support needs of parents with an intellectual disability in the Family Support practice point:
- attend and respond to family needs, that is, both the interests of children and parents
 - provide long term support, allowing for skill acquisition and reinforcement but also the time for a trusting relationship to be established
 - provide support in the home, where newly learnt skills can be applied
 - provide support in a manner that will build the parent's self esteem and self confidence, by being open, honest, respectful, encouraging decision-making and self sufficiency

- assist parents to be active in their local community
- ensure that the parent's learning needs are integrated in planning and delivery of services, for example:
 - do not provide written information the parent can't read
 - explain a point as simply as possible and check that you are understood before moving onto the next point
 - simplify tasks by breaking them down into manageable steps
 - demonstrate where possible
 - create opportunities for the parent to repeat a new task
 - reinforce and encourage newly acquired skills and abilities.
- teach a new skill in a way that maximises the parent's likelihood of success, and identify strategies to work around any cognitive limitations the parent has e.g. poor short term memory
- assist the parent to identify potential barriers to change and developing solutions
- understand how parents can maintain learnt skills and generalise these skills, and build this into planning when teaching a new skill.

Sometimes practitioners mistakenly believe that a parent with an intellectual disability is unwilling to make changes when the practitioner has not provided an explanation that matches the parent's learning needs. A Frequently Asked Questions on the Healthy Start site provides the following practice points to ensure that this is not the reason for a lack of compliance:

- check that the parent has understood you (see [tip sheet](#))
- check that your goal and the family's goal are the same

Brighter Futures workers that join the [Healthy Start Network](#) are connected with other practitioners in the health, disability, child and family service sectors, with whom they can share their knowledge and experiences. The Network provides Brighter Futures workers with a further opportunity to identify and share best practice principles for working with parents with an intellectual disability.

Brighter Futures workers should access specialised services and programs through their local networks, including DADHC, NSW Health, and NGOs to support appropriate work with families with learning disabilities.

Endorsed research and resources

[Healthy Start](#) – This website contains a comprehensive range of resources for working with parents with an intellectual disability and their children. While Healthy Start's focus is on resources that support parents

with children under 5 years, the principles and strategies used in the parenting programs may apply to older children. To search for journal articles and other publications go to the [Article Search](#) page.

Healthy Start is also trialling two programs to support mothers with an intellectual disability. [Healthy Start for Me and My Baby](#) is a booklet and audiotape that promotes the health and well being of pregnant women during the antenatal period and birth. The [Australian Supported Learning Program: Me and My Community](#) aims to assist mothers with children under school age to identify their own learning needs and aspirations, and to help them create learning opportunities and to connect with resources available in their local communities.

Other useful websites with online resources

[Raising Children Network](#).
[The Australian Parenting Website](#) – An Australian website to help parents and carers raise children aged 0-8 years. The Raising Children website provides practical tools and up-to-date information on child health, safety, nutrition, learning, parental wellbeing, family management and kids' activities. See the [section on intellectual disability](#).

[Australian Institute of Family Studies \(AIFS\)](#) – An excellent source of research and information on family wellbeing, including families where parents have an intellectual disability.

The Australian and Family Disability Studies Research Collaboration provides information that can assist when working with parents with an intellectual disability. In particular the 'in practice' section includes information on assessment; support and services; parent education services; and child protection.

The Family Support and Services website also contains information on working with parents with an intellectual disability. The site is under development so some sections are blank however the practice points and research sections are very informative.

The Early Childhood Australia *Every Child* magazine contains informative articles on aspects of early childhood such issues as health, education and social trends, and also book reviews. See Intellectual Disability and Parenting.

Other useful websites in the UK

Norah Fry Research Centre – One of the leading centres in the UK for research into services for people with learning difficulties. Their website provides a range of resources that can be downloaded, including resources that can be provided to families. See Finding the Right Support.

Disability, Pregnancy and Parenthood International – UK organisation that promotes better awareness and support for disabled people during pregnancy and as parents.

Disabled Parents Network – UK organisation of and for disabled people who are parents or who hope to become parents. It has information for all parents, including parents with learning difficulties.

Special Parenting Services – UK website describes a home-based parenting assessment and intervention service for parents with learning disabilities. It includes descriptions of research by members of the service. The site also has pictorial resources practitioners can use when working with parents who have learning difficulties.

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