



## **Parents with intellectual disability in practice**

Contact: Professor Gwynnyth Llewellyn

Email: [gwynnyth.llewellyn@sydney.edu.au](mailto:gwynnyth.llewellyn@sydney.edu.au)

# Parents with intellectual disability in practice

## Assessment

### What we know:

- The level of a parent's intellectual ability bears little relationship to their parenting ability
- How mothers manage their parenting role is influenced by their mental maturity and stability - having a positive and realistic picture of oneself, feeling valued as an individual, and feeling that one is an asset to one's children
- Parental capacity assessments play a big part in what happens for families, particularly families in which a parent or parents have an intellectual disability
- Generally requested for two reasons - to inform and to justify intervention - assessment outcomes however, can be problematic. This is because what is being assessed - parenting and family life, are essentially subjective and dynamic, and therefore open to many variables
- There are multiple limitations inherent in current parenting capacity assessments:
  - \* An absence of any clear definitions as to "what is parenting?" and "what is good enough parenting?"
  - \* An inappropriate use of assessment tools
  - \* An over-reliance on IQ testing
  - \* A preoccupation with the parent's intellectual disability as the reason for any difficulty in parenting, over and above other factors such as poverty, emotional distress, social isolation and harassment
  - \* An undertaking of assessments in inappropriate contexts and circumstances rather than in the family's own home and environment
  - \* A lack of predictive validity
  - \* A failure to link assessment findings to intervention
- For parents with intellectual disability, the conditions under which they are assessed will have a significant bearing on their performance such that their usual parenting behaviour may not be truly represented. This is particularly the case when the stakes are high eg., in cases where assessment findings will determine whether children will stay at home or be placed in care

### What we can do:

The most appropriate way for workers to determine just who are parents with intellectual disability is to use an approach that is not just deficit and diagnosis-focused, but which also formally recognizes the parent's intellectual disability and acknowledges their resource and support needs. This involves:

- Using acceptable standardized tests of intelligent quotient and adaptive behaviours;
- Assessing a person's strengths and weaknesses across four dimensions: intellectual functioning and adaptive skills, psychological/emotional considerations, physical/health/aetiology considerations, and environmental considerations (living situation, work, education); and
- Assessing those areas in which the person is thought to need support (eg., personal resources, other people, technology and services) and the intensity of support required (intermittent, limited, extensive and pervasive).

### Assessments need to be undertaken under the following conditions:

- Both the referrer and the assessor need to clarify and be clear about what is wanted from the assessment
- An independent professional who does not have divided loyalties or biases that will influence assessment results should conduct the assessment
- Parents should be informed about what the assessment will entail and what is expected of them. The process should be inclusive and collaborative. It is also important that the views of all family members and those involved with the family are canvassed

### Assessments need to use the following methods:

- Conducted in the family's home and community
- Conducted across time and family routine. The assessment must take more than a snapshot of the family. It needs to be conducted over multiple visits, preferably at different points in the family routine
- Be multidisciplinary. Regard should be given for the expertise that a range of professionals, including workers who provide in-home support and are involved with the family on a regular basis, can contribute to the assessment process
- Because different tools focus on specific aspects of parenting, professionals need to be au fait with what tools are available; be able to access them; be proficient in administering them; and use them in a combination that appropriately covers all areas of parenting

### Assessments also need to have the following scope:

- **Multi-dimensional/ecological approach.** The assessment approach needs to take account of the interplay between the multi-systems that impact on the family
- **Functional/performance base.** Assess what parents understand, do and are capable of doing in terms of their care responsibilities. McGaw's Parent Assessment Model provides a useful tool that investigates different functional dimensions of parenting
- **Beyond a typical constellation of parenting skills.** Service workers need to look beyond the parents' cognitive limitations and look at the parent as a whole: the mother's way of perceiving things, her judgement, her reflection, her interaction as well as her role in caring for the health and safety of her child
- **Resources and Constraints.** In addition to deficits the assessment needs to identify strengths and potential resources and supports that are found in the family's environment
- **Linked to therapeutic intervention and support.** Assessment findings need to be translated into intervention strategies and inform individualized support planning
- **Specific limitations reported in findings.** Assessors need to be clear about what can and cannot be concluded from their assessments. Given the current limitations of assessment tools and the lack of consensus regarding minimal parenting standards, assessment findings should be interpreted and reported conservatively

### Based on the Wisconsin Council's Developmental Disabilities Supported Parenting Project, below is a comprehensive model of four key assessment areas:

1. Family Environment - housing, basic physical needs, household organization, neighbourhood, social and other support networks
2. Family Structure and Function - family roles, current status of the family, relationships within the family, generational and current family traditions

3. Parent/adult - parental childhood experiences; health status; self image; capabilities; skills/knowledge; learning abilities; what parents already know, how this was learnt and how they learn best
4. Child - pregnancy/birth/developmental history, health status, behaviour/emotional status, school history

This type of interactional approach to assessment acknowledges the complexity of families and parenting, and helps in identifying parental, child and environmental factors that individually and together may affect parenting capacity.

**Want to know more? Check out these publications:**

Spencer, M. (2001) [Proceed with Caution: The Limitations of Current Parenting Capacity Assessments Developing Practice](#), Winter, 16 - 24.

Llewellyn, G. (1997) [Support and Services for Parents with Intellectual Disability: What? When? How? By Whom?](#) Report prepared for the Australian Family and Disability Studies Research Centre, School of Occupational Therapy, Faculty of Health Sciences, University of Sydney.

Llewellyn, G. (1997) [Parents with Intellectual Disability: Learning to Parent: The Role of Experience and Informal Learning](#) *International Journal of Disability, Development and Education*, 44 (3), 243 - 261.

Llewellyn, G. (1995) "First Hand Experience" - Parents with Learning Difficulties. *Disability, Pregnancy & Parenthood International*, 11 (July), 10 - 12.

# Family support

## What we know:

### (1) Overall Influences on Parenting

- While some generalizations can be made, parents with intellectual disability are a heterogeneous group. Thus their support and service needs will vary from parent to parent and family to family.
- A range of presumptions about parents with intellectual disability have been shown to be more fallacy than fact:
  - \* intellectually disabled parents do not have significantly more children than other parents;
  - \* they do not give birth to intellectually disabled children at a rate higher than that found in the general population;
  - \* their children do not necessarily have birth disabilities or become disabled;
  - \* parents with intellectual disability will not inevitably abuse or neglect their children;
  - \* they will not inevitably provide inadequate child care; and
  - \* they are able to learn and apply adequate parenting skills.
- Various factors contribute to successful parenting or predispose others to inadequate parenting. These factors are:
  - \* Number of children
  - \* Income level
  - \* Additional health issues of the parents
  - \* The parents' own upbringing
  - \* The availability of parent education resources which take into consideration the specific learning needs of parents with intellectual disability
  - \* Available familial supports
- There is no statistically significant correlation between the developmental status of pre school-aged children and characteristics of the mother or home/environment. Parents with intellectual disability should not be thought incapable of providing the stimulation children need to develop 'normally'.
- A preliminary study shows the health of parents with intellectual disability to be significantly worse than that of the general Australian population. Further, when controlling for socio-economic status, participants' reported health was significantly worse in all but one category.
- Parents with intellectual disability are not inevitably incapable of caring for their children. Sometimes this seems to be the case because only those struggling with the tasks of parenting are known to support services.

### (2) Support Networks

- Parents with intellectual disability, like other parents, exhibit a preferred sequence in seeking help, beginning with their partners, then family members, and finally, professionals.
- Family members are central to the support networks of mothers with intellectual disability. However, not all family members are supportive and competence promoting; some inhibit parents' competence.
- Service providers make up the second largest group of people who provide support to parents with intellectual disability.
- Mothers typically have few friends or neighbours who they regard as supportive.
- Mothers' support networks vary considerably according to their household living arrangement. Generally, mothers living alone with their children have widely dispersed family ties and access service centred supports. In contrast, mothers living in a parent

household primarily have stable, local family centred supports. Those living with their partners have a high proportion of relatively dispersed family ties.

- Support networks are not always resources; at times they serve as constraints to parent competence and well-being.
- Parents play an active role in determining what support they want, from whom, and in what way it is to be received and used. In other words, they actively determine and manage the presence of others in their family lives. Parents are not necessarily 'victims' of their support networks.

### (3) Support required By Parents

- The most common support need reported by parents, their family and service providers is help with child care and child development. These include understanding child development, knowing how to stimulate a child, how to discipline a child, how to maintain a child's hygiene and safety, and how to deal with medical emergencies.
- Parents also report needing assistance in the community participation area: exploring work options; 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.

### Programs and Services

- The primary purpose of programs for parents with intellectual disability should be to understand the demands on parents and to work toward reducing the gap between the parent's capabilities and the demands of their environment. This can be broken down into three broad outcome areas:
  - 1. The level of independence of the parent in their community**

Indicators of this include frequency of service use, frequency of requests for assistance, level of integration into services for other parents and their children, the nature of their living environment, and their productive activity in terms of work/community participation.
  - 2. The quality of performance in everyday parenting activities**

This can be measured from the perspective of parents in terms of their sense of well-being and competence, as well as from the perspectives of their significant others and service providers.
  - 3. The parent's level of competence in relation to that of others in the same community**

Potential measures include reduced or zero frequency of maltreatment; increased positive ratings on child health, wellness and development; decreased problem identification to social service agencies and child-oriented agencies; and increased problem resolution in relation to social service agencies.
- Effective service provision will be underpinned by the following assumptions:
  - \* Parents truly want the best for their child
  - \* The greatest impact on parent, child and the family comes when the support given is based on the needs, dreams and wishes of the family
  - \* Parents are more apt to expand their skills and learn new skills when we build on their existing skills and strengths
  - \* Informal support networks are a primary resource for many families and should be strengthened as much as possible, taking into account the parent's wishes
  - \* The fundamental goal of supporting parents is to help them enjoy parenting and their child as much as possible
  - \* A good program must meet the needs of parents so as to, in turn, meet the needs of their children
- Services will most effectively meet the support needs of parents with intellectual disability if they are:
  1. Tailored to individual family's needs - services must be responsive to each individual parent's and each individual child's specific support needs. To this end, a family centred

approach where the interests of both parents and children are served is required.

2. Provided over the long term - services that provide ongoing rather than one-off support are able to address the changing needs of both parents and children, reinforce newly acquired skills, allow for effective working relationships built on familiarity and trust, and be best placed to avert future crises.

3. Home-based - services provided in a natural setting are more likely to be better received and applied. They also allow practitioners to identify any issues relevant to the child's welfare in relation to their home environment.

4. Empowering - practitioners need to be open and upfront about their role; invite, listen to and respect the parent's opinion; involve parents in decision-making by providing options and a freedom to choose; encourage parents to speak up for themselves; and, teach parents skills rather than simply doing it for them.

5. Pro-active - services need to actively and routinely follow up parents; actively assist parents to become part of their local community by raising awareness about available support services; and, seek out those parents reluctant to use services and who are rarely referred to services to offer support and assistance if parents require this.

6. At a level parents can understand - service providers need to take into account the special learning needs of parents when designing and implementing programs eg., be aware of each parent's reading ability; simplify explanations; break tasks down into manageable components; demonstrate new skills; and provide opportunities for repetition and reinforcement; and, give parents many opportunities to practice the skills in the situations where they are needed.

- The effectiveness of any intervention offered will be enhanced if the difficulties with learning frequently encountered by parents with intellectual disability are taken into account, including:
  - \* Tendency to overgeneralise instructions
  - \* Difficulty following complex instructions, or modifying instructions
  - \* Problems with long and short term memory
  - \* Difficulty in correctly recognizing cues and responding to the child
  - \* Difficulty in recognizing problems and problem solving
  - \* Difficulty with reading or only able to read basic words
  - \* Difficulty with judgement and decision-making
  - \* 'Splinter skills' - parents may exhibit very good abilities in some areas and yet have a surprising lack of skills in others
- Parents with intellectual disability will make most use of mainstream services if:
  - \* they are accessible and widely known about in the community
  - \* they are welcoming to parents with intellectual disability
  - \* they are specifically funded to provide transport as necessary so that parents can attend
  - \* staff have the knowledge and skills about parenting, intellectual disability, the impact of intellectual disability on learning, and how to advocate for parents
  - \* they are specifically funded to develop and distribute plain English information and alternative forms of information for non-literate parents and those of non-English speaking background.

### **What we can do:**

- Operate from a sound working knowledge of current empirical research, rather than relying on unfounded opinions or past methodologically flawed research about this parent group. Use this knowledge to raise awareness in the health, social services, education and legal sectors, and in the community at large.
- **Research**
- Adopt a macro approach to the parents you are working with, and consider the socio-economic and community context of each parent. These contexts are critical to parenting success.

- Consult parents as to what they perceive their service and support needs to be. They are the best judge of what they would like. They may need help to recognize shortcomings - as do most parents - but particularly so if they have had little prior experience with children or poor parenting models.
- Involve parents in any discussion or decision-making about their children, their partner/spouse and their family.
- Promote stable, long term support networks by providing opportunities for parents to establish and develop supportive ties with neighbours and friends. This is of particular importance for those mothers living alone.
- Facilitate participation and belonging in the community by engaging mothers in activities outside the family home. Linking parents into their community is critical for ongoing, long term parenting success.
- Be sensitive to mothers' living arrangements, and the influence of these on her access to support, when considering the nature of your intervention.
- Be wary of viewing 'family' as mother, father and children, without any attention being paid to family constellations, parent networks, and relational processes.
- Individually assess the support available to parents, taking into account the parents' views of this support as promoting or inhibiting their competence as parents.
- Provide opportunities for parents to acquire friends by initiating parent-to-parent support groups and by teaching parents skills in developing friendships.
- Attempt to understand parents' life experiences and the impact of these on current behaviour. Consider parents' self-esteem, social skills, internal/external control, social role, and problem solving skills. Many have been encouraged to remain dependent on family or service providers, and so may not have had adequate preparation for adult life or the challenges of parenthood. Remember that parenting is a socially determined process carried out within a family, social and community context.
- Pay particular attention to parent health status given the observed poor health status of parents and the associated high risk of poor long term health status for their children.
- Be wary of labeling. Many children who, whilst labeled at school as being intellectually disabled, successfully integrate as adults into the wider community without needing specialist services for people with intellectual disability or attracting the intellectual disability label.
- Develop inter-agency collaboration that promotes:
  1. A family-centred focus so that the interests of both parents and children are served;
  2. Preventative work as a priority rather than crisis intervention; and
  3. Access to mainstream services for parents and their children rather than reliance on specialized support services
- Believe that these parents can succeed
  - \* Focus on personal growth as opposed to skill acquisition.
  - \* Be ready to learn from them.
  - \* Work to a person-centred approach in which the parents participate in setting the agenda.
  - \* Offer a flexible and responsive support program, allowing parents to participate on their own terms and learn at their own pace.
  - \* Focus on peer mentoring and narrative learning, that is, by ways of stories shared.
  - \* Look beyond the disability label. Be careful not to lose sight of each individual's ability in the face of their disability.
  - \* Talk to parents, not at them or through others. And talk to them as adults, not as children.
  - \* Do things with them not for them. Be wary of imposing your advice and/or giving overwhelming amounts of advice.
  - \* Explain things slowly and get straight to the point. Provide information in non-ambiguous, direct short statement. It is often necessary to repeat the information, perhaps over several visits. Ask the parent to explain to you what they think the information means - this will help you to know whether they have understood.
  - \* Talk to parents face to face.
  - \* Be honest with them.

- \* Offer support in the spirit of accepting that young and older adults with intellectual disability dream of parenthood and share the drive to procreate.
- \* Uphold their right to be regarded as the parent of the child.
- For strategies particular to parents with older children, see Llewellyn, G., McConnell, D., Grace-Dunn, R., & Dibden, M. (1999) *Parents with Intellectual Disability and Older Children: Strategies for Support Workers*.
- Where possible, provide support to parents that extends well beyond helping them understand and more competently raise their children and which meets their identified needs for social, vocational and community skills i.e.
  1. Parenting skills - educating parents about child development; how children's needs change over time; how to stimulate child development through play; how to discipline children; how to recognise when children are at risk from others or their own behaviour; how to set boundaries for safety; and how to respond to the challenges of adolescence
  2. Living Skills - equipping parents to use public transport, budget, shop, and cook nutritional meals
  3. Self Esteem and Assertiveness Skills - fostering a greater inner strength and confidence
  4. Informal Social Support - facilitating the development of supportive relationships with other people, particularly other parents
  5. Access to Mainstream Services - providing information, if not introducing parents to, generalist local community services
  6. Advocacy - either advocating on the parent's behalf or empowering them to advocate for themselves

**Want to know more? Check out these publications:**

McConnell, D., Llewellyn, G., Mayes, R., Russo, D., & Honey, A. (2003) [Developmental Profiles of Children Born to Mothers with Intellectual Disability](#) *Journal of Intellectual and Developmental Disability*, 28 (2), 1-14.

Llewellyn, G., McConnell, D., & Mayes, R. (2003) [Health of Mothers with Intellectual Limitations](#) *Australian and new Zealand Journal of Public Health*, 27 (1), 17 - 19.

Llewellyn, G. & McConnell, D. (2002) [Mothers with Learning Difficulties and their Support Networks](#) *Journal of Intellectual Disability Research*, 46 (1), 17 - 34.

Strike, J., & McConnell, D. (2002) [Parents with Intellectual Disability: Just the Same, Only Different](#) *Interaction* 15 (4), 11 - 15

Strike, R., & McConnell, D. (2002) [Look At Me, Listen to Me, I Have Something Important to Say](#) *Sexuality and Disability*, 20 (1), 53 - 63.

Llewellyn, G., McConnell, D., Cant, R., & Westbrook, M. (1999) [Support Networks of Mothers with an Intellectual Disability: An Exploratory Study](#) *Journal of Intellectual & Developmental Disability*, 24 (1), 7 - 26.

Llewellyn, G., McConnell, D. & Bye, R (1998) [Perception of Service Needs by Parents with Intellectual Disability, Their Significant Others and their Service Workers](#) *Research in Developmental Disabilities*, 19 (3), 245 - 260.

Llewellyn, G., Bye, R., & McConnell, D. (1997) [Parents with Intellectual Disability and Mainstream Family Agencies](#) *International Journal of Practical Approaches to Disability*, 21 (3), 9 - 13.

McConnell, D., Llewellyn, G., & Bye, R. (1997) [Providing Services for Parents with](#)

- Intellectual Disability: Parent Needs and Service Constraints** *Journal of Intellectual & Developmental Disability*, 22 (1), 5 - 17.
- Llewellyn, G. (1995) **Relationships and Social Support: Views of Parents with Mental Retardation/Intellectual Disability** *Mental Retardation* 33 (6), 349 - 363.
- Llewellyn, G. (1994) **Generic Family Support Services: Are Parents with Learning Disability Catered For?** *Mental Handicap Research* 7(1), 64 - 77.
- Llewellyn, G. (1994) **Being a Parent with Intellectual Disability: A Battle Against the Odds** *Community Bulletin*, 18 (1), 9 - 13.
- Llewellyn, G. (1994) **Parenting: A Neglected Human Occupation. Parents' Voices Not Yet Heard** *Australian Occupational Therapy Journal*, 41, 173 - 176.
- Llewellyn, G. (1993) **Living Proof: Being a Parent with Intellectual Disability. Proceedings from the 29th Annual Conference of ASSID**, *Quality and Equality* Nov 30-Dec 5, 1993, Newcastle University.
- Llewellyn, G. (1993) **Talking with Parents with Intellectual Disability. In Johnston, C. (Ed) Does This Child Need Help?** *Identification and Early Intervention* Sydney: Australian Early Intervention Association (NSW Chapter) Inc.
- Llewellyn, G. (1993) **Parents with Intellectual Disability: Facts, Fallacies and Professional Responsibilities** *Community Bulletin* 17 (1), 10 - 19.
- Llewellyn, G. (1990) **People with Intellectual Disability as Parents: Perspectives from the Professional Literature** *Australia and New Zealand Journal of Developmental Disabilities*, 16 (4), 369 - 380.
- Llewellyn, G., McConnell, D., Grace-Dunn, R., & Dibden, M. (1999) **Parents with Intellectual Disability and Older Children: Strategies for Support Workers**. Melbourne: Victorian Government Department of Human Services.
- Llewellyn, G., McConnell, D., & Bye, R. (1995) **Parents with Intellectual Disability: Support and Services Required by Parents with Intellectual Disability**. Report to the Disability Services Sub-committee (DDSC) of the Standing Committee of Community Services and Income Security Administrators, Department of Human Services and Health, Canberra.
- Llewellyn, G. (1997) **Support and Services for Parents with Intellectual Disability: What? When? How? By Whom?** Report prepared for the Australian Family and Disability Studies Research Centre, School of Occupational Therapy, Faculty of Health Sciences, University of Sydney.

# Parent education

## What we know:

- Parents with intellectual disability frequently encounter difficulties with learning that can impact on the effectiveness of any intervention offered:
  - \* Difficulty retaining and applying new skills
  - \* Tendency to overgeneralise instructions
  - \* Difficulty following complex instructions, or modifying instructions
  - \* Problems with long and short term memory
  - \* Difficulty in correctly recognizing cues and responding to the child
  - \* Difficulty in recognizing problems and problem solving
  - \* Difficulty with reading or only able to read basic words
  - \* Difficulty with judgement and decision-making
  - \* 'Splinter skills' - parents may exhibit very good abilities in some areas and yet have a surprising lack of skills in others
- Parent education interventions should be based on family identified needs, with parents being involved in the planning and implementation of the program.
- Parent education programs will be more effective with parents with intellectual disability if they are:
  1. Specific - programs must be specifically targeted to the parent's individual needs for learning;
  2. Situational - the tasks must be taught where the skill is needed i.e. in the home; and
  3. Structured - this involves behavioural principles being incorporated into programs; tasks and skills being taught in small steps, modeling new tasks, giving feedback, and providing opportunities for practice and repetition.

The relationship between educator and parent should emphasise reciprocity and partnership, acknowledging that each person can be a resource to the other. Parents with intellectual disability also learn about parenting as they experience and practice it. The extent to which this is the case of course, will depend on the parents' interest in and support for learning.

- Support needs to be long term, ongoing and consistent if parents are to integrate new parenting strategies over the lifespan of their children. Skills are more likely to be maintained if the teaching includes generalization training, where parents are given experience and tools to generalize their new skills in a variety of settings and situations. Unless there are opportunities for parents to apply their learning to everyday situations, to learn, revisit and discuss successes and disappointments in their attempts, there is a risk that they will not remember what they will have learned.

## What we can do:

- Structure programs in keeping with the aforementioned principles
- Be aware of operating value systems: your own value base and that of the program you are using.
- Prior to formulating parent training programs consider the significant effects of parental childhood experiences and respect for family traditions when assessing parent knowledge and skill.
- Individually assess what parents already know, how this was learnt, and how they learn best.
- Specific practice guidelines for workers implementing a home-based parenting education programme with parents with an intellectual disability are as follows:
  - \* Make good use of pictures that are realistic and concrete
  - \* Allow for the active and practical participation of parents
  - \* Provide opportunities for learners to monitor and reinforce their learning

- \* Set activities that are achievable within the context of the person's home
  - \* Provide information in non-ambiguous, direct short statements
  - \* Incorporate repetition of information using various methods. It is often necessary to repeat the information, perhaps over several visits.
  - \* Ask the parent to explain to you what they think the information means - this will help you to know whether they have understood.
  - \* Present material that is useful/relevant to the parent's needs and experiences
  - \* Be flexible enough to adapt to and/or work around the disruptions and distractions of the home environment
  - \* Take into account individual learning styles and personalities
  - \* Build good rapport with parents and develop knowledge about their lives and experiences in order to effectively relate these to the home learning program
  - \* Know about child health and safety issues beyond the necessarily restricted items covered in a time limited home learning program
  - \* Be familiar with theories and sequences of child development
  - \* Assess parents' abilities and tolerance levels for learning 'on the run' and be flexible enough to adapt the lessons accordingly
  - \* Be sensitive to the individual learning styles and preferences of parents and adapt the lessons accordingly
  - \* Be aware of the influences of cognitive limitations on learning as well as the social experiences of people with learning difficulties and the effects of these on their attitudes towards learning
  - \* Be respectful, as a guest, of parents' authority in their own homes and their differing priorities and immediate needs
  - \* Assess the impact of the attitudes and behaviour of significant others - utilize these when helpful to parents learning and help parents work around them when they are a negative influence
  - \* Assess parents' abilities (including utilisation of social supports) to make the required changes to their homes and to offer practical assistance where necessary
  - \* Work with significant others to help them understand the importance of the program and the information and skills it teaches
- More broadly, practitioners also need to consider:
1. *The home environment as a place for learning*  
Although this offers parents individualized, context-specific learning, there is the reality of a home with young children to contend with. Practitioners need to be flexible in managing these frequent distractions eg., schedule home visits during school hours/term or when the baby is sleeping; provide children with food and entertainment prior to the lesson starting; include children where possible
  2. *First things first*  
This relates to the competing needs and priorities of parent participants and educators. For parents, the relationship with their educator and the opportunity to offload their immediate concerns may be more highly valued than the home learning activities. For parents it can be a case of needing to air personal issues before being able to concentrate on the task at hand. This requires parent educators to allow plenty of time for the home visit and to be good listeners and provide practical support, advice and information. Further, educators will need to be extremely flexible to fit into parents' sometimes hectic routines.
  3. *Parent readiness to learn and apply knowledge*  
Parents vary greatly in their readiness to learn and apply knowledge and past experience seems to be an important factor here. When previous learning experiences are characterized by failure and negative judgements, and/or parents' behaviour is being monitored by child welfare authorities, educators need to be particularly encouraging in helping these parents get started on the learning activities.
  4. *Parent ability to make changes*  
Some parents have little or no control over the home environment and feel quite powerless to apply the knowledge they have learned. Thus practitioners need to be aware that the effects of home visiting programs will be moderated by the parent's degree of control over the household.

In light of these issues, parent educators need to be aware of the following practice points to ensure that parents are ready and able to participate fully and freely in a home-based learning program:

- Be prepared to listen to and if possible address the concerns of parents before commencing a teaching activity
- Be flexible in planning to take into account individual parents' immediate needs and priorities in their everyday family lives
- Be aware of parents' previous experiences with learning (either in the school system or informally) and be prepared to adapt strategies and offer plenty of positive reinforcement
- Be prepared to reflect critically and in an ongoing way on personal values and assumptions and to guard against falling into the trap of 'knowing what is best for all parents'
- Be open to and interested in parents' life experiences and those of their family and friends so that these can be used in teaching and learning activities
- Be open to and aware of parents' home situations particularly others who influence the parent and be prepared to work with and engage significant others in assisting the parent to learn if at all possible.

**Want to know more? Check out these publications:**

Llewellyn, G., McConnell, D., Russo, D., Mayes, R., & Honey, A. (2002) [Home-based Programs for Parents with Intellectual Disabilities: Lessons from Practice](#) *Journal of Applied Research in Intellectual Disabilities*, 15, 341-353.

Llewellyn, G. (1997) [Parents with Intellectual Disability: Learning to Parent: The Role of Experience and Informal Learning](#) *International Journal of Disability, Development and Education*, 44 (3), 243 - 261.

Llewellyn, G. (1995) "First Hand Experience". *Parents with Learning Difficulties. Disability, Pregnancy & Parenthood International*, 11 (July), 10 - 12.

Llewellyn, G., McConnell, D., Grace-Dunn, R., & Dibden, M. (1999) [Parents with Intellectual Disability and Older Children: Strategies for Support Workers](#). Melbourne: Victorian Government Department of Human Services.

Llewellyn, G., McConnell, D., & Honey, A. (2001) [Healthy and Safe. NSW Parent-Child Health and Wellbeing Research and Development Project](#). Report to the NSW Department of Ageing, Disability and Home Care Services. University of Sydney.

Llewellyn, G. (1997) [Support and Services for Parents with Intellectual Disability: What? When? How? By Whom?](#) Report prepared for the Australian Family and Disability Studies Research Centre, School of Occupational Therapy, Faculty of Health Sciences, University of Sydney.

# Child protection

## What we know:

Australian and international research shows parents with intellectual disability to be subject to unusually high rates of state intervention in the care of their children. Moreover, a significant number of their children are made state wards and placed in out-of-home foster or residential care. That this is the case is not merely indicative of inevitable parenting incompetence. A range of often overlooked political, social and institutional factors make the task of parenting for those with intellectual disability more difficult. Further, there is widespread evidence that shows these parents to be disadvantaged and discriminated against in child protection proceedings.

Practitioners need to be acutely aware of the nature of these factors and the impact they have on both an individual's ability to parent and on care proceeding outcomes. These factors are:

- The widely held but unfounded presumptions that intellectual disability equates with parenting incompetence, that parenting deficiencies are irremediable, and that children of people with intellectual disability will inevitably be harmed;
- False attribution, that is, parents' difficulties being attributed to their disability, when in fact they derive more from poverty, poor housing, social isolation, harassment and the lack of appropriate support services;
- The shift from a culture of social to individual responsibility for children. For parents with intellectual disability this has meant a lack of support services, coupled with a keener mandate of the state to protect those most vulnerable in society (by implication, children of parents with intellectual disability);
- Within the courts, parenting competence being assessed only as a function of innate ability. The diagnostic-prognostic rationality of decision makers is at cross roads with the strong empirical evidence that intellectual disability per se is not an adequate predictor of parenting capacity or an insurmountable barrier to learning. Further, IQ has been shown to be a poor indicator of parenting capacity; and
- Disadvantages inherent in the adversarial process eg., constraints on child protection workers who lack the time, training and resources to adequately support parents with intellectual disability; the need for parent compliance; the current practice of risk assessments being made without any theoretical and empirical basis; difficulties experienced by people with intellectual disability in adhering to imposed rehabilitation plans; legal representatives usually being court appointed, having limited time and with limited understanding of disability issues; court proceedings not being explained in an accessible manner; the court environment on the whole alienating and disempowering parents with a disability.

## What we can do:

- Give parents with intellectual disability access to parenting skills training specifically tailored to cater for this client group. Contrary to popular thinking, research clearly states that parents with intellectual disability are capable of learning new skills and unlearning negative patterns of behaviour if these exist
- Advocate for more appropriate proactive services to support and assist parents
- Evaluate the appropriateness and effectiveness of alternative initiatives to court intervention eg., family group conferencing and alternative dispute resolution
- Develop and maintain web-based resources for parents with an intellectual disability and their children, including those with a support services directory and with plain English information on the court process and what parents' rights and responsibilities within it are
- Lobby for adequate legal aid funding so as to allow parents with intellectual disability access to the best possible representation

- Review the court environment and its procedures and processes so as to ensure appropriate accessibility by people with a disability as required under the Disability Discrimination Act 1992 (Cth) and the Anti-Discrimination Act 1997 (NSW)
- Review the use of expert assessment practices that rely heavily on IQ tests
- Develop guidelines which clearly specify the limitations of diagnostic-prognostic assessment, the need for functional assessment, and ways by which this functional assessment can occur
- Ensure that those professionals involved in child protection proceedings - magistrates, child protection workers, psychologists/psychiatrists, and legal representatives - become familiar with current empirical research that clearly demonstrates that intellectual disability per se is not an adequate predictor of parenting competence or an insurmountable barrier to learning. That they also examine their own beliefs and assumptions is encouraged. To these ends, the development of a training module that addressed these issues would be invaluable
- Actively promote the participation of parents with intellectual disability in all aspects of court proceedings eg., have an independent third party acting as a support person; develop interactive media, video and plain English resources that explain the court process and empower these parents
- Challenge the negative and widespread presumptions about parents with intellectual disability at every opportunity
- Repoliticise the social disadvantage that leads to children being removed from parents on the grounds of their parents' presumed incapacity.

**Want to know more? Check out these publications:**

Llewellyn, G., McConnell, D. & Ferronato, L. (2003) [Prevalence and Outcomes for Parents with Disabilities and their Children in an Australian Court Sample](#) *Child Abuse & Neglect*, 27, 235 - 251.

McConnell, D., Llewellyn, G., & Ferronato, L. (2002) [Disability and Decision-Making in Australian Care Proceedings](#) *International Journal of Law, Policy and the Family*, 16, 270 - 299.

McConnell, D. & Llewellyn, G. (2002) Stereotypes, [Parents with Intellectual Disability and Child Protection](#) *Journal of Social Welfare and Family Law*, 24 (3), 297 - 317.

McConnell, D. & Llewellyn, G. (2000) [Disability and Discrimination in Statutory Child Protection Proceedings](#) *Disability & Society*, 15 (6), pp. 883 - 895.

McConnell, D., Llewellyn, G., & Ferronato, L. (2000) [Parents with a Disability and the NSW Children's Court](#). Report to the Law Foundation of NSW. University of Sydney.

McConnell, D. & Llewellyn, G. (1998) [Parental Disability and the Threat of Child Removal](#) *Family Matters*, 51 (Spring/Summer), 33 - 36.