Parent and Family Support

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

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 judgment 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 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.

Services will most effectively meet the support needs of parents with intellectual disability if they are:

A. **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.

B. **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.

C. **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.

D. **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.

E. **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.

F. **At a level parents can understand** – service providers need to take into account the special learning needs of parents when designing and implementing programs e.g.., 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.

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.

- 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 neighbors 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

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.

A. 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

B. Living Skills – equipping parents to use public transport, budget, shop, and cook nutritional meals

C. Self Esteem and Assertiveness Skills – fostering a greater inner strength and confidence

D. Informal Social Support – facilitating the development of supportive relationships with other people, particularly other parents

E. Access to Mainstream Services – providing information, if not introducing parents to, generalist local community services

F. Advocacy – either advocating on the parent's behalf or empowering them to advocate for themselves

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.

Further Reading

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.

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Llewellyn, G., McConnell, D., Cant, R., & Westbrook, M. (1999) Support Network 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.

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