

Working with Families Headed by a Parent With a Learning Difficulty

This submission brings to the attention of the reader the issues confronting many community service workers and/or professionals across Australia when working with Parents who have a learning difficulty/intellectual disability. Moreover, it outlines the growing need for specialised support services to provide a fair and equitable service to these families and proposes concepts and guidelines for such a service.

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Many parents with learning disabilities (PWLD) are coming to the attention of our Health and Social Services. As this group of parents are comparatively “new”, their particular difficulties and needs, both as parents and individuals, are often a challenge to understand and meet. Information derived from research is growing slowly and models of good practice are beginning to be established but still we have much to learn. Changing values within society means that we must continually re-evaluate our professional stance, assessment processes and interventions.

Many terms are used to describe people who have learning difficulties. However, the different terminology generally means the same thing. That is, the person has difficulties learning new information, and may need extra time and support to learn and to undertake activities in everyday living. For the purpose of this submission I will interchange between Parents with a Learning difficulty (PWLD) and Parents with an Intellectual Disabilities (PWID).

The American Association on Intellectual and Developmental Disabilities defines learning difficulty as ... “significant limitations both in intellectual functioning and in adaptive behaviour as expressed in conceptual, social, and practical adaptive skills. This disability originates before the age of 18.”

Adaptive behaviour:

- Conceptual (e.g., communication, reading, money)
- Social (e.g., interpersonal, responsibility, following rules, gullibility)
- Practical (e.g., self-care, home living, work)

Llewellyn et al (1995) states, “Families where one or both parents have a Learning Disability now represent a sizeable population, with a range of needs which are neither adequately nor coherently addressed by Australian Health and Social Services.”

Lamont and Bromfield (2009) report that; parents with intellectual disabilities represent a modest number of all parents in Australia (estimate 1-2%). However, they are over-represented in child protection and legal proceedings (Booth, Booth, & McConnell, 2005; McConnell, Llewellyn, & Ferronato, 2000). For example, in Victorian Child Protection cases first investigated in 1996-97, cases in which a parent had an intellectual disability were almost twice as likely to be substantiated, and more than three times more likely to be re-substantiated than cases where parents did not have an intellectual disability (Allen Consulting Group, 2003). In 2007-08, parental intellectual disability was a characteristic in 12.5% of cases reviewed by the Victorian Child Death Review Committee (2008). In reviewing 285 court files in two children’s courts in New South Wales, McConnell and colleagues (2000)

found that 8.8% of cases featured a parent with an intellectual disability. This over-representation is a characteristic in other jurisdictions and internationally. For example, a UK study of data collected in 2000, found that 15.1% of child protection cases before two English family courts featured a parent with learning difficulties (Booth et al., 2005). Research suggests factors contributing to the over-representation of parents with intellectual disability in child protection include discrimination, prejudice and a lack of support services (Booth & Booth, 2005; McConnell et al., 2000; Mildon, Matthews, & Gavidia-Payne, 2003). (Sighted in; Parental Intellectual Disability And Child Protection: Key issues NCPC Issues No. 31, 2009)

While a precise division cannot be made between parents who are and who are not affected by learning difficulties, studies have shown that people who identify as having learning difficulties, with an IQ range between 65 and 75, are most likely to exercise their right to have children. Parents with Learning Difficulties share a "commonality of need" which requires specialist knowledge and response. Thus, service providers need to avoid the argument that all parents should be treated alike and offered the same services as the mainstream population (2013, Healthy Start Workshop, Victoria.) Many services do not feel they are equipped to deliver this response and have acknowledged the need for Specialist Support Services.

Many Community Service Workers, both professional and support workers state that they do not feel adequately equipped to work effectively with parents who have a learning difficulty. At the same time, many adult learning disability services also struggle to effectively support parents with learning difficulties. Whilst the same values about safeguarding and promoting the welfare of children should be applied to the children of PWLD's as to the children of non-learning disabled parents, such families have specific needs which require particular knowledge and skills if the professionals working with them are to provide an equitable service to

these children and their parents. Thus, a specialised response is often required when working with families where the parent(s) has a learning difficulty.

Intellectual Disability from an instructional perspective defines ID as "...the need for specific training of skills that most people acquire incidentally and that enable individuals to live in the community without supervision". Thus, placing emphasis on the development of competencies and skill acquisition on those who teach, not on the learner and provides a clear guide for action in that it specifies what must be taught, that is, the skills that are required to live without supervision. So, the purpose of identifying disability is to identify what teaching is needed so that people can live independently. (sighted, Healthy Start training slides, Victoria)

Concurrently, this definition assists to emphasise the purpose of this submission and the importance of developing Specialised Support Services that primarily focus on training and skill acquisition for working with PWLD's.

Parents with learning difficulties often need longer to assimilate knowledge and may not be able to understand concepts such as 'good enough parenting' in the way that community service workers and/or professionals have been trained to present it. This causes frustrations for both the worker and the client with a learning difficulty, when time constraints expect ideas to be grasped and learned within a short space of time. Therefore, it must be recognised that professionals working with families headed by a PWLD will need to use a range of specialised teaching and support techniques over an extended period of time.

It is important that we recognise that the need for long-term support does not mean that parents cannot look after their children or that their disability restricts them from learning new skills. Some parents with learning difficulties will only need short-term support, such as help with taking care of a new

baby, to develop understanding of childhood stages and development and/or developing skills in childcare tasks. Others, however, will need on-going support. Most may need support at various different stages of their family's life cycle. This is due to their cognitive impairment, which is for a life time and the constant developmental stages that their child/children experience throughout their life time. Just as someone with a physical impairment may need personal assistance for the rest of their life so a person with learning disabilities may need assistance with daily living, particularly as new situations arise.

To ensure that parents with learning difficulties have equal opportunities to be parents and bring up their children we must promote equality of opportunity within our services. Thus, provide parents with learning difficulties equal access to community support services.

The following recommendations in support of specialised support services has been derived from many discussions around this issue within Integrated Family Support Services team, practitioner and allocation meetings, Healthy Start Professionals in Victoria and with clients and their families.

- Restructuring of community support services intake and assessment procedures to include assessment of parenting capacity, ensuring that it remains within best practice guidelines in this area. (see below ref 1)
- For every community service provider to have one trained, specialised worker who will work on a reduced case load capacity when working with these families in order to meet the specialised needs of their clients. Thus, ensuring that these clients receive a professional service equal to those parents who do not have learning difficulties.
- Extension to expected time of service delivery. Recommendations concerning the provision of services

and supports for the parent and their family should take into account what is realistic and feasible. Currently many community service programs are goal oriented with an expected duration. PWLD's may require support that covers a child's life time. To meet this requirement a similar model to that of the active monitoring process within Tasmania's Gateways Local Area Co-ordinator program may be of benefit. In addition, where a need for long-term support with parenting tasks is identified and/or assumed, it should form part of the original referral/assessment.

- Forming a multi-agency consultation group with relevant services, including, private practitioners, child protection, housing services, advocacy agencies and adult learning disability services to develop universal protocols and meet on a regular basis to offer support/advice/referrals to professionals/agencies that work with families headed by a parent with a learning difficulty.

In conclusion, balancing the rights and responsibilities of parents with learning disabilities and the welfare of children is highly complex. Although the gaps in the research on what works when supporting such families is evident, some clear messages for practitioners emerge. First, service delivery must be done with sensitivity and respect. These families are vulnerable and often powerless and are easily exploited. Parents with learning difficulties often receive attention from too many professionals rather than too few and are often over rather than under assessed. Second, there are as yet few specialist services and more specialists training is needed. Finally, careful assessments followed by interventions which are intensive, reliable and where necessary long-term are most likely to give the best outcomes for both parents and children.

Reference

1. <http://www.healthystart.net.au/images/resources/02-Practice-Points/Practice_Point_Parenting_Assessment.pdf>
2. Lamont, A., & Bromfield, L. (2009). Parental intellectual disability and child protection: Key issues. NCPIC Issues 31. Melbourne, Australian Institute of Family Studies.
3. <<https://www3.aifs.gov.au/cfca/publications/parental-intellectual-disability-and-child-protection-key-i>>
4. Parental Intellectual Disability And Child Protection: Key issues NCPIC Issues No. 31, 2009
5. Integrated Family Support Services Allocation Meetings – Missions Australia, Rosny, Tasmania 2013 -14
6. Integrated Family Support Services Practitioners Meetings , 2013, Southern Tasmania
7. Team meetings, Pittwater Family Support Service, Midway Point, Tasmania.