

The right of people with disabilities to be parents

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Article 23 of the United Nations Convention on the Rights of Persons with Disabilities, to which New Zealand became a signatory in 2007, specifies that:

“States Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others, so as to ensure that:

(a) The right of all persons with disabilities who are of marriageable age to marry and to found a family on the basis of free and full consent of the intending spouses is recognized”

The Article goes on to say that “State Parties shall render appropriate assistance to persons with disabilities in the performance of their child-rearing responsibilities” and that “in no case shall a child be separated from parents on the basis of a disability of either ... one or both of the parents”.

The former Minister of Health, the Honourable Pete Hodgson, in a speech at Parliament on 14 November 2006 entitled “The End of Institutionalisation” celebrating the closure of the Kimberley Centre, reiterated the focus of the New Zealand Disability Strategy (2001) that disabled people should have an “ordinary life”. This view was reinforced by the publication of the report *To Have An Ordinary Life Kia Whai Oranga ‘Noa’*, from the National Advisory Committee on Disability. Currently, the New Zealand Disability Strategy promotes people with an intellectual disability doing all the day-to-day things other citizens take for granted. For many, this includes falling in love, having a sexual relationship and having children.

The reality for parents with intellectual disabilities

In most Western countries, the definition of an intellectual disability is having an IQ of less than 70. However, as Lamont and Bromfield (2009) explain, intellectual limitations vary from individual to individual. IQ testing is unable to assess the way individuals adapt to their environment, so assessment must explore ability to live in the community, communicate, and be self-aware and independent.

Therefore, assessment of parental skills must be carefully undertaken on a case-by-case basis.

Mirfin-Veitch et al (1999) reported that 2.5 per 1000 families had one or more parents with an intellectual disability in New Zealand. They suggest that this figure could be higher, since some families may not be counted as they do not access support services. They also reported that the majority of parents with an intellectual disability live in low socioeconomic environments, which compounds their parenting difficulties, and that they are at higher risk of being seen as incompetent by child protection agencies and having their children removed.

In an Australian study, Lamont and Bromfield (2009) estimated that 1–2% of parents have an intellectual disability. They found that these parents “are over represented in child protection cases and legal proceedings” and state prejudice and lack of understanding as contributing factors to this higher incidence. More importantly, they report that a diagnosis of intellectual disability is a poor indicator of risk for child abuse and neglect. While Lamont and Bromfield point out that it is in fact unclear whether parents with

disabilities are more likely to abuse or neglect their children, they note that these children have been shown to have a higher rate of sexual abuse, perhaps a consequence of the tendency of perpetrators to try to avoid detection by targeting children perceived to be vulnerable to victimisation.

Best practice

Lamont and Bromfield (2009) quote research that suggests that best outcomes for parents with intellectual disability are achieved by service provision that:

- ⋮ is family-centred
- ⋮ is provided over the long-term
- ⋮ focuses on strengths rather than deficits
- ⋮ is home-based
- ⋮ features participatory rather than relational elements of practice
- ⋮ is performance – rather than knowledge-based

To achieve the above often requires intensive, time-consuming work.

Assessments need to be thorough, taking account of the particular capabilities of individual parents and identifying and exploring the risks and the protective factors.

This can best be done when a respectful, trusting relationship is established between the social worker and the family. Fortunately there are a growing number of practitioners (social workers and differential response coordinators) with the skills, knowledge and lack of prejudice to achieve success for families where parents have an intellectual disability. The following case studies are two excellent examples.

Case study # 1

Both parents of this family have an intellectual disability and neither is in paid employment. The family lives in a small rural town, in a Housing New Zealand property and are estranged from their extended family. They have twin girls who

are now seven years old, both of whom have a diagnosis of global developmental delay. The girls attend the local primary school part-time, but with insufficient teacher-aide hours. The family receives minimal support from the disability sector.

Child, Youth and Family has received a number of notifications from various sources, all expressing concerns for the children due to the parents' intellectual disability. None of the notifications has resulted in any care or protection concerns being substantiated and their file has been closed after each notification.

Numerous professional agencies have been involved with the family. The parents, however, stated that this had been “confusing; lots of people being involved but no-one doing anything; being told different things by different people; feeling scared and not knowing who to trust; not being advised of meetings, feeling we were being ‘kept in the dark’; not having things explained to us in a way we understood”.

The most recent referral, in September 2009, was allocated to a differential response coordinator. The coordinator quickly developed an engaging relationship with the family, demonstrating respect, reinforcing positive qualities and highlighting the family's strengths.

By way of the Strengthening Families model, community services, education providers and health and disability services were brought together to help plan for this family's future. The family, of course, were integrally involved in the process. The resulting ‘action plan’ outlined the activities required to achieve agreed outcomes, who would carry out the activities, and clear timeframes for the activities to be achieved.

The family now has:

- ⋮ access to home support through a community-based disability provider, assisting the parents with activities of daily living, including parenting skills
- ⋮ access to regular respite
- ⋮ support for the girls through the provision of another adult in their lives to regularly work

on improving their communication skills and also provide additional play stimulation

- ⋮ OSCAR funding approved allowing the girls to participate in a holiday programme
- ⋮ a joint inter-professional request to the Ministry of Education to increase the allocated teacher-aide hours to support the girls to attend school full-time
- ⋮ the local resource centre engaged to provide ongoing advocacy support
- ⋮ the public health nurse maintaining regular contact with the family to discuss any health concerns they may have.

This has been an excellent example of engaging local and appropriate professional resources to provide the right support at the right time for a family in need. The process has applied strengths-based practice with no prejudice, judgement or pre-conceptions. It has ensured that these intellectually disabled parents are supported to continue to live their 'ordinary lives' in their community.

With these wrap-around supports in place, the family has received a discharge letter from Child, Youth and Family. The parents feel stronger and more secure in their parenting role and now know who to turn to for what supports they may need.

Case study # 2

The parents of this family both have significant physical disabilities. The father's disability has been life-long but the mother's disability is recent, as the result of a motor vehicle accident, and has resulted in her becoming paraplegic.

The 11-year-old foster daughter has lived in this family for the past nine years and has significant disabilities herself. She has an intellectual disability and cerebral palsy and requires assistance with most daily routines such as feeding, dressing and showering. While able to walk short distances at home or in her classroom, she requires a wheelchair for longer distances. The 14-year-old son has been diagnosed with autism.

Social workers have been closely involved in supporting this family since the foster daughter was placed with the family and, prior to the mother's accident, discussions were underway with the caregivers around legal permanency for the foster daughter. However, because of the accident, the parents have been reluctant to pursue this, but remain very committed to their foster daughter's care as she is an important member of the family.

Social workers have ensured that the local Needs Assessment and Service Coordination Service (NASC) is well engaged to support the father and the children, and that ACC is engaged to support the mother. This support includes:

- ⋮ significant alterations to their home
- ⋮ an outdoor matted play area for the children
- ⋮ daily home support to assist with housework
- ⋮ sleepover support for seven hours each night
- ⋮ a modified van for the family
- ⋮ 21 days per year of respite care for the foster daughter.

The foster daughter is also well supported at school with an Ongoing and Reviewable Resourcing Schemes (ORRS) funded teacher aide for six hours each day. She also has a specialist team available to her at school, which includes a psychologist, occupational therapist, speech therapist and physiotherapist.

With the ongoing support of the social workers involved with this family and the package of supports that have been co-ordinated across health (through the NASC) and education services, and ACC, this family is successfully managing to stay together and live a full and happy life.

Conclusion

These two case studies are typical of many families with disabled parents that Child, Youth and Family supports across the country, either through partnered response or through direct involvement. While in the past society was quick to assume that disabled people were not capable of successfully parenting children, we now appreciate that with support, disabled people make wonderful parents.

This support may require intensive work initially to engage extended family and other community and government agencies. However, once a sufficient range of supports have been accessed and are in place, families with disabled parents are able to provide their children, and in some cases foster children, with the loving fulfilling homes that we expect for all children in New Zealand. ■

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