

Parenting a Disabled Child: The Chosen and Those That Choose



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Most people and professionals feel sorry for a child with intellectual disability. Over ninety five percent of pregnant mothers with a seriously abnormal child will choose to have a termination. Yet contrary to the traditional professional view for those with a family member with intellectual disability, life and parenthood is not a chronic state of sorrow. So fixed on loss of anticipated expectation were the early researchers and clinicians that reports of any positive benefits of caring for a handicapped child were dismissed as denial or overcompensation of parental guilt.

There are some well documented extra stresses: increased chronic dependency needs (average of 7 hours a day 7 days a week), increased risk of psychiatric disturbance (60%), increased economic burden (approximately \$15,000 a year), and lack of adequate social or professional support. Parental depression (20%) and relationship problems are moderately elevated in keeping with other stressful situations.

The human spirit is such that people do respond to adversity and there is a

growing research literature reporting not just satisfaction with life with a young person with intellectual disability but the benefits and advantages.

How can this be? Initial acceptance of a developmentally delayed child takes an average of 2 years. 15% of families place a handicapped child into care and the main reason varies with the age of the child:

1. problems of acceptance in infancy,
2. burden of care in childhood,
3. behaviour disturbance in adolescence and
4. family breakdown in adulthood.

The title 'the chosen and those that choose' indicates a specialness of these parents and a creative capacity to find meaning in being different, stigmatised and challenged. The reported advantages include:

- A. a source of happiness and joy, marvelling at events in the life of their child;
- B. increased sense of purpose and priority, around love, affection, caring, and simplifying life;
- C. expanded personal and social networks and community involvement, adding

meaning to a relationship, learning who your real friends are and involvement in a caring community;

- D. *a source of increased spirituality*, faith in humanity
- E. *family unity*, bringing a family closer together, sometimes experienced as a make or break experience;
- F. *increased tolerance and understanding*, for the parents but also for the siblings, not just for disability but for all human difference
- G. *a source of personal growth and strength*, persistence, bringing out the best in themselves.
- H. *a positive impact on others*, the community and professionals, who were handicapped by their own preconceptions or prejudices.

This thematic literature on the difference of disability evidently illustrates what are the fundamentals of what is needed to cope with any adversity and to build a caring community for children. There is as yet almost no research on the more complex notion of a parent's hope for their child to complement that of personal hopefulness.

Having appropriate expectations and knowing what to do to be helpful enables acceptance and adjustment.

But what is the community, professional and welfare contribution to enable such a sense of positiveness?

1. Early intervention studies for young people with Down's syndrome show that with intensive early intervention and optimal service provision 80% of parents are satisfied with life with their handicapped child. When research on family interactions shows the way a child's behaviour elicits parenting, and much of this process is contributed to by genetics in both child and parent, then it becomes likely that this will be distorted and delayed in the interaction with those with intellectual disability.

These studies showed that teaching detailed developmental sequences and sophisticated skills in developmental promotion and prompting improves the parent-child relationship which is the best long term investment for any child, but the intervention makes little difference to the long term developmental outcome. Having appropriate expectations and knowing what to do to be helpful enables acceptance and adjustment.

Psychiatric disorder has been shown in a number of studies to be the greatest burden for families with a member with intellectual disability and adolescence is the age at which psychiatric disturbance is generally at its worse.

2. My own research into a generally more disabled group of adolescents and less well serviced group of families showed that 30% were generally satisfied with life. In this study the **availability of informal practical help** from a friend or relative for the primary carer was scarce but strongly related to the parent/carer coping. The sense of indispensability and exclusive responsibility for the disabled young person must increase the risk of family breakdown from the burden of care. As yet there is no intervention research on how to enable families to share the burden of care, but innovative approaches to funding wider family and friends to provide respite care of different sorts might have a normalising effect on this difference of a handicapped family.
3. Psychiatric disorder has been shown in a number of studies to be the greatest burden for families with a member with intellectual disability, and adolescence is the age at which psychiatric disturbance is generally at its worse. In

NSW there is a need for coherent services for the psychiatric disability of this group. There is an intensive behavioural programming service, reactive to the worse case scenarios, but there is precious little multidisciplinary cooperation and very few psychiatrists with appropriate training or experience.

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4. Family burnout, disillusion and disintegration are the default position if our services lack an epidemiological approach to funding and organisation of community care for this group. Yet the number of people who have first hand experience of caring for someone with intellectual disability either as a family member or as a professional that actively chooses to care and nurture a young person or adult with intellectual disability is impressive.

When sceptics say that the reports of the benefits of caring for a handicapped person is philosophical wish-wash, it is evident they haven't met these people or seen what examples of love and care they provide. I would like to see our community have greater faith in encouraging and supporting such special people to enable them to “come out” and enabling a post-modern version of family and community care to grow.

References:

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Do not let us deny or belittle the challenge involved in parenting, especially of those with special needs. But we must also recognise, respect and learn to nurture the capacity and resilience of the human spirit for adjustment, commitment, caring and love, especially when caring for children. Some of us may not have the capacity, but we have much to learn from those who create positive environments out of such adversity. There is considerable research on the way adversities accumulate exponentially to create increased risk of psychiatric disorder including through a 'cumulative continuity' whereby circumstance shapes the individual and the individual shapes his future adverse circumstances. Less is known about individuals' capacity to break vicious cycles and create positive long term or virtuous cycles in the face of difference.

