

Chapter 7

Children With Developmental Disability: Is Providing Care A Burden?

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Introduction

I tried to teach him everything, to just say one word, or how to shower...going to all the meetings...I tried my best with everything, in the end, he just stopped learning... He kept trying to hurt me...after that I gave up. [Mother of a 17 year old male with autism and intellectual disability].

It is clear that carers of children with severe disability have a role that is far in excess of usual parenting responsibilities. Further, the care provided for the person with a disability is not always by the parents. Both the ageing carer population and the increasing survival of children born with significant disability are having an impact on the role of carers in our community. The burden of chronic conditions in adolescence is also increasing as larger numbers of chronically ill children survive beyond the age of 10 years.

It was quite clear to the Carer Payment (child) Review Taskforce (FaHCSIA, 2008) that the role of carers of children with severe disability or medical conditions was substantially greater than the usual parenting role. Although it is difficult to define 'usual' parenting, the fundamental nature of parenting is the provision of a level of care that decreases over time and is replaced by monitoring, supervision, and finally, independence as the child becomes more competent. Parents who are also carers of children and adolescents with significant disability may not have the same decrease in their caring and supervisory roles. This is also coupled with increases in personal responsibility for the judgments and decisions about the child or adolescent's care, disability or medical condition. But what do we know about who is providing the care, and what are the extra care needs at different levels of impairment or with different types of disability? What factors determine whether the extra care is considered to be a

burden or stressful by the carers? What factors influence the parents' ability to cope with extra care demands and what lessons do these have for service providers?

Children Should Live In A Family Home

Current Australian and international policy is that children with a disability should remain with their family. The NSW Department of Ageing, Disability and Home Care states in its *Supporting Children and Young People with a Disability* (DADHC, 2004) policy document that its vision is 'to enable them [children and young people with a disability] to live as part of a family and community so that they have opportunities to reach their full potential at all stages of their lives' (p. 3). The American Association of Intellectual and Developmental Disability states in its *Inclusion Position Statement* (AAIDD, 2002b) that 'children should live in a family home' (Position section, ¶ 1) and in its *Family Support Position Statement* (AAIDD, 2002a) that 'Federal, state and local governments must recognize the important role played by parents when they keep their children with mental retardation and related disabilities at home' (Fiscal and other public policies must support families section, ¶ 5).

The Consequences Of Providing Care To Children With A Significant Disability

In order for children or an older person with a disability to remain or to choose to live at home, substantial support from family and friends may be needed. To describe this sort of care as 'informal' is somewhat of a misnomer as there is nothing casual about taking primary responsibility for another person's welfare. An Australian Bureau of Statistics (ABS) survey in 1998 (Australian Institute of Health and Welfare (AIHW), 2004) revealed that 60% of care recipients always needed assistance with one to four activities

of daily living and a further 24% always needed assistance with five to nine activities of daily living. In addition, the ABS survey revealed the following information about carers in Australia;

- 70% of primary carers were women;
- Over 50% of primary carers spend 20 or more hours per week in the caring role and over 33% spend 40 hours or more per week in an unpaid carers role;
- 75% of primary carers had spent at least 5 years in the caring role and 40% had been caring for at least 10 years;
- Carers had a lower labour force participation rate (39%) than people who were not carers (68%) and for carers in paid employment, the caring role can have a significant impact on their work e.g., reduction in work hours after commencing, time off to meet care needs (ABS, 2005) and declining job transfers or paid jobs (Trute & Hiebert-Murphy, 2002).
- 46% of people with severe to profound restriction received assistance only from family and/or friends, 48% received assistance from family and friends, supplemented by formal services, and 3% received assistance only from formal services (AIHW, 2004).

Substantial financial costs are born by carers as a result of both income limitation and increased costs associated with the child or adolescent's disability. Estimates have been made that the costs of disability correspond to 29% of equivalised household disposable income. However, when a more extensive disability variable was used to do the calculations, the estimate increased to just over 37% of disposable income (AIHW, 2004). Where there is someone in the household with a disability, the costs of disability represent a substantial percentage of disposable income, poverty rates

are higher, and hardship is more prevalent (Emerson, 2003b; Saunders, 2006). In 2005, Access Economics researched the economic value of informal care for people with disability or chronic illness and the frail aged. They found that if all informal care was replaced with formal care, the cost was estimated at \$30.5 billion annually (Access Economics, 2005).

The Extra Care Required For Children With Different Levels Of Impairment

Intellectual disability is a disability characterised by significant limitations both in intellectual functioning and in adaptive behaviour (AAIDD, 2009). Intelligence involves the ability to reason, plan, solve problems, think abstractly, comprehend complex ideas, learn quickly, and learn from experience (AAIDD, 2009). Adaptive behaviour represents the ‘conceptual, social, and practical skills that people have learned to be able to function in their everyday lives’ (AAIDD, 2009; Key concepts in the AAIDD system section, ¶ 3). These skills may include reading, money skills, the ability to follow rules, maintenance of personal care, preparation of meals, housekeeping skills, and occupational skills. Significant limitations in adaptive behaviour have an impact on an individual’s daily life and affect his/her ability to respond to a particular situation or environment. The ‘supports approach’ of the AAIDD evaluates the specific needs of the individual then suggests strategies and services to optimize individual functioning. The supports approach also recognizes that individual needs and circumstances will change over time.

Results of an international study conducted by Haveman, Van Berkum, Holscher, and Van Wallegam (2000) suggested that time demands and expressed need for services were higher for children diagnosed with severe intellectual disability and

comorbid conditions (e.g., epilepsy, cerebral palsy, heart failure, vision impairment). If the child has additional severe physical impairments or health problems, they may require daily exercises to prevent contractures, regular interventions for constipation (e.g., stool softeners, bowel stimulants, and occasionally enemas), daily administration of medications, and gastrostomy tube feeding (involving complex preparation of formulae and use of an electrical pump for long periods of time) in order to maintain nutrition (Cooley, 2004). The carer may be required to attend frequent appointments with doctors, therapists, and other professionals, and may experience repeated hospitalisation of their child. Wallander and Noojin (1995) found that mothers of children with disabilities reported a wide range of problems in parenting their child. They found that almost half of the mothers' concerns centred on their child and how they were functioning.

The Impact Of Different Types Of Disability On Care Needs And Carer Stress

My day begins with that adrenaline pump and muscle clench I always feel when I hear [my son] first stir in the morning. Perhaps you can imagine a 6 foot 100 kg 3 year old going through that terrible time when they want your constant attention, except [my son] isn't a toddler you can pick up and put down somewhere safe while you take a break or catch your breath. The things most people take for granted like taking a shower, talking to a friend on the phone, or simply doing the housework, I cannot do without first making sure that [my son] is entertained or that someone else is caring for him. My subconscious is always focusing on [my son] no matter what I am doing. That kind of vigilance is

exhausting. [Extract from a letter of a mother of an 18 year old male with intellectual disability].

High care needs due to impairments in adaptive behaviours do not necessarily predict high stress levels for carers. Higher rates of maladaptive behaviours, not age, intelligence, mental age or other variables, were the strongest predictors of increased stress in parents of children with genetic aetiologies in studies of intellectual disability (Hodapp, 1997). However, while other studies have also failed to find an association between the child's level of intellectual disability and parenting stress (Hassall, Rose, & McDonald, 2005; Walker, Van Slyke, & Newbrough, 1992), some studies have found that there is a relationship between parenting stress and level of intellectual disability (Minnes, 1998; Eisenhower, Baker, & Blacher, 2005). Generally it seems that specific characteristics associated with the disability are more important correlates of parental stress (Minnes, 1988). These include the child's communication skills (Frey, Greenberg, & Frewell, 1989) and particularly the child's behavioural difficulties (Quine & Pahl, 1991).

Challenging behaviour has been found by others to predict family stress levels and the ability to maintain the child with a disability in the family home. A survey of mothers of 103 young adults with severe intellectual disability identified that behaviour and/or mental health problems significantly predicted the mothers' perceived negative impact of the young adult on the family, as did better young adult health and the mother's higher educational attainment (McIntyre, Blacher, & Baker, 2002). Other researchers have also confirmed that parents perceive the psychiatric or behavioural problems of their child to be an extra burden, making it more difficult to raise and

manage such a child, and that as a result, they tend to seek support from services (Maes, Broekman, Dosen, & Nauts, 2003).

The impact of caring for a child with intellectual disability varies throughout life. For carers of a child with an intellectual disability, the impact may vary from the period of anticipatory care, to diagnosis with potential lasting effects of disclosure, through the period of struggle to maintain a 'normal life' in the face of extra care demands, to the time of 'letting go' as the child reaches adulthood (Grant, Nolan, & Keady, 2003). It has been noted in the literature, that the adolescent period is one of the most critical phases in the lives of people with intellectual disabilities. There is a view that this phase is marked by greater parental malaise and increased levels of parental stress influenced by significant life transitions (Baxter, Cummins & Polak, 1995).

Explanations for the relationship between adolescence and increased parental stress are diverse. For the most part, the major disruption in service provision and the uncertainties this invokes are typical explanations, as are concerns over the developmental progress of their child and its social implications (Thorin, Yovanoff, & Irvin, 1996; Heslop, Mallett, Simons, & Ward, 2002). This is reported to hold true even where the mother had viewed the early years of parenting as similar to those of her friends, a 'life as ordinary'. However as the social content and events of the middle years of parenting prompt a realisation that carers' lives and, for some cases, their sense of 'self', are undergoing considerable change (Todd & Jones, 2005).

There are suggestions that the underlying cause of the intellectual disability may predict parental stress. Studies have suggested that a diagnosis of Fragile X Syndrome creates more challenges to maternal psychological wellbeing than a diagnosis of Down Syndrome (DS), and that the combination of Fragile X Syndrome and autism can be

particularly challenging (Lewis et al., 2006). Even by the preschool years, mothers of children with autism may show an elevated risk for high stress, and this stress parallels behavioural difficulties (Noh, Dumas, Wolf, & Frisman, 1989). However, not all of the maternal stress can be explained on the basis of behavioural problems (Eisenhower, et al., 2005). Furthermore, the lower personal well-being, or stress, of care-givers of children with autism, and more reported maladaptive behaviours, may persist through to the time the child reaches adulthood, regardless of cultural group (Blacher & McIntyre, 2006). In some cases, other factors can influence the response of parents. In contrast to correlates with the DS group, stress levels of fathers of children with other types of intellectual disability seemed to be more influenced by such demographic variables as the child's gender and their own level of education (Ricci & Hodapp, 2003).

The Relationship Between Children's Care Needs And Carer Stress And Coping

Persistent, constant demands for care and support can be exhausting for carers, who are sometimes referred to as 'perpetual parents' (Grant et al., 2003). The Australian Institute of Health and Welfare (AIHW) in its report *Carers in Australia* (AIHW, 2004) found that many factors influence the caring experience for carers. These factors include: personal circumstances and characteristics of the carer and care receiver; the nature and strength of the relationship; living arrangements; and the level of support available from formal services and social networks. The financial, emotional, and physical hardships, always being 'on call' even when a child is school-aged and attends an educational facility, time pressures associated with caring, and responding to the demands of education staff for care-related assistance in school life, combine to place intense pressure on carers. In addition, the AIHW (2004) reported that 'the physical and

psychological demands of the caring role itself can lead to adverse health outcomes for carers' (p. 23). Caring can increase levels of fatigue, worry or depression, and impact adversely on wellbeing. Parents who care for their disabled children often report ineffective coping and feel overwhelmed by their responsibilities (Johnson, 2000).

The interaction between informal support networks and the degree of disability in the child for the carer was highlighted by a population based survey conducted by Leonard, Johnson and Brust (1993). They found that one-third of their sample of care givers of children with disabilities reported that they needed more help managing the care or could not manage much longer when the children were more severely impaired and functionally dependent. The mothers in this survey reported that they were in poorer physical and mental health, had greater demands on their time and finances, and received less emotional support from family and friends.

However, the relationship between stress and level of care needs is not at all straight forward with some studies clearly implicating psychological processes in the response of the carer to high care demands. In the parenting domain, self efficacy has been shown to impact on parental behaviours and parenting stress (Harty, Alant, & Uys, 2007), as has expressed emotion towards the child (Datta, Russell, & Gopalakrishna, 2002), parental locus of control, and parenting satisfaction (Hassall et al., 2005). Hassall et al. (2005) demonstrated that when child behaviour difficulties were added to parental locus of control and parenting satisfaction, only a further 5% of the variance in parenting stress was added to that accounted for by the first two variables (i.e. self efficacy and expressed emotion) that accounted for 54%.

Cognitive appraisal has also been shown to be an important factor in parental stress, and that positive and negative appraisals are independent (Leonard et al., 1993).

Further, the appraisal parents hold of the family impact of childhood disability, is formed early in the life of the child with the disability and tends to remain unchanged through to the pre-adolescent years of the child. Identifying parents who are at risk of high levels of stress while the child is young provides an important opportunity for preventative child mental health services (Trute & Hiebert-Murphy, 2002).

The complexity of the journey through identification of disability, diagnosis, and day to day living presents huge challenges for parents. Straddling behaviour embodies the parents' precarious balancing on three levels of parental functioning:

1. Living with one foot in the present and one foot in the past (e.g., diagnosis);
2. The dilemma of trying to view the child as 'normal' when in fact, as evidenced by the parents' activities to secure special services, they are not 'normal'; and
3. Dealing simultaneously with child's issues and feelings, and parent's issues and feelings (Johnson, 2000).

However, it is important to acknowledge that while some parents experience high care demands, and at times overwhelming stress levels, many parents do not. Researchers have increasingly adopted the view that families with a disabled child are not generally characterised by high levels of pathology and that families may employ various strategies to adapt successfully to the demands posed by the child (Stoneman, 1997, Kenny & McGiloway, 2007).

Lessons For Service Providers

Children with significant intellectual or developmental difficulties are usually cared for by parents, particularly their mother, at home. While this is often associated with significant employment and financial costs, in many cases, it is not associated with

significant psychological distress. However, it is clear that some child and carer characteristics are likely to lead to increased stress that may eventually result in breakdown of the family situation. These characteristics include substantially increased care needs of the child or adolescent, the presence of challenging behaviour, and substantial communication limitations, certain diagnoses such as autism, impaired parental locus of control, and perceived parental efficacy. Further, it is likely that the trajectory of increasing carer stress and negative appraisals are initiated early in the life of the child.

Thus, provision of intervention and support services directed towards challenging behaviour and communication impairments are a priority. Services to address these issues should be available from the early preschool years. Identification of those carers with psychological responses that have been shown to be associated with increased stress, might enable counseling (with an emphasis on increasing the sense of parental control) to be offered. The service system should be designed to be responsive to parental needs rather than being a bureaucracy that offers services far too late to meet the needs of the child/ adolescent, carers and family.