Parents of adults with an intellectual disability

There are an increasing numbers of adults with an intellectual disability living into middle and old age, and often these adults are cared for by their parents in the family home. Individuals who live in other accommodation generally still receive both practical and emotional support from their parents. This review of the literature details some of the demands and strains experienced by parents of adults with an intellectual disability, and examines factors that research suggests may affect parents’ capacities to cope with these.

Two changes in the lives of individuals with an intellectual disability, increased longevity (Adlin, 1993; Janicki, Dalton, Henderson, & Davidson, 1999) and the shift from institutional care to living with family, have had enormous implications for Australian parents of adults with an intellectual disability. Parents of children with an intellectual disability typically care for their child at home, and then continue to provide care, generally in the family home, until they die or are no longer able to offer this support because of their own illness or frailty (Beange & Taplin, 1996; Bigby, 2000). Extended caregiving is the term often used to describe caring for offspring with a disability into adulthood.

According to the most recent data published by the Australian Bureau of Statistics (2003), there are 38,100 parents aged over 45 years whose son/daughter with a disability lives with them, with 4,100 parent carers who are over 65. These data do not distinguish between those parents who care for an adult child with an intellectual disability and those whose child has a different type of disability, however based on data from the Australian Institute of Health and Welfare (2006) it is likely that the majority of parents engaged in extended caregiving have a child with an intellectual disability. A large majority of primary carers of adults with an intellectual disability are mothers, even when both parents are retired (Essex, Seltzer, & Krauss, 2002). The published literature typically focuses on mothers’ experiences and uses mothers as informants and so the following review of issues related to the experiences of parents of an adult child with an intellectual disability reflects this.

Why do parents continue to provide care into their own old age?

There are a number of reasons parents give for their continued co-residence with their adult child with an intellectual disability. These include the belief that it is their responsibility to provide what they see as necessary for their son/daughter (Krauss & Seltzer, 1998; Llewellyn, 2003) and that this is the preference of their child (Krauss & Seltzer, 1998). This sense of parental responsibility often occurs alongside the belief that there are no alternatives (or that the alternatives are unacceptable) (Krauss & Seltzer, 1998; Llewellyn, 2003). In addition to these motivations, parents often see mutual benefits to their situation, including receiving companionship, assistance with household tasks, and emotional support (Grant, Ramcharan, McGrath, Nolan, & Keady, 1998; Heller, Miller, & Factor, 1997; Krauss & Seltzer, 1998; Rimmerman & Muraven, 2001). In some situations, the adult child also provides care to elderly parents, assisting them to stay in their own home (McCallion, Janicki, & Grant-Griffen, 1997). As well as these more external aspects, parents also identify personal benefits from their caring role, including personal growth and improved family relationships (Muirhead, 2002; Schwartz, 2003). It is important to recognise that, even in situations when parents no longer co-reside with their adult child, they generally remain very involved (Seltzer, Greenberg, Krauss, & Hong, 1997), with many continuing to provide assistance to meet their child’s daily care needs (Llewellyn, 2003). Neither the satisfactions nor stresses of caring necessarily end when the child leaves the family home.

Two conflicting hypotheses have been proposed regarding parental response to the demands of extended caregiving. The first, called the ‘wear and tear’ hypothesis, suggests that parents become worn down by the accumulated demands of caregiving and both their physical and psychological resources become depleted (e.g., Johnson & Catalano, 1983). The second hypothesis is that parents develop skills as a result of their experiences and so make a better adjustment to their circumstances as time goes on (Olson et al., 1983). There would appear to be more empirical support for the latter proposition, however, only longitudinal investigations are capable of fully testing these hypotheses because of the different experiences of different cohorts of parents.

Several cross sectional studies have found older parents of a child with a disability to be coping at least as well as younger parents. For example, McDermott et al. (1996) found that, of parents with an adult child with intellectual disability, those who were over 60 years of age were functioning as well as those who were under 60, and Grant and Whitell (2000) reported an increase in the use of cognitive coping strategies as parents aged. There is a great deal of variability between individuals in their capacities to meet the demands of caring for an adult child with a disability, however. There is also variation within individuals, i.e., individuals may cope differently at different times or under different circumstances, although this aspect is less well understood. A number of parents experience quite deleterious outcomes as a result of their caring responsibilities, and this is taken up below.
Demands facing parents of an adult child with an intellectual disability

There are a number of demands that are faced by parents of an adult child with an intellectual disability. Some of these are also faced by parents whose children follow a typical developmental pathway (although generally the demands are experienced over a shorter time span), and others are shared by carers in different circumstances, for example, one spouse caring for another. Many parents need to provide assistance with the daily tasks associated with living – feeding, dressing, toileting, and mobility. Physical health care needs will be paramount for some families while for others their priority may be managing the consequences of mental health problems such as depression and dementia. These latter problems increase in the population of adults with an intellectual disability as they age (Janicki & Dalton, 2000; Prasher & Cunningham, 2001) and increase the demands on those caring for them.

Parents are regularly placed in the position of having to advocate for their child to obtain appropriate services and/or to maintain the quality of services to their child. Of particular interest to parents of adult offspring with an intellectual disability are out-of-home living and services that provide daytime activities (Haverman, van Berkum, Reijnders, & Hellar, 1997; Minnes & Woodford, 2005). Australian families interviewed by Llewellyn, Gething, Kendig, and Cant (2004) had a number of concerns related to services. Some of these had to do with current frustrations with services – inadequate provision, poor relationships with staff, a perceived lack of recognition of their expertise in relation to their son’s/daughter’s needs and character, inexperienced staff and frequent staff turnover. Parents also had constant concerns about the future, fearing changes to service provision, either as a response to policy or funding changes, or services becoming unwilling to continue to provide for their child due to behavioural difficulties, complex health needs or deterioration in function.

Parental interaction with services

Despite the availability and quality of services being a major concern for parents of adults with an intellectual disability, they are relatively minor users of services, with this pattern found across a number of countries including Australia (e.g., Bigby, 2000; Haverman, van Berkum, Reijnders & Heller, 1997; Smith, 1997). According to a number of researchers, between 25 per cent and 50 per cent of ageing carers are not using any formal service and so are unknown to service providers (Cameron, 2004; South Brisbane CCRC, 2004). A number of possibilities for the relative lack of engagement with services by the parents of adults with disabilities have...
been posited and include lack of appropriate services (Nolan, Davies, & Grant, 2001), the belief that no one else is capable of doing the job (Grant & Whitell, 2000; Llewellyn, 2003), lack of perceived need due to the experience of coping without external assistance in the past (Hayden & Heller, 1997) and previous negative experience with service providers “ (p. 393), Llewellyn et al. classified families into one of four types: (a) parents who were unlikely to seek support as they were confident in their capacity to provide what their adult child required; (b) those who were reluctantly involved with the service system because they saw no alternative, even though they were dissatisfied and wanted more influence on the services their child used; (c) those who had good, trusting relationships with staff and had worked out a satisfactory solution for themselves and their adult child; and (d) parents who were generally unhappy with the life available to their child but who felt they had no alternative but to leave decision making up to the service provider.

Additional strains experienced by parents

Conflict with staff is a potential area of strain for parents. As mentioned above, parents feel a responsibility to ensure that their children receive services that are of good quality and responsive to their individual needs. In some instances, parent/staff conflict may be around issues of quality of services, however, there may also be conflict around issues regarding what is appropriate for the adult child. Staff may feel that parents are putting their own needs (for example, ensuring their son/daughter’s safety or arguing for more money for respite care) ahead of the needs of the adult (for example, for independence or for insisting more resources be put into community housing). The arena of sexual activity of the adult with intellectual disability is one that clearly has the potential for staff/parent conflict. Cuskelly and Bryde (2004) found that staff had significantly more liberal attitudes than parents with respect to the behaviour of adults with an intellectual disability, although they suggested the differences were likely to be generational rather than role based.

Associated with this, is parental concern about sexual harm and exploitation of their adult child and of the possible consequence of pregnancy (Cuskelly & Bryde, 2004). Some parents are concerned with protecting their child from these perceived dangers and others are dealing with their reality. Some parents provide extensive assistance to support adult children who have children of their own (O’Hara, 2003), thus further extending their caregiving.

Employment of mothers of children with a disability is significantly lower in comparison with those without a child with a disability, both while the child is young (Cuskelly, Pulman, & Hayes, 1998; Shearn & Todd, 2000) and in adulthood (Einam & Cuskelly, 2002). The Disability, Ageing and Carers Survey 1998 (Australian Bureau of Statistics, 1998) and Time Use Survey 1997 (Australian Bureau of Statistics, 1999) showed that primary carers of individuals with a disability (more broadly defined than intellectual disability only) of any age were substantially disadvantaged in terms of employment (Gordon, Rosenman, & Cuskelly, in press).

One of the frustrations of the mothers of adult children with multiple disabilities in Einam and Cuskelly’s study was the hours of operation of the services used by their adult children. They generally had shorter hours than school hours, thus limiting mothers’ capacity to work outside the home. The impact on fathers’ employment has rarely been studied, however, Einam and Cuskelly (2002) found a bimodal distribution in fathers’ working hours with approximately half the fathers in their study working part time in order to provide support for their wives and the remainder working very long hours.

Lack of employment outside the home has not only economic consequences but can also result in social isolation. Parents of adults with a disability are regularly identified as being more socially isolated than their peers (Hare, Pratt, Burton, Bromley & Emerson, 2004; Seltzer, et al. 1997). Social isolation contributes to dissatisfaction with life and is implicated in the development of depression in the general population (Arcán & Reynolds, 2005) as well as in mothers of an adult child with a disability. Thorin, Yovanoff, and Irvin (1996) identified a number of dilemmas facing parents of young adults with an intellectual disability including the desire to develop a separate life for themselves while continuing to provide the level of care that was necessary for their adult child.

An important area of strain for some parents is their relationship with their son/daughter with an intellectual disability (Grant et al., 1998). Some adults are demanding, uncooperative, display substantial behavioural problems, and/or mental health problems. Parents may feel that their adult child does not contribute to the household as much as he/she could and that the adult interferes with other family relationships (Nolan, Grant, & Ellis, 1990). Other family relationships may also contribute to the experience of strain, particularly if other family members are perceived to be providing too little support for the parent (Nolan et al., 1990).

Grant et al. (1998) found that parents experienced negative emotional reactions to some of the personal consequences of caring for another. These included, but were not restricted to, distress at the lack of private time, anger, and guilt in response to feeling angry or burdened. These emotions did not necessarily occur in the context of a poor relationship between parent and child, but were a response to the unremitting responsibility for their adult child.

What are the consequences for parents of these demands and strains?

Stress is generally understood to occur when the demands facing an individual are seen by him/her to be greater than the personal and or collective resources available to cope (Lazarus, 1993; Olson, 1997). Stress may manifest itself in a number of ways including psychological and physical illness. Seltzer, Greenberg, Floyd, Pettee, and Hong (2001) found parents caring for adult offspring with an intellectual disability to be significantly at risk for both physical and mental health problems. Depression has been the focus of a number of studies and it is clear that parents of an adult with an intellectual disability are more likely to experience depression than are parents whose adult children are all developing typically. In a study by Minnes and Woodford (2005), for example, sixteen per cent of parents were above the cut-off on an instrument measuring clinical depression. Nevertheless, it should not be forgotten that negative consequences are not inevitable (see, for example, Carr, 2005; Chen, Ryan-Henry, Heller, & Chen, 2001).
What contributes to individual differences with respect to these consequences?

Clearly, parents differ in their response to the demands and strains of parenting an adult with intellectual disability. A number of aspects contribute to these differences including the attributes of the person being cared for and those of the carer; the characteristics of the informal and formal systems in which care is provided and the sociopolitical context. It is important to recognise that individuals’ capacities and responses change over time – for example, parents’ skills may increase (Olson et al., 1983) but demands may also change. Having a child with a disability does not protect families from other negative life events that are common to all families. These negative events – such as the death of a parent or partner - occur quite frequently in the lives of those in middle age and older. Dealing with these events may undermine an individual’s or family’s capacities to continue to cope as effectively with the demands and strains associated with caring for their child with a disability.

Attributes of the person requiring care

In a longitudinal study of maternal coping, Seltzer et al. (1997) found that those mothers who reported the most caregiving also reported the highest levels of subjective burden at a later point in time, and that depression was positively related to the amount of caregiving. A similar association between caregiving hours and depression was reported by Cannuscio et al. (2004), although their study was focused on a different caregiving group. Generally, mothers of adults with a disability reported feeling less burdened when their adult child moved to an out-of-home placement (Seltzer, et al., 1997), but their levels of depressive symptoms did not change. A high level of caregiving is generally required for those with more severe or multiple disabilities. Those individuals who have associated behaviour problems and/or mental health conditions also make additional demands on parents.

Maladaptive behaviour on the part of the adult offspring is a major contributor to parental distress (Heller & Factor, 1993; Minnes & Woodford, 2005; Westling, 1996). There appears to be an increase in the psychiatric morbidity of at least some groups with an intellectual disability with age (Janicki & Dalton, 2000; Prasher & Cunningham, 2001), increasing the likelihood of lowered wellbeing in families supporting these individuals.

Attributes of the carer

There are a number of personal characteristics that contribute to differences in parents’ response to the demands and strains of caring for an adult child with an intellectual disability. For example, optimism has been shown to be linked to positive mood, to effective problem solving and to good health (Peterson & Steen, 2002) and has been found to be related to improved physical and mental health in mothers of an adult child with a disability (Greenberg, Seltzer, Krauss, Chou, & Hong, 2004). Effective problem solving strategies have been identified to include planning, suppression of other competing distractors in order to deal with the stressor, and positive reinterpretation (Krauss & Seltzer, 1998). Other coping strategies found to protect mothers from negative psychological outcomes include gaining knowledge, reframing the situation, expressing their feelings, resolving negative feelings, and seeking help and support (Olson, 1997). In general, problem-focused coping is beneficial while emotion-focused coping is less effective and is associated with reductions in mothers’ well being (Kim, Greenberg, Seltzer, & Krauss, 2003).

As parents age, there is likely to be an increase in their own ill health and perceived deterioration in their own function. There has been found to be associated with increased depression (Minnes & Woodford, 2005). An additional attribute of the family that is relevant to coping with a child with a disability is socio-economic status. Socio-economic need within families will increase the difficulties parents face when caring for an individual with an intellectual disability and is likely to lead to increased distress in this group (Emerson, 2003).

Cultural beliefs about disability are likely to contribute to parental response to disability in their child. Families in the United States of America that are not Anglo-American appear to be less involved with the formal systems than are Anglo-Americans (Grant-Griffen, 1995; Heller & Factor, 1988). For some individuals, accepting out-of-home support may be completely unacceptable as it indicates a failure of the family and community to provide care (Cuskelly, Brown, Shearer, & Singh, 2006). Some cultural groups may be supportive of the intention to “hide” a family member with a disability for reasons of shame. There appears to be a general loosening of traditional beliefs as generationally people move from the migrating generation (McCallion, Janicki, & Grant-Griffen, 1997). It is of course, important to understand that not all members of a cultural group hold the same views (McCallion et al., 1997).

Attributes of the support system

There are two major support systems for families for a child with a disability – their family and friends and the system that provides services to their child. It is rare for a service to have the families of adults with a disability as their primary object of support. Being part of a cohesive family that is flexible and has effective communication has been found to assist parents cope with the demands of their caregiving role (Olson, 1997). Social support in the broader context is also important, with depression being negatively associated with the size of individuals’ social networks (Seltzer et al., 1997).

Parents’ perceptions of the availability of the necessary supports for their adult child has been found to be associated with increased stress and less caregiving satisfaction (Heller & Factor, 1993a; Llewellyn et al., 2004), with those who have larger unmet needs reporting poorer outcomes. When the contributions services make to parent wellbeing are considered, it must be realised that interactions with professional staff can be a very significant stressor for families (Lustig, 1996). Parents find a lack of acceptance of their expertise and an inability to influence the services received by their child to be frustrating.
Minnes and Woodford (2005) found that the number of services their adult child was associated with acted as a protective factor for parents, although as they pointed out, it was not possible to determine what aspect of service use was helpful – for example, it could be that families who were engaged with more services felt better supported, or it may be that these families were less concerned about the future as they believed one of the services would provide what was required. Services such as respite that are more directly related to parental needs are generally perceived to be inadequate and inflexible (Llewellyn et al, 2004).

**Sociopolitical context**

Higher financial support from government has been found to be associated with lower stress in families of children with a disability (Herman, 1991). Countries differ in the level of services and the financial support they provide to individuals with a disability and their families (Heller, 1999). These differences may explain differences in parent behaviour. As an example, parents in the Netherlands have been found to be more likely to make future plans concerning their adult with an intellectual disability than are parents in the United States of America (Heller, 1999). In discussing the American situation, Seltzer and Krauss (2001) made the point that family support programs receive only three per cent of the public expenditure for individuals with intellectual or developmental disabilities, although approximately 60 per cent of these individuals live with their families.

Direct funding to families may, in some cases, result in increased family satisfaction with services and improved community integration for the adult with an intellectual disability (Caldwell & Heller, 2003; Heller, Miller, & Hsieh, 1999). Direct funding means that families receive an amount of money that they can then use to directly purchase the services they require. This occurs in Britain under the Carers and Disabled Children Act 2000 & Carers (Equal Opportunities) Act 2004 (Department of Health, 2005) for those individuals who provide care for another adult or a child with a disability under 18 years of age. We do not currently have a great deal of information on what makes direct funding work well, but it seems very likely that not all services that parents want and need are available, even if families have the money to pay for them.

**Conclusions**

While the material that has contributed to this review is primarily drawn from research with families with an adult child with an intellectual disability, it is important to recognize that parents of adult children with other disabling conditions also provide care of a continuing or episodic nature. Parents of an adult child with an intellectual disability differ somewhat from other parents in that they are likely to have provided continuing care to the child well into old age. It is also important to recall that there is an uncertain (but predicted to be large) number of families with an adult with an intellectual disability who are unknown to service systems (see discussion in Bigby, 2000) and are therefore unlikely to be included in research.

Llewelyn (2003) reminds us that parents see their role with respect to their adult child as that of parent, as opposed to carer (the language used in policy documents and by professionals), this latter designation suggesting a distance that does not reflect their lived experience. The difference in terminology is more than semantic as it reflects different understandings of roles and responsibilities. These different understandings may contribute to misunderstandings and disagreements between parents and those in professional roles and may also contribute to parental reluctance to avail themselves of some of the services available to them, such as respite.

Parents of adults with an intellectual disability are ageing, along with their sons and daughters. Their own ageing, plus additional responsibilities that often attend getting older, such as providing care for one’s own parents or spouse, may decrease their capacities to provide care for their adult child with a disability (Cuskelly et al., 2006). These extra demands are almost certain to deplete their resources to cope with any unexpected events or crises in the life of their adult child. Who will provide care for these adults in the future? Some siblings may wish to accept this responsibility but others may not. As Grant (2001) has pointed out, changing family demographics (smaller families, divorce, multiple types of sibling relationships) as well as different community values such as expectations for women to be in the workforce, are likely to decrease the capacity of the extended family to provide care.

It seems clear that more attention needs to be paid to parents of adults with an intellectual disability. While there may be some tension between providing appropriate services to the adults themselves and to their families, it is generally possible to accommodate the needs of both. Indeed, for many parents the provision of adequate, responsive, stable services that meet the needs of their adult child now and into the future would address most of their concerns. It is insufficient, however, for the community to be satisfied with a system that fails to address the needs of these parents.

**References**


