

Submission

Inquiry into Planning Options and Services for People Ageing with a Disability

Community Affairs References Committee

Terms of Reference

Access to planning options and services for people with a disability to ensure their continued quality of life as they and their carers age, and to identify any inadequacies in the choice and funding of planning options currently available to people ageing with a disability and their carers.

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PART 1 Introduction

1) Summary

Planning for the future is an important task for people living with disability and their families. This submission will focus on the importance of considering the whole family when developing planning options and services. It will not focus on the different planning options and services for people ageing with disability; this will be left for those with expertise in this area.

Adult siblings are likely to be in the life of the person with disability longer than anyone. However, in Australia there is no real attempt to understand the sibling perspective. There is very little data about the number of adult siblings in Australia and the roles they play in regard to supporting the person with a disability over a lifetime. There has been very little research done on the nature of these sibling relationships and the impact they have on both the sibling and the brother or sister living with disability. This submission will argue that there needs to be much greater attention given to siblings when considering planning options and services for people ageing with disability. It will also discuss some of the barriers to families planning for the future, policy implications and recommendations regarding the support of families to undertake this planning.

2) Background

In Australia the majority of adults with development disabilities live in the family home accounting for around 240,000 people (Llewellyn et al. 2003, Dew et al. 2004). This figure does not include those with chronic illness or mental illness. In addition, due to medical advances, the life expectancy of people living with disability has increased markedly in recent times. It is now likely that people with disability will be living longer than their parents, and this will create a number of challenges, not only for families but also the community. Such a scenario may also bring about a number of opportunities for people with disabilities, their families and the community.

A recent focus in disability literature has been the impact of the ageing population on disability service provision. There are large numbers of people living with disability who will, in the near future, need to transition from being supported by parents to being supported by the disability service system or by other family members/carers, or a combination of both. This will create a need to consider not only the changing accommodation and financial needs of people ageing with disability, but also their health needs – encompassing their physical, emotional, spiritual, and social/community participation needs.

With regard to accommodation, there is general consensus that there is an emerging crisis in accommodation for people with a disability who now live at home with parents who are ageing. Little is being done to develop appropriate accommodation options and it is easy to assume that there is some expectation from governments that other family members will identify themselves as ‘carers’ and will take over when parents are no longer able to provide care. The current generation of ageing parents and people with disability have been given little choice when it comes to care options. However the next generation is likely to demand more from governments and the community in terms of support services for people living with disability.

Current discussions at both community and government level around the issue of ‘ageing carers’ give little attention to the contribution and role of adult siblings. For people living with disability who have siblings, it is most often those adult siblings who become involved in their future life when parents age and are no longer able to provide the same level of support (Smith & Greenberg 2007; Heller & Caldwell 2006). The sibling relationship will likely be the longest of any. Parents often have an expectation that adult siblings will take over support roles (Degeneffe & Lynch, 2006; Seltzer 1993) and many adult siblings themselves expect that they will take on support roles in the future (Heller & Kramer 2009; Krauss 1993). It is likely therefore that adult siblings will become an increasingly important part of the support networks for people living with disability. As Hodapp & Urbano (2007: 1026) suggest, “it seems critically important to understand the characteristics and relationships of these individuals.”

At the same time, studies carried out in Australia (Strohm & Waldren 2010) and the United States (Heller & Kramer 2009) show that many families do not develop clear plans for the future care of the person living with disability. Freedman, Krauss & Seltzer (1997) found that less than half of the families in their research project had developed plans for the future.

The picture this presents is one where many adult siblings are likely to take on a supporting role for their brother or sister living with disability with either no plan in place or a plan that is in place which has had no input from the adult sibling and possibly no input from the person living with disability. This is obviously not the best option for the adult sibling or for their brother or sister living with disability, and it may not indeed ultimately fulfil the intentions held by parents. This situation points to a need for encouraging and assisting ageing caregivers to develop plans and include adult siblings as well as the person living with disability in these plans. The Australian Government's report, *Succession Planning for Carers* (FAHCSIA, 2007), highlighted the fact that planning for the future when a family member lives with disability can be complex and difficult. The Report states that "*future planning is a sensitive issue, challenging family assumptions and requiring people to face their own mortality and discuss personal issues and information*".

The provision of information to families on topics related to future planning (such as legal and financial issues) would seem a useful strategy for encouraging future planning. However, this alone without further psycho-educational or peer (other family) supports is not likely to result in increases in the number of families actually going on to develop a plan (Preston & Heller, 1996). Models for such processes have started to be developed both in Australia and overseas. Further research is needed into the best ways to encourage all family members to be involved in planning for the future, particularly in an Australian context. The model proposed by Heller & Caldwell (2006) might be a starting point, but it would also need to incorporate adult siblings into the planning process. Part of this research would need to focus on the barriers to such planning as well as the development of best practice interventions to facilitate effective future planning.

3) Siblings Australia

Siblings Australia is a unique national organisation committed to enhancing the wellbeing of siblings of children and adults living with disability. The organisation's mission is to assist siblings to become acknowledged, connected and more resilient. Siblings Australia provides workshops and networking opportunities for families and providers across Australia and overseas. Most of the work carried out by Siblings Australia has had a preventive approach (Strohm, 2008).

The organisation recognises that research and anecdotal evidence supports the view that illness and disability affect the lives of all family members. Understandably, in the early years, significant resources may be spent addressing the needs of the child with special needs. By the same token, research has now substantiated the fact that siblings of these children may themselves have significant needs. Without support, these siblings are at risk of developing longer-term physical, emotional and psychological problems.

Support for siblings, from a young age, allows them to feel less isolated, helps them to develop effective coping strategies, and helps them build resilience. As a result, they will be more likely to develop to their full potential and also to contribute to the quality of life of their brother or sister with special needs. Support at this young age may indeed flow into lifelong benefits, with siblings remaining active in the life of the person with a disability for much longer. Certainly anecdotal evidence from parents of children who have attended sibling programs shows that these children interact more positively with a brother or sister with disability after contact with other siblings through the group.

Although it has focused on providing services and resources to young siblings, their parents and the professionals who work with families, Siblings Australia has, since its inception in 1999, been acutely aware of the role and needs of adult siblings. Early investigation through surveys and focus groups reinforced an understanding that the role of siblings was poorly understood and the needs of siblings were largely overlooked. The organisation has developed some resources and services, but these have been limited in scope due to a lack of funding. One important service has been an online forum for adult siblings, where they have been able to share experiences and information. For many this has been a truly moving experience, to

learn that they are not alone and to finally gain support in sorting through some important issues. In some cases, such support has led to renewed or improved contact with a brother or a sister living with disability.

As well as its own work with adult siblings, Siblings Australia has maintained close contact with other adult sibling services in the UK and the US. The research and support being carried out in these countries has demonstrated and reinforced the need for further work to be done in this area in Australia.

In 2008-9, Siblings Australia carried out an Adult Sibling Project, funded by the Julia Farr MS McLeod Foundation. Whilst this project contributed considerably to the understanding about sibling relationships when one sibling is living with disability, it also highlighted that there needed to be much more research and service development in this area (Strohm & Waldren, 2010), particularly around the needs of adult siblings as both the sibling and the person with a disability ages.

PART 2 Sibling relationships over a lifetime

1) Impact on person with disability

Research suggests that the sibling relationship can contribute much to the quality of life for brothers and sisters living with disability (Smith & Greenberg, 2007). Many people living with disability, in particular cognitive disability, rely on family or family friends to provide their social networks. Adult siblings have a unique position in the lives of their brothers and sisters living with disability, as closeness in age may often result in relationships based on friendship thus extending the social network of the person with a disability. Adult siblings may choose to take on varied roles in the lives of their brothers or sisters thus becoming part of the informal support network for their brother or sister living with disability. One sibling involved in the Adult Sibling Project (Strohm & Waldren, 2010) described siblings and their contributions as a 'silent army'. This unique position enables adult siblings to potentially have an ongoing, meaningful and positive impact on the lives of their brothers and sisters living with disability. As the lifecycle progresses and the sibling may go on to have their own family, other family members such as in-laws, nieces and nephews may also contribute much to the support and wellbeing of the person with disability. These connections may be particularly important to the person with a disability as they age and lose other connections from their youth. In many situations, the support can also be quite reciprocal in nature.

If it can be determined what factors influence the involvement of adult siblings in the lives of their brothers and sisters as well as the types of supports that adult siblings require to remain involved, such services would also enhance the quality of life of people living with disability.

Certainly if there is no consideration of sibling issues there can be quite disturbing outcomes. Siblings Australia has found that some siblings, when relationships become too difficult, move right away from the family, which results in the sibling and their brother or sister living with disability, missing out on any relationship in their adult years. There is a need to understand the issues, and support siblings, both as individuals and also as a support person to a brother or sister living with disability. Strengthening sibling relationships will be of benefit to both the sibling and the brother or sister living with disability.

2) Impact on siblings

Disability affects the whole family. Many siblings of people living with disability are enriched by their experiences whilst growing up. Others face many challenges along the way, both in relation to family relationships and through the reactions of others.

Research has shown that, as a result of their experiences, some siblings may develop anxiety and low self esteem. If they do not access support to cope with the challenges, they are at risk of longer term problems such as depression or relationship difficulties (Burke 2004, Fisman et al 2000, Lamorey 1999, Strohm 2002).

Much of this research into the effects of disability on siblings has focussed on children and young people, but there is evidence emerging that suggests that any effects in childhood can carry through into adulthood. However, there is a lack of awareness of adult sibling issues and there are few services provided for their

support. It is important to understand more about the concerns and needs of adult siblings so that appropriate resources and services can be developed.

Research has long highlighted the poorer levels of both physical and mental health experienced by carers of people living with disability and mental illness (House Standing Committee on Family, Housing, Community and Youth, 2009; McAuliffe, Andriske, Moller, O'Brien, Breslin & Hickey, 2009; Llewellyn, Gething, Kendig & Cant, 2003), including increases in stress and depression (Degeneffe, 2001). These studies have rarely acknowledged the particular needs of siblings in families where parents provide care or support for a person living with disability.

The special report, *The Wellbeing of Australians: Carer Health and Wellbeing* (Cummins et al, 2008) documenting the largest ever survey into the health and wellbeing of Australian carers, found that more than one third of family carers in Australia are severely depressed and/or stressed. In fact carers have been found to have the lowest collective wellbeing of any group yet researched. The survey also showed that the presence of a person in the household who requires care severely compromises the wellbeing of other family members, whether they have primary carer responsibility or not. The Australian Institute of Family Studies report, *The nature and impact of caring for family members with a disability in Australia* (Edwards et al, 2008) reinforced these findings and showed that not only carers have higher rates of depression, but also the other children in the family, especially when a parent has also experienced it.

The ABC's Four Corners program has run several stories on the impact of caring on families. One of these, *The Hidden Army*, highlighted the impact on a young sibling, the lack of support he was able to access, and the tragic outcomes, not only for the sibling but for his family as well. Another more recent program, *Breaking Point*, resulted in a huge number of posts on an online forum. Many highlighted the lack of attention on siblings in the program. (<http://www.abc.net.au/4corners/>)

It is crucial, when considering the role of siblings in supporting their brother or sister living with disability, across a lifetime, to explore their experiences growing up and into adulthood. The experiences of siblings and the support they are able to access to manage their own challenges will affect enormously their ongoing involvement or otherwise in the life of their brother or sister.

3) 'Siblings' vs 'Carers'

One of the very strong messages from the participants in the Adult Sibling Project (Strohm & Waldren, 2010) was that they preferred to be known as siblings, not carers, to their brothers and sisters living with disability. They did not feel that carer organisations reached out to them in any meaningful way, the literature from such services was not at all sibling inclusive, and siblings themselves did not relate to the term 'carer'. Very few accessed these services. When asked what services they would like, they strongly supported resources and services that were provided by sibling specific organisations and not 'carer' organisations. Carer organisation services are targeted at family members who are providing considerable primary care. Some siblings provide little or no 'hands on' care to a person living with disability. However, they can still contribute much to the well-being of their brother or sister and still be in great need of support, both as children and as adults. In addition, for a whole range of reasons, including dignity and social inclusion, people with disability do not want their brothers and sisters to be known as their 'carers' – they want them to be brothers and sisters first.

Some families see the use of the term 'carer', especially when applied to siblings, as a way for governments to quietly hand over the care of people living with disability to their other family members and, in the process, abdicate the responsibility of the community to support families. A major campaign in the eastern states a few years ago, by the parent run Carer Coalition, demanded that siblings be free to choose a life of their own and that there needed to be a stop in cost-shifting of the unpaid care and support from parents to siblings. This was not about trying to break down family ties and the natural give and take of sibling relationships. Most siblings want to be involved in the lives of their brother or sister living with disability, to have fun together and share in many of the activities that other siblings share, as well as provide support as needed to a brother or sister. However, the campaign focussed on the expectations in terms of 'hands on' caring of people living with disability and the role of governments in the support of people living with disability.

As one parent said on an online forum after the recent Four Corners program, *Breaking Point*:
I think the government is hoping siblings take on the caring role as parents become not able to. These same people have to establish themselves whilst caring. I know how difficult this has been and not always understood by employers. I am a parent of a child with Autism. I feel this was one thing that wasn't really covered on tonight's program, as good as it was. It missed how "breaking point" affects the siblings who nobly inherit the role of parents who can no longer care for their children for whatever reason.

4) Concerns of siblings about the future

"I have nightmares nearly every night regarding the future of my brother and my mum", adult sibling

A Siblings Australia online survey, along with studies overseas, have shown that many siblings want greater involvement in the lives of their brothers and sisters living with disability, but need more information, networking, opportunities, and supports. Through the online survey, siblings identified a number of concerns regarding the future for themselves, their parents and their brother or sister living with disability (Strohm & Waldren 2010). These included:

- personal costs (financial, time, relations with spouse/partner)
- availability of services (housing, recreation, respite, transportation)
- dividing responsibility amongst family members
- a brother or sister's health, safety, and happiness
- the wellbeing of parents
- juggling their responsibilities for their brother or sister and parents with those associated with their own family
- what will happen when parents die
- concerns about what will happen with their own death
- helping from a distance

Siblings also worry about creating their own independent lives, whether they might find a partner who will share in their responsibilities, whether they should have children themselves and the possibility of any such children having a disability. Unlike many parents, most siblings have not had an opportunity to share these concerns with other siblings.

The survey also highlighted a number of difficulties in discussing family expectations for the future. The following are just three examples of sibling concerns:

Since mum will not approach the subject of future plans or wishes for my brother, I will have to guess.

What are the consequences of my parents becoming older or if they were to die or become very ill suddenly?

My parents assume that she will come and live with me once they go. It's never been discussed.

Some siblings develop very close relationships with their brother or sister living with disability and choose to remain actively involved in their lives, in some cases, leading to shared living arrangements. Others do not choose this course, but are left with no other options, when a parent dies. In some cases, siblings are left instructions in a parent's will about the responsibility they need to assume for their brother or sister. Still others have distanced themselves from their family over time and have limited or no contact with the person living with disability. In many cases, this has come about because the siblings did not receive any support as children to cope with their many varied experiences. Again, if we can strengthen these relationships from a young age and provide supports to siblings across a lifetime, there will be benefits for siblings, for people living with disability, for parents and, indeed, for the whole community.

PART 3 Future planning

1) Sibling involvement in future planning

Planning for the future may involve considerations regarding the following issues in relation to a person living with disability:

- health/medical issues
- accommodation
- guardianship

- financial plans (including wills and special needs trusts)
- identification of future caregivers
- developing a 'letter of intent', which is a non-legally binding planning document that lays out the wishes of parents and/or the person living with disability

Such planning must also include consideration of the emotional and social well-being of all members of the family, including the person living with disability, the adult sibling/s and parents. The involvement of all relevant family members in this discussion is clearly paramount. This includes involving the person with a disability in the discussion in the ways most meaningful to this person in the context of any cognitive or intellectual limitations.

Few families talk about these issues (Heller & Kramer, 2006; Strohm and Waldren, 2010). Even fewer families involve siblings in discussions. Those siblings who are involved in planning tend to be those siblings who are older, female, and are already involved in disability-related activities. Whether or not families had completed plans, siblings were most likely to be involved in identifying future caregivers and in making residential plans. Siblings were less likely to be involved in formal tasks (i.e., establishing a special needs trust, creating a letter of intent, and establishing powers of attorney for their siblings with disabilities)(Heller & Kramer, 2006).

Siblings want to be included in programs designed to help families of people with disabilities. They want more psycho-educational groups, greater use of internet support groups for long distance siblings, and more information on future planning to effectively transition financial, residential, and leisure responsibilities from parents to sibling caregivers (Heller & Caldwell, 2006; Heller & Kramer, 2009; Strohm & Waldren, 2010).

2) Barriers to future planning

There are many barriers to families developing plans for the future including the reluctance of parents to consider their own mortality, negative experiences with service systems and lack of information.

Little research has been done to date looking at the reasons for this reluctance. It has been suggested that parents do not want to burden the adult sibling with worries about the future for their brother or sister living with disability. However, these ageing parents often do not realise that many adult siblings have been worrying about the future for their brother or sister living with disability for just as long as their parents (Heller & Factor 1991).

Most families do not develop clear future plans for their child/brother/sister living with disability. Some reasons for this include;

- Uncertainty about how to go about the process of future planning and a lack of readily accessible information about planning.
- Adult siblings and their parents may have difficulty engaging each other in conversations about the future.
- Adult siblings may have left-over emotional responses from their childhood experiences which make discussions difficult
- Parents may feel reluctant to involve siblings or the person living with disability in discussions
- Uncertainty about how to involve the person living with disability in these discussions.
- Planning for the future raises sensitive issues such as ageing and declining abilities of parents.
- Parents may be reluctant to discuss financial issues, eg wills, with adult siblings
- Uncertainty about what services are available to the person living with disability.
- Some ageing parent carers may have experienced service systems which were not responsive to their needs and may be used to going it alone.
- Some adult siblings may be concerned that parents will expect them to provide more care to the person living with disability than they are able to provide.
- Some ageing parents may feel that they do not want to 'burden' adult siblings with responsibilities.
- Adult siblings may be feeling resentful of the assumption that they will automatically 'take over'.
- Adult siblings who live interstate or overseas may be unsure about how to be involved at a distance.
- For Culturally and Linguistically Diverse families there may be additional barriers such as the feeling that it is not appropriate to have care provided outside of the family home.

PART 5 Recommendations

1) Implications for Policy and Practice

As parents of people living with disability age and are less able to be involved with services, service providers will likely face a changing scenario, where the family member who will be involved will increasingly be one or more adult siblings.

Siblings have expressed the view that providers often do not respect the adult sibling role or their needs. In order to be able to provide the most relevant services for people living with disability, services will need to adapt to the changing face of family members and to understand the different concerns and needs of these family members over a lifetime.

Many ageing carers have come from a generation that 'accepted what they were given' and did not feel comfortable challenging the services provided. Services are likely to find that adult siblings and younger parents are not as easily accepting of services that do not meet their expectations.

It is difficult to access adult siblings – they are not routinely included in databases or organisation records. In addition, adult siblings who have difficult experiences tend not to volunteer to be involved in research. Recruitment into research studies is usually by self-selection, so adult siblings who are no longer involved in the lives of their brother or sister tend not to be part of research samples. In addition, many siblings are reluctant to seek any support for themselves, seeing their own needs as unimportant. Adult siblings often have limited time and they may simultaneously have involvement with ageing parents, a brother or sister living with disability, and with their own family. At the present time, it is mainly sisters who become involved in services or research and it would be wise to consider how to increase the involvement of brothers of people living with disability.

There are very few sibling specific services and no 'best practice' guidelines for providing services to adult siblings. Carer organisations provide some services that may be appropriate for some siblings, especially those who are providing primary care to a brother or sister living with disability. But, generally, adult siblings do not access 'carer' services, nor do they want to be seen as 'carers'.

Siblings will be in each other's lives longer than anyone else. It makes good sense to understand these relationships in order to provide services that are relevant and timely to the whole family. Like most people, people living with disability grow up in families, and it is these families that provide the most support and care over a lifetime. Anything that enhances the quality of these relationships is good for the whole family, but especially, for the person living with disability. As an emerging area of interest and research, it is important that resources are provided for further research and service development in order to strengthen relationships in families which include a member living with disability.

2) Recommendations

Based on existing research and analysis, this submission provides the following recommendations, grouped under the following headings:

1. Policy
2. Family support
3. Research and education
4. Workforce development

Recommendation 1: Policy development

1. Policies around planning options and services for people ageing with disability need to include a 'whole family' approach when considering what is best for the person living with disability.
2. Governments need to recognise the lifelong contribution of siblings and their particular needs.
3. Siblings and their unique perspective should be included when developing policies that will benefit people living with disability and their families.

4. Particular efforts should be made to include siblings in policy considerations regarding the issue of 'ageing carers' and to show respect for their unique perspective.
5. Siblings should be included in government/organisation agendas as a group separate from 'carers'.

Recommendation 2: Family services

1. When developing programs for people living with disability, services need to ensure a 'whole person' approach, eg, health, housing, family and other connections.
2. Ensure family support aims to strengthen all family relationships, including sibling relationships, not just parent-son/daughter relationships.
3. Include siblings in any programs that target parents or ageing carers of a person with a disability.
4. Ensure services respect the unique contribution and perspective that adult siblings bring to the table, through improving sibling consultation.
5. Develop pathways for families to plan for the future, ensuring that teen and adult siblings can be in such discussions.
6. Ensure appropriate resources for the support of siblings across the lifespan and to sustain the involvement of siblings in the lives of their brothers and sisters living with disability.
7. Ensure services are developed that enable siblings to connect with other siblings via face to face or online programs.
8. Support Siblings Australia to continue and expand its development of resources and provision of services around future planning (eg website information, online forums, toll-free information line).

Recommendation 3: Research and education

1. Develop accurate data about the numbers of siblings and the roles they play in the lives of their brothers and sisters with a disability.
2. Promote more research to understand the lifelong concerns and needs of siblings.
3. Research the methodological difficulties in conducting research with adult siblings, eg, recruitment.
4. Explore differences in concerns/support needs between sisters and brothers of people with disability
5. Expand research into the personal support and social networks of people with a disability and their adult siblings.
6. Ensure people living with disability and their siblings have a 'voice' in research and program development eg research into innovative models of accommodation support, or best practice models for 'shared care' arrangements.
7. Explore schemes to encourage budgeting, saving and financial planning as part of early intervention measures for families and carers with young children with disabilities.
8. Support Siblings Australia to be a 'clearinghouse' of research information through its website.

Recommendation 4: Workforce development

1. Develop a national collaborative framework for organisations working with families to share information about the lifelong roles and needs of siblings of people with disabilities.
2. Develop models of effective collaboration between families and service providers, in order to support providers to reach out to the whole family.
3. Develop workforce development around raising understanding of the issues for siblings and how they can be supported to be involved with their brother or sister living with disability.
4. Develop practice guidelines regarding the role of different providers eg disability/health.

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