Siblings
AUSTRALIA INC

Final Report

Connecting Siblings Project

March 2010

NB This Project focussed on Adult Siblings of people living with disability. Most of the findings could be applied equally to Adult Siblings of people living with a chronic illness or mental illness.

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Contents

Executive Summary

Research and anecdotal evidence supports the view that illness and disability affects the lives of all family members. Siblings will be in each other's lives longer than anyone. However, little work has been done to explore these relationships and how they might be strengthened for the mutual benefit of the sibling and the person living with disability.

This is the report of an Adult Sibling Project, exploring the roles and needs of siblings of people living with disability, and their relationships with the person living with disability. It was funded by the Julia Farr MS McLeod Benevolent Fund and carried out during 2008-9. The aim of this project was to improve connections between Adult Siblings of people living with disability and other Adult Siblings as well as to improve connections between Adult Siblings and their brothers or sisters living with disability.

Whilst the Project was very extensive and produced a lot of information and resources, there were a number of challenges. The Project showed that there is a need to do much more work in this area in order to improve understanding of these relationships over a lifetime, and to develop services and resources that are timely and relevant to the whole family. Siblings talked about the roles they play in the life of their brother or sister living with disability, but they also talked about feeling overlooked, both within their family and the community. Both siblings and the person living with disability expressed the importance of these relationships.

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.

Specific recommendations for future directions have been included at the end of this report.

Introduction

Background

The sibling relationship is potentially one of the longest relationships in our lifetimes. Sibling relationships are complex, dynamic relationships influenced by many factors. One of the many factors that may influence this relationship is whether one of the siblings is living with disability. Responses from Adult Siblings worldwide reveal a group of people who care deeply for their brothers and sisters living with disability and, for many, their lives have been enriched by the relationship. However, many also struggle with their own significant emotional difficulties, which have continued since childhood, and with how they can best support their brother or sister. Some feel their life choices are limited and they may not be able to pursue their own life goals etc. Many are thrust into an even greater caring role in later life with few resources to support them in that role. Most express a desire to be involved in the life of their brother or sister, but are often ill-equipped to take on various support roles and may be frustrated and angry about the supports available, both at an emotional and practical level.

Some Adult Siblings take over a direct caring role in adulthood (either full-time care or brief periods of accommodation as respite from institutional care), when parents are no longer able. Other siblings will not provide direct care in terms of accommodation etc but may play an active, varied role as advocate, guardian, organising and transporting to medical appointments, overseeing accommodation, employment and recreation needs etc. And then there is a group of siblings who do

not have much at all to do with their brother or sister with disability. No matter what level of direct care Adult Siblings take on, they can still struggle with emotional issues. Even if siblings are not involved in day to day practical care, hence not identifying themselves as 'carers', they may need support to deal with a myriad of experiences and feelings.

As siblings get older they might be balancing the needs of frail/aged parents, a brother or sister living with disability, and their own partner and teenage children. Such a mix has led this group of siblings (more often females) to be referred to as 'the club sandwich generation'. Once parents are no longer alive, and their own children have left home, the sibling relationship might continue to present caring responsibilities into old age, especially with medical advances aiding in a person with disability living much longer. The sibling relationship might last 70 years, long after parents and other significant people have gone.

Many Adult Siblings identify that they worry about the future of their brother or sister living with disability and the roles they might want, or be expected, to play. A recent survey of Adult Siblings by Siblings Australia showed that siblings can struggle to discuss issues with their parents, especially those related to planning for the future needs of the person living with disability.

Unfortunately resources for people living with disability and their families are limited and programs which aim to strengthen relationships within families are virtually non-existent. In some extreme cases, family relationships break down completely and siblings may not have any contact with their family, a huge loss for them but also for their brother or sister living with disability.

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 (see Strohm, 2008)

The organisation recognises that research and anecdotal evidence supports the view that illness and disability affects 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 experience significant mental health problems such as anxiety, depression, low self-esteem and relationship difficulties if their needs are left unaddressed. 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.

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 the idea 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 reinforced the need for further work to be done in this area in Australia.

Project Brief

Who are Adult Siblings?

For the purpose of this project an Adult Sibling is defined as a person 18 years or older who has a brother or sister living with disability. We chose to neither limit, nor exclude, any type of disability as we felt that the Adult Sibling's perception of whether or not their brother or sister had a disability was of primary importance.

There are no clear records that tell us how many Adult Siblings of people living with disability are resident in South Australia or Australia.

Project Purpose and Aim

The purpose of the project was to improve the connections between Adult Siblings of people living with disability and other Adult Siblings as well as to improve connections between Adult Siblings and their brothers or sisters living with disability.

Why do we need a project for Adult Siblings?

1. Potential effects on well being for Adult Siblings

As mentioned above, there has been considerable research showing that disability affects the whole family. Much of this research has focussed on children but there is research evidence emerging that suggests that there are negative effects on well being for Adult Siblings of people living with disability. Although this research is in its formative stages there is enough evidence to suggest a need for concern. Many individual authors have anecdotally described the difficulties they have experienced as the Adult Sibling of a person living with disability. However, there is a lack of awareness of Adult Sibling issues and there are few services provided for their support. The current 'carer' system does not reach out to siblings in any meaningful way and very few Adult Siblings access this type of support. It is important to understand more about the concerns of Adult Siblings so that appropriate resources and services can be developed.

2. Benefits for people living with disability

Emerging research also suggests that the sibling relationship can contribute to a more positive quality of life for brothers and sisters living with disability. (Smith and Greenberg, 2007)

Adult Siblings have a unique position in the lives of their brothers and sisters living with disability. They 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. 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. Of course, in many situations, the support can be quite reciprocal in nature. If we are able to determine the factors that 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, and then provide these supports, we would be simultaneously impacting the quality of life of people living with disability.

Certainly if there is no consideration of siblings 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.

3. Ageing carers and future planning

In Australia, there is much discussion about 'carers' and, in particular, 'ageing carers'. There is general consensus that there is an emerging crisis in accommodation for people with a disability who live at home with parents who are ageing. Little is being done to develop accommodation options and it is easy to assume that there is some expectation from governments that Adult Siblings will identify themselves as 'carers' and will take over when parents were no longer to provide care. However, Adult Siblings are not being consulted in any of the processes of consultation around this issue. 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. This project aimed to be a starting point in exploring some of the issues and to develop directions in strengthening these family relationships.

Literature review

This literature review will examine some of the emerging themes in the literature about Adult Siblings as well as examining some of the methodological issues which still need to be addressed.

Research into the experiences and needs of Adult Siblings of people living with disability is still in its early stages and has not developed consistent themes and/or methodologies. The majority of the literature published about sibling issues focuses on children.

1. Research involving carers

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) as well as increases in stress and depression (Degeneffe, 2001).These studies have rarely acknowledged the needs of Adult Siblings in families where parents provide care or support for a person living with disability.
One recent study, *The wellbeing of Australians – Carer Health and wellbeing*, has highlighted the effects of caring for a family member living with disability on all members of the family therefore including siblings in the research focus. The study suggests 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 responsibilities or not." (Cummins, Hughes, Tomyn, Gibson, Woerner & Lai,2007; 38). This highlights the fact that the wellbeing of Adult Siblings may be compromised either by their experiences from childhood or their current experiences as a member of a family providing care.

2. Research involving ageing carers and / future planning.

A recent focus in disability literature has been the impact of the ageing population on disability service provision. As the general population ages, along with the ageing of people living with disability, there is a developing recognition of the 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 carers or a combination of both.
For people living with disability who have siblings it is most often those Adult Siblings who become involved in the future life of the person living with disability when parents find they are no longer able to provide the same level of support as both they, and their son or daughter living with

disability, age (Smith and Greenberg 2007; Heller and Caldwell 2006). Parents often have an expectation that Adult Siblings will take over support roles (Degeneffe and Lynch, 2006; Seltzer 1993) and many Adult Siblings themselves expect that they will take on support roles in the future (Heller and 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."

Many families, however, do not develop clear plans for the future care of the person living with disability (Heller and Kramer 2009). Freedman, Krauss & Seltzer (1997) found that less than half of the families in their research project had developed plans for the future. 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 or lack of information. Another barrier can also be the reluctance of some parents to involve either their adult child living with disability or the Adult Siblings in discussions about the future (Heller and Caldwell, 2006). 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 parents (Heller & Factor 1991).

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.

Smith (2004) suggests that family discussion involving Adult Siblings is an important part of the process for future planning for people with severe mental illness but that many families need help to do this. Research has not yet determined the best practice support for encouraging discussions between ageing parents and Adult Siblings.

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 but this, without further psycho-educational or peer supports has not resulted in increases in the number of families actually going on to develop a plan (Preston & Heller, 1996). Heller and Caldwell (2006) suggest that the best practice for encouraging future planning is the use of peer support and the involvement of the person living with disability. Research has not yet examined whether the same approach, involving Adult Siblings would increase the numbers of families involving Adult Siblings in the future planning process.

This situation points to a need for encouraging ageing caregivers to develop plans and include Adult Siblings as well as the person living with disability in these plans. Research is needed into the best ways to encourage all family members in planning for the future, particularly in an Australian context, perhaps using the model proposed by Heller and Caldwell (2006) but also incorporating Adult Siblings into the planning process. Part of this research would need to focus on the reasons for the reluctance of ageing parents to discuss the future with Adult Siblings as well as the development of best practice interventions to facilitate this.

3. **Research examining Quality of Life Issues for the person living with disability**

There is general agreement that a positive sibling relationship can improve the quality of life of the person living with disability. Smith and Greenberg (2007) examined the effect of the sibling relationship on the life satisfaction of adults with schizophrenia and found that adults with schizophrenia who reported close and supportive sibling relationships also reported higher levels of life satisfaction. For people with schizophrenia, who often do not marry and have children, the

sibling relationship may be an important lifetime bond. This is similar to the situation for many people with developmental disabilities.

The research focus here on the benefits for the person living with disability is not intended to imply that Adult Siblings are responsible for the well being of their brothers and sisters living with disability. It is acknowledged that many Adult Siblings experience difficulties themselves with their own quality of life. By acknowledging, however, the contribution that the sibling relationship makes to the Quality of Life for people living with disability, perhaps Adult Siblings will be able to gain recognition for the important roles they play in the lives of their brothers or sisters living with disability.

Smith, Greenberg and Seltzer (2007) also found that Adult Siblings with positive relationships with the person with schizophrenia were more willing to consider future care-giving roles for their brother or sister living with disability. Given this, it would seem appropriate for disability agencies to be investigating the best practice for supporting positive relationships between siblings.

4. Evidence for negative effects on wellbeing for Adult Siblings

There is research evidence emerging that suggests that there are negative effects on well being for some Adult Siblings of people living with disability. (Taylor, Greenberg, Seltzer and Floyd, 2008); Degeneffe and Lynch, 2006; Hodapp, Glidden and Kaiser, 2005; Dew, Llewellyn and Ballandin, 2004). Some of this research is also suggesting a differential effect depending on the type of disability that the brother or sister experiences. For example, Taylor et al (2008) found in their study that Adult Siblings who had a brother with mental illness experienced lower levels of well being when compared with Adult Siblings who had a brother or sister with mild intellectual deficits or Adult Siblings who had a brother or sister without disability. This may be explained in part by the unpredictability of mental illness when compared with mild intellectual disability and also in part by the increased risk for mental health problems for people who have a family member living with mental illness but the relationship of these and other factors is not clear. Also, Hodapp and Urbano (2007) found that Adult Siblings who had a brother or sister with Down Syndrome experienced less negative effects on wellbeing than Adult Siblings who had brothers or sisters with Autism.

Many individual authors have anecdotally described the difficulties they have experienced as the Adult Sibling of a person living with disability. (McHugh, 2003; Strohm, 2002)

There is also research to suggest that Adult Siblings hold a number of concerns about the future for their brother or sister living with disability which, without appropriate support, may impact on the wellbeing of the Adult Siblings. Looking at Adult Siblings of people living with traumatic brain injuries Degeneffe and Olney (2008) found that Adult Siblings were concerned about their brother's or sister's recovery and whether they would regain independence, whether they would become a future caregiver, the quality of and ongoing funding for professional care services and the extent to which their brother or sister were socially isolated and vulnerable.

Although the research into possible negative effects on wellbeing for Adult Siblings is in its formative stages there is still enough evidence to suggest a need for concern and further investigation in this area.

5. Evidence for positive effects on wellbeing for Adult Siblings

Research evidence also exists that suggests that there are either no differential effects or positive effects on well being for some Adult Siblings of people living with disability. For example Taylor et al (2008) found that Adult Siblings who had a brother or sister with an intellectual disability did not differ from a control group of people who had brothers or sisters without disability when looking at

measures of psychological wellbeing, distress or personality. Hodapp and Urbano (2007) found similar results.

Many individual authors have anecdotally described the joys and opportunities they have experienced as the Adult Sibling of a person living with disability. (McHugh, 2003; Strohm, 2002) **So how do we reconcile these studies which seem to be presenting opposing points of view?** Like many other physical and mental health issues the effects of experiencing life as the Adult Sibling of a person living with disability are differentially influenced by a number of mediating and moderating factors such as;

- Characteristics related the person living with disability such as the type and severity of the disability, gender, age,
- Characteristics related to the Adult Sibling such as whether they received appropriate support as a child, individual coping and social skills, educational level, gender, birth order,
- Characteristics of the family such as whether there was one or two parents in the household, access to resources which may depend on socio-economic status, coping skills of parents,
- Methodological issues such as the type of measure used to determine wellbeing, the way in which Adult Siblings are selected to participate in a study or the life stage of the Adult Sibling at the time they participated in the study. Cross sectional studies do not allow us to draw causal links between the presence of disability in the family and the effects on Adult Siblings,
- The impact of the cultural background of the family

Future research is needed to determine which of the factors mentioned above lead to more positive or negative effects on wellbeing for Adult Siblings. Research is also needed to determine appropriate interventions for those Adult Siblings who are experiencing difficulties.

International context

1. Australia

The concerns of Adult Siblings in Australia have been given very little consideration. What has been done has been the result of individual researchers or providers having an interest in the area. There has been no co-ordinated strategy for researching the experiences, needs and/or roles of Adult Siblings or for providing support services. In recent years there has been a lot of research into, and support for, carers' issues, in particular, ageing carers, but there has been little or no consideration of siblings in those processes. Often the word 'family' is used but with no real inclusion of siblings in thinking or practice. For example, the national consultation on the National Disability Strategy led to the report, *Shut Out: The experience of people with disabilities and their families in Australia,* which does not mention siblings in any meaningful way.

Disability Organisations
Many disability organisations provide services for siblings of the person living with disability. Most of these services focus on child siblings but some include young Adult Siblings. Again this is often dependent on individual workers' priorities and interests. At a government level, there is no recognition of the contribution and needs of Adult Siblings. Government services around Australia are targeted at people living with disability and their primary carers.

Carer Support Organisations
As with disability organisations some carer organisations provide programmes which can be accessed by young Adult Siblings who provide considerable primary care to the person living with disability. There are no services for these Adult Siblings to continue involvement once they are deemed too old for these young carer programmes. Older Adult Siblings who are Primary Carers can

access services that other Primary Carers can access. Carer resources produced by these organisations do not reach out to Adult Siblings. Adult Siblings do not feel that the carer support literature is relevant to them as it is very much targeted at parents. Also many siblings do not relate to the term 'carer'; they see themselves as brothers and sisters, not carers, to the person living with disability.

Carer Mediation and Counselling Service

A family mediation and counseling service is available to help families who are considering future care arrangements for a family member with disability. This service is tailored to family circumstances and may be delivered in individual, couple or family settings. Although not a sibling specific service Adult Siblings may access the service as family members of the person living with disability.

The Carer Mediation and Counseling services are administered through different organisations in different states of Australia. In South Australia the service is available through the Uniting Care Wesley Adelaide Inc.

Future Planning and/or Developing Personal Networks for the person living with disability

1. The Carer Support & Respite Centre Inc, in South Australia, has been providing 'Planning in partnership' programs for ageing cares looking at future planning for both the person living with disability and the ageing carers. Although not directly aimed at Adult Siblings, unless they are the primary carer, Adult Siblings would be welcome to attend sessions with their ageing parents. www.carersupport.org.au

2. PlanNET, also in South Australia, offers support with developing and maintaining networks for people living with disability. As has already been mentioned Adult Siblings may hold a unique place in the support networks of their brothers or sisters living with disability. www.plan-netsa.com.au

Siblings Australia

Siblings Australia continues to be the only organisation in Australia which focuses solely on the needs of siblings, both children and adults. Services for Adult Siblings have been limited but have included website resources and services eg an online peer support forum.

2. US/UK

Services for Adult Siblings in the United States and United Kingdom that provide information and support to Adult Siblings tend to be in a more advanced state of development than services available in Australia.

United States

There is no strong 'carer' movement/model of services within the US. Adult sibling services in the US grew out of a number of organisations/services providing information and support to Adult Siblings. Some examples follow:

- *Fox Valley Sibling Support Network* offers a range of supports and services to Adult Siblings. They run conferences and also offer Adult Siblings a series of educational and networking sessions called Future is Now, developed by the University of Illinois at Chicago.

- *Ohio SIBS (Special Initiatives by Brothers and Sisters)* is an organisation that has been interested in education, support, and advocacy issues relating to Adult Siblings of people with disabilities for nearly 20 years. Each year the organisation hosts the Ohio Adult Sibling Conference in Columbus, Ohio. At the Conference adult brothers and sisters of people with disabilities gather together to hear directly from professionals, educators, politicians, and other Adult Siblings.

- *Tennessee Adult Brothers and Sisters* run an annual conference in Nashville, for Adult Siblings, siblings-in-law, and professionals interested in sibling issues. Programs cover

futures planning, caring for the caregiver, research, legislation and advocacy, and family dynamics and relationships.

- *Sibling Support Project,* based in Seattle offers a range of services to Adult Siblings, including an online forum, Sibnet, which has been functioning for nearly 20 years.
- *Sibling Leadership Network* provides information and support to Adult Siblings with a focus on helping Adult Siblings to share experiences, support one another and advocate with and for their brothers and sisters living with developmental disabilities. The Sibling Leadership Network has held two national conferences in 2007 & 2008, developed a policy White Paper about sibling issues and published research articles in peer-reviewed journals (Heller, T., Kaiser, A., Meyer, D., Fish, T., Kramer, J., Dufresne, D. ,2008).

United Kingdom

The United Kingdom also operates under a 'carer' model, similar to Australia. However the support of young siblings is very much seen as an important process in itself. Siblings, in fact, are mentioned in the legislation relating to children with a disability, and their support is laid out in policy.
The main independent organisation that supports siblings (adults and children) is SIBS - **http://www.sibs.org.uk/.** SIBS has organised several national conferences for Adult Siblings to come together and share information and experiences, and to gain support, both emotional and practical.

Project Activities

1. Initial Consultation Process

Methodology

1. Contact was made with over 35 organisation/services across the Disability, Carer Support and Mental Health sectors in South Australia in order to determine which organisations provided direct or indirect support to Adult Siblings.
2. An email distribution list was developed based on these initial contacts as well as Adult Siblings and family members who were already in contact with Siblings Australia.
3. Three surveys were developed to gather information from Adult Siblings, parents and service providers and distributed through this initial email network.
4. An Initial Forum was held on 1 May 2008 with relevant stakeholders.

Results

1. Most organisations/services indicated that if the Adult Sibling were a primary carer for their brother or sister living with disability they would be able to access any support available from that organisation/service that was available to primary carers.
2. The initial distribution list of 155 members grew to 230 members by the end of the project.
3. SURVEY SUMMARY (See Appendix 1)
    a. Surveys were received from 17 Adult Siblings, 3 parents and 3 service providers.
    b. Most Adult Siblings (82%) were in regular contact with their brother or sister living with disability.
    c. Adult Siblings provided a range of practical and emotional supports to their brother or sister living with disability.
    d. Adult Siblings expressed a range of feelings about the quality of their relationship with their brother or sister living with disability ranging from descriptions of a positive relationship "close and loving", descriptions of quite negative relationships "hanging by a thread" and descriptions of relationships which had both negative and

positive qualities "strained as he can't communicate any more, however I have a strong relationship with him..."

    e. Adult Siblings expressed a need for

        i. Practical Information – 65% (planning for the future, information about the disability, information about services for the person living with disability as well as carer services, legal issues, advocacy, etc)

        ii. Contact with other Adult Siblings – 41% ("May make me feel less alone and not so guilty about how i feel toward my sib...")

        iii. Acknowledgement of the Sibling Role - 18% ("respect for being a sib by disability services...", being involved in decision making by parents and service providers, understanding of potential negative impact on Adult Siblings' well being)

        iv. Development of self-acceptance, self confidence and self esteem - ("Lack of confidence and self worth, I feel my value is not in being myself but in what I can do for others")

4. INITIAL FORUM

    a. An initial forum was attended by 8 people (Adult Siblings – 2, Parent – 1, Service providers – 5)

    b. A number of issues were brainstormed within the group including;

        i. Why are Adult Siblings overlooked?

        ii. What issues are Adult Siblings facing?

        iii. How do we get Adult Siblings "on the agenda"?

        iv. What services are available to Adult Siblings?

        v. Where are there gaps in services to Adult Siblings?

        vi. Where to from here?

    c. See Appendix 2 for a summary of the issues discussed

Information gathered from these initial Adult Sibling Surveys and the Initial Forum held with stakeholders informed the development of the project plan and time frame.

2. Continued consultation and promotion of the project

The project was temporarily without a Project Officer from June 2008 until August 2008.

Consultation and project activities resumed when the new Project Officer was employed on 31 August 2008. A brochure was developed to publicise the project and upcoming focus groups. 500+ brochures were distributed via disability organisations, advocacy organisations, carer organisations, the Disability Expo 2008 and the d'Arpa AGM. A newsletter piece was developed and included in the Minda Communique, the Orana newsletter and Disability SA's internal newsletter. A presentation about the project was made to Disability Alliance in October 2008, the Disability Advocacy Network of Australia in November 2008 and 'Our Voice' in January 2009. Email updates were sent to the email distribution list throughout the project time frame.

3. Focus groups
a. <u>Planning</u>

Planning for the Adult Sibling Focus Groups began in September 2008. Brochures for the 'Connecting Siblings' Project, Flyers for the Adult Sibling Focus Groups and a newsletter piece were developed

and distributed through the project's email distribution list as well as to specific disability organisations. Information was also available on the Siblings Australia website. The intent in running the Focus Groups was to provide a forum for participants to express their concerns and needs as Adult Siblings of people living with disability. Our belief was that an informal small group format would provide a safe environment for Adult Siblings to speak about their experiences knowing they were with others who were in similar situations. A plan was developed for running the Adult Sibling Focus Groups which asked siblings to contribute answers to four specific questions about their concerns and needs. See below.

Five sessions were planned to take place during November and December 2009. Dates, location and number of attendees are outlined in the table below.

DATE	LOCATION	RSVPs RECEIVED	ATTENDEES
12 November 2008 7-9pm	Minda Inc, King George Ave,Hove, SA, 5048	2	2
18 November 2008 7-9pm	Balyana Conference Centre, Strathcona Avenue,Clapham, SA, 5062	4	1
24 November 2008 7-9pm	Community Lifestyles Inc, 6 Third Street,Murray Bridge, SA, 5253	0	0
4 December 2008 12-2pm	Uniting Care Wesley, Perry Room, 10 Pitt Street,Adelaide, SA, 5000	3	1
9 December 2008 7-9pm	Café, The Parade,Norwood, SA, 5067	4	4

In total only seven adult siblings attended the Focus Groups (one sibling attended two groups). Although numbers were low, those adult siblings who attended shared their thoughts on their own experiences as well as their concerns and needs as Adult Siblings of people living with disability.

b. Areas of discussion

The focus groups were run in an informal manner with the facilitators using four specific questions to structure the time. Facilitators shared the responsibility for posing the questions and noting participants' answers. The four specific questions were;

Question 1: *What support have you accessed for yourself as a sibling?*
Question 2: *What support would have helped?*
Question 3: *As a sibling of a person living with disability, what do you need now?*
Question 4: *What are the barriers to maintaining contact with your brother/sister with disability?*

c. Responses

Question 1: What support have you accessed for yourself as the sibling of a person living with disability?

- Attendance at Family Network Groups / Parents and Friends Associations run by disability service providers
- Support through the Brain Injury Network of SA
- Support from a church minister
- Accessing the Carer's allowance (when primary carer role taken on)
- Reading Kate Strohm's book *Siblings – brothers and sisters of children with special needs*
- Siblings Australia – informal ongoing network of siblings developed through an initial meeting organised by Siblings Australia
- Counselling through Carers SA

Adult Siblings who attended the Focus groups had accessed no support while growing up.

Question 2: What support would have helped?

As a child	As both a child and an adult
- Respect as the sibling - Emotional support when feeling embarrassment over their brother's/sister's unusual behaviour - Education for parents of issues for siblings - Interaction with other siblings at school age	- Knowing other siblings' experiences - Connecting with siblings to share a commonality - Open discussion of issues within the family and also within society generally

Question 3: As a sibling of a person living with disability, what do you need now?
Concerns
- Worries about deinstitutionalization, lack of consultation with family members& lack of services once the person living with disability moves out of the institution
- High staff turnover in accommodation services – difficult to develop a trusting relationship with staff for both sibling and their brother/sister living with disability
- How to maintain good communication with staff in accommodation services
- How to relate to staff when you have negative feelings about the staff or the service

Needs
Individualised funding
- Individualized funding for services that meet the needs of their brother/sister living with disability
- Information about how the individualized finding process works
- Information about what services are available for brother/sister living with disability

Sibling role
- Sibling role to be acknowledged & siblings to be included in planning and decision making
- Raised awareness of sibling role
- Acknowledgement of siblings as a resource to staff as holders of information about their brother/sister living with disability
- Acknowledgement that siblings are still siblings when they are adults
- Recognition of the role of the wider family

Future Planning
- Information about how to plan for the future (future planning) for their brother/sister living with disability including guardianship, legal & financial issues, advocacy and wills.
- A checklist for future planning
- Help with how to talk to parents about future planning for their brother/sister with disability

Sibling Networking
- Social networking opportunities for siblings to keep in touch
- Care for the brother/sister living with disability so that the siblings who are primary carers can meet
- Social networking opportunities for siblings and their brothers and sisters living with disability together
- Organisations to keep data about siblings to enable networking and communication
- Ideas for recreational activities to do with their brother/sister living with disability
- Siblings as mentors for other siblings

Training
- Well trained staff to work with their brother/sister living with disability

- Training for staff in family/sibling issues

Information
- Written information such as 'Fact Sheets available for siblings

Question 4: What are the barriers to you maintaining contact with your brother/sister living with disability?

Lack of acknowledgement of sibling role
- Lack of respect, lack of recognition of importance of sibling in life of person with disability
- Siblings feeling unfairly treated by service systems
- Siblings not fitting into, or being acknowledged by, the service system
- Staff not understanding or acknowledging the sibling role
- Suspicion from service providers about why the sibling wants to be involved
- Lack of encouragement to maintain the relationship from service providers
- Feeling angry with staff
- Parents not understanding or acknowledging the sibling role

Terminology
- Dislike of the term 'relinquished care' if the brother/sister living with disability has moved into an accommodation service
- Dislike of the term 'carer'

Financial issues
- Financial costs as primary carer
- Expense of providing food, costs of recreational activity for the brother/sister living with disability if the person's Disability Support Pension goes to an accommodation service

Time
- Lack of time, particularly if the sibling has a family of their own

Transport
- Issues with transport if their brother/sister living with disability has a physical impairment

Organisational policies
- Organisations expecting siblings to comply with organisational policies, eg 'No Lift' policy.
- Inflexibility in organisations re OH&S and insurance issues

Limited family support
- Assumption by services that if there is more than one sibling then all the siblings are equally involved when there might only be one sibling still involved
- Other siblings in the family not wanting to be involved

The issues discussed by the Adult Siblings of people living with disability at the Focus Groups are consistent with issues raised in the scientific literature about sibling issues.

d. <u>Evaluation</u>

Although only a small number of Adult Siblings attended the Focus groups the Adult Siblings who attended shared with us information about their lived experiences as siblings of people living with disability, the supports they have accessed and would like to have accessed, the supports they would like in the future and barriers to maintaining connections with their brother or sister living with disability. The information that was shared was invaluable for shaping the project.
A number of factors may have contributed to low attendance rates at the Focus Groups:
1. It is difficult to directly target Adult Siblings for information distribution as disability organisations do not systematically keep records of siblings of people with disability.

2. Information distributed about the Focus Groups may not have gone to Adult Siblings. It is likely that the information often went to parents and it is not known whether the information was passed on to Adult Siblings.
3. Adult Siblings may not have identified themselves as being part of a group which either needs or warrants support.
4. Some Adult Siblings may not feel comfortable about coming to a group setting.
5. Adult Siblings often have multiple commitments to their own families and children, ageing parents, work and leisure activities.

4. Information sessions

Session 1: Legal Issues for Adult Siblings
Based on feedback from Adult Siblings involved in the initial surveys and also the Focus Groups the decision was made to present a session focussed on legal issues that might be of interest to Adult Siblings. Contact was made with Ian Bidmeade AM who is a South Australian lawyer with particular interest in mental health & disability issues. Ian developed an information session which he presented on the evening of 26 March 2009 at the Disability Information and Resource Centre in Adelaide and attended by participants, mostly Adult Siblings but included Sibling-in laws also. The information session covered areas such as roles of Adult Siblings, important agencies, wills, trusts and special disability trusts.

Information Session Evaluation
Participants were asked to evaluate the Information Session on 'Legal Issues for Siblings'. Overall participants were very satisfied with the session. Participants reported that they found information about wills, guardianship, trusts and definitions of legal terms useful.

Future Information Needs
Participants were asked to fill in a questionnaire telling us what they would like to hear more information about in the future. The most requested topics for further information were;
a. Future planning for my brother/sister living with disability
b. Legal Issues
c. How to advocate for my brother/sister living with disability

Participants were asked how they would like to receive information about these topics. The most popular methods for receiving information were;
a. On-line information/support
b. Group information sessions
c. Networking with a group of siblings
d. Books, brochures, fact sheets

More details about participants' perceptions about their future information needs can be found in Appendix 3.

Session 2: Future Planning
Based on feedback from, and the interest in, the first information session a second information session addressing Future Planning was planned to be held on 25 June 2009. This session was developed to cover areas such as what is involved in future planning , how Adult Siblings can be involved in future planning and how to talk with parents about future planning.
Unfortunately the session was cancelled due to a lack of interest. Possible reasons for lack of interest include;

1. The Future Planning session information was advertised less widely than the information session on "Legal Issues for Adult Siblings" as we believed that we had developed a large enough network throughout the project for the information to be disseminated widely.
2. The first information session was held with a professional speaker external to Siblings Australia whereas the Future Planning information session was advertised as a more informal session with staff from Siblings Australia presenting an overview of Future Planning with a view to developing further sessions with relevant professionals. Potential participants may have been more attracted to the idea of speakers they perceive to have specific knowledge of a topic. Adult Siblings, with limited time available due to commitments in their own lives may need to weigh up the perceived value of an information session in busy lives.
3. Some Adult Siblings may have been reluctant to attend the topic of Future Planning as the topic implies the need for actions that Adult Siblings and/or families may not be ready to undertake.

5. Fact sheets

Initial research into the development of the Fact Sheets began in November 2008 with a review of information available to Adult Siblings in both hard copy and on-line. We did not find any Australian Fact Sheets which were written with an Adult Sibling audience in mind.

With the view to developing a Fact Sheet about Future Planning issues a meeting was held in May 2009 with representatives from 'Parent to Parent' to discuss their experiences of assisting families with future planning for people living with disability. 'Parent to Parent' is a Queensland organisation that provides support and information to parents, caregivers and families who have a member with a disability or health impairment in order to assist with the development of a futures plan.

The Project Reference Group provided invaluable feedback on the Fact Sheets throughout the development stages. Feedback was also gathered from attendees at the Carer Support and Respite Centre's Carer Wellbeing Fiesta in June 2009 where Siblings Australia hosted a display.

A brief description of the fact Sheets developed during the course of the project is outlined below.

1. **Sibling Roles:** Looks at the types of roles and different levels of support that an Adult Sibling may undertake in the life of their brother or sister living with disability. This Fact Sheet highlights the right of Adult Siblings to access support for themselves in carrying out these roles as well as the need for Adult Siblings to have a choice about their involvement in the life of their brother or sister living with disability.
2. **Advocacy:** Provides information about advocacy for/with people living with disability that Adult Siblings might want to know about. This Fact Sheet highlights the right of Adult Siblings to access appropriate advocacy services for themselves and/or their brother or sister living with disability as well as the need for both the Adult Sibling and their brother or sister living with disability to have choices about their involvement in advocacy roles.
3. **Emotions:** Looks at the emotional experiences for Adult Siblings of people living with disability. This Fact Sheet highlights the right of Adult Siblings to receive the emotional support that they need for themselves. This Fact Sheet highlights the need for Adult Siblings to have a choice about the extent to which they share or seek support for their emotional experiences.
4. **Future Planning:** Provides information about Future Planning issues that might be of interest to Adult Siblings of people living with disability. This Fact Sheet highlights the right of Adult

Siblings to be involved in Future Planning for/with their brother or sister living with disability so long as this is the choice of the person living with disability.

5. **Families Talking:** Provides a starting point for families to come together and talk about issues related to having a family member living with disability. This Fact Sheet highlights the right of Adult Siblings to have their concerns discussed in a respectful manner.

6. **Information for Providers:** Discusses information that service providers need to be aware of when in contact with Adult Siblings of people living with disability. This Fact Sheet highlights the right of Adult Siblings to be acknowledged and valued by service providers and recognises that a strong relationship with a sibling can add to the quality of life of the person living with disability.

7. **Useful Contacts and Resources:** Provides information about agencies which provide a range of services that may assist Adult Siblings of people living with disability. This fact Sheet highlights the right of Adult Siblings to access information and support for both themselves and their brother or sister living with disability.

It is envisaged that the Fact Sheets will collectively form part of an Information Pack that can be distributed to Adult Siblings, other family members, people living with disability, service providers and government. The Fact Sheets will also be downloadable from the Siblings Australia website.

6. Consulting people living with disability

People living with disability are often overlooked as active participants in research projects. Given the intimate and reciprocal nature of the sibling relationship we felt that it was imperative to gain some insight into the views of people living with disability about their views of their relationships with their siblings. As one half of the sibling dyad the brother or sister living with disability has their own unique and valuable experience which adds another layer of information that can be used to develop strategies for supporting sibling relationships. Our aim was to give people living with disability, as well as their siblings, a voice in this project.

Information Sheets about the project were developed for people living with disability including an Easy English version, as well as an Information Sheet for parents/carers/guardians. Consent forms were also developed for people living with disability and for parents/carers/guardians where necessary.

Presentations were made to "Family & Friends" groups within a local disability organisation in March and June 2009 in order to further raise awareness of the project as well as explaining the aim of consulting with people living with disability. Approaches to disability organisations requesting information began in June 2009. Minimal interest was received from disability organisations in assisting with recruiting people living with disability for consultation.

Six people living with disability were consulted in 1:1 interviews with the Project Officer. These participants all had mild to moderate intellectual disabilities. Each had a unique view of their sibling relationship. Issues that arose included;

- **Dislike of their Adult Siblings telling them what to do:** This poses a dilemma for Adult Siblings who believe that their brother or sister requires assistance with daily living activities such as maintaining personal hygiene, saving money, keeping the house tidy and health issues such as diet or smoking. Is their role as an Adult Sibling to be a mentor/parent figure or just to be a peer/sibling?

- **Siblings as holders of shared memories:** When parents have passed away siblings are the only people who hold the same childhood memories as the person living with disability. For a person with an intellectual disability who may not be able to articulate their past memories with staff who do not have knowledge of the person's childhood circumstances, it is siblings who provide this opportunity for reminiscence.

- **Feelings of not being in control of the sibling relationship:** Many of the participants indicated that they would like to see their siblings more often, particularly favourite siblings,

but did not know how they could make this happen. They seemed to take a more passive role in the relationship waiting on their sibling to organise times to get together.

- **Importance of extended family:** Many participants talked enthusiastically of the siblings' spouses and children and seemed to take pride in their relationships with their nieces and nephews. None of the participants were in long term relationships so this extended family may take on extra importance.
- **Adult Sibling Roles:** Participants discussed their siblings being important family members for whom they felt affection even if there were conflicts. Activities with siblings included: shopping for groceries, clothes and household appliances; help with budgeting and paying bills; meals out together; family get-togethers often with a focus on nieces and nephews; working together on the family farm; talking about parents who had passed away; talking about childhood memories and looking at family photos; sharing a house.

7. Website development

The grant from the Julia Farr MS McLeod Benevolent Fund allowed us to further develop our website. It is much easier for us to manage independently and it has been an advantage to be able to monitor use and downloads. The new forums have allowed us to provide a very real peer support initiative.

1. Forums

The two relevant forums for this project were Sibchat and Teensibchat. Sibchat now has 100 members and there have been 290 posts on 51 topics. Teensibchat has 60 members with 640 posts on 49 topics. Sibchat, in particular, has had a number of threads dealing with concerns about the future, relationships with their brothers and sisters and maximising the potential of their brother or sister who is living with disability.

2. Social Networking

The website development has also allowed us to develop such activities as social networking sites eg Facebook. We now have about 170 members of our Facebook 'page' and can continue to update members on Siblings Australia activities. This also allows us to keep in touch with adult siblings and developments overseas.

The website has enormous potential to be developed further if funding can be found.

8. On-line Questionnaire

Development of an on-line survey to examine the needs and experiences of Adult Siblings began in August 2009. The survey was based on the paper based survey used in the initial stages of the project. Based on feedback from the initial survey as well as research into questionnaire development the survey was adjusted in order to avoid questions which could have been perceived as leading. The aim was to develop a more objective, robust tool for gathering information in areas which were often highly emotive for survey participants.

There are both benefits and drawbacks to using an on-line self-administered questionnaire. For example the use of technology precludes some respondents who may not have access to computers, lack computer literacy etc) and respondents who self-select may be more likely to be those who have had more positive experiences. Although the particular methodology requires careful interpretation, for this project it was a methodology that allowed us to gather the views of a large number of Adult Siblings without expecting them to attend a group or individual interview.

A preliminary analysis of the on-line survey data was undertaken prior to the Siblings Australia Conference in November 2009 and the information formed part of the presentation made at that conference. A more in depth analysis will hopefully be made in 2010.

Information from the preliminary survey analysis

1. Participants ranged in age from 17-73 years, most respondents were female and the vast majority identified being from an Australian cultural background.

2. Most participants (88%) were in contact with their brother or sister living with disability. The most common type of contact was by telephone or face to face.

3. Most Adult Siblings were satisfied with their relationship with their brother or sister living with disability (43.2%). 6.8% were very unsatisfied, 14.8% were unsatisfied, 14.8% were neutral and 20.5% were very satisfied. **From a survey group who were perhaps more likely to have had positive experiences approximately 20% were unhappy with the relationship with their brother or sister living with disability.**

4. 64.8% of respondents indicated that they provided care or support for their brother or sister living with disability. The most common types of support provided were practical support, emotional support, respite (for brothers and sisters living with parents), advocacy, transport.

5. Adult Siblings described a range of experiences with both benefits and challenges related to their sibling experiences. For example benefits included "I am extremely patient with people and non- judgemental" and "Empathy and appreciation for health and life". Challenges included a range of childhood stresses as well as ongoing concerns and, in some cases, significant mental health issues. Responses included, "I worry about the future e.g. living arrangements" and "Sometimes it can be very time consuming and just tiring. Sometimes I feel isolated because I struggle to find time to see my friends."

6. Adult Siblings described how their experiences changed over their lifetimes suggesting a need for a lifespan perspective when working with Adult Siblings. One Adult Sibling wrote "We were close as young children (I admired my big sister) and now as we enter middle age we have developed a more comfortable relationship again. During the middle years there was a 'frosty' tone to our relationship – a lot of repressed anger on both our parts".

7. Adult Siblings were asked whether they saw themselves as a "carer" or a "sibling". The vast majority (92%) saw themselves as 'siblings' rather than carers.

8. Only 20% of respondents had ever accessed support through 'carer' services but 55% thought that they would access support in the future, perhaps indicating that a large number of Adult Siblings anticipated taking on a carer role in the future.

9. The majority of Adult Siblings said that they would prefer to access support through services designed specifically for siblings rather than through carer services.

Interpretation of the results from this survey is limited as we do not have normative data with which to compare our results. Nevertheless the results indicate a group who contribute to the lives of their brothers and sisters living with disability and who, at times, are in need of support. Survey details can be accessed through Siblings Australia.

9. Conference

Siblings Australia held their second Australian Conference "Creating Connections" on 19 & 20 November 2009 which coincided with the final stages of the Adult Sibling Project. The Project Officer presented at the conference on the topic, *The Silent Army: Learnings from the Adult Sibling Project.*

One of the streams of the "Creating Connections" conference included on Adult Siblings only. Sessions programmed in the this stream were facilitated by the Director of Siblings Australia, Kate Strohm, and the Project Officer for the Adult Sibling Project, Vicky Waldren. These sessions were informed by the findings of the project at the time of the conference and information from the conference further informed the final project findings. These sessions allowed for much informal input. A number of themes emerged throughout the Adult Sibling sessions;

1. Recognition of the Adult Sibling Role

Many Adult Siblings discussed attending the conference in order to gain a feeling of recognition, acknowledgement or validation of their experiences as an Adult Sibling. Adult Siblings also discussed their experiences of a lack of awareness by many service providers about Adult Sibling issues.

2. Need for Information

Many Adult Siblings discussed the difficulties that they have experienced in finding and accessing services for both themselves and for their brother or sister living with disability.

3. Connections

Many Adult Siblings discussed the importance of meeting with other Adult Siblings to share their own experiences and listen to the experiences of others.

4. The Future

Collectively, Adult Siblings were all experiencing concerns about the future, both for themselves and for their brother or sister living with disability. Some common concerns expressed were;

   a. Planning for the Future: Adult Siblings discussed the difficulties they experience in knowing how to plan for the future for their brother or sister living with disability including where and how to find information about legal issues or about services that their brother or sister can access. Adult Siblings also discussed concerns about how they would maintain contact with their brother or sister living with disability in the future, how they would encourage other family members to consider planning for the future as well as how and where to keep information about the person living with disability.

   b. Lack of appropriate quality services for the person living with disability in a system that seems crisis driven rather than proactive.

   c. Promoting independence for the person living with disability: Adult Siblings were keen to know appropriate strategies for helping their brother or sister living with disability to achieve maximum independence. Adult Siblings also discussed sometimes experiencing conflict with parents over what levels of independence might be achievable for the person living with disability with Adult Siblings considering a higher level of independence achievable.

   d. Respite/time out for Adult Siblings for Adult Siblings who cohabit with their brother or sister living with disability whether as primary carer or not.

   e. Support services for Adult Siblings: The facilitators of the Adult sibling Sessions found they often needed to remind Adult Siblings to consider what they needed for themselves rather than what their brother or sister living with disability needed. Adult Siblings seemed to automatically focus on the needs of their brother or sister first. When encouraged to focus on their own needs Adult Siblings expressed a desire to be able to access counselling services designed specifically for Adult Siblings with counsellors who 'get it'. The ideal was described as a "one stop shop" where Adult Siblings could access counselling if needed as well as information about services for themselves, their brother or sister living with disability and/or parents.

   f. Terminology – Sibling or Carer: Many Adult Siblings expressed concern at being labelled carers when they really wanted to maintain the identity of the Sibling relationship.

Discussion

The aim of this Adult Sibling Project was to understand more about the relationships between siblings when one or more of the siblings are living with a disability. Through greater understanding it was envisaged we could contribute to greater wellbeing for Adult Siblings, strengthen their relationships with their brothers or sisters living with a disability and also develop networks between Adult Siblings for ongoing support.

The Project highlighted a number of themes which confirmed much of our previous thinking that Adult Siblings are a largely unrecognized group who collectively contribute enormously to the lives of their brothers and sisters living with disability and who are, at various times in their lives, in need of support.

Varied lived experiences
- The Adult Siblings' stories contributed through the Focus groups and surveys showed a vast range of lived sibling experiences ranging from those where Adult Siblings felt their lives had been enriched by their experiences of having a brother or sister living with disability to those where Adult Siblings struggled with ongoing issues which they attributed to their sibling experiences.

Awareness and acknowledgement of Adult Siblings
- There is a general lack of awareness in the community and within disability services about the roles that Adult Siblings play in supporting their brother or sister living with a disability (both emotionally and practically) across the lifespan and the contribution this makes to their brother or sister, their family and the community (in the case of the community, this contributes much in $ savings). One Adult Sibling used the term, the 'Silent Army'.
- There is a general lack of awareness about the lifelong concerns of Adult Siblings and their support needs; hence siblings can feel quite overlooked and isolated.
- Adult Siblings do not feel respected or acknowledged by disability services
- There is a lack of awareness of family issues as parents age and are no longer able to provide care for the person living with disability
- There is a lack of awareness of the importance of involving Adult Siblings in future planning processes for or with the person living with disability

Services for Adult Siblings
- There are no 'best practice' guidelines for involving Adult Siblings in research projects or for providing services to Adult Siblings
- There are no best practice guidelines to guide disability organisations in developing and maintaining sibling relationships
- There are very few Adult Sibling specific services
- 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
- Generally, Adult Siblings do not access 'carer' services
- Adult Siblings do not see themselves as 'carers', nor do their brothers and sisters living with disability want their siblings to be known as their 'carers', they are **brothers and sisters**, regardless of whether the Adult Sibling is providing direct care or not

- Planning for the future is a difficult topic for families to discuss (it can bring up a range of emotional issues for all family members) – some parents do not wish to include Adult Siblings at all, while others expect that Adult Siblings will just 'take over' when necessary

The Project faced a number of challenges including:
- In the early stages, finding consistent project staff
- Difficulty in accessing Adult Siblings – they are not routinely included in databases or organisation records. Also, 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 are not part of research samples. Adult Siblings are often time poor and they may simultaneously have involvement with ageing parents, a brother or sister living with disability, and with their own family. Adult Siblings also seem unaccustomed to focussing on their own needs rather than the needs of their brother or sister living with disability. In many ways Adult Siblings do not view themselves collectively as a group in the way that carers do.
- Difficulty in accessing people living with a disability. Discussions at the Focus groups suggested that issues may be most complicated for Adult Siblings who have a brother or sister with a cognitive impairment so we focussed on this client group when consulting with people living with disability. This particular group of people living with disability often are not able to come to a central location to meet due to transport issues, often need individual rather than group consultation and need careful consideration regarding consent for project involvement. This combination of factors resulted in consultation with only a small number of people living with disability. There is a need to do more work in this area, in order to understand the dynamics of sibling relationships and how they can best be supported.

Overcoming challenges
As time went on we were able to raise the level of awareness of both the Project and Adult Sibling issues, and by the time we developed our second survey (which was on-line and much more robust than the first survey) we were able to access many more siblings (97 Adult Siblings responded). However, in the overall picture, this is still a very small number of siblings.

Outcomes
As well as contributing to understanding about sibling relationships when one is living with disability, other outcomes included:
- Written and online resources for Adult Siblings
- Information sessions on issues affecting Adult Siblings
- More networking opportunities for Adult Siblings

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, 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.

Recommendations

Based on the information collected, some recommendations have been developed by the project team. These recommendations have been grouped under the following headings:

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

Recommendation 1: Policy development

1. Wherever relevant, government policy recognise the important contribution and needs of Adult Siblings of people living with disability
2. Governments recognise the lifelong nature of the caring relationship between siblings when one has a disability, and the particular needs of Adult Siblings over a lifetime
3. One government department be identified to take responsibility for the needs of this group
4. Siblings and their unique perspective are included when developing policies that will benefit people living with disability and their families
5. Particular efforts be made to include siblings in policy considerations regarding the issue of 'ageing carers'
6. Siblings be included in government and organisation agendas as a separate group from 'carers'

Recommendation 2: Family support

1. When developing programs/services for people living with disability ensure a 'whole person' approach taking into account their family connections
2. Family support should enhance the life of ALL family members, and strengthen all family relationships
3. Include siblings in any programs that target parents or ageing carers of a person with a disability
4. Develop pathways for families to plan for the future, including teen and Adult Siblings in such discussions

Recommendation 3: Adult sibling support

1. 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
2. Ensure services are developed that enable siblings to connect with other siblings via face to face or online programs
3. Support Siblings Australia to continue its development of resources and provision of services (eg website information, online forums etc)
4. Develop pathways for siblings to access services as brothers and sisters, not necessarily as 'carers'.

Recommendation 4: 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 concerns and needs of siblings
3. Research the methodological difficulties in conducting research with Adult Siblings eg identification, recruitment
4. Expand research into the personal support networks of people with a disability with a focus on the roles of Adult Siblings

5. Explore how these networks might support Adult Siblings as well as their brothers and sisters living with disability
6. Ensure both people living with disability and their siblings have a 'voice' in research and program development
7. Support Siblings Australia to be a 'clearinghouse' of research information through its website

Recommendation 5: Workforce development
1. Develop a national collaborative framework for organisations working with families to share information about the roles and needs of siblings
2. Develop models of effective collaboration between families and providers, in order to support providers to reach out to the whole family
3. Develop practice guidelines regarding the role of different providers eg disability/health workers, GP's
4. Develop training materials that could be more widely used by the relevant sectors – disability, health, education and community services. The Siblings Australia website provides an ideal opportunity to expand this training.

References

Cummins, R.A., Hughes, J., Tomyn, A., Gibson, A., Woerner, J. And Lai, L. (2007) "The Wellbeing of Australians – Carer Health and Wellbeing", Australian Centre on Quality of Life

Degeneffe, C. E. (2001) "Family caregiving and traumatic brain injury", *Health and Social Work, 26:4,* 257-268

Degeneffe, C.E. and Lynch, R.T.(2006) "Correlates of depression in Adult Siblings of persons with traumatic brain injury", *Rehabilitation Counselling Bulletin, 49:3,* 130-142

Degeneffe, C.E. and Olney, M. F. (2008) "Future concerns of Adult Siblings of persons with traumatic brain injury", *Rehabilitation Counselling Bulletin,51:4,* 240-250

Dew, Angela, Llewellyn, Gwynnyth and Balandin, Susan(2004) "Post-parental care: a new generation of sibling-carers", *Journal of Intellectual & Developmental Disability, 29:2*, 176-179

Freedman, R. I., Krauss, M. W., & Seltzer, M. M. (1997). Aging parents residential plans for adult children with mental retardation. *Mental Retardation*, *35*, 114-123.

Heller, T. & Caldwell, J. (2006). "Supporting aging caregivers and adults with developmental disabilities in future planning", *Mental Retardation, 44(3)*, 189-202.

Heller, T. and Factor, A. (1991). "Permanency planning for adults with mental retardation living with family caregivers", *American Journal on Mental Retardation, 96*, 163-176.

Heller, T., Kaiser, A., Meyer, D., Fish, T., Kramer, J., Dufresne, D. (2008) "The Sibling Leadership Network: Recommendations for Research, Advocacy, and Supports Relating to Siblings of People with Developmental Disabilities".

Heller, T., & Kramer, J. (2006). "Involvement of Siblings of Adults with Developmental Disabilities in Future Planning". *Research Brief*. Chicago: Rehabilitation Research and Training Center on Aging with Developmental Disabilities.

Heller. T. & Kramer, J. (2009) "Involvement of Adult Siblings of persons with developmental disabilities in future planning", *Intellect Dev Disabil., 47:3*, 208-219

Hodapp, R., Glidden, L.M. and Kaiser, A.P.(2005) "Siblings of persons with disabilities: Toward a research agenda", *Mental Retardation, 43:5,* 334-338

Hodapp , R. & Urbano, R. (2007) "Adult Siblings of individuals with Down syndrome versus with autism: findings from a large-scale US survey" Journal *of Intellectual Disability Research, 51:12*, 1018-1029

House Standing Committee on Family, Housing, Community and Youth (2009) "Who Cares...? Report on the inquiry into better support for carers", Canberra

Llewellyn, Gwynnyth, Gething, Lindsay, Kendig, Hal and Cant, Rosemary (2003) "Invisible Carers: Facing an Uncertain Future", A report of a study conducted with funding from the National Health and Medical Research Council 2000-2002 Faculty of Health Sciences, University of Sydney

McHugh, M. (2003) Special Siblings: Growing up with someone with a disability, Brookes Publishing Company Incorporated

The National People with Disabilities and Carer Council (2009) "Shut Out: The experience of people with disabilities and their families in Australia"

Preston , L., & Heller, T. (1996, October). *Working partnerships to individualize future planning for older families from diverse groups.* Paper presented at the Sixth Lexington Conference on Aging and Developmental Disabilities, Lexington , TN. Cited in Heller, T. & Caldwell, J. (2006). "Supporting aging caregivers and adults with developmental disabilities in future planning", Mental Retardation, 44(3), 189-202.

Smith, G. C., (2004) "Predictors of the stage of residential planning among aging families of adults with severe mental illness", *Psychiatric Services, 55,* 804-810

Smith MJ, Greenberg JS, Seltzer MM. (2007) "Siblings of adults with schizophrenia: Expectations about future caregiving roles", *American Journal of Orthopsychiatry, 77*, 29-37.

Strohm, K. (2002) Siblings: Brothers and sisters of children with special needs, Adelaide, Wakefield Press

Strohm, K. (2008). "Too important to ignore: Siblings of children with special needs". *Australian e-Journal for the Advancement of Mental Health,* 7(2)

Taylor, J.L., Greenberg, J.S., Seltzer, M.M. and Floyd, F.J.(2008) "Sibling of adults with mild intellectual deficits or mental illness: Differential Life course Outcomes", *Journal of Family Psychology, 22:6,* 905-914

Appendices

APPENDIX 1
Adult Sibling Survey

Findings from Initial Adult Sibling Survey, April 2008

Target Audience;

The returned surveys were predominately from female siblings aged between 21-61 yrs of age, the majority were employed with 5 studying.

Sibling with Special needs;

There was an even mix of genders and ages ranged from 15 to 53 years.

The type of disability included;

- o Autism
- o Cerebral palsy
- o Multiple Sclerosis
- o Acquired brain injury
- o Spinal injury
- o Down Syndrome
- o Spina Bifida
- o Intellectual disability

Living arrangements

Most brothers or sisters living with disability were still living at home with parents or living in supported accommodation, others were living with family members, including siblings, and some living independently.

Employment status of person with a disability

Employment status varied between;

- o Students

- o Supported employment
- o Open employment
- o Day options
- o Staying at home with mum.

Functional Abilities

Functional abilities were very varied, across the measures of self care, mobility, social activities

Feelings about growing up with a brother or sister living with disability

Feelings varied across the group of respondents, from positive to more difficult feelings such as resentment, guilt, pressure to be the 'good child', difficulties with social activities, and on to fears concerning the future eg whether they should have children of their own.

Speaking with parents about their brother or sister living with disability

The majority of Siblings felt they could not speak to their parents about feelings (negative or positive) concerning their brother or sister living with disability. This was due to a variety of feelings such as guilt and anger, some didn't want to upset the parents and some just were not permitted to speak of the issue.

Comments made were:
- o I felt I should be more loving and tolerant
- o I felt guilty
- o I would not let myself feel anything negative about my brother, there is something in me that just blocks it, any hint of negativity about my brother or childhood makes me feel guilty, like it's a betrayal of those I love, so it was/is hard enough to think about let alone speak about.
- o Never spoken of for fear of rejection, better to keep all that anxiety inside, it was not safe to verbalise any feelings.
- o Didn't feel I could discuss.
- o It was a matter of fact, obvious sis had DS, easy to talk to friends and family.
- o It was not permitted
- o We were migrants and didn't need the extra stress
- o I could talk about him but not sibling issues, as it's taken as criticism.
- o Could never talk to parents but closest 3 friends have been overburdened.
- o Difficult due to a lot of emotion and not much opportunity
- o Family was pretty good with anything goes, mum was pretty rational about it, kind of never really occurred to me to be worried about mixed feelings, I had mixed feelings about everyone.
- o Mother was not receptive to such discussions
- o Get emotional when I do, I get angry when we talk about the future as their expectations are lower than mine, and worried he won't be ready for independent living as parents do way too much for him.
- o Felt I could deal with any issues by myself; I wanted to be supportive rather than add to concerns.

Siblings used a variety of coping strategies such as:
- o Self medication (alcohol, drugs), antidepressants, talking, counselling, music, art, moving on with life, journal, writing, other sibs, friends, working, exercise, travel, study, being good, self harm, relaxation, self talk, diary about life (not bro specific)

Impact on Siblings' physical health:

This had a mixed response from quite a few Siblings and some did specifically not want to blame their brother or sister for everything that was wrong with them.Some of the responses were: Anxiety; Weight gain, due to now living a sedentary lifestyle; Alcohol dependence; Allergy; intolerances due to high anxiety when young; Eating disorder; Anorexia; Depression; OCD; Social phobia; Stomach ulcer; Constant headaches from anxiety; Self harm; Heavy dependence on panadene to help cope with acute neck tension; I don't like putting my problems onto other people or asking for help so I tend to bottle things up a bit and don't tend to cope with stress very well, I also tend to look after peoples and worry about their problems for them as a result I tend to get migraines.

Do you think your experiences as a Sibling have impacted on your mental health? For example have you experienced depression, anxiety, or sleeping problems? Have you needed medication?

Again the answers were varied and some did not want their brother or sister blamed but most acknowledged the situation in one way or another contributed to any mental health issues,

medication was used and varied from self medicating using alcohol to, sleeping pills, tranquilizers and anti depressants.

- o Depression-maybe more anxious when bro needs help
- o Depression due to being a drama queen and a family history not because of sis, however anger due to injustices dealt to sis.
- o Eating disorder
- o Depression
- o Sleeping problems
- o Anxiety
- o Low self esteem
- o Insomnia
- o Sleep is problematic
- o Hospitalised 11 times in last 7 yrs for mental health issues.

Do you think your experience as a Sibling have had an impact on your emotional well-being? Have you experienced low self esteem or lack of confidence?

- o No
- o Growing up had low self esteem, didn't aim for anything, in the last 10 yrs have been very successful in my career which led to the exact opposite..
- o Lack of confidence and self worth, I feel my value is not in being myself but in what I can do for others.
- o Chronic low self esteem and confidence
- o Low self confidence and self esteem , I was never a good enough daughter or sister
- o Sometimes when im put down or humiliated by workers in the disability sector
- o Feelings of being different to other families
- o Guilt feelings and finding it hard now, I have my own family we have no time to care for bro
- o Quieter and more serious; this has stopped me from having fun-low self esteem, doubting myself
- o Very shy as a teen which affected school work, employment and life decisions.
- o Lacking confidence, try not to rock the boat with family or others, I suppose that's avoiding conflict situations and bottling things up, have high expectations of myself
- o Very low self esteem, and almost no confidence

Are you able to see positives in your experiences as a Sibling? Do you believe you have greater compassion or tolerance for others, improved life skills?

In general sibs felt more tolerant, compassionate and sympathetic to others.

- o More sympathetic to the plight of others
- o Undoubtedly more compassion and tolerance, can be too tolerant
- o Broadened my horizon, appreciate life and uniqueness of individuals
- o Empathy and tolerance is now used in job and defines me as a person
- o Glad to have become more aware of others lifestyles and appreciate the simplicity of the life that people with a disability have to live eg restricted incomes and opportunities
- o Sure I think the biggest is learning to embrace imperfections, diversity, and get passionate about marginalisation and social justice
- o I have greater compassion for people that started behind the 8 ball, conversely I really stick the knife in when it's the other way around.
- o Different perspective to some of the realities in life compared to my friends, im compassionate and tolerant however sometimes I think that I have been so tolerant growing up that im less tolerant with others these days.
- o I feel rather blessed in this regard; I feel that I would not have the qualities that I like most about myself if not for this. I don't think I would be as patient, caring, compassionate, or imaginative if I didn't have bro. I also think my family is closer because of him and that we learnt valuable lessons about what is important in life through him.

Has being a Sibling affected your goals and plans for the future? Such as career choice, marriage, having a family or where to live?

Most were affected; however it is pretty well split as in positive and negative ways they were affected.

- o Having to care for sib when parens can no longer do so, so can't move away.

- Opened up my eyes to the plethora of different community jobs, came home from OS to be near sis as she does not speak and after 10 years I really missed her and need to be near for when parents are no longer able to be her guardian and advocate.
- Left home and married at 19 to get out of home, had no goals but was I aware I just needed to survive.
- High anxiety with having my own children and chose to live interstate
- Followed my dream and goals, had a family and lived where my family was directed to go for work and study.
- I am married, major impact would have been when considering family and whilst pregnant
- Do not strive for higher positions at work as there is already additional stress and responsibilities in personal life, husb wants to move overseas but reluctant to do so, does not want to dump all responsibility on other bro.
- I am employed to advocate for the inclusion of children with special needs, have said yes to marriage proposal knowing he understands the implications for the future and bro and need to settle where mum and dad are.
- Career choice, she is the reason I do human service policies and future living arrangements
- Non disability related career, coping with the thought of having children with a disability, issues with doing everything for other men in life.
- Not really, mum always said we should do what we want to do, but I would feel bad if I moved away now leaving the pressure on other sis.
- No
- Completely changed everything in my life
- I want to live close by
- Do not trust anyone, particularly parents, too scared to date, don't think I deserve to and no one would have me, tend to shut myself off from people, I think it played a large role in me going into special ed, working in disability and the decision NOT to have children.
- Forming relationships
- When I choose a partner they need to be the right sort of person for him as well as me. I do have a life at the moment, I live interstate but feel it's not really my life and it is temp until needed.

Do you have any other comments about growing up with a brother or sister with special needs?
- Impact on families when a person is young can be enormous, parent is consumed by the child with a disability, other children are left to fend for themselves, there is no peace in the home-always disrupted by misbehaviour of sib with a disability.
- The injustice I felt was dealt to her, particularly when she had t move out because mum and dad could no longer lift her, there was no such thing as in home care that was a dark time, feeling like we had abandoned her.
- My mother was completely over protective of my sis until the day she died, carers need education in striking the right balance
- Learnt resilience at an early age as we lived in the country and not much info was around to assist family life.
- He will always be my little brother but as he grows I challenge him more and more.
- Growing up with her was normal to us, she stayed in family and was a part of family and we grew up with her needs.
- Im still trying to understand this situation myself, I hadn't even thought about it other than positives, until I stumbled across the sib Aust website, late last year, then I bought Kate's excellent book, it is something I definitely need to explore further.

Your current situation;
- The majority of sibs are in contact with bro/sis
- Most had face to face contact followed by phone, email then letter
- The majority have contact weekly followed by fortnightly, daily, monthly then annually.

Activities enjoyed by sibs with their brother or sister living with disability;
Family gatherings, Movies, Cafes, Drives, Meeting friends, Shopping, Browsing special interest shops such as electronics, Nintendo Wii, Cooking, Playing games, Singing, Dancing, Playing sports, Arts and crafts (making cards), Writing letters, Going to friends parties, Fitness classes, Birthday gatherings, Whatever they want to do, Ice cream, Reading, Watching movies, Dinner, Foot massage, Not much interaction unless on his terms

How do Siblings relate with their brother or sister living with disability now?
- Not great
- Quite normal
- Close and loving
- Like the relationship with other sibs
- Poor
- Keeps me alive
- Disjointed, interference by service providers who think they have primary relationship with her.
- Better than it used to be but still a lot of resentment and jealousy toward them
- Do not have the patience to listen to him and try to understand as speech is limited and I am so busy
- Hanging by a thread
- Patchy
- Needs a lot of work
- 5 out of 10
- very important, much love between us
- strained as he cant communicate any more, however I have a strong relationship with him, very protective, and caring

How the relationship has changed over the years;
- less tolerant
- normalised
- growing up was like having any younger sis, just a lot slower
- excellent relationship, until mum died and I was shut out of my sis life plans by service providers who think they know her needs and wants
- it has matured, fairly standard I think
- have never been close
- the feelings associated with growing up identified, became more heightened
- a bit more tolerant and understanding as I ve gotten older and researched their disability- gotten more of an insight.
- See less of him since marrying, feel obliged to make weekly/fortnightly trip to see him, feel bad if I don't
- Disintegrated as I grew up and remained the same
- I don't think it changed much
- Understand each other and are close, resentment has now faded and have a good adult relationship, worried this will change when she becomes the main carer when mum and dad pass
- I still find it hard to relate to her and have to have patience when her behaviour towards mum is bad
- Very intense during childhood and has now distanced due to life changes
- Prob hasn't, still act as big sis and have big expectations of him

Relating to other Siblings;
Just fewer than 50% have current contact with other sibs for support; some of the comments made by those that have had support were;
- Sent to sib workshop at 11, didn't connect until I was 14, felt connected to these people and indirectly led to career path
- It would have been a significant aspect for me that none of my peers were in a similar situation having a sib with a disability
- Only recently through e mail forum
- Went to sib group, parents were involved in the disability scene; quite a few mates had sibs with a disability.
- Only in last few years through sibchat
- Interesting and nice to know that there are others
- Opportunity to share experiences, new friendships formed, opportunity to share ideas and resources.

Comments made by those that have not yet had contact were;

- May make me feel less alone and not so guilty about how I feel towards my sibs at times.
- To get practical tips on services that are available locally, the other would be a social thing, I would like to do activities where I and sis aren't the stumbling block for everything it would be nice to do something in public with some sibs and their sibs and when something goes wrong not to worry too much, to have a group that understands that whatever you are doing is for a reason.
- It sounds maybe a little scary or confronting but I think it would be good
- Yes, would be good
- Absolutely
- Yes although it would be confronting to talk to others

What information/services/resources would help you in your current role as an Adult Sibling?

- People to talk to
- Respect for being a sib by disability services, more positive attitude to sib relationship, holistic approach to sibs and family.
- Having access to other sibs via Sibs Aust
- Chance to talk/hear from others in the situation, medical info on the disability
- A place or avenue where one can vent or discuss life as a sib
- Guardianship, advocacy, public trustee
- Finances, Special trusts that the fed govt have developed
- Carer support
- What the sib with disability can access via centrelink
- DSP stuff
- A place to keep sis info-keeper of her info-a central keeper of her info
- Flexible private carer support
- Better taxi service, more access to buildings
- Accessible holiday accommodation
- A list of things we can do together that are not boring old disability groups
- Accommodation issues for elderly
- Info for the future
- How to deal with the effects of the past
- What will be my role in planning for the future
- How parents can enjoy retirement
- Wills
- Life support
- Wills, taxes on inheritance
- Trust funds and when to set them up
- Caring from interstate….how?
- Ongoing doubts about having children
- Respite care
- Meeting group for people who care for special needs adults
- Time to talk to other sibs, share feelings, and maybe socialise
- Learning how to communicate with someone who cant communicate back
- Ideas, activities you can do with someone who is unable to do physical activity
- Maintained service provisions to people with ID (accommodation, employment & day options) aged care services to be expanded and transition to aged care programs to be available for people with ID and their families informed and included in decision making.

The Future;
100% of sibs have concerns for the future of their brother or sister with disability including:
- Health
- Financial
- Happiness
- Being abused, victimised or exploited and no one will notice
- Becoming isolated and unfulfilled because she cant initiate or speak for herself
- Abused in disability service and no one in power cares
- How she will manage when parents are gone
- Aged care and adequate health services available and retirement services

- o What will happen when my parents can no longer care for them? How will I cope? What if I don't want anything to do with them? What if I leave the area?
- o Accommodation
- o What role will I play, how will it limit my life, will she continue to be satisfied
- o How he will be supported financially when I have kids and mum and dad are gone
- o What impact will it have on my family and my sis family as 2 bros have already said they can't have her because of the wives, mum wants home care not group home for her.
- o Health, emotional and living arrangements
- o Not sure what it holds, he will be my responsibility and I want to make sure I do a good job of it as well as maintaining my own life and identity
- o That mum and dad will still be going on holidays with bro in tow, want them to spend time together, respite options
- o Community participation
- o Rapid progress of illness and the level of care currently needed and which will be needed in the future
- o Firstly I have to outlive her so that anything I plan can happen
- o Pension, dole, carers payment

Have parents involved sibs in planning for their brother's or sister's future? For example, discussions on finances, guardianship, medica issues, accommodation or employment options?

Most had discussions with parents but not all were productive and some were only directive.

- o Yes all of the above
- o I saw mums will once showing me as guardian, other than that I have never talked to them about it, I think they are too guilty to talk tome about it, they are grateful that I am able to be there but are torn up about it at the same time.
- o They have told us what they put in their wills, that my older brother and I will have joint guardianship but didn't discuss it wit us when they were making them.
- o Have always been open, mum and dad made it clear we have no obligations to look after her but we want to be involved as much as we can, although there's only so much because we have our own lives too.
- o I was involved to some extent but in the end my mother went her own way on these matters.
- o No we always told it was none of our business but it was always our business as they involved us in other ways.
- o Was involved in her schooling, teenage years, post school learning and developing to an adult
- o Not much, limited discussion about current situations only
- o My parents have told me I will have guardianship/custody because they don't want my younger brother to have the responsibility, no details discussed.
- o No, done automatically
- o Yes but I don't know where to start
- o No – tell me what they have planned don't want me to feel responsible, rather talk about it openly, choices about his employment and housing, finances, with no input from me.
- o We have tried but mum does not want to deal with it, it wont be her problem
- o No
- o Yes have discussed will, guardianship, accommodation, employment options, they have low expectations, I think he has more potential and want programs set up in time not when parents are 100, expected to take on guardianship, want him to live independently, and not be in day options as he has strong interests in electronics, parents have never used respite, I look after him.

Do Adult Siblings think they would benefit from practical information about planning for their brother's or sister's future?

Most said yes to this question, other responses were;

- o I need this more than anything else
- o We as a family are interested in being informed
- o Generally they must be of assistance
- o Yes, we have discussed medical issues, not up to other areas yet
- o Not sure

- o Definitely
- o Been there and implemented plans for accommodation, work, social interaction, and financial security

What are the hopes for the future of both the Adult Sibling and the brother or sister living with disability?

- o Happiness and good health
- o That I last long enough to look after sis for all of her life
- o Adequate support for retirement, through to aged care through to death
- o We both have full happy lives, financially secure and have a good social network of family and friends
- o I live one day at a time so as not to tip over the edge, I have plans to travel and study, not sure about bros future
- o My future-happy and healthy family, sis-to get work and feel better about herself
- o Not sure
- o An environment that fosters improvements, personal care and social skills
- o Happy and satisfied, able to find a group home she is happy with, have my own family and my own life, play a role in hers on my terms and my values, and be the one to continue religion in her life when parents cant.
- o That we can live the lives we want to without being too reliant on each other
- o Love for her to be more independent, have a job, meet new people, but I worry its too late.
- o That we can live happily relating to each other and we feel safe and supported by the community
- o That he is reaching his potential, living happily, independently and him being part of my life and seeing each other nearly every day and him getting to know my children when I have them and for mum and dad to feel they don't have to carry the load.
- o Meaningful work as a teacher for me, for sis, that she services neglect in the system.

APPENDIX 2
FORUM SUMMARY
1 May 2008

Why are Adult Siblings overlooked?

- The person living with disability is the family focus rather than siblings
- The parent, as the primary carer, receives the support services
- Sibs are not recognised by families or service providers
- Adult Siblings do not volunteer the information that they are a sib and need support, they just do what is required
- Society has the attitude that Siblings should feel 'lucky' because they are ok

What issues are Adult Siblings facing?

- looking for a keeper of information for their brother or sister living with disability so their life history/story is not lost when mum and dad pass
- finding a family support network has become harder because of the special needs involved
- looking at planning for the future
- don't want to go from being a sibling to being a carer, they want to remain a sibling
- accommodation for the brother or sister living with disability is an issue on many different levels, for example worrying about getting accommodation, what is suitable accommodation, abuse in accommodation, costs involved in accommodation, location and quality of life in the accommodation service
- guilt is perceived as normal, not something that needs to be resolved

- feel as though they are the peacemakers of the family and are accepting the role of carer when mum and dad pass, however its not what they want, but what they feel the parent wants them to take on this role
- don't know where to start with wills, trusts, taxes, Centrelink, pensions, etc
- want to know what day options support is available
- Adult Siblings want acknowledgement
- No data base or register of siblings
- How do Adult Siblings talk to parents?

How do we get Adult Siblings "on the agenda"?

- Data Collection
    - Agency registers
    - Who and where are Adult Siblings
- Included in Census for data
- Forums
- Raising awareness in among service providers
- Advertising
- Support groups for Adult Siblings
- Raising awareness in government
    - Minister for disability
    - ODAC – acknowledge Sibs
    - Leader of opposition (Martin Hamilton Smith)
    - Nick Zenaphon
- Demand Benchmarks
- Acknowledgement of Adult Siblings in policy

What services are available to Adult Siblings?

- Counselling
    - Carers SA – 5 sessions through selected counsellors $5 each session (Adult Siblings may not get support, depends on timing and situation)
    - Carers Mediation and Counselling Service – offering counselling to any family in danger of breakdown – free service – mediation – referrals to other services for power of attorney, wills information ect.
- Future Planning information through "Planning in partnerships" (65+) – Carer Support and Respite Service
- Support for living (Pam Travis) – internet site, interactive, small fee but it's a lifelong service.
- Circles of support
- CARA connect families – teen vacation sessions with sibs
- Internet forums
- Books

Where are there gaps in services to Adult Siblings?

- Peer support groups, mentoring
- Resources
- Brochures (are you an Adult Sibling?)
- Keepers of information – how to store information
- Information about services, accommodation, guardianship, finances
    - Sibling friendly organisations

Where to from here?

- Develop brochures, web site material
- Sib provider packs
- Information sessions
  - To be on weekends
  - Guardianship to be a whole day
- Possibility of forming a voluntary Data base on Sibling Australia's site which services for sibs could access
- Possibility of developing a web based keeper of information, a few of the net support sites could provide this
- Siblings Australia – possibility of developing a brochure outlining services available and have the links on our web site
- Develop a DVD for/about Adult Siblings, (TAFE at Modbury develop community DVD's)
- Getting the Siblings Australia website link and brief run down on Siblings Australia included onto all service providers' websites
- Starting regular information sessions on Adult Sibling issues
- Encouraging the carer support networks to coordinate adult sib groups

APPENDIX 3
FEEDBACK FROM 'LEGAL ISSUES FOR ADULT SIBLINGS'
26 March 2009

1. **Participants would like more information about or more support with:**
   - Future planning for my brother / sister living with disability
   - Legal Issues
   - How to advocate for my brother / sister living with disability,
   - Current research into sibling issues
   - Accommodation options for my brother / sister living with disability
   - Networking with other siblings
   - How to deal with service providers
   - Financial Issues
   - Navigating the service system
   - Relationships and sexuality issues for people living with disability
   - Counselling about sibling issues
   - Age related changes for people living with disability
   - How to talk with ageing parents about my brother / sister living with disability
   No-one responded with a yes to the needing info re 'looking after myself'.

2. **Participants would like the following issues addressed in the future:**
   - I would like to start more at the basics

3. **Participants would prefer to receive information and / or support in the future through the following means:**
   - On-line information / Support
   - Face to face support / information
   - Sessions like tonight
   - Networking with a group of siblings
   - Books, brochures, fact sheets
   - Telephone support / information

Siblings Australia Conference 2009

As part of the Adult Sibling sessions at the conference, participants were asked to consider their needs for the future.

Participants' responses fell into one of two categories.

1. Information, strategies & services that would benefit them directly
2. Information, strategies & services that would directly benefit their brother or sister living with disability and therefore indirectly benefit Adult Siblings

Direct benefit to Adult Siblings	Indirect benefit to Adult Siblings
	Transport for the person living with disability
	Personal care support for the person living with disability
	Housing for the person living with disability
	Tools/strategies for promoting the independence of the person living with disability
Tools/strategies for maintaining contact with their brother or sister living with disability	Tools/strategies for maintaining contact between brothers and sisters
Information about developing wills – where to start?	
Contact list of legal professionals who have knowledge of disability issues for creating wills	
Info about accommodation options – where to start?	
Counselling – from people who "get it"	
Counselling services specifically designed for siblings	
Services where siblings can gain skills in advocacy	
Family mediation services that understand sibling issues	
Learning to ask for help	
Sibling partnerships with disability organisations	
Facilitation of dialogue within families about future	
Sibling mentors	
Challenge assumptions that siblings either need to be protected or will take over everything when parents are no longer able	
Tools/strategies for "how to ask the hard question" such as future planning	
Step by step guide to future planning	
Recognition of the sibling role	
Recognition of the difference between the sibling role and the role of "carer"	
	Information document about the needs of the brother or sister living with disability
	Information about the needs of the person living with disability for a 24 hour period in case of emergencies eg; medication, health issues, challenging behaviours
Tools/strategies for dealing with differing expectations between parents & siblings regarding the independence or possible future independence of the person living with disability	
	A service system that is proactive rather than reactive and crisis driven
Parents need to <u>involve</u> siblings in future planning	
"One stop shop" for <u>siblings</u> on disability issues, services available for selves and brothers or sisters living with disability, legal & financial issues	
Respite/time out/ space for siblings	Quality respite services
	Support for parents
	Funding for home modifications