



SibsWest Focus Group Forums

Report

SibsWest is a peer support organisation for Adults who have a sibling living with disability.





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Introduction

Adult Siblings have a unique position in the lives of their brothers and sisters living with disability. The sibling relationship is potentially one of the longest relationships in our lifetimes. Sibling relationships can be complex, dynamic relationships influenced by many factors and every sibling of a person with a disability has had their own unique experience.

Many siblings choose to take on varied roles in the lives of their brothers or sisters and form an invaluable part of the person's informal support network for their brother or sister living with disability.

The National Disability Insurance Scheme recognizes that families are an important part of the lifelong quality of life of people with disability. Siblings can play an integral role in the planning and implementation of their brothers and sisters NDIS Plans. It is therefore important that siblings are able to develop and strengthen their own support networks both now and into the future and receive support for this.

Background.

SibsWest was founded in 2015 following a workshop held in Perth with Kate Strohm who was visiting from Siblings Australia in South Australia. A group of adult siblings who attended the workshop continued to meet locally with the aim to share experiences, information and knowledge of being an adult sibling.

This peer support network has developed and is now known as SibsWest. The group has developed a website sibswest.com.au/ and two active Facebook pages – one for Siblings: facebook.com/group/sibswest and an open page for interested parties – facebook.com/group/sibswestnetwork; and a Twitter account.

Siblings

Quote....

“We will become caregivers for our siblings when our parents no longer can.

Anyone interested in the welfare of people with disabilities ought to be interested in including us.”



The Forums

SibsWest received a grant from Developmental Disability WA through the NDIS Disability Support Organisations Project aimed at developing new local peer support groups.

The goals of these new peer support groups are to build the capacity of people with disability and their families to:

- Exercise choice and control
- Effectively engage with the NDIS
- Effectively engage with mainstream programs, services and activities
- Increase opportunities for independence, self-management and community inclusion

Through this grant SibsWest engaged Bronia Holyoak from Valued Lives, a sibling herself to facilitate two Focus Group Forums on 26 August 2015 hosted by The National Disability Insurance Agency in Midland, Western Australia.

FORUM 1 SERVICE PROVIDERS AND OTHER STAKEHOLDERS

Sibling Services and the NDIS

The purpose of this forum was to discuss the importance of sibling relationships within the context of the National Disability Insurance Scheme and to ascertain current supports and services currently available in Western Australia and how they engage with siblings.

There were 14 participants including siblings, service provider representative's parents and sibling groups representatives.

Introductory Presentations

Mary Ashe, NDIS

Mary Ashe, Assistant Director of the Engagement team at NDIS Perth Hills Trial Site opened the forum and welcomed the group to the NDIA Office in Midland. Mary acknowledged the importance of the sibling relationship and how they were often strong advocates for their brothers and sisters with a disability. The NDIS welcomes siblings joining participants in all planning conversations and the reviews of plans.

Tracy Destree, SibsWest

Tracy Destree from SibsWest provided an overview of why it is important to recognise sibling relationships and the need to engage with siblings.

- Adult Siblings are taking an increasing role in disability support, care and management.



- In an increasingly ageing population, Siblings are emerging as Primary Carers, and can find themselves with multiple caring roles (i.e. siblings, parents, children)
- Siblings are not formally recognised in current Health Policy, disability legislation or as Social Support Groups
- Current services and research has focused on supporting Siblings during childhood but there is little engagement with Adult Siblings, or understanding of current issues
- The sibling relationship can be the longest of one's lifetime. From childhood, the relationship can range from being enriching, positive and supportive through to complex, strained or painful and a source of sustained stress
- Increased risk of depression, substance abuse and family estrangement, and this can manifest in the quality of care and support that is available for PWD throughout their lives
- There is limited data of the role of Adult Siblings and participation in the management and support of people living with disability (PWD)
- Siblings are largely absent in health and disability management policy
- Siblings need to be recognised in planning processes, as a primary carer, in legal administration, and to the type and level of services provided

Sibling Support in Western Australia

The forum heard that there are limited resources available for sibling support currently in WA, particularly for adult siblings. Younger siblings have some support available but they are dependent upon funding which tends generally to be one off grants, and most relate to respite activities and do not provide a means to discuss concerns or challenges that Siblings may face.

Siblings Australia have delivered workshops in Western Australia but do not have a local presence and service programs are ad hoc and unfunded. It is based in South Australia has been seeking ongoing funding without success for many years, but without success.

Siblings support projects in WA include:

- SibsWest
- Carers WA – Young Carers program
- Kalparrin Sibling Awareness Project
- Disability Support Commission (DSC) – Art programs for children
- DSC Intensive Family Support Funding (Combined Application Process)
- Siblings Australia (SA) -Sibshops for children, Adult Sibling forums



- Big brother and Big Sisters – mentoring program for children at risk (WA program now closed, centre based in Victoria)
- Some Local Government initiatives
- Some service providers try to engage in capacity building initiatives with all family members including siblings

Bronia Holyoak, Valued Lives

The facilitator Bronia Holyoak, CEO Valued Lives, presented her experience of living with her sister and provided information about what is known about the sibling relationship.

- Siblings will likely have the longest relationship of any with a brother or sister with a disability.
- If siblings are supported well they are likely to contribute much to the emotional wellbeing of their brother or sister (and parents)
- Many siblings take on a very active advocacy role for their brother or sister and for people with disability in general. They can play a major role in ensuring the quality and safeguarding of services provided to their brother or sister
- Siblings can have a variety of experiences in supporting their brother and sister – some good – some not so good! But if nurtured they can be a strong advocate in ensuring that their sibling has a good life.
- Funding for sibling support is limited yet essential.

FORUM 1 GROUP DISCUSSIONS

Forum 1 Participants were invited to discuss the following questions:

Question 1: What needs to happen to ensure that siblings access the support that they require, for example sibling peer support in NDIS?

Question 2: How do you as service providers reach out to brothers and sisters?

Group Discussion Outcomes

QUESTION 1:

What needs to happen to ensure that siblings access the support that they require, for example sibling peer support in NDIS?

It was felt that Siblings should be invited to participate in the planning and subsequent implementation of their siblings plan and that the NDIS Planning and Support



Coordinators should actively seek to engage siblings through direct contact with permission from the participant.

A capacity building strategy in the NDIS support clusters to assist siblings develop their own skills through funding in an NDIS plan, for activities such as

- Learning about inclusive practice
- Developing siblings and friendship relationships
- Reaching out to siblings specifically
- Whole of family futures planning
- Support with training and education to empower siblings to advocate for their brothers and sisters.
- Training for parents and siblings to build resilience
- Counselling for siblings but not confined to “clinical counselling” – akin to “Life coaching”
- Provide support to bring family unity (informal supports) together to get the best outcomes in participant’s plans. Reach out to siblings

Other suggestions:

- Use “Coordination of Support” provider to engage siblings
- Survey siblings directly about how to engage in the NDIS.
- Actively involve siblings directly when there are at “points of crisis” or when “Future Planning” is required as parents may not want to “bother” siblings.
- Use technology platforms to engage siblings in the NDIS.

Information Linkages and Capacity Building - (ILC)

ILC is a key component of the NDIS insurance model and will contribute to the sustainability of the NDIS by building the capacity of the community, people with disability, their families and careers. Funding for ILC strategies will be available from July 2016 through the NDIA. Support could be made available through this funding strategy for;

- Support for adult sibling peer groups
- Provision for information, linkages and referrals for siblings into mainstream services.
- Web-based support services
- Telephone information and counselling
- Individual Face to face information and sibling group information sessions about the NDIS.
- Support through Local Area Coordinators



Question 2: How do you as service providers reach out to brothers and sisters?

- **What strategies do you use?**
- **Are they effective?**
- **What are the barriers that you face in engaging members of the family other than parents?**
- **What more can you do as an organisation to actively support siblings in decisions about the care and support needs of their brothers and sisters?**

Forum participants stated that trying to engage adult siblings can be difficult and that although they had tried to include brothers and sisters in events and activities with variable results. Early engagement with siblings results in more longstanding relationships.

Forum Participants stated:

- Ethnic families tend to be more likely to be naturally engaged.
- Siblings are often busy and are getting on with their own lives.
- Connection with siblings will depend on experience/ family dynamics
- Invitations to siblings go out to attend BBQ's and events through parents as they are a natural point of connection.
- Food/ event/ functions are a good way of engaging with siblings
- Surveys to parent's siblings welcome to provide feedback.

Barriers:

- Parents can sometimes a "barrier" to siblings, often with comments like; "I don't want to bother them"
- We need to acknowledge and accept that some siblings will not engage and that is their choice.
- There are many activities in which to engage brothers and sisters but siblings have "family life" and many other competing needs
- Physical location of siblings makes connection difficult.
- Emotion barriers from early sibling experiences – how do we transcend this?
- Some siblings have guilt and emotional barriers and this needs to be considered.
- We don't open up enough direct opportunities for siblings to be involved.
- Funding is needed for research to gain answers as to why relationships with siblings with disability can be fractious/distant/disinterested.



Ideas for better connection:

- We should engage the whole of the family not just parents.
- Futures planning – siblings need to be included and engaged.
- Engage in “possibility” thinking early with all family members – Don’t wait for a crisis to occur and expect siblings to engage.
- Focus on inclusive and good lives for our siblings –we want our brothers and sisters to have the best lives possible.
- When there is trouble siblings will need to engage so include them early.
- A sense that siblings were engaged but when services become involved they step back.
- More success found when engaging siblings early.
- Parents need to encourage sibling engagement and service providers need to reach out to siblings both through parents and in other ways.
- Resource siblings support group/networks.
- Funding for research to gain answers as to what is best practice in engaging with siblings, what makes for positive relationships with siblings? What makes the siblings relationship fractious/distant/disinterested?
- Research/ investigate benefits of interactions with whole family.
- Use technology for communication/engaging with family sibling.

The forum closed with the final overview from the facilitator

- Siblings have a “Right to Their Own Life” this needs to be remembered.
- Acknowledging Siblings’ Concerns - a wide array of often-ambivalent emotions regarding the impact of their siblings’ needs. These feelings should be both expected and acknowledged.
- Opportunities to Meet Peers. For most parents, the thought of “going it alone,” raising a child with a disability without the benefit of knowing another parent in a similar situation would be unthinkable – same goes for siblings they need to know that they are not alone!
- Knowledge is power. If you provide information to parents the same should be afforded to siblings (often we leave them in the dark and expect them to pick up the pieces if things go pear shaped!)
- Brothers and sisters worry about the future.....engage them in conversations along the way.
- Include siblings in the definition of “family” – they are exactly that! – Family centred practice means engagement of the whole of the family.
- Include siblings on Advisory Boards and in Policies regarding family members. They will add a different perspective.
- Parents may not want to "bother" brothers and sisters but behind the scenes "they are bothered!"



- It is up to everyone providing supports and services to engage siblings as they are often the most enduring support around a person with a disability.

FORUM 2: SIBLINGS

The Sibling Experience

Background:

SibsWest was founded in 2015 after a group of siblings shared contact details at a Sibling Workshop. They have met on several occasions and connect mostly through technology on the SibsWest Facebook Page. The group has grown to 18 siblings.

The second forum of the event was for these siblings to discuss and consider pathways into the future for SibsWest. A small group of four attended the forum.

Siblings Group Discussion

The first part of the forum was set aside to share sibling experiences. The group shared stories about their siblings including; their childhood and growing up experience of being a sibling, where they lived, how they were supported, their relationship with their siblings and how that impacted their lives.

The discussion content related to the Siblings Experience was recorded in principle only with the specifics remaining in confidence.

The group then discussed and what they wanted to get out of being a member of SibsWest, the journey of the peer network to date and some of the experiences and challenges that they had faced thus far.

FORUM 1 DISCUSSION OUTCOMES

Statement: Who We Are

SibsWest is a Peer Support Network for adults who have a sibling living with a disability in Western Australia.

Purpose of the group.

To facilitate and provide welcoming forums for adult siblings to connect with their peers share information, knowledge and experiences together.

How will we connect?

Forums will be ongoing through the on line Facebook Page and face to face workshops and social events during the year (Bi – monthly)



Governance:

The group discussed future governance arrangement for SibsWest,

Options 1: Continue as a local informal independent peer support group with the aim to develop and increase SibsWest membership over the next 12 months.

Option 2: Convene an interim board and lodge application to become an incorporated association.

The group felt at this stage the work entailed to become an incorporated association was not required and that focusing on this activity may take energy that could better used in developing and strengthening the group.

The group decided that option 1 was the preferred form of governance for the next 12 months. To be reviewed August 2016.

Continue as a local informal independent peer support group with the aim to develop and increase SibsWest membership over the next 12 months.

Members discussed options for auspice and considered current organisation that would provide an appropriate fit to SibsWest. These included:

Appropriate Fit Organisations for Auspice:

- Peer support group model organisations

Less Appropriate Fit Organisations for Auspice:

- Disability specific support organisation – SibsWest includes all types of disabilities
- Carer Organisations – Wide ranging services including aged care; not all siblings are carers
- Larger Service Provider Organisation – profit based, would not provide right level of support for a small organisation like SibsWest
- National based organisations – we need to keep focused on WA and provide local services

Funding for SibsWest

SibsWest currently has a \$5000 grant for peer support activities which has been made available through Development Disability WA for the next 12 months

Any future opportunities for funding will likely to be through establishing an auspice arrangement through an incorporated body.



Support for SibsWest Members.

The group discussed alignment with existing organisations with similar purposes such as Siblings Australia. It was decided that for the next 12 months SibsWest will be an independent adult sibling peer support network who will seek alignment with other peer support organisations in Western Australia. This needs to be explored further over the next few months.

Next Steps:

- Organise dates for next meeting
- Distribute notes from the forum

Bronia Holyoak

Facilitator

October 2015