Creating Capacity – Support for Adult Siblings

FINAL REPORT

Project

Creating Capacity: Support for Adult Siblings Project was developed to build the capacity of siblings to understand the NDIS and to support their brothers / sisters in the transition to the NDIS environment. The focus of the Creating Capacity project has been twofold:

1. Develop a range of online information resources for siblings about issues of importance to them and their brother or sister with disability
2. Develop opportunities for peer support and mentoring for adult siblings, both online and in person.

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- Dr Ariella Meltzer, social policy and disability researcher at UNSW Sydney, and sibling
- Tommasina Owens, psychologist working in the Education Sector, and sibling
- Eban Pollard, Snr Project Officer, My Choice Matters, and sibling

Siblings Australia would like to thank the adult siblings who took the time to complete the online survey and the adult siblings who volunteered to take on peer leader roles. See **Appendix D** for information about Siblings Australia

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Background

See **Appendix C** for a reading list related to this report.
The sibling relationship is potentially one of the longest relationships in our lifetimes. It can be complex and dynamic, influenced by many factors. Disability affects all family members, and will have an impact on the sibling relationship. Worldwide, siblings have been found to be a group of people who care deeply for their brothers and sisters with disability and, for many, their lives have been enriched by the relationship. However, many also struggle, not only with their own significant emotional difficulties in processing the challenges of living with a sibling with disability often from a young age but, also, with how they can best support their brother or sister.

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 or other supports 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 or nothing to do with their brother or sister with disability.

Even if siblings are not involved in day to day practical care or emotional/administrative or social support, 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 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 with disability and the roles they might want, or be expected, to play.

However, in spite of the known challenges and contributions, siblings continue to be largely overlooked in the disability sector and more broadly. Support for siblings allows them to feel less isolated and helps them build resilience. Also, it is likely to enhance their capacity to contribute to the quality of life of their brother or sister with disability. Sibling support also enables the whole family to function more positively.

Siblings Australia (see end of this document) has worked with adult siblings since 1999. It has carried out surveys, focus groups, run online support options and provided opportunities for face to face contact. Online support options have provided much for adult siblings, over many years, with some siblings describing it as 'a lifesaver'. A more extensive adult sib project was completed in 2009, and the report can be viewed here. It included a literature review and recommendations, which have been adapted and included below in this report. Unfortunately these were not taken up by government. This current project hoped to revisit the issues and explore further the needs of adult siblings.
NB: This Project focused on adult siblings of people with disability. Most siblings who responded to the survey and who attended groups during the project had a brother or sister with intellectual disability or autism. It is likely that the findings could be applied to adult siblings of people with a mental illness (psychosocial disability).

Overview of Project

The focus of the Creating Capacity project has been twofold:

1. Developing a range of online information resources for siblings about issues such as:
    - Informal and formal roles they may play in the lives of their brother or sister with disability
    - How the NDIS works
    - Issues to consider when advocating for, and with, people with disability and
    - How to engage in difficult discussions with parents;
2. Developing opportunities for peer support and mentoring both online and in person.

Key Outcomes

- The survey developed for adult siblings had 336 responses. It showed that adult siblings play a large role in the lives of their brothers and sisters with disability. Many also play significant caring roles, directly assisting people with disability or their parents on a regular basis. Approx. 41% of siblings are in daily contact with their brother or sister, and another 22% are in weekly contact, with 41% providing either weekly or daily care or support. See Appendix A for more details. It also showed that many siblings know little about the disability system in general and more specifically, the NDIS.
- The survey also highlighted the support needs of siblings themselves, and emphasised the range of emotions that siblings experience in their relationship with a brother or sister with disability. Some responses from siblings within the survey included:
    - *Communication is difficult and fraught. I have a lot of guilt*
    - *We get on very well and she comes to stay regularly with me*
    - *I just wish there was someone to share the responsibility – sometimes it just gets to me*
    - *I am too anxious to be left alone with him*
- Based on survey outcomes the project developed online information for siblings about the NDIS, and by way of introduction to that, the project team developed introductory material about the roles that siblings can play, how to think about future planning, supported decision-making and a range of other issues relevant to them.
- The survey showed that 88% of respondents had a brother or sister with intellectual disability or autism. This group of siblings might be more in need of support and information, given the nature of the disability
- Based on the survey outcomes and the request for peer support, the project recruited and trained 20 peer support leaders, through email, webinar and written resources. A short film was made by JFA Purple Orange about the process.
- Peer support groups were run in 5 capital cities and the overall message from attendees was that they valued enormously the opportunity to connect with other siblings. As one said ‘I don’t feel so alone anymore’. However, more time is needed to fully develop the sustainability of these groups.

Project activities

Aims

The overall aim of the project was to build the capacity of siblings to understand the role of the NDIS and to support their brother or sister with disability in the transition to the NDIS environment. The more detailed aims of the project included:

- To develop a better understanding of the needs of siblings.
- To develop a range of online resources (including links to existing resources) on Siblings Australia website to build siblings' capacity to understand the role of the NDIS and to support their siblings transition to the NDIS environment.
- To develop infrastructure to assist siblings to access a range of peer support and mentoring opportunities both online and in person

Activities

The project activities were completed according to scope, quality and budget defined in the Activity Plan. This is shown in the table below:

Project area/activity	**Work completed**
Reference group	• Reference group was established with 6 members, with personal sibling experience and/or professional experience.
Survey	• A survey of adult siblings was drafted and finalised with input from reference group. • The survey was circulated via Siblings Australia contacts, Facebook and via Reference Group member contacts. • 336 people participated in the survey. • The survey results were analysed. The analysis is detailed in **Appendix A**. • The survey responses were used to inform the resources developed and the type of information provided in peer groups.
Website material	• Information for website was developed. • There were some delays in the development of the website material, due to the complex nature of the information required and varied needs of audience. • The website material has been reviewed by the reference group and a number of adult siblings and has been verified by the NDIS – it is expected that the material will be online by mid-August.
Peer groups	• There were 28 expressions of interest for the peer leader roles. • Only 5 geographical areas had two or more possible leaders (the Project Team decided that this would be a requirement to go ahead with the groups); we established groups in only those areas, with a total of 20 leaders. • Over time, some leaders pulled out of the role (due to other commitments, including to their brother or sister with disability) and we now have the following number of peer leaders – Brisbane (3), Sydney (4), Melbourne (2), Adelaide (3) and Perth (2). • 60 siblings have registered for the peer groups. A summary of the group activity can be found in **Appendix B.**

Challenges

A number of challenges influenced the project:

Survey

- When designing the survey, changes were made to the number of follow up questions regarding how often a sibling sees their brother or sister, so that it would be less confronting to survey participants. However, that came at a cost to knowing more about the amount of time siblings spend on supporting a brother or sister with disability

Website information

There were some delays with finalising the web material.

- To enable the information developed for siblings to be more readily accessible, the Siblings Australia website required upgrading. There were considerable delays with this, given the fact a university developed/hosts the website due to lack of funds. The upgrade needed to be done through them and via a student. The information should be uploaded to the new website by mid-August 2017.
- When developing the website information, it became increasingly difficult to capture all the information – much of the information siblings requested is complex information that differs across states on some matters (e.g. guardianship and decision-making). Further, the continuing development of NDIS policy and procedure meant that ensuring that the information was, and continues to be, up-to-date is an ongoing task.

Peer groups

- With respect the peer support groups, there was a very successful call out for peer leaders, a number of groups have been run but there remains a lack of capacity to reach adult siblings. This was more difficult than expected, in spite of social media and email campaigns. There remains a lack of avenues for accessing siblings to inform them about the groups– there are no central databases and providers also don't often keep sibling information. When siblings are accessed, many are often stretched in providing support to ageing parents, their own family and their brother or sister with disability, and so it can be difficult to commit to a peer group. The question remains whether online or face to face support is preferable as a peer support model to siblings and there needs to be more work done on the best options for sibling support.
- Although the project finished at the end of June this work will continue until the end of 2017 in the hope that more siblings can be involved in the peer support groups. There are also online support options for siblings – both SibChat and a possible discussion forum due for launch shortly.
- Another issue was that some leaders needed to withdraw from their peer leader roles – this was largely due to their own health issues or demands of supporting their brother or sister with disability.

Implications for the broader disability sector

The conduct and findings of the project highlight several implications for the broader disability sector. These findings are contextualised by siblings usually having the longest relationship of any with the person with disability – and therefore sibling relationships and adult siblings are too important to ignore:

1. Although the survey within this project was a small sample, it highlighted the amount that siblings are contributing to the life of the person with disability, parents and the wider community.
2. As minimal data is collected about siblings' roles and their support of their brother or sister, the dollar value of the contributions that siblings make to their family is unknown; it is likely to reflect considerable financial savings to the Government which would otherwise need to be provided via NDIS funding.
3. There is still very little known about the roles that siblings play, their challenges and their needs, and what barriers/enhancers influence the relationship between siblings and the roles played.
4. There is also a lack of knowledge about the experience and needs of siblings from regional and rural areas, as well as from different cultures.
5. As the project attempted to engage with disability/parent groups, there was some resistance to the idea that siblings might need support. There was a definite lack of understanding about the impacts on siblings.
6. Siblings are still overlooked in policy/programs at a national level. Parent carers have some voice/support via major funded advocacy/support organisations outside of the NDIS. Any national peak organisation for siblings will require significant ongoing funding to ensure adequate support for siblings.
7. There are very few specific services for siblings of people with disability, in spite of their own challenges, and in spite of their contributions to people with disability.
8. There is evidence that many people with disability, especially those with intellectual disability, become isolated and more vulnerable to neglect and abuse. More consideration should be given to why family relationships break down and how they could be strengthened. Some siblings move away from the family and the person with disability as they are not able to cope. More support options from childhood might prevent that happening.
9. There is a sense that siblings will simply 'take over' once parents are no longer able to continue caring. This expectation raises two issues for the disability sector. First, if the sector does have an expectation that siblings will move into this role, then it is imperative that more resources are provided into supporting that transition. Second, if siblings are not expected to take over these roles, then the disability sector needs to be planning now for when ageing parents are no longer able to provide care.
10. Many siblings take over the parent/primary carer role at the expense of their own life goals. Further consideration should be given to whether this is the best approach for either the sibling or the person with disability. It is a situation that can contribute to resentment within families, can disrupt siblings enjoying a relationship just as siblings (not as carer and cared-for) and may influence the breakdown of sibling and other family relationships.

Recommendations

Based on the information collected through this project, and referring back to the recommendations from earlier projects, the recommendations below have been developed and 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 should recognise the important contribution and needs of siblings of people with disability
2. Governments should recognise the lifelong nature of the relationship between siblings when one (or more) has a disability
3. One government department should be identified to take responsibility for the needs of siblings of people with disability
4. Siblings and their unique perspective should be included when developing policies that will benefit people with disability and their families
5. Particular efforts should be made to include siblings in policy considerations regarding the issue of 'ageing carers'
6. Siblings should be included in government and organisation agendas not only as 'carers', but as an important and distinct cohort within families in their own right

Recommendation 2: Family support

1. When developing programs/services for people with disability ensure a person-centred approach that takes into account their family connections
2. Family support should include *all* family members, and should strengthen *all* family relationships
3. Include siblings in any programs that target parents, families or ageing carers of a person with a disability
4. Develop pathways for families to plan for the future, which include teen and adult siblings in such discussions, alongside the person with disability and other family members
5. Foster more collaboration between disability groups, parent groups and adult siblings to ensure greater mutual understanding

Recommendation 3: Adult sibling support

1. Ensure appropriate resources are provided for the support of siblings across the lifespan and to sustain the involvement of siblings in the lives of their brothers and sisters with disability
2. Ensure programs are developed that enable siblings to connect with other siblings via face to face or online programs and via other evidence-based methods of peer support
3. Support a national peak body for siblings to collect data, carry out research, develop resources and services (e.g. website information, online forums etc.) and act as a co-ordinating body for the sector
4. Develop pathways for siblings to access support as brothers and sisters, not necessarily through 'carer' services
5. Provide more resources to siblings living in regional and rural settings and to siblings from CALD and indigenous backgrounds
6. Encourage the 'voices' of siblings to be heard, e.g., by including them in policy development; showcasing sibling case studies and stories in the media and in publications about the impact of disability within families.

Recommendation 4: Research and education

1. Develop accurate data about the numbers of siblings of people with disability in Australia and the roles they play in the lives of their brothers and sisters with disability
2. Promote more research to understand what siblings are contributing, their challenges and needs, the barriers/enhancers to their involvement with the person with disability and the implications for their relationships. This should include cost benefit analysis of what siblings contribute.
3. Support evaluation of and research into different peer support models for siblings in order to extend the evidence-base for effective models of sibling peer support
4. Research the difficulties in reaching adult siblings for peer support, e.g. identification and recruitment
5. Expand research into the personal support networks of people with disability with a focus on the roles of adult siblings, including exploring how the personal support networks of people with disability might support adult siblings as well as their brothers and sisters
6. Ensure both people with disability and their siblings have input into research and program development
7. Support a national peak body for siblings to be a 'clearinghouse' of research information

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 and ways to support them
2. Develop models of effective collaboration between families and providers, in order to support providers to reach out to the whole family
3. Develop 'national practice guidelines' to improve capacity of service providers to support and enable siblings to develop a 'good life' for the person with disability and themselves
4. Develop training materials that could be more widely used by the relevant sectors – disability, health (including GPs), education and community services.

Appendix A
Analysis of the Survey for Adult Siblings

Background

Siblings Australia is a national organisation that is committed to improving the support available for siblings of children and adults with disability, chronic illness and mental health issues. It aims to create connections between siblings, between parents and siblings, and between families and professionals, with a focus on strengthening families.

During late 2016, Siblings Australia undertook a survey as part of their Department of Social Services (DSS) funded Capacity Building Project "Creating Capacity: Support for Adult Siblings". The project aims to develop opportunities for peer support between siblings of people with disability, and develop online resources for adult siblings about the NDIS and the different roles that siblings might play in supporting their brother or sister with disability.

The purpose of the survey was to find out from siblings their needs in relation to supporting their brother or sister becoming involved in the NDIS. The survey was developed by the project's Reference Group, and circulated widely through email listings, Facebook, Siblings Australia website and personal contacts. The survey remained open for approximately one month, and reminders were sent prior to closing.

Key Findings

In total, 336 responses were received from each state and territory, with approximately 70% from metropolitan areas. The largest age group of respondents was in the 25-34 age bracket (approx. 30%), followed by the 18-24 age bracket (approx. 21%).

Eight percent of respondents spoke a language other than English at home, and approx. 15% had more than one brother or sister with disability. Intellectual disability / cognitive impairment was the most highly represented disability (approx. 62%), followed by autism (26%).

More than half of the respondents' brothers or sisters with disability live with their parent, and 16% live in group homes or similar. Approx. 41% of siblings are in daily contact with their brother or sister, and another 22% are in weekly contact, with 41% providing either weekly or daily care or support. The majority of siblings (57%) said that they were happy with the amount of contact they have with their brother or sister with disability. Some wished they could have less contact but the sense of responsibility made that unlikely.

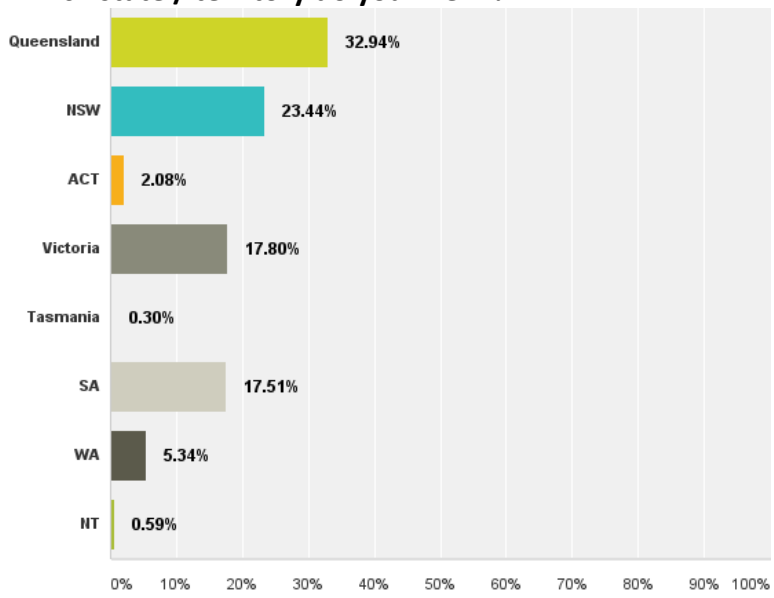
The severity of the disability and the resultant daily impacts influences how a sibling interacts with their brother or sister with disability. Sometimes siblings are more able to have a more 'sibling' role, enjoying outings and each other's company. Other siblings perform primary caregiving roles either on their own or alongside parents or other service providers. The most common type of support provided was emotional, with respite for parents, direct care, community outings, financial support, transport and advocacy all being mentioned.

Approx. 40% of respondents said they know 'a little' about the NDIS, and 25% said they know nothing or only that it exists. The majority (54%) said their brother or sister was 'unlikely to understand' the NDIS. Of these, 68% indicated their brother or sister lived with intellectual or cognitive disability; 26% indicated autism.

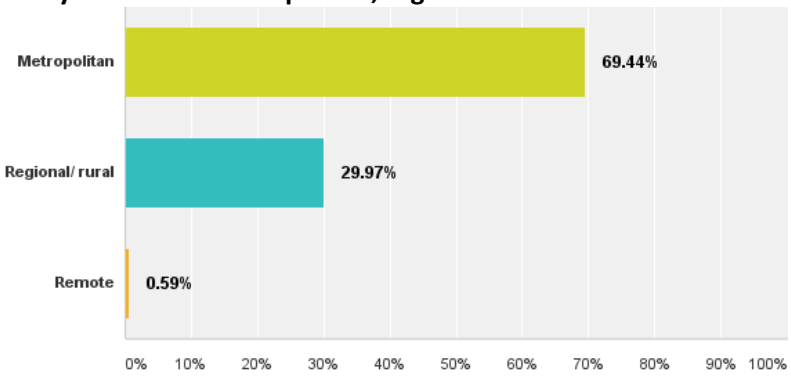
The majority of siblings (69%) want to know more about what supports are available under the NDIS and 53% want to know about what support is available for families through the NDIS; other information siblings are keen to know about includes: sibling roles in service systems; support available to siblings; the impact of being a sibling; planning ahead for their brother or sister and issues in advocacy. Further detail about each of these areas is outlined below.

Detailed responses

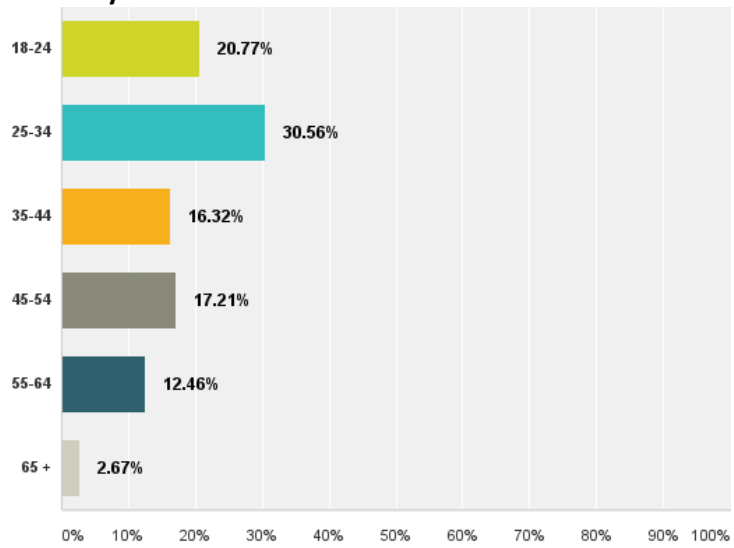
Q1: Which state / territory do you live in?



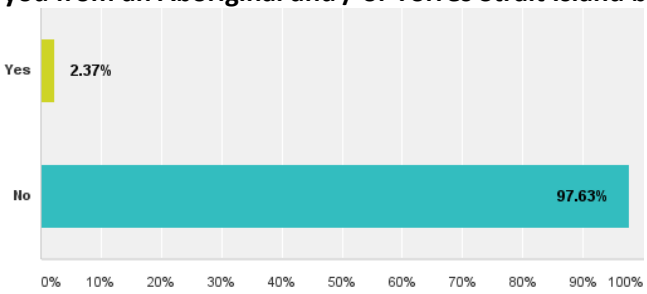
Q2: Do you live in a metropolitan, regional or rural area?



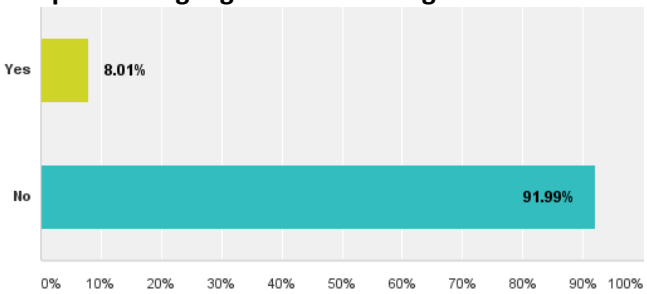
Q3: How old are you?



Q4: Are you from an Aboriginal and / or Torres Strait Island background?



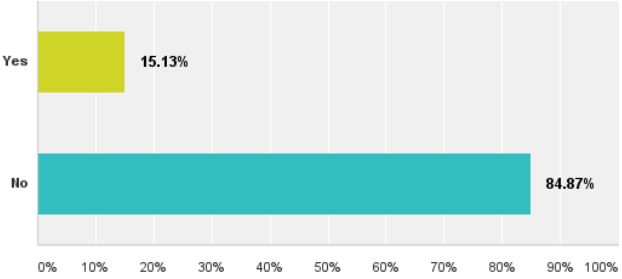
Q5: Do you speak a language other than English at home?



Q6: If yes, what language do you speak?

Auslan, Spanish, Italian, Tagalog, Bahasa, Greek, Korean, Mandarin, German, Arabic, Tigre, Singhalese

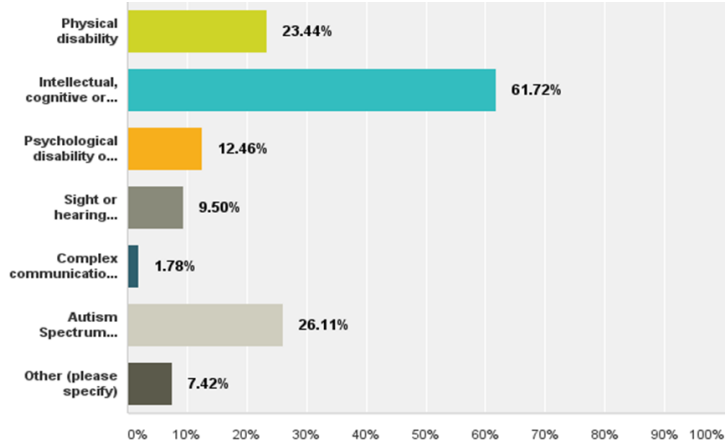
Q7: Do you have more than one brother or sister with disability?



Q8: If yes, how many brothers or sisters with disability do you have?

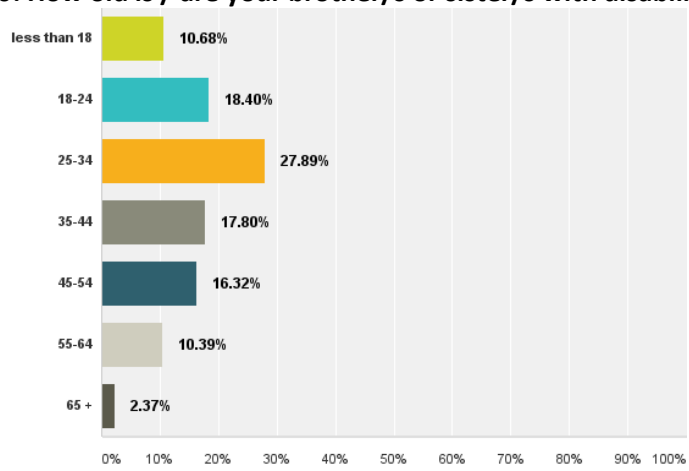
- 35 respondents have 2 siblings with disability
- 4 respondents have 3 siblings with disability

Q9: What type of disability/ies do your brother/s or sister/s have?

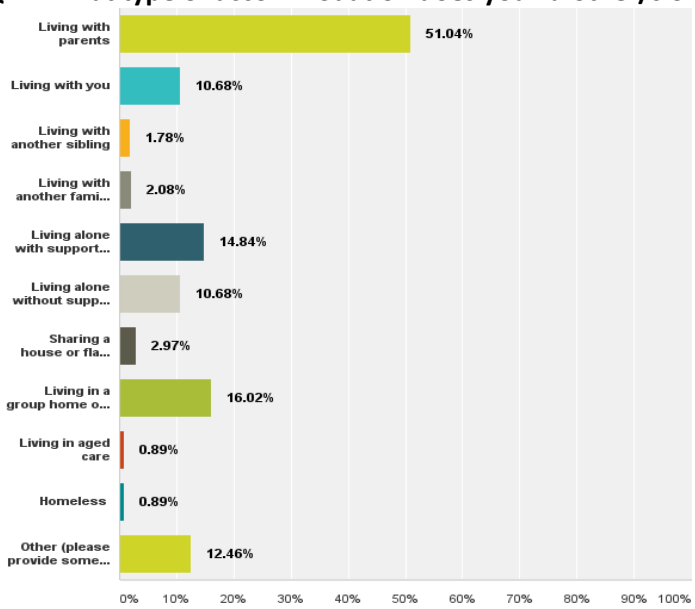


'Other' includes epilepsy and ADHD

Q10: How old is / are your brother/s or sister/s with disability?

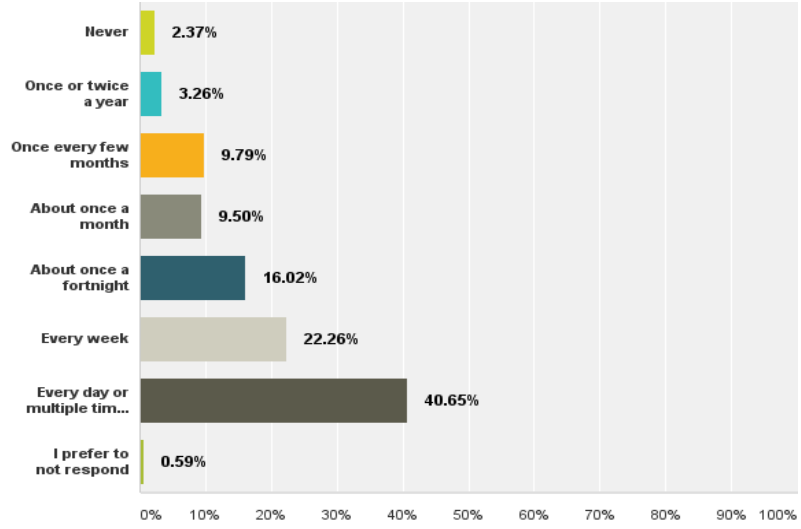


Q11: What type of accommodation does your brother/s or sister/s live in?

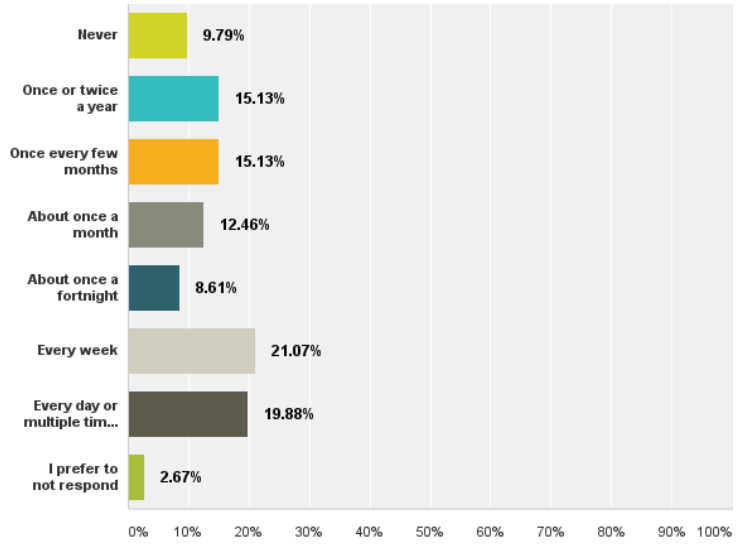


Responses under 'other' generally provided more detail of the option ticked above, but also other scenarios included living with partner with/without support services, living in family home with parents and siblings.

Q12: How often are you in contact with your brother/s or sister/s with disability?



Q13: How often do you provide care or support for your brother/s or sister/s with disability?

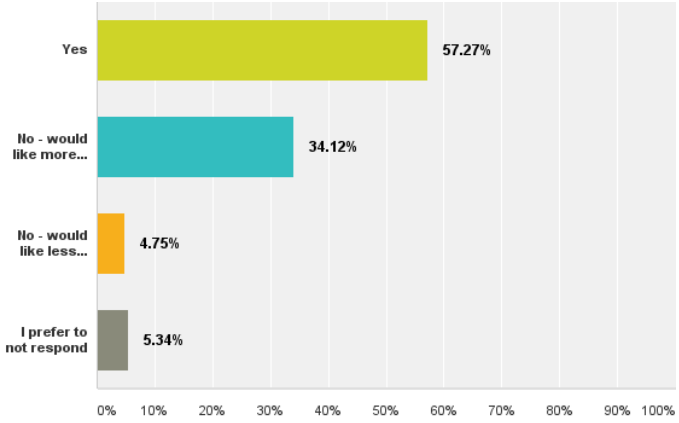


Q14: If you do provide care or support, what sort of support do you give (e.g. emotional support, transport, taking to appointments etc)

There were 275 responses to this question all detailing a range of different inputs from siblings. Whilst it cannot show the full picture, a brief summary of these inputs is provided in **Annexe 1**, ranging from being like other brothers and sisters, where there is no disability, to very significant hands-on caregiving roles. The severity of the disability and the resultant daily impacts influences how a sibling interacts with their brother or sister with disability. Sometimes siblings are more able to have a more 'sibling' role, enjoying outings and each other's company. Other siblings perform primary caregiving roles either on their own or alongside parents or other service providers. From the answers given to this question it is clear that siblings are providing a huge amount of support for their brothers and sisters with disability. Even if the person with disability accesses good support services (and this might improve under the NDIS) it is likely that siblings will still perform a range of crucial tasks – managing services or finances, helping with medical decisions, providing emotional and social support.

The follow shows a word cloud of most frequently used words in response to this question; the bigger the word, the more it was mentioned.

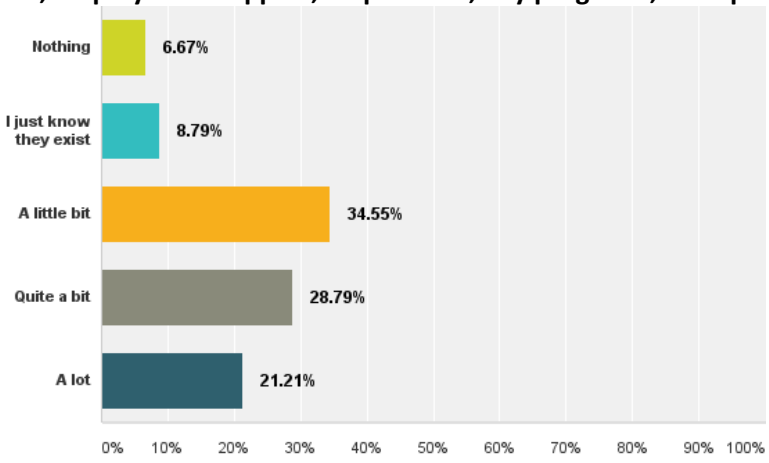
Q15: Are you happy with the amount of contact you have with your brother/s or sister/s?



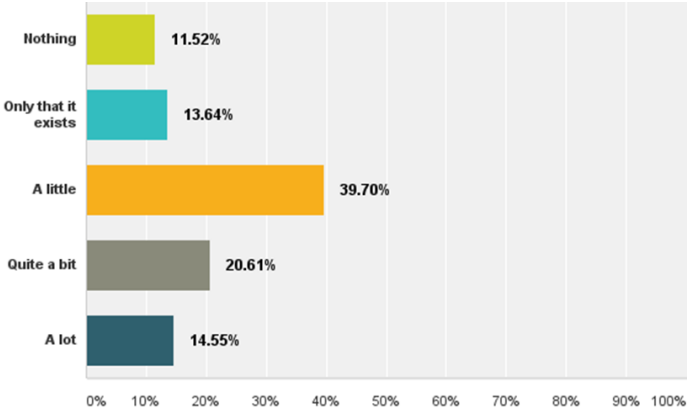
Q16: If you would like to, please give some background to your answer on Question 15

The majority of siblings (57%) said they were happy with the amount of contact they have with their brother or sister with disability. Some wished they could have less contact but their sense of responsibility made that unlikely. Many are in the so-called 'club sandwich' generation, commenting on the needs of their ageing parents and their own children, in addition to their relationship with their brother or sister with disability. A brief summary of responses is provided in **Annexe 2**.

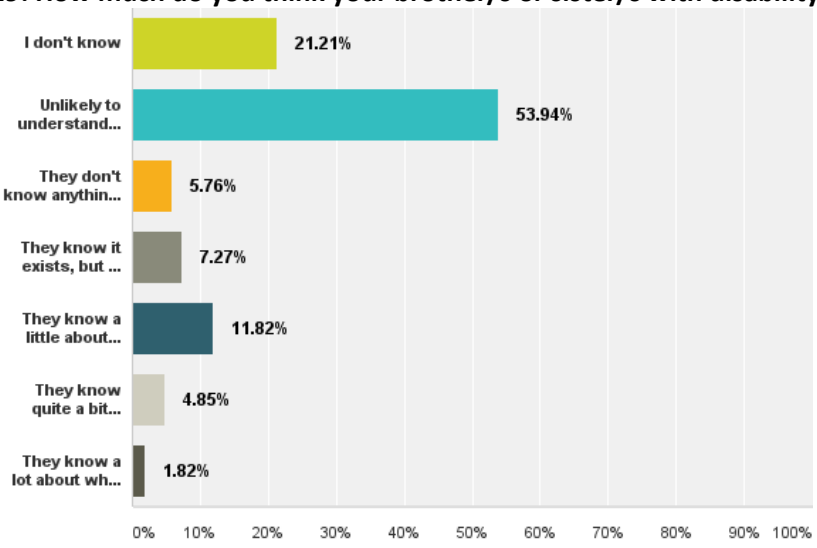
Q17: How much do you know about disability support services (e.g. paid care support, advocacy services, employment support, respite care, day programs, therapies)?



Q18: How much do you know about the NDIS?

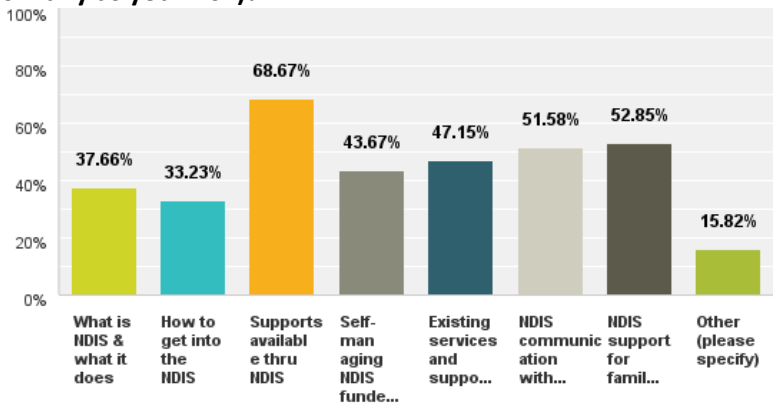


Q19: How much do you think your brother/s or sister/s with disability knows about the NDIS?



178 people said their brother or sister was “unlikely to understand”. Of these 178, 68% indicated their brother or sister lived with intellectual or cognitive disability; 26% indicated autism.

Q20: What would you or your brother/s or sister/s like to know more about with regard to the NDIS (pick as many as you wish)?

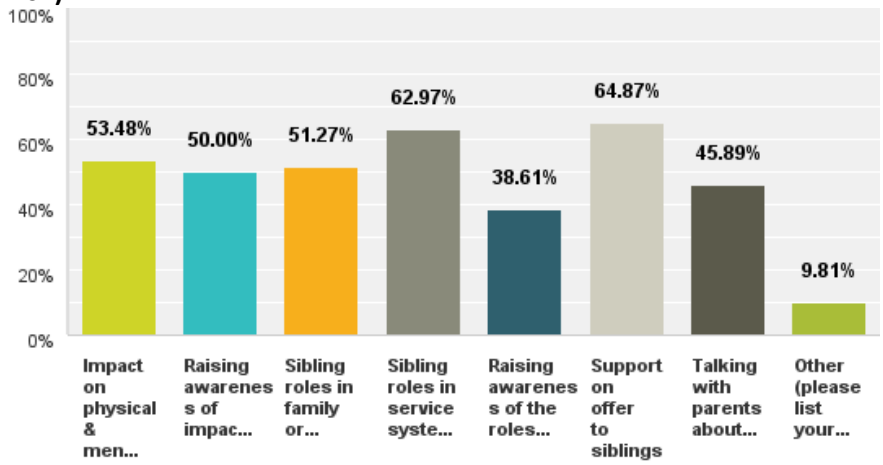


‘Other’ included:

- intersection of aged care and NDIS,
- gaining more financial assistance,
- leisure activities under the NDIS,
- family succession planning to assist person with disability,
- lack of NDIS information from service providers,
- paying for shared accommodation support under the NDIS,
- cultural needs being met by NDIS, appealing NDIS decisions.

The answers to these questions showed the complexity of the situations faced by siblings of PWD. The most needed information was about the services and supports available through the NDIS but there was a range of other issues that people would like information about.

Q21: What information about siblings of people with disability would be helpful to you? (pick as many as you wish)

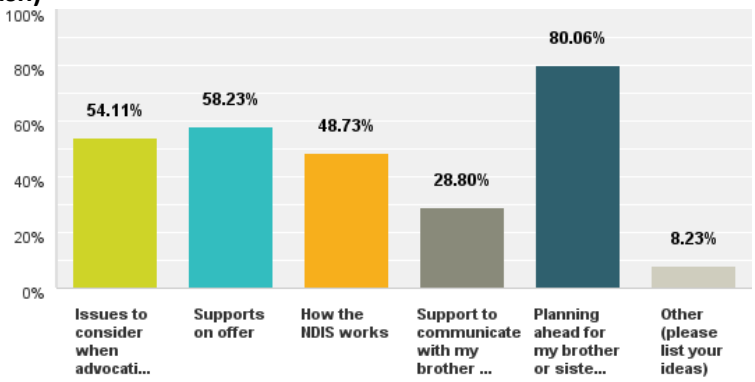


Most were interested in what support was available to siblings, followed by more understanding of the roles siblings can play within the service system, the impact on siblings' physical and mental health, and what roles siblings might play in the family.

'Other' included:

- taking over from parents when they die,
- sibling support groups for over 65,
- support groups for siblings of people with psychiatric disabilities,
- raising government awareness of siblings,
- respite,
- siblings with intersectional challenges e.g. from minority backgrounds that further impact care-low socioeconomic background, migrant or refugee background, indigenous background, etc.,
- preventing exploitation from service providers.

Q22: What information would be helpful to you in supporting your brother or sister? (pick as many as you wish)

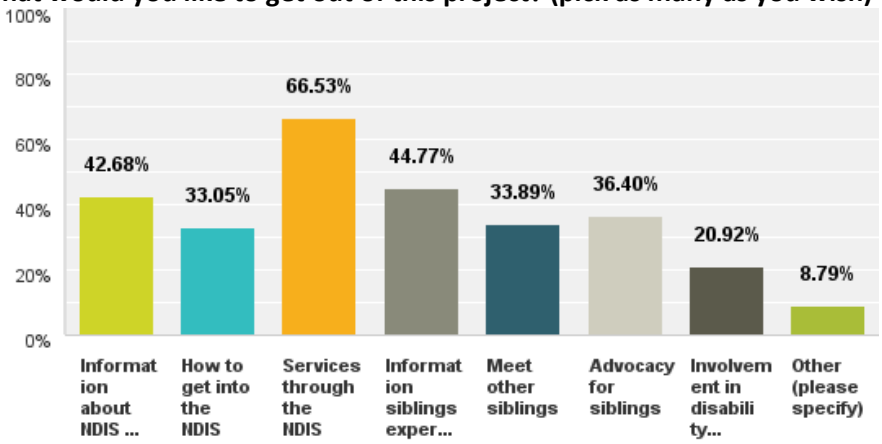


Other included:

- Guardianship
- Residential care for people over 65 with mental health issues
- Planning now
- Having the system recognise siblings in same way as parents when parents are deceased
- Available advocacy services
- Legal implication as next of kin without having formal guardianship
- Improved services and facilities in regional areas
- Dating service for people with intellectual disability
- Rights and how to make complains with service providers

- Mental health support to adult siblings who are carers
- Doing you will to provide for sibling
- Support for dual diagnoses

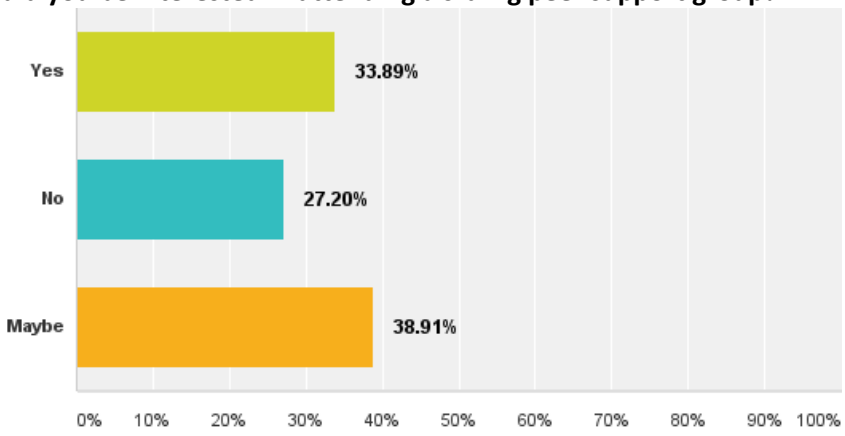
Q23: What would you like to get out of this project? (pick as many as you wish)



'Other' included:

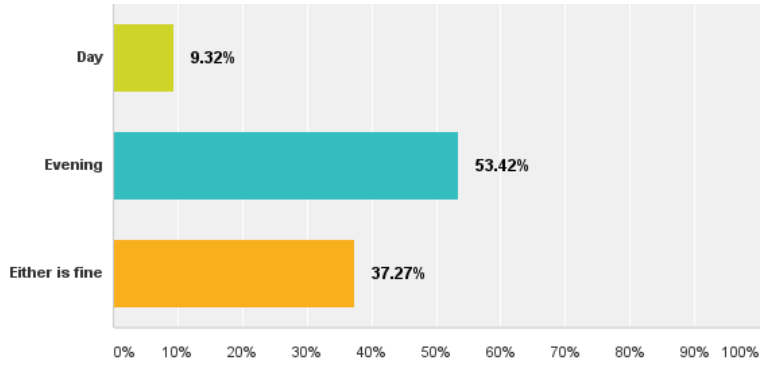
- Recognition from Govt about amount of involvement siblings play in unpaid care, plus support from Govt
- Raising awareness about impact of disability on all family members
- Caring from a geographic distance
- Development of supports which actually do support the person and their family
- A tool that directs people to key NDIS info for quick reference
- Succession planning
- Support to develop a great NDIS plan
- Importance of people with disability have an 'ordinary life'
- Whole of family approach needed in disability policy
- Keeping individual with disability engaged when families have all control

Q24: Would you be interested in attending a sibling peer support group?

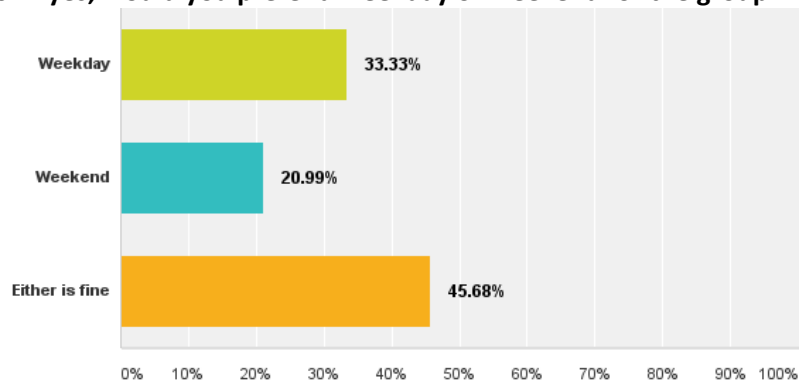


Reasons for answering 'No' included: feeling that they didn't need support, or that they already had a good support network, social anxiety, having their own disability or illness, being too busy or overseas, not wanting to be involved in hearing others' 'inspiring stories' or not wanting to be involved in hearing others' negativity

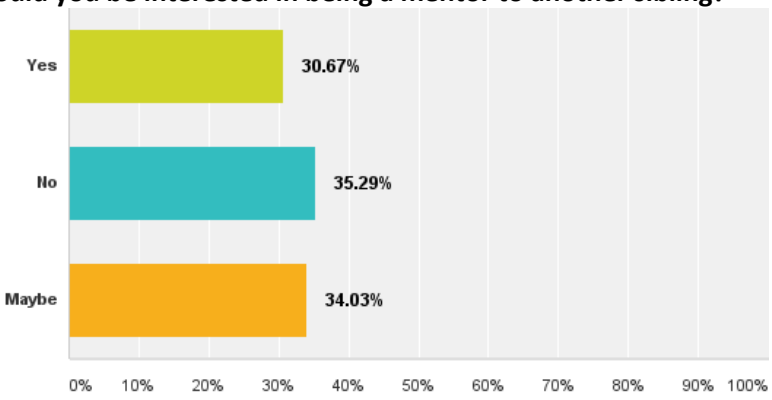
Q25: If yes, would you prefer day or evening for the group?



Q26: If yes, would you prefer a weekday or weekend for the group meeting?

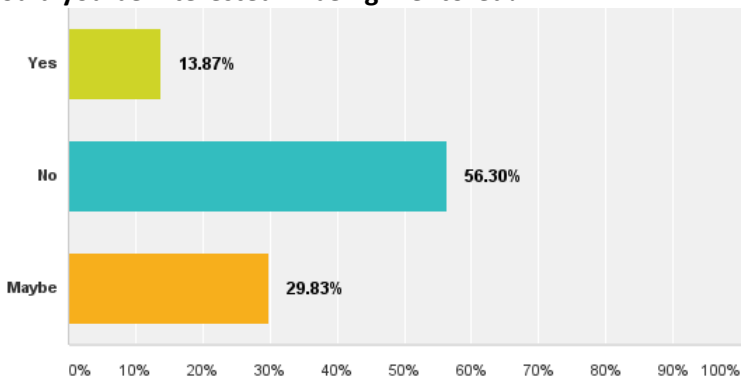


Q27: Would you be interested in being a mentor to another sibling?

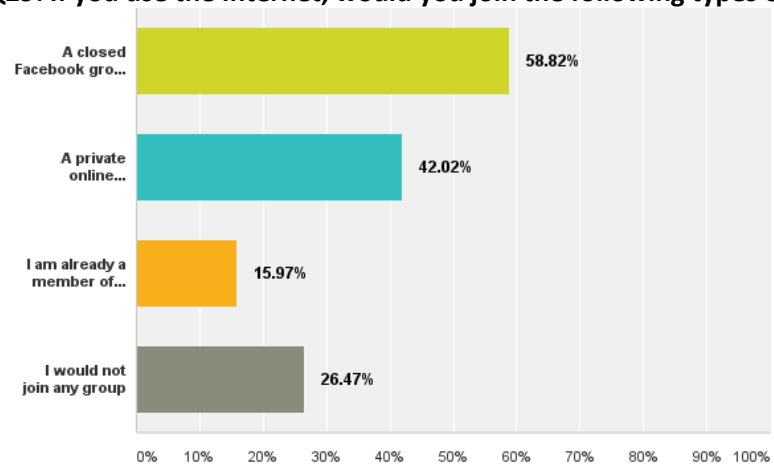


Reasons for answering 'No' included: being too busy, it being too emotional, or too similar to their job

Q28: Would you be interested in being mentored?



Q29: If you use the Internet, would you join the following types of groups (tick all that apply)?



Most siblings wanted a closed Facebook group or a private online forum.

Q30: Any there any other issues or comments you would like to make?

- Suggest having a state or national award to recognise outstanding siblings. Help raise community awareness
- Awareness of siblings in rural and remote areas
- Important to engage early with siblings in the case of brother or sister acquiring disability
- Make sure project maintain focus on value of people with disability, as siblings, family members and community members
- Advocacy for siblings in schools – to assist teachers understand what may be occurring in student's life e.g. information pack for teachers
- Stories from siblings whose carer parents have passed away, and how the transition occurred
- Tools for siblings about confidence building
- Information about mechanisms to assist the person with disability less reliant on family e.g. circles of support
- Have casual sibling social groups not just formal support groups e.g. cinema group where you don't always have to talk about your situation
- Siblings with mental health have unique experiences – best to have separate support groups for these people.
- Siblings may also have their own disabilities, particularly those which are genetic based.

Annexe 1 – Question 14 detailed summary

If you do provide care or support (for a brother or sister with disability), what sort of support do you give (e.g. emotional support, transport, taking to appointments etc)

1. Being a brother or sister
   - *Spending time with. Going places e.g. movies, beach etc*
   - *Just being a brother. Going for beers, taking him on my truck or just chilling out at family events*

2. Emotional support

   Many siblings identified 'emotional support' as something that they provide very regularly. Sometimes this is the only thing they provide; most times it was included in lists of other contributions. Sometimes it includes help with decision making. The word cloud shown previously indicates how often emotional support was mentioned in relation to other supports. There were 150 instances of the word 'emotional' in response to this question.
   - *I provide my brother with emotional support in the sense that we are friends and he confides in me anything that is bothering him e.g. work or social issues*
   - *Just a good solid relationship, emotional support plus lots of love and patience*
   - *Phone support if he is anxious or lost or getting bullied at the bus stop*
   - *Walks, make dinner, talk, encourage*

3. Giving parents a break or support

   Sometimes this involves taking over the care of the PWD so parents can have a break or it can involve debriefing with parents to support them
   - *My brother has come to stay with me while my parents were overseas*
   - *Respite for my parents. I take him out shopping and support him to further his independence.*
   - *Stay with her so my parents can go out, have respite…feed her; help her into wheelchair, transfers to bed. Give her cuddles, talk with her and give her foot massages*
   - *Respite for my parents. Full care*

4. Community access
   - *Access to community to do things he enjoys e.g. having a coffee or eating lunch out. Catching the Citycat*
   - *Transport, going out, recreational, financial, socialisation*
   - *Inviting to social events, trying to stave off loneliness*
   - *Support in maintenance of friendship networks*

5. Some caregiving alongside other caregivers (paid and unpaid)
   - *I take him out shopping and support him to further his independence. Teach him life skills*
   - *My brother does receive support services morning and night, but often these are not enough. I spend a great deal of time with him, I cook, I clean, I keep him company, I monitor his 24 hour oxygen and respond to emergencies*
   - *Physical care – personal needs, hygiene, transport, medical appointments, staff training, staff liaison*

6. Major caregiving
   - *Everything - emotional, transport, doctor and therapy appointments, nursing hygiene care, therapy exercises, community access, companionship, carer for holidays or work related events, medical support, financial support, guardianship support when parents are not available or not able to help, forms and applications for disability support etc Companion Carer for community events, sport, concerts. Fundraising etc.*

7. Other activities like transport, taking to medical appointments

8. Finances

   Some siblings provide money to their brother or sister at different times; some manage their finances, or help the person with disability to manage their money. Sometimes this occurs even if the sibling is far away.

   - *Managing all financial and business transactions from afar [in different states], helping with all staff recruitment, checking time sheets for pays. All guardianship matters come through me re health and finances. Phone in or attend all network meetings each 6 weeks. Visit 4 or more times a year and work as live in carer for my sister for 10-14 days at a time.*

9. Interacting with the service system, and current or upcoming NDIS involvement
   - *Advice re transition to NDIS ; support in the process of transition to NDIS*
   - *Centrelink correspondence nominee Assisting with DSP and NDIS applications*

10. Advocacy
    - *Assistance to speak up about anything that concerns her*

11. Whole of life support

    Many siblings listed a wide range of roles they play
    - *Everything because she lives with me*
    - *Transport, sleepover, assist with personal care, give medication, emotional support, take to appointments, family functions, fill in numerous forms, do finances, do paperwork for her respite, QCAT forms, disability trust forms, manage her finances and health care needs*
    - *Emotional, physical, transport, medical, advocate, domestic (laundry, cooking, cleaning), personal hygiene and personal safety and security support provided by me 24/7 when he is with me and not at workshop 3 days a week*
    - *Emotional and practical support, appointments, advocacy, care co-ordination, administration, counselling, access liaison etc. Basically an unpaid social worker and psychologist*

Annexe 2 – Question 16 detailed summary

If you would like to, please give some background to your answer on Question 15 (contact with brother or sister)

Some people would like less contact, but the sense of responsibility made that unlikely.

- *The situation would be untenable if I was not involved.*
- *I act like a case manager. I'd prefer to just be his brother.*

Some would like more contact, but this was difficult due to distance issues (see below) or because the person with disability did not want more or any contact. And sometimes the relationship is different with different family members. Certainly many siblings show a lot of love and care in relation to their brother or sister.

- *Love her to bits. Happy to help her whenever she needs.*
- *I care for him as if he was my child.*
- *I don't see my older brother much which I am happy about but I am very involved with my younger brother who has autism, dyspraxia, bipolar and depression. My relationship with him is important to me and I like being able to help my parents support him.*

Even if siblings are not providing direct care they can still provide important support.

- *My brother can call me up to 4 times a day for re-assurance and because he is lonely.*

Emotional impact was frequently mentioned.

- *There's always a mixture of emotion involved to varying degrees at different times, guilt, shame, sadness, hopelessness, despair, anger, pity, frustration, hope, love, sometimes fun*
- *It can get overwhelming with the pressure of the emotional and mental support.*
- *I find the level of emotional support and advice is draining.*

The difficulties experienced by siblings can be due to a number of issues. The following is just a few of the factors and sibling responses.

<u>Isolation</u>

- *I am happy to see him and be supportive but I wish there was someone else to share the responsibility.*
- *I would like some time to myself, it would be nice if someone could help me out.*
- *A lot of the time it is just me helping him and sometimes it just gets to me and I can't deal with it.*

<u>Distance</u>

Many talked of distance as being the main reason they had less contact with their brother or sister with disability. Some live in a different city or different country, but some are in the same city but with a reasonable distance between.

- *My parents moved with my brother to Tasmania last year. I wish I could see them a lot more than I do.*

<u>Own commitments</u>

Others find that with their own full-time work and young children (or other commitments such as ageing parents or in-laws) it is difficult to give more. Some feel very guilty about this.

- *I work full-time; have children and a very busy life. Whilst I should spend more time with my sibling with disability it is very hard to prioritise. I also have a parent with dementia.*
- *I often find myself feeling very conflicted …. and guilty ….and tired.*

<u>The future</u>

Many siblings talked about the fact that even if they are not seeing a brother or sister as much as would prefer in the present time, they realise that this will need to change as parents age and become less able.

- *We currently live about 2 hours away from each other and I don't see him as much as I would like. I am hoping this will change soon as I am aware that as our parents get older I am going to need to take a greater role in providing physical support to him.*

- *I think I provide plenty of support now, but know as my parents get older I will have to take on a lot more responsibility for my sister*

Difficulty with parents

For some siblings, the relationship with parents has broken down and so contact with their brother or sister who still lives with parents has become limited. Others clash with parents on what is best for the person with disability.

Parents have difficulty handing over the caring role so it is hard to start future planning and overwhelming to think about all that I don't know.

Difficult behaviours

Sometimes the behaviour of the person with disability means the relationship between siblings is difficult.

- *I can only see my brother if mum and dad are around because I am too anxious to be alone with him.*
- *My brother has very severe autism and is deaf so up until he was relinquished by my parents 2 years ago he made my life hell for the 18 years he was a part of it. I want to see him but it is better if I don't.*

One said, '*I want to (have more contact) but I self-protect myself*'.

- *Contact with both siblings is fraught with difficulties. It's like walking on eggshells. It has become more difficult as we age.*
- *I need to look after myself and have boundaries, therefore weekly or a couple of times a week supports my own wellbeing without it negatively impacting*
- *Because of the early trauma of having 2 siblings with quite severe disabilities, I have ended up living on the other side of the country due to developing depression/anxiety by early adulthood. I effectively 'ran away' as a coping mechanism. I am now in another State. I remain close and would like more contact but it is practically very difficult.*
- *Only when his violence toward me escalated have the Disability Services Department stepped up their game. My anxiety about his serious violence is now creating medical issues for me.*

Sometimes it can be a combination of factors such as busy-ness but also behaviour issues.

- *I would like to see her more but working full-time and having very young children it is hard to find the time. I need to have another adult with me if I have my kids and sister as my sister has seizures unexpectedly or can be aggressive with my toddler.*

When designing the survey we changed the number of follow up questions re how often a sibling sees their brother or sister, so that it would be less confronting to survey participants. However, that came at a cost to knowing more about the time spent by siblings in supporting a brother or sister with disability.

Appendix B
Report on peer support groups

1. Number registered

60 siblings registered for the peer groups, from around Australia

2. Age range

Age Range	Under 20	21-30	31-40	41-50	51-60	61-70	Over 70
numbers	1	19	20	4	7	1	1

Some attendees did not indicate their age

3. Disability of brother or sister

The following disabilities were represented:

Autism	15
Intellectual	13
Down Syndrome	8
Cerebral palsy	8
Multiple	5
Sensory	4
Mental illness	3

CMCT, ABI, Cornelia De Lange syndrome, Cystic Fibrosis, x-culb4, epilepsy, high physical care needs were each noted once by a sibling. Again, as with the survey findings, it seems that siblings of people with intellectual disability are more in need of support and information.

4. Reason for registering

The following were cited as reasons for wishing to be involved in the group:

- Support x 8
- Understanding x 6
- Chance to share knowledge and experience in how to deal with family, sibling and support agencies including NDIS
- To meet other sibs
- New friends, advice on coping
- New friends, ways to cope when times are tough
- Knowledge
- Moral support
- Support and advice for the future as I will most likely be the primary carer of my brother when my parents can no longer look after him.
- Reassurance that I'm not alone, help others understand they’re not alone. Share ideas and have a common interest. Others with "normal" sibs often don't relate to me about my family
- Safe space to share feelings/thoughts on particular struggles/and triumphs of being a sib.
- Support, like-mindedness and advocacy
- Understanding of how NDIS is working and best options
- Learn from other siblings about their experiences
- Connections, ideas, advocacy
- Disability services information, peer/social supporter
- Understanding from people who actually do understand.
- Gain more confidence in articulating to those that cannot understand, what it is like to grow up alongside a person with disability and what impact that has had on my life
- Just a chance to connect with people who get it

- To meet other sibs and develop a little community; to discuss the research I'm interested in.
- Meeting other siblings and sharing experiences
- Freedom
- Contact and support from other sibs. Information sharing, providing support to build resilience in each other
- Learning from others experiences on how to support a sibling later in life
- Friends and contacts for opportunities that better my sister
- Coping mechanisms - how not to let my brother's issues in life consume me without leaving him vulnerable; how to deal with agencies and carers that just want to tick endless boxes and lose sight of the individual and their family
- Meet others and learn more about the disability system and how we can support our siblings into the future.
- Meeting other people who have experienced the same thing as me and just chat about those experiences.
- Sharing ideas, networking
- To find strategies to manage stress through different situations
- Ideas and experiences with caring for/involvement in adult siblings' lives, and NDIS
- Find out what we can expect in years to come for my brother (opportunities, health, care) and what funding is open to supporting him and his caregivers.
- Knowledge & understanding to plan for independence and living for sibling
- Friendship, support
- Share experiences with people who understand
- Making connections with other sibs, being able to share concerns about the future, provide support to other sibs.
- To meet others who know how hard it is, talk things through, share ideas and suggestions, talk about what helps.
- Friendship, advice, emotional support, Social Worker help with grief etc
- Family overseas
- info about DSC accommodation
- Perspectives growing up
- I attended a sib forum some time ago and since this time I have really become more self-aware of what my life has been like and which parts of it have to do with my upbringing. I have been challenged many times since then trying to explain this to others (parents, partner, friends, and colleagues) and no one seems to understand the impact or its relevance to life today. Bringing awareness to myself has also brought out a few frustrations and some changes in my personality. I am so excited to be able to better articulate the "sib experience" to a) improve my relationships and b) help other sibs AND parents understand.
- I think that it is important that there is a network for siblings. So thank you for organising this. Looking forward to this opportunity :)

5. Group event details

Groups were run as follows:

Location	Date	Total number attendees	Number of leaders
Brisbane	April 1 May 20	10 4	3 3
Sydney	April 1 June 3	13 12	3 2
Melbourne	April 8	6	2
Adelaide	April 1 May 6	10 8	4 3
Perth	April 8 May 6	8 5	8 2

6. Evaluation

Nineteen sibling group participants responded to a short evaluation survey.

Q: Do you think peer support is important for adult siblings?

All participants reported that peer support was important.

Q: Are you pleased that you attended the sib peer group?

Most (95%) participants (*n*=18/19) were pleased they attended the group.

Group Location	Comments
Brisbane	Good to make contact with others in a similar situation. It was nice to be in a group where people understood my (mixed) feelings regarding my sibling. Connection. It was such a good opportunity to meet people in similar situations and know that I'm not alone Great to know others are in the same position and you can share information and experiences with no judgement
Sydney	Incredibly useful to meet and learn from peers with similar life experiences. It's encouraging to meet others who have lived similar experiences. And many of them have different types of knowledge and wisdom to share - from NDIS to dealing with parents to getting good care etc. the group was and will be so valuable! Interesting Great to connect with other siblings! A rare opportunity and great energy in the room
Melbourne	Low numbers, would like to see more people attending
Adelaide	I have met few people in the past who share similar experiences to me with a sibling with disability. It's important for people who are having to meet an extra challenge in life to have extra support which can be provided by others in a similar situation. Pleasing to see others connect with Sibs for the first time. Good to meet other sibs and start to share experiences Gives a better understanding that others have been through similar experiences and that you may be able to assist in discussions or others may be able to assist you Emotional support
Perth	I don't really know other people who are siblings of someone with a disability, so it was nice to meet other siblings. First time I have just been able to share 'face to face' the experiences we face. I felt a sense of belonging that I haven't had the chance to before. Important to find support and a peer group which can be difficult in the wider community. Much of services is (necessarily) disabled person based but the wider family group has its own impact which is largely ignored. I think it's important to start young though.

Q: What is one thing you most enjoyed about the group?

Group Location	Comment
Brisbane	Participants immediately recognised common experiences and feelings although diversity of ages, disabilities, situations. The feeling of understanding Hearing everyone's stories. The innate understanding we had for one another regarding our experiences as siblings, regardless of the type or severity of our sibling's disability.

	Shared understanding.
Sydney	That I can talk with them about issues that non-siblings just don't understand. Planning for future meetings - what the group will cover in the way of sharing experiences and knowledge. Was a bit overwhelmed, new worker and late so didn't exactly enjoy. *This is referring to the fact that the sibling supports her brother and the worker who was going to watch him while the sib went out was late for the shift so sib was late to peer group* There was a lot of enthusiasm for the group and some really interesting people in the room. Some great ideas came out about ways to keep the group together and things to do together
Melbourne	Common stories
Adelaide	Hearing diverse experiences of others The sense of community with others in the group. Seeing others connect and have ah ha moments when they realise they are not alone in their experiences and feelings. Meeting other sibs. Sharing experiences and planning out other groups – exciting! Relaxed atmosphere and ease of discussions
Perth	Sharing experiences about our siblings Just meeting others, particularly a couple of sisters around my own age and talking about expectations put upon us by parents etc. But also meeting younger sibs and welcoming them. I wish I had has this opportunity when I was younger. Meeting everyone and seeing their individual response to growing up with a disabled sib.

Q: Did you feel welcome in the group?
All participants reported that they felt welcome in the group. One participant further commented that leaders very welcoming and respectful.

Q: What could be improved about the group?
Suggestions included ensuring there is an understanding that not all sibs are interested in 'transition of care from parent to sibling'. Some sibs may not want that. Suggestions mainly focused on practical issues like spreading the word more broadly to ensure more attendees, wanting it closer to their own home, splitting the group into different age groups, some organised presentations.

Q: Do you feel more connected since attending the group?
A majority (71%) of participants who answered this question (*n*=12/17) felt more connected since attending the group. (Two participants weren't asked this question.)

Q: Do you hope the group continues?
Most (*n*=18/19) participants hoped the group continues. (One participant did not respond to this question.)

Q: Other comments

- Small inaugural group - need to build numbers early so group remains viable as not everyone will be able to attend each meeting.
- I think the group has potential if it can be open to all siblings not just those who want to take over care of their brother or sister with disability and show understanding of the variety of impacts.
- I wish I could have attended something like this from my teenage years. And I really hope this initiative can spread more widely
- This is a tremendous idea which should definitely continue!
- Keep up the great work! Thank you!
- I'm still trying to organise to get there on Saturday. Could we try a Skype in option or another way of access too? Hope I can make this month's session

- I felt more connected during the group but being only the first meeting I am hoping there will be enough momentum to keep going on to create some more connection. I felt quite aware that I was a solo sibling compared to some others in the group. I even commented that I felt a little jealous that they could support each other, I do feel quite alone in not having any other sib (or one that is involved) for me to support my brother with disability. I often close down from contact with him as I feel it is too stressful to do on my own. It is hard to ask people outside the immediate family to support you.

7. Peer leaders

There were 28 adult siblings who applied to become Peer Leaders. A training webinar was developed and follow up material provided on managing groups, common pitfalls, develop meeting agendas etc.
Some did not take on the role as they were the only one in a certain location (usually more regional areas). If support can be found, developing more regional groups could be a priority going forward.
Some had to pull back from the role due to other commitments but we now have a group of 14 committed leaders. The project sought to provide ongoing support to these leaders via emails, Facebook etc

Appendix C
Further reading

Research studies in the field

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Appendix D
Siblings Australia

Siblings Australia was established in 1999 with a focus on siblings of children and adults with disability or chronic illness. Over a period of 18+ years Siblings Australia has developed a national and international reputation for its work with families and professionals. It aims to create connections between siblings, between parents and siblings, and between families and professionals, with a focus on strengthening families. The organisation's Mission is a simple one: *Siblings: Acknowledged, Connected, Resilient*.

Siblings Australia has built relationships with family, mental health, youth, education and disability agencies, in an attempt to increase the availability of information and support services for siblings, through increasing awareness, understanding, and skills at three levels:

- direct support to siblings (both children and adults)
- enabling parents to support their children
- working with service providers who, in turn, offer support to families (disability, health and education)

Information and support services take the form of written and online materials, workshops, a website and networking opportunities for families and providers. The organisation uses a 'settings' approach to improve the capacity of all areas in which a sibling operates – family, school, community. For a discussion about mental health promotion, in particular, for siblings and the need for policy directions see the guest editorial, published in 2008 in the Australian e-Journal on the Advancement of Mental Health.

Workshops

Workshops have been run for thousands of siblings, parents and service providers all around Australia (in both metropolitan and regional areas) and the Executive Director has been asked to present in the UK, US, Canada and several times in Italy. The workshops, in particular, have served to empower parents in supporting their whole family. Feedback has been overwhelmingly positive. The service provider training has included professionals from a number of sectors, including, health, disability, counselling and education, and where appropriate has included training in the *SibworkS* model developed by Siblings Australia in 2004.

However, with no imperative for agencies to include siblings, and given the constraints in funding for most agencies, the uptake of such activities has gradually reduced. In fact, since the introduction of the NDIS, requests for the above workshops have almost completely stopped.

Resources

The organisation has developed a range of resources both in hard copy and online, including:

- *Sibworks* peer support program for siblings aged 8-12 years
- *Stronger Siblings* DVD for parents
- *Siblings and Mental Health factsheet*

These resources can be purchased or downloaded at no cost via the website, which also includes a range of information and networking opportunities, including a directory of sibling support services. The organisation has a strong social media presence and facilitates closed Facebook groups for siblings, one in conjunction with the US Sibling Support Project. There is potential to greatly improve the quality and reach of these. In addition, the Executive Director's book, *Siblings: Brothers and Sisters of Children with Disability (*first published in 2002 and revised in 2014*)*[1] generated very powerful responses from around Australia and overseas. It has also been published in the US, the UK, and translated into Korean.

[1] Strohm, K.E. (2014). *Siblings: Brothers and Sisters of Children with Disability (revised edition).* Wakefield Press: Adelaide

Research

The organisation has played an important role in areas of research to inform social policy makers about the needs of siblings. These can be viewed on the website here

Advocacy

Siblings Australia has provided a number of submissions to government and other inquiries. There have been regular meetings with government Ministers and department representatives. Other bodies have also highlighted the needs of siblings, either as a focus or as part of an overall interest in child wellbeing. These can be found here. Of particular note are the Position Statement and Issues Paper from the RANZCP (this was endorsed by many organisations and provided to government) and the follow up paper (*Towards improved recognition and support for siblings of those with a chronic condition: A report on consultations*) by Families Australia and Siblings Australia that highlighted concrete directions for the future through a range of sectors.

In 2004, and again in 2009, Siblings Australia hosted a national conference on sibling issues, which brought together families, service providers, researchers and policymakers (including several from overseas). At each event delegates reinforced the need for a co-ordinated approach to sibling support measures and called on the Australian government to support such a measure. However, this was not taken up by government.

Siblings Australia deals with a high volume of enquiries on sibling issues, both through direct contact (phone, email) by parents and providers, and through the website. People continue to express concern about available services for siblings and that the value of Siblings Australia may not be sustained into the future, including through a petition in 2008, forwarded to government when funding was lost, and another in 2015. Comments from some of the signatories for the first petition can be viewed here and the second here.