

Submission to NDIS Quality and Safeguards consultation paper

Introduction

Siblings Australia welcomes the opportunity to contribute to the discussion around the National Disability Insurance Scheme (NDIS) Quality and Safeguards. This submission recognises that there are broad ranging issues surrounding quality and safeguards in relation to services for people with disability, but will leave most of these to be explored by those with much more relevant expertise. This submission will focus on issues related to siblings of children and adults with disability.

The literature around the NDIS states that it is a ‘new way of providing individualised support for eligible people with permanent and significant disability, their families and carers’. It should be noted that ‘families’ are included in this, and from this we can infer that the NDIS has some interest in siblings of people with disability.

How siblings are/might be included in the NDIS is still unclear, and Siblings Australia has been seeking to have further conversation with the NDIA about this matter. The organisation has also provided a response to the paper which sets out policy parameters for information, linkages and capacity building (ILC), in the NDIS.

First, this submission will address how siblings of people with disability might interconnect with the NDIS and the implications of that regarding the quality and safety of services for a person/people with disability (PWD). Siblings Australia believes very strongly that the best safeguard for PWD is for them to be surrounded by people who care about them and have a relationship with them. The sibling relationship is usually the longest relationship of any and so should be nurtured from a young age. Second, the submission will highlight the importance of quality and safety standards in relation to sibling support approaches.

How siblings intersect with the NDIS

The NDIS should have an interest in siblings for the following reasons:

1. Siblings will likely have the longest relationship of any with the person with disability. If siblings are supported they are likely to contribute much to the emotional and social wellbeing of their brother or sister. This is particularly important because many people with disability, especially intellectual disability, can become isolated. Without effective support, siblings have a tendency to move away from their family, with long term consequences for the whole family and for the person living with disability
2. 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 safety of services provided to their brother or sister. Some take over the ‘caring’ role when parents are no longer able, and are further stretched if this role extends to aged care. The effectiveness of this level of care is affected by the health and wellbeing of the sibling.

3. In cases where siblings take over the primary carer role, the handover period should be well planned and managed to facilitate a smooth and low stress transition. The family relationship provides an additional level of stress to the transition period, and where it is well planned, the safety and security of the person living with disability is better protected.
4. People with disability are at risk of physical and emotional abuse both within the family and in other community services. If we nurture and strengthen the sibling relationship from a young age there is less likelihood of harm to the person with disability in the home, and a greater likelihood that the sibling will be present to provide a supportive environment.
5. Siblings are at risk themselves due to the stresses and trauma that can be involved with growing up with a child with disability (CWD). There are risks to their physical, emotional and social health. We know that they have an increased risk of depression¹. Siblings Australia's report [Siblings and Physical Harm](#) showed that they can also be at risk of harm from a person with disability when the disability includes particularly difficult or aggressive behaviour.
6. The sibling support sector is under-funded, unco-ordinated and lacking in skills, capacity and resources. If siblings are provided with support, either through the NDIS or by other services, the NDIS should be requiring governance to ensure these services are safe and of high quality, to ensure the best outcome for siblings and for the whole family

In summary, siblings have much to contribute to the person with disability over a lifetime. However, they face their own challenges and need to be recognised as a key social support group, be considered in the planning process and have access to appropriate support, where required. This will have lifelong benefits for the sibling, the person with disability, the whole family and the whole community. Ultimately the best safeguard for people with disability is for them to be surrounded by people who care about them.

At this stage, in spite of siblings being identified as an important part of the informal support network for a person with disability the support options under the NDIS for this group are particularly unclear. It is encouraging that there are indications that this will become clearer.

Certainly, if siblings' lives are impacted by the disability, there needs to be consideration given to how these impacts can be managed and how a sibling can be supported through those. Of course, with better services through the NDIS for the child with disability, some of the impacts might be reduced. However, there are other less understood impacts that are just as important to consider. As siblings move into adulthood, they might take a more active role in supporting a brother or sister, particularly when parents age and are no longer able to meet those responsibilities. They need support to choose what role they are able/willing to play, understand and navigate the service system and to ensure appropriate outcomes for their brother or sister with disability and for themselves.

¹ Edwards, B., Higgins, D.J., Gray, M., Zmijewski, N., & Kingston, M. (2008). *The Nature and Impact of Caring for Family Members with a Disability in Australia*. (Australian Institute of Family Studies, Research Report No. 16.) Melbourne: Australian Institute of Family Studies.

The need for a quality and safeguarding framework

The consultation paper states that ‘as the NDIS rolls out there will be rapid change and a need to ensure that the services that are provided for people with disability are of a high quality’. The paper also stresses the need for national consistency in services.

The NDIS should provide scope for an assurance program that measures service performance and verifies the level of quality provided meets the client, NDIS and community expectations.

However, if families are indeed included in the NDIS then it is important to have a framework to ensure quality and safety of those services as well. For some groups of family members these frameworks may already exist external to the NDIS eg Carer associations, counselling services. However, in relation to services for siblings there is no quality framework.

If siblings are recognised in the NDIS or in its programs then there needs to be some oversight by the NDIA to ensure where services are provided to siblings from other sources, quality and safeguard assurances are in place. It is in the best interests of the PWD and the whole family if this is the case.

In summary, the Quality and Safeguarding framework is relevant to siblings in two main ways:

1. Siblings can play an important role in ensuring that the services for their brother or sister are safe and of high quality
2. If siblings are included in the NDIS there is a need to ensure that the services provided are measured for quality and safety OR if siblings are not included then the NDIS should be advocating for sibling services to be included in some quality framework.

Structure of a national quality and safety framework

This section will explore the structure of the framework, including excerpts from the consultation paper, followed by responses to that component.

The structure of the proposed quality and safeguarding framework starts with the individual and there are three broad areas – developmental, preventative and corrective. This submission will only address the first two of these.

Developmental

This domain aims to

- build individuals’ own natural safeguards
- strengthen natural supports
- build the capacity of participants for self-direction and self-advocacy
- supporting individuals to make choices
- support carers

QUESTIONS

1. Are there additional ways of building natural safeguards that the NDIS should be considering?
2. What can be done to support people with a limited number of family and friends?

Quality and safeguarding programs should consider and embody the principles of all relevant Australian Standards for Quality management, quality assurance and risk management.

In terms of strengthening natural supports, siblings may play a major role in all of the above. A strong sibling relationship may mean that the sibling of the PWD will be there to help the individual build their own natural safeguards, build capacity for self-direction and advocacy and support the individual to make choices. This involves strengthening this relationship from a young age and that includes giving the sibling the support they need to reach their own potential but also to help their brother or sister reach their potential. Sibling support is crucial to developing natural supports. Siblings often become the PWD's main advocate, protector and friend.

In addition to supporting people with limited numbers of family/friends there should be effort put into looking at the reasons why these numbers are limited. We should be researching

- the nature of sibling relationships when one has a disability
- what promotes strong sibling relationships with a PWD
- the reasons why some siblings are involved and some are not
- the barriers and enhancers to siblings being involved

This research would help us to better understand sibling relationships and help to build these natural supports.

Preventative

The preventative domain includes 'risk management strategies developed between individuals and the NDIA, as well as measures that encourage providers of supports to deliver safe, high-quality supports. This can involve support for providers to build their capacity, including training of frontline staff. It also includes the requirements that providers need to meet to be registered with the NDIA'.

The issue of individual safeguards and risk assessment/management strategies have partly been covered above. Siblings can play a role in these preventative risk management strategies, and the sibling bond needs to be developed and strengthened to be effective.

With respect the measures that encourage providers of supports to deliver safe, high-quality supports, there are two considerations:

1. Siblings can be involved in ensuring their brother or sister is receiving safe and high quality supports. Especially as adults, siblings often play an advocacy and overseeing role of services. Nurturing the sibling relationship can provide another set of eyes and ears to monitor services, verifying the quality of services delivered. As time goes on, siblings can have more capacity than their parents for this. But again with responsibility for ageing parents, their own family and their brother or sister, they may need support to manage their different roles, understand and navigate the service system and develop their advocacy skills.
2. In relation to quality of sibling support programs, if sibling support options are included in a participant's plan then consideration should be given to mechanisms for ensuring safe, high quality programs for siblings.

With many groups of providers in the disability sector there are already in place particular training courses, guidelines for practice and registration with peak bodies. However this structure does not exist for sibling support services and so will the NDIS have the capacity to determine if providers are skilled and trained effectively to provide sibling support?

There is a risk that if sibling support is now included within the NDIS, providers will introduce new programs with limited experience or competence in the area. Any positive change to recognise siblings in the NDIS should engage relevant stakeholders to ensure the needs are understood, programs developed are appropriate and consistent, and quality standards are defined.

Funding for research into understanding the demographics, health and social issues related to adult siblings has been limited, with the majority of studies focusing on the health of siblings in childhood. In 2009 a report by [Siblings Australia](#) sought to map existing services and identify gaps in supporting siblings, including adult siblings. There is little data available in the five years since the report was released, and the recommendations remain relevant today. The 2009 Project that Siblings Australia carried out showed a sibling support sector that was inadequate, unco-ordinated and un-evaluated.

The study found that there were some programs available for siblings of CWD. It found that some providers used a program from overseas, others used the Siblings Australia program, Sibworks, and others just used an in-house model. There had been no adequate evaluation of these services, with most providers stating more resources and professional development were needed. There were no reported programs for supporting adult siblings.

The NDIS will need to initially understand the range, scope and number of services that are provided and determine how the safety and high quality is measured. As children, siblings are particularly vulnerable to poor quality approaches.

If siblings are not included in the NDIS then the NDIA needs to be considering where siblings might get support and how will programs be evaluated with respect to safety and quality. If the NDIS does consider informal supports to be important, then there needs to be some consideration of the possibly longest relationship of all with the PWD.

QUESTIONS

- What kind of support would providers need to deliver high-quality supports?

Sibling support would benefit from research and national standards that define best practice guidelines and training requirements. Siblings Australia is best placed to lead this research and program development.

Recommendations

In conclusion, the best safeguard comes from people with disability being surrounded by people who care about them and have a relationship with them. In order to promote this Siblings Australia recommends the following:

1. Siblings are recognised as important members of the family, and their influence on the health, safety and security of the child/adult with disability should be recognised, and appropriate support provided over their lifetime.
2. Research is carried out to determine the numbers of siblings, their different roles and the barriers to engagement, resulting in greater understanding of the factors that support a sibling to remain involved in the life of the PWD.
3. Siblings Australia is recognised for its experience in working with families and providers.

Siblings Australia

Siblings Australia is the only organisation to focus on service development, research and advocacy for siblings of children and adults living with disability. Since 1999, it has built a national and international reputation for its work with families and providers, with Government and regulators. It's Director has presented in Italy, Scotland, England, US and Canada, and has international publications.

The organisation has developed a number of resources and services for siblings, parents and providers, including:

- sibling groups for young siblings, forums for adult siblings and provides online support services for adult and teen siblings (the latter in conjunction with a leading sibling support agency in the US). When connecting with peers in a safe environment siblings have shared very openly a wide variety of concerns and have given each other enormous support. They have expressed enormous gratitude for the opportunity to share with others who understand. One sibling reconnected with her brother, after many years of estrangement, having had the online support of other siblings.
- fact sheets for adult siblings as part of its [Adult Sibling Project](#) in 2009. The report highlighted a number of issues that still come up in our connections with adult siblings.
- workshops and online/print resources for parents
- professional development regarding the support of siblings, both here and overseas. Again, feedback has been extremely positive. The *Sibworks* program for young primary school aged siblings, developed by the organisation some years ago, has been used by providers around Australia. The DVD, *Stronger Siblings*, was developed to assist organisations to support parents to support their children who are siblings. It includes discussion notes to be used with a group of parents.
- research regarding a number of issues relevant to siblings. Several reports are available via the [website](#)
- advocacy for the needs of siblings to be recognised. [Submissions](#) have been provided for a number of situations and [advocacy](#) by other agencies has been supported. The RANZCP highlighted the issues for siblings in their [Position Statement](#) and Issues Paper.

In addition to the above, Siblings Australia hosts a website; this includes a large amount of information and links to resources. The organisation receives many enquiries (via the website, email, Facebook and phone) from siblings, parents and providers from around Australia, asking for information and advice.

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