Siblings australia inc

for siblings of children and adults with disability/illness

NDIS Review Submission

May 2023

Siblings: acknowledged, connected, resilient

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Siblings Australia is the only national organisation to focus on siblings of children and adults with disability. Over a period of 24 years it has developed a national and international reputation for its work with families and the professionals who support them, its advocacy and research, and it welcomes the opportunity to contribute to the NDIS review.

Background

For context we provide the following:

- In relation to the NDIA Act, one of the aims listed under the 'purpose of the NDIS' is to:

    - *facilitate the development of a nationally consistent approach that provides support to eligible Australians, ensuring that people with disability and their* ***families*** *(emphasis added) get the support they need when they need it.*

The General Principles of the Act include:

- *the role of families, carers and other significant persons in the lives of people with disability is to be acknowledged and respected (section 4(12));*

- *the supportive relationships, friendships, and connections with others of people with disability should be recognised (section 5(e)).*

In addition, the NDIS Practice Standards (Early Childhood Supports Module) apply to NDIS providers who are registered to provide early childhood supports to NDIS participants. These standards also include a focus on the active involvement of the participant's support network in the participant's development. They include:

- *The strengths of the family are promoted and developed.*

- *Appropriate information, knowledge, skills and expertise are in place to deliver quality supports to families.*

- *The capacity of the child, family and collaborating providers involved with the child is built through coaching, capacity building supports and collaborative teamwork.*

For further reading on ECEI see the Siblings Australia submission to the NDIS Review of its ECEI Approach, and finally, the Tune Review emphasised the need to build capacity in families, the government has reiterated that, 'The NDIA has an important role to assist families and carers of people with disability to identify, and in turn engage with or strengthen the natural relationships that exist within their home and community.'

However, despite recorded government support for Tune's recommendations, there is little evidence of change with respect the acknowledgement of siblings within the NDIS.

Regarding this submission, there are three main problems that Siblings Australia has identified that need to be considered as part of this review: the lack of recognition of the sibling relationship; the lack of understanding about its importance; and no clear pathways for support.

The problems will each be explored, followed by the generalised impacts of those problems, with possible solutions offered.

- Problem 1: A lack of understanding and recognition of the needs and contributions of siblings of people with disability within the NDIS.

- Problem 2: A lack of understanding about the nature of the sibling relationship between people with and without disability.

- Problem 3: No clear pathways of support for siblings.

Problem 1 - Recognition

There continues to be a lack of recognition of siblings within the NDIS. Whilst the NDIA Act clearly considers 'families' and its principles specify that children's plans, where possible, should strengthen and build the capacity of their families, there remains no meaningful recognition of siblings. The Tune Review also highlighted this lack of recognition and provided many examples of the gaps in this space.

Siblings are not included in any of the outcomes frameworks related to the disability sector, e.g., the Australia's disability strategy 2021–2031 outcomes framework: first annual report. The NDIS Review Terms of Reference states that the NDIS aims to empower people with disability and support them "*to achieve their goals and participate in the community and economy. The NDIS takes a lifetime approach to achieving these outcomes, investing in people with a disability early to improve outcomes later in life and improve system sustainability.*

An effective NDIS will improve outcomes for:

- *people with disability and their* ***families*** *and carers, helping them achieve their life goals and participate in social and economic life;*" (emphasis added)

The question needs to be, 'where and how are the outcomes for families, including siblings, and their capacity to support a person with disability measured, recorded and reported?'

Participant Plans are directly linked to outcomes; and if outcomes are not recorded, participants and families are discouraged from including them in plans. Thus, they can fall aside in favour of other items that have clearly articulated outcomes, regardless of their real world importance.

There is no recognition of siblings in the list of support items that can be used as part of a Participant Plan. The only support item included in plans that relates to family is Item number 15_038_0117_1_3, 'training for carers/parents', and is designed to work towards increased functional independence and social participation. There is nothing about increasing capacity of siblings to understand their brother/sister or on improving relationships in the family.

Despite continued advocacy by Siblings Australia for this to change to 'training for families/carers', it remains the same. It is not appropriate to assume that siblings are carers and can be to the detriment of the natural relationship between people with disabilities and their siblings to conflate the two. If we want to achieve proper inclusion, we need to lift the person into authentic belonging within their family unit. [Read more in the Siblings Australia submission to the National Disability Strategy Position Paper (2020) and Strohm[1].]

If parents have a Plan or Self-Managed plan for their child, or they come under ECEI, there is extra flexibility in how money can be spent, but again sibling support is rarely included. Sadly, in this situation, an 'either/or' scenario is set up where a parent might need to choose between another speech pathology appointment, say, for their child with disability and funded supports for a sibling. With a strong emphasis for parents on the importance of early intervention/therapies this type of decision can add further stress for a parent.

The recognition of early intervention into therapies should take the next step into recognising the need for early intervention into sibling relationship support. Sibling relationships are usually the longest relationship of a person's life: without proper scaffolding, this relationship can easily fall over. This is to the detriment of the whole family and can prove a safeguarding risk as the person with a disability gets older and no longer has parents supervising their care.

Within the NDIS are support items related to Behaviour Support, Item number 11_022_0110_7_3, Specialist Behavioural Intervention Support, but these do not (or, if so, rarely) include engagement with siblings.

[1] Strohm, K.E. (2018) Commentary on "Perceptions of non-caregiving roles among siblings of adults with intellectual and developmental disabilities" (Lee, Burke, Arnold, & Owen, 2018), *Research and Practice in Intellectual and Developmental Disabilities*, 5:2, 128-137, DOI: 10.1080/23297018.2018.15253

Major guidelines that are released by the NDIS do not include siblings in any meaningful way. For example, the Autism CRC in their report 'Interventions for children with autism: A synthesis of research evidence', highlighted how important siblings were (often referred to as 'agents') in the development of children with autism. However, there was no meaningful acknowledgement by the NDIS of siblings in the follow up paper on interventions for children with autism. They were mentioned once, in the context of a child with autism 'hitting out' at a sibling, as if inevitable collateral damage – a recognition of the sometimes stressful position siblings can find themselves in; even if no further consideration was given to this fact or the longer-term consequences that this may have for the person with a disability. The follow up summary report also had little attention given to siblings.

There is no meaningful focus on the whole family within the NDIS. Whilst there is some understanding of the importance of the broader family dynamic to the wellbeing of people with disability, and there is some push for 'family-centred approaches', the reality is that 'family-centred' does not always mean the whole family and many of these approaches focus on parents/carers.

The Senate Select Committee (SSC)'s report, Services, support and life outcomes for autistic Australians (aph.gov.au), includes several examples of the impacts on families and also includes evidence that children are often considered in isolation from their families. Even in the SSC report, although it highlights the importance of 'family centred approaches', it concludes that 'there is an urgent need to address deficiencies in state-based services for parents and carers'. Again, siblings are overlooked.

Similar examples of this narrowing of focus can be found in many publications within the disability sector. Siblings Australia argues that siblings should be included in these publications, with associated meaningful actions, and that 'family-centred' should mean 'whole family'.

Adult siblings report that providers do not respect their role both as a sibling but also as a support person (and in many cases as a caregiver) for the person with disability. See the Siblings Australia Report: Creating Capacity – Support for Adult Siblings.

There is no policy that recognises siblings specifically which means there is no imperative for any action regarding their support, either by governments, organisations or practitioners.

It should be noted, in terms of this problem of recognition, siblings are not good self-advocates. Growing up with a someone with disability means they have learnt to put their own needs behind those of others ('who am I to complain?'). Parents can be both physically and emotionally stretched and can lack confidence/'bandwidth' to support siblings. And agencies/practitioners are also stretched. Their focus is usually on the child with disability.

There are many gaps in data in relation to siblings of children with disability. At a most basic level, the numbers of siblings in Australia can only be determined by extrapolating data related to children with disability. The Longitudinal Study of Australian Children would have been a good opportunity to include such data, but this is lacking. Also, there is no information about the numbers of adult siblings, how many are still involved in family life, how many take an active role in support or advocacy for a brother or sister with disability?

Problem 1 – Impacts

Without appropriate recognition siblings do not receive the support they need to reach their own potential and to contribute to the potential of the child/adult with disability. See the 2018 Siblings Australia report Mapping project: Support for siblings of children and adults with disability

As mentioned, the SSC report highlighted that 'the failure to provide adequate services and support comes at a significant cost to families, and society more broadly'. The SSC heard 'first-hand accounts of the devastating impact that inadequate or inappropriate support has on the lives of autistic people and their families'. It continued to say that it 'heard accounts of social isolation, exhaustion and depression among parents and siblings of autistic people'. Other reports and work done by Siblings Australia confirms this. If the disability includes challenging behaviours the impact can be even greater and can lead to families relinquishing their child with disability. (See A socio-ecological exploration of adolescent violence in the home and young people with disability: The perceptions of mothers and practitioners - ANROWS - Australia's National Research Organisation for Women's Safety and Siblings Australia's Report: Aggression toward siblings from a brother or sister with disability).

Most siblings love and care about their family member with disability, and many enjoy loving relationships. However, they also report ongoing challenges and stresses, usually beginning in childhood, when they lack the understanding and maturity to cope. They talk of poor sleep, isolation, grief, guilt, confusion, and low self-worth, all of which can then lead to education impacts and a range of mental and physical health problems over their lifetime. Without support for the family, siblings can grow up feeling less important within their family. Most importantly, without this early support, the sibling relationship can become strained and even break down. Siblings can disconnect from their family as they age, resulting in losses for the whole family.

Sibling relationships are the longest of any. They have the potential to be rewarding for both siblings but, for a person with disability, they can play a huge role in their wellbeing, social inclusion and safety over a lifetime. If the sibling relationship breaks down, the potential losses can be huge.

Problem 2 – Lack of understanding of sibling relationships

All sibling relationships are complex and ever-changing. When one has a disability, the relationship can be even more complex and less understood.

Every sibling experience is unique. So often their experiences are generalised, misjudged or dismissed.

There has been no research on what the value of a sibling relationship might be to a person with disability (both in monetary terms given the varied supports that siblings provide, but even more importantly, to the wellbeing, social inclusion and safety of a person with disability). There has been no research into the barriers and enhancers that might play a role in the strength of a sibling relationship. This is surprising, given the importance of this relationship to people with disability and, over time, to the NDIS, particularly given the insurance model of the national disability scheme. Other forms of insurance take into consideration the mitigation strategies surrounding risk, but this is not included in this model.

In terms of the sustainability of the NDIS, it would be advisable to consider the difference in outcomes both for the Participant and the NDIS, in the case of, say, a 50-year-old Participant who has a close relationship with a sibling and one who doesn't have any family in their life.

Problem 2 – Impacts

The lack of understanding of the experience and needs of siblings, again means that there is inadequate, or inappropriate support for these relationships, as follows.

Siblings of children with disability do not access help to understand the disability and, if present, challenging behaviours, to learn how to interact and play, and, in some cases, how to stay safe themselves. Without that support, the relationship can be at risk.

Within the NDIS there is much more focus on children with disability developing relationships in the community than on relationships in their family, again showing the lack of understanding of the importance of the family.

There is significant emphasis on respite for families and, whilst all families need breaks from each other, there is little focus on building the capacity of families to function more positively when they come back together, especially in situations where there are concerning behaviours.

There is too much focus in the NDIS on 'carer' roles rather than relationships, despite one of the key themes of the NDIS being 'relationships'. This can have negative impacts on relationships and doesn't respect or validate the nature and importance of relationships. As Siblings Australia has highlighted for some time now, a carer policy umbrella does not work well for siblings of people with disability, nor people with disability. And this means there are policy gaps for siblings.

If siblings can be supported and the relationship nurtured from an early age there are likely to be huge benefits for both siblings and the whole family both immediately and in the long term.

Problem 3 – No clear pathways of support

The SSC and others have reported that the change to the NDIS and the ceasing of block funding means that many agencies do not have the scope/resources to include family support in their activities. Only activities that can be funded through a NDIS Plan, or other funding, can be pursued.
There is no clear pathway within the NDIS for siblings to access support. Certainly, the NDIS promotes 'capacity building' for family members. The Act itself has certain principles including:

a) *the role of families, carers and other significant persons in the lives of people with disability is to be acknowledged and respected;*

b) *strengthen, preserve and promote positive relationships between them and their parents, family members and other people who are significant in their life;*

However, the principles do not translate to clear actions, again highlighted in the Tune Review.

Problem 3 – Impacts

Siblings do not access support, they can feel isolated and become vulnerable to mental and physical health problems which can grow over time. Parents struggle to support all their children and family relationships can be strained so that the person with disability does not have a strong family to support them both as a child and into adulthood. Recognised therapies are a small part of what determines the developmental outcomes, wellbeing and social inclusion for a child with disability. Their family environment is what truly matters, not only in childhood but also over their lifetime.

Possible solutions (generalised over all 3 problems)

Support for siblings and for their relationship with the person with disability needs to start early. It is the early years that establish all relationships so the more that can be done to support siblings and the people that work with them and the child with disability sets the scene for the lifetime relationship between both siblings. However, the relationship and needs can change over time and siblings may need support to understand more about the sector that supports their brother or sister and learn how to advocate for and with their brother/sister within the sector and learn how to 'walk beside' their brother/sister within that sector. This, in addition to:

- Ensure siblings are included in meaningful ways within the NDIS and that the term 'families' is defined to explicitly include siblings.
- Ensure that NDIS providers (both internal eg LACs, ECEI partners etc) and external (disability/health agencies) recognise and respect the sibling relationship, but also the role of siblings as support people to people with disability.
- Give siblings and the person with disability choice as to how they want their relationship characterised. Do they want their relationship to be seen through a sibling lens (including support which, in some cases, can be mutual), or through a carer/caree lens with its connotations as above.
- Improve the understanding within the NDIS and the disability community more broadly, of the complexity of sibling relationships when one has a disability and the needs of the whole family, through relevant and appropriate workforce development (including ECEI partners, LACs, Support Co-ordinators, Planners, Partners in the Community)
- Ensure siblings are included in the collection of data related to children and adults with disability. The current work being done on the National Disability Data Asset should consider what data would be useful to collect regarding siblings and their relationship with the person with disability.
- Support research into the barriers and enhancers to sibling relationships
- Support research into the value of the sibling relationship
- Focus on the sibling relationship rather than the carer role
- Ensure parents and professionals have access to resources/services to increase their level of understanding of the needs and contributions of siblings
- Identify responsibility for siblings – is it through the NDIS and, if so, is it via Participant Plans or via ILC or elsewhere?

If siblings can be supported through NDIS Plans, the following needs consideration:

1. An initial assessment of an individual's strengths, challenges, goals, and preferences is critical to developing intervention targets that are meaningful to the child and family. This assessment must also include the impacts along with the possible contributions of the whole family, including siblings.

2. Clarify what 'reasonable and necessary' means in relation to sibling supports.

   A submission by Siblings Australia to the discussion paper, 'Best practice interventions for children on the autism spectrum' provides a more detailed exploration of 'reasonable and necessary' in relation to siblings. As siblings age, this should include capacity building in terms of planning for the future (including communication support for the whole family and consideration of different roles), learning about the NDIS, how to advocate with and support their brother or sister with disability within that system.

3. Clarify suitable goals within a NDIS Plan that would build capacity in siblings, e.g. 'I would like my sibling to be supported so that our relationship can be stronger'. Another goal might be 'include my sibling in the behavioural support interventions that I access to ensure our relationship can be supported'.

4. Change the relevant support item to read 'training for families/carers'

5. Whilst there is more flexibility through ECEI Plans, parents sometimes need support to make choices that ensure siblings are supported alongside the child with disability – there need to be clear pathways for both.

If, in spite of the above references to the NDIA Act, sibling support is deemed not to be a 'reasonable and necessary' support and so should not be included in Plans, identify clearly how they might be supported elsewhere within the NDIS e.g., ILC, or outside the NDIS – e.g., disability, health, education. The NDIS needs to steer some cross sector discussions if this is the case.

Siblings Australia appreciates the support it has accessed from 2020-mid 2024 through the ILC grant program but there is no security beyond that, and a path forward (including core funding) needs to be identified so that these vulnerable children/adults are recognised and connected to pathways of support to ensure better outcomes for the whole family. ILC is intended to be '*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 carers*'.

There should be some consideration given to the inclusion of a sibling peak body within the National Disability Advocacy Program.

08 8253 4936

info@siblingsaustralia.org.au

siblingsaustralia.org.au