

Submission to National Disability Strategy Position Paper

Siblings Australia welcomes the opportunity to contribute a submission to the above.

Summary

For a majority of NDIS participants, the longest lifetime relationship they will have is with their sibling/s, however Australia and, in particular, the NDIS does not adequately acknowledge or support the needs of siblings of people with disability. This must change in the new National Disability Strategy. Strong relationships with siblings are a crucial precursor, from early childhood until end of life, to broader inclusion for people with disability. In addition, during a likely period of financial pressures on Government over the next 10 years, it makes sense to invest in supports that are likely to yield the greatest economic benefit i.e. lower NDIS costs due to stronger relationships between the PWD and siblings.

Background

Siblings Australia, established in 1999 and directed to this day by Kate Strohm, herself a sibling of a person with disability, is the only national organisation to focus on the experience and needs of siblings of children/adults with disability. The organisation recognises the importance of siblings in the lives of people with disability (PWD) over a lifetime, aims to support them to develop a good life for themselves and to contribute to a good life for their brother or sister with disability. It has developed a national and international reputation for its work with families and professionals.

Both the National Disability Strategy (NDS) and the more recent NDIA Act (a key process through which the NDS is implemented) clearly consider families in key documents. The original National Disability Strategy was agreed by all levels of government and claimed that 'for the first time in Australia's history, all governments had committed to a unified, national approach to improving the lives of people with disability, their **families** (emphasis added) and carers'.

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)).

Also, in response to the Tune Review, which 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, within the original and the proposed new NDS there is a noticeable gap in terms of relationships and their importance, especially within families. And when relationships are considered, the focus is on the caring role. The Strategy overlooks the importance of the lifelong relationship with siblings, who may or may not play a carer role but, nevertheless, can contribute much to the lifelong wellbeing and social inclusion of PWD.

Submission

This submission on the new NDS will respond briefly to those questions from the Position Paper (extracted below) which might relate to the issue of siblings and their involvement or otherwise with the PWD. It will focus on the gap within the sector in understanding the complexity but importance of the sibling relationship and suggest ways that this might be addressed.

Question 1:

During the first stage of consultations we heard that the vision and the six outcome areas under the current Strategy are still the right ones. Do you have any comments on the vision and outcome areas being proposed for the new Strategy?

The current outcomes appear to cover key areas, but there are some more general issues that would benefit from further consideration.

For example, the vision outlined in the current Strategy was based on extensive consultation as part of the Shut Out report (2009). Recent consultations have highlighted that it continues to be relevant today. However, although the Shut Out report was titled, 'The Experience of People with Disabilities and their Families in Australia', it did not consider in any meaningful way the experience, contributions or needs of families of PWD, and certainly not siblings. This was despite siblings likely having the longest relationship of any with PWD.

The preamble to the Position paper on the new NDS states, 'The new Strategy will also continue to recognise the vital role carers play in providing care, support and assistance to people with disability in order to reach their full potential'. Of course, the role of carers is vital, but this language can negate the importance of relationships per se. In current policy there is an overemphasis on the carer relationship rather than the other dimensions of relationships especially with family including siblings.

Relationships are key to anyone's wellbeing and, to have a holistic approach, there needs to be as much emphasis on them as there are on the more practical things like employment, accommodation, therapies etc. Strong relationships can be just as important as, and often contribute to, the 6 outcome areas listed in the old Strategy. They are a crucial precursor, from the very beginning, to broader inclusion for PWD.

Furthermore, one of the key life domains in the NDIS outcomes framework (alongside work, health, learning etc) is '**relationships**'. Sadly, the latter is largely overlooked in participant plans and the NDIS price guide. When relationships are considered, the focus is mainly on parents/carers, with siblings largely overlooked. Even if siblings provide no or minimal caregiving, they can still contribute significantly to the relationship with the PWD. An enduring and supportive relationship with the sibling will increase the likelihood of the person with disability having a good life and will likely result in significant economic benefits i.e. lower net NDIS costs for the PWD over their lifetime.

As an aside, there are subtle downsides, in terms of the inclusion of PWD, to the use of the term 'carer'. It sets a power imbalance of a carer 'doing to' the 'caree' and immediately sets up PWD as people who need extra care, rather than seeing them as people capable of mutually supportive relationships. It reinforces the

charity model of disability and adds nothing to the dignity to a PWD. Even the term 'caregiver' might be preferable as it does not depict such a power imbalance.

Recommendation: Ensure there is much more recognition within the NDS of the importance of relationships (including those with siblings), ensure there is rigorous research on the barriers and enhancers of such relationships, and provide supports to strengthen them.

Question 2:

What do you think about the guiding principles proposed here?

Again, the principles seem appropriate but there is a need to ensure that the term family is considered fully, not just in terms of carers. The Position Paper Introduction states that 'The new Strategy will also continue to recognise the vital role **carers** play in providing care, support and assistance to people with disability to reach their full potential.' This statement should also specifically refer to families including siblings. Families need to be front and centre as it is families that provide our first and most important social contact. Whilst it is crucial to provide practical support for those who are providing direct caregiving, it is just as important to nurture relationships, in their own right, especially those that might last a lifetime.

One of the questions asked in the section on Principles is; How have the needs of the family, carers and circles of information and formal support for the person with disability been considered in the development of the policy or program? Again, I would ask what avenues have there been for siblings or in fact whole families to have input into policies/programs?

Recommendation: If the term 'family' is used in the NDS, including in its principles, consideration needs to be given to the whole family, and the importance of these family relationships. It follows that siblings need to be considered in the development of policies/programs. Siblings Australia would like to contribute to this.

Question 3:

What is your view on the proposal for the new Strategy to have a stronger emphasis on improving community attitudes across all outcome areas?

Certainly, any strategy related to disability should emphasise the improvement of community attitudes, and that needs to include the whole community taking responsibility for that process. At the same time, advocacy is an important tool to ensure that PWD access what they need to function well and to take part in community activities. Many people with disability can advocate for themselves, to try to remove barriers and shape attitudes. However, many cannot, and in those situations it is often siblings and parents who work alongside the PWD to influence attitudes of, and inclusion in, the community. Siblings are often the staunchest of allies for a PWD; they also can play a huge role in assisting a PWD to reach their potential and to access the community, but they also need to access supports for themselves, in order to build their capacity to fulfill that advocacy role.

Language can also be a big influencer on community attitudes. Often, the words used in relation to people with disability reinforce a charity model of people with disability being deficit focused. On the other hand, stories often focus on those people with disability who have been able to achieve greatly. This doesn't make it easier for those who might struggle to reach those heights. The language around 'carer' can also contribute to stereotypes regarding disability, as discussed above in relation to Question 1.

Recommendation: Ensure the whole family is included in activities to improve their capacity to influence community attitudes. Be mindful of presenting balanced views when engaging with the community. Neither an approach which focuses on disability as a 'burden' in need of charity, nor an approach that includes what Stella Young branded as 'inspiration porn' is an effective way to engage meaningfully.

Question 4

How do you think that clearly outlining what each government is responsible for could make it easier for people with disability to access the supports and services they need?

There is often a silo approach to government and community services, not only for PWD but also more broadly. PWD and their families would benefit from a system that was more easily navigated.

Also, it would be beneficial to have a clearer outline of what each government is responsible for. Certainly, it is not clear which part of government is responsible for siblings. Families are often mentioned in policy but it is not necessary to drill too far down to find that the focus is on parents and the PWD. Carers have a clear line of connection with Carer agencies, and there is clear policy related to their needs. Young carers are also catered for in policy and, whilst there may be some overlap, the experiences and needs of siblings can be quite different to those of young people who are providing a primary caregiving role. Siblings are not in policy anywhere despite having the longest relationship of any with the PWD. With no policy, there is no imperative for agencies to include sibling support and, as a result, they continue to be overlooked.

Recommendation: Develop a clearer outline of policy and where responsibility lies for those policies, considering the gaps that currently exist, especially in relation to siblings.

Question 5

How do you think the Strategy should represent the role that the non-government sector plays in improving outcomes for people with disability?

Both government and non-government sectors should be engaged to improve outcomes for PWD. These outcomes need to take a holistic approach.

Recommendation: A mapping of both government and non-government services should be carried out to reduce duplication and identify gaps.

Question 6

What kind of information on the Strategy's progress should governments make available to the public and how often should this information be made available?

Information on progress needs to include indicators for the whole family and across all domains. The NDIS Family and Carer Outcomes report focuses on parents only and their ability to keep working, contribute to the development and learning of their child/adult with disability, their social interaction and engagement with the community and their health. If this is going to reflect 'family' outcomes it needs to include outcomes for the whole family, but also outcomes that reflect more meaningfully on family functioning.

Key outcomes for siblings which can also, ultimately, lead to benefits for the child/adult with disability, the whole family, and the community, include:

- understanding of the disability and the impact of that on their brother or sister
- ability to explain the disability to other people and manage others' reactions;
- capacity to cope with a range of stresses;
- support for their mental health;
- capacity to engage with the PWD, especially if there are challenging behaviours;
- connection with other siblings who share similar experiences; and
- as they become older, understanding the disability service system, and finding the right services for their brother or sister.

A strong sibling relationship over a lifetime will bring benefits to both siblings, with and without disability, and also to the community.

Recommendation: Ensure clear reporting on all indicators related to whole family capacity. Also, ensure disability/health agencies, schools, and other community agencies:

- understand the complex challenges faced by siblings;
- have tools that identify all members of a PWD's family, including siblings;
- can support siblings reach their own goals, alongside contributing to those of a brother/sister; and
- measure progress on these activities.

Question 7

What do you think of the proposal to have Targeted Action Plans that focus on making improvements in specific areas within a defined period of time (for example within one, two or three years)?

Recommendation: Ensure all Target Action Plans,

- have no gaps and collect meaningful data accessible to all
- include not only practical targets but also those things that nourish a life, especially relationships.

Question 8

How could the proposed Engagement Plan ensure people with disability, and the disability community, are involved in the delivery and monitoring of the next Strategy?

Recommendation: Ensure all Engagement Plans include:

- the participation of PWD and their families, in meaningful ways, in both delivery and monitoring of the Plan to ensure the best outcomes;
- the voices of those who have not had a voice, including those with disability who cannot advocate for themselves; and
- considerable workforce development so that providers understand the needs of the whole family including siblings and the benefits of that in terms of strengthening the family and the PWD.

The conclusion within the new National Disability Strategy discussion paper states that this is a key opportunity for governments, private sector, and the whole community to work collaboratively to improve outcomes for all PWD. Targeted consultations are being conducted following the publication of this paper to inform the development of the new Strategy. This needs to include siblings, regardless of their caregiving roles. As the only organisation of its type, Siblings Australia is in an ideal position to contribute further to this discussion, ensuring the needs of families including siblings, and the value of relationships with the PWD, are appropriately recognised.

Recommendation: Make available to the public a record of who is being contacted for targeted consultations, and a summary of the key recommendations from those people/organisations.

Kate Strohm

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