

Submission to Community Affairs Legislation Committee Inquiry on the National Disability Insurance Scheme Bill 2012

By Kate Strohm, Director, Siblings Australia

This submission aims to reinforce the importance of including families in the implementation of the NDIS Bill. The Bill certainly recognises families but in order for this to move beyond principle and into practice there must be greater emphasis on families in the planning of the structure and implementation of the NDIS.

NDIS Bill

The NDIS Bill has a number of objects which aim to support the social and economic independence of people with disability, provide necessary supports including early intervention and enable people to have choice and control in pursuit of their goals.

The general principles guiding actions under this Act include many that refer to the rights of people with disability. However there are several instances where the family of the person with disability is highlighted.

For example, one of the principles underpinning the Act states, “(12) The role of families, carers and other significant persons in the lives of people with disability is to be acknowledged and respected.”

Later in the document, there are outlined a number of principles in relation to participants’ plans. This section includes the following:

“The preparation, review and replacement of a participant’s plan, and the management of the funding for supports under a participant’s plan, should so far as reasonably practicable:

- (a) be individualised; and
- (b) be directed by the participant; and
- (c) where relevant, consider and respect the role of family, carers and other persons who are significant in the life of the participant; and
- (d) where possible, strengthen and build capacity of families and carers to support participants who are children; and
- (e) consider the availability to the participant of informal support and other support services generally available to any person in the community.”

The Act also outlines some of the functions of the Independent Advisory Council and includes the following:

“(2) In providing advice, the Advisory Council must have regard to the role of families, carers and other significant persons in the lives of people with disability.”

The importance of family

It is impossible to consider the rights and wellbeing of people with a disability without also considering the roles and needs of their family. It is the family that is the first source of love, learning, acceptance and early intervention.

However, there can be huge impacts on the whole family when a diagnosis is made; and the way in which the family navigates the changes and challenges that occur over a lifetime will largely be influenced by the support the whole family can access from the very beginning. These support needs are not only connected to any caring role that the family member may play, but also relate to a mix of feelings and reactions that occur in response to such a diagnosis, as well as the impacts of the disability on the whole family's day to day living, both at home and in the community, across a lifetime.

Siblings

Research suggests that the sibling relationship can contribute much to the quality of life for brothers and sisters living with disability. Many people living with disability, in particular cognitive disability, rely on family or family friends to provide their social networks. Siblings have a unique position in the lives of their brothers and sisters living with disability, as closeness in age may often result in relationships based on friendship thus extending the social network of the person with a disability over a lifetime. Siblings may choose to take on varied roles in the lives of their brothers or sisters thus becoming part of the informal support network for their brother or sister living with disability. As parents become less able, siblings may also take on more of a direct caring role. This unique position enables siblings to potentially have an ongoing, meaningful and positive impact on the lives of their brothers and sisters living with disability. As the lifecycle progresses and the sibling may go on to have their own family, other family members such as in-laws, nieces and nephews may also contribute much to the support and wellbeing of the person with disability. These connections may be particularly important to the person with a disability as they age and lose other connections from their youth. In many situations, the support can also be quite reciprocal in nature.

If it can be determined what factors influence the involvement of adult siblings in the lives of their brothers and sisters as well as the types of supports that adult siblings require to remain involved, such services would also enhance the quality of life of people living with disability.

Certainly if there is no consideration of sibling issues there can be quite disturbing outcomes for both the sibling and the person with disability.

Siblings

If siblings are not supported they can have difficulty managing the challenges they face. A 2008 study by the Australian Institute for Family Studies found that families which included a child with disability experienced greater stress than other families. Parent carers had the lowest wellbeing of anyone in the community and had higher rates of depression. However,

other children in the family (siblings) also had higher rates of depression regardless of any caring role they may or may not play.

Work that Siblings Australia and others have done (see www.siblingsaustralia.org.au) has shown that siblings can develop a range of emotional, mental and physical health problems. Also, some siblings are physically harmed by a young person with disability, if the disability involves difficult behaviours.

Siblings Australia has found that some siblings, when relationships become too difficult, move right away from the family, which results in the sibling and their brother or sister living with disability, missing out on any relationship in their adult years. There is a need to understand the issues, and support siblings, both as individuals and also as a support person to a brother or sister living with disability. Strengthening sibling relationships will be of benefit to both the sibling and the brother or sister living with disability.

Siblings Australia

Siblings Australia is a unique national organisation committed to enhancing the wellbeing of siblings of children and adults living with disability. The organisation's mission is to assist siblings to become acknowledged, connected and more resilient. Siblings Australia provides workshops and networking opportunities for families and providers across Australia and overseas. Most of the work carried out by Siblings Australia has had a preventive approach.

Understandably, in the early years, significant resources may be spent addressing the needs of the child with special needs. By the same token, research has now substantiated the fact that siblings of these children may themselves have significant needs.

Support for siblings, from a young age, allows them to feel less isolated, helps them to develop effective coping strategies, and helps them build resilience. As a result, they will be more likely to develop to their full potential and also to contribute to the quality of life of their brother or sister with special needs. Support at this young age may indeed flow into lifelong benefits, with siblings remaining active in the life of the person with a disability for much longer. Certainly anecdotal evidence from parents of children who have attended sibling programs shows that these children interact more positively with a brother or sister with disability after contact with other siblings through the group.

Although it has focused on providing services and resources to young siblings, their parents and the professionals who work with families, Siblings Australia has, since its inception in 1999, been acutely aware of the role and needs of adult siblings. Early investigation through surveys and focus groups reinforced an understanding that the role of siblings was poorly understood and the needs of siblings were largely overlooked. The organisation has developed some resources and services, but these have been recently limited in scope due to a lack of funding. One important service was an online forum for adult siblings, where they were able to share experiences and information. For many this was a truly moving experience, to learn that they were not alone and to finally gain support in sorting through some important issues. In some cases, such support led to renewed or improved contact with a brother or a sister living with a disability.

As well as its own work with adult siblings, Siblings Australia has maintained close contact with other child and adult sibling services in the UK and the US. The research and support being carried out in these countries has demonstrated and reinforced the need for further work to be done in this area in Australia.

In recent times Siblings Australia has been involved in a range of advocacy activities to gain recognition of the importance of siblings. Various submissions by Siblings Australia and others, as well as position papers and research papers can be found on the Siblings Australia website. Unfortunately, at this time, the organisation cannot access funding from the federal government to continue the development of a national initiative to ensure there continues to be 'best practice' approaches, workforce development and effective research.

Key issues

- A person with disability must be seen in the context of their family and their community
- When a person has a disability the whole family is affected
- Many families break down as a result of stresses involved in caring for the child with disability
- Families need practical and emotional support from the time of diagnosis
- Siblings are not immune to these stresses and can face a number of challenges in growing up with a brother or sister with disability, both within their family and in the community
- If unsupported, siblings are at risk for their own emotional and mental health issues
- There is also evidence that some siblings are at risk of physical harm by their brother or sister if the disability includes difficult or aggressive behaviour
- Siblings will most likely have the longest relationship of any with a person with disability
- If we strengthen that relationship from the early years it is likely to be an enduring relationship with mutual benefit for both siblings

Recommendations

In moving forward with the NDIS, there must be consideration given to the support needs of families, not just in a practical sense but also emotional. Whilst better services for people with disability is at the core of the NDIS, and will no doubt benefit people with disability AND their families, it is important that any implementation of the scheme acknowledges the support needs of whole families in concrete ways. These must include clear pathways of support from diagnosis, and may include counselling, peer support or other services. If the NDIS itself cannot support such initiatives it should at least ensure that these services are available in the community. Siblings Australia would have much to contribute in this regard.

NB References can be provided as needed, but most of the documents/work referred to can be accessed via the Siblings Australia website, in particular the advocacy and research pages.