

Response by Siblings Australia to a Framework for Information, Linkages and Capacity Building in the NDIS

Introduction

Siblings Australia (see later a description of the organisation and its work) is pleased to respond to the paper (The Paper) which sets out policy parameters for information, linkages and capacity building (ILC), in the National Disability Insurance Scheme (NDIS).

The core proposition advanced in this submission is that The Paper, whilst commendably seeking to address *“the support needs of people with disability, their families and carers”*, adopts a too general approach that fails to acknowledge the particular needs of brothers and sisters (‘siblings’) of people with disability. Whilst it is encouraging that reference is made in The Paper to ‘families’ (separately from ‘carers’), there is a lack of specificity about what this really means. In particular, this generalised reference to ‘family’ throughout The Paper does not recognise that different components of the family have quite distinguishable needs that require specific attention and support if the person with disability (PWD) within the family is also to be fully supported. The needs of parents are generally well understood, whereas the needs of siblings are much less so. The Paper does not set out clearly how siblings of people with disability might be recognized and supported. There is a similar issue with a lack of recognition of siblings’ needs in the wider disability, health, education and social policy areas despite, for example, the strong [advocacy](#) of the Royal Australian and NZ College of Psychiatrists and other major bodies on this matter. The NDIS provides an opportunity to address this problem in a constructive way. It is therefore submitted that The Paper should be revised to incorporate at appropriate points some specific references to the particular support needs of siblings within the family context, as part of its proposed *“effective, integrative response to disability”*.

This submission will first explore why siblings are important and identify the gaps in The Paper in relation to siblings and why they should be recognized more clearly, including their contributions and needs. The submission will also explore the different streams listed in The Paper and how these could be strengthened by specifically referring to the support needs of siblings.

It will also give information about what Siblings Australia has done in the past and how it might add value to current NDIS policy and approaches. Finally, some recommendations will be included to improve the gaps that exist now regarding sibling acknowledgement and support.

Why siblings are important

Siblings are likely to have the longest relationship of any with the PWD. They have the potential to add much to the emotional and social wellbeing of the PWD, regardless of any ‘carer’ role they may or may not play, and such relationships can be mutually satisfying over a lifetime. However, these relationships can face a range of complex challenges and, in many cases, there is breakdown of the bonds. Sadly, many people with disability become socially isolated, which may have been prevented if family relationships were strengthened earlier.

Siblings are also important in their own right. Whilst some can be enriched by their experiences of growing up with a brother or sister with disability, others face a situation of major stress without the maturity to cope. This can have immediate and longer term impacts on their mental, emotional and social and physical health. Some siblings are physically abused by a brother or sister with disability.

An AIFS report from 2008 showed that siblings have higher rates of depression regardless of any caring role they may or may not play. An Adult Sibling Project carried out by Siblings Australia in 2009 showed that many siblings struggle into adulthood and turn to unhealthy coping strategies. Regrettably, many siblings move away from their family as the stresses become too much and they lack the support during childhood and into adulthood to manage those stresses.

Many siblings, however, have a very close relationship with their brother or sister with disability and a strong concern for their wellbeing. For those who do remain involved it can be difficult managing the needs of their ageing parents, their brother or sister with disability and their own family, including children. They have often been referred to the 'club sandwich' generation.

And finally, parents often worry about the impact of the stresses on their 'other' children. They often say that siblings become more of a worry than the child with disability. Sibling support is an important part of assisting parents to feel stronger and more competent.

The UN Convention on the Rights of People with Disability has been signed by the Australian government and is one of the enablers of good disability practice in this country. However, the rights of families and siblings, in particular, must not be overlooked.

Early intervention in strengthening families is crucial. Siblings Australia parent consultations and workshops about sibling support have had very strong endorsement for many years – one parent described the session as a 'lifesaver'. And many parents have told us that after participating in sibling support programs their 'other' children interact more positively with their brother or sister with disability. These services can be a starting point for further intervention.

Intervention later can also have benefits for both the sibling and the person with disability. One adult sibling became involved in Siblings Australia online support. She had not had contact with her brother who had intellectual disability for many years. She had felt enormous panic being with him as he had often abused her when they were younger. With the online support of peers, alongside reading stories from other siblings and therapy, she was able to eventually renew contact with her brother and they now enjoy a full relationship, especially important as both parents have died.

If individuals in the family can access relevant and appropriate support and if relationships can be nurtured from a young age then siblings (both the child with disability and those who are able-bodied) are likely to be more adjusted and healthy, and less reliant on social services in the longer term. ILC is a crucial part of that support.

A Response to The Paper

The draft states that 'ILC should be broadly scoped, flexible and responsive to the support needs of people with disability, their families and carers. A broad definition will ensure that those supports can evolve over time to meet those needs. ILC is 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 which in turn will reduce the need for funding of supports for people with disability through Individual Funded Packages.'

With respect to The Paper, there is a lack of clarity about what 'family' support can mean in practice. Certainly, 'carer' support is easier to define and make provision for, but the nature and purpose of whole family support is less clear.

The Paper notes that there are five streams of service under ILC which provide support to people with disability, their families and carers, and community and mainstream services. The streams are:

1. Information, Linkages and Referrals
2. Capacity building for mainstream services

3. Community awareness and capacity building
4. Individual capacity building
5. Local area co-ordination (LAC)

Below I will explore these streams, especially with respect to siblings. Content from The Paper will be in italics.

Stream one: Information, linkages and referrals.

Information, linkages and referrals will efficiently connect people with disability, their families and carers with appropriate disability, community and mainstream supports.

Response: As well as more general initiatives which can be of use to the whole family, there needs to be more specific sibling initiatives, including:

- information for parents on what sibling services are available in their local area
- information for parents on how they can support siblings themselves, including links to a variety of resources
- information for adult siblings on what services are available for them and also for their brother or sister with disability
- information for adult siblings about the different roles they might play, what advocacy involves, how to talk with parents about the future, how to engage with services, how to manage the needs of their brother or sister with disability alongside their other commitments
- peer support opportunities for siblings of all ages

Stream two: Capacity building for mainstream services.

People with disability, their families and carers, like all community members, access and interact with mainstream and universal systems and supports. NDIS will fund supports to enhance social and economic participation for people with disability, but it is not a funding source for mainstream services.

Response: If mainstream services are not meeting the needs of families, in particular siblings, it is imperative that the NDIS highlights this and advocates for relevant services to be improved, or if necessary, developed.

Stream three: Community awareness and capacity building.

Investing in community awareness and capacity building will create opportunities for the social and economic participation of people with disability, their families and carers, improving personal outcomes and strengthening the connection between people with disability and their communities.

An objective of community capacity building is getting organisations (not for profit organisations, local councils, businesses) and people within communities to be inclusive of people with disability, and understanding of the needs of families and carers.

Initiatives under this stream may include:

- *Consulting with, or incorporating the views of, people with disability, their families and carers in the provision of community activities and other goods and services.*

Response: Organisations in general do not have an understanding of the needs of siblings in particular. There needs to be included in this stream specific mention of increasing the awareness in the community about sibling experiences and needs. A 2009 Siblings Australia Scoping Project showed that there was a paucity of sibling support programs. The sibling support system in Australia was unco-ordinated and lacking in capacity, evaluation and 'best practice' approaches. How do we know they are providing benefit and not doing harm? Providers highlighted the need for further training and resources in this area.

Also, siblings are rarely consulted for their views. Often 'families' are consulted but the focus is usually on parents. Various reports eg the *Shut Out* report might supposedly be about 'families' but often, as in this case, siblings were not mentioned. There needs to be a greater emphasis on gaining sibling views. Siblings can play a major role in advocating for people with disability and raising awareness within the community re the needs of PWD, but they need to be acknowledged.

Stream four: Individual capacity building

Individual capacity building fosters the principle of choice and control, improving outcomes for people with disability, their families and carers as well as driving market changes, including potential cost reductions, through innovation as participants' needs and expectations evolve.

This funding stream can support courses, groups and organisations to help build capacity; facilitate mentoring and peer support; and help provide people with information to support choice.

Examples of supports may include:

- *Programmes for carers and counselling for people who are caring for someone with disability or mental illness;*
- *Parent breaks and programmes to provide parents with skills and information about disability;*
- *Professional development e.g. for parents and education providers;*
- *Diagnosis specific peer support groups.*

The NDIS should encourage the continued operation of organisations and activities, and may contribute funding recognising both the broad community benefit and the benefits to individuals, families and carers.

Response: This stream focuses on the PWD and parents or carers. Again there is a gap in relation to siblings. They too should be able to access information, counselling and peer support programs, regardless of the nature of their 'caring' role. Certainly, as siblings age their roles can be similar to that of a 'carer'. And sometimes the resources/services provided by 'carer' organisations may be relevant. However, many do not wish to identify as a carer for a number of reasons (including dignity of the person with disability) and this should be respected. They want to be brothers and sisters first. The majority of siblings surveyed as part of the Adult Sibling Project stated that they wanted to access such supports from a sibling focused organisation. Needs may overlap with carer supports, but siblings have their own particular needs that can be quite different to 'carers'. As with people with disability there should be a focus on 'choice and control' and the voices of siblings being heard. And professional development needs to include knowledge and skills around sibling support. This may then mean more siblings reach out to services, resulting in benefits for them but, also, the PWD.

Stream five: Local area co-ordination (LAC)

LAC is the development of relationships between the NDIS, people with disability, their families and carers, and the local community (including informal networks, community groups, disability and mainstream services).

LAC will ensure that people with disability, their families and carers, are able to make full use of the mainstream and other services (including diagnostic-specific information) available to them. LAC will also help to streamline their NDIS experience and assist them to navigate the variety of NDIS supports. Active involvement in building the capacity of other community services to respond to the needs of people with disability and carers and to develop natural networks of support around people with disability;

- *Building and supporting informal support systems;*
- *Formal services and funding as the last, not the first, response. This role is delivered through:*
 - *working with people with disability, their families and carers to consider their immediate and future goals and how these might be best achieved.*

- *working with individuals and their families to achieve their goals by building new networks and accessing support and services in their community.*

Response: Siblings should also be included in meaningful ways within this discourse. They too need support to achieve their own goals surrounding career, managing their own families and also supporting ageing parents alongside the person with disability. There must be some choice and control and not an expectation that these family members will just 'take over'. Just as 'nothing about us without us' has been a popular catchcry in the disability community, there needs to be an understanding that siblings should be acknowledged and considered in meaningful ways and connected to appropriate sources of support.

Some siblings come to play an active role in supporting the PWD later in their lives, when parents are no longer able to play this role. They may have had no experience in navigating the disability (or NDIS) sector. They need to be able to be supported in finding what services are right for them and for their brother or sister with disability.

Where do siblings fit within the NDIS?

From written materials and in personal communication it would seem that the NDIA does consider siblings as an important part of the system of support for people with disability, regardless of whether they play a hands-on caring role. In other words, it seems that the NDIA recognises that siblings can contribute much in the way of social and emotional support (informal support) over a lifetime. However, when it comes to the detail in The Paper which sets out policy parameters re ILC and the actual clusters of support and support items that are available for planning, there are gaps in relation to siblings specifically, and this gap will need to be addressed. There would need to be provision for the appropriate delivery of services to siblings (eg peer support programs across the ages), information and resources for people who support siblings in different settings (eg family, schools, disability/health agencies and the general community). It is important that these services are co-ordinated, with trained providers who follow national guidelines for practice. At present there are some very questionable approaches to sibling support.

Recently Siblings Australia was registered in SA (applications for registration in other States are currently being assessed) to provide supports in the clusters *Development of daily living and life skills*, specifically Support Item 15007 and *Assistance in co-ordinating or managing life stages, transitions and supports* (support item 08004). These items lack clarity on how siblings might be supported; there are no support items that directly relate to siblings and no mention of peer support ie support groups. Item 15007 allows for parent consultations on how they can support siblings. It doesn't make it clear if this can happen in group sessions as well. And it isn't clear if item 08004 allows for counselling or group sessions for young and adult siblings?

If, however, the NDIA believes that sibling support does not come under its responsibility, then there needs to be further discussion about how siblings might be supported elsewhere. They are not included in general policy or programs at a national level.

The Paper suggests that *ILC will allow the NDIS to influence and shape the delivery of supports at a systemic level to provide better outcomes for people with disability, their families and carers.'*

Siblings Australia would welcome the opportunity to be part of these discussions.

Siblings Australia

Siblings Australia is the only organisation to focus on siblings of children/adults with disability. Over a period of 16 years, it has developed a national and international reputation for its work with families and providers. It's Director has been asked to present in Italy (3 times), Scotland,

England, US and Canada. Her book on siblings has been published in Australia, the UK, and US, and has been translated into Korean.

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.
- 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.

In addition to the above, Siblings Australia also hosts a website, which 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 the country, asking for information and advice.

During the last 8 years this work has been carried out through the mainly voluntary efforts of its people (Director and committee of management). Without the capacity to train others in this work, the future is very uncertain. It would be regrettable if the knowledge and expertise developed over many years were lost.

Recommendations

1. Siblings are recognised as an important part of the lifelong social support system for people with disability regardless of whether they are playing a direct caring role or not
2. Within the NDIS (and the ILC framework specifically) there is consultation on how best to support siblings (including the voices of siblings), both for their own benefit but also for the benefit of their brother or sister with disability.
3. Siblings need to be included in meaningful ways within NDIS documents such as the ILC framework
4. Siblings Australia is recognised within the NDIS as a valuable resource for both families and providers, and an important contributor to the overall principles of the NDIS, through its contributions in the areas of
 - a. Individual capacity
 - b. Strengthening of 'informal supports'
 - c. Information, linkages and referrals
 - d. Counselling and peer support for families, including siblings
 - e. Improved capacity within parents to support their whole family

- f. Improved capacity of siblings to be a lifelong supporter of the PWD
 - g. Improved capacity of the disability and other sectors to support the whole family
5. The NDIS should encourage the continued operation of Siblings Australia and assist in improving its capacity to ensure 'best practice' regarding the support of siblings and, ultimately, the whole family. As part of this Siblings Australia is supported to develop a strategic plan over the next 3 years to increase the capacity of the disability sector to support siblings
 6. 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, and the barriers to engagement

Conclusion

This submission is likely to raise some questions in relation to the NDIS and its intended outcomes in relation to people with disability. We cannot consider people with disability without considering the needs of their family.

Whole family support makes good sense – if family capacity is improved there are benefits for the person with disability, their parents, brothers and sisters, and the wider community. Siblings Australia would have much to offer if given the opportunity to discuss these issues in a meaningful way to ensure the best possible outcomes.

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