

## Questions re the NDIS

I would like to ask some questions about the NDIS or Disability Care as it is now called. But first I would like to provide the following context.

*The NDIS website says that the NDIS will recognise that disability is for a lifetime, and so it will take a lifelong approach to providing care and support. This means that assessment will look beyond the immediate need, and across the course of a person's life. ....*

*Taking a lifelong approach also means focusing on intensive early intervention, particularly for people where there is good evidence that it will substantially improve functioning or delay or lessen a decline in functioning.*

*Importantly, an NDIS will support choice for people with disability, their families and carers, and put people in control of the care and support they receive, based on need.....*

*An NDIS will ensure people are no longer "shut out" from opportunities and from independence by providing the appropriate and necessary supports that allow people with disability to reach their full potential.*

*It will nurture and sustain the support of families, carers and friendship groups — the very communities of support that are critical to improving the lives of people with disability.*

Clearly there is recognition that families are an important part of the lifelong quality of life of people with disability. I would add that whole families are important regardless of any caring role they may play eg a sibling may not play a direct caring role as such, but they may contribute much to the social and emotional wellbeing of the person with disability over a lifetime. Any assessment of need should reflect this.

Also at the heart of the NDIS is the notion of considering the lifelong needs of a person with disability and 'caring for the carer' or ensuring that care networks are strong over a lifetime. Siblings will usually have the longest relationship of anyone with the person with disability, long after parents and special educators are around. Also, in relation to parent carers, they have consistently said (via various reports) that siblings are one of their big concerns. If we can support parents to support all their children their role as carer will be an easier one.

Given that background I would like to ask if the following activities could be included in a funding package for families:

- Information workshops for parents on how to support the sibling(s) and how to nurture the sibling relationship
- Online/printed resources for families on how to support siblings (some of this has already been developed by Siblings Australia and other organizations; some of the resources developed by others are not 'best practice' and even counter-productive)
- Peer support programs for siblings of children with disability which give information about the disability, help siblings express their feelings about what is happening in their family and learn ways to manage the challenges. Parents have often said after such programs that the sibling interacts more positively with the child with a disability.
- Online/printed resources for siblings to gain greater understanding of the disability, the impacts on both their brother or sister and themselves.
- Focused interventions for siblings who are experiencing particular challenges eg how to stay safe if a brother or sister is violent, how to manage if schooling is affected, how to take part in community activities when this is very difficult for their family

- Programs that contribute to nurturing the sibling relationship eg shared community activities, sibling engagement in playgroups or early intervention activities

The above activities are primarily focused on families where there is a CHILD with a disability. If a sibling is supported from a young age, they can not only reach their own potential but more effectively contribute to their brother or sister reaching their potential. This has long term benefits for the sibling and the person with disability.

There is also a huge need to engage adult siblings, not as ‘carers’ necessarily, but as brothers and sisters. The use of the term ‘carer’ can deter some siblings from becoming involved – there is anecdotal evidence that some siblings move away from the family as it all becomes too stressful for them and the expectations of them becoming ‘carers’ can be too much. Rather we need to see brothers and sisters as a possible support person who contributes, as mentioned earlier, to the social and emotional wellbeing of the person with disability. Could the following activities be included in any family package of support?

- Information sessions for young adult and adult siblings about what role they would like to play in the life of their brother or sister, how best to consider future planning, accommodation/recreational options for their brother or sister, medical issues etc, and navigating the system. An adult sibling project run by Siblings Australia a few years ago suggested that many siblings would prefer to access this support through sibling focused organizations rather than ‘carer’ focused ones.
- Online/printed resources for the above

The NDIS may not be able to provide for these services directly but there is a need to recognise the importance of sibling relationships. There are organizations that attempt to support parent carers and so parents can access these outside the NDIS. There is no such co-ordinated support options for siblings and if the NDIS does not provide for this then there needs to be consideration of where this support could come eg through disability services, mental health services, education. Siblings Australia has been working in this area for 14 years and in that time as developed a national and international reputation for its work with families and providers. However, it cannot access government support and so its future is uncertain. One of the key issues is the lack of workforce development in this area. Siblings Australia has done considerable work in this area but there needs to be a more co-ordinated approach so that there is more understanding of indicators for sibling support and ‘best practice’ approaches.

When considering assessment tools it is complex. Some siblings will not show signs of their distress even when they experience it – they may want to protect parents or not ‘rock the boat’. However some signs that siblings might be experiencing stress include: ‘acting up’ behavior, withdrawal, anxiety, depression, physical symptoms, social difficulties, school difficulties, perfectionism. If a child with disability is showing aggressive or violent behavior than the sibling must be deemed to be ‘at risk’ and so interventions that help the child manage and keep him or herself safe are imperative. (Respite is not the full answer as it does not change what happens at home when the child returns.)

I am happy to provide further information.

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