

Siblings Australia, the only sibling-specific organisation operating in Australia, ascertains that the sibling cohort is a vital group that can readily assist governments in achieving the desired outcomes of the improved NDIS.

The sibling relationship is often the longest of a person's life, but despite their significance, they are an often-overlooked group in the disability community. They play essential roles in their brother's and sister's lives. However, their own needs as well as their contributions to their siblings' lives have historically been under-represented and under-supported. As an insurance model, the NDIS is underwritten by the assumption that a person has strong and enduring informal supports in place, but the scheme itself provides little scaffolding to shore up those relationships.

Most siblings love and care about their family member with disability, and many enjoy loving relationships. But 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, 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.

The reality of the rollout of the NDIS has meant that "family" supports are almost entirely focused on parent supports for child participants, and without explicit reference in the new list of supports, this is likely to continue.

***Family is the foundation of society; and the sibling relationship is the longest relationship of a person's life. We need to make sure it is strong and supported.***

Families in which disabilities are present experience a range of complexities that are outside the "norm". For siblings of people with disabilities, this can be particularly complex – they may not have any experiences outside of a life where disability is a reality, but they are aware that their own experiences are not necessarily like those of their peers.

Siblings of people with disabilities are more likely to experience [adverse mental health outcomes than the general population](#), after feeling like what is colloquially known as "[glass children](#)". Without support, siblings may choose to disengage from their families as they get older.

For people with disabilities, and particularly complex disabilities and communication limitations, this disengagement of family is a significant concern from a safeguarding perspective in the longer term. After parents are gone, siblings can provide the strongest direct support, as well as advocacy and oversight of a person's care.

But the importance of supporting and maintain sibling relationships is not just about safety. As Siblings Australia's white paper, "[Why are siblings important to achieving disability policy goals in Australia? The case for considering siblings of people with disability a critical partner in achieving the Australian Disability Strategy 2021-2031](#)" demonstrated, sibling relationships have tangible positive outcomes on the lives of people with disabilities in all areas.

And whatever the complexities, research has shown that the bond between siblings is the most enduring inside the family,<sup>1</sup> regardless of whether disability is present.<sup>2</sup>

For too long, the sibling relationship has been considered a secondary relationship by those implementing the scheme. The NDIS is an insurance scheme predicated on informal supports. For those supports to be truly sustainable such that they can be relied upon as the predicated 'informal support' within the NDIS ecosystem, they need to be bolstered. Siblings Australia is well-positioned to present part of the solution for governments about how they approach the NDIS Mark II.

To be an effective enabler of change, siblings need the following to be reflected in NDIS supports:

- **Siblings support needs to be embedded**

At present, sibling support is at best ad hoc and at worst completely overlooked. Evidenced-based and effective programs designed by Siblings Australia are funded through some NDIS Plans with other families being told that these programs do not fit within "their plan". Thus some families miss out because of the whims of individuals signing off on spending which can appear capricious at times.

Sibling support needs to be considered an integral part of the disability landscape. At present, when "family supports" are referenced the system is talking about support for parents. The brothers and sisters whose lives are also impacted are rarely considered. If respite care is provided it is short-term and any support to help the family operate as a whole once that respite is over is minimal. Once parents have passed away, for many people with disabilities, the responsibility sits with siblings to provide advocacy and safeguarding for their brother or sister and in many cases, legal guardianship.

Without early and ongoing support, this role can be lost.

It is not just about safeguarding, though. Consider the difference in quality of life for a person with disability who is living in supported accommodation with no engaged extended family, as compared to the person in the same accommodation who is actively engaged with their brothers and sisters. Or the young person with a disability whose brother or sister has felt 'looked through' their whole life, so chooses to go to university interstate; as compared to the sibling who has felt supported and seen so chooses to attend a campus within close geographical proximity to their brother or sister.

Good quality support for siblings results in a better quality of life for people with disability.

NDIS supports need to explicitly state that sibling supports can be incorporated.

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<sup>1</sup> Travers H. E., Carlton M. E., Carter E. W. (2020). Social connections among siblings with and without intellectual disability or autism. *Intellectual and Developmental Disabilities*, 58(1), 19–33; McHale S. M., Updegraff K. A., Whiteman S. D. (2012). Sibling relationships and influences in childhood and adolescence. *Journal of Marriage and Family*, 74, 913–930

<sup>2</sup> Rossiter L., Sharpe D. (2001). The siblings of individuals with mental retardation: A quantitative integration of the literature. *Journal of Child and Family Studies*, 10(1), 65–84.

- **Siblings need recognition outside of the carer model**

Oftentimes at present, if siblings are included in any discussions at a policy level, it is so often shoehorned into the carer space. This is of particular prominence in the youth space. Brothers and sisters should have the space to be just brothers and sisters. The natural relationship should be preserved if the scheme is to focus on true inclusion.

- **The authority of the sibling relationship needs to be upheld**

Conversely in the adult space, Siblings Australia often hears from adult siblings about the lack of recognition for the primacy of their relationship with their brother or sister as adults. Even when parents pass or their capacity diminishes and siblings *do* take on a carer or guardianship role, the NDIA and other organisations within the sector do not give their relationship the credence that it deserves. Because the sibling relationship is so poorly recognised in policy and practice, the importance is misunderstood. One of the most common grievances aired in Siblings Australia's moderated online support group, SibChat, arises when siblings are trying to work with an agency or other organisation to advocate for their brother or sister, only to be told their relationship does not have importance because they are not a parent.

- **Sibling support needs to be lifelong**

Sibling relationships change over the course of a lifetime, and the support that siblings needs also fluctuates as times go by. Siblings Australia offers programs and supports that cover the entire lifespan, and is working to expand the breadth of our services within current constraints. Like many of the disabilities that the NDIS supports, there is no "fix" to be had; rather a continuum of support is required to suit the evolution of a person's experience.

Siblings Australia has never sought to duplicate work being done by other organisations; instead, we have looked to complement and add value to that which is already occurring. With very meager financial support, we have worked with thousands of families, sometimes at crisis-point, but ideally – and like the NDIS when it is at its best – as an early intervention to support families before the pressure of circumstance has led them to that crisis.

To do so, sibling support needs to be embedded and not left to the whim of individuals.