



Siblings Australia Inc

Australia's National
Autism Strategy

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 **Siblings**
australia inc

for siblings of children and adults with disability/illness

Siblings Australia welcomes the opportunity to contribute this submission to the National Autism Strategy. Siblings Australia is the only Australian organisation to focus on the needs and contributions of siblings of people with disability over the last 24 years and has developed an international reputation for its work with siblings, families, professionals, advocacy, and contribution to research.

The Strategy is hoped to be a starting point for further input from Siblings Australia and a wider and more nuanced understanding of the role of siblings.

Too often, when “family” supports are discussed, it is almost entirely focused on parent supports. We are buoyed by the emphasis in the discussion paper to the Strategy being developed along a person and family-centered approach. We hope that the same mistake – of conflating “family” with “parent”, which happens particularly within the NDIS – is not repeated in the Strategy.

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

1. Introduction

In families of autistic people, the whole family can be impacted to greater or lesser degrees. Siblings Australia would argue that there needs to be more consideration given to the mental health and well-being of both the autistic person and their sibling(s) and also the strength of the relationship between siblings. Not only will this benefit the sibling but a stronger relationship (given the sibling relationship will likely be the longest of any) will have huge impacts on the well-being, social inclusion and possible safety of the autistic person over their lifetime.

The NDIS was created with the goal of a more inclusive community. It was meant to help eligible people gain more time with family and friends, greater independence, and improved quality of life.

For many people, it has been game-changing. But it has also reinforced a medicalized model of disability.

The focus on therapies and the push to get the biggest bucket of money to access the most therapy they can, has stretched families. In trying to do the best they can for their child with disabilities, mums, dads, and carers are juggling a vast number of commitments.

A holistic approach to family support has been forgone in favour of a system that demands measurable impact, where autistic people are something to be “fixed”. Because the majority of the funding is tied up in individual plans, and individual plans are so focused on the delivery of goals, it has indeed become the only oasis in the desert. The broader support has, by and large, fallen by the wayside, including support for siblings.

To provide the foundations that result in true inclusion, the Strategy must involve all members of families

As diagnosis of autism often occurs in childhood, siblings can be overlooked as family attention focuses on the needs of the autistic person and their immediate needs. While understandable, the Strategy should consider the impacts of this on the whole family. Supporting siblings benefits the whole family by ensuring all members are having their needs met.

In a [recent white paper](#), Siblings Australia demonstrated how siblings are already supporting the goals of Australia's Disability Strategy, and how they further would with additional supports.

Unsupported, siblings themselves can be identified as a vulnerable cohort in their own right, for the following key reasons:

a) Siblings of people with disability are vulnerable too.

The issues for siblings of people with disability can be complex. Each person has a unique set of internal characteristics and external challenges and there are several factors that affect their adjustment to these. Even within one family, siblings may respond very differently to what is happening around them. And their experiences and reactions will change over their lifetime.

It is well-accepted that disability impacts the whole family. A 2008 Australian Institute of Family Studies report¹ found that parents of children with disability have higher rates of depression than the general population and siblings also had a significantly increased risk of depression, regardless of any caring role. Often these parents do not access services for themselves or their other children as the focus is on the child with disability. If they do recognize the challenges for siblings, support options are limited.

Siblings can experience significant stress, confusion, and difficult feelings like grief, guilt, anger, fear and embarrassment. There is also a lot of pressure on them to not 'make waves', to be perfect and not add to any stress for parents. They might try to squash any of the difficulties they face and rarely ask for help themselves, which then increases the risk of mental and physical health problems².

As the The Royal Australian and New Zealand College of Psychiatrists (RANZCP) stated in an issues paper regarding siblings, 'There is reasonable consensus that siblings of children with chronic conditions are at risk for behavioural, mental and physical health problems. If left unaddressed, the challenges which siblings face can increase their risk of developing longer term mental health problems, at considerable cost to them, governments, and the community.' ([see this and other related documents here](#)).

b) Siblings have been highlighted as being at risk in other publications from a mix of sectors (these publications are available upon request).

Siblings Australia's own Mapping Project from 2018 highlighted the contribution and needs of siblings, the gaps in services, and offered recommendations for the future. The **2012 – Report from surveys re: aggression**, highlighted another concerning issue for siblings that is rarely discussed.

c) Siblings can play an important role in the development of young people with disability.

The relationship between siblings is often the longest of a lifetime. If this relationship is strengthened and nurtured from a young age it can set up better outcomes for both children going forward. A strong sibling relationship between siblings can enhance the well-being, social inclusion, and safety of a young person with disability.

¹ Edwards, B., Higgins, D.J., Gray, M., Zmijewski, N., Kingston, M. (2008). The nature and impact of caring for family members with a disability in Australia. Australian Institute of Family Studies, 2008. Research Report, no. 16

² Hogan, D., Park, J., & Goldscheider, F. (2003). Using Survey Data to Study Disability: Results From the National Health Interview Survey on Disability. *Research in Social Science and Disability*, 3, 185-205.

The Autism CRC highlighted that siblings were significant ‘agents’ in the development of young people with autism in their report [Interventions for children on the autism spectrum: A synthesis of research evidence](#).

2. Recommendations for the National Autism Strategy

a) **Ensure that a “family-centered” approach focuses on all family members**

More connected families are more successful families. The entire ecosystem of the autistic person’s life needs to be considered. The Strategy needs to make sure that when it is looking at “family-centered”, often the longest relationship of a person’s life is also centered. This may mean at different times and in certain families, siblings require additional support.

b) **Provide recognition of the importance of the sibling relationship**

Peer-to-peer supports and resources, co-designed with young people and those who work in this space, could help improve their social and emotional well-being. Recognition of the impacts of being a sibling, outside of the young carer model, should also be prioritized.

Siblings have known an autistic person throughout their lives, which places them in an excellent position to be key figures in their social, recreational, sporting, religious and cultural lives, as well as to be good quality communication partners with them who can help them navigate dialogue with others. They also can provide critical assistance to autistic people when they are communicating their needs to service providers across education, service provision and healthcare contexts; this communication support role is particularly important for the portion of the autistic community who have complex communication needs and/or limited other social connections to assist them in advocacy.

By virtue of being in a peer-like sibling relationship, sometimes with a more egalitarian or ‘horizontal’ power dynamic than autistic people have with a range of others in their lives, siblings want their brother or sister to realise as many of the same rights/opportunities in life as themselves as possible and do not want to have undue responsibility for their autistic brother or sister.

In addition, the downplaying of the sibling relationship across some parts of policy areas contradicts the emphasis of the aims of the Strategy to be inclusive of First Nations and culturally diverse communities, where extended kinship networks take a prominent role in how families interact.

The benefits and importance of this relationship need to be acknowledged and supported. These are often unheard voices that offer an important perspective. The creation of the National Autism Strategy is considering what can be done to better support autistic people across their whole of life. The sibling relationship is the longest of a person’s life, and it needs to be a prominent feature of the Strategy. Siblings often have important perspectives or information to share about their autistic brother or sisters. Wider recognition of their perspectives and their challenges would be beneficial for autistic people, and their siblings.