Siblings australia inc

for siblings of children and adults with disability/illness

Submission to the NSW Select Committee on Foundational and Disability Supports for Children and Young People

INTRODUCTION

Siblings Australia welcomes the opportunity to contribute to the inquiry into foundational and disability supports available for children and young people in New South Wales. As the only national organisation focused exclusively on supporting siblings of individuals with disability, Siblings Australia has over 25 years of experience advocating for the inclusion, recognition, and support of siblings as integral component of the care ecosystem.

We acknowledge the importance of early intervention and foundational supports for children and young people with disabilities or developmental concerns. Equally, we emphasise the need to support their siblings, who play vital roles in fostering wellbeing, inclusion, and long-term care stability for individuals with disabilities. This submission highlights key areas in which sibling support is relevant to the Committee's inquiry, addressing workforce, service gaps, and cross-sector collaboration.

The inclusion of siblings in the foundational supports framework is critical to achieving the goals of a robust and sustainable system. Siblings play lifelong roles in the lives of people with disabilities, commonly stepping into care, advocacy, service coordination, and safeguarding roles, and most particularly as parents age or pass away. These roles are invaluable, yet they remain largely unacknowledged and unsupported in current disability support structures.

The reality of the rollout of the NDIS has meant that “family” supports are almost entirely focused on parent supports for child participants.

With the sibling relationship often the longest of any, the potential for this to be rewarding for both the sibling and person with disability, plays a huge role in their well-being, social inclusion, and safety over a lifetime. If the sibling relationship breaks down, the potential losses for the person with a disability and their sibling can be huge – and in turn, can leave everyone in need of even more support.

This submission is intended to be read in conjunction with the complementary papers that Siblings Australia has created: “Positioning Siblings Australia in a Reformed NDIS” and our white paper, “Why are siblings important to achieving disability policy goals in Australia?”.

A CRITICAL NEED FOR LONG-TERM FUNDING

Short-term, project-based funding - such as that provided through the Information, Linkages, and Capacity Building (ILC) program - is inadequate for sibling supports. The sibling relationship spans a lifetime and requires evolving, tailored support at different life stages. For example:

- Young siblings need resources to understand disability and learn to acknowledge and process emotions.
- Adolescents benefit from peer support to navigate identity and familial roles.
- Adult siblings often take on care, advocacy, and service coordination roles, requiring practical tools, education, and legal/financial advice.

The instability of short-term funding cycles not only disrupts service delivery for organisations like Siblings Australia, but also limits the ability to attract and retain a skilled workforce, including those with lived experience. Adequately skilled professionals are reluctant to commit to roles with uncertain funding, hindering the development of sustainable programs. Long-term funding cycles, tied to foundational supports, are essential to ensuring that siblings receive the continuity of support they need across their journey.

SIBLINGS AUSTRALIA: A TRUSTED PARTNER WITH PROVEN IMPACT

Siblings Australia has a well-established reputation for delivering effective, evidence-based programs that improve the lives of siblings and their families. Over the course of our previous ILC funding (2020-2024), our reach grew exponentially:

- 2021: 2,500 participants
- 2022: 5,000 participants
- 2023: 10,000 participants
- 2024: 20,000+ participants

Recent economic modelling shows that, conservatively, **Siblings Australia delivers $28 of community benefit for every $1 invested which equates to an annual community benefit of at least $19,643,800 in saved NDIS and other health care costs**.

We have supported over 500 organisations and government agencies, providing specialist resources, training, and consultation. Our programs, such as SibWorks, TeenSibs, and SibConnect, have been shown to reduce isolation, improve sibling relationships, and empower siblings to support their brothers and sisters effectively.

New initiatives like the Life Changes project (focused on transitions - a focus area of the consultation paper), SibPlan (a future planning tool), and our forthcoming children's portal demonstrate our commitment to meeting siblings' needs across their lifespan.

Siblings Australia is the only organisation in Australia to provide sibling-specific support, and have been providing a range of supports and services to other organisations to ensure a holistic approach is taken to disability supports. For example, Family Planning NSW received funding from the NSW Department for Health to develop resources for siblings through their "Planet Puberty" program. The information included in this portal leant heavily on our resources. We encourage any decisions regarding funding for sibling-programs to consider the intellectual property, experience, and reputation of Siblings Australia as the preeminent organisation in providing this crucial family support service.

RESPONSE TO TERMS OF REFERENCE - THE ROLE OF FOUNDATIONAL SUPPORTS IN A CHILD'S OVERALL DEVELOPMENT, HEALTH, AND WELLBEING

Sibling relationships profoundly influence a child's development. Research shows that strong sibling bonds contribute to better mental health outcomes for both children with disabilities and their siblings. Providing foundational supports for siblings - through education, peer connection, and emotional wellbeing initiatives - enhances their capacity to engage positively with their brother or sister, fostering long-term social inclusion.

Types of services and supports available and measures to improve access
Siblings Australia offers several key programs:

- **SibWise:** An e-learning module designed for parents and professionals who care for, support or come into contact with siblings of children with disability. This learning program assists people to better understand and respond to sibling needs and challenges.

- **SibWorks**: An evidence-informed peer support program for children aged 8-12 that is designed to support siblings by building their emotional wellbeing and resilience. SibWorks is also delivered as an e-learning module to train professionals in the health, education, disability or community services sectors to facilitate SibWorks workshops.

- **TeenSibs**: Peer support groups for adolescents, providing a safe space to network with other teen siblings and share experiences, delivered online and in-person.

- **SibSupport telehealth**: Counselling services for siblings and families, addressing geographic barriers to access by being offered in a secure online environment (or in person on request).

- **KidSibs**: An online resource for children aged 5-12 which is currently under development (but currently on-hold as Siblings Australia navigates the complexity of service delivery in a system that has been undergoing years of transformation with no clear end in sight).

To improve access in regional and remote NSW, we recommend increased funding for digital solutions and locally delivered sibling programs.

DIAGNOSTIC SERVICES AND ADDRESSING GAPS IN ACCESS

Timely diagnosis is critical, not just for the child with disability but for their siblings. Siblings often feel confusion and anxiety when a diagnosis is delayed or poorly communicated. Ensuring that diagnostic services include sibling engagement and education helps to build understanding and reduce emotional distress.

Recent research out of Denmark suggests that family stress during the early years of childhood is what significantly matters with regards to sibling mental health – ie, the time around and immediately following diagnosis.

GAPS AND BARRIERS TO ACCESSING EARLY INTERVENTION

The primary barriers for siblings are:

- Lack of awareness: Many early intervention services do not acknowledge sibling needs, in part because of lack of awareness of the importance of this by practitioners; but also due to the funding model of the NDIS at present.

- Funding limitations: Short-term project-based funding disrupts the continuity of sibling-specific programs. In addition, funding for families to access supports is scant. SibWorks is our evidence-informed program for 8-12-year-olds, locally delivered by service providers or schools with training, resources, and support provided by Siblings Australia. While providers may be able to fund the program, there remains a significant cost to families who are often on-charged for the delivery of the program. The cost of staff delivery of the program was previously factored into budgeting before the advent of the NDIS; now, with a focus on “billable hours”, the time staff are spending delivering the program has to work on a direct cost-recover model.

- Geographic inequity: Rural and remote families have limited access to sibling support services.

To address these gaps, we recommend embedding sibling considerations in early intervention policies and funding models.

OPPORTUNITIES FOR CROSS-SECTOR ENGAGEMENT

Cross-sector collaboration is essential for effective sibling support. We propose:

- Partnerships with educational settings to implement school-based sibling programs.

- Integration with health services, ensuring that paediatric and allied health professionals are trained to consider sibling wellbeing in care plans.

- Engagement with Aboriginal Community Controlled Organisations (ACCOs) to develop culturally appropriate sibling supports.

BEST PRACTICE MODELS OUTSIDE NSW

Siblings Australia's programs have been implemented nationally and internationally as best practice models. The UK's Sibs charity and the USA's Sibling Support Project, with whom Siblings Australia has a collegiate information and resource-sharing model with, have similarly demonstrated the effectiveness of sibling-specific programs in improving outcomes for families of children with disabilities.

WORKFORCE ISSUES

Professionals in child development and early intervention often lack training on sibling needs. We recommend:

- Upskilling professionals through targeted training on sibling wellbeing.
- Developing a specialist sibling support workforce to deliver programs across NSW.

MEASURES TO IMPLEMENT RECOMMENDATIONS OF THE NDIS REVIEW AND DISABILITY ROYAL COMMISSION

Both the NDIS Review and Disability Royal Commission highlighted the importance of informal supports. Siblings, as lifelong supporters, are crucial in ensuring sustainable care and safeguarding for people with disabilities. Implementing foundational sibling supports aligns with the NDIS's goal of fostering strong informal support networks.

The critical roles siblings play in care, advocacy, and decision-making also place them in a unique position to influence positive outcomes in safeguarding and quality of life. However, without proper education and support, siblings may unintentionally contribute to abandonment, neglect or unsafe practices. Engaging and equipping siblings with knowledge about disability rights, empowerment, and supported decision-making is vital. This ensures that their contributions are constructive, rights-based, and empowering for their brothers and sisters with disabilities.

With additional resources, Siblings Australia would be able to provide broader coverage and additional support to buttress the longest informal support system of the lives of people with disability.

KEY RECOMMENDATIONS

- Embedding sibling-specific supports in foundational and early intervention frameworks.
- Expanding sibling support programs, such as peer support, education, and capacity building.
- Improving collaboration across sectors, including education, health, and disability services, to ensure that sibling needs are recognised and addressed.
- Developing and funding sustainable service models to ensure long-term availability of supports.
- Addressing workforce gaps by upskilling professionals to understand and support sibling experiences.

CONCLUSION

Supporting siblings is a smart investment in the long-term sustainability of disability support systems. By embedding sibling-specific supports in foundational frameworks, we can enhance the wellbeing of families, improve safeguarding for individuals with disabilities, and foster a more inclusive society. Siblings Australia is ready to collaborate with the NSW Government to develop and implement these critical supports.

Siblings 25 YEARS
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