Siblings 25 YEARS australia inc

for siblings of children and adults with disability/illness

Strengthening Foundations: the critical role of Siblings Australia in delivering the promise of foundational supports

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Executive summary

The 2023 Independent Review of the National Disability Insurance Scheme (NDIS) marked a turning point in disability policy by recommending the establishment of a foundational supports system to sit alongside the NDIS. These supports aim to create a more equitable, inclusive, and sustainable approach to disability across Australia. However, one vital stakeholder group remains largely absent from policy frameworks and service design: siblings of people with disability.

Siblings Australia is the only national organisation dedicated to supporting these siblings. For over 25 years, it has led the way in research, service delivery, and advocacy, equipping siblings to thrive in their own lives while also acting as advocates, carers, and safeguards for their brothers and sisters with disability. The inclusion of siblings within general and targeted foundational supports is not just a matter of fairness or sentiment – it is a strategic, cost-effective, and evidence-based investment in the success and sustainability of the broader disability ecosystem.

This paper makes the case for:

- Immediate recognition of siblings as a stakeholder group within foundational supports frameworks.
- Ongoing core funding of $750,000 annually to support Siblings Australia's base operations.
- Investment of up to $7 million per year to enable national, hands-on service delivery across the country.
- Scalable funding models within this window to support staged growth and innovation.

This is a practical solution to one of the most pressing structural gaps in disability policy today. To build a sustainable future for people with disability, we must support the people who support them.

Introduction: a new chapter for disability support

The NDIS Review has opened the door for a reimagined ecosystem of disability support. Its recommendation to develop a foundational supports system recognises that individualised funding cannot, and should not, bear the full weight of supporting people with disability. Foundational supports are the connective tissue that enable inclusion, build resilience, and ensure that all Australians with disability - whether or not they are NDIS participants – can access the support they need.
Yet, siblings, often the longest-standing and most consistent support people in the lives of those with disability, have been overlooked in both language and logic. In policy documents, funding decisions, and service planning, "family" has too often meant "parent". This narrow lens ignores a critical reality: siblings are foundational supports. And when equipped and supported, they are among the most effective, committed, and enduring allies for people with disability.

> *"If I could sit down with a new minister and tell them one thing, it would be this: if you support me, you support my sister – and if you support my sister, you support me".*

Siblings Australia is the only organisation in Australia (and one of only a handful globally) dedicated to sibling support. It is ideally placed to deliver, scale, and evaluate sibling-focused foundational supports that align with the intent and scope of the NDIS reform agenda.

Why siblings matter

The sibling relationship is frequently the longest of a person's life. For people with disability, this relationship often becomes the cornerstone of continuity, stability, and advocacy across a lifetime.

Siblings can be:

- Informal carers who provide physical, emotional, and logistical support
- Advocates and navigators who assist in navigating services, policies, and systems
- Natural safeguards, especially when parents age or pass away.
- Trusted allies who promote rights-based outcomes and social inclusion.

Yet, the impact of being a sibling is profound. Many experience what is known as "glass child syndrome" – growing up in the shadow of a sibling's high needs. Without support, they face increased risk of mental health challenges, disengagement from family, and strained relationships. The ripple effects of this disengagement impact not only the siblings themselves, but also their brother or sister with disability, and the broader service system that depends on their informal support.

Investment in sibling support is both preventative and enabling. It is a smart policy lever that strengthens families, reduces service demand, and improves the life trajectories of both siblings and people with disability.

Siblings Australia: Proven, trusted, ready to scale

Siblings Australia has:

- Supported over 20,000 siblings in the last four years through our local partnership approach, working with more than 500 organisations nationally to embed sibling-informed practice
- Developed high-impact programs including ***SibWorks*** (for children), ***TeenSib*** (for adolescents), ***SibConnect*** (for adult peer support), ***SibPlan*** (for future planning), and ***SibSupport*** (for tailored counselling)
- Delivered digital tools and in-person delivery to urban, regional, and remote areas
- Provided professional training to thousands of educators, clinicians, and service providers

> *"Siblings Australia helps me understand I am not alone and there's many siblings out there going through very similar things I am experiencing. This has helped me to be more confident in myself and my brother who I love but got embarrassed of most the time we were out".*

Independent economic modelling, undertaken by Hudson Howells, has demonstrated that Siblings Australia delivers $28 of community benefit for every $1 invested, primarily through reductions in long-term healthcare, NDIS cost deferrals, and carer stress.
Despite this, Siblings Australia has never received core operational funding. Its work has relied on short-term project grants, which limit continuity, innovation, and workforce retention. A foundational supports ecosystem needs foundational infrastructure. Siblings Australia is that infrastructure.

General foundational supports: siblings as natural connectors

Siblings play a central role in achieving many of the key objectives outlined in the foundational supports framework. They are often instrumental in fostering inclusion by actively supporting their brother or sister's participation in recreational, educational, and social activities. Siblings also help promote and maintain connection—both by facilitating peer relationships and by strengthening social ties that are vital to wellbeing. They contribute to knowledge-sharing, often assisting their sibling to access services, understand their rights, and navigate supported decision-making processes. Importantly, siblings provide continuity and stability across life transitions, particularly during times of change such as school-leaving, aging parental care, or service shifts. In doing so, they act as informal safeguards against isolation, neglect, and system failures.

"Being a sibling has shaped nearly every part of my life. Since my sister was born, our family has faced many challenges trying to get her the care and support she needs. I remember being separated from my mum when my little sister had to be urgently flown to a bigger hospital after having seizures as a baby. That was the start of a long journey. Now, 12 years later, and after so many appointments and specialist assessments, she has only just received a provisional diagnosis of cerebral palsy, among other diagnoses - even though her difficulties have been obvious since she was little".

"We have a really special connection. I even learned key word sign to help her with her language and communication. I always can understand her in ways others might not".

Siblings Australia is uniquely placed to support this critical cohort. We deliver digital and locally tailored peer support programs that connect siblings and reduce isolation. We offer professional education to build capacity within the broader disability and community services workforce. Our resources—such as SibPlan—serve as trusted hubs of online and in-person information and guidance. We also design early intervention programs for siblings in early childhood and school years to build resilience, understanding, and confidence from an early age. In addition, we work to ensure that sibling support is integrated into existing service systems, encouraging providers to recognise and engage siblings as key partners in support and care.

These services are relevant regardless of disability type, geographic location, or stage of life. Whether a sibling is five or fifty, in a metro centre or a remote community, and whether their brother or sister's needs are physical, cognitive, or psychosocial, the need for connection, knowledge, and continuity remains. Siblings Australia is committed to ensuring that all siblings are seen, supported, and equipped to contribute meaningfully—both in their own lives and in the lives of those they care about.

Targeted foundational supports: meeting complex needs

In addition to our work in general foundational supports, Siblings Australia plays a vital role in delivering targeted early intervention supports to vulnerable sibling cohorts – groups whose needs are often overlooked or unmet by traditional service systems. These early interventions are designed to prevent long-term harm by addressing the unique emotional, social, and practical challenges siblings face *before* they escalate into more entrenched mental health issues, behavioural concerns, or disengagement from education and community life.

Among the most at-risk are children growing up in families with high medical or behavioural complexity. In these settings, the needs of siblings can be inadvertently deprioritised due to the intense focus on their brother or sister's care. Without early support, these siblings may internalise their stress, develop feelings of guilt or resentment, and struggle with anxiety or emotional regulation. By intervening early, we can help build resilience, validate their experiences, and ensure they are supported during critical developmental windows, and ultimately divert them from entering systems themselves from spiralling mental health.

Other targeted groups include grieving siblings who have lost a brother or sister to disability or chronic illness. Early support can be critical in helping these children and young people process complex grief and avoid long-term emotional fallout. Culturally and linguistically diverse siblings also benefit from early engagement that reflects their cultural context, strengthens family communication, and supports their inclusion in both community and formal service systems.

> *"Most families have the freedom to go out together without a second thought. For us, the thought of going out is not simple at all. The few times we do go out its never for too long as he can't handle being out of his usual routine or being around unfamiliar people or places. There are many times when I feel left out and miss out on activities my friends take for granted. As I'm the eldest child, I have taken on extra responsibilities in looking after both of my siblings when I was younger but even now I would be the main primary carer for my brother. I do feel frustrated and upset by it at times but when I do get to go out with my friends and for that I am very grateful".*

Siblings Australia delivers a range of early intervention initiatives tailored to these needs. These include SibSupport, a specialised counselling service for siblings and families that addresses emotional wellbeing and strengthens family dynamics from an early stage. For culturally and linguistically diverse families, we are developing age-appropriate, culturally adapted resources and offering in-language support to ensure early access and meaningful engagement.

These targeted early interventions reduce the risk of compounding disadvantage, mental ill-health, and social isolation. They create a strong foundation from which siblings can grow into empowered, connected, and stable individuals, better able to support their brother or sister, and to thrive in their own right.

What funding could deliver

The NDIS Review Report clearly identified the inherent limitations of the Information, Linkages, and Capacity Building (ILC) grant program as a mechanism for delivering foundational supports. While the ILC was initially designed to promote inclusion and community connection, in practice it has fallen short of providing the secure, sustainable infrastructure needed for organisations to deliver consistent, high-quality support. One of the most significant shortcomings of the ILC model is its project-based funding structure, which precludes long-term planning, undermines organisational stability, and restricts the ability to invest in core functions.

Under the ILC framework, funding is typically short-term, competitively allocated, and tightly scoped around deliverables. This creates a fragmented landscape in which organisations must continually reapply for funding, redirect staff resources to grant writing, and adapt programs to fit shifting criteria, rather than responding to actual community need. It also makes it impossible to maintain continuity of service, which is particularly damaging for vulnerable cohorts like siblings of people with disability, who rely on trusted, ongoing relationships and tailored support that evolves over time.

Furthermore, ILC grants do not allow for the coverage of essential organisational costs, such as governance, workforce development, technology systems, evaluation, or communications infrastructure, that are critical to delivering safe, scalable, and accountable services. As a result, many small and specialist organisations like Siblings Australia are forced to stretch limited project funds to cover core operations, or else divert time and energy to sourcing supplementary philanthropic or one-off government support. This not only distracts from mission delivery but also increases the risk of burnout, service disruption, and organisational closure, even when community need is high and outcomes are demonstrably positive. Further, philanthropic opportunities seldom support core business supports either, with individuals wanting to see “where their money is going” in project delivery.

The NDIS Review’s recommendation to replace ILC grants with a structured foundational supports system represents an important recognition that essential, non-clinical supports must be funded in a way that reflects their long-term, systemic value. To be effective, foundational supports must be underpinned by ongoing, core funding arrangements that allow providers to embed quality, invest in workforce capacity, collaborate meaningfully with other services, and build the sector-wide architecture needed to deliver inclusion, resilience, and sustainability. Siblings Australia is a case in point: while our impact has been widely acknowledged, the absence of secure base funding has made it difficult to retain staff, maintain national programs, and scale to meet growing demand.

A shift away from project-based ILC grants toward stable foundational support funding is essential—not just for the sustainability of individual organisations, but for the coherence and equity of the entire disability support ecosystem.

Outlined below, in high level, are the two ends of the funding spectrum that would allow Siblings Australia to appropriately service the sibling community.

Base-level funding: $750,000/year

- Sustain national coordination and program delivery
- Maintain peer programs, digital tools, and sector education
- Safeguard against loss of specialist expertise and intellectual property
- Build infrastructure for collaborative foundational support models

Scalable funding: up to $7 million/year

- Expand local delivery teams in every state and territory
- Reintroduce and grow on-hold programs like KidSibs
- Deliver regional and remote sibling hubs
- Invest in sector partnerships and co-design with communities

A flexible funding model would allow staged implementation, targeted pilots, and adaptive innovation as the foundational supports system evolves.

Siblings Australia is not asking for indefinite funding without accountability. It is seeking the same recognition and investment that has been afforded to other national peak or specialist bodies delivering proven, high-impact services. Funding sibling support is not a cost. It is a protective investment in the people who will help realise and uphold the long-term vision of the NDIS – a scheme designed to provide lifelong, sustainable support for people with disability.

"The most important thing I have learnt is having a community the importance of having a village behind you is ultimately what gets you through. My family, friends, and school community all play a vital role in supporting me. The challenges will never go away but knowing I have siblings Australia to turn to when I need it is comforting, I am very grateful I'm a part of this community and have people who I can relate to and talk to about the things I'm going through without feeling out of place or judged".

Recommendations

- Formally recognise siblings as a stakeholder group within foundational supports frameworks
- Fund Siblings Australia with $750,000 annually to deliver core supports
- Invest up to $7 million per year to enable scaled, localised service delivery across Australia

- Embed sibling-specific supports across general and targeted foundational supports
- Incorporate siblings in governance and consultation of the foundational support system
- Develop shared measurement frameworks that capture the value of sibling engagement in disability outcomes

Conclusion: an investment in people, not just policy

The success of the foundational supports system will depend not only on structures, but on people. Among the most important of those people are siblings. They are already supporting, already safeguarding, already stepping in when systems fall short.

But they cannot do it alone.

Siblings Australia has spent 25 years building the knowledge, the tools, and the trust needed to support these hidden heroes. With core investment and vision, it can scale its work to meet the moment.

It is time to back siblings. It is time to fund the foundations.

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NOTE: The sibling quotes included in this submission are from young siblings aged under 18 years.