Submission to the Australian Government Consultation on Foundational Supports

December 2024

"The work of Siblings Australia has deeply affected my life. The impact of my childhood on my personal development will forever be deeply marked by growing up with 3 brothers with disability. All my life I have battled with the fall-out of being born into my extraordinary family, both negative and positive. It has made me both tough and fragile. In my moments of fragility, I am deeply grateful that Siblings Australia exists."

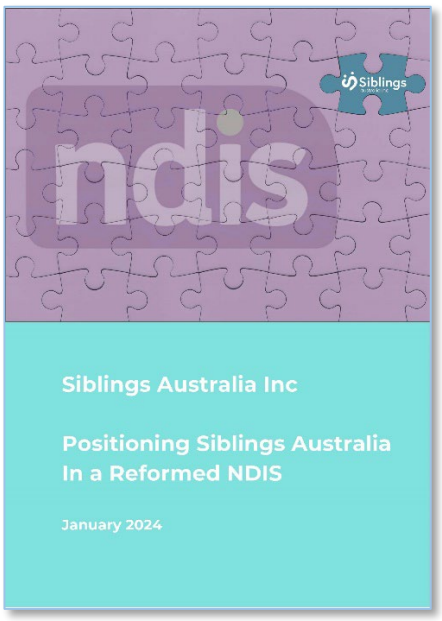
Introduction

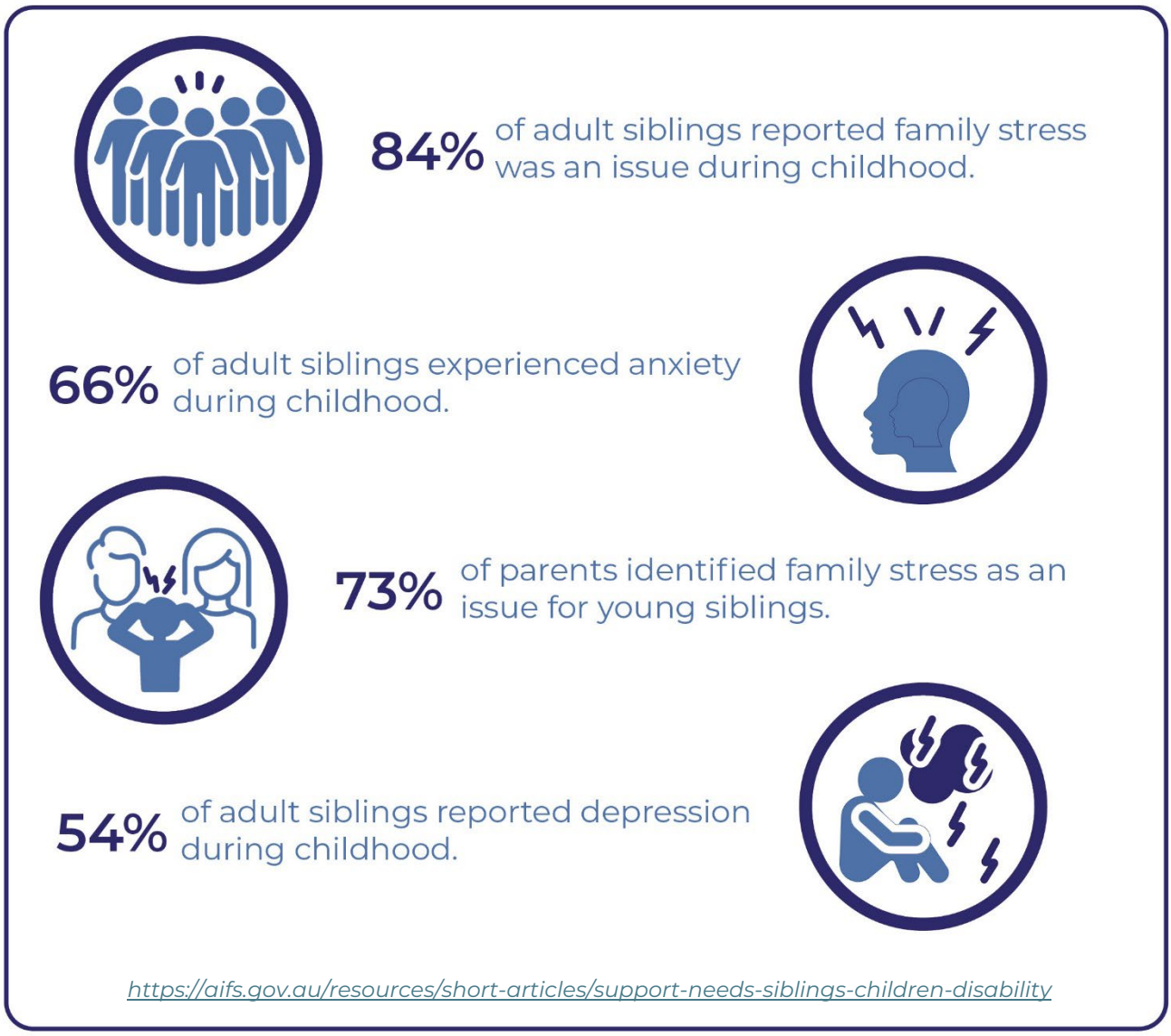
Siblings Australia welcomes the opportunity to contribute to the Australian Government's consultation on Foundational Supports. As the only national organisation currently delivering supports dedicated to siblings of children and adults with disability, Siblings Australia has for the last 25 years, advocated for recognition, support, and inclusion of siblings as essential members of the eco system of support.

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.

"A BIG thank you, the emotion from some mothers shows how raw a lot of this is. We are so focused on the child with a disability, but it really is a family issue, and I agree that the NDIS needs to be set up better for this. Looking forward to checking out your website too."

This submission is intended to be read in conjunction with the complementary papers that Siblings Australia has created (click on each image to access a PDF):





The lifelong role of siblings

The sibling relationship is often the longest of a person's life. For individuals with disabilities, and especially for those with intellectual disabilities, siblings provide an essential link to continuity, stability, and advocacy. Their roles often include:

- Care: Providing informal or formal caregiving support.
- Advocacy: Ensuring their sibling's rights, wishes, and needs are met.
- Service coordination: Managing and liaising with service providers and agencies.
- Emergency support: Responding in times of crisis.
- Oversight of professionals: Monitoring the quality and appropriateness of supports.

Siblings also play a key role in promoting their brother or sister's social inclusion, safeguarding, and decision-making. Their egalitarian, peer-like relationship often enables them to advocate for rights-based outcomes in life domains such as employment, independent living, and financial decision-making. However, to maximize these contributions, siblings need robust education and support to navigate available options, policies, and rights-based practices for their siblings effectively.

It is imperative that foundational supports consider the ways in which siblings access this information and support through channels that are tailored to their needs.

Without early and sustained support, these roles can become overwhelming, leading to burnout, strained family dynamics, and potential disengagement. The ripple effects are felt not only by siblings and their families but also by the person with a disability, whose informal support network can weaken over time if not reinforced, thus increasing the risk of adequate safeguarding.

A critical need for longer-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. Longer-term funding cycles, tied to foundational supports, are essential to ensuring that siblings receive the continuity of support they need across their journey.

Digital and locally tailored solutions

"SibWorks is an amazing program for Siblings. While each child was nervous and wasn't sure how it would relate to them, by the end of the first session they all spoke so highly of it. Watching them interact and share their stories in a safe environment, knowing and understanding that they were not alone was such an honour to watch. Their feedback was highly positive, and every single child said they were so glad that they participated. Being a part of providing this much needed service to children and their families is a great privilege."

As referenced in the consultation paper, Siblings Australia has embraced digital solutions to ensure accessibility for families across Australia, regardless of geographic location or social isolation. These include:

- SibSupport telehealth counselling: Providing direct support to siblings and families.

- Online peer support groups: For adults and teenagers, reducing isolation and fostering connection.
- KidSibs: A portal under development for children aged 5-12. This resource will help children understand disability, process emotions, and learn how to express their feelings to trusted adults.

"SibSupport has helped my colleague beyond belief. Since using the service along with the SibPlan resource, she is now able to share the support required to help her sister and reconnect with her husband - she has have even managed to plan a holiday with her husband, which she did not think was possible."

In addition, we partner with a wide range of organisations across Australia to provide the local and connected support services required in specific communities. In the last 18 months, this has included working with more than 500 organisations and government agencies to provide support or sibling centric training. These partnerships ensure that digital offerings complement and integrate with locally delivered, face-to-face supports. This dual approach ensures that services are both high-quality and community-connected, addressing the diverse needs of families and individuals.

"I have found the SibWise for professional program such a helpful learning tool to better understand the needs of siblings of children with disabilities and their families. I love that Siblings Australia can support siblings in this way to gain useful tool, strategies and resources and offer a learning platform for professional to gain increased awareness and understanding of what is available for siblings and families. Thank you Siblings Australia for this valuable resources to support families to build capacity and stronger bonds."

Siblings: Safeguards and supporters

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 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.

Moreover, the aged care system is seeing a significant increase in older primary carers transitioning out of their caregiving roles. Siblings often transition into these roles, yet the current system does not adequately recognise or support them. Siblings Australia launched its own online support, SibPlan, to help bridge the gap for those who are future planning with their brother or sister with disability. However, this service will be constantly evolving with the disability landscape and therefore supports like this need to be given priority to prevent strain on families and ensure continuity of care.

"SibPlan is an excellent suite of resources. One of its best features is that it is specific to the Australian context, meaning that Australian siblings no longer have to rely on English or American future planning resources. Critically, SibPlan is also tailored directly to the sibling experience, but simultaneously well-connected into the existing resources and infrastructure of the disability sector, including those crafted by organisations representing people with disability, those working on rights-based approaches and those doing family advocacy. This gives SibPlan legitimacy and shows it is well-informed and well-connected to other related work and contemporary perspectives. It is fantastic to see Australian siblings now able to use these resources."

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

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 life transitions - a focus area of the consultation paper), SibPlan (a future planning tool), and our children's portal (in the final stages of development) demonstrate our commitment to meeting siblings' needs across their lifespan.

Recommendations

To ensure that foundational supports meet the needs of all Australians, Siblings Australia recommends:

1. Embedding sibling support in both general and capacity building foundational support framework

2. Recognise siblings as a critical part of informal support networks and fund programs that address their unique needs across the lifespan, including ongoing support for Siblings Australia's proven programs.

3. Implementing longer-term funding cycles
   Move away from short-term, project-based funding to longer-term cycles that allow for the appropriate/adequate development, delivery, and evaluation of effective sibling support programs, noting that there does remain a place for project-based funding. However, core funding for organisations such as Siblings Australia, who have demonstrated their effectiveness, expertise, and need, is critical.

4. Expanding access to digital and local solutions
   Provide funding for Siblings Australia to continue to invest in and develop further digital tools and locally focused delivery models to ensure equitable access to quality supports for all siblings, including those in regional and remote communities.

5. Educating siblings on rights-based practices
   Provide support for Siblings Australia to continue and expand their programs focused around education on supported decision-making, disability rights, and empowerment to equip siblings to advocate effectively and constructively.

6. Recognising siblings' roles in aged care transitions
   Address the growing reliance on siblings as older carers transition into aged care, ensuring siblings are supported in taking on these roles through the work of Siblings Australia; and provide appropriate recognition within the system that siblings are shouldering this work.

Conclusion

Siblings are an untapped resource in the disability ecosystem. By supporting and strengthening sibling relationships, the Australian and state governments can enhance the sustainability of informal support networks, improve the quality of life and safeguarding of people with disabilities, and create a more inclusive society.

As the global recognition of siblings' vital contributions gains momentum—highlighted by Inclusion International's new siblings working group, which acknowledges siblings as an invaluable and underutilised resource—embedding sibling supports at the commissioning stage of foundational supports presents a unique opportunity for the government to lead the way internationally.

Siblings Australia is equipped to partner with governments and stakeholders to deliver these outcomes. We urge the government to embed sibling support as a cornerstone of the foundational supports framework, ensuring that siblings are recognised, supported, and empowered to contribute meaningfully to the lives of their brothers and sisters with disabilities.

"Siblings Australia has been an eye-opening organisation to engage with. I had been struggling throughout my adolescent and adult years with caring responsibilities. I was at odds with this and not managing well. It has been life changing to learn that I am not alone in this journey and through Siblings Australia I now have access to tools and resources to help me navigate my sibling journey."