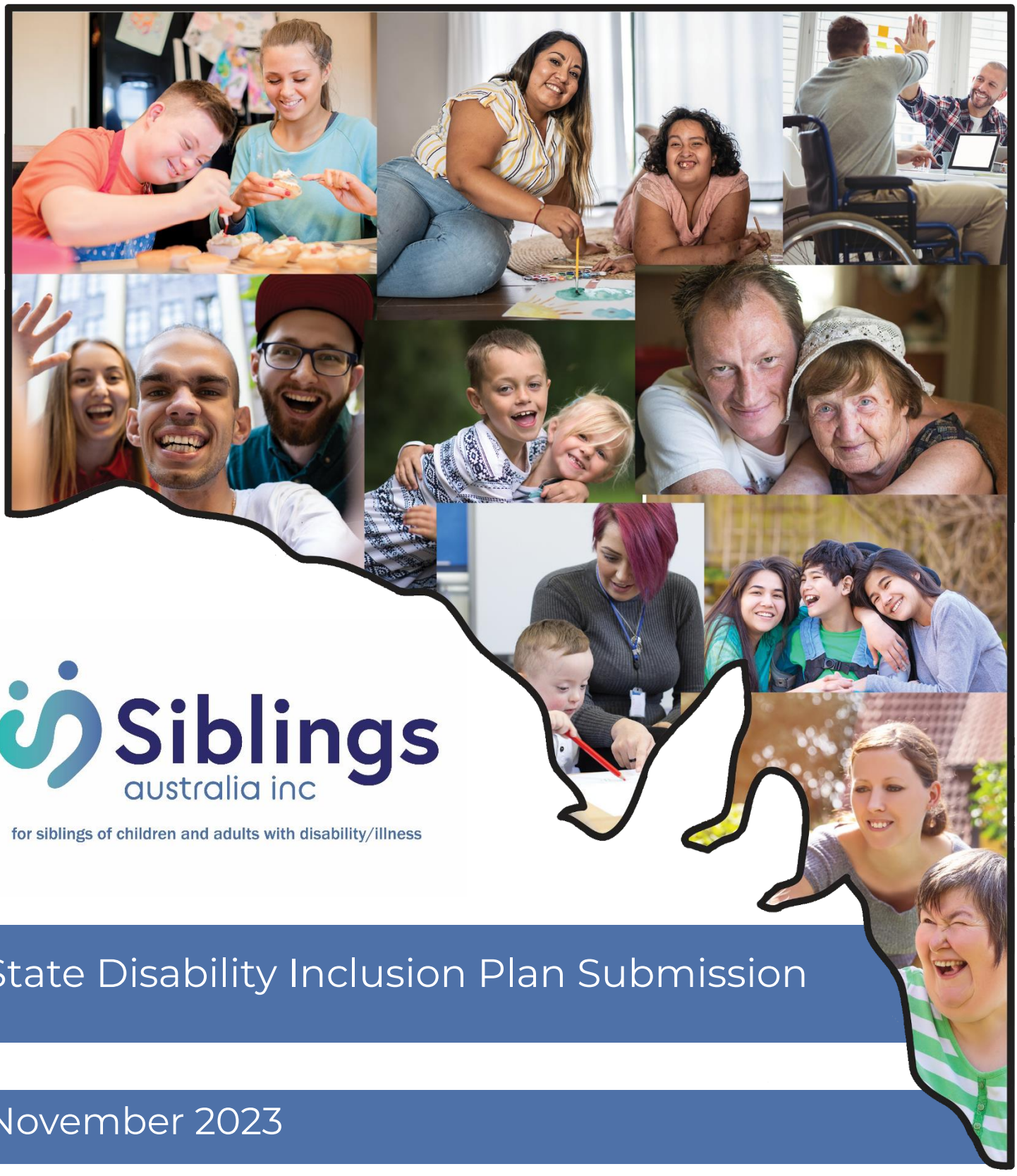

Siblings
australia inc

for siblings of children and adults with disability/illness

State Disability Inclusion Plan Submission

November 2023

Siblings Australia welcomes the opportunity to contribute this submission to the State Disability Inclusion Plan (State Plan).

Siblings Australia is the only Australian organisation to focus on the needs and contributions of siblings of people with disability over the last 25 years and has developed an international reputation for its work with siblings, families, professionals, advocacy, and contribution to research.

Regrettably, there has been scant mention of 'family' when the inclusion of people with disability (PWD) has been discussed in previous Inclusion Plans or in the *Disability Inclusion Act* (2018), including the first State Disability Inclusion Plan 2019–2023 – Inclusive SA (Inclusive SA) and those developed in 2019, 2020. This is despite families playing such a crucial role in the inclusion of PWD.

This submission will not answer specific questions that are included in the State Plan Discussion Paper (SPDP) but, rather, outline how family is so important to the 7 Outcome Areas defined within the SPDP: Liveable communities; The right to be safe and feel safe; Accessing personal and community supports; Physical, mental and social wellbeing; Access to meaningful employment opportunities; The right to lifelong learning; Advancing positive community attitudes. These outcome areas have been developed to align with the national agenda as outlined in the new Australia's Disability Strategy 2021–2031 (ADS). In a recent white paper, Siblings Australia demonstrated how siblings are already supporting the goals of Australia's Disability Strategy, and how, with additional supports, they could do this more effectively.

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.

Siblings: Acknowledged. Connected. Resilient.

Introduction

The *Disability Inclusion Act 2018* (SA) acknowledges that PWD have the same human rights as other members of the community; and, as a signatory to the United Nations Convention on the Rights of Persons with Disabilities, Australia has an obligation to ensure those rights are upheld. However, rights can only go so far in terms of inclusion for PWD. It is the attitudes of the community and the social networks of PWD that determine inclusion outcomes for PWD.

Family is the first social network for PWD. Siblings will likely have the longest relationship of any with the PWD and, if supported, they are likely to be part of the last social network for PWD. If this relationship is strengthened and nurtured from a young age it can set up better outcomes for both children going forward. 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. Siblings can act as mentors, playmates, and models of social skills. If developed early, a strong sibling relationship can enhance the well-being, social inclusion, and safety of a PWD over a lifetime.

There is much discussion in the disability sector about the importance of both foundational and informal support.

With the introduction of the NDIS, many of the supports available to families via the community have been reduced. Moving to an 'individual' funding model has meant that many organisations have become less able to provide services such as family support. Often, the focus is on individual therapies, rather than ensuring the family, especially those who support a person with more significant disability, has the capacity to convey their needs, manage their challenges, and to access the community. Any meaningful discussion on inclusion for PWD must include processes for developing the capacity of families to support PWD, from an early age.

How families/siblings can contribute to the 7 outcome areas

1. **Liveable communities**

Access is not just about physical spaces; it is about community attitudes (see number 7 below) and how easily PWD can be included in community activities. Families play a crucial role in introducing, supporting, and advocating for inclusion of PWD. Siblings have been specifically shown to facilitate their brother or sister's leisure and recreation across the life course, from childhood through to adulthood. Siblings typically remain a close contact for PWD, with sibling pairs commonly participating in recreational, sporting and cultural activities together in adulthood. As such, siblings play a key role in connecting PWD to local community and neighbourhoods.

In terms of physical space, recent research has identified the importance of considering social and relational context when conducting home modifications for PWD who live with their families. This work highlights the importance of considering home modification implications for siblings in relation to safety, space, structure, support and style of the family home – noting that such considerations help to achieve living environments that are not only physically accessible for children and young adults with disability, but that also support their ongoing relationships with family. This suggests that considering siblings in home modification practices has benefits for achieving accessible built environments for people with disability that also preserve family relationships.

2. **The right to be safe and feel safe**

One of the best safeguards for PWD is to have family involved closely in their lives, especially as they age: a parent monitoring closely the personnel involved in their child's schooling, an adult sibling regularly dropping in unannounced to supported accommodation provided to their brother or sister with disability. These types of activities ensure that PWD have people around them who are committed to safe and good service provision.

Siblings of PWD often play a key role in 'monitoring and influencing' formal care providers, particularly increasing their monitoring and vigilance when they are not confident in the quality of formal staff. This kind of family monitoring, influence and advocacy within formal care settings can be a critical factor in people with disability being and feeling safe from institutional violence, abuse, neglect and exploitation in residential care contexts.

Siblings are also more inclined to see the PWD's strengths and possess more egalitarian views of their sister or brother with disability than perhaps others within their ecosystem are. They seek to maximise reciprocity and minimise unequal power dynamics with the PWD. These attitudes position siblings as an effective ally or partner to PWD in helping to promote, uphold and protect the rights of PWD, both within and outside the family, especially as siblings are also often very keen to seek and use resources to ensure that people with disability achieve good outcomes and their entitlements in key rights-based areas such as housing, finances and employment.

3. Accessing personal and community supports

In the case of a child with disability, it is parents who support them to access the supports they need, whether that be aids, therapies, appropriate schooling, recreation opportunities. As they move into adulthood, siblings may take on more of the responsibility to ensure the PWD can access those supports that are needed for daily living. Particularly in the case of people with disability who have high support needs, many have few people who know them well. Siblings may be a key part of a small circle of people who have a deep understanding of them as a person and their preferences, and who can therefore truly advocate a nuanced understanding of their long-term preferences, likes and dislikes.

As the SPDP states, 'While state-based supports are crucial to improving wellbeing outcomes for people with disability, informal support provided by parents, siblings, kinship guardians, partners, children, other family members and friends is vitally important'. However, there is nothing in the SPDP about how those informal supports might be strengthened or nurtured, or how the relationships might be supported so PWD are included in the social networks of families. Of course, sometimes a whole family struggles to access community activities and there needs to be greater focus on this in any action plans related to inclusion.

Substantial research highlights the support needs of families of people with disability, including siblings. Well-documented needs include: the requirement for clear tools, resources and information about disability; peer support and validation of their emotional experience of disability in their family; support with skills development; support for family interactions and functioning; safety (in cases of challenging behaviour); and assistance to engage in education and employment in cases of significant caregiving. When siblings are acknowledged and well-supported, they are more likely to maintain ongoing support roles in the brothers and sisters with disability in adulthood. Therefore, addressing the needs for informal supports are critical to fostering positive relationships between these supports and PWD.

4. Physical, mental and social wellbeing

As the SPDP states, 'The wellbeing of people with disability should not only focus on physical health but should also include mental health outcomes'. Relationships are key to anyone's wellbeing but with communication and other challenges, sometimes family relationships need extra support to be as strong as possible. Given the evidence that siblings commonly take up roles with people with disability such as guardianship or 'person responsible' for medical decisions when parents age or pass away, siblings have a key role in engaging with healthcare service providers for their brothers/sisters. In healthcare settings, they – along with other family members – can have roles in communication, advocacy, protection, information exchange, direct care, and emotional support. As such, they are important in liaising with healthcare service providers to ensure these providers have the information they need to service their brothers and sisters well. This potentially includes flagging new areas of capability that need to be developed and/or checking that healthcare service providers do have the capability required.

For mental health supports and services to be appropriate, effective and accessible for people with disability, there is commonly a need for the close connections of people

with disability to help those with disability access mental health support. As siblings commonly have the longest relationship with people with disability in their lifetime and are commonly people who can be effective communication partners for them, siblings may have a key role in recognising the mental health care needs of people with disability and in helping them to communicate with mental health care providers.

5. Access to meaningful employment opportunities

Family can assist PWD in exploring the different options that might be available to them to ensure they can live independent lives and experience better mental and physical health and well-being outcomes, personal and career success, and fulfillment. Families have shown to frequently use their local knowledge and connections to assist PWD in finding suitable work opportunities. They also help provide suitable resources to assist with employment, as well as mobilise their social capital to help improve the employment prospects of their brothers and sisters with disability.

Young adult siblings are important in the transition of PWD out of school and into adult employment. PWD have noted that 'normative' transitions of their siblings may act as a reminder to their parents to aim high for what PWD can do in adulthood. In this sense, engaging well with siblings who are moving into the workforce themselves may assist with the transitions of their brother or sister with disability to employment, by providing others (such as parents and service providers) with the motivation to imagine big and work to help them find and retain employment as well.

6. The right to lifelong learning

Families set the scene for how a child learns.

Siblings are often a PWD's earliest play-partner during early childhood, where they may help the PWD enhance their social skills. Quality of play between siblings may also be enhanced by the right family education and support. As such, appropriate and effective supports can help build the sibling relationship and nurture social and peer interaction skills, which may in turn assist their social engagement when in formalised early childhood settings. Further, where siblings with and without disability attend early childhood settings together, having a sibling nearby who is already a skilled play-partner may be beneficial for at least some children with disability.

Where siblings with and without disability attend the same schools, siblings can be an important source of contact and connection for children with disability throughout the school day. In some situations, siblings may also assist school staff in understanding their brother or sister's support needs in educational and social contexts at school. While siblings' involvement in this way is not desirable as a formalised or frequent strategy, it may be beneficial for students with disability on individual occasions when siblings are well-supported in this role and have autonomy over when and how they contribute and may help to build the inclusive capacity of staff for individual students.

7. Advancing positive community attitudes.

As previously highlighted, siblings commonly have a key role in helping people with disability to communicate well with a range of service providers, including those in dedicated disability services such as group homes, education settings, and healthcare. As such, siblings play a critical role in assisting the relationship between people with disability and some key professional workforces they interact with, thereby assisting in the overall goal of helping these workforces to confidently and positively respond to people with disability.

Siblings also often see their brother or sister's capacities rather than limitations. They see their brother or sister as an equal and do not burden them with soft discrimination of low expectations. These sorts of attitudes can permeate more broadly advancing positive community attitudes about people with disabilities, and the Plan would do well to harness this power.