Siblings Australia Inc

South Australia's Youth Action Plan

July 2023

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for siblings of children and adults with disability/illness

Siblings Australia welcomes the opportunity to contribute this submission to South Australia's Youth Action Plan 2023-26. Based in South Australia, it has been 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 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.

1. Introduction

The Consultation Paper states "The new SA Youth Action Plan aims to ensure the South Australian Government better meets the needs of young people, by delivering **fairer and more equitable access to opportunities, resources, and supports**."

One of the vulnerable groups cited in the consultation paper includes those with a disability, but there is no mention of their siblings outside of the carer banner.

In all situations where there is any kind of disability or illness, the whole family is impacted. And young people who are siblings do not often have the emotional and cognitive maturity to cope with what is happening around them. Siblings Australia would argue that there needs to be more consideration given to the mental health and well-being of both the person with disability and their sibling(s) and also the strength of the relationship between siblings. Not only will this benefit the sibling but also 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 safety of the person with disability over their lifetime.

As diagnosis of a disability often occurs in childhood, siblings can be overlooked as family attention focuses on the needs of the person with the disability and their immediate needs. While understandable, the Youth Action Plan should require that siblings themselves be identified as a vulnerable cohort within this context, either in their own right, or as a key sub-group, for the following main reasons:

a) Siblings of people with disability are vulnerable too.[1]

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 report[2] 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 problems[3].

[1] Lamorey, Suzanne. (1999). Parentification of Siblings of Children with Disability or Chronic Disease. In Nancy D. Chase (Ed.), Burdened Children: Theory, Research and Treatment of Parentification. Thousand Oaks, California: Sage Publications

[2] 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

[3] 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.

As the 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).

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.

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.

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. Gaps in current considerations

There is a lack of government policy which recognises both the contributions and the needs of siblings. As a result, no one sector takes responsibility for them.

Siblings Australia has long argued that siblings should be included in any approach to support people with disability, but that they should also come under attention from health, mental health, education, and child protection sectors to ensure they do not 'fall through the gaps' in terms of policy and programs.

In the case of siblings of people with disability the issue of 'whose responsibility' it is to provide support is unclear.

The term "glass children" or "well child syndrome" is one that has been gaining traction for siblings through social media to help them understand their own experiences. This phenomenon is used to describe siblings who feel as though they have been "looked through" because the needs of their brother or sister with a disability or chronic illness were given priority.

These young people can feel an overwhelming pressure to be problem free; they may have a hard time expressing their emotions because they do not feel they are given space to do so; they can be people-pleasing to their own detriment. They can feel like they are inconveniencing people when they have their own problems, and can go on to neglect their own needs in relationships.

Long-term, this "invisibility" can impact on their sense of self and their relationships with others.

There has been some attempt to include siblings under the 'young carer' policy, but this is not necessarily in the best interests of siblings or the young person with disability. Further discussion about this issue can be found within the Mapping Project report mentioned above, under Section 5.1 Policy Issues.

Government understanding of and approach to siblings is not currently nuanced in a way

that comprehends the gamut of experiences lived by siblings. Under the present approach, for siblings to gain any sort of support or recognition, they must choose to identify as a young carer because of this general lack of recognition in policy. While a number of siblings may undertake some carer responsibilities, there are a significant number struggling who do not necessarily fit under this banner.

Not only does the sole focus on the young carer model push expectations on young people that they may not wish to take on; it can also interfere with the natural relationship between brothers and sisters. For a truly inclusive approach, the "ordinary" needs to be celebrated and supported. That means supporting siblings in that role and not just as young carers.

3. Gaps in data/research

Siblings Australia has developed and contributed to several research studies related to siblings and these are available through the organisation's website linked HERE

International research also shows that these children are vulnerable. This research is available on request.

However, consistent data has not been collected on the number of siblings in South Australia. Extrapolating out information from current NDIS participation rates and corresponding fertility rates, it can be ascertained that there are approximately 23,000 South Australian siblings under the age of 18 who have a brother or sister receiving NDIS funding, with about 5,000 of those being between 15-19. There are a significant number of other young people with disability who do not receive support through the NDIS, further increasing this number.

4. Recommendations for South Australia's Youth Action Plan

a) Social and emotional well-being and mental health

Research demonstrates the impact that on siblings of a person with disability can lead to complex mental health issues. As a cohort, they are significantly more likely than the general population to suffer depression, anxiety, and stress. 66% of adult siblings report anxiety during their childhoods; 54% report that they experienced depression. Overall, 84% of adult siblings report that family stress was an issue in childhood.[4]

This should be given due consideration in this section of the Youth Action Plan.

There needs to be better identification, through systematic and organised outreach, to young people at risk, including those that are not obvious or who do not speak up about their struggles. As outlined above, siblings are in fact less likely to speak out because they believe that their problems are not "significant" enough as compared to their brother or sister with a disability. This outreach needs to be through all the settings in which a sibling operates – family, school, community – and not left to parents to manage.

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.

b) Young people with a disability

True inclusion is achieved when people can experience the magic of the ordinary. Supporting young people with disability to engage with their siblings as a brother or sister, without the assumption of a caring role, helps those with disability achieve greater inclusion.

c) Young carers

[4] https://aifs.gov.au/resources/short-articles/support-needs-siblings-children-disability

Support for young carers is critical and must be provided. However, a more nuanced approach about the role of siblings should also be considered. At present, government does not, by-and-large, recognise issues of siblings unless they identify under the 'carer' banner. This raises a question as to whether the numbers of young carers are accurate; or whether young people are self-identifying as such just to get any form of recognition.

Siblings often have important perspectives or information to share about their brother or sister with disability. Wider recognition of their perspectives and their challenges would be beneficial for young people with disabilities, and their siblings.

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