

Siblings Australia: Submission to Stronger Outcomes for Families consultation

As outlined in the Background Paper developed by the DSS, many Australian families face significant challenges despite governments investing heavily in services aimed at making a positive shift in outcomes.

Historically, one particular vulnerable group, the siblings of children with disability, has been overlooked in both government policy and programs. It is estimated that there are close to 200,000 children aged 0-18 years with a severe or profound disability. Disability can affect the whole family, regardless of whether a particular family member plays a caring role or not, with research showing increased stress and mental health problems in both parents and siblings of children with disability.

This submission will add to the discussion in relation to these families and how they might intersect with the Family Support Program.

Responses to some of the questions asked as part of the Discussion paper are below – some have not been answered as they are not applicable.

Principle 1

- *Do these three outcomes encompass the most important outcomes for families and children that you see? Why/Why not?*

Siblings Australia supports the three outcomes suggested and agrees that children need to grow up in a safe nurturing environment with strong relationships. They also need to be ready to learn. All of these outcomes are relevant to siblings of children with disability – many of these families need support to become stronger, to be safe (siblings can be physically and emotionally harmed by a brother or sister with disability if that child has intellectual or behavioural disability which includes aggression – see the [report](#) on this by Siblings Australia in 2012), and many siblings can have their education compromised through stress at home or school.

- *Do the outcomes in your service or organisation align to the ones proposed?*

Yes, in particular, Siblings Australia aims to increase the recognition of the contributions, challenges and needs of siblings of children with disability, connect them to sources of support and through that ensure they are able to develop greater strength and resilience. This can result in stronger family relationships. With limited resources, over a period of 19+ years, the organisation has developed a national and international reputation for its work with siblings, parents and providers.

- *How long would it take for you to adjust your services to achieve these outcomes?*

Siblings Australia has no current funding but, if this changed, services could readily be expanded. Certainly, within 1-2 years, there could be marked improvement in national outcomes. The approaches are available, they just need resources to plan and implement, to work toward the above outcomes.

Funding

Siblings Australia supports the three proposed funding streams i.e. universal, targeted and location

- *If you are a service provider, would the three streams proposed above provide sufficient scope for you to provide services to families and children in the community/communities that you operate in? Why/why not?*

Yes it would as, currently, Siblings Australia has a targeted approach with one particular vulnerable group i.e. siblings of children with disability.

Principle 2

The principle of targeted interventions states that families who have 'disability or carer responsibilities are also at risk of experiencing poorer outcomes and difficulty accessing appropriate services'. (This statement should be clarified as the whole family is at risk regardless of whether they play a caring role or not.)

Over 19 years Siblings Australia has been highlighting these poorer outcomes for siblings, in particular, through various research projects, submissions and direct contact with government programs, including the FSP, and attention has been given to supporting siblings and parents, as well as providing workforce development.

A recent project carried out by Siblings Australia, the Mapping Project, highlights the challenges for siblings and the difficulty in parents accessing support for them. This leads to poorer outcomes for the whole family. This report is essential reading for policymakers and providers in the area of families and children; it includes a broader exploration of the needs and availability of support and a list of references. Certainly, the report shows that this is a family issue – the challenges affect the whole family and support services would benefit the whole family. Such support services need to be developed separately to the 'carer' sector, although collaboration could occur.

The Prime Minister in 2017, as mentioned in the Stronger Outcomes for Families Background Paper, recognised the importance of the first 1000 days of a child's life. Other international research has found that the stress experienced by children in the early years can have detrimental effects for life.

Siblings often grow up with considerable stress which can lead to higher risk of depression and anxiety. Their parents (who, in most cases, are the primary carers for the child with disability) are also at risk of a range of mental health problems, relationship breakdown and other difficulties, which in turn can impact their parenting.

The 2011 National Disability Strategy (NDS) highlighted the importance of family in the life of people with disability, and called for a co-ordinated, high level, strategic policy to address the complex needs of people with disability, their *families* (emphasis added) and carers in all aspects of their lives. However, several years after the NDS was released, there is still very little attention given to whole families and, in particular, siblings. The more recent national disability approach, the National Disability Insurance Scheme (NDIS), focuses on the child/adult with disability. As shown by the Mapping Project, above, support for siblings has actually decreased since the introduction of the NDIS. Parent and other carers are included in a range of policy and programs, but the rest of the family, in reality, are not.

- *Which clients should priority be given to?*

Siblings Australia believes priority should be given to siblings of children with disability as for too long they have been overlooked at both policy and programs, to the detriment of siblings, the whole family and the community. As mentioned earlier, this is a large target group. Not only would support for this group lead to better outcomes for the children themselves in terms of wellbeing and mental health, but also for the whole family and for the community (with less drain on social services in the longer term)

- *How could we improve access to our services and improve outcomes for these clients?*

By including siblings in policy (not as carers but in their own right), and providing resources through a national agency that could co-ordinate national best practice guidelines for their support, carry out further research and develop the workforce development needed.

- *If you are a service provider, how long would it take you to develop the partnerships, approaches and service delivery mechanisms needed to service these clients?*

Siblings Australia already has a significant number of contacts around Australia and has worked in partnership with a number of agencies. However, with inadequate resources, this has not been able to be done in any co-ordinated or effective way. Resources could enable the organisation to readily improve the services for these clients.

Principle 3

- *What do you think is the minimum evidence that should be supplied to demonstrate that a service is supported by evidence while still enabling innovation?*

Self-reports from end users is the most easily accessible evidence, both regarding the service's usefulness but also how it could be improved. More formal research about effectiveness should also be done, with suitable assessment tools, but this is often resource limited.

- *If you are a service provider, how do you know that the program you are delivering is making a positive impact on outcomes for family/children?*

Sibworks has been evaluated through a controlled study by Adelaide University, and has been included in the Communities for Children Participating Partners Evidence based programs [here](#).

Workshops for parents/professionals have included copious feedback options all of which have been very positive.

- *If you are a service provider, would you be able to demonstrate that your services are supported by evidence? How long would it take for you to demonstrate this?*

Yes, as mentioned, some is available now. Other evidence is limited due to inadequate resources.

- *What does success look like for families and children in your community and/or service? How do you measure this? What changes do you expect to see in the short, medium and long term?*

Success means that siblings are managing the stresses more effectively and feel less alone. Families are able to share and support each other. Apart from *Sibworks* (which is not currently offered due to a lack of funding), other measures of success have been limited due to a lack of resources. Short term we expect to see parents more able to support their children who are siblings, medium term we expect to see siblings who are stronger and more resilient and families functioning more positively, and longer term, we expect to see better mental health outcomes for siblings and better outcomes for the whole family e.g. better communication, more mutual support. Another component to this is the need to develop greater understanding, knowledge and skills in the various sectors that support families.

- *Should there be consistent indicators and measures across Australia or should there be consistent indicators with different measures for different communities? Why?*

There should be consistent indicators and measures for siblings and families across Australia in a broad sense but different children within the cohort may need different things e.g.

some siblings need a group support approach, others need mental health intervention, others might need assistance to deal with aggression from a brother or sister. For some families, parent education can make a huge difference to family outcomes. Indicators would need to be modified for these different scenarios.

- *Would you be supportive of reporting on client outcomes through the Partnership Approach?*

Yes, if suitable resources were provided.

- *If you are a service provider, what tools and supports would you need to implement the Partnership Approach? How long would you need?*

We would need funds to support the engagement of suitably qualified staff to implement this approach. With staff we could do the basic set up within 12 months.

- *If you are a service provider, what support would you like over the course of a funding agreement to ensure that your services remain supported by evidence and data to improve outcomes for families and children?*

Relevant staff with relevant skills to manage the evidence and data.

Principle 4

- *If you are a service provider, what early intervention and prevention services do you currently provide that help achieve the three outcomes proposed?*

With limited resources we have developed a number of resources and services e.g. developed *Sibworks*, a peer support program for young siblings, provided online opportunities for peer support for teen and adult siblings to connect, provided training for parents and providers in supporting siblings early, (in recent years the latter has virtually ceased as there is no imperative for providers to consider siblings).

The following article from several years ago is still relevant for this cohort.

<http://siblingsaustralia.org.au/wp-content/uploads/2017/09/AeJAMH-editorial.pdf>

A recent anecdote from a group of 3 sisters highlights the impacts of siblings being overlooked, and the need for early intervention and prevention. The 3 sisters had a brother and another sister, both with significant disability. No-one had ever asked these 3 sisters if they needed any support and all three struggled with depression well into middle age. Early intervention with relevant support to enhance protective factors may well have led to different outcomes for this family and led to less costs to the community with regard their ongoing mental health difficulties.

Crucial to such early intervention is the availability of good quality assessment tools and appropriate referral pathways.

- *If you are a service provider, what is preventing you from providing early intervention and prevention services to improve the three outcomes identified?*
 - a lack of understanding from government and the community about the contributions and needs of siblings
 - a lack of recognition within government policy of this vulnerable group
 - inadequate recognition of and resources for Siblings Australia to allow the organisation to do what it needs to do to ensure the outcomes identified in relation to this group.

- *How could government and service providers better balance crisis support with early intervention and prevention activities?*
 - Talk to those who have the expertise in the relevant areas e.g. Siblings Australia has 19+ experience in working with families and providers and would have much to offer
 - Look at the relevant research and advocacy around the needs of siblings, e.g., there are many documents on the Siblings Australia website under [research](#) and [advocacy](#), both by Siblings Australia and other agencies. One example is the RANZCP [Issues Paper](#), a comprehensive look at the needs of siblings, possible approaches to their support, and the gaps.

Principle 5

- *If you are a service provider, how confident are you that you have developed meaningful relationships with relevant stakeholders in your community? What could we do to help you develop these relationships?*

Siblings Australia has developed many meaningful relationships. For example, Siblings Australia has 1300 on an email list for updates on its work; over 3000 'likes' on the organisation Facebook page. Whilst these include siblings, parents and providers, and all are not necessarily engaged, they indicate strong evidence of interest in this group. We have developed many meaningful individual relationships with families and providers. We also receive many enquiries from parents regarding support for their children who are siblings. Sadly, there are few relevant referral pathways and we do not have the capacity to offer what they need, e.g., peer support programs such as *Sibworks*.

The First 1000 Days of Life Working Group recommended strategies that included cross-sector collaboration. In the case of siblings this cross sector approach would be of particular benefit. Sadly, there continue to be barriers to collaboration, for example:

- The competitive nature with regard funding of the social services sector. Siblings Australia has experienced this first hand when it has pursued collaboration. And there is a preference in government to funding larger agencies at the expense of smaller agencies that might hold particular knowledge and experience about certain target groups.
- Given the above, larger agencies can have an attitude of wanting to ‘pick your brains’ but, without committing to true collaboration, agencies with more universal approaches can lack the expertise to follow through effectively. This can also affect trust.
- A lack of imperative of different sectors to consider siblings, due to gaps in relevant and specific policy. Siblings come under families, child protection, education, disability, mental health, and other sectors but no one area takes responsibility for this vulnerable group. Siblings Australia has repeatedly called for cross-sector attention to be given to siblings, but this has not eventuated in any meaningful way.

Siblings Australia would be happy to elaborate on any of the above points.

- *If you are a service, do your existing referral mechanisms support families and children to access a holistic service response? What could be done to improve this process?*

No, because there are virtually no suitable referral options. Many parents, siblings and providers contact Siblings Australia but there are so few effective services/programs available. Again, there is a lack of imperative and skills for agencies to develop these and Siblings Australia has the expertise but not the resources to address this.

- *What could Government do to support you to build these collaborative relationships and referral mechanisms?*

Funding to build capacity. Also, the Family Support Program could play a key role in developing cross sector collaboration between policy makers and other government representatives to ensure that siblings do not continue to be overlooked. As part of that process, one sector/government program or department could be given responsibility for this vulnerable group and for the inter-sectoral approach to sibling support.

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