

Siblings Australia is pleased to make this submission to the Draft Service Delivery Model (Draft Model) for a future carer support system.

It believes that the Draft Model is a very comprehensive one, but consideration needs to be given to ensuring that the specific challenges and needs of siblings of people with disability (including chronic and mental illness) are articulated and addressed.

### Previous submission

Siblings Australia provided an earlier submission to the *Designing the new integrated carer support service – Discussion paper*

<https://engage.dss.gov.au/wp-content/uploads/2016/06/Integrated-carer-support-submission.pdf>

This earlier submission by Siblings Australia discussed the drawbacks in including siblings under the ‘young carer’ and ‘carer’ policy and practice umbrella for four main reasons – it overlooks many siblings who do not provide care but still need support for the challenges they face; the support needs of young siblings can be quite different to those of ‘young carers’; it adds to identity issues for siblings in the longer term; and it does not consider the dignity issues for young people, in particular, with disability. For many siblings other challenges are more stressful than any caring role they may play. The ‘young carer’ approach is not always appropriate or relevant for siblings. They need their own system of support approaches. And they should be seen as siblings first. However, as the previous submission highlighted, the reality is that at various stages in their lives, siblings are likely to play various caring roles, which might range from providing the normal support that all siblings would to brothers or sisters to taking on primary carer roles in the future. If we are to encourage and support a caring role by brothers and sisters, there needs to be acknowledgement of their needs over a lifetime and support approaches that start from the beginning of their sibling journey.

In spite of this previous submission, which outlined the need to consider siblings as a unique group which needs particular attention, there is no mention of siblings in this new Draft Model.

The Draft Model introduction states that ‘the DSS is working with carers, service providers, peak bodies and individuals with carer-specific expertise in a process of co-design’. It also states that it is ‘necessary to understand how carers access and receive support and services today’ and that ‘DSS has undertaken a number of research activities to support this understanding’. Not only has the above submission from Siblings Australia been overlooked in the new Draft Model, but Siblings Australia, as the only advocacy organisation for siblings in Australia, has not been consulted as part of this research. At the very least, there needs to be greater research into what roles siblings are playing; whether they access ‘carer’ services or other services; which services are meeting their needs and, most importantly, where there are gaps. This is necessary as current approaches to sibling support through carer services and/or other services are rarely relevant or adequate.

### Siblings and the carer sector

The situation with regard to siblings and the carer role is complex, as is their need for support. Siblings intersect with the carer service system in two main ways.

1. First, they are children of parent carers. One of the objectives listed in the Draft Model is to ‘proactively support carers earlier, and build their capacity to sustain their caring role’. Parent carers have regularly highlighted their concerns about their children who are siblings of a child with disability. Some say that they become more of a worry than the child with disability. The AIFS 2008

study into the wellbeing of parent carers found that this group had the lowest wellbeing of any group in the community. It also showed that such carers had higher rates of depression than the general community AND that the other children in the family (ie the siblings) also had higher rates of depression.

If the aim is to provide support to parent carers 'earlier', there need to be more services to help them feel confident in parenting all of their children to ensure their wellbeing from the very beginning. From the time of diagnosis of a child with disability, parents need assistance in knowing how to support siblings, and this needs to come from a workforce that has the relevant awareness and training. Siblings Australia has been the only organisation providing this training over the last 18 years but it is very limited in its capacity.

There also needs to be adequate and relevant referral pathways to sibling support options, to decrease the worry for parents. A disability affects the whole family and there must be some inclusion of support pathways for the whole family, again from the time of diagnosis, if we are going to support parent carers effectively.

Siblings Australia receives many enquiries from parents about the needs of siblings and what services are out there, but unfortunately does not have the resources to be able to meet the needs of parents for information and support adequately.

2. Second, at some stage siblings may take on a greater 'carer' role – either as children or as adults, alongside parents or when parents are less able to care. This might be sporadic in nature, for example, during times that a parent is temporarily less able, or in relation to supporting a brother or sister with fluctuating mental health issues. The mainstream carer supports that are available may or may not be appropriate or best practice for siblings. Again, if carers are going to be supported earlier, when should that be done in the case of siblings? If the aim is to also 'build their capacity to sustain their caring role' as mentioned in the Draft Model, how and when should this happen with siblings? Considering these issues is difficult as it can become very complex. Let's take a more in depth look at siblings and how they intersect with the carer support system.

Most caring situations involve an adult becoming the carer. A child is born with disability and adult parents become carers. If a spouse develops a physical or mental incapacity, their adult partner usually steps in to care for them. If an ageing parent becomes less able to care for themselves, an adult child often takes over some responsibility so that the parent can remain living independently. For some adults, the role is finite, for others it might continue for many years, e.g., a child with disability might eventually need active parenting for 60+ years.

For siblings the experience is distinct and different. They are thrust into the role of sibling to a child with disability as a child themselves. The relationship might continue for 70 odd years or more. During that time, a sibling might take on a number of roles, both informal and formal, in supporting their brother or sister. The relationship might be a mutually supportive one which brings a lot of joy. On the other hand, there may be significant challenges. In the early years, whilst siblings are still children without the maturity to cope, the challenges can lead to a range of stresses which may subsequently lead to longer term social, emotional, physical and mental health issues.

During the lifetime of the sibling relationship, siblings may go from being a sister or brother to also taking on a carer role, to reverting back to a more brother/sister role. And the nature of that role might change over their lifetime – from more informal supports to more hands on primary caring. For some siblings who take on a more intensive role their own life is put on hold.

A recent survey by Siblings Australia of 330+ siblings showed that they are providing a huge amount of regular informal supports that might include emotional support, socialising, transport, taking to medical appointments, managing finances, giving parents a break etc. Few, if any, of these siblings

receive any allowance to compensate for the time they put into this, and for a large percentage this is a daily contribution. And few would identify as 'carers'; instead they view themselves, as they should, as brothers and sisters. Sometimes they are contributing alongside parents, for others they are doing it all. They do need support but, in most cases, the support provided through 'carer' avenues is not appropriate or attractive. Siblings prefer to connect with people who 'get it', that is other siblings who share a similar path.

Another complication might be that there is conflict between a sibling and the primary carer (usually a parent). For example, a sibling might feel frustrated at the low expectations of a parent for the person with disability. This can be totally understandable, given the parent's lifetime of struggling for services etc. Or, at the opposite end, a parent may be concerned that the sibling will not continue to advocate and care adequately for the person with disability once a parent is gone. There may be conflicts about how much the person with disability can contribute to decision making. Some siblings resent the fact that parents have always, from young childhood, put extreme pressure on them to 'take over'. At the other extreme, siblings can be frustrated that the parent(s) will not discuss anything with them. A sibling might want to have input into say the medical or social needs of their brother or sister, but find themselves shut out by both providers and parents. And when a parent dies, a sibling may be left with the responsibility for their brother or sister with disability, in some cases, with no knowledge of the service system or what particular services have been engaged for that person.

Adding to the confusion are the differences across the country on what formal roles siblings need to adopt to have input. There is so much conflicting information. Siblings might be told they don't need guardianship, for example, but their experience can be different. Without the paperwork they may not be allowed by a provider to support their brother or sister, help make decisions re medical care or finances.

Of course, the NDIS will bring changes but with limited rollout for adults with disability currently, it is still too difficult to know exactly how things will change for families.

Siblings often need support to develop a 'good life' for their brother or sister, whilst also considering their own needs and goals. How will they pursue their own lives alongside their responsibility to a brother or sister with disability? Will they find a partner to share the responsibility? Should they have children themselves?

The above is just a small glimpse into the complexities that can arise in families with disability. But it reinforces that there needs to be greater consideration of the support needs of siblings and the most appropriate ways for them to receive that support. Their support needs might be quite different to parent or spouse carers, and that needs to be acknowledged before appropriate support options are considered. Again in order to 'proactively support carers earlier, and build their capacity to sustain their caring role', there needs to be more research and discussion about the particular needs of siblings.

## Recommendations

1. The existing model has quite an emphasis on supporting carers to maintain their caring role. However, Siblings Australia believes that there should be more emphasis on outcomes for siblings that include their own development outside of any caring role they might play. This must be included in the quality framework.
2. In order to more fully understand the sibling experience and the caring roles they might play, there are a number of questions that need to be researched
  - a. What are the barriers/enhancers to siblings maintaining a strong relationship with the person with disability? What are the barriers/enhancers to them taking on a caring role, either formal or informal?

- b. What criteria does a sibling need to meet to be able to access a Young Carer program? What about those who don't meet the criteria? What are the differences in experience and need between young carers and siblings?
  - c. How can a sibling balance their own life goals with those of their brother/sister with disability?
  - d. Is it ok for a sibling to be 'groomed' to take over the care of a brother or sister with disability, at the expense of their own life goals?
  - e. Is it ok for governments to continue to overlook the huge contribution that siblings make within the 'carer' space and not provide support for a sibling focused organisation that provides specific advocacy, support and training?
3. If there is acknowledgement that siblings do play a part in the 'carer' space, either providing informal supports or more formal roles, then there must be an opportunity for siblings to be involved in service design, development and evaluation. Siblings Australia is willing to be involved in developing the model further to incorporate the needs of siblings but also to explore what services might be necessary outside the Model. This would also involve an exploration of appropriate and relevant referral pathways.