

Response by Siblings Australia to:

## *Designing the new integrated carer support service – Discussion paper*

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Siblings Australia is pleased to contribute to this discussion. Direct quotes from the Discussion Paper (DP) will be in italics throughout. Following a brief introduction the submission will address a few of the issues raised in the DP, with particular emphasis on siblings of children and adults with disability (referred to as Siblings throughout this document), as follows:

- Caring is stressful
- Current Carer Support Policy, in particular Young Carers, respite support and MyTime
- The system is hard to navigate
- A shift to prevention
- Draft Service Concept
- Research and evidence based approaches
- Parent support

It will also address the Service Concept in relation to the needs of parents to find information and support to enable them to feel more confident in supporting their other children ie the Siblings

### Introduction

The DP states that, *Carers include family members, friends, relatives, siblings or neighbours. Those carers who are grandparents or foster carers of a child with disability, medical condition (including terminal or chronic illness) or mental illness are also included as carers. All of these people are defined as carers regardless of the amount of care, support and assistance they provide. Many people who are carers may not identify themselves as such and therefore remain 'hidden'.*

It should be noted that the experience for Siblings can be quite unlike other groups mentioned. The majority of the groups identified assumed the caring role on becoming a parent or transitioned into the role later in life as a loved one aged. Parents of children with disability have likely had 20-30 years free of caring responsibilities. For those caring for spouses, other family members, friends, neighbours, the term of caring is likely to begin when they are adults and also more likely to be of limited duration.

Siblings are often born into the stresses described below, and hence are likely to have limited maturity to cope with the challenges involved. They may take on a number of informal and formal roles in the life of their brother or sister with disability and these may change dramatically and without warning at different stages. They may be involved throughout their entire lifetime and, given this unique experience, they should be considered as a particular group within a family impacted by disability. There should be greater emphasis in government policy and programs on 'whole family' support. Currently the emphasis is very much on parents and carers. See point 3, *Identity Issues*, under Young Carers below, for more on this.

### Caring is stressful

As the DP says, many carers experience a range of stresses and this is the case with Siblings too. The Australian Institute for Family Studies 2008 report on carer wellbeing found that Siblings had higher rates of depression regardless of any caring role they may or may not play.

Of course, many Siblings care deeply for their brother or sister with disability and there can be an ongoing very mutually satisfying relationship. However there can also be a number of serious challenges, which are similar to those listed in the DP for 'carers', but can have greater impact given

their lack of maturity and place in the family. The research done by Siblings Australia, including an adult sibling project, can be viewed [here](#)

For Siblings who may not provide direct care these might include:

- difficulty watching a brother or sister struggle with daily living;
- stresses in relating and interacting with their brother or sister;
- general stresses that parents are experiencing eg difficult behaviour by child with disability, lack of sleep, isolation, worry about child with disability
- experiencing a parent with mental illness (eg depression, anxiety brought about by their parent carer role)
- a sense of being less important; a strong need to be 'good', to help and to self-sacrifice, sometimes to please parents or to try to 'make things right' - this can carry over a lifetime
- a range of feelings that are difficult to express eg grief, guilt about own abilities, fear, resentment, isolation, extra responsibility
- dealing with others' reactions eg teasing of self or brother or sister with disability
- a range of obstacles to participate in community activities, e.g., it may be difficult for parents to get them there, or there may be limited finances to pay for such activities
- worry about the future of their brother or sister
- Fear for the physical and emotional safety of themselves, their brother or sister or parents

These Siblings often take on responsibilities and significant worries quite young, before they've had a chance to have a childhood

For Siblings who are providing direct care the stresses are similar to those listed in the DP:

- *lack of confidence in their own skills/ability to meet the needs of the person needing care;*
- *the time spent caring leaves some carers with little personal time;*
- *their caring responsibilities can lead to social isolation, even from family and friends;*
- *difficulty navigating and accessing government services;*
- *negative impacts to their own health and wellbeing;*
- *for those carers living outside of capital cities, access to services can be difficult;*
- *inability to participate in their community;*
- *stress from juggling multiple responsibilities such as employment and education; and*
- *grief where activities or hobbies are no longer possible due to caring responsibilities*
- *a greater propensity for financial hardship.*

*These challenges can have a negative impact on the health and well-being of informal carers.*

For Siblings moving into young adulthood the stresses can change as they start to plan for their own life and balance that with their responsibility to their original family. Is it okay to move away from home? Should they marry? How will they find a partner who is happy to take on/share the extra responsibility or perceived risk? Should they have children of their own? What if they have a disability? How will they balance the needs of their own children with those of a brother or sister with disability and possibly ageing parents? Siblings have often been referred to as the 'club sandwich generation', due to their multi-generational caring responsibilities.

Some Siblings move away from the family due to the stresses involved. Others don't provide direct care but provide a range of informal supports depending on the capacity of the person with disability (PWD). For example, they may contribute much to the social and emotional wellbeing of the PWD, assist by driving to appointments, helping to make decisions about medical care, accommodation, employment. Others take on a primary carer role, sometimes because they wish to and other times through no choice/lack of services when parents die or become less able. And the impact can be huge on their health and wellbeing as well as their social connections, and ability to work. There is

less understanding amongst employers when a sibling, rather than parent, is taking time off etc. Others are told from a young age that they will be responsible for their brother or sister. Siblings have described being 'groomed' to be carers, with little 'choice and control'.

These are all very unique challenges and should be considered distinctly.

Taking a preventative approach as this DP calls for below, Siblings should be supported from a young age to manage any stresses and plan for a good life for themselves and their brother or sister with disability. They need appropriate and flexible support whenever they access the service system.

## Current Carer Support Policy Framework

*The Australian Government currently funds support services for carers through a range of programmes, of which, three are transitioning to the National Disability Insurance Scheme (NDIS).*

This submission will comment on three, recognising that the first two are due to transition to the NDIS:

- Young Carers Programme
- Respite Support for Carers of Young People with Severe and Profound Disability
- MyTime: Peer Support Groups

## Young Carers

Siblings Australia believes the policy related to Young Carers needs to be re-considered with reference to Siblings.

Of course there are some great Young Carer programs that do an excellent job of supporting young people who have extra caring responsibilities. Where Siblings are able to access these programs (dependent on eligibility) it is wonderful that Siblings can gain support through such an avenue. Some young carers and Siblings wear the term 'young carer' with pride, but many Siblings do not wish for this and nor do parents. We do not make comment about the term Young Carer being used for children and young people who care for parents or other relatives. Whilst in principle we again believe that there are problems with this in terms of Children's Rights, we understand the origins, and are not in a position to comment further as this is not our target population. However, slowly, Siblings are being included under this 'Young Carer' policy umbrella, and we believe that the underlying presumption for this is totally inappropriate, for several reasons.

1. If we go down the 'young carer' path, we will miss many Siblings.

A little four year old with an older brother with a disability that involves difficult, even aggressive behaviour may not provide any care but is certainly in need of support. A 'carer' model overlooks many family members – it is focused on the carer role, and in order to be eligible for such support, a family member needs to satisfy certain requirements. I have known of some Siblings who have not been able to access 'young carer' programs because they are not the primary carer (most families with a child with disability have at least one parent who takes on the primary carer role) or, in one case, only one of two Siblings was allowed to attend the program as only one could be identified as a 'carer'. Some parents resist the idea of their child attending a 'young carer' program.

Of course, some Siblings *are* performing significant caring roles, but many others do not play any extra caring role beyond the usual helping out that happens in all families. Even if Siblings are not playing a significant caring role they can still contribute much in terms of emotional and social support to a child/adult with disability, and this should be recognised and supported. Sometimes the Sibling provides emotional support to a parent as they struggle with some aspects of the carer role.

We know that Siblings can be at risk regardless of any caring role, and that many of the concerns of Siblings are not related to a caring role. In fact, if Siblings do provide care, that may be one of the less stressful aspects of their experience. Whilst national Young Carer programs are funded by the Australian government not one sibling-specific national program is yet to receive similar financial support. If this funding model continues, over time, many Siblings will miss out on valuable, and possibly critical, support. And lack of support when they're young will mean they're won't have the capacity to provide support for their brother or sister with disability in the future.

So whilst young carer programs are providing a very useful service for many young people, Siblings should have their own distinct policy and programs. One size does not fit all. With a young carer policy it is easy to assume that Siblings are being supported, but the policy does not meet the needs of all Siblings.

Within various consultations by Siblings Australia, adult Siblings say they would prefer to access support via sibling support services (by Siblings for Siblings) rather than 'carer' services, but they acknowledged that there was little, if any, available.

## 2. The differences between sibling and 'young carer' experiences

As mentioned, many Siblings do play an active 'carer' role for their brother or sister with disability. They may love and care about their brother or sister and do all they can to make life easier for them. But, for many, the responsibility and other presenting challenges can cause stress and anxiety. The relative experiences of on the one hand; a parent providing care to their disabled child or a child providing care to a parent, and on the other; growing up next to a brother or sister with significant additional needs are necessarily and fundamentally quite different. A sibling might be quite confused by what is happening around them, especially if there are significant medical or behavioural issues. Their sense of personal identity might be affected, and they may grow up feeling less important than the child with disability - which can have huge impacts on their self-worth. There can be enormous grief and guilt about their brother or sister, when growing up next to them, and in realising that the child with disability is not able to do many of the things a sibling can do – a kind of 'survivor guilt'. There may be a lot of stress at home which can lead to anxiety, and embarrassment (or even enduring and undefined shame) when out in public. Other people's reactions or fear of others' reactions can multiply the stress, often leading to them isolating themselves from support. Many Siblings take on a lot of responsibility for a brother or sister, and can worry about the future in terms of what might happen if mum and/or dad is no longer able to provide care. This responsibility can carry over a lifetime, impacting the sibling's own life decisions as mentioned earlier.

Siblings often feel isolated and unable to share their feelings and concerns. In many cases Siblings are socially isolated and factors such as limited parental time, lack of transport and cost mean Siblings are not provided with the same opportunities to build a greater social support. Siblings are often reticent to detail or disclose they are a 'Sibling'; many perceive themselves to be a rarity and therefore unable to relate their experience to a friend or fear their brother or sister with a disability may be unfairly targeted. As such, Siblings remain "hidden" in terms of accessing programs.

Children who provide care to a parent may have some of the same issues but many will be quite different. There may be more practical issues for these children. They may need more support to manage their education and stay involved in the community. Of course, Siblings can also require support for these more practical issues but it is often the psychological issues that predominate. Siblings Australia research has explored further the lifelong and complex challenges and impacts for Siblings.

### 3. Identity issues

There are identity issues related to a 'carer' or 'young carer' model. Even parents don't always like being referred to as 'carers' – they want first and foremost to be acknowledged and identified as parents. Such terms can add to the sense of difference that many families with disability feel. For Siblings, such a label can add to their sometimes unhealthy sense of responsibility. Many Siblings grow up as the 'good child', the 'helper', or 'giver', which can lead to a number of problems, including with adult relationships. The book *Burdened Children* addresses this in the chapter, *The Parentification of Siblings of Children with Disability or Chronic Disease* (Lamorey, 1999). Certainly, Siblings can gain much from contributing to the family in a number of ways, but I question the increasing use of the label 'young carer' for children who may have increased responsibility. It serves to reinforce/validate their narrow view of themselves as a helper or carer for others, subjugating their own needs in the process. Such approaches go against the principles included in the International Convention on the Rights of the Child, to which Australia is a signatory.

### 4. Role of Siblings in the future

As mentioned, many adult Siblings play a crucial role in the emotional and social wellbeing of their brother or sister with disability. The relationship can be mutually satisfying; much like the sibling relationships of those without disability. Other Siblings of people with disability do not remain involved. For some, the stresses are too great or the expectation of being a 'carer' becomes too much and they move away from their family.

At a Siblings Australia event, one father who had previously attended a consultation with other parents of an adult child with disability, relayed that all 17 parents who attended had other adult children (Siblings) who had moved interstate. Of course, there could be any number of reasons why this was so, but it seems a high percentage and suggests an area for further investigation.

There is a need for research on why these family relationships may be strained but, in hearing the situation with many families, two main reasons emerge. First, many Siblings have had no support and subsequently may struggle into adulthood, and therefore feel a need to distance themselves from family issues. And second, many Siblings become concerned that they may be left with the responsibility of full-time caring if anything happens to their ageing parents. Some believe that governments are trying to include Siblings under the 'carer' model so that families, governments and the community can expect that Siblings take responsibility when parents are no longer able to, no matter the costs to the sibling's health and wellbeing. As one Sibling said, *It is wrong to groom other children to be carers and to expect them to give up their lives. I could have been a whole human being once. I am now 40 and I am realizing just what was done. This sacrifice was not by my own choice.*

In Australia there is now much discussion about 'ageing carers' and the implications of this. If we were to listen to Siblings and provide what they need over a lifetime, i.e. support regardless of any caring role they may play, outcomes might be very different, both for them and for their brother or sister with disability. Given that many people with disability, especially intellectual disability, become isolated, we should be strengthening the sibling relationship independent of any possible carer role.

### 5. Dignity and stigma issues

Finally, it is important to consider the impact of a 'carer' model on those with disability. This model sets up a power differential and does not consider dignity issues for people with disability. What 16-year-old boy wants his 14-year-old sister to be known as his 'carer'? The use of this term isolates him further from other young people in the community and can add to the sense of being a 'burden'.

Families of children with disability want to take part in the community, just like other families. What is needed is a 'family support' model that is more enabling and inclusive, not more isolating.

### Respite support for Carers of Young People with Severe or Profound Disability

Whilst having a break can be good for all members of a family, whether there is a disability or not, certainly 'respite' is a key support activity for families impacted by disability. However, there are other very important aspects of managing a disability that need to be given further consideration.

If there are difficult or aggressive behaviours respite will not diminish the stresses. When the respite is over the stresses are still there unchanged, or even amplified. There needs to be more support for families to learn the skills to manage the difficulties, as well as providing breaks.

### MyTime Peer Support Groups

Siblings would benefit from more peer support options. Millions of dollars are spent on this program alongside other parent support programs. There needs to be acknowledgement that Siblings too experience many of the same stresses (plus other Sibling specific stresses) at a young age and can benefit from peer support.

The Siblings Australia *Sibworks* peer support program has now been included in the Communities 4 Children Facilitating Partners Evidence-based Program Profiles developed by the Australian Institute for Family Studies. The program manual can be ordered, along with other resources, via our [website](#), and Siblings Australia is available for training in the model.

We also provide online opportunities for adult Siblings to access information and peer support. These have been going for a number of years and provide enormous benefit to Siblings, but the organisation has no funding and so the continuation of these is at risk.

*The SibChat group has been a life saver. Honestly, finding that group has helped lift the loneliness so much and knowing that I have a dedicated spot to go to for information, advice and support makes a big difference. It is a crucial lifeline that cannot afford to be abolished due to a lack of funding to moderate and maintain the group.*

### The system is hard to navigate

*Both the Carer Service Development Research (AMR Australia, 2015) and the Current State Analysis (Department of Social Services, 2015) found that the system as it stands is difficult for carers to navigate.* Adult Siblings who might be taking over a more direct role have huge difficulty navigating the system. Some Siblings take over this role suddenly if parents die or become infirmed, and with limited experience, this can be even more stressful. Adult Siblings have repeatedly said that they prefer to access services from sibling focused agencies or other Siblings.

Sibling contact details are not typically kept on file by disability services unless a formal relationship such as guardianship exists. This means siblings are often unaware of the supports being accessed and once their parents die or difficulties occur for the individual with a disability they can be at a loss of how to access help.

Also, when siblings attempt to deal with service providers later in life (teen or adult), the response can be negative. Siblings can have a different approach to parents in the support they provide. Research indicates that some Siblings are more likely to support an individual with disability to reach their potential compared to parents who may be more likely to be protective. The change in the type of support provided to the person with disability can elicit a strong response from service providers, which can in turn cause even more stress and anxiety for the Sibling who is attempting to advocate for their brother or sister with a disability. Some Siblings have talked of services being lost as a result of complaints made.

Some Siblings have talked of disability services making value judgments about the family's need for services when the advocate is a Sibling – in our culture this is not typical; it is usually a parent doing the advocacy. Service providers may not be sensitive to the role of the Sibling and in some cases can be critical of the support they provide. This can disempower the Sibling and after multiple negative experiences can make them at risk further stress, anxiety and depression. It can be even more difficult when a Sibling is trying to support more than one brother or sister with disability, alongside trying to maintain employment and raise their own children.

### A shift towards prevention

The DP states that *services and supports which are put in place for carers are usually reacting to an immediate or urgent need and have less focus on planned or preventative service provision.*

Siblings Australia has been saying for some time now that there should be a greater focus on preventative approaches for Siblings. Given the risk to their own mental health and the risk that Siblings move away from their families, there should be early intervention approaches to strengthen Siblings and to also strengthen the relationship with their brother or sister with disability.

Unfortunately there is no imperative for this work to be done without relevant policy. Policy changes are urgently needed to address this critical and costly gap in the disability and mental health system. Failure to do so further exacerbates the problems faced by people with disability and their Siblings.

There are likely to be long-term benefits in supporting Siblings from a young age (prevention/early intervention) and equipping them with strategies and education early so that they may be prepared and willing to play an active role (informal or formal) in the life of their brother or sister, over their lifetime. As well as improved wellbeing of both the Sibling and the PWD there would be financial benefits for the whole community, due to less demand on social and health services.

### The Draft Service Concept

The draft Service Concept proposes eight services as outlined in the table below.

- Awareness  
This should include an attempt to collect data on Siblings of children and adults with disability. Currently there is no data that accurately tells us how many Siblings there are, what roles they play, why some adult Siblings remain involved and why some don't. Of primary value would be clarification of what are the barriers and enhancers to this involvement. Siblings Australia should be engaged to develop this data
- Information  
There needs to be specific sibling focussed information. Siblings Australia has attempted to provide some of this but needs more resources. For example, what are the different roles that a sibling can play? When is guardianship or administration necessary? When is 'responsible person' adequate? What services are there for them to support their brother or sister with disability but also what is available for their own support?
- Intake  
Collect information that helps to connect Siblings to services targeted to them
- Education  
Education and training programmes aimed at increasing a sibling's knowledge, educating them about the resources available and teaching skills (e.g. problem solving, lifting techniques)
- Peer support  
Connect Siblings to provide informal support networks through relationship building and shared experiences between Siblings with similar circumstances. Siblings Australia is already doing this in a restricted way but with adequate resources could do so much more

- Counselling  
Individual and group counselling sessions for Siblings
- Needs identification and planning  
Gather information about a sibling's situation, and assist them with planning their personal and service-based supports. Deliver a single package of interventions. The DP states that *Purcal and Co (2012) suggest that a more holistic approach to 'whole of family' support should be taken from the outset within the health care setting.* This is certainly the case for Siblings, who are overlooked both in policy and programs. As soon as a child is diagnosed with a disability there should be a focus on the whole family and their needs. These needs will change over a lifetime for Siblings, as they and their brother or sister move into adulthood, and this should be catered for in a systemised way.  
Enabling support spaces where Siblings are able to facilitate and engage through virtual mediums will allow much better identification and engagement and improve the ability to provide early and targeted support programs

## The state of research on interventions to support carers

Siblings Australia has done considerable research on the needs of Siblings, but there is still a huge gap in certain areas eg data and policy re Siblings, best practice approaches for this population. There should be a focus on more research on interventions to support the whole family.

## What interventions are supported by evidence?

As mentioned above, The Siblings Australia *Sibworks* peer support program has now been included in the Communities 4 Children Facilitating Partners Evidence-based Program Profiles developed by the Australian Institute for Family Studies. This was based on published controlled studies on its effectiveness. The approach we have taken with other aspects of our work (adult sibling peer support, workshops for parents and professionals on support for Siblings) has continuously received very positive feedback, but with a lack of resources, we have been unable to undertake further evaluation or conduct a longitudinal study.

Siblings Australia has been accepted as a [Healthdirect](#) partner. This is a huge acknowledgement that the online resources are trusted, relevant and reliable. The organisation has developed a national and international reputation for its work with families and professionals over a period of 17 years. In order to continue and expand this meaningful and necessary work to broaden assistance to Siblings there needs to be policy change and further funding.

## Parent Support

In various research reports over many years, parents regularly identify one of their stresses as being related to the impacts on their other children i.e. Siblings. Some parents say that the Sibling becomes more of a concern than the child with disability.

Parents should be able to access support to feel more confident and less stressed in parenting ALL of their children. In order to do this they need help to understand the impacts on the Sibling(s) and what to look for in terms of early signs of stress in Siblings. Sometimes behaviour support plans suggested by therapists put a lot of pressure on parents and don't consider the impact on Siblings. Service providers should move to a family (system) perspective rather than being solely person-centred to a point that may be harmful for the family unit.

Parent support should start with Intake and Needs Identification and Planning Support, where the whole family is identified as being impacted and sources of support identified for all members of the family.

Parents need information, resources, training on how they can support Siblings in their home but also the various support options that might be available for Siblings through disability, health, education and the general community, e.g. counselling, peer support. Unfortunately these are still limited but Siblings Australia is working toward greater availability and awareness of what is available. It is also trying to increase professional development in this area. The Siblings Australia website has a range of information and resources available to parents, which should be integrated into any Carer Service Concept. However, this needs to be expanded to fully meet the future needs of families.

## Recommendations

An integrated care support service needs to include the points addressed above under the Draft Service Concept, but also needs to include the following:

- Recognise both the unique contribution and needs of Siblings across the lifespan
- Develop a Sibling policy that is distinct from that for parent/carers and young carers (if this Sibling policy is not possible through the carer support policy arena then identify where this should be)
- Explore where Sibling needs overlap with carer programs and where they don't in order to facilitate effective collaboration
- Ensure that the digital carer gateway provides content that is directly aimed at Siblings and access pathways enabling those who identify as a Sibling to easily navigate to the content. The content should be developed by Siblings for Siblings.
- Ensure, when designing demographic collection fields to be utilised, whether via the digital gateway or through the contact centre support platform that "Sibling" be an identified type of caller/contact
- Ensure parents are linked to reliable, specialised, and evidence-based resources, information and training regarding the support of their children who are Siblings.
- Improve awareness amongst service providers of the distinct experience and needs of Siblings and provide appropriate education and resources