

Family Support Program Future Directions Discussion Paper October 2012

Submission by Siblings Australia, November 2012

Please accept this short submission in response to the FSP Directions Discussion Paper. In summary, the Family Support Program is committed to support those families in most need and one of the groups included in the list is families with disability. Disability affects the WHOLE family. A range of federally funded programs are available for parents of children with disability, but there are no similar specific support programs for siblings of children with disability. These children are at risk themselves for a range of mental health issues and this is a serious omission. The discussion below includes a brief overview of the sibling experience, current services and gaps in those services, and some thoughts on the future.

The sibling experience

In Australia, there are approximately 200,000 young people under the age of 25 with a severe or profound disability. We can assume a similar number of siblings. Some siblings are enriched by their experience of growing up with a brother or sister with disability; others face significant challenges but they may not have the cognitive and emotional maturity to cope with those challenges. Research both here and overseas shows that, without support, they can be at risk for a range of mental and emotional health issues, at huge cost to themselves, their family and the community. For example, the 2008 AIFS report¹ showed that siblings had higher rates of depression, regardless of any caring role they may or may not play. There is some evidence that their physical health can also be affected². Also, there is emerging evidence that some siblings experience direct physical harm from their brother or sister with disability. Siblings Australia has developed a [draft report](#) based on a small survey it conducted re this issue.

In Australia, attention to the needs of siblings has come from a number of professional organisations. For example, the RANZCP has released a [Position Statement](#) and Issues paper, *Addressing the needs of siblings of children with disability or chronic illness*, which was endorsed by over 70 major organisations around Australia. Families Australia has developed a [paper](#) in response to the RANZCP papers, *Towards improved recognition and support for siblings of those with a chronic condition: A report on consultations*. In addition, AICAFMHA's Position paper, *Improving the mental health of infants, children, and adolescents in Australia*, and the *Report of the Inquiry into the Mental Health and Wellbeing of Children and Young People in Western Australia*, by the Commissioner for Children and Young People, both refer to the risks for and needs of siblings. In addition, Families Australia and Siblings Australia together developed a [National Action Plan](#) (along with a [briefing paper](#)) leading up to the last Federal election which was presented to Jenny Macklin, the Minister for Families, Housing, Community Services and Indigenous Affairs (FAHCSIA).

Current services and gaps

Since 1999, Siblings Australia has been the only organisation in Australia to focus specifically on the needs of siblings of children with disability. It has developed resources and services, provided education and training, taken part in research and advocated for the needs of siblings to be addressed at a national level. In spite of scant resources, it has developed a national and international reputation for its work with siblings, families and providers. Via its workshops the organisation has had contact with thousands of families and providers. The stories from both families and providers, together with the countless requests for information about services, reinforce the above research about the need for sibling support.

Certainly national supports such as respite and carer allowances etc are available and contribute indirectly to siblings. In addition, substantial funding has gone into direct parent support programs such as counselling and the MyTime peer support program. However, in spite of siblings experiencing many of the same stresses and

¹ 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*

² 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.

isolation as parents, there are no national support services that are directed specifically at the needs of siblings themselves in order to help them cope with their situation. Some organisations do provide sibling support programs but, as shown in the 1999 Scoping Project from Siblings Australia, these services are sporadic, underfunded, uncoordinated and lacking in evaluation.

As the Minister responsible for the FSP says, the Australian Government believes ‘every child should have the best start in life through being safe and nurtured’. If Siblings Australia or parents ask the government what services are available for siblings who are struggling, they are usually directed to the National Carer Counselling Program or to community mental health programs. The first option does not lead to any meaningful intervention. The second is tackling the needs of siblings from the wrong end. The message that this option conveys is that these children, while being at risk of developing mental health problems, do not deserve support from the beginning (i.e. upon diagnosis of their brother or sister). Instead, they will need to deal with the wide-ranging stresses without direct support and, if they develop mental health problems at a later stage, then the government may be able to provide support through existing programs, by adapting such services to meet the needs of these children. This places treatment before preventive strategies and is very misguided.

Current Family Support Program

The ‘best interests of children’ is the fundamental principle that underpins all FSP services and reflects the Australian Government’s commitment and responsibilities as a signatory to the United Nations Convention on the Rights of the Child.

The FSP aims to:

- target vulnerable and disadvantaged families, through a more holistic understanding of the nature of disadvantage and its impacts;
- support children’s social, emotional and cognitive development, as a pathway to lifelong learning and wellbeing;
- deliver prevention, early intervention and secondary services, to support the safety and wellbeing of children;
- provide support to parents, through counselling and parenting skills training;

Certainly, the needs of many at risk groups of children are addressed through specific programs within the FSP; e.g. Supporting Children after Separation, and the Find and Connect Support Services to assist Forgotten Australians. Other government programs address the needs of other at risk children e.g. children of parents with a mental illness, refugee children, indigenous children, young carers. It should be noted here that whilst some siblings are also ‘young carers’ this is not the case for most siblings. Whilst it is important to think about how the two groups may overlap, it is poor policy to only include siblings under the ‘young carer’ umbrella.

The current government has been made aware of the needs of siblings since it came to power at the end of 2007. It has had 5 years in which it has received extensive submissions, conference resolutions, petitions, project reports and election proposals from Siblings Australia (as mentioned earlier), in some cases in conjunction with other organisations. In spite of this, there are no specific services for siblings of the same kind as there are for other at risk children. It is unfortunate that the Federal government has not recognised these children. Siblings are at risk from the very beginning of their life journey and need support to build resilience to manage in a positive way, both for themselves and their brother or sister with disability. Siblings Australia suggests that continuing to overlook this cohort and failing to address the risks that they face means that the government, given its current knowledge about sibling experience, is at risk of overlooking its responsibilities as a signatory to the Convention on the Rights of the Child.

The future

According to the FSP consultation paper, a comprehensive family support service framework demonstrates a number of key elements, including the development of place-based services, i.e., ‘integrated services planned and delivered in socio-geographic areas’. This would appear to be a reasonable approach where there is knowledge and skills to carry out these services. Another key element is that services should be ‘evidence-based and effective in addressing disadvantage, and where evaluation is in place and the workforce is skilled to deliver’. In terms of supporting siblings, there is much more work to be done in the area of ‘best practice’. As mentioned above, the 1999 Scoping Project certainly showed the need for more resources and workforce

development. There need to be guiding principles developed and tested. Some of the information/resources that are currently available to families in support of their other children are less than beneficial.

In moving toward support for siblings of children with disability or chronic illness the following should be the goal of any Family Support Program:

- Siblings have their lifelong role and needs recognised, not as carers or 'young carers' but as brothers and sisters
- The whole family is supported from the time of diagnosis to manage their different responses/feelings and to ensure families stay together
- Parents are helped to support all of their children
- Siblings are supported to manage their varied experiences, both at home and in the community – this may include information about the disability, how to keep themselves safe, how to manage their many feelings and deal with others' reactions and, as they become older, how to decide what role(s) they are willing/able to play in the support of their brother or sister
- Siblings are given opportunities to connect with other sources of support eg other siblings, school and community programs
- There is significant workforce development to ensure relevant sectors – health, disability and education – have the necessary skills and training to support the whole family.
- There is more research into best practice in terms of whole family support

Siblings Australia would have much to offer in the development of these approaches.

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November 2012