

Every Chance for Every Child Discussion Paper 2012

Submission by Siblings Australia, November 2012

Please accept this brief submission in response to the Every Chance for Every Child Discussion Paper. In summary, Siblings Australia would like to highlight the needs of one particular group of vulnerable children who are overlooked at policy and practice levels – the siblings of children with disability.

The discussion paper asks, “How can we best support children to learn and develop” and responds by saying that “we start by looking at the whole child and by looking at the child in the context of their family and community”.

Disability affects the WHOLE family. There are a range of programs for the child with disability and their parents but there is no specific support for siblings of children with disability, who are at risk themselves for a range of mental health issues, and this is a serious omission.

Below, discussion includes a brief overview of the sibling experience, responses to various parts of the discussion paper content and, 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 experiences 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.

Since 1999, Siblings Australia has been the only organisation to focus on the needs of siblings. 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, and the countless requests for information about services, reinforce the above research about the need for sibling support. Such stories outline a range of stresses due to the disability of a brother or sister, family experience and also societal attitudes. Siblings may feel overlooked and isolated within their family as parents focus on the child with disability. There may be added stress if the parents’ relationship breaks down (a more likely occurrence in this group), and the single parent, usually the mother, is also likely to have depression. These children may miss out on a childhood as the responsibilities can seem so great. At a community level, these children may miss out on recreational opportunities due to the demands on parents, their educational experience may be affected, and they may experience discrimination and stigma.

Also, there is emerging evidence that some experience direct physical harm from their brother or sister with disability. Siblings Australia has developed a [draft report](#) 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*

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.

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 election and this was presented to the Minister for FAHCSIA.

Every Chance for Every Child discussion paper

Principles for the new legislation

The proposed new child development legislation aims to be inclusive and states that the "legislation should enable all to participate and demonstrate that children and young people are able to benefit from any changes. The legislation should recognise the special needs of certain groups, such as Aboriginal and Torres Strait Islander children and young people, children and young people under the Guardianship of the Minister and children with disabilities".

As mentioned above, disability affects the whole family and children who are siblings of a child with disability should have particular attention given to them. Also siblings have the potential of contributing much information about the child with disability but, in addition, can contribute much to the social and emotional wellbeing of the child with disability. If we are going to expect this, however, we need to recognise that they face their own difficulties and need support.

United Nations Convention on the Rights of the Child

Australia is a signatory to the United Nations Convention on the Rights of the Child.

The Convention draws on both the Charter of the United Nations and the Universal Declaration of Human Rights, and specifically addresses the duty of State Parties, like Australia, to take appropriate measures to ensure that the rights of children and young people are protected.

The United Nations Convention is built on four fundamental principles relating to: non-discrimination; the best interests of the child; survival, development and protection; and children's participation and voice in decisions that affect their lives.

In continuing to overlook siblings, the government is overlooking its obligations as a signatory to the above Convention. Siblings, like other children, have a right to a childhood free from stress and emotional/physical harm. One disturbing trend is that siblings are starting to be included in policy under the 'young carer' umbrella. Whilst this may be a misnomer for many siblings who do not provide care, using this label can also be seen as a violation of children's basic rights.

Future directions

The development of children and young people is, according to the DECD "best supported through coordinated, holistic efforts that address the unique needs of each child". In order for this to move beyond rhetoric there must be some concerted effort to recognise siblings as a vulnerable group of children and to ensure they are included in policy and practice.

The Child Development Council should have as one of its priorities a plan to recognise and support siblings of children with disability, both for the benefit of siblings but also for the benefit of children with disability.

In following the Convention on the Rights of the Child, the Australian government must consider the needs of siblings of children with disability in the same way as the Children's Act in the UK.

The needs of brothers and sisters should not be overlooked, and they should be provided for as part of a package of services for the child with a disability.

Children Act 1989, UK

If children with disability are to live in their family homes, which is the preferred situation, the rights of these children cannot be considered in isolation, and without consideration of the rights of the other children in the family. These other children (siblings) also need support to be able to reach their own potential and express their own right to a safe and happy childhood and full participation in community life.

In moving forward the following should be the goal of any 'Every Chance for Every Child' policy:

- Siblings have their lifelong role and needs recognised, not as carers or ‘young carers’ but as brothers and sisters
- Data collection in education settings includes information about siblings
- 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, deal with others’ reactions and, as they become older, 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 teachers, early childhood workers, school counsellors, and other support workers have the necessary skills and training to support siblings
- There is more research into best practice in terms of sibling support in schools and early childhood centres

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

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 December 2012

Further reading

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