

Siblings Australia submission to PC Inquiry into role of mental health in supporting social and economic participation

Prepared by Kate Strohm, Director.

Introduction

Siblings Australia welcomes the opportunity to contribute to the Productivity Commission's inquiry into the role of mental health in supporting social and economic participation, and enhancing productivity and economic growth. Essentially the inquiry is asking how best to enable people to reach their potential in life, have purpose and meaning, and contribute to the lives of others. Siblings Australia has a particular interest in the health and wellbeing of siblings of children and adults with a chronic condition (disability, mental/chronic illness). Further references regarding information in this submission can be provided if requested.

There are an estimated 250,000 people under the age of 25 years with a severe or profound disability. In addition, as the PC Issues Paper states, almost half of the population experience mental ill-health at some point in their lives. Many more have other forms of chronic illness. This submission will focus on siblings of people with disability and/or mental ill-health (disability/MI). Understandably, significant resources are spent on addressing the needs of children and adults with disability/MI both within families and in the community. However, research and anecdotal evidence supports the view that illness and disability affects the lives of *all* family members. Of course different conditions will result in very different impacts, but what siblings, in particular, need is very similar regardless of the condition.

At the outset, Siblings Australia would like to highlight the cross-portfolio approach needed to address appropriately the needs of siblings. Family, school and wider community services comprise the settings within which sibling support approaches should operate and hence the Education, Disability (Social Services), and Health portfolios can all play a role in supporting siblings. More integrated approaches are recognised both nationally and internationally as the optimal way of meeting the needs of children and families. In this particular submission, the focus will be on the mental health sector.

Summary

Siblings intersect with the health system in two main ways:

- 1) They are a vulnerable group themselves in terms of their own physical, mental, emotional, and social health due to the stresses of growing up with a brother or sister with a disability/MI.
- 2) They can be an important support person to someone with a disability/MI.

This submission will explore both of these aspects of the sibling experience, discuss the current situation regarding the awareness of sibling needs, and highlight the gaps in support services. It will also provide some recommendations based on various themes of the PC Issues Paper to ensure the needs of siblings are recognised and addressed appropriately. Appendix 1 will document the work of Siblings Australia.

1. Why siblings are vulnerable to mental ill-health

Certainly many siblings of people living with disability/MI become enriched by their experiences. However, many can face significant challenges. Those challenges usually begin in the early years when a child does not have the cognitive or emotional maturity to cope. A 2008 Australian Institute of Family Studies report found that parents of children with a disability have higher rates of depression than the general population and siblings also had a significantly increased risk of depression, regardless of any caring role¹. Often these parents do not access services for themselves or their other children as the focus is on the child with disability. Other

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*

studies from overseas have shown that these children have increased rates of physical health problems too². Other work by Siblings Australia also confirms the risks of anxiety and depression in particular. (See Appendix 1) The following is a list of reasons why siblings may be vulnerable to a range of mental health problems, in no particular order:

- Parent relationship may break down due to family stresses (it is well accepted that the rate of marriage breakdown is higher in this population)
- Having a depressed parent (usually the mother)
- Ongoing stress due to the demands or difficult behaviour of the child with disability. Some siblings are both physically and emotionally harmed by a brother or sister with disability
- Physical harm to a sibling is often not reported by parents as they are fearful of what social services might do
- Possible trauma from seeing the impacts of the disability on their brother or sister, e.g. seizures, psychotic episodes, 'meltdowns'
- Teasing or bullying from peers; feeling the stigma
- Growing up with the needs of someone else taking priority; they learn to put their own needs second which can also have implications for relationships over the lifespan
- Feeling neglect, which can be intensified in terms of identity and self-esteem when another child in the family is very 'un-neglected'
- Extra responsibilities that can lead or add to anxiety and other problems
- Confusion about their feelings – on the one hand, love and protection towards their brother or sister, but at the same time, they may feel resentment, embarrassment, guilt, sorrow and fear. Such feelings can lead to low self-esteem, shame or a sense of worthlessness³
- Worry about their brother or sister and a possible lifetime of responsibility for them

Education outcomes for siblings may be affected by anxiety, tiredness, depression, social stigma and worry for parents and/or their brother or sister.

Limited access and availability of appropriate services and the practicalities of family life, where the needs of a brother or sister take greater priority, exacerbate all of these problems. Without support, these siblings are at risk of developing longer-term emotional and psychological problems.

For example, 3 sisters who had a brother with disability, and sister with mental illness, contacted Siblings Australia and talked of realising that at no stage in their lives had anyone ever asked them how they were managing and if they needed any support. All three had experienced ongoing depression from an early age.

In 2011 the Royal Australian and New Zealand College of Child Psychiatrists concluded in their Position Statement on siblings of children with a chronic condition, *"There is reasonable consensus that siblings of children with chronic conditions are at risk for behavioural, mental and physical health problems. If left unaddressed, the challenges which siblings face can increase their risk of developing longer term mental health problems, at considerable cost to them, governments, and the community."* See [Position Statement](#) and [Issues Paper](#) from the RANZCP.

A recent article in the journal *Pediatrics* (2013; 132: e476–e483Pa), reported significant impact on siblings and concluded that *'Health care professionals need to consider a family-based health care approach for families raising children with disability.'*

As siblings move into adulthood, the challenges might change significantly. They can start to worry about the future and what roles they might be expected or willing to play, and how they can balance their own life

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.

³ Lamorey, Suzanne. (1999). Parentification of Siblings of Children with Disability or Chronic Disease. In Nancy D. Chase (Ed.), *Burdened Children: Theory, Research and Treatment of Parentification*. Thousand Oaks, California: Sage Publications

goals with the needs of their family. Siblings Australia has carried out much work with adult siblings, the most recent being outlined in this [adult sibling project report](#).

2. Siblings as important support for people with mental ill-health

Siblings are one of the first social networks for people with disability/MI. Research both here and overseas has shown the huge contributions that many siblings make to the social and emotional wellbeing of children and adults with disability/MI. These were highlighted in the adult sibling project report mentioned above.

For many siblings, supporting a brother or sister is an important and rewarding part of growing up in a family. It can have benefits for both the sibling and the child with disability/MI. As time goes on, like all relationships, the one between siblings will be complex and ever-changing. Siblings will likely have the longest relationship of anyone with the person with disability/MI, and yet there is so little consideration given to the varied roles they might play and, more importantly, to understanding the enhancers/barriers to a strong relationship between siblings.

As time goes on, siblings might become what has been referred to as the 'club sandwich' generation i.e. caring for elderly parents, their own children AND a brother or sister with disability/MI. For some, the stresses and expectations might become too much and they move away from their family of origin.

If siblings access support themselves, and responsibility is kept in balance, there is evidence that the relationship is more likely to be strong and mutually beneficial.

Current situation

At a broad level, there is some emphasis in our community on the prevention of mental health problems. There is also an understanding of the profound effect the early years have on a child's development and their longer-term health and wellbeing. It is widely accepted that resilience and wellbeing in childhood are critical precursors to a healthy adulthood. Childhood resilience is influenced by both risk and protective factors. When children are exposed to risk factors (such as a brother or sister with disability/MI in their family), support is essential in terms of providing additional protection for them. There are economic and social benefits in intervening early and ensuring that young people who may be at risk are able to access relevant support services, in order to prevent longer-term health problems.

The Australian government has recognised these needs by providing a large investment in a number of programs that have supported the mental health of our youth. Examples include the Mental Health in Education Initiative, National Workforce Support in Child Mental Health Initiative, National Support for Child and Youth Mental Health Program, National Youth Mental Health Foundation (headspace), and National Centre of Excellence in Youth Mental Health. More recently, there has been the establishment of programs such as Emerging Minds and *Be You*. However, these programs tend to be more generic/universal. None of these programs has had, or is likely to have, any real impact on the specific support needs of siblings.

In spite of advocacy and research by Siblings Australia and other organisations both here and overseas, the needs of siblings have been largely overlooked at both policy and service level in Australia. This was highlighted again in a recent [Mapping Project](#) carried out by Siblings Australia. Policy regularly aims to benefit 'people with disability/MI, their families and carers', but this is rarely carried through to the whole family; instead, programs focus exclusively on the person with the condition and their carers. Without policy, and resources, there is no imperative for agencies to cater for the needs of siblings in any meaningful way.

There are major national initiatives for carers, but not for siblings, in spite of the long term nature of these relationships. There have been some attempts to include siblings under the 'carer' policy umbrella, but this is regrettable for a number of reasons:

- The needs of siblings go way beyond managing any caring role they may or may not play;

- Some siblings provide no care to a brother or sister but still face significant challenges and health risks;
- If sibling support goes down the path of ‘carer’ services many siblings will miss out on support;
- Carer services, especially when siblings are younger, are neither relevant or appropriate;
- Focussing on the ‘young carer’ role can actually add to the risks for mental health problems in this cohort (and could also be argued to be an abuse of children’s rights);
- As siblings age and possibly take on more significant caregiving roles they often need different types of support than those offered by carer services; they especially need peer support from other siblings who understand their experiences;
- People with disability/MI do not necessarily wish their brother or sister to be known as their ‘carer’ – their dignity should be respected.

The issue of whether to use the term ‘sibling’ or ‘carer’ can be a complex one. Certainly, in many cases, there is some overlap, but siblings also need to be recognised and supported in their own right. A recent article explores this further.⁴

Outcome measurement

Another huge issue is that current measures of outcomes do not include siblings. The PC Issues Paper states that ‘measurement and reporting of mental health outcomes can play a pivotal role in improving supports for individuals living with mental ill-health, their families and carers’. Whilst there are certainly some measures in place to measure outcomes for people with disability/MI, and for ‘carers’, there are virtually none for siblings.

The Gaps

- Very few siblings access any support services
- Very few parents are assisted to support their children who are siblings which adds to parent stress
- There are no policies or strategic national approaches to sibling support; no imperatives for agencies to provide sibling support
- Current mental health programs/policies for young people do NOT meet the needs of siblings
- There is no national funding available for sibling support; local programs are sporadic and piecemeal
- There is little, if any, collaboration/co-ordination between the very few providers who offer sibling support programs
- There is a lack of recognition of the needs of siblings and a lack of skills to manage those needs within primary and broader allied health services, as well as other sectors (disability, education)
- If siblings are identified as being at risk, there are virtually no appropriate referral pathways
- There has been little evaluation done of existing programs; no best practice guidelines due to a lack of resources in this area
- There is no measurement of outcomes for siblings, only for the person with disability/MI and carers

Why siblings are overlooked

There are a number of reasons why siblings continue to be overlooked in current policy and services, including:

- They are not good self-advocates. Having grown up with another’s needs taking priority, they learn to not ‘make waves’, in order to protect parents from further stress. They can feel guilty if they raise their own concerns, especially if they see a brother or sister struggling.
- Parents are stretched, both emotionally and practically. Many obviously (from the number of enquiries Siblings Australia receives) recognise the impacts on siblings but feel powerless to change anything. Others are so focussed on the child with extra needs that they might overlook the needs of siblings, especially if the sibling appears to be managing.

⁴ Kate Strohm (2018) Commentary on “Perceptions of non-caregiving roles among siblings of adults with intellectual and developmental disabilities” (Lee, Burke, Arnold, & Owen, 2018), *Research and Practice in Intellectual and Developmental Disabilities*, 5:2, 128-137, DOI: [10.1080/23297018.2018.1525306](https://doi.org/10.1080/23297018.2018.1525306) (a free e-link is available on request to author kate@siblingsaustralia.org.au)

- Health professionals, teachers, and other providers often lack understanding of the concerns and needs of siblings. The issues can be complex.
- Due to a lack of funding, providers who do understand the needs of siblings are often restricted in what they can do. Programs have been started by committed providers but then may not be able to continue.
- In spite of intense advocacy, siblings are nowhere in government policy and so there is not co-ordinated approach to sibling support.

RECOMMENDATIONS

The inquiry has stated it will ‘assess how effective are existing, and potential alternative, services and supports in meeting the needs and preferences of people at risk of mental ill-health, their families (emphasis added) and carers’. The following recommendations relate to a number of the particular themes/sections of the Issues Paper.

POLICY

- Ensure that all approaches to mental ill-health recognise the importance of, and impacts on, the whole family across the lifespan, including siblings
- Include siblings in the list of particular demographic groups that miss out on services/supports
- Ensure a greater focus on prevention and early intervention for at risk groups and better identification of these at risk groups

ASSESSMENT

- Ensure that hidden populations who are at risk of mental ill-health (e.g. siblings) are included in approaches to find out more about the consequences, about the gaps in services, and possible interventions
- Ensure that whole families are included in such assessments.
- Ensure that whole families are included in any outcome measures related to people with disability/MI
- Provide more resources to investigate the costs and benefits of supporting siblings.
- Collect relevant data on the contributions and needs of siblings
- Initiate and manage the research required to underpin effective sibling support

SIBLING SUPPORT

- Research the risk and protective factors involved in how siblings manage the challenges they face
- Research the barriers/enhancers to stronger sibling relationships when one has disability/MI
- Recognise and support the value of peer support for siblings across their lifespan
- Develop a national strength based approach to their support which includes providing information, peer support and skills development

HEALTH WORKFORCE

- Address the lack of recognition of the needs of siblings and the lack of skills to manage those needs within primary care settings and broader allied health services.
- Explore the education and training needs of the health sector and other relevant sectors, such as education, disability, child protection, social services
- Provide resources for education and training in the health sector to ensure greater capacity to support siblings, using ‘best practice approaches’
- Address the lack of imperative for agencies to provide sibling support through better policy directions
- Ensure appropriate data collection (including inclusion in case notes) re the contributions and needs of siblings

- Ensure adequate assessment tools for the whole family, and appropriate referral pathways
- Recognise the risks to physical safety for some siblings and develop appropriate measures to address these
- Facilitate effective collaboration between sectors and organisations
- Explore partnerships with relevant government programs to add value to what is happening already in mental health approaches (youth and adult)

INFORMAL CARERS

- Change how siblings are viewed, not necessarily as ‘informal supports’ or ‘carers’, but as important family members who both contribute much but also have their own needs, which change over different life stages
- Recognise the value of strong sibling relationships in the participation and inclusion of people with disability/MI
- Support siblings to contribute to developing a ‘good life’ for their brother or sister with disability/MI and for themselves

For a more detailed look at particular strategies re families, school, and community, please refer to the table included in the Families Australia paper [*Towards improved recognition and support for siblings of those with a chronic condition: A report on consultations*](#) (a follow up to the RANZCP work – see ‘Advocacy’ in Appendix 1). 2012

Benefits of sibling support

With better supports, siblings would be more likely to reach their own potential AND also contribute to the quality of life of people with a disability/MI. This would lead to benefits for siblings themselves (better health/mental health), for people with disability (greater social and emotional support), for the community and for governments (considerable savings due to less health/mental health problems and more engagement of siblings in the lives of people with a disability).

The impact of this on social and economic participation for siblings, the person with disability/MI, and the community in general is difficult to define without resources being allocated to such investigations. Certainly evidence shows that there is a huge cost to social and health services through longer term mental and physical health problems. There is some evidence that, if siblings are supported, it can lead to stronger sibling relationships which then have a significant influence on the social inclusion, health and wellbeing of the person with disability/MI.

With support in place, siblings are more likely to develop strength, resilience and tolerance. They are less likely to feel isolated or develop health issues and more likely to contribute to the well-being of their brother or sister with additional needs. The whole family is likely to function more positively.

Access to relevant information and support programs enable siblings to:

- understand issues pertaining to their sibling’s disability or illness
- understand that they are not alone with their particular concerns and feelings
- accept that it is normal to experience a range of mixed feelings, including love, sadness, guilt, anger
- receive support to express and deal with these feelings
- learn skills to manage the challenges
- develop greater strength, resilience and tolerance
- develop a stronger relationship with their brother or sister, leading to greater contributions to the well-being of the person with disability/MI

The whole family is likely to function more positively if siblings are supported. Also, if just a few cases of depression or anxiety in siblings can be prevented, the costs of intervention will be more than saved over

time. Siblings are too important to ignore - support benefits not only families (including the child with disability/MI) but also governments, the community and taxpayers through longer-term savings in health and social services.

Appendix 1 Siblings Australia

Siblings Australia is the only organisation in Australia dedicated to addressing the needs of brothers and sisters of people with special needs [chronic illness, disability and/or mental health issues].

The organisation's Mission is a simple one: *Siblings: Acknowledged, Connected, Resilient*.

Over a period of 20 years, Siblings Australia has made huge progress in creating awareness and providing support within the different settings in which a sibling operates, for example, families, schools, community. It has built relationships with family, mental health, youth, education and disability agencies, and developed both a national and international reputation for its work. With a strong emphasis on prevention and early intervention, Siblings Australia has worked to build resilience and coping skills of children, young people and families, and raise community awareness about sibling issues.

Research and anecdotal evidence supports the view that illness and disability affects the lives of *all* family members. The focus is on strengthening families so they are more able to support each other and more able to access support from outside the family. Consequently, the aim is to increase the availability of information and support services for siblings, through increasing awareness, understanding, and skills at three levels:

- direct support to siblings
- enabling parents to support their children
- working with service providers who, in turn, offer support to families (disability, health and education)

Information and support services take the form of written and online materials, workshops, a website (96K visitors/480K visits/year) and networking opportunities for families and providers. The organisation uses a 'settings' approach to improve the capacity of all areas in which a sibling operates – family, school, community.

For a discussion about mental health promotion, in particular, for siblings and the need for policy directions see the [guest editorial](#), published in 2008 in the Australian e-Journal on the Advancement of Mental Health.

Workshops

Workshops have been run for thousands of parents and service providers all around Australia (in both metro and regional areas) and the Executive Director has been asked to present in Italy (4 times), the UK, US and Canada. The workshops, in particular, have served to empower parents in supporting their whole family. Feedback has been overwhelmingly positive. As one parent said at the conclusion of a parent workshop, "I have been looking for something like this for over 10 years".

There is continuing contact with providers around Australia and similar organisations overseas. The service provider training has included professionals from a number of sectors, including, health, disability, counselling and education, and where appropriate has included training in the *SibworkS* model developed by Siblings Australia in 2004.

However, these workshops have virtually ceased in recent times, as there is no policy and therefore no imperative for agencies to consider siblings.

Resources

The organisation has developed a range of resources both in hard copy and online, including:

- [Sibworks](#) peer support program for siblings aged 8-12 years
- *Stronger Siblings* DVD for parents

- *Siblings and Mental Health [factsheet](#)* for siblings of young people with mental health issues

These resources are available for purchase or for free download via the [website](#), which also includes a range of information and networking opportunities. In addition, the Executive Director's book, *[Siblings: Brothers and Sisters of Children with Disability](#)*,⁵ generated very powerful responses from around Australia and overseas. (It has also been published in the US, the UK, and Korea and the second edition was released early in 2014.)

Siblings Australia has been providing services, including education and training, for many years for families and professionals, and feedback has always been very positive, but it has not had the resources to do significant evaluation. It's peer support program for young siblings has been evaluated by the University of Adelaide (see research link below) and been included in the [Communities for Children Evidence based program profiles](#) but again the organisation has not had the resources to actually run the program or do further work in evaluation. At the same time, service providers rarely run this program due to their own lack of resources.

Siblings Australia has provided a range of online and face-to-face opportunities for siblings to connect and support each other. These include closed Facebook groups for adult and teen siblings (the latter in collaboration with the Sibling Support Project in the US). Siblings have regularly described the value of connecting with people who 'get it'; one described it as a 'lifesaver'. These groups, in some cases, have also resulted in the re-establishment of sibling relationships, which may have broken down due to a variety of stresses. Having accessed support for themselves, siblings have then been more able to reach out to their brother or sister with disability/MI.

Research

The organisation has played an important role in areas of [research](#) to inform social policy makers about the needs of siblings, including the recent [Mapping Project](#), which confirmed a huge need for, but lack of, sibling support services.

Advocacy

Siblings Australia has provided a number of [submissions](#) to government and other inquiries. Other bodies have also highlighted the needs of siblings, either as a focus or as part of an overall interest in child wellbeing. (See [here](#).) Of particular note, as mentioned earlier, are the [Position Statement](#) and [Issues Paper](#) from the RANZCP and the follow up [paper](#) by Families Australia that highlighted concrete directions for the future.

In 2004, and again in 2009, Siblings Australia hosted a national conference on sibling issues, which brought together families, service providers, researchers and policymakers (including several from overseas). At each event, delegates reinforced the need for a co-ordinated approach to sibling support measures and called on the Australian government to support such a measure. However, siblings continued to be overlooked. There is a need for another such gathering to share and learn from each other.

Siblings Australia deals with a high volume of enquiries on sibling issues, both through direct contact (phone, email) by parents and providers, and through the website. This highlights how the awareness of sibling issues and demand for services and resources is growing by both parents and providers in Australia but, sadly, this demand cannot be met.

Funding History

In the early years the organisation received funding from a variety of government and community sources, but with project based funding being so limited, it struggled to develop sustainability. Over a few years prior to 2007 the organisation received funding through the FAHCSIA run Stronger Families and Communities for

⁵ Strohm, K.E. (2002). *Siblings: Brothers and Sisters of Children with Disability*. Wakefield Press: Adelaide

Children initiatives via the federal government and in 2007 received funding through DOHA, via the Mental Health, Early Intervention and Prevention area. Relationships developed with a number of DOHA funded programs, including Beyond Blue, Mind Matters, Kids Matter, KidsHelpline, but more work was needed.

Toward the end of that year government officers encouraged the submission of a proposal for the following year's funding. Before that task could be completed, a federal election was called and so no new contracts could be considered. When the new government came into office, the organisation was told that this funding would not continue. Since then it has been continuing to operate as best as it can, largely through the voluntary efforts of its people.

The difficulty for Siblings Australia is developing sustainability, as funding has been sporadic and short term. Without policy in this area and with no one government department taking responsibility for this group of vulnerable children/adults, there is little imperative for siblings to be recognised and the future for the organisation is very uncertain. This would mean a loss of 20 years of expertise and experience.

April 2019