

## Submission by Siblings Australia Inc.

### *Intentional self-harm and suicidal behaviour in children: an inquiry by the Children's Commissioner*

## Introduction

This brief submission will focus on the issue of self-harm in siblings of young people with disability. Whilst it is acknowledged that there are various factors that can contribute to self-harm, there are several risk factors for siblings of young people with disability, in particular, that might contribute to this behaviour. Unfortunately, to date, siblings are very much overlooked when it comes to national policy and programs and, with limited resources, there has been very little data collection and research in this area.

Since 1999, Siblings Australia has been the only organisation in Australia to focus specifically on siblings of children with disability or chronic illness. During that time it has developed a range of resources and services, run workshops around Australia and overseas for parents and service providers, carried out research and lobbied hard to have siblings recognised as a group in need of support. For further information on the work of Siblings Australia see Appendix 1.

This submission will address the four main parameters raised by this inquiry, ie,

1. Why children and young people engage in self harm and suicidal behaviour
2. The barriers which prevent children and young people seeking help
3. The types of programs and practices that effectively target and support children and young people
4. Improvements which could be made to accurately identify, record and report on intentional self harm and suicide in children and young people.

## Why children and YP engage in self harming behaviours

### A) General population

There are a number of reasons why young people in general adopt self-harming behaviours. Some young people have described how they have felt huge emotional pain and how the cutting or other forms of harm can feel better than the original pain. In other words, the physical pain can be easier to cope with than the pain they feel inside. Some young people who self harm feel disconnected and isolated from those around them. Self harm usually signifies a lack of coping skills. Some of the risk factors include: high levels of stress; presence of anxiety or depression, and childhood trauma. And the behaviours are often carried out in secret without family and friends being aware.

### B) Siblings

With respect to siblings of children and young people with disability, in particular, there is no research available that directly links the experience of being a sibling to self harm behaviours. However, there is considerable anecdotal evidence. The Director of Siblings Australia has run workshops for many years around Australia and the organisation has run a variety of face-to-face

and online forums. There have been many stories of young siblings self harming, either directly from siblings themselves or through parents and providers. Siblings Australia believes that there are a number of risk factors for siblings that make this group vulnerable to such behaviour as a way of trying to cope, and that further work needs to be done in this area.

Whilst many siblings take a range of positive things from their experiences, many others face significant challenges and, without support, are at risk of developing longer term mental and physical health problems. The Royal Australian & New Zealand College of Psychiatrists, in late 2011, released a [Position Statement](#) and Issues paper which highlighted the risks for siblings.

Earlier, an Australian Institute for Family Studies research project (Edwards, 2008) found that siblings (as well as parents of a child with disability) have higher rates of depression than average, regardless of any caring role they may or may not play. Depression often arises in the context of unexpressed anger or other feelings that have been repressed. This often goes unnoticed and if a young person feels depressed, they may hesitate to express it to their family because their problems may feel insignificant alongside the problems of their brother or sister. They may not be able to talk to people outside the family either if they are trying to hide the reality of their home life. For some siblings, a sense of helplessness can build up. There can be pressures (both external and internal) on siblings to be perfect and deny their feelings, and this can eventually take its toll.

Certainly, Siblings Australia has found strong evidence for depression and anxiety amongst siblings, along with a sense of isolation. Often they want to protect parents as they see the stress they are under. And they can feel that others don't understand. In 1999 Siblings Australia carried out an adult sibling project which told us much about the experiences of siblings. Through focus sessions, online surveys and submissions we heard of the many challenges faced by siblings. Whilst some could certainly identify a range of positives, like developing compassion and patience and embracing diversity and a sense of social justice, many also identified the costs to both their physical and mental health. Impacts included depression, anxiety, OCD, eating disorders, social phobia, self harm, sleep problems and very low self esteem. Some siblings also talked of previous suicide attempts.

In addition, siblings identified self harm as one way of coping. They told us that they used a variety of coping strategies. Some were able to use effective strategies (such as counselling, the arts, journaling, contact with other siblings, relaxation) but others talked of self medicating with drugs and alcohol, taking antidepressants or self harming from a young age.

## Barriers which prevent children & young people from seeking help

This section will not discuss the barriers for the general population but will document some of the reasons why siblings, in particular, can find it difficult to seek help.

Through direct conversations, online forums and research projects, we have heard about the following issues which arise for many siblings:

- Isolation
- Denial of feelings which can then lead to low self esteem and a sense of helplessness

*We siblings are not supposed to feel angry and resentful. Such feelings imply selfishness and insensitivity.*

- Feeling 'out of control'
- Feeling unable to speak to parents due to guilt and anger, or not wanting to upset parents, or being given the message that they shouldn't talk of such things

*I would not let myself feel anything negative about my brother, there is something in me that just blocks it, any hint of negativity about my brother or childhood makes me feel guilty, like it's a betrayal of those I love, so it was/is hard enough to think about let alone speak about.*

*I don't want to bother my parents or make them worry, I never do I think it's because of they have to go through I don't want to add to it all.*

- Feeling unable to take their problems to other people as they feel guilty complaining (what are their concerns compared to a brother or sister with disability?) and so things get bottled up
- Schools in general do not have an understanding of the needs of siblings. Often schools do not know if a child is a sibling
- There are very few, if any, services where siblings can go for support. Siblings have gone to mainstream mental health services but not gone again as they could not receive what they needed. As one teen said, *what would they know?*
- There is a lack of data surrounding siblings, a lack of documentation in schools, disability and health services.

## Types of programs/practices that effectively support children/YP

Again this section will just focus on siblings rather than general programs.

For a start, siblings need to be recognised in national policy somewhere. Unlike the UK none of our national policy related to children and young people includes siblings.

There needs to be a national initiative developed that can develop the data and research required to underpin best practice approaches. Programs need to provide support across the lifespan and across settings ie within the family and outside the family (schools, disability/health organisations and the general community).

The aim of such programs should be to address the isolation that siblings often feel, give them the information they need and connect with opportunities to learn skills to manage the stresses they experience. One of the best ways of providing this support, for many siblings, is through peer support programs such as the Siblings Australia *Sibworks* program.

## Siblings of young people who self harm

Much of the above also relates to siblings of young people who self harm and it is important to take a 'whole family' approach when planning interventions for young people who self harm. Siblings can play a role in the outcomes for a young person who is self harming but at the same time they also need their own support.

## Improvements in order to identify, record and report self harm

There need to be major improvements first in identifying siblings per se. At the moment they are not included in policy or national programs and so this is the biggest barrier to identifying any issues for siblings, including self harm.

As mentioned there needs to be a national initiative which can take the lead in raising awareness about the needs of siblings across the different settings in which they operate and improving

community capacity to support them. We need a prevention model which supports these children from a young age so they are more connected and more resilient.

There also needs to be more effective ways of addressing the needs of those siblings who do develop mental health problems ie through family support but also through a systematic program of workforce development.

Flags should go up when a child with disability is recorded as having a brother or sister. The disability or health agency needs to encompass a whole family approach but also families need to be given the tools to support all their children. Settings like schools and other community groups need to have the skills and resources to identify issues for siblings and then provide support or refer to other sources of support. See both appendices for further information.

## Appendix 1

### Briefing Paper 2013-14

#### Background

There are estimated to be 300,000 people under the age of 25 years with a severe or profound disability, chronic illness, or mental illness. Understandably, significant resources are spent on addressing the needs of children and adults with disability or chronic illness, 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. In spite of this, the needs of siblings have been largely overlooked at both policy and service level.

At a broader level, there is much emphasis in our community about the prevention of mental health problems. There is an understanding of the profound effect the early years have on a child's development and their longer term health and wellbeing. There are economic benefits in intervening early and ensuring young people who may be at risk are able to access relevant support services.

#### The sibling experience

Certainly many siblings of people living with disability are enriched by their experiences. However, many can also face challenges. A recent Australian Institute of Family Studies report found that parents of children with disabilities have higher rates of depression than the general population and siblings also had a significantly increased risk of depression, regardless of any caring role<sup>1</sup>. Often these parents do not access services for themselves or their other children as the focus is on the child with special needs. Other studies from overseas have shown that these children have increased rates of physical health problems too<sup>2</sup>. In many cases, these children have to deal with separated parents (it is well accepted that the rate of marriage breakdown is higher in this population), a depressed parent (usually the mother) and also the ongoing demands or difficult behaviour of the child with special needs. Their education outcomes may be affected by anxiety, tiredness, depression, social stigma and worry for parents. Also, they may face a lifetime of responsibility for a brother or sister.

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<sup>1</sup> 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*

<sup>2</sup> 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.

It is recognised that siblings often grow up in a situation of considerable stress, without the cognitive and emotional maturity to understand the mix of feelings they experience. Siblings can experience a range of feelings and reactions to having a brother or sister with disability or chronic illness and these can vary over time. Often there is confusion about those feelings. On the one hand, a child may feel loving and protective toward their brother or sister. At the same time, they may feel resentment, embarrassment, guilt, sorrow and fear. Such feelings, left unaddressed can lead to lowered self esteem, shame or a sense of worthlessness<sup>3</sup>. These problems are exacerbated by limited access and availability of appropriate services and the practicalities of family life where the needs of a brother or sister take greater priority. Without support, these siblings are at risk of developing longer-term physical, emotional and psychological problems.

*“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.”* RANZCP Position Statement, see under [Advocacy](#) below.

## Sibling support

It is important to intervene early and provide support to these children. This needs to include approaches within all the settings in which the child operates, for example, family (immediate and extended), friends, peers, school and community. This support needs to continue over the lifespan, as issues change.

## Benefits of sibling support

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 special 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

## The Gaps

- Very few siblings access any support services
- Very few parents are assisted to support their children who are siblings
- There are no policies or strategic national approaches to 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 between providers who offer sibling support programs

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<sup>3</sup> 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

- There are no standard, co-ordinated policies with regard sibling support programs
- There has been little evaluation done of existing programs; no best practice guidelines

## Appendix 2

### 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 14 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. 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 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.

#### 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, 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 recently at the conclusion of a parent workshop, "I have been looking for something like this for over 10 years".

We are in close 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.

#### 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](#)

These resources can be purchased or downloaded via the [website](#), which also includes a range of information and networking opportunities, including a directory of sibling support services. In addition, the Executive Director's book, *Siblings: Brothers and Sisters of Children with Special Needs*,<sup>4</sup> 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 will be released early in 2014.)

### Research

The organisation has played an important role in areas of research to inform social policy makers about the needs of siblings, including (from newest to oldest):

- [Phone-in re sibling support](#) 2013

Siblings Australia conducted a phone-in on January 12th to gauge families' thoughts on the availability of sibling support and what would help.

- [Sibs and physical harm](#) 2012

For some time Siblings Australia has been concerned about the issue of siblings being physically hurt by a brother or sister with disability. We developed surveys for parents, siblings and service providers and whilst we understand this is a sensitive topic, we also believe that it is an issue worthy of consideration. We hope that this small research project will lead to more extensive research through which we can gain more insight into the support needs of families.

- [Scoping Project](#) 2009

This research investigated what sibling programs were operating around Australia, what models were used and what workforce development was needed. Over 100 providers of sibling programs responded and reinforced the idea that there needed to be more collaboration, more resources and skill development as well as more funding for these programs.

- [Adult Sibling Project](#) 2009

This research explored the concerns and needs of adult siblings of people with disability. It also produced some resources for adult siblings, available [here](#).

- [ARACY Collaboration Report](#) 2008

Siblings Australia had long been concerned about the lack of collaboration and co-ordination around research into sibling issues and models of support. After contacting researchers around the country we established a group of researchers and together we were successful in gaining a small encouragement grant to facilitate some collaboration between researchers and service providers.

- [Evaluation of Sibworks](#) 2007

This was a very small sample and so the results were not very conclusive. The University of Adelaide, Psychology Department currently has funding to carry out a more extensive evaluation on this program.

### 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. These can be found [here](#). Of particular note 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.

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<sup>4</sup> Strohm, K.E. (2002). *Siblings: Brothers and Sisters of Children with Special Needs*. Wakefield Press: Adelaide

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, support for this could not be found. 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.

The difficulty for Siblings Australia is developing sustainability as funding has been sporadic and short term. No one government department takes responsibility for this group of vulnerable children/adults and they do not fit into one policy area. They could easily fit into Mental Health, Families and Communities, or Education. Ideally they should be considered by all of these portfolio areas.

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.

### *Funding History*

Siblings Australia was first established in 1999 and since that time has developed a national and international reputation for its work with families and professionals. 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 Children initiatives via the federal government and in 2007 received funding through DOHA, via the Mental Health, Early Intervention and Prevention area. We began to develop relationships with a number of DOHA funded programs, including Beyond Blue, Mind Matters, Kids Matter, KidsHelpline, but more work was needed.

Toward the end of 2007 we were invited by two government officers to submit a proposal for the following year's funding. Before we were able to complete that task 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 it could not access funding. Since then, Siblings Australia has continued to advocate for this group of vulnerable children as well as provide services as best as it can, largely through the voluntary efforts of its people.

### **Why Siblings Australia should be valued and supported**

- The organisation has over 15 years of experience in this area and is in an ideal and unique position to carry this work further – if it is not supported this expertise will be lost
- Siblings Australia continues to hear from many families and providers who express concern about available services for siblings and the value of Siblings Australia, including through a petition in 2008 when funding was lost

[http://www.petitiononline.com/mod\\_perl/signed.cgi?SIBLINGS](http://www.petitiononline.com/mod_perl/signed.cgi?SIBLINGS)



- The work that is being done across Australia is unco-ordinated – Siblings Australia with its extensive networks and experience has the capacity to ensure greater consistency in approach
- Siblings need to have their concerns addressed through national policy and strategic directions, in a similar way to the Children of Parents with a Mental Illness (COPMI) national initiative
- 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 or illness) but also governments, the community and tax-payers through longer term savings in social services

### **Siblings Australia Board of Management**

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