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**RESPONSE TO THE PROPOSED NATIONAL YOUTH AGENDA  
OF THE AUSTRALIAN RESEARCH ALLIANCE FOR CHILDREN AND YOUTH  
December 2007**

## **INTRODUCTION**

This document is a response by Siblings Australia to the National Youth Agenda. Siblings Australia is the only organisation in Australia whose prime focus is the needs of siblings of children with special needs. We endorse the National Disability Services submission to the National Youth Agenda, but would like to add our own perspective in relation to siblings of young people with disability. We also note that for some of the National Youth Agenda values that are addressed within this document our arguments would apply just as equally to sibling issues related to chronic illness and mental illness. We ask that the focus on 'all' young people takes full account of those with special needs (disability, chronic illness and mental illness) AND their brothers and sisters. Siblings are important in their own right but also in relation to their contribution to the young person with special needs.

Research and anecdotal evidence supports the view that illness and disability affects the lives of all family members. Brothers and sisters of children with special needs often face a family situation which involves considerable stress, but without the understanding, emotional maturity and coping skills required to deal with their experiences. They can feel isolated and confused and become 'at risk' for a range of emotional, mental and physical health problems, which can continue into adulthood. Yet siblings are regularly overlooked within their family, as well as by agencies and policy makers, even though they will likely have the longest relationship of anyone with the person with special needs. These young people regularly fall through the gaps in policy – they could easily fit into the families, disability, mental health or education sector – but none of these areas takes overall responsibility for this group of young people.

Siblings Australia endorses the approach taken by the Youth Agenda document and will only comment here on those general issues/concerns and strategies which are relevant and specific to siblings. This submission will then include some recommendations for the National Youth Agenda.

### **1. INVOLVEMENT, ENGAGEMENT AND RIGHTS**

All young people have the right to be heard and to be involved in decisions that affect them. The National Youth Agenda rightly highlights the needs of young people with disabilities, who can 'have difficulties in participating in all areas of life'. We would add that siblings of young people with special needs have their own set of concerns. The overwhelming response from siblings after reading the book, *Siblings*,<sup>1</sup> has been that this is the first time they feel they have had 'a voice'.

The nature of the sibling relationship will also have a huge impact on the lifelong quality of life and social connectedness of the person with special needs.

Regarding issues of juvenile justice, there is some anecdotal evidence to suggest that siblings are over represented in the juvenile justice system. This might be an avenue worthy of research.

And regarding youth policies, policy development should occur in consultation with young people with disability AND their siblings.

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<sup>1</sup> Strohm, K. (2002). *Siblings: Brothers and Sisters of Children with Special Needs*. Adelaide, Wakefield Press.,

## 2. VALUED RECOGNITION

### Bullying in schools

Siblings can be particularly vulnerable to bullying or teasing. One little girl found that others would not play with her as she had 'disability germs'. Peter Burke, in the UK, has written at length about the concept of 'disability by association'<sup>2</sup>. Siblings can also be stressed by the bullying of their brother or sister with special needs or in fact other children with special needs.

The impact of bullying or teasing on siblings is not acknowledged or understood.

## 3. HEALTH AND HUMAN DEVELOPMENT

### Mental health

Research has shown that mental illness often originates in the teen and early adult years. Anxiety and depression are the most common mental health problems for people aged 12 -17 years.<sup>3</sup> Early intervention increases the chance of recovery for these young people but siblings, in particular, often have difficulty asking for help.

Certainly many siblings are able to take very positive things from their experiences. With support, many develop greater maturity, compassion and an understanding of what is important in life. However, many others struggle. Siblings can experience a range of feelings and reactions to having a brother or sister with special needs 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. Without the cognitive skills and emotional maturity to understand and deal with those feelings, a child's self esteem can suffer. Anger and guilt can turn inward and lead to shame and a sense of worthlessness. Without support, these children can develop a range of emotional and mental health issues.

In the book, *Burdened Children*<sup>4</sup>, a whole chapter is devoted to siblings of children with special needs. It states that the majority of studies done with this group of children show increased depression, social isolation, anxiety and insecurity, and increased risk for aggression, oppositional behaviour, delinquency and peer difficulties. In addition, even without primary carer responsibilities, these children can carry a burden of responsibility. These problems can lead to further problems such as self-harming behaviour and drug use.

Further research from the US<sup>5</sup> suggests that siblings are at greater risk for negative physical health as well. The article concludes, "Even if a child is without disability but has a sibling with a disability, he/she experiences an increased likelihood of lower health status, unmet need for medical care, and bed days sick. Indeed the health impact of living with a sibling with a disability is greater than the impact of being poor, and similar to the impact of belonging to an ethnic minority group."

Support for siblings allows them to feel empowered and less isolated, and it helps them build resilience. As a result, not only will they be more likely to develop to their full potential, but also more likely to contribute support to their brother or sister.

The cost of not providing support can be significant not only for the child and family, but for the community in general through greater demand for social and health services.

### Drugs, alcohol and substance misuse

As mentioned above, siblings are vulnerable to a range of mental and emotional health issues. Anecdotal evidence suggests that this increases the chance of them turning to risk-taking behaviour, including drugs/alcohol. Some time ago the ABC Four Corners program looked at several caring situations in its documentary, *The Hidden Army*. The following

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<sup>2</sup> Burke, Peter. (2003). *Brothers and Sisters of Disabled Children*. UK: Jessica Kingsley

<sup>3</sup> 'Young People and Mental Health' at

<http://www.mhca.org.au/AboutMentalHealth/factsheets/AdolescentYouthMentalProblems.html>

<sup>4</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

<sup>5</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.

transcript extract from that program has the journalist, Quentin, exploring the impact of having two children with special needs, both on mother, Felicity, and her other child. The full transcript can be found at (<http://www.abc.net.au/4corners/content/2005/s1330245.htm>)

QUENTIN McDERMOTT: When she was younger, Felicity embarked on a successful career as a nurse. Then, after her children's disabilities were diagnosed, she and her husband split up, a common occurrence in families caring for disabled kids.  
FELICITY: My full-time career came to a grinding halt after the end of my marriage, and the support needs of the children sort of meant that I needed to be at home, and so I had to quit work.  
QUENTIN: The emotional stress of caring for her two disabled children was compounded by the devastating effect on her third and eldest child.  
FELICITY: He was teased unmercifully at school because both his brother and sister had a disability. Also, his feeling of being neglected, and I had, you know, a young man of 11 crying to me one day, saying, "If I had a disability, would you love me, too?" And, I mean, that just rips your heart out. For him, his inability to cope, or his self-esteem within a family dynamic, has resulted in drug and alcohol abuse, addiction, um, with criminal activity, and, um, he now has an acquired mental illness.

### **Over-, under-weight and eating and lifestyle disorders**

Anecdotal evidence suggests a vulnerability to eating disorders by siblings. Further research is needed.

### **Care and protection from abuse and neglect, and out-of-home care**

It is understandable that energy and resources in a family can be stretched when a child has special needs. Parents can be overwhelmed with the demands, and other children in the family can be at risk of being neglected. As one sibling said, "My needs were always left on the back burner." Another issue that is overlooked is the abuse of siblings by a child with special needs. Some special needs involve very aggressive behaviours and siblings are not always protected.

### **Education, training and employment**

School can be a source of stress for siblings (due to teasing, feeling isolated, not feeling they can ask for help etc) or it can be a haven from the stresses of home. The education sector needs training to understand the issues/support needs for siblings.

## **4. SOCIAL INTEGRATION**

### **Family life and parenting**

Many marriages break down under the stress of parenting a child with special needs. More should be done to support both parents at the time of diagnosis to help them understand their own reactions (shock, grief etc) and to enable them to support each other. Both the young person with special needs and their sibling(s) will benefit if the family unit is stronger and able to support all members.

Down the track, most support services concentrate on parents with little attention given to siblings. The sibling relationship is likely to be the longest of any within the family and so more should be done to nurture this relationship.

In addition, parents can play a crucial role in supporting siblings – but many are too stretched to be able to provide sufficient support.<sup>6</sup> Parent workshops by Siblings Australia empower parents to support their whole family. One parent said that she "had been looking for something like this for 10 years". Various reports have highlighted the concerns of parents for siblings but still there is no support available for such parent education programs.

<sup>6</sup> [www.carersaustralia.com.au/images/stories/Wellbeing.pdf](http://www.carersaustralia.com.au/images/stories/Wellbeing.pdf)

### **Community connections**

Siblings of young people with disability are also at risk of becoming socially isolated. They may not have opportunities to bring friends home, attend community activities, etc. It is often too difficult for parents to transport them to activities outside the home. They can have family responsibilities that preclude them from sharing in peer activities. Young siblings often say that other people don't understand the pressures on them.

## **5. MATERIAL WELLBEING**

It is recognised that families in which there is a child with special needs can struggle with financial issues. Not only are there extra medical costs but also many of these families are single parent families. When there are two parents, one is often restricted in the amount of outside work that can be done.

Siblings are also impacted by these family circumstances. Later, as parents age and are no longer able to provide care for the person with special needs, they can face a complex situation as they try to provide financially for all their children, whilst at the same time trying to find suitable accommodation for the person with special needs. There should be more support and information for families as they attempt these difficult discussions.

### **Opportunities in remote areas**

Along with outreach programs for young people with disability living in rural and remote areas it is important to also provide support services for siblings in these areas.

## **RECOMMENDATIONS**

Siblings Australia encourages the National Youth Agenda to highlight the needs of siblings of young people with special needs, as, without support, they can be a group 'at risk'.

One option would be to include under Section 1(d), 'Young people with disabilities', the following issue and strategies.

### Issue

Siblings of young people with special needs can have a range of concerns themselves, which can have an impact not only on their own development but also on the sibling relationship.

### Strategies

There needs to be more research to understand the concerns and needs of siblings.

There should also be support of community organisations to enable young siblings of people with special needs to give voice to their issues and to gain access to support within the various settings in which they operate.

### **About Siblings Australia Inc.**

Siblings Australia is the only organisation of its kind in Australia, the only organisation to focus entirely on the needs of siblings of children with special needs. The incorporated body grew out of the work of the Sibling Project, established in 1999 within the Department of Psychological Medicine at the Women's and Children's Hospital. In 2002, our Director, Kate Strohm's book *Siblings: Brothers and Sisters of Children with Special Needs* was published by Wakefield Press. It has since been published in both the UK and the US.

The work of Siblings Australia is increasingly recognised nationally and internationally. Our director has presented workshops around the nation and, more recently in Italy, the UK, US and Canada. In 2004, Siblings Australia staged an international conference focused on sibling issues and support. It was attended by 140 professionals and families from around Australia which included 10 registrations from overseas.

Our work focuses on three main areas; ensuring peer support for siblings, strengthening families through enabling parents to be more able to support siblings, and improving the capacity of agencies and organisations to support siblings and the whole family.

Some key activities over the last 8 years have included:

- Internet discussion groups for young, teen and adult siblings
- Presentations to parent groups around Australia and overseas
- Development of a brochure of sibling support strategies for parents
- Service provider training around Australia and overseas
- Establishment of an internet discussion group for service providers
- Training workshops, development of manual for facilitators of sibling groups
- Collaboration with educational services (Siblings Australia has done considerable work with schools, and in recent times has begun contributing to Mind Matters and Kids Matter to improve understanding of sibling issues).
- Collection of extensive reference library, including books, articles etc
- Website established – [www.siblingsaustralia.org.au](http://www.siblingsaustralia.org.au)
- Contribution to undergraduate health professional training
- Support of research into sibling issues and sibling support
- Extensive networking, locally, nationally and internationally
- Advocacy for sibling support at both policy and organisational level

### **The benefits of our work**

The work of Siblings Australia contributes to strengthening families and improving the capacity of the organisations that support them.

Young siblings who join our peer support groups or internet forums finally find other young people who ‘understand’ and, through sharing their stories, feel stronger and more able to cope. Adult siblings talk about similar feelings of relief through connecting with others who can share the grief, guilt and isolation. Other siblings have reported that the peer support has enabled their relationship with their brother or sister to become stronger.

Parents of children with special needs, who themselves are under stress; find the workshops an empowering experience, with many feeling much more able to support their whole family. Service providers also gain enormous insight into the needs of families and go away with clearer directions for family support.

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