

Submission to Standing Committee on Family, Community, Housing and Youth, *Inquiry into better support for carers*
By Kate Strohm, Director, Siblings Australia Inc, (www.siblingsaustralia.org.au) June 2008

EXECUTIVE SUMMARY

This submission will address the particular issues and needs of siblings of people with special needs. For this group, there can be some very unique issues that are quite different from those resulting from other carer roles. Also, the role of a sibling, unlike many other caring roles, can be a lifetime one and the complex needs of siblings will change enormously over that time.

Siblings of people with special needs can be at risk for a range of mental and physical health problems, and yet their needs have been largely overlooked both at government and community level. Whilst there are some grassroots programs available for siblings there is little co-ordination or evaluation of such programs and they are largely the result of individual efforts rather than ongoing policy-directed activities. One national organisation, Siblings Australia, has tried to address this gap and has done enormous amounts of work in raising awareness, developing skills and providing sibling support programs. Over nine years it has developed a national and international reputation for its work but it has been unable throughout this time to attract ongoing support from government or the community for its core operations and needs. Early this year, it was forced to close its office and release staff due to funding difficulties. It now is operating in 'caretaker' mode and, without support, is likely to be forced to close down completely. In addition to losing the expertise and experience developed over that time by this organisation, there will be a significant gap with respect the provision of support and services to this important group of carers in Australia as no other organisation currently provides this particular service.

1. Introduction

Over recent years there has been growing recognition of the role and contribution of carers in our society. Carers might support parents, children, siblings, spouses, other family members or friends. Also there has been greater understanding of the impact of this caring role on carers' health and wellbeing. The special report, *The Wellbeing of Australians: Carer Health and Wellbeing*¹ (the largest ever survey into the health and wellbeing of Australian carers) found that more than one third of family carers in Australia are severely depressed and/or stressed. In fact carers have been found to have the lowest collective wellbeing of any group yet discovered. The survey also showed that the presence of a person in the household who requires care severely compromises the wellbeing of other family members, whether they have primary carer responsibility or not. The Australian Institute of Family Studies report, *The nature and impact of caring for family members with a disability in Australia*, highlights the risk of siblings of people with special needs experiencing mental health problems, eg depression.²

In recent times there has also been growing awareness of the role and contribution of 'Young Carers'. Siblings can be left out of the equation when considering Young Carers, partly because they and others don't always see them as carers, when parents are available to take on a primary carer role. Even though they might be secondary carers, the impact on siblings can be quite significant, not only because of their own experiences as a sibling, but also because parents may be stressed and depressed and so not as available to them for support. As secondary carers, siblings might have responsibilities not only for the child with special needs but also other children in the family. As they age, siblings' responsibility for a brother or sister with special needs might increase as parents become less able to play a caring role due to their own ageing. Then, siblings might be called on to take over the primary caring role.

¹ Cummins, R. A., Hughes, J., Tomy, A., Gibson, A., Woerner, J., & Lai, L. (2007). *Australian Unity Wellbeing Index Survey: 17.1. The wellbeing of Australians: Carer health and wellbeing*. Melbourne: Deakin University, Carers Australia and Australian Unity.

² 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*

A note about the 'Young Carer' label

At the outset of this submission I would like to stress my concern about the use of the term 'Young Carer' in a general sense, but also particularly when used to refer to siblings of children with special needs.

1. *Person first language.* Much effort has gone into using person first language in the disability sector. Instead of using such terms as a 'disabled person' or a 'diabetic', people are encouraged to use language that is less defining in terms of the special needs, where the disability or illness is just a part of their identity. If we describe someone as a 'person with disability' or a 'person with diabetes' we can more easily imagine them also being a fine musician or sports fan. Why cannot we define a young person with caring responsibilities as just that eg a 'child who cares'? That way we and the child themselves will be more likely to see such children as children first, who also have caring responsibilities, but who may also have other parts to their identity. Many siblings of a child with special needs become over-responsible, perhaps taking on the role of 'mummy's little helper', and identifying themselves as a helper and carer from the very beginning. As one said, "I just wish I could have been a kid, without all those responsibilities". Even without primary carer responsibilities, these children can carry a burden of responsibility. Given the lifelong nature of the sibling relationship the responsibility might continue for a very long time. In addition, research shows that many siblings go into caring professions. This makes a lot of sense as, with the skills acquired through their caring role, they have much to offer. However some talk of feeling that this was their only choice – having grown up identifying themselves as carers and seeing others' needs always taking precedence.
2. *Primary vs secondary carers.* Many services for carers have historically been for primary carers only. Whilst some change is occurring, many government disability bodies or carer associations have a focus on providing 'support to the person with special needs and their carers', where 'carer' in practice is defined as 'primary carer'. Using the term, 'young carer' can make it easy for providers to overlook the important role of secondary carers. During their early years siblings are more likely to be secondary carers, with parents playing the primary carer role. Often, service providers and the family themselves do not recognise the role of siblings and the impact of this role.

2. Siblings of children with special needs

The sibling relationship is often the longest of any. In recent times, there has been more interest in sibling relationships in general and research has highlighted their significance in the formation of identity. Through relationships with brothers and sisters, children learn to express emotions such as love, loyalty, anger and rivalry. They gain companionship and support and learn to give and take. Siblings help teach each other social skills and play an important role in each other's identity development. When one sibling has special needs, some aspects of the relationship can change enormously.

YOUNG SIBLINGS

In Australia, there are over 200,000 people under 25 years with a severe or profound disability or chronic illness. There are significant numbers with mental illness. It is reasonable to assume that most of these people have on average one sibling.

Understandably, significant resources are spent on addressing the needs of children with a disability or chronic illness. By the same token, research and anecdotal evidence supports the view that illness and disability affects the lives of all family members. The Carer Wellbeing Report referred to above reinforces this, as does the anecdotal evidence from many families.

The following section will outline some of the concerns of young siblings, highlighting those that impact on 1) family connections and those that impact on 2) connections outside the family

Family life and parenting

Of course many families are able to take very positive experiences from their caring responsibilities and are able to become stronger and closer as a result. However, for some, the stresses take a significant toll on family relationships. Evidence suggests that the rate of parental separation or divorce is higher in these families. Often parents don't receive enough support in the early stages of diagnosis to deal with the myriad of feelings they experience. Expectant parents, on being asked about what gender child they would like, inevitably say they don't care as long as the child is healthy. It is not surprising that there might be significant feelings should the child not be healthy.

Fathers and mothers can experience and deal with their grief and other feelings in different ways and may not be able to support each other. Relationships can break down due to the pressures, compounding the responsibilities and isolation. There can be added financial pressures; not only are there extra medical costs but also many of these families are single parent families. Even if there are two parents, one is often restricted in the amount of outside work that can be done, and this can add to the isolation, compounding depression further.

With energy and resources stretched when a child has special needs, and parents feeling overwhelmed with the demands, other children in the family can be at risk of being neglected. Parents who might be struggling with their own mental health concerns may be too overwhelmed by the demands of the child to seek support for their own concerns or those of their other children. Sometimes overlooked is the abuse of siblings by a child with special needs. Some special needs involve very aggressive, even life-threatening, behaviours and siblings are not always protected.

Parents can potentially provide support to siblings but many are so stretched both practically and emotionally to be able to do this adequately.³ Several reports on the needs of parents^{4, 5} have highlighted the concerns of parents in relation to the support of their other children. This is confirmed through the many parent workshops Siblings Australia has run around Australia and overseas, which empower parents to more ably support all their children and strengthen families. Parents have made comments about the value of these workshops, such as, *"It was like finding water in a desert, it is hard to explain, I was just desperately looking for information"* (Telstra Early Beginnings Evaluation Report of Siblings Australia) and *"I have been looking for something like this for over 10 years"*. Parents also highlight the overwhelming need for support programs for siblings.

Community Connections

Whilst siblings might struggle to gain attention within their families, outside the family they may struggle to feel connected. They might have difficulties with peer relationships and teasing directed at themselves or their brother or sister with special needs. 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'⁶. 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.

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. 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 future

As they move through their teen years, many siblings begin to have concerns about the future. Should they go out with friends and leave a parent to deal with the situation on their own? Should they move away for study or career opportunities, or stay close to home? What will happen when parents can no longer care? Will they find a partner who will help carry the responsibility for a brother or sister? Should they have children themselves? How will they manage their responsibilities to any possible children with those of a brother or sister and ageing parents?

ADULT SIBLINGS

Many adult siblings talk of the emotional struggles they experienced as children and which still continue. Some are not able to pursue their own life goals etc. Many are thrust into an even greater caring role in later life with few resources to support them in that role. Most express a desire to be involved in the life of their brother or sister, but are often frustrated and angry about the supports available, both at an emotional and practical level. Responses worldwide reveal a group of people who care deeply for their brothers and sisters but who can also struggle with their own significant emotional difficulties and with how they can best support their brother or sister.

Often adult siblings have limited choices and feel obliged to take on responsibilities for which they are ill-equipped, with some siblings taking over a direct caring role in adulthood (either full-time care or brief periods of

³ www.carersaustralia.com.au/images/stories/Wellbeing.pdf

⁴ School of Social Work and Social Policy, LaTrobe University. (2002) *Listen to Us: Identifying service responses that impact on the risk of family breakdown*. Victorian Government Department of Human Services: Melbourne

⁵ Centre for Community Child Health. (2004). *Parenting Information Project*. Department of Family and Community Services, Australian Government: Canberra

⁶ Burke, Peter. (2003). *Brothers and Sisters of Disabled Children*. Jessica Kingsley: UK

accommodation as respite from institutional care), when parents are no longer able. Other siblings will not provide direct care in terms of accommodation etc but may play an active, varied role as advocate, guardian, organising and transporting to medical appointments, overseeing accommodation, employment and recreation needs etc. And then there is a group of siblings who do not have much at all to do with their brother or sister with special needs. No matter what level of caring siblings can still struggle with emotional issues. Even if siblings are not involved in direct day to day practical care, hence not identifying themselves as 'carers', they may need support to deal with a myriad of experiences and feelings.

As siblings get older they might be balancing the needs of frail/aged parents, a brother or sister with special needs, and their own partner and teenage children. Such a mix has led this group of siblings (more often females), in certain circles, to be referred to as 'the club sandwich generation'. Once parents are no longer alive, and their own children have left home, the sibling relationship might continue to present caring responsibilities into old age, especially with medical advances aiding in a person with special needs living much longer. The sibling relationship might last 70 years, long after parents and other significant people have gone.

Many siblings identify that they worry about the future of their brother or sister and the role they might be expected to play. A recent survey of adult siblings by Siblings Australia showed that siblings can struggle to discuss issues with their parents, especially those related to planning for the future needs of the person with special needs.

3. Impact on Siblings

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, if a family is stressed it is likely that children in the family will also be stressed but, unlike parents, they can be too young to understand and cope with the mix of feelings they experience. 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/or 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.

They can feel isolated and confused and if their needs are left unaddressed can become 'at risk' for a range of emotional, mental and physical health problems (including anxiety, depression, low self-esteem and relationship difficulties), which can continue into adulthood. In the book, *Burdened Children*⁷, 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. These issues can lead to further problems such as eating disorders, self-harming behaviour and drug use. 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. The book also highlights that siblings might not only take on the role of carer to a brother or sister, but might also become over-concerned about their parents and, in some ways, become a parent to their parents.

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.⁸ Early intervention increases the chance of recovery for these young people. For siblings, the usual adolescent issues relating to identity development and future goals can be even more complex and difficult but, again, siblings can be overlooked or they can have difficulty asking for help and finding someone who will listen and understand their needs. 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*⁹. One story highlighted the experience of a mother of two children with disabilities and the devastating effect on her third child. After the children's disabilities were diagnosed the mother lost her career and her marriage. She describes how the youngest of her children was teased unmercifully at school because his brother and sister had a disability. He also felt neglected and came to her at 11 years of age asking "If I had a disability would you love me too?" His inability to cope led him into drug and alcohol abuse, criminal activity and eventually an acquired mental illness.

⁷ 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

⁸ 'Young People and Mental Health' at <http://www.mhca.org.au/AboutMentalHealth/factsheets/AdolescentYouthMentalProblems.html>

⁹ <http://www.abc.net.au/4corners/content/2005/s1330245.htm>

Further research from the US¹⁰ 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."

The sibling role, unlike many other caring roles, is a lifetime one and the complex needs of siblings will change over that time. There may be certain transition times during which siblings are particularly vulnerable.

4. About Siblings Australia

Siblings Australia is the only organisation in Australia that is dedicated to addressing the needs of brothers and sisters of people with special needs [chronic illness, disability and/or mental health issues]. Over a period of nine years the organisation has made huge progress in creating awareness and providing support within the different settings in which a sibling operates, for example, families, schools, peer groups, community. It has built strong relationships with a number of key mental health, youth and client support organisations. With a strong emphasis on promotion, prevention and early intervention, SA has worked to build resilience and coping skills of children, young people and families, and raise community awareness about sibling issues.

This work 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. There is tremendous support for the conference to be repeated, especially with a focus on sibling support programs being run currently in Australia.

Research and anecdotal evidence supports the view that illness and disability affects the lives of *all* family members. Our 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, we aim to increase the availability of information and support services for siblings of people with special needs, through increasing awareness, understanding, skills and capabilities 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 materials, workshops and a website. The organisation also plays an important role in areas of research and advocacy to inform social policy makers about the needs of siblings. The Executive Director's book, *Siblings: Brothers and Sisters of Children with Special Needs*,¹¹ provided a 'voice' for siblings and generated very powerful responses from siblings and parents from around Australia and overseas (It has also been published in the US and UK). For many it has been the catalyst for a release of hidden feelings.

The Director is regularly asked to present workshops around the country for both parents and for service providers, in which sibling issues are addressed. Parents, in particular, are crying out for support, and thousands of parents have attended these workshops. Parents leave these workshops feeling empowered to more ably support all their children. They also stress the need for sibling support programs.

For some time Siblings Australia has taken the lead in workforce development on sibling issues and support. Since 2002 our Director has presented workshops for providers, from within the disability, health and education sectors, all around Australia (and overseas). We have also provided undergraduate training in the areas of nursing,

¹⁰ 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.

¹¹ Strohm, K.E. (2002). *Siblings: Brothers and Sisters of Children with Special Needs*. Wakefield Press: Adelaide

education, disability studies, and psychology. The goals of such training have been to raise awareness, add to knowledge and skill development in communicating with children and families, and provide opportunities for networking and collaborative practice. Outcomes include a greater capacity for individuals and agencies to support and strengthen families. These providers gain enormous insight into the needs of families and go away with clearer directions for family support. They also stress the need for sibling support programs. Many are already running programs and report on the value of this type of support, not only for siblings but also for the whole family.

There has also been ongoing involvement in contributing to the understanding of sibling issues in schools. In 2007 the organisation contributed to aspects of both Mind Matters and Kids Matter (national mental health initiatives for secondary and primary school students) but much more needs to be done.

Siblings Australia has produced a manual for people wanting to run the sibling support program, SibworkS, for children aged 8-12 years. The uptake has been strong and feedback has been extremely positive in terms of outcomes for siblings, but there is a need for more extensive evaluation.

Siblings Australia manages several sibling internet forums on its website: SibChat4Kids; TeenSibChat; Sibchat; and, one for service providers, SibServices. The stories on SibChat [adult siblings] in particular have been both powerful and moving as many discuss not only their love and caring for a brother or sister but also the recognition that some of their adult struggles are related to their childhood experiences. These discussion groups hold huge potential for supporting siblings. 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, but also the opportunities. Other siblings have reported that the peer support has enabled their relationship with their brother or sister to become stronger. With the upgrade of our website in 2007 the format for the forums changed and there needs to be much work done on developing and promoting these forums.

Siblings Australia deals with a high volume of enquiries on sibling issues, both through direct contact by parents and providers with the organisation and through our website (2000 visits/48000 'hits' per month). This highlights how the awareness of sibling issues is growing and the importance of providing more services and resources that can be accessed by both parents and providers around Australia. Through our workshops and a recent survey (over 80% of responding organisations) there has been strong endorsement for a directory of services so that parents and providers can access information about their local programs. The Siblings Australia website has a preliminary list of programs but this needs further work to make it more comprehensive.

Currently, Siblings Australia is undertaking a short term project in South Australia (with funding through the Julia Farr MS McLeod Foundation) that will research issues related to adult siblings and develop resources and services.

In 2007 the Director of Siblings Australia brought together a group of researchers to apply for seed funding through ARACY (the Australian Research Alliance for Children and Youth) for a new collaboration of researchers and providers who are interested in sibling issues. The group was successful in attracting an 'encouragement grant' which enabled researchers, providers and family members to come together at a forum to discuss an agenda for sibling research and to explore evaluation processes of current sibling programs. The aim of the ARACY funding is to enable researchers with common interests to work together to apply for larger research funding through various avenues, for example, Australian Research Council Linkage grants. Much was achieved but there needs to be more support to take the work further. The task is quite difficult in that the issues are quite complex and there needs to be greater involvement of policy makers in the process.

5. Benefits of Support

Support for siblings allows them to feel less isolated and helps them build resilience. As a result, they will be more likely to develop to their full potential, and also to contribute to the quality of life of their brother or sister with special needs. Sibling support also enables the whole family 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 full range of contradictory feelings, including love, grief, anger and guilt
- receive support to express and deal with these feelings in constructive ways
- learn ways to cope with the different experiences they face – both within and outside their family
- make a positive adjustment to their family situation, which will mean they are more likely to be mentally healthy and more able to contribute to the quality of life of their sibling with a disability
- have less need for social services in the longer term

6. Summary

This submission has highlighted the role and contribution and needs of siblings of people with special needs. There have been a number of barriers to participation explored. It is very difficult for siblings to get support in dealing with these barriers, mainly because there is a lack of recognition of their important role and the impact on their lives of growing up with someone 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 has done an enormous amount of lobbying and grant-seeking but it is very difficult to get siblings on the agenda.

Through networking and contact with thousands of parents and providers around Australia and overseas, Siblings Australia is at the forefront of understanding issues for families. It is imperative that the organisation is supported in this work or there is a real risk that the expertise will be lost. The organisation has highlighted the importance of intervening early and providing support to children who are 'at risk' of developing emotional problems. Providing such support needs to include approaches within all the settings in which a child operates, for example, family (immediate and extended), friends, peers, school and community. It is imperative that any promotion, prevention and early intervention plans, both at State and Commonwealth level, consider the needs of these children.

I urge the Community Affairs Committee to: acknowledge the needs of this group of young people and adults; to ensure this group is on the agenda; and to identify which government department should take ultimate responsibility to ensure their needs are addressed. 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. Siblings of children with special needs are too important to ignore. They are likely to have the longest relationship with the person with special needs. If they can gain support they are more likely to contribute to the lifelong wellbeing of the child with special needs. In fact, sibling support benefits everyone – siblings, families, organisations that support them, governments, taxpayers, and the general community.

7. Recommendations

The following recommendations take a general perspective in relation to sibling support, with some key priority areas for action. The recommendations are listed under 5 particular focus areas: policy, family support, sibling support, research, and workforce development. Developing policy is the first priority. In the UK, the Children Act 1989 is the framework for the support offered to children with special needs. It emphasises that the child is part of their family, and states that "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"¹². Once appropriate policy is developed, there is a need to develop (through collaboration) a strategic action plan for the provision of sibling support nationally. Siblings Australia is in an ideal position to be engaged to do this work (using the extensive network developed already). The action plan could include the following strategies. Siblings Australia recommends that:

POLICY

1. Siblings of children with special needs be recognised as an 'at risk' group and their needs acknowledged accordingly
2. Governments recognise the lifelong nature of the caring relationship between siblings when one has special needs, and the particular needs of siblings over a lifetime of care.
3. One government department is identified to take responsibility for the needs of this group of children
4. Siblings are included in government and organisation agendas
5. Strengthen/reorient services towards prevention approaches, using Ottawa Charter for Health Promotion

¹² The Children Act Guidance and Regulations, Vol.6 (1991) London: HMSO

6. Siblings Australia be engaged to develop, in collaboration with families and providers, a strategic action plan for the provision of sibling services nationally

FAMILY SUPPORT

1. Ensure more support is available at diagnosis for parents to work through together their mix of feelings and to enable parents to support each other.
2. Provide information to parents about sibling support programs
3. Provide information to parents about how they can support siblings through printed and online resources
4. Develop pathways for families to plan for the future, including teen and adult siblings in such discussions (could be developed in conjunction with the Family Mediation and Counselling Centres through FAHCSIA)

SIBLING SUPPORT

1. Ensure greater opportunities for inclusion and community participation by siblings
2. Carry out a scoping project to document sibling support programs available around Australia and have the information available on the Siblings Australia website
3. Ensure sibling support takes a lifespan approach and includes young, teen, adult siblings in future directions
4. Ensure sibling support takes a 'settings' approach, developing strategies for all settings in which a sibling operates eg family, school and the community
5. Include strategies for those siblings who are in rural or remote areas of Australia
6. Support the further development of sibling forums and ensure a safe on-line experience

RESEARCH

1. Promote more research to understand the concerns and needs of siblings
2. Identify and reduce risk factors, and identify and increase protective factors for these children
3. Ensure quantitative research into the effectiveness of the SibworkS program (some has been done) in order to determine the reliability and validity for the effectiveness of the program
4. Develop appropriate evaluation measures to ensure best practice sibling support – for individual, family or group interventions.
5. Develop a set of policies and principles to ensure different sibling support programs meet best practice
6. Develop knowledge and mechanisms regarding identification of appropriate levels of intervention for children at different levels of need eg children who are coping well but might need some support still, and those who are particularly vulnerable and need protection

WORKFORCE DEVELOPMENT

1. Carry out more rigorous evaluation of the professional development carried out by Siblings Australia
2. Develop models of effective collaboration between families and providers
3. Develop practice guidelines regarding the role of different providers eg disability/health workers, GP's, teachers
4. Develop training materials that could be more widely used by the relevant sectors – disability, health, education and community services. The Siblings Australia website provides an ideal opportunity to expand this training.