

## **Submission**

*Long-term Disability Care and Support Scheme (DCSS)*

### **Public inquiry**

The Australian Government has asked the Productivity Commission to undertake a public inquiry into a long-term disability care and support scheme.

### **Executive Summary**

Siblings Australia (see Appendix 1 for an overview of the organisation) applauds this attempt to move to a more 'rights-based' approach to disability support. For too long, people living with disability and their families have had to live with a government/charity model. For some, this model has provided the necessary supports well. For the vast majority, however, the system has left them struggling to access the most basic of supports and services. Disability can strike anyone anytime. It is crucial that this country develops a DCSS that is fair and equitable and that enables people with disabilities and their families to choose the supports necessary to maximise their quality of life.

This submission recognises that a person with disability is more than just their physical self; their social, emotional and mental health are equally important, and a DCSS needs to take into account all of these different elements if it is going to truly enable the person to be a fully participating member of their community. This will be a huge task and this inquiry, understandably, is focussed on how this major overhaul might be developed and implemented.

However, this submission argues that any DCSS must consider the support needs of the whole family. A person living with disability, in most cases, grows up in a family. It is this family that has an enormous impact on the physical wellbeing of the child but also on other aspects of their life, including their social, emotional and mental wellbeing. However, at the same time, the disability has an impact on other family members and a child with disability cannot be viewed in isolation. There is much rhetoric about family support but it is crucial that this public inquiry truly reflects a commitment to the whole family – not just parents but siblings too, and regardless of any 'carer' role they may or may not have.

Because this is a relatively overlooked area of interest, this submission will provide considerable background. In particular, it will give an overview of what we know now about families of a child with disability – that whilst some families manage extremely well and are strengthened by the experience, many others struggle to access the support they need and become quite distressed and isolated. They can develop a range of mental health problems, including depression, and families may become broken, unemployed and welfare dependent. But it does not need to be that way.

This submission will explore the current lack of policy in relation to siblings and cautions against siblings becoming lost under the 'carer' umbrella. It will explore possible pathways for family support and the benefits of such support, for whole families and for the community, through long term economic benefits. Finally, it will make recommendations for the future, including the establishment of 'one stop shops', where families can access information and referrals in one place, and have their own Case Manager to help them co-ordinate services, both those available through DCSS funding and others in the community.

Families need to be supported as part of 'family support' policy, not in relation to any 'carer' role they may or may not have. In the longer term, more family focussed approaches make good social and economic sense, for the child with disability, the family and the whole community.

## **1. Background**

In most cases people with disability grow up and continue to live with their family. Siblings, in particular, are likely to be in the life of the person with disability longer than anyone. Research suggests that the sibling

relationship can contribute much to the quality of life for a brother or sister living with disability. Many people living with disability, in particular cognitive disability, rely on family or family friends to provide their social networks. Siblings have a unique position in the life of their brother or sister living with disability, as closeness in age may often result in relationships based on friendship thus extending the social network of the person with a disability. Adult siblings may choose to take on varied roles in supporting their brother or sister, thus becoming part of the informal support network for their brother or sister living with disability. This unique position enables adult siblings to potentially have an ongoing, meaningful and positive impact on the life of their brother or sister. As the lifecycle progresses and the sibling may go on to have their own family, other family members such as in-laws, nieces and nephews may also contribute much to the support and wellbeing of the person with disability. These connections may be particularly important to the person with a disability as they age and lose other connections from their youth. In many situations, the support can also be quite reciprocal in nature.

However, in Australia there is no evidence of real attempt to understand the sibling perspective. There is no data about the number of siblings of people with disabilities in Australia and the lifelong roles they play in supporting the person with a disability. There has been little research done on the nature of these sibling relationships and the impact they have on each individual. Siblings are excluded from policy directions.

## 2. Family experience

The following summary of issues has been developed, based on input from parents, siblings and providers and also through various publications.

### **What we know about families with a person with a disability**

In Australia there are over 200,000<sup>1</sup> young people under 25 years who are living with a severe or profound disability – many more over 25 years of age. The number of families which include someone with a disability is increasing. A family which includes disability is just like other families – they love, laugh and cry, they value their family relationships and they enjoy being part of a community. Often, the difficulties that families face are less to do with the disability itself, but more with community attitudes and the lack of support services.

### **What we know about parents of a child with disability**

- Some parents are enriched by their experiences, and cope very well, whilst many need more support
- Parents can experience a mix of feelings when they receive a diagnosis of disability in a child – including protectiveness, care and concern, shock, grief and loss, anger, confusion and fear. The experience of parents has been likened to Post Traumatic Stress Disorder<sup>2</sup>. It can be very difficult to express the feelings that arise and parents receive very little support to deal with their grief and other emotions. Through Siblings Australia's contact with hundreds of parents, it is clear that, for many, the 'grief' of lost dreams and lost opportunities never leaves. They just learn to live with it and manage it as best they can. In time many parents are able to move forward with strength but this depends on the amount and nature of support they access – both from formal services and informal support networks.
- Couples with a child with disability experience a greater rate of marriage breakdown – anecdotal estimates have suggested it is up to 80%. The feelings and how they are expressed can be quite different for the father and mother and it can be difficult for them to support each other.
- Parents of a child with a disability have higher rates of depression. *The Wellbeing of Australians: Carer Health and Wellbeing*<sup>3</sup> (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.

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<sup>1</sup> Australian Institute of Health and Welfare (from estimates made from the Australian Bureau of Statistics, 1998 *Survey Of Disability, Ageing and Carers* confidentialised unit record file)

<sup>2</sup> Bruce, E.J. *Elite Parenting: Mother, father, siblings and children adapting to disability*. Sourced from <http://www.emotionalhealthcentre.com.au/elite.htm>

<sup>3</sup> Cummins, R.A., Hughes, J., et al. (2008) *The Wellbeing of Australians: Carer Health and Wellbeing*

- National coordinated programs for parents to have contact with other parents of a child with a disability are becoming more prevalent eg the national *MyTime* program etc. Most of these are focused on younger children; there is not much for parents of older children.
- Many parents express concerns about their other children – the ones without disability

### What we know about siblings

- Each sibling experience is unique – and it changes over a lifetime.
- Siblings may be enriched by their experiences, cope well (just like some parents), and many talk about having acquired greater compassion, understanding of differences, and maturity.
- However, the survey *The Wellbeing of Australians: Carer Health and Wellbeing* (Cummins 2008) referred to above, also showed that the presence of a person in a household who requires care severely compromises the wellbeing of other family members, whether they have primary carer responsibilities or not.
- Many siblings face a number of challenges and need more support (just like many parents). Unlike parents they experience many of their challenges as children when they lack the maturity to understand and interpret what is happening around them. They may:
  - lack information about the disability – the cause and the impact on their brother or sister
  - feel overlooked; that their needs don't matter
  - have a mix of difficult feelings but also feel guilty about those feelings
  - experience physical aggression or abuse from the child with disability
  - feel isolated and not have anyone to talk to about their concerns, not be able to take part in community activities or have friends over to play
  - feel expected to take on greater responsibility for a brother or sister with disability or for other siblings<sup>4</sup>
  - experience the stigma of disability and be teased themselves or see their brother or sister teased<sup>5</sup>
  - have concerns about the future as they and their brother or sister become older and what role they will play when parents are no longer able to provide care or support<sup>6</sup>
  - one sibling's comment encapsulates the experience of many: *I felt completely isolated. I thought I couldn't share any of that part of my life with my friends. They didn't understand and I felt alienated from them. Other kids never had the same responsibility*<sup>7</sup>
- Siblings, like parents, also have higher rates of depression. 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 experiencing depression, especially when a parent has also experienced it.<sup>8</sup> They are at risk of developing other mental and physical health problems<sup>9</sup>.
- Very few siblings meet another sibling during their lifetime.
- Very few siblings access support services – there is no national coordinated response to siblings.
- If their parents' relationship breaks down, siblings of a child with disability may grow up in a single parent household, with that parent often depressed, and feeling the loss of their other parent. There are also likely to be financial issues as the family income can be adversely affected due to added costs and reduced income.

### What we know about adult siblings

Much of the work of Siblings Australia has focussed on younger siblings. However, in 2009 the organisation completed an Adult Sibling Project which explored adult sibling experiences, roles and support needs. The report can be found at [http://www.siblingsaustralia.org.au/ps\\_cprojects.asp](http://www.siblingsaustralia.org.au/ps_cprojects.asp). The project highlighted the difficulties faced by siblings as they grow up and move into adulthood. Very few of the siblings involved had accessed any support, either as children or adults. Many of them expressed the wish that they had been able

<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> Burke, Peter. (2004) *Brothers and Sisters of Disabled Children*, Jessica Kingsley, London

<sup>6</sup> Strohm, K.E. (2002) *Siblings: Brothers and Sisters of Children with Special Needs*. Wakefield Press, Adelaide.

<sup>7</sup> Strohm, K.E. (2002) *Siblings: Brothers and Sisters of Children with Special Needs*. Wakefield Press, Adelaide. P.19.

<sup>8</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>9</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.

to meet other siblings during childhood. Many of the respondents talked of issues with depression, which confirms other work Siblings Australia has done in the past and emerging research here and overseas<sup>10</sup>. One of the big concerns in adulthood was the issue of future planning for the needs of their brother or sister when parents were no longer able to provide care, again reinforcing some of the work being done here and overseas with adult siblings<sup>11</sup>.

Recently, Siblings Australia provided a submission to the Inquiry into Planning Options and Services for People Ageing with a Disability: see

[http://www.aph.gov.au/senate/committee/clac\\_ctte/planning\\_options\\_people\\_ageing\\_with\\_disability/submissions/sub12.pdf](http://www.aph.gov.au/senate/committee/clac_ctte/planning_options_people_ageing_with_disability/submissions/sub12.pdf). This submission focuses on people ageing with disability and the importance of

recognising and consulting siblings when planning for the future needs of people with disability. Historically, any discussion about ageing carers has overlooked siblings. Many people are of the view that governments expect siblings to take over the caring role. Many siblings may want to take on that role but many don't; others feel they have no choices. Some siblings give up their own lives to care for a brother or sister. Most siblings want to be involved in the lives of their brother or sister living with disability, and to share in many of the activities that other siblings share, as well as to provide support as needed to a brother or sister. The complex issue of siblings' roles and their needs should be further researched.

The 'Australians Mad as Hell' submission to this inquiry (number 153) includes a contribution from a young adult sibling. She says she is one of the many thousands of Gen Ys who have a brother or sister with disability. They don't have a disability themselves but have it 'by association'. She adds:

*They live with the tantrums, the staring, the knowledge that their brother or sister is not quite like the others. They face the ultimate depression and acceptance of having a sibling with a disability. Most importantly, they see their parents, their tired parents who have had to give up careers, dreams and in some cases marriages in order to care for their disabled sibling so that in some instances, their other child does not have to. They have seen their parents fight for basic services, such as wheelchairs, inclusion at the local school, a mobile bed, a van to fit a wheelchair or respite, so that the family can have a break from caring for a little while.*

*Caring about, and caring for are two different things which are worlds apart. I will never stop caring about my brother, my role as his sister and his advocate and friend will continue for the rest of my life. But I do not see that I should have to care for him. I don't want to be faced with that burden of care. And I am as mad as hell that at 21 years of age, a budding professional should be faced with that road ahead but unless things in this country change, I and the hundreds like me will be faced with that choice of caring for our brothers and sisters.*

### 3. Current concerns in policy

#### SIBLINGS UNRECOGNISED

One of the difficulties when considering sibling support is that siblings are not recognised anywhere in current government policy so it is difficult to create a mandate for action. This contrasts with the UK, for example, where siblings are very specifically referred to within policy related to children with disability. The Children Act 1989 is the framework for the support offered to children "in need", including those with disabilities. **It emphasises that the child is part of their family.** The guidance under the Children Act, which refers to children with disabilities, 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"<sup>12</sup>. Siblings are provided for at the policy level which means that there is an expectation that they will be considered by agencies. In addition, the UK report, *Aiming High for Disabled Children: Better Support for Families*, often refers to the needs of siblings and stresses the importance of "focused, effective support early in life and at key transition points... which promotes emotional and social development for disabled children and their siblings, to help to improve outcomes for all"<sup>13</sup>.

<sup>10</sup> Degeneffe, C.E. and Lynch, R.T.(2006) "Correlates of depression in Adult Siblings of persons with traumatic brain injury", *Rehabilitation Counselling Bulletin*, 49:3, 130-142

<sup>11</sup> Heller, T., Kaiser, A., Meyer, D., Fish, T., Kramer, J., Dufresne, D. (2008) "The Sibling Leadership Network: Recommendations for Research, Advocacy, and Supports Relating to Siblings of People with Developmental Disabilities".

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

<sup>13</sup> HM Treasury and the Department for Education and Skills, May 2007. *Aiming High for Disabled Children: Better Support for Families*. <http://www.everychildmatters.gov.uk/search/IG00222/>

Siblings Australia has lobbied hard for siblings to be recognised in government policy and strategic directions. However, in spite of many submissions to major consultations, the reports from these inquiries have continued to largely overlook siblings. For example, the National Disability Strategy report, *SHUT OUT: The Experience of People with Disabilities and their Families in Australia*<sup>14</sup> does not mention siblings. There is much rhetoric about the experience and needs of ‘families’ but in reality this is not matched by action.

Another complicating factor is that services for disability are split between the State and Federal governments in Australia. Most services for families who have a member with a disability are run by the State departments, and therefore there are eight somewhat different systems across the country. Throughout, there is strong recognition of and commitment to the needs of ‘carers’ – any family member who has an unpaid responsibility for a relative with a disability. Yet, in practice, such a commitment often does not differentiate between the needs of different types of family members. As parents are usually the ‘primary carers’, they often become the focus. Siblings are beginning to be mentioned within individual discussion papers, research and some specific service descriptions and policies. However, due to the different service systems in each State, these commitments cannot be systematic or consistent.

The new COAG disability agreement between the States and the Federal government [http://www.coag.gov.au/intergov\\_agreements/federal\\_financial\\_relations/index.cfm](http://www.coag.gov.au/intergov_agreements/federal_financial_relations/index.cfm) (Schedule F) includes in its desired outcomes that “families and carers are well supported” and one of the agreed policy directions to achieve this is to “support the role of families and carers including strengthening their informal support networks”. NSW has made some attempt to address these outcome goals, through the DADHC Support Networks Program, but the reality, in most states, does not involve siblings.

#### SIBLINGS LABELLED AS YOUNG CARERS

It is cause for some concern that siblings are starting to be mentioned as a sub-set within the ‘young carer’ label. Originally the term ‘young carer’ was coined to describe children who were providing primary care to a parent with illness or disability. Many people have concerns about the term ‘young carer’ because it legitimises the roles played by these children. Governments are inclined to pat these young people on the head and provide some support programs. Whilst some caring responsibilities can be beneficial to children, sometimes this can go too far. If the wellbeing of a child is compromised, they should not be playing these roles; instead governments should be providing more relevant and extensive services.

Slowly the meaning is being broadened to include other young people who might play a caring role, such as siblings. However, in the case of siblings, there is usually a parent present who takes on the role of primary care. Siblings may provide considerable support to the primary ‘carer’, especially a single parent, but, regardless of any caring role they may play, siblings are still impacted considerably. Even if they provide no care as such, they can still be at risk, but are generally overlooked by such ‘young carer’ programs.

In addition, siblings do not want to be known as ‘carers’ – they are brothers and sisters first. Nor, for a range of reasons, including dignity, do people with disability want their brothers and sisters to be known as their ‘carers’. What 15 year old boy wants his 13 year old sister to be known as his ‘carer’? Also, unlike children caring for parents, siblings are likely to be playing various caring roles for a brother or sister with disability over a lifetime – the label of ‘carer’ will stay with them for a very long time. Many families are concerned that the term ‘young carer’ and then ‘carer’, in relation to adult siblings, reinforces an expectation by governments that siblings will take over the main role of primary care when parents are no longer able to do so. The slow approach by governments to the development of suitable housing options for people with disability reinforces this belief.

#### 4. Possible pathways for support

The following section discusses the various activities that might be effective in supporting the whole family. Some could and should be an essential part of any DCSS. However, some will need to be financed as part of other government or community programs, and a DCSS should provide mechanisms which enable access to

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<sup>14</sup> The National People with Disabilities and Carer Council (2009) “Shut Out: The experience of people with disabilities and their families in Australia”

these. Some need to be made available immediately after a diagnosis; some will be needed at various stages over a lifetime.

In order to effectively and efficiently support people with disability, their families and carers, there needs to be a 'cradle to grave' approach. As well as regular disability services that support a person with disability to manage daily living activities, the whole family may need help to communicate with each other and share any difficulties they experience. They may need support to develop appropriate skills to manage any challenges, both within the family and also in relation to community attitudes. Families need strong connections with family and friends, with other parents and siblings, and with outside sources of support, eg school, community programs.

#### SUPPORT AT DIAGNOSIS

As soon as a diagnosis is made, the needs of the whole family should be considered. Families need to know what services are available in terms of practical support related to the needs of the child with disability (therapies, services). These are likely to be covered by other submissions to this inquiry from people with disability, parents or organisations. A Case Manager assigned to the family immediately could help with this often complex process.

Equally important, but often overlooked, is emotional support to process the experiences and feelings that might arise for all family members. These types of support might include counselling, peer to peer support programs, and assistance in developing social networks. The whole family needs to be assessed to consider individual needs. This needs to be a key part of the 'one stop shop'.

Unlike the current system, this emotional support needs to be automatic. Often, parents are not moved to access support for themselves or their other children as their main priority is gaining support for the child with disability. If parents could access such counselling, families would be much stronger and less at risk of breakdown. Parents could be assisted to ensure that siblings are also supported within the family or through counselling or group programs. A medical centre in the US that carries out an early intervention, short term counselling program with siblings and parents reports that parents find less anger and acting out by the well sibling, improved communication in the family and there is much gratitude for the help they receive<sup>15</sup>. Such processes for whole family assessment could be repeated every twelve months, maybe in conjunction with any support plans for the child with disability.

#### ONGOING SUPPORT

Again, the whole family needs to be considered when following up with support. Siblings, in particular, will need information about the disability to understand the impact on their brother or sister, and on themselves. In some cases, they need help to learn ways to interact and play with the child with disability. Families may benefit from assistance in learning effective ways to communicate with each other and to manage stress.

Respite services can support the whole family to participate in community activities. This can include formal or informal approaches and also different activities. For example, some respite can help the whole family participate together in the community; some can help by giving the child with disability the opportunity to develop some independence and their own social networks (either with day or overnight services). At the same time, such services enable parents and siblings to take part in their own activities. Support should also be available to enable the whole family to take a holiday together if they wish, ie providing a support worker to provide targeted support to the child with disability on holiday.

Another major task for families is to plan for the future care and support of the person with disability when parents are no longer able to provide that care and support. A Case Manager would have referral points for families to assist in this sometimes complicated and difficult task. Certainly more research needs to be done to ensure the best way to support families with these processes.

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<sup>15</sup> "The Sibling Center: A pilot program for siblings of children and adolescents with a serious medical condition" by Joanna H. Fanos, Ph.D., Kathleen Fahrner, Ph.D., Mojgan Jelveh, Ph.D., Richard King, MA, and David Tejada, M.D. The Journal of Pediatrics, Volume 146, Number 6 (June 2005): Elsevier.

## COMMUNITY SUPPORT PROGRAMS

As mentioned, a DCSS funded Case Manager could refer family members to services within government and the community through relevant sectors eg disability, health and education.

For siblings, the support needs to be continued through the different settings in which a sibling interacts – their family, peers, school and the community. Such support may need to be intensified at different times, eg, the teen years, or when parents' caring role changes. Schools need to have greater awareness of how they can support siblings with regard to issues such as teasing of themselves or their brother or sister with disability, social difficulties, or in relation to difficulty completing homework etc.

All family members may need assistance to improve their social networks, and to find group support programs in the community. For example, the *MyTime* parent peer support program is a wonderful initiative to help parents find support from other parents. A national initiative similar to the *MyTime* program would be very beneficial for siblings. Again a case manager could take responsibility for assisting family members to access such programs.

### 5. Benefits of support

#### SIBLINGS

Support for siblings, from a young age, allows them to feel less isolated, helps them to develop effective coping strategies, 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. Children gain enormous strength from learning that they are not alone (*"At least I have somewhere I can talk where no-one laughs"*<sup>16</sup>), and from sharing experiences and strategies. Support at this young age may indeed flow into lifelong benefits, with siblings enjoying better mental health and remaining active in the life of the person with disability. Certainly anecdotal evidence from parents of children who have attended sibling programs shows that these children interact more positively with a brother or sister with disability after contact with other siblings through the group.

#### WHOLE FAMILY

With relevant and timely support, families will be able to develop stronger and more supportive family relationships, and will be less likely to experience social isolation. All members of the family are more likely to reach their potential, including the child with disability, parents and siblings. All members of the family are more likely to take part in study or employment, earn income, pay tax etc.

#### ECONOMIC BENEFITS

Families will be more engaged in the community and more able to contribute to the community through employment, taxes etc. There will be less need for family members to access social services and medical treatment for physical and mental health problems, leading to cost savings not only for family members but also the whole community. For example, it has been estimated that the cost of each case of depression is approximately \$10000 per annum<sup>17</sup>. If we can intervene early and reduce the incidence of such cases, the savings at a population level can be huge.

### 6. Recommendations for the DCSS

This submission makes a number of recommendations about what should be considered when developing a DCSS. These may not seem like priority issues when the basic services for people with disability are in such disarray. However, for the longer term quality of life for people living with disability and their families, as well as for the moral integrity of our country, it is essential that these issues are embedded into any planning around a DCSS. Overarching these recommendations is the necessity to develop a more inclusive family policy framework, irrespective of any caring role family members may or may not have.

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<sup>16</sup> Quote from participant in SibworkS peer support group

<sup>17</sup> Sobocki P, Jonsson B, Angst J, et al. Cost of depression in Europe. *J Ment Health Policy Econ* 2006; 9 (2): 87-98

## CORE ELEMENTS OF DCSS

A DCSS and any funding that may arise through such a scheme should extend beyond current elements to provide:

- 1) support, not only for the physical wellbeing of a person with disability but also their social and emotional health; and this support be provided through individualised, self directed funding
- 2) support for the whole family, including siblings, across the lifespan and regardless of formal caring roles
- 3) 'one stop shops' for people with disabilities and their families to access information and referral to appropriate services
- 4) a scheme for the accreditation of professionally-qualified case managers who would have the responsibility to coordinate the provision of services (both those funded through the DCSS as well as other programs) to both the person with disability and their immediate family

## RELATED ACTIVITIES FOR CONSIDERATION

A range of other community approaches need to be considered and linked to DCSS processes to ensure effective, efficient whole family support across a lifetime, including the development of:

- 5) a national process of collaboration between family support programs, both government and community based, eg the Family Support Program (FAHCSIA), carer programs, family mental health programs (DOHA), parent programs, eg, the *MyTime* peer support program, various education initiatives and sibling support programs
- 6) a range of consistent resources that are relevant to families when seeking support for all family members
- 7) a comprehensive workforce development program to increase awareness of the importance of meeting the needs of ALL family members
- 8) further research into the most effective models of intervention in order to strengthen families which include a member living with disability
- 9) a National Action Plan (link to proposed Plan can be found at the end of Appendix 1) for siblings of people with disability, to ensure their unique needs are addressed effectively and efficiently

## Appendix 1

### Siblings Australia ([www.siblingsaustralia.org.au](http://www.siblingsaustralia.org.au))

For over 12 years Siblings Australia has been supporting siblings through direct services (online forums, sibling peer support groups); through supporting parents to be more able to support their children who are siblings (printed and online resources, parent workshops); and through providing training and online and print resources to service providers (disability, health, education etc) on how to take a whole family approach. It has developed a model of sibling peer support, Sibworks<sup>18</sup>, which has had very encouraging outcomes. Many parents say that their child has interacted more positively with the child with a disability after attending such a group. However, more evaluation needs to be conducted to ensure best practice in this area. The organisation has also worked to create networking opportunities for families and providers and maintains links with similar programs overseas. The following article published in the Australian e-Journal for the Advancement of Mental Health explores some of the work of Siblings Australia, especially in relation to mental health promotion and prevention.

<http://pandora.nla.gov.au/pan/107363/20091002-1309/auseinet.com/journal/vol7iss2/strohmeditorial.pdf>

However funding for the organisation has been sporadic and it has been difficult to develop the resources and services needed. Many organisations around Australia provide one-off sibling support programs but there is no co-ordination, no shared policies and procedures, very little collaboration. Siblings Australia has the programs but no resources to implement them in any meaningful way. The organisation conducted a Scoping Project in 2009 which highlighted the need for more collaboration and training. The report from this project can be found at [http://www.siblingsaustralia.org.au/ps\\_cprojects.asp](http://www.siblingsaustralia.org.au/ps_cprojects.asp).

The proposal for a National Action Plan for Siblings, developed in conjunction with Families Australia in 2010, can be found at <http://www.familiesaustralia.org.au/publications/pubs/siblingselection2010.pdf>

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<sup>18</sup> Nesa, M., Strohm, K.E. (2005) *Sibworks: Facilitator Manual, Groups for Siblings of Children with Special Needs*. Siblings Australia Inc., Adelaide