The Royal Australian & New Zealand College of Psychiatrists

Addressing the needs of siblings of children with disability or chronic illness

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working with the community

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Executive Summary

There is much emphasis in the 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. It is also recognised that there are economic benefits in intervening early so as to ensure young people who may be at risk are able to access relevant support services.

Understandably, significant resources are spent on addressing the needs of children and adults with chronic conditions, 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 fact, there is reasonable consensus that siblings of children with chronic conditions are at risk for behavioural, mental and physical health problems. The Royal Australian and New Zealand College of Psychiatrists' previous report, *Prevention and early intervention of mental illness in infants, children and adolescents: Planning strategies for Australia and New Zealand* highlighted siblings as a high risk group who should be considered for targeted prevention and early intervention programs, along with their brothers and sisters with chronic conditions. In spite of this, the needs of siblings have been largely overlooked at both policy and service level.

This report is an attempt to synthesise the current state of sibling support measures for children (0-18 years) in Australia and New Zealand. It discusses possible modes of intervention, and makes recommendations for future directions both in services and in advocating for the needs of siblings for these services. 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. However, in spite of considerable lobbying over a number of years, there remains a lack of coordinated activities and national action to support this group of at risk children.

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1. About the RANZCP

The Royal Australian and New Zealand College of Psychiatrists (RANZCP) is the principal organisation representing the medical specialty of psychiatry in Australia and New Zealand and has responsibility for the training, examining and awarding the qualification of Fellowship to medical practitioners. There are approximately 3000 Fellows of the RANZCP who account for approximately eighty-five per cent of all practicing psychiatrists in Australia and over fifty per cent of psychiatrists in New Zealand.

Through its various structures, the RANZCP accredits training programs and administers the examination process for qualification as a consultant psychiatrist; supports continuing medical education activities at a regional level; holds an annual scientific congress and various sectional conferences throughout the year; publishes a range of journals, statements and other policy documents; and liaises with government, allied professionals and community groups in the interests of psychiatrists, patients and the general community.

This report has been developed by an expert reference group, convened by the Royal Australian and New Zealand College of Psychiatrists' Faculty of Child and Adolescent Psychiatry.

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2. Introduction

This Report, from the Royal Australian and New Zealand College of Psychiatrists Faculty of Child and Adolescent Psychiatry, is an attempt to synthesise the current state of sibling support measures for children (0-18 years) in Australia and New Zealand. The term, 'siblings', refers to the brothers and sisters of children with a chronic condition. The term 'chronic condition' refers to any developmental delay, disability or chronic illness, including mental illness.

This paper outlines the experience of siblings, explores what is happening now in terms of sibling support, discusses possible modes of intervention, and makes recommendations for future directions both in services and in advocating for the needs of siblings for these services. The siblings of children with disability may face a number of challenges which, if left unaddressed, can increase their risk of developing longer term mental health problems, at considerable cost to them, governments and the community. However, in spite of considerable lobbying over a number of years, there remains a lack of resources for coordinated activities and national action to support this group of at risk children. In order to address this, delegates were invited from a range of organisations to attend a roundtable discussion, convened by the Royal Australian and New Zealand College of Psychiatrists (RANZCP) Faculty of Child and Adolescent Psychiatry. The stated aim of this roundtable was: *"to consider strategies that allow better mental and physical health outcomes for children (0 - 18 years) who have siblings with chronic conditions".* A list of attendees can be found at appendix 3 of this report.

The roundtable allowed key stakeholders from the health and disability sectors, and public and private providers, to meet to consider how to create a high-level commitment to the well-being of siblings, as well as discuss the priority areas that require addressing to meet the needs of siblings. Roundtable attendees considered current support and initiatives available, and identified gaps and challenges, with a view to mapping a strategy to better meet the needs of these children. It was agreed by attendees that there is need for a national and bi-national (Australia and New Zealand) effort to improve outcomes for siblings, and that a coordinated voice was necessary to raise community and government awareness of the roles and needs of siblings.

In addition, the RANZCP's report, *Prevention and early intervention of mental illness in infants, children and adolescents: Planning strategies for Australia and New Zealand* (RANZCP, 2010), has highlighted siblings as a high risk group who should be considered for targeted prevention and early intervention programs, along with their brothers and sisters with chronic conditions.

Whilst this paper focuses on siblings, effective interventions to support them will likely have positive impacts on the relationship between siblings, the social and emotional wellbeing of the child with a chronic condition, as well as whole family functioning. Although the paper focuses on children aged 0-18 years; there is an emphasis on the early years, as a preventive approach has the potential to strengthen relationships over a lifetime. It is also acknowledged that the influence of chronic conditions on the family unit is not static and siblings will need to continually adapt to changes within the family system throughout the developmental stages of childhood and adolescence, therefore the need for prevention and early intervention is ongoing.

3. Background

There is much emphasis in the 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. It is also recognised that there are economic benefits in intervening early so as to ensure young people who may be at risk are able to access relevant support services.

There is currently a lack of data regarding the number of siblings of children with disability or chronic illness. Numbers have to be extrapolated from other data. For example, the 2003 census showed that there were over 200,000 young people under the age of 25 years with a severe or profound disability (ABS, 2009). Many more would have a chronic illness or mental illness. It is reasonable to assume that these children would, on average, have at least one sibling.

Understandably, significant resources are spent on addressing the needs of children and adults with chronic conditions, 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 fact, there is reasonable consensus that siblings of children with chronic conditions are at risk for behavioural, mental and physical health problems (Williams et al., 2003; Hartling et al., 2010; Hogan et al., 2003). In spite of this, the needs of siblings have been largely overlooked at both policy and service level.

4. The sibling experience

Many siblings will face challenges, but ultimately grow from the experience (for example, developing greater compassion and tolerance, more understanding of differences, maturity and useful life skills) or be seemingly largely unaffected. Others, however, will be affected detrimentally – overburdened and under-nurtured. Siblings may have increased internalising and externalising problem behaviour, feelings of loneliness, and peer problems (Meadan, Stoner & Angell, 2010; O'Brien, Duffy & Nichol, 2009; Williams, 1997).

Siblings may experience a number of direct stressors due to the needs or behaviour of the child with disability. But more significant might be internal family stressors (parent stress, socio-economic status, family functioning, and increased care-giving) (Dyke, Mulroy & Leonard, 2009), as well as external stressors such as peer or community attitudes. It is important to note that these possible stressors will change over a lifetime, but here we will focus on children.

Identifying the nature of the impact of these stressors on siblings is complex. Again, there are many variables. An individual's and family's coping skills and resilience, a sibling's age, birth order and personality, along with the external resources available, will all help to determine the impact.

4.1 Family stresses

A family with a child who has a chronic condition is exposed to a significant and long term stressor (Fisman, Wolf, Ellison & Freeman, 2000: Berge & Patterson, 2004). Conditions that involve behavioural problems or disturbed sleep patterns are more likely to contribute to family stress and social isolation (Ross & Cuskelly, 2006; Petalas, Hastings, Nash, Lloyd & Downey, 2009; Dyke et al., 2009). All relationships in the family are likely to be affected – parent to parent (e.g. marital stress), sibling to sibling (e.g. sibling rivalry/alliances) and parent to child (e.g. needs of child with disability prioritised over siblings). Thus sibling's adaptation and coping cannot be considered without reference to the wider family context in which they are embedded.

4.1.1 Parent issues

A recent Australian Institute of Family Studies (AIFS) report found that parents of children with disabilities have significantly decreased mental health and vitality and higher rates of depression than the general population (Edwards et al., 2008).

In time, many parents are able to cope very well and move forward with hope, joy and strength. However, in the early stages, in particular, they are likely to have a mix of difficult feelings – not only love and protectiveness, but also shock, grief, guilt and anger. There may be added stress if there was difficulty in gaining a diagnosis, and parents' sense of competence can be undermined. The grief associated with the loss of dreams and opportunities can continue indefinitely, and be magnified at various transition points during the child's life such as starting kindergarten, primary or high school for example. The research into rates of marriage breakdown when a child has a chronic condition is mixed but anecdotally it seems that the stresses can strain a couple's relationship, especially if the condition includes difficult behaviour.

Many parents express concern about the effects on siblings. However, some are too stretched both physically and emotionally to be able to meet the needs of their other children. Families may avoid discussing the difficult parts of their experience, in an effort to protect each other, which then may add to the distance between family members.

4.1.2 Sibling issues

Siblings are facing these stresses as children and so will lack maturity and understanding to interpret what is happening around them. If their parents' relationship breaks down, siblings may grow up in a single parent household and feeling the loss of their other parent. There may be ongoing financial concerns due to added medical and related costs and reduced income due to caring demands. The AIFS study mentioned above also found that siblings have a significantly increased risk of depression, regardless of any caring role they may or may not play in the family (Edwards et al., 2008).

Siblings may:

- lack information about the condition; the cause of, and the impact on, their brother or sister
- feel overlooked and that their needs don't matter
- resent daily disruptions to family functioning and social plans, or the apparent favouring by parents of their brother or sister
- experience a mix of feelings – love and protection toward their brother or sister, together with anger, embarrassment, grief and sorrow, guilt and fear, but feel reluctant to express them, leading to lowered self esteem
- feel expected to take on greater responsibility for a brother or sister with a chronic condition or for other siblings. Also they may feel a duty to 'take care of' their parents who they see are struggling, and try to be perfect so they do not add to parents' stress
- fear for the safety of their brother or sister, especially if the condition is life-threatening
- experience physical or emotional abuse by their brother or sister.

(Fisman et al., 2000; Barr & McLeod, 2010; Barak-Levy, Goldstein & Weinstock, 2010; Lamorey, 1999).

4.2 Outside the family

Families of children with disability can feel quite isolated. Siblings, in particular, may face a number of challenges when it comes to their relationships with peers, school and participation in the community. They may not be able to take part in activities in the community due to the difficulty of parents providing transport. Or they may find it difficult to have friends over to play. They may feel different to other children, experience the stigma of disability and be teased themselves or see their brother or sister teased, which can add to their sense of isolation.

As one sibling says, *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* (Strohm, 2002, P.19.).

Without the opportunity to express their concerns and without support, these stresses can build up and, as mentioned, result in longer term problems.

5. Current Sibling Services

This section will briefly explore some of the services that are currently available to families of children with disability. The discussion will not include details of direct services for the child with disability. Unfortunately, due to a lack of resources, little evaluation has been carried out on the benefit of services for siblings. This will be discussed later in the paper.

5.1 Siblings

There are growing numbers of services designed to provide information, networking opportunities, and supports for siblings. In 2009, a Scoping Project of sibling services around Australia (Paior & Strohm, 2009), found 90 organisations providing some kind of support, but most were sporadic and fairly limited due to funding restrictions.

There are books and resources that have been written for siblings, to help them understand the disability and also gain ideas on how to manage the situation or their feelings. Some resources are condition specific, e.g., related to siblings of people with cancer (CanTeen) or mental illness (SANE).

There are numbers of online services for siblings, including peer support forums, and increasing numbers of organisations around Australia and New Zealand provide support groups, workshops and/or camps for siblings. Sometimes they are condition specific.

However, only a very small percentage of siblings will access support programs, and it is likely that many of the children who do will come from families which are reasonably well connected to their community. Other siblings, who do not gain support through these avenues, may come to the attention of their school or enter the health system, and perhaps access mainstream child mental health services which often have little understanding of sibling issues. These situations usually involve a child who is already showing symptoms of distress. There are little, if any, opportunities for interventions such as counselling which might prevent such outcomes. Whilst sibling issues are considered in some circumstances, in general, more awareness is needed across all sectors.

5.2 Parents

Parents are the most important source of support for their children. However, as mentioned, some parents may be too stretched to provide direct support to siblings, even though they may worry about their 'other' children and the impact on them of growing up with a child with disability. Growing numbers of parent or disability focused organisations have branched out and now provide information to parents on how to support siblings. However, there is no quality assurance related to this information and whilst most is appropriate, some can be quite counter-productive.

Parents might access a range of services, in relation to the disability, which may have indirect benefits to siblings. These might include web-based information about the management of the disability or forums to connect and share with other parents. Nearly $20 million has gone into the national program, MyTime, which provides support at a local level for parents to socialise and share ideas with other parents. Face-to-face support groups are also provided by many organisations. Participation in these activities and use

of such resources can lessen feelings of isolation and provide important information about local services and supports.

There are respite services available that vary from being focused as a 'break' for parents to also providing other programs for parents e.g. workshops on stress management. Some organisations provide 'couples respite' weekends which aim to nurture the parent relationship. Some activities include the whole family in time away together. Some respite allows siblings to have time alone with parents, which can have benefits for both the child and parents. However, in general, respite services are inadequate and, even when there is respite available, many families do not access it (Edwards et al., 2008). There is a need to explore the barriers to families accessing respite.

6. Gaps in Sibling Support

In spite of the obvious need, siblings continue to be overlooked and services remain inadequate. At an immediate level, siblings are not good advocates for themselves; they arerarely 'a squeaky wheel', as they often feel guilty or disloyal if they discuss their concerns. Of course, parents are often so stretched emotionally and physically that it is difficult for them to always address the issues or advocate for more sibling support. However there are a number of systemic gaps that contribute significantly to the inadequacy of services for siblings, including:

6.1 Policy/Strategy

First, siblings are not recognised as an important at risk group. They are not mentioned in any government policies or strategic directions, either in Australia or New Zealand, unlike in the UK, where they are specifically referred to within policy related to children with disability (The Children Act Guidance and Regulations, 1991). This legislation 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". Siblings are provided for at the highest policy level which means that there is an expectation that they will be considered by agencies (Contact a Family, 2008). The most common type of support offered to sibling in the UK is a sibling peer support program. In addition, the UK report, *Aiming High for Disabled Children: Better Support for Families*, (HM Treasury and the Department for Education and Skills, 2007) 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".

Siblings are missing not only from State and Territory government policy but also from national strategic directions, which means it is easy for them to 'fall through the cracks'. In spite of submissions regarding sibling needs to major consultations, the reports from these inquiries have continued to largely overlook siblings. For example, the report, *SHUT OUT: The Experience of People with Disabilities and their Families in Australia* (The National People with Disabilities and Carer Council, 2009) does not mention siblings. There is much rhetoric about the experience and needs of 'families' but in reality this is not matched by action. Too often the term 'family' does not mean the 'whole family'; instead, in reality it only means parents.

Also, there are many national strategies focused on vulnerable children in which siblings do not rate a mention. For example, the national Early Childhood Development Strategy '*Investing in the Early Years*' focuses on reducing social inequities through strengthening universal maternal, child and family health services and support for vulnerable children. Similarly Australia's *National Framework for Protecting Australia's Children* recognises childhood disability as a risk factor for emotional and financial

disadvantage. Neither of these recognise that siblings are a group 'at risk' for a range of mental and physical health problems. One hopeful sign was the inclusion of sibling issues in the submission to the National Disability Strategy by the Commissioners for Children and Young People around Australia.

http://www.ccypcg.qld.gov.au/pdf/submissions/National-Disability-Strategy-submission.pdf

However, the National Disability Strategy, despite this submission and others, does not include siblings. This is hard to comprehend when siblings are likely to have the longest relationship of any with the person with disability.

The lack of policy/strategy in Australia and New Zealand means that no one government department takes responsibility for this group of children. Another complicating factor, which will not be discussed further here but needs to be included in future considerations, is that services for disability in Australia are split between the State and Federal governments. 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.

The new COAG disability agreement between the States and the Federal government 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 Department of Ageing, Disabilities and Home Care (DADHC) Support Networks Program, but the reality, in most states, does not involve siblings.

It is not only the lack of appropriate government policy regarding siblings that is of concern in Australia. Some policy directions related to disability and families in general may actually add to the stress or burden on siblings. Instead of a focus on families, regardless of individual caring roles, there is a growing focus on 'carers' and 'young carers', and siblings are starting to be included under the 'young carer' umbrella. If such models were to be adopted fully, then many family members who do not play a caring role will continue to be overlooked. Some siblings *are* performing significant caring roles, but many others do not play any extra caring role beyond the usual helping out that happens in all families. The AIFS study (Edwards, 2008) shows that siblings can be 'at risk', regardless of whether they play any caring role. Importantly, many of the concerns of siblings are not related in any way to a caring role. In fact, if siblings do provide care, then that may be one of the more beneficial aspects of their experience. Other significant stresses may have a far greater impact and siblings need support to manage these. A sibling may feel isolated, be teased or need to deal with a myriad of issues which are not related to a 'carer' role. If governments continue to use a 'young carer' model, and do not focus any resources to specific sibling support, then it is likely that many siblings will continue to be overlooked in the future.

Another cause for concern is the identity issues related to a 'carer' or 'young carer' model. Although for some, there is a sense of validation or recognition through the use of such terms, for many siblings, such a label can add to the sometimes unhealthy sense of responsibility they may already feel. It can add to their very narrow view of themselves as a helper or carer for others, subjugating their own needs in the process. This added burden of responsibility can be taken into adulthood. The submission by the Commissioners for Children and Young people, mentioned above, also shows concern about the use of the term 'young carer' for siblings.

6.2 Data

One of the big difficulties in designing and implementing both research and interventions is the lack of available data. Siblings are not routinely included in organisation databases or government data collection. Numbers and ages of siblings are usually only estimates. Better data would make it easier to access siblings to assess their concerns and needs, to define broader impact on the community, and to develop a framework for intervention.

6.3 Assessment tools

Identification and assessment of sibling needs, along with referral pathways, is critical in helping siblings obtain appropriate supports and services. A number of instruments have been developed to support assessment, when siblings do come into contact with services. However there is a lack of good quality and easy to use assessment tools.

Some have suggested that it might mean that multiple measures, including sibling self-report and parent reports, are necessary to really assess sibling needs (Senner & Fish, 2010). One of the difficulties with self-reports is that siblings may be loathe to admit any difficult feelings for fear of upsetting parents or being disloyal to the child with disability and parents, (Waldren & Strohm, 2010). Often, siblings need permission to express the good and not so good things about being a sibling, which can only be provided in a safe environment and with specialist approaches. Without appropriate and effective assessment tools, there is a danger of missing many children who might appear to be managing well but who, in reality, are struggling with a range of issues. As a result, there needs to be caution in developing assessment tools.

Also, there needs to be consideration given to universal versus targeted approaches. By targeting all siblings from a young age and enabling them to learn how to ask for help, recognise and manage a range of feelings, and connecting them with sources of support, there is more chance of strengthening a larger number of siblings, regardless of their situation.

6.4 Workforce skills

The Scoping Project, referred to above, highlighted the lack of understanding of sibling issues by relevant health, disability, education and community services. Workers stated that they needed more resources and skills training (Paior & Strohm, 2009). There have been some attempts to develop workforce training but, again, without resources, this has been limited. As mentioned, some local networks of workers have been formed to learn from each other, but there is much more work to be done in the area of workforce development. Whilst organisations may acknowledge the importance of sibling support they may not have the resources to train and provide staff to carry out interventions. The Scoping Project reinforced the lack of funding allocated to developing specific sibling support as being one of the major barriers for workers who would like to continue or establish new sibling programs. In addition, there is much rhetoric about family support, but often organisations do not have the capacity (funding or skills) to ensure this is whole family support.

Another issue is that workers who come into contact with families through the child with disability may have more of an understanding of sibling issues, but workers in more mainstream health, education or community services may have less understanding of sibling issues and needs.

6.5 Co-ordination/collaboration

Whilst organisations around Australia and New Zealand provide sibling support programs, there is no co-ordination in relation to such programs, no shared policies and procedures, and very little collaboration.

The Scoping Project found that the most common form of sibling support is a support group program for the 5-12 year old age group. These support programs are formed with the intention to reduce feelings of isolation experienced by siblings and to improve their level of support. There is a mix of models used throughout Australia with little interaction between workers.

The lack of co-ordination means it is difficult to monitor demand for services, distribution of resources, geographical access and evaluation. It is likely the wheel is being reinvented, repeatedly. Some local networks have been developed to share resources and experiences, but there is no national co-ordinating body that brings all of the information together in one place for easy access and consistency. A national reference group was established in 2007, but without resources to manage it, the group was disbanded. Also there is a growing amount of information available online and families and professionals go to a variety of places for information re siblings. Some of the information is appropriate but some is not.

6.6 Evaluation

There are many sibling support programs being run in Australia. The Scoping Project found that the program models used, level of research evidence, and evaluation measures, varies greatly. Over half the organisations had developed their own in-house program model; others were using SibworkS, a model developed by Siblings Australia (Nesa & Strohm, 2005), or an adaptation of such, and some used a US model. It was also identified that there is limited evaluation currently being completed within the sibling programs. Certainly, qualitative evidence suggests that group programs here and overseas are effective in reducing isolation, helping siblings to cope with their experiences, and to relate better to the child with disability. However, the lack of quantitative evaluation makes it difficult to argue a good case for the quality and effectiveness of these programs. Even if resources were available for evaluation this would be difficult as there is such a variety of interventions.

Conclusion

In conclusion, addressing the gaps listed would lead to siblings being more recognised and more able to access interventions. At the moment services are scarce and parents should not have to go through such difficult processes, especially when they lead nowhere. The following section explores some possible interventions, but it should be noted that there needs to be further resources put into research on what works best with families and siblings.

7. Models for possible intervention

If the above gaps were addressed and sibling support was seen as a priority, significant attention would need to be given to possible intervention models. Clearly, interventions need to be focussed inside the family or in outside settings, but the earlier the intervention can be put in place, the more likely there will be better outcomes.

Key issues in planning
It is important to ensure that interventions:

- consider other factors that also impact on the sibling such as the behaviour of the child with disability, parental stress, family functioning, accessing services, economic disadvantage and social networks
- include a ‘settings’ approach, i.e. they need to take place in all of the settings in which a sibling operates; at home, with extended family and friends, with peers, at school and in the community. Interventions also need to take a ‘systems’ approach, including the mainstream health care system, disability, education, and community services, with links between them

- build on family strengths and take a family focus
- target ALL families with a child with disability
- include clearly identified pathways of support and referral.

Below is a very preliminary exploration of particular issues to consider when interventions are being proposed.

7.1 Family

A intervention needs to be developed for all families at the time of diagnosis, based on assessment of their current strengths, level of knowledge, and the family's support network, as well as each individual's needs in relation to these. Also this support needs to continue over the lifespan.

Interventions need to include: counselling, support in communicating with each other, developing social support networks, accessing appropriate services and supports. All of these should aim to help families to feel competent in supporting themselves and each other but also in accessing services outside the family.

The family unit is "among the most powerful influences on child development and well being" (Giallo & Gavidia-Payne, 2006). Reducing stressors at the family level (either by developing skills such as communication or by building on the strengths of the family) will clearly impact on the adjustment of siblings. Bellin and Kovacs (2006) concluded that "fostering resilience in siblings is undoubtedly tied to bolstering the inherent strengths, resources and functioning of the surrounding family unit" (p. 213), and that "a family's capacity to mobilise extended family members, as well as formal community supports, to manage crisis periods and chronic stressors related to a child's health condition enhances positive psychological outcomes for siblings" (p. 214).

Bayat (2007) points out that service providers will often have a focus on the difficulties being experienced by families, and may miss the opportunity for growth that comes with utilising strengths. How a service communicates with a family will impact on them recognising their own capacities for resilience and growth. Many of these families are feeling quite vulnerable and so can be sensitive to questioning. Feelings and responses can be difficult to discuss, both within the family and with others. Services need to support families in communicating effectively. It is important to engage siblings in these processes. Siblings of children with a chronic condition often have unique experiences and insights that can assist understanding within family-centred interactions (Barr & McLeod, 2010).

Respite services need to be much more available and flexible, i.e. providing support for the whole family to do things together (including the child with a chronic condition) or providing periods for the child with the condition to spend time away from the family and be able to do meaningful things.

7.2 Parents

Parents, in particular, need interventions designed to:

- help them manage their own wellbeing
- increase their sense of competence
- promote family functioning
- help them support siblings.

Support to both parents as soon as possible after diagnosis (or during uncertain diagnosis), enables them to develop the tools to look after themselves, to support each other and their whole family.

Counselling at diagnosis should be an ’opt-out’ process not an ‘opt-in’ one as many parents will be focussed on therapies for the child with disability and overlook their own needs and those of other family members. With support and training, parents are more likely to manage the stressors more effectively and keep their family together.

Often it is the behaviour of the child with disability that can be the strongest stressor and so particular interventions on managing this are important too.

Following on from this, parents need more information and resources to enable them to support siblings at different ages. Special consideration should be given to infants in relation to parent time and parent well being which can affect infants’ health and development. Parents need information at the time of diagnosis and practical support in terms of having time available to be with an infant or, if they are unable to, have another caring adult to be with the infant. Infants are unable to make meaning of this kind of situation and can only respond to parents’ availability and caring.

7.3 Siblings

Interventions targeted at siblings can include general family focused strategies; ones that help families to communicate and connect with each other. In addition, they need to feel valued in their family and, whilst their contributions need to be acknowledged, it is important that responsibility does not become too onerous. Siblings can be helped to gain understanding about:

- what the disability means for their brother or sister
- how they might be able to play and interact with their brother or sister
- how to explain the disability to others
- the mix of feelings they may experience and how to express/manage them
- how to manage difficult situations.

There are increasing numbers of books that have been written which help siblings to understand the disability and to learn ways of coping. Such stories also help them to feel less alone.

As a child grows and moves into other settings (peers, school, community) it is important to assess how the sibling operates in all of these. Family interventions are still important but siblings can also start to access support through other avenues. Feeling connected is a major part of resilience. Siblings can be supported to connect with sources of support, including direct contact with other siblings or through hearing the stories of others in a similar situation via a range of media. Adult siblings regularly say they wish they had been able to connect with other siblings during childhood, either formally or informally, to share experiences and feel less isolated (Waldren & Strohm, 2010).

Primary school is timely for peer-group support, as it is at school that some of the issues related to peers begin to show up, and siblings can become very aware that their lives are different. Being with other children who experience similar things can help enormously in terms of self-worth and reduced isolation. A child at school can be assessed in terms of their understanding of the disability, their ability to carry out homework, social networks at school, whether they are bullied, and whether they have excessive responsibility for their brother or sister. Such assessment could be carried out on a yearly basis, in line with any individual education plans for their brother or sister with disability.

The teen years may bring further challenges but if the sibling has been supported from a young age to communicate their concerns and ask for help, they are likely to face these new challenges with greater strength and confidence.

Hartling et al (2010) argues that it is important to target those who would most likely benefit from support but this is very complex in the case of siblings. It can be difficult to judge who needs support as seemingly well adjusted children may internalise their difficulties and not show obvious signs of distress. Not all siblings will have difficulties, of course, but if they do, and if they do not express them, they may be at greater risk for longer term problems such as anxiety and depression. Certainly, siblings are not good self advocates. Internalising behaviours in siblings are often overlooked by parents and other adults around them. And externalising behaviours are often dismissed as 'attention seeking', with little or no follow-up. With siblings, selective prevention strategies that target all siblings will include decreasing risk factors and increasing protective factors, or both. Again, there need to be clearly identified pathways of support and referral.

8. Recommendations

In order for siblings to access the support they need to develop physical wellbeing and mental health the RANZCP recommends that the Federal government address the gaps identified earlier as follows:

1. Policy

- Review existing national policy related to siblings
- Identify avenues where siblings might be included in current policies/strategies
- Identify one existing government department to take a lead role and responsibility for siblings.

2. Data

- Support the development of effective data collection about siblings in conjunction with relevant organisations to estimate numbers and needs of this cohort.

3. Assessment tools

- Support the development of quality assessment tools to ensure that siblings access appropriate and relevant interventions. This could be achieved through identifying existing assessment tools on which to build and develop simpler tools.

4. Workforce development

- Support a workforce development program to ensure workers in relevant sectors (not only disability, but also mainstream health, early childhood education and community services) are aware of the needs of siblings and have the skills to identify risk and implement effective interventions. This could be achieved through education via formal professional development courses, but also through other avenues such as online support tools and general awareness raising of issues and services.

5. Co-ordination/collaboration

- Establish a national NGO resource centre, to provide a coordinated and collaborative voice for raising awareness of the particular roles and needs of siblings. The resource centre would be a central point, or clearinghouse, for collating information in relation to research and practice as well as a "go to" point for all interested parties. The Children of Parents with a Mental Illness (COPMI) is one model of a central clearinghouse of information based on extensive consultation and collaboration http://www.copmi.net.au/ .

  This initiative would:

- Take a leading role in the development of data collection processes, assessment tools and workforce development
- Facilitate effective collaboration and consultation with different sectors and organisations, to achieve flexible sibling support programs and to target existing health, disability and family support programs
- Develop a national strengths- based service delivery model, and provide resources for its evaluation
- Maintain a national overview of sibling support initiatives in order to address gaps and reduce the risk of duplication
- Co-ordinate the collaborative research required to underpin effective sibling programs
- Develop and implement quality assurance systems that ensure consistent delivery, evaluation and reporting of sibling support programs
- Link families to early intervention and support services, using a lifespan approach.
- Develop resources for health professionals to encourage a more family focussed approach when assessing the impact of a chronic condition.

6. Evaluation

- Support evaluation of identified interventions with families/siblings to ensure 'best practice'.
- Ensure that programs and interventions for siblings are rigorously evaluated on the benefit to the children and not just on parent or other reports.

9. Current advocacy directions

As part of current advocacy directions, the RANZCP has developed a position statement and, along with other signatories to that Statement, is committed to:

- Ensure that the needs of siblings are considered in future initiatives and policy documents
- Explore relevant areas where siblings support could be incorporated into existing programs
- Support the health care professional workforce to identify sibling issues in families with a child with a disability and to respond with appropriate interventions or referral to effective and available services or programs for siblings. Support an increase in much needed services and programs for siblings.
- Encourage research and data collection in respect of siblings
- Support the development of a national organisation to act as a clearing house for information and services

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Appendix 1

Previous advocacy

Since 1999, Siblings Australia has been actively involved in advocating for the needs of siblings at a national level. The main focus has been on the Department for Families, Housing, Community Services and Indigenous Affairs (FAHCSIA) and the Department of Health and Ageing (DOHA). The organisation has secured funding at different times from both departments but this funding has always been project based and short term. Services or resources or research is developed but cannot be maintained.

When funding was not continued after a 12 month grant from DOHA in 2007 (after a change of government), a petition was developed that included signatures and comments from 661 parents, siblings and providers from around Australia and overseas, over a very short period. The petition asked the Federal government to identify a government department that would be responsible for siblings, and to support the work of Siblings Australia. The petition was sent to all relevant Ministers, including the Prime Minister. See http://www.petitiononline.com/mod_perl/signed.cgi?SIBLINGS

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 the end of each event delegates reinforced the need for a co-ordinated approach to sibling support measures and endorsed conference resolutions that called on the Federal government to recognise the need for more resources in this area.

Conference resolution

We the delegates at the Siblings Australia 'Creating Connections' conference held in Adelaide 19-20 November 2009 affirm that siblings of people with a disability or serious physical or mental illness:

- *have the longest relationship with, and often play a vital role in the support of, their brothers and sisters who live with a disability, but can face serious challenges in fulfilling this support role across their lives*
- *face risks in relation to their long-term emotional, mental and physical well-being, irrespective of their caring role*
- *have difficulty, both individually and collectively, in speaking out about their own needs; and*
- *currently have inadequate recognition or support within government programs related to health, families and disability*

We therefore call on the Australian government to acknowledge the important needs and contribution of siblings of people with a disability or serious physical or mental illness by:

- *recognising that support for siblings is a good investment and reflecting this in relevant policy*
- *nominating a single Australian government department to take lead responsibility to encourage a whole of government approach for child and adult siblings*
- *ensuring fair access to funding for quality services for siblings across their life span*
- *providing secure resources for a national siblings body with responsibility for advocacy, advising government, disseminating information and facilitating collaboration, training, research and evaluation practices.*

In 2007, Siblings Australia was instrumental in a group of researchers from around Australia, gaining an ARACY New Network Encouragement Grant, 'Support for the siblings of children with disabilities or chronic illness: Needs, services and research approaches'. As part of that, a 2-day forum was organised to connect researchers, service providers, siblings and family members of children with a disability, chronic illness, or life threatening illness. Again key issues from that forum included:

- At a Federal and State Government level, the development of policies that focus on the needs and supports for siblings is critical.
- A national strategy to ensure a coordinated and consistent approach to the funding and provision of sibling support is critical to ensuring that all siblings and families have access to the information and support they require to promote their health and wellbeing.
- A scoping study or needs analysis of the service sector around the provision of sibling support in Australia is needed.
- A national strategy to strengthen the capacity of the service system to meet the needs of siblings and families is needed, including the exploration of various models/approaches and the development of communication strategies between stakeholders.

Further work with the network was not continued as resources were lacking.

In 2009, Siblings Australia conducted a Scoping Project of over 90 sibling support services around Australia. The Project highlighted the need to develop a national model of sibling support and to provide greater training and resources to people who are providing sibling support in order to develop best practice and consistency in approaches. It also reinforced the need for sibling support, with providers highlighting that siblings were indeed a group at risk.

In 2010, Siblings Australia worked with Families Australia to develop a Briefing Paper, a National Action Plan and election proposals leading up to the Federal election. See http://www.familiesaustralia.org.au/publications/pubs/siblingselection2010.pdf.

They stated “that empirical and anecdotal evidence confirms the national effort to support siblings is uncoordinated, under-funded, fragmented and sometimes duplicated. We know that siblings and their families will benefit from coordinated and holistic individual and social support” and listed establishing a national co-ordination service as their highest priority. They called for urgent joint action by both Federal and State/Territory governments to ensure that the concerns and needs of siblings are given attention. However, the Federal government has ignored these calls.

Siblings Australia has continued to talk to Ministers, Ministerial advisers, bureaucrats, and public servants, but has been told repeatedly that there is no funding available for sibling support. They state that siblings can access support through other services, but this is not the reality. Both FAHCSIA and DOHA refer to the carer based programs that they run, but most of them are irrelevant and inappropriate for siblings; others that might be suitable lead to dead-ends when enquiries are made.

Siblings Australia has lobbied hard for siblings to be recognised not only in government policy but also various national strategic directions. However, in spite of many submissions to major consultations, the reports from these inquiries have continued to largely overlook siblings.

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 twelve 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 strong relationships with key mental health, youth 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. (Strohm, 2008) 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.

The organisation has supported 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 (Nesa & Strohm, 2005), 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 online forums for siblings have had a huge impact on some siblings – teen and adult siblings in particular have found real value in connecting with other siblings. Participants have said things like "it's a lifesaver" or that it has given them the "power" to cope with some of their experiences. Some adult siblings have even renewed contact with a brother or sister after gaining strength from other siblings. Unfortunately, without proper resources, these forums have not been able to reach their full potential.

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 at the conclusion of a parent workshop, "I have been looking for something like this for over 10 years". Siblings Australia has developed a checklist that can be used by providers and parents to assess how a sibling is faring. It includes information about the child's understanding of the disability, their emotional reactions and signs of any distress, their social interactions etc.

The organisation is in close contact with providers around Australia and similar organisations overseas. The service provider training has included training in the SibworkS model developed by Siblings Australia in 2004. The facilitator manual and participant booklets have been distributed to nearly 200 providers. Training provided by Siblings Australia has included professionals from a number of sectors, including, health, disability, counselling and education. There is also information on the Siblings Australia website for GPs, teachers, and providers in general, on assessing the needs of siblings. Further research is urgently needed in this area. A directory of sibling support services around Australia is also available on the website but without resources this is difficult to maintain.

The organisation also plays an important role in areas of research and advocacy to inform social policy makers about the needs of siblings. Various reports are available on the organisation's website.

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 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.

Appendix 3

Roundtable attendees

Attendee	Organisation
Mr Nick Xenophon	Independent Senator for South Australia
Ms Elizabeth Sommerville	Australian Association of Social Workers
Ms Rhonda Wilson	Australian College of Mental Health Nurses
Dr Nick Kowalenko	Australian Infant Child Adolescent & Family Mental Health Association
Ms Elizabeth Fudge	Children of Parents with Mental Illness (COPMI)
Dr Brian Graetz	Beyondblue
Ms Pandora Patterson	CanTeen
Ms Jessica Beswick	Carers Australia
Ms Pam Linke	Early Childhood Australia
Ms Stella Conroy	Families Australia
Mr Steve Hackett	Family Relationships Services Australia
Mr Chris Tanti	Headspace
Ms Kathryn l'Anson	Kids Help Line
Ms Bice Awan	Mental Health Commissioner NZ
The Hon Rob Knowles OA	Mental Health Council of Australia
Ms Sue Farnan	Mental Illness Fellowship of Australia
Ms Janne McMahon OAM	Private Mental Health Consumer Carer Network
Dr Lena Sanci	Royal Australian College of General Practitioners
Dr Phillip Brock	Royal Australian & New Zealand College of Psychiatrists
Dr Jon Jureidini	Royal Australian & New Zealand College of Psychiatrists
Ms Teri Snowdon	Royal Australian & New Zealand College of Psychiatrists
Ms Felicity Kenn	Royal Australian & New Zealand College of Psychiatrists
Dr David Bettany	Starship Children's Hospital