

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

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Definition

The term, 'siblings', refers to the brothers and sisters of children with a chronic condition. The term 'disability' refers to any developmental delay, disability or chronic illness, including mental illness.

Background

This statement has been developed by the Royal Australian and New Zealand College of Psychiatrists' Faculty of Child and Adolescent Psychiatry and aims to synthesise the current state of sibling support measures in Australia and New Zealand. The statement outlines the experience of siblings, explores what is happening now in terms of sibling support, and makes recommendations for future directions both in services and in advocating for the needs of siblings for these services. This statement has been endorsed by a range of organisations with an interest in sibling health and welfare as listed at the end of this statement (this list will be continually updated).

A more detailed paper, which more fully addresses issues relating to sibling support is available at http://www.ranzcp.org/Files/ranzcp-attachments/Resources/siblings_report-pdf.aspx. This report discusses possible modes of intervention which, whilst outside the scope of this position statement, will be useful to those designing interventions to help support siblings.

Evidence

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 2009 census showed that there were over 200,000 young people under the age of 25 years with a severe or profound disability. 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 disability or chronic illness, both within families and in the community. However, research and anecdotal evidence supports the view that illness and disability affects the lives of all family members. In fact, there is reasonable consensus that siblings of children with chronic conditions are at risk for behavioural, mental and physical health problems [1-5].

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.

Priority areas for improvement and action

Despite their obvious need, siblings continue to be overlooked and support services remain inadequate. At an immediate level, siblings are not good advocates for themselves as they often feel guilty or disloyal if they discuss their concerns. Parents are often so stretched emotionally and physically that it is difficult for them to address issues or advocate for more sibling support. There are a number of systemic gaps that contribute significantly to the inadequacy of services for siblings, as outlined below.

Policy/Strategy

In Australia and New Zealand, siblings are not included in government policies or strategic directions. This means that no one government department takes responsibility for this group of children. Another complicating factor 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.

Data availability

One of the difficulties in designing and implementing both research and interventions for siblings support 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. Improved 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.

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. 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.

Workforce skills

There have been some attempts to develop workforce training but, without resources, this has been limited. Whilst organisations may acknowledge the importance of sibling support they may not have the resources to train and provide staff to carry out interventions. 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 their issues and needs.

Evaluation

There has been very limited evaluation of the different sibling support programs being conducted; the program models used, level of research evidence, and evaluation measures, varies greatly. Qualitative evidence suggests that group programs are effective in reducing isolation, helping siblings to cope with their experiences, and in strengthening sibling relationships. However the lack of quantitative evaluation makes it difficult to argue for the quality and effectiveness of these programs.

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. There is no national coordinating body that brings all of the information together in one place for easy access and consistency. A national clearing house would help address this issue.

Recommendations

In order for siblings to access the support they need to develop physical wellbeing and mental health the following recommendations are made to government to address the gaps identified:

- 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
- Support the development of effective data collection about siblings in conjunction with relevant organisations to estimate numbers and needs of this cohort.
- Support the development of quality assessment tools to ensure that at risk siblings access appropriate and relevant interventions. This could be achieved through identifying existing assessment tools on which to build and develop simpler tools.
- 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.
- Support evaluation of identified interventions with families/siblings to ensure 'best practice'.
- Establish a national NGO resource centre, to provide a coordinated and collaborative voice for raising awareness of the particular roles and needs of siblings for families, providers and researchers. 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.

To further the objectives of this position statement, the RANZCP, together with the signatories to this statement, are committed to:

- Ensure that the needs of siblings are considered in future initiatives and policy
- 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 establishment of a national NGO sibling resource centre

References

- Hartling, L., Milne, A., Tjosvold, L., Wrightson, D., Gallivan, J., & Newton, A. S. (2010). A systematic review of interventions to support siblings of children with chronic illness or disability. *Journal of Paediatrics and Child Health*, Jun 27. [Epub ahead of print] doi:10.1111/j.14401754.2010.01771.x
- Hogan, D. P., Park, J. M., & Goldscheider, F. K. (2003). The health consequences of a disabled sibling for school-age children. In B. Altman, S. Barnartt, G. Hendershot, & S. Larson (Eds.), *Research in Social Science and Disability Vol 3*, (pp 185-205). Emerald Social Sciences eBook Series Collection.
- Meadan, H., Stoner, J. B. & Angell, M. E. (2010). Review of literature related to the social, emotional, and behavioral adjustment of siblings of individuals with autism spectrum disorder. *Journal of Developmental and Physical Disabilities*, 22, 83–100.
- O'Brien, I., Duffy, A., & Nicholl, H. (2009). Impact of childhood chronic illness on siblings: A literature review. *British Journal of Nursing*, 18(22), 1358-1365.
- Williams, P. D., Williams, A. R., Graff, J. C., Hanson, S., Stanton, A., & Hafeman, C. (2003). A community based intervention for siblings and parents of children with chronic illness or disability: The ISEE study. *Journal of Pediatrics*, 143, 386–393.

Signatories

ACT Playgroups Association Inc.
Alfred CYMHS (Child and Youth Mental Health Services)
Aspect Vern Barnett School (Autism Spectrum Australia)
Association for Children with a Disability
Association of Genetic Support of Australasia
Attention Disorder Association of SA Inc.
Australasian Society of Genetic Counsellors (ASGC)
Australian College of Children and Young People's Nurses
Australian Infant Child Adolescent and Family Mental Health Association
Australian Medical Association
Autism & Aspergers Support Group Inc
Autism Northern Territory
Autism SA
Autism Spectrum Australia (Aspect)
bestchance Child Family Care
Black Dog Institute
Carers NZ
CanTeen The Australian Organisation for Young People Living with Cancer
CatholicCare Diocese of Wollongong
Centre for the Advancement of Adolescent Health
Christie Downs Community House
Commission for Children and Young People and Child Guardian
Cooperative Research Centre for Young People, Technology and Wellbeing
Daw House Hospice Foundation
Down Syndrome Association of Queensland Inc.
EDuCARE Support Service - Hunter New England Local Health District
Epilepsy Centre of SA & NT Inc
Families Australia
Family Relationship Services Australia
Haemophilia Foundation Australia
Headspace
Hunter Institute of Mental Health
Interaction Disability Service
Interchange Inc
Kids Helpline
Learning Difficulties Coalition of NSW Inc
Lifestart Co-operative Ltd

Melbourne Citymission
Mental Health Commission NZ
Mental Health Council of Australia
Mental Illness Fellowship of Australia
Mental Illness Fellowship of Victoria
Mildura Early Childhood Interventions Services, Mallee Family Care
Moira Interchange Southern
Muscular Dystrophy Association
Private Mental Health Consumer Carer Network (Australia)
Purple Orange (The Julia Farr Association)
Queensland Kids
Ronald McDonald Learning Program
Royal Australasian College of Physicians
Royal Australian and New Zealand College of Psychiatrists
SANE Australia
Sensory Connections Occupational Therapy Services
SeQual Assn Inc
Siblings Australia
SIDS and Kids Australia
SIDS and Kids Western Australia
SIDS and Kids Victoria
Skylight New Zealand
Starlight Children's Foundation
Suicide Prevention Australia
Sydney Children's Hospital Parent & Consumer Council
Te Ao Maramatanga New Zealand College of Mental Health Nurses
The Council for Care of Children
The Developing Foundation Inc.
Whitehorse Community Health Service
Xavier Children's Support Network
VCFS 22q11 Foundation
Victim Support ACT
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