

## **Introduction**

Thank you for the opportunity to comment on the SA service system improvement framework for ASD (SASSIF) consultation. I am providing these comments in my role as Executive Director of Siblings Australia, an organisation that has developed a national and international reputation for its work with families and providers. The comments are very brief in nature and do not explore fully the complexity of these issues. There are suggestions for further reading at the end of this document.

The discussion document highlights the importance of family in the life of a person with ASD. It certainly concurs with the 2007 Senate Inquiry into the Commonwealth, State and Territory Disability Agreement (CSTDA), which led to the National Disability Strategy. The CSTDA report highlighted the need for *a co-ordinated, high level, strategic policy to address the complex needs of people with disability, their families and carers in all aspects of their lives.*

For a long time there has been much rhetoric about ‘family support’ but, if this is explored more fully, the support available is often for the person with disability and the primary carer (usually the mother). There are very few specific programs for siblings. It is understandable that a lot of time and resources need to be directed toward the child or adult with ASD, but siblings are also very much in need of understanding and support.

Furthermore, siblings are likely to be in the life of the person with ASD longer than anyone. If we nurture that relationship from an early age, not only will the sibling be stronger and more able to cope with any challenges, but they are more likely to contribute to the social and emotional well-being of their brother or sister with ASD over a lifetime.

## **Why siblings need support**

The Australian institute for Family Studies report (Edwards et al, 2008), found that family carers had higher rates of depression and the lowest wellbeing of any other group in the community. It also stated that 1) carers worry about the impact on other family members; particularly the brothers and sisters of a child with a disability; and 2) apart from carers themselves having significantly higher rates of mental health problems, their partners and children also experience high levels of depression.

Certainly many siblings are enriched by their experiences. However, siblings may grow up with considerable stress and, without the maturity to manage the challenges, can be at risk of developing a range of mental, social, and physical health problems. They are often overlooked within their families and in the community as the attention is directed toward the person with ASD. One of the biggest issues highlighted by adult siblings is the sense of isolation that they experienced as young people.

The overwhelming message from families is that they need help to support all members of the family. Parents are crying out for information. Parents at workshops run through Siblings Australia have said things like, “I wish I had this information 10 years ago” or “I have been looking for something like this for so long”. As mentioned earlier, research with parents has highlighted their concern for the brothers and sisters of the child with disability. Siblings Australia receives many enquiries from around Australia from such parents. Just last week a mother described how she has a child of 14 with Aspergers Syndrome. She has grave concerns about her older daughter who is 16 and struggling at school due to the stresses involved. Her younger 7 year old son has said that he wants to kill himself as he doesn’t like being in his family.

Again through the work of Siblings Australia, we know that some siblings move away from their family in adulthood, perhaps due to the lack of support as a child; perhaps because they are worried about their future responsibilities. This is a tragedy for all concerned as they miss out on what might have been meaningful relationships, but also because there is much that could be done to prevent this happening. More research is needed in this area.

### **Benefits of support**

On the other hand, support for siblings enables them to connect with others and feel less isolated. They can learn ways of dealing with stressful experiences and in the process become stronger and more resilient. Parents have often told us that the sibling interacts more positively with the child with ASD after attending a sibling support program. In the longer term, if we nurture child sibling relationships, there is likely to be benefits for the sibling, child with ASD, the whole family and the community.

### **A sibling support model**

As a start, siblings need to be included in any service system improvement model that might be developed. Ideally this will include a 'family support' model rather than a 'carer model, involving the whole family from the very beginning after diagnosis, including counselling, information and referral. There need to be specific sibling support programs/services. With younger children this will be family focussed but as they age siblings should be connected to other siblings and other resources for support. For example, Siblings Australia runs a recreational program for siblings, which enables them to take part in a range of community activities like bowling or ice-skating, things that can be difficult for families with a child with ASD. With more resources, this could be expanded very easily.

Support for siblings needs to use a 'settings' approach ie support needs to be provided through their family, school and the community. In order for that to happen, parents need the tools and resources to support their children who are siblings – through education, counselling or written/online resources. In addition, workers in disability, health, education and community need training on how to support the whole family. Workers have expressed the need for further skill development and resources. Siblings Australia has had much experience in developing resources for parents and providers as well as in workforce development in this area. There is a need for a co-ordinated, collaborative response to sibling support, based on research and best practice guidelines.

I will make comment on key considerations and questions that are relevant to siblings within the discussion paper; they are below, highlighted in blue

#### Key considerations as outlined in discussion paper

It is critical that a South Australian service system improvement framework for people with ASD achieves the following:

– Aligns with the National Disability Strategy while recognising and understanding ASD as a distinct disability;

[The National Disability Strategy is a commitment to a 'unified, national approach to improving the lives of people with disability, their families and carers, and to providing leadership for a community-wide shift in attitudes.'](#) If this is to move beyond rhetoric then the SASSIF must consider siblings in its definition of family.

– Provides a framework for national and State efforts to improve the quality of life of people living with an ASD, reduce the cost of those conditions, and reduce the impact on individuals, their carers and communities;

[If families are going to be supported through the SASSIF then we need to use a whole family approach and not just focus on 'carers'. A seven year old sister of a child with ASD may not provide any caring role but she may be subjected to a range of stresses.](#)

– Rationalisation of resources via service delivery of evidence based approaches to people living with ASDs;

There needs to be further development of evidence based approaches in relation to family support across the lifespan

– Promotes better outcomes for economic and social participation for people with ASD;

One of the key groups of people to influence the social participation of people with ASD is likely to be siblings, again, over a lifetime. There needs to be particular consideration of the roles that siblings play as well as their support needs

– Gathers accurate data that assists in guiding policy decision at a Federal and State level;

There needs to be accurate data of families ie information on all members of the family including ages of siblings in relation to the person with ASD

– Delivers a service program from the disability, health and education sectors that is collaborative, comprehensive, unified and person centred; and

Support for siblings needs to be considered in relation to disability, health and education sectors. For example, when yearly education/therapy/social plans are developed for a child with ASD the needs of siblings should also be considered eg can they complete homework, are they often tired due to lack of sleep, are they teased due to the disability of a brother or sister, are they abused by the child with ASD, are their own social interactions limited? In addition, there needs to be consideration given to how the sibling can be helped to interact with the child with ASD in constructive ways, how to play, how to learn and have fun together.

## Questions

The following questions have been identified

– How can the availability and quality of information and services that support carers in their role be enhanced?

This needs to be changed to include family members as well regardless of any caring role they may play

– How can strategies be developed and implemented that ensure continuity of care in the management of ASD between health professionals, educators, and other care and support providers?

There needs to be greater workforce development across different sectors around the needs of the whole family to ensure greater collaboration and referral

– How can capacity for self-management be improved? How can people with ASD (and their families) be supported to develop the knowledge, skills and confidence to self-manage the condition?

Families need support to develop knowledge, skills and confidence to manage their experience. Siblings Australia could help with this.

– How can access to consistent, evidence-based information on ASD, including options for management, be improved for individuals, their families, educators, health professionals, and other care providers be improved?

Resources are urgently needed to develop greater information, support and education for families as well as workforce development to ensure there are pathways of support for families

– What mechanism can be put in place that ensure staff delivering services and supporting people with ASD have appropriate skills?

Again Siblings Australia has a lot of expertise in this area and would be able to contribute much to this workforce development

## Brief summary

- Siblings need to have their lifelong role and needs recognised and they need to be central to any SSIF, not as carers or 'young carers' but as brothers and sisters
- The whole family needs support from the time of diagnosis to manage their different responses/feelings and to ensure families stay together

- Parents need help to support all of their children
- Siblings need support to manage their varied experiences, both within the home but also in the community – this may include information about ASD, how to keep themselves safe, how to manage their many feelings, deal with others' reactions, and decide what role(s) they are willing to play in the management of their brother or sister's ASD
- Siblings need opportunities to connect with other sources of support eg other siblings, school and community programs
- There needs to be significant workforce development to ensure relevant sectors – health, disability, education – have the necessary skills and training to support the whole family
- There needs to be more research into best practice in terms of whole family support

### Further reading

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

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*

Harris, S. & Glasberg, B. (2003). *Siblings of Children with Autism: A Guide for Families*. Woodbine House, Bethesda, MD.

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

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.

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

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

A position statement and issues paper, *Addressing the needs of siblings of children with disability or chronic illness*, by the Royal Australian and New Zealand College of Psychiatrists can be found at:

<http://www.ranzcp.org/policy-advocacy/addressing-the-needs-of-siblings-of-children-with-disability-or-chronic-illness.html>

More books, articles are available from Siblings Australia [www.siblingsaustralia.org.au](http://www.siblingsaustralia.org.au)

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