



Peer support and resilience

by Belinda Rahman

“I’d felt I was alone. It helped so much to know there’s other people in the same situation as me.” (parent comment, Solomon, Pistrang & Barker, 2001)

All families can face stressful and demanding situations, and families with a child with a disability are no different. These families also face many challenges and difficulties related to their child’s disability and special needs as they face feelings of grief and loss, stress, stigmatisation and social isolation (Ainbinder et al., 1998). Over the last 30 years, research has highlighted the importance of social support for families with children who have a disability or special needs. Social support has shown to reduce stress, help to increase coping and adjustment as well as increasing self-esteem (Campbell, Phaneuf & Deane, 2004). The term “peer support” is used to refer to the social support from someone who shares a similar set of experiences. The focus of peer, parent-to-parent or mutual support groups is to provide information, practical assistance and emotional empathy and comfort to members.

Health professionals become inherently involved in a child’s life if they have special needs; doctors, physiotherapists and speech therapists are often an integral part of the treatment or management of child with a disability. While these individuals are an invaluable source of medical and educational information, what is often lacking in these interactions is a sense of emotional support and empathy. In contrast, peer support is an important resource for emotional support. Kerr and McIntosh’s (1999) study of parents with children with a physical disability revealed that for most participants only other parents in a similar situation would “truly understand”. This type of interaction allowed parents to feel that they were able to express their concerns, anxieties, guilt and anger in an understanding and supportive environment without fear of judgement. Comparing one’s own experience with others that are similar also helps to normalise experiences and responses.

What parents found most helpful from a peer support group was the information they gained about their child’s condition (Solomon, Pistrang & Barker, 2001). Practical

advice and information was made more meaningful because it came from people in the same situation, who had the same concerns and were facing similar challenges. Parents considered the information shared to be trustworthy and reliable. Informational support not only increases knowledge, understanding and coping skills, it also acts to enhance an individual’s sense of control. As one parent in this study commented, knowledge is power. This has even led to parents becoming advocates for their child’s rights;

“Previously, I’d been fighting on my own for a number of things already. But after joining the [peer support] group, I felt much stronger about the things I was fighting for because a number of people were fighting for the same thing. For the group to take on issues and work through them is encouraging for individuals in the individual battles.” (Parent comment from Solomon, Pistrang & Barker, 2001)

Several studies (Kerr & McIntosh, 1999; Ainbinder et al. 1998) have found that another benefit of being involved in peer support was being able to give support as well as receive support. Members who had initially required a lot of support found that as time went on they were both more willing and able to offer their support to new parents. Frank Reissman described this as the ‘helper therapy principle’; self-esteem and confidence is enhanced not only by sharing experiences and feelings with others in similar circumstances, but also by the opportunity to help others (Reissman, 1965, as cited in Campbell, Phaneuf & Deane, 2004).

Families with a child with a disability, whether it be physical or intellectual, can often feel isolated from society. Individuals and families can be isolated by physical barriers such as inaccessible facilities, transportation issues, and also by social barriers where there is a lack of inclusion in and availability of social activities. A known benefit of peer support programs is the sense of belonging and community that they create. Parents and family members often describe feeling less lonely

and isolated, and more included if they are part of a peer or social support group. In Solomon, Pistrang and Barker's (2001) research parents reported feeling "not the only one" and "not different anymore" by being involved in a parent support group. It is not only the ability to share similar experiences and opinions that fosters this sense of belonging, but also the increased social networks, new friendships and involvement in activities.

When most families first learn that their child has a disability they feel overwhelmed and experience a period of grieving and adjustment. Families vary in their ability to cope and adjust to the difficulties and challenges confronting them. Some families learn to cope and adjust better than others and are able to thrive, leading happy, satisfying lives whereas others struggle to cope. The term "resilience" is often used to refer to the capacity to bounce-back from stressful events and adapt to change. (Gardner & Harmon, 2002) Resilient families often become strengthened and more resourceful as a result.

For many years, research examining resilience and hardiness focused on how families have failed to cope and struggle to adjust. More recently the trend in research has been to identify how individuals and families are able to bounce-back. As Bayat (2007) describes, "...there is increasing evidence that families of children with disabilities demonstrate a great degree of strength". Heiman (2002) studied families with one or more children who had an intellectual, learning or physical disability. Family members described the need for "...a strong belief in the child and in the child's future, in maintaining an optimistic outlook" as a factor which contributes to resilience. Bayat (2007) also describes the need for a positive outlook as a key part of a family becoming resilient. Peer support can be seen to help foster this kind of positive thinking and optimistic attitudes. Participants in Solomon, Pistrang and Barker's (2001) study described how the relationship with their child had changed; parents described feeling more accepting and understanding of their child's disability since being part of a support group.

Peer support groups also allow for parents to meet other parents and children who were older or at different stages. This acts to encourage parents to feel optimistic and confident about the future – parents realised that their children could in fact cope very well. Kerr and McIntosh's (1999) study revealed that new parents, from interactions with other group members, were able to visualise a normal, social and active life for their child. Again, these feelings of increased confidence and positivity help a family's ability to cope, in turn increasing resilience.

Ultimately, enhancing the resilience of parents or a family requires a respect of the impact of the disability on the family and helping them to identify their strengths and resourcefulness not only to cope, but to also see the "...joy and hope in the reality of disability." (Gardner & Harmon, 2002) Peer support groups provide not only a real understanding of the difficulties faced by these families, but resilient families can also act as a role model for families which are struggling to cope as well.

Peer support can also assist families to make the necessary adjustments and accommodations required to cope and thrive in the face of adversity. Academic research in this area of peer support and disability has confirmed what many parents already know; parents of a child with a disability or with special needs are uniquely qualified to help each other.

References

- Ainbinder, J.G. et al. (1998). *A Qualitative Study of Parent to Parent Support for Parents of Children with Special Needs*. *Journal of Pediatric Psychology*, 23, 99-109.
- Bayat, M. (2007). *Evidence of resilience in families of children with autism*. *Journal of Intellectual Disability Research*, 51, 702-714.
- Campbell, H.S., Phaneuf, M.R., & Deane, K. (2004). *Cancer peer support programs – do they work?* *Patient Education and Counseling*, 55, 3-15.
- Gardner, J., & Harmon, T. (2002). *Exploring resilience from a parent's perspective: A qualitative study of six resilient mothers with children with an intellectual disability*. *Australian Social Work*, 55, 60-68.
- Heiman, T. (2002). *Parents of Children with Disabilities: Resilience, Coping, and Future Expectations*. *Journal of Developmental and Physical Disabilities*, 14, 159-171.
- Kerr, S.M., & McIntosh, J.B. (1999). *Coping when a child has a disability: exploring the impact of parent-to-parent support*. *Child: Care, Health and Development*, 26, 309-322.
- Solomon, M., Pistrang, N., & Barker, C. (2001). *The Benefits of Mutual Support Groups for Parents of Children with Disabilities*. *American Journal of Community Psychology*, 29, 113-132.
- Belinda Rahman is a final year Genetic Counselling student at the University of Melbourne. Belinda spent eight weeks at Down Syndrome Victoria on a student placement in late 2008. Part of her project involved a literature review of research about peer support and resilience. Our website www.downsyndromevictoria.org.au has links to this research.

Down Syndrome Victoria has peer support groups throughout Victoria. Page 27 of this journal provides contact details of group facilitators. If you would like to form a group in an area where none presently exists, please contact Sue Modra – Family Support and Training Coordinator on 1300 658 873 or email sue@dsav.asn.au. MyTime groups are for parents of pre-school aged children with a disability or chronic illness, family network groups are for parents of school aged children with Down syndrome and 15+ groups are for parents of adults and young adults (aged over 15 years) with Down syndrome. There is also a blokes group for fathers of a person with Down syndrome and an online community.