Siblings of children with autism spectrum disorder

What is the issue?

Caring for a child on the autism spectrum can be emotionally and physically demanding for parents and can have a disruptive impact on the wider family life. In particular, there are a variety of challenges that may be faced by other children in the family as a direct or indirect consequence of having a brother or sister with ASD.

These include:
- Isolation or resentment because of the amount of time and energy parents must devote to the child with ASD
- Confusion, distress or embarrassment at the way in which ASD manifests itself in the affected sibling, for example, through volatile emotions, a disinterest in collaborative play, or inappropriate behaviour in public
- Missing out on some of the benefits of well-functioning sibling relationships, such as the growth of self-identity, social skills, companionship and mutual support.

What does the research say?

A number of research studies have explored the impact on children and young people who have a sibling with autism. Their findings have been extremely varied, reflecting the fact that no two families or situations are exactly the same. Factors such as the severity of ASD in the affected child, availability of social support, socio-economic status, degree of family cohesion, parental well-being, and individual character traits are all likely to play a role in determining outcomes for the neurotypical children of families affected by ASD (O’Brien et al., 2009).

Nevertheless, at a broad level, research has identified the following risk areas for siblings of children with ASD (Bågenholm & Gillberg, 1991; Hastings, 2003; Ross & Cuskelley, 2006; Petalas, 2012):

- Loneliness
- Concern about the future
- Behavioural disturbances
- Poor relationships with peers
- Anger towards the sibling with ASD (particularly if that sibling is aggressive)
- Vulnerability to stress and depression.

At the same time, it would appear that there are a number of factors that can act as ‘buffers’ to these risks, and therefore improve the likelihood that the siblings of children
with ASD will grow up psychologically and socially well-adjusted (McHale et al., 1986; Kaminsky & Dewey, 2002). These include:

- the siblings are part of a large family
- the child with ASD is younger than his or her sibling(s)
- parents show minimal favouritism, including setting aside dedicated time to spend with their non-ASD child(ren)
- parents facilitate opportunities for all children in the family to engage in shared activities
- siblings are well-informed about the nature of ASD
- the family has a high level of social support
- safeguards are in place for the future care of the child with ASD.

In terms of formal interventions, research has suggested that one of the most effective ways of promoting well-being and positive adjustment in siblings of children with ASD is to involve them in a support group or program (O’Brien et al., 2009). Support groups and programs may be designed for the entire family, or run exclusively for neurotypical siblings. Some operate on a regular basis, while others take place more infrequently but on a larger scale. A good example is the annual Siblings Camp organised by Autism Spectrum Australia (Aspect).

Children who attend these groups and events are given opportunities:

- to meet and establish relationships with other young people in similar circumstances to their own
- to learn more about their sibling’s condition and discuss issues of personal concern
- to express their feelings and experience peer support
- to have some fun and relaxing time to themselves away from the pressures of family life (Smith & Perry, 2004).

However, as beneficial as such interventions are, it is clear that they should not act as a substitute for more informal, family-based information sharing, inclusive activities, and sibling support (Giallo & Gavidia-Payne, 2008).

Finally, it is important to emphasise that there are many ways in which having a brother or sister on the autism spectrum may positively impact upon other children in the family. Growing up with a ‘special needs’ sibling may encourage qualities such as tolerance, patience, compassion and independence. Young people in this situation can frequently exhibit a ‘maturity beyond their years’, and some will go on to become active spokespeople and advocates within the disability community.
In summary

Research suggests that children who have siblings with ASD can have positive outcomes, especially when they have good levels of family and community support.

References


Resources

For parents
http://raisingchildren.net.au/
http://www.autismspectrum.org.au
http://www.siblingsaustralia.org.au

For siblings
An online community/forum for siblings of children with a serious illness, chronic health
http://www.livewire.org.au