

## Siblings of children on the autism spectrum

Research shows us that while children, adolescents and adults who have siblings on the autism spectrum can face a variety of challenges, this can also be a positive experience that offers them opportunities to learn and grow.

Some key factors in a sibling's childhood are associated with positive outcomes, including open communication in the family about living with a person on the autism spectrum, parental recognition of the sibling's experiences and feelings, well-being of the parents, degree of family cohesion and good community support.

Other factors that are outside of the family's influence, such as the severity of autism, family size, birth order of the sibling, socio-economic status, and individual character traits are all likely to play a role in determining outcomes of siblings.

It is also important to note that no two families or situations are exactly the same, and findings from various research studies are mixed.

However, the general conclusion from the majority of the research is that having a sibling on the autism spectrum does not, in itself, pose any significant risk to a child's well-being.

### The childhood experience

Children who have siblings on the autism spectrum can face a variety of challenges, including:

- Feelings of loneliness, isolation or resentment, often because of the amount of time and energy parents must devote to the child on the autism spectrum, and the relative lack of attention or validation given by parents to the sibling's experiences, needs and feelings
- Confusion, anger, distress or embarrassment at the way in which autism 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 sibling relationships, such as the growth of self-identity, social skills, companionship and mutual support
- Behavioural disturbances
- Poor relationships with peers and others outside of the inner family group
- Vulnerability to stress and depression
- Concern about the future.

Research also shows that there are many ways in which having a sibling on the autism spectrum can be a positive experience with benefits for other children in the family. Compared to others, people with a sibling on the autism spectrum tend to:

- have more positive self-concepts
- show greater social competence
- exhibit qualities such as tolerance, patience and compassion, with a greater tendency to accept people as they are and avoid judging others
- be more independent at an earlier age.

Characteristics that people with a sibling on the autism spectrum identify with include altruism, sensitivity, having a strong sense of duty and responsibility, being available for others, having an openness to others, and being smart, funny and kind.

Young people with a sibling on the autism spectrum frequently exhibit a 'maturity beyond their years'.

Importantly, people with a sibling on the autism spectrum hold more positive views of the behaviour of people on the autism spectrum than do the general population, and some go on to become active spokespeople and advocates within the community.

## Support for siblings in childhood

Research has identified a number of strategies that a family can adopt to improve the experiences and outcomes for siblings of children on the autism spectrum. These include:

- Family communications are open, frank, informed and inclusive
- Parents encourage children with a sibling on the autism spectrum to share their feelings and concerns with their parents
- Parents show minimal favouritism, including setting aside dedicated time to spend with each child

- Parents facilitate opportunities for all children in the family to engage in shared activities
- Siblings and the extended family are well-informed about the nature of autism and how autism affects their sibling on the autism spectrum
- The family has a high level of social support
- Safeguards are in place for the future care of the child on the autism spectrum.

There are also a number of formal supports that can be put in place for siblings of children on the autism spectrum.

One of the most effective ways of promoting well-being and positive adjustment in siblings of children on the autism spectrum is to involve them in a **sibling support group or program**.

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
- learn more about their sibling's condition and discuss issues of personal concern
- express their feelings and experience peer support
- have some fun and relaxing time to themselves away from the pressures of family life.

Families may also choose to take part as a unit in a **family support group** and/or **family therapy**.

While these formal supports have been shown to be effective, they cannot substitute for informal, family-based information sharing, inclusive activities, and sibling support.

## Adult siblings

Research with adults who have a sibling on the autism spectrum shows that over time the relationship between the siblings evolves and deepens. This is associated with an increasing acceptance and understanding over time of their sibling and their autism, and an appreciation of their sibling's positive characteristics.

Many express that the experience of having a sibling on the autism spectrum, while sometimes placing limitations on their personal and social life, has also led them to be a better person, valuing traits such as compassion, patience and empathy, and often leading to careers working with people with special needs.

Most adults who have a sibling on the autism spectrum play a significant role as a caregiver or support person, and their concern for the future of their sibling plays a central role in their plans for their own future. The desire for their sibling on the autism spectrum to gain a degree of

independence, or further their independence, is a key issue for these adults. For those whose parents are alive and playing a carer role, good communication within the family about formal plans for the future care, guardianship and financial support of the sibling on the autism spectrum is vital.

## Resources

### **For parents**

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

<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>

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