

What are the needs of siblings of children on the autism spectrum and how might support services address their needs?

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Editorial comment

Ruth Heeks has a son on the autism spectrum and works in an autism outreach service. In this paper, she considers the issues for brothers and sisters who have a sibling on the autism spectrum, from both a personal and a professional perspective. She has run a parent workshop on the needs of siblings and been involved in a youth group and argues that the concerns of parents and of siblings might not be addressed unless action is taken to identify these.

Introduction

As the family support co-ordinator of an autism outreach service (AOS), I am often asked for advice and information on issues relating to siblings. More often than not, parents are acutely aware of the demands made of the siblings, and this can add to family stress. In this paper, I will consider a range of ways that siblings can be supported by the AOS and signposted to other services.

Within this essay, I will be drawing on my personal experiences with my 16 year old son Joseph, brother of Max, aged 13, who has autism without learning difficulties. I will also refer to families I have been involved with, in my role at the AOS, in visiting families at home, running parent workshops, and through my recent involvement at a youth club for children on the autism spectrum and their siblings. I have changed the names of all the children throughout.

Family characteristics

Family factors can have a bearing on the demands made on a sibling, younger, older, gender, age gap, other siblings and the severity of autism. I have tried to use examples of differing types of family settings, using examples from different stages of growing up, early years, middle childhood 9-12 years and adolescence. In the examples I hope to illustrate some of the potential demands that can affect siblings such as embarrassment, loneliness, responsibility and dealing with violent outbursts.

Parents' fears for their 'typical' children

I have found that my own concerns around not meeting the needs of Joseph, because of Max, are mirrored in other families that I meet. The fear is that siblings could be psychologically damaged by internalizing and externalizing feelings (Hastings, 2003a; Ross & Cuskelley, 2006) and that they may not have healthy, functional relationships within the family or with peers (Hastings, 2003a; Kaminsky & Dewey, 2002).

Research studies on siblings

Much of the research done is based on parents' or professionals' perceptions of the sibling's feelings. However, research carried out for the Joseph Rowntree Foundation by Edwards, Hadfield, Mauthner (2005) gained the perspective of typical children on their relationships with their siblings who did not have disabilities. Some common statements made by these typical children on their siblings included, "always having someone there for them", "strong sense of identity and being part of a group", "talking together" for girls, and "doing things together" was important to boys. These positive statements from children on their relationships are the things that siblings of those on the autism spectrum may find harder to achieve with their brothers and sisters.

Much of the research into siblings and autism uses comparison groups of children with learning difficulties and Down syndrome (eg McHale, Sloan, and Simeonson (1986); Bagenhol and Gillberg, 1991). All the families I am involved with have children on the autism spectrum, most without significant learning difficulties. However, the demands made on the siblings are still significant and may be increased if the children attend the same school.

Inclusion in mainstream schools of children on the autism spectrum

The inclusion of children on the autism spectrum into mainstream education now means that siblings are far more likely to attend the same local school, bringing with it challenges for siblings. School is a place where social skills are acquired, unstated rules are presumed and where children on the autism spectrum often struggle most. Myles, Schelvan, and Trautman (2004) and Harris and Glasberg (2003) writing on the caretaking role of siblings warn:

'The sense of being different can make a child feel angry, ashamed, embarrassed, sad or defiant.' (p. 19)

I recall my son, Joseph, aged 10, coming home from school angry and upset that in a school assembly, someone in his class had laughed at Max for acting inappropriately. Max had recently been integrated into our local mainstream primary school from a special school. I praised Joseph for not retaliating and for telling me about how he felt (which was unusual for him). As a parent, I felt guilty for putting Joseph in this position. Inwardly though, I was proud and pleased that he cared about his brother. This was sometimes difficult to see in the normal family life of squabbles and rivalry. It was an incident that influenced our decision to send the boys to separate secondary schools, so that Joseph could avoid the potential demands of embarrassment and conflict in defending Max.

The incident at school also highlighted the need for information that Joseph needed to understand autism. I found that my explanations given to him earlier, as a younger child, needed updating. In the early days, I said things like:

'It's nobody's fault he's different; You can't catch autism; His brain works differently; and he just hasn't learned how to talk yet,'

Harris and Glasberg (2003) write about the need for ongoing information on autism for the siblings and for this information to be age appropriate. Joseph needed to know what autism actually was and to have a better explanation for Max's behaviour to share with his peers. We also wanted Joseph to feel comfortable and confident with the diagnosis, just as we wanted for Max. Faherty (2008) speaks of the need for people on the autism spectrum to have the ability to self-advocate, and Joseph demonstrated this need for siblings too.

My professional role

In my work, I help parents to look at both the advantages and disadvantages of children being at different schools. It often comes up during discussions on secondary transition in Year 6. Having children at different schools can be one way of avoiding conflict and embarrassment, but it is not always practical or wanted by families from different cultures and backgrounds, or indeed the sibling. For example, Grinker (2007) refers to parents who choose to keep the sibling *'free from the burden they shoulder'*, but concludes that:

'This view also suggests that the person with autism is a burden only, rather than an asset.'
(p296).

A case study, Kevin (aged 12 years)

I am currently working with Kevin, aged 12, who attends a local mainstream secondary school and has Asperger syndrome. He has a brother, Charlie, who has severe autism, aged 10 years, who attends a special school. Kevin shares a bedroom with Charlie. I was asked to get involved with Kevin as he had recently been excluded from school for 3 days for hitting someone. He had also been banned from the autism youth club for a similar incident. Kevin had refused to talk about or to explain his actions.

My involvement was to talk to Kevin about his diagnosis (myself, his teacher and his mother). Although he knew he had Asperger syndrome, we wondered whether he was comfortable with this and whether this was a reason for his recent angry outbursts. The sessions were relaxed, taking place at school and Kevin talked to me freely. It became apparent after two sessions, that Kevin was comfortable with his diagnosis, but that he had concerns about his brother, Charlie.

Kevin was angry that he never had friends around because he was "too embarrassed" about people meeting Charlie. At the same time, he was very protective of Charlie. Someone had called his brother "a retard" and this had developed into a fight at the autism youth club. He also worried that if someone came around to the house, that they might leave the door open, and Charlie might "run into the road."

At the end of a session where Kevin had been angry and upset about a lot of different incidents at school, he said he was angry that:

'Science had allowed autism to happen.'

and packing up our things, he said;

'I feel like I'm an only brother, and I'll always have Charlie to look after.'

This simple statement summed up and revealed the feelings that siblings can have when they are the only sibling in a family, that is, loneliness and a sense of responsibility. Although larger families can come with extra parental demands, such as less individual time with the children, loneliness can be less of an issue (Jackson, 2003).

There is a danger of siblings having their own needs overlooked (Sibs, 2008). However, because of my involvement with Kevin, I was able to discuss some of Kevin's concerns with his mother. His mother arranged for Kevin to have friends around when Charlie was at the short break unit. Although she was concerned that Kevin had got into a fight about Charlie, she was also surprised and proud that he cared about his brother. This wasn't previously apparent to her, or to others involved with Kevin.

The issue over the bedroom was harder to solve, but the family are looking to partition the bedroom to give the boys their own personal space. Having a child with a disability has a financial impact on families who often live in poorer and inadequate housing (Every Disabled Child Matters, 2008).

Demands on parents' time

It is often difficult for parents to make the time to listen to the needs of their children. Sometimes children are reluctant to share their thoughts with parents as they do not want to burden them further (Harris & Glasberg, 2003). Sometimes too, siblings can feel guilty for having negative thoughts about their brother or sister.

A parent might not be the best person for a sibling to share their thoughts with. It is good for families to have a "significant other" (Carpenter, Addenbrooke, Attfield and Conway 2004). This can be someone who understands the family dynamics and the impact of autism on the sibling. Gold (1993) found that having no one to talk to had a negative impact on siblings.

Copying the behaviour of the child on the autism spectrum

The issue of behaviour being copied by younger siblings, is highlighted by a family that the AOS is involved with at the moment. Mary, aged 5 years, has recently received a diagnosis autism and is in the Reception class at the mainstream school. Her brother Harry, aged 3, also attends the school in the Pre-School Nursery, which is next door to Reception. Nursery and Reception children play together so the two children are together a lot of the time at school and at home.

The Psychiatrist, whilst in the process of diagnosing Mary, observed behaviours in Harry, which suggested that he too could have autism. Their mother is struggling to come to terms with Mary's recent diagnosis. She thinks that Harry is just mirroring Mary's behaviour and does not think he has autism. Whilst she understands that Harry can't catch autism and waits to see if he too gets a diagnosis, she needs support to maintain faith in her parenting skills. I recommended the National Autistic Society's (NAS) EarlyBird plus programme for her, where there is an emphasis on involving children and siblings in play (Shields, 2004). By attending this, she could be addressing the needs of both children, whether Harry had a diagnosis of autism or not. Harris and Glasberg (2003) devote a chapter on helping children play together to encourage sibling bonds.

Play between siblings

It is important for parents to help siblings to interact as much as they can together as feelings of rejection can lead to loneliness in younger children. This can be a reality for siblings of those on the autism spectrum when their attempts to play are rejected or can cause a tantrum. They may after time, decide to give up altogether. Parents need to be aware that they may be needed to encourage play and intervene when necessary (Harris & Glasberg, 2003).

Families with other family members on the autism spectrum

Many families who do have a child on the autism spectrum may also have other family members with the condition too. A considerable proportion of our families do have more than one child on the autism spectrum, as with Kevin and Charlie. Other families recognize similarities in family members or "traits" in siblings. There is a need for parents to recognize and allow for this, not expecting the child without a diagnosis to fit their own perception of "normal". There is sometimes pressure from an expectation in parents for the "normal" child to behave perfectly and not to make any allowances.

Mothers often share their worries with me that they have 'missed something' in their other children. I myself had the same worries with Joseph when he was young. With time, through acceptance and understanding of the diversity of autism, worries have diminished. At a recent siblings workshop that the AOS put on for parents, a lot of discussion ensued when the title on the power point slide, "*Have I missed something?*" came up, especially with parents of younger children. I wondered if this parental stress was passed on to cause stress in siblings who might then worry about having something wrong with themselves.

Extra responsibilities and siblings' knowledge of autism

There is a tendency for siblings to take on extra responsibilities that can lead to resentment (Sibs, 2008). Rebecca, aged 17, who attends a local FE college, had recently taken on the responsibility for taking her brother Edward, aged 8, with Asperger syndrome, to school in the morning. Her mother contacted the AOS for help as Rebecca and Edward were fighting in the mornings. Edward was refusing to cooperate in getting ready for school, which was making Rebecca late for college. Their mother had to leave early to get to work some mornings. Edward was ready on time on the mornings his mother took him to school. During a home visit to discuss the use of visual prompts and timetables to help Edward get ready, it became apparent that his mother had not shared much information with Rebecca on autism, even though the diagnosis was not new. Rebecca had also voiced concerns to her mother though about the chances of having a child of her own with autism.

There is an ongoing need for information on autism for siblings throughout growing up (Harris and Glasberg, 2003). In Rebecca's case, not only was there a need for help in dealing with her brother's uncooperative behaviour, but also for information or possible direction towards genetic counselling. An openness and acceptance in families about autism from the start is an advantage. In much the same way as it is encouraged to help an acceptance of their differences in the child with autism, this is essential for siblings too.

Physical safety of the siblings

The physical safety of the sibling, though not the most commonly talked about issue with parents, has to be recognized as a potential issue. Siblings need to know where they can go to escape a potential meltdown and how to respond to or avoid violent behavior. Parents and siblings need to be directed to information and services where they can be helped with challenging behaviour. Low arousal and physical intervention training have been commonplace for professionals working with children and adults on the autism spectrum, but little training in this area has been available for families. Woodcock, Hatton, and Burden (2006) discuss the need for families to have the same training made available to them. In 2006, Autism West Midlands started practical intervention training programmes for parents.

Families are often reluctant to admit to physical abuse happening in the home through shame, or guilt and also for fear of their children being taken into care. As a service, the AOS needs to let families know of the availability of training if it is felt that a family may have issues around physical abuse and to encourage them to feel safe about admitting to their need. Intervention training should be available for siblings as well as parents, if they are mature enough to attend.

Case study, Harry aged 15 years

Harry, is aged 15 years, and has Asperger syndrome. He had been excluded for a week from school for violent behaviour towards staff and pupils. A home visit revealed that Harry was also attacking his parents physically and his two younger sisters were witnessing this behavior. I was able to direct the family to a "Practical Intervention" programme within travelling distance. As a service, we are not approached very often for this type of support, and we are concerned that there may be more of a need than we are made aware of.

Destruction of possessions

A more common theme is the destruction of sibling's possessions and the need for siblings to have their own space and safe place for possessions. I often talk to parents about making sure that parents tell siblings to remove themselves from situations if there is an explosive situation about to happen and to go somewhere safe. I advise parents on respecting sibling possessions and recommend lockable places for items, if necessary.

Support and training for parents and siblings

It has been well documented, nationally, NIASA (2003) and regionally FREDA and Jones (2006) that there is a need for autism services to provide families with information and support at the right time. As a service it was recognized that to support pupils in mainstream schools successfully, information and support was needed in the home too. In a recent study carried out on Barnardo's Cygnet autism spectrum training programme for parents, Raghavan and Raghavan, (2008) identified that parents wanted more training in awareness and understanding of sibling issues.

As a service, the AOS tries to respond to the needs identified directly from the families, and recently delivered a two-hour workshop on sibling issues for parents. The workshop identified the possible demands made on siblings and then went on to explain things that parents could do to help support them. The aim of the workshop was to be positive and not to place any extra worries on parents. A lot of ideas and experiences were shared. One parent commented that it

would be really beneficial to put a workshop on specifically for siblings. The service plans to run one next year through the local youth club which siblings can attend.

Literature for siblings

The AOS has a good bank of books to lend to siblings of different ages. For young children under the age of about 6 years, I find many of the books written for children on the autism spectrum appropriate for the siblings too. For the older child, around the age of 10, Fiona Bleach's book *"Everybody is different"* is easy to understand, but at the same time informative. For the adolescent, biographies written by those on the autism spectrum, such as Luke Jackson's, *"Freaks Geeks and Asperger Syndrome"*, can be interesting and appropriate.

Time away from siblings and youth groups

For children who need time away from their brother or sister, the Young Carer's organisation offers weekly youth clubs for siblings of children on the autism spectrum. A youth club for children on the autism spectrum in my area was initially set up just for those with autism, but often siblings wanted to stay too. Having an opportunity to meet other children who had siblings on the autism spectrum gave them the opportunity to feel free from embarrassment by their brother or sister's unusual behaviour and to meet others like themselves.

Concluding comments

The potential for extra demands being made on siblings is real. However, if parents are given positive and practical support, they can become empowered to do the best for every child in their care. Without exception, all parents want the best possible outcome for all their children. The extra demands of bringing up a child on the autism spectrum, does not change that desire.

Siblings have often only known life with their sibling. They can accept them in a positive way if the attitude of parents is also positive (Harris & Glasberg, 2003). Being given the right support when they need it by parents, being listened to, having their grievances acknowledged, and being made to feel special, make that positive outcome a real possibility.

Not all research findings are negative. Some studies report positive outcomes for siblings, such as better emotional and behavioural adjustments (Hastings 2003b), and better social competence and self concept (Macks & Reeve, 2007). Siblings can grow into well-balanced, caring individuals, many finding careers in the caring professions.

I conclude with a very positive comment on Joseph's view of his future, an hour or so after arguing with Max. I said,

'At least when you grow up you'll be able to have your own place,'

to which Joseph replied:

'Yes, my own flat, a 2 bedroom place though, with a room for Max.'

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