The Autism Families Research Study: Siblings of Children with ASD

Research Summary Report

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Background

While some siblings of children with autism spectrum disorder (ASD) appear not to be affected negatively by growing up in a family environment with a child with ASD, other siblings may experience emotional and behavioural difficulties. However, *Why* and *How* some siblings experience problems is not entirely clear from the research literature.

There are at least three ways that we might expect siblings in families of children with ASD to be affected. First, their parents might be experiencing significant amounts of stress, and this might in turn affect the siblings. Second, like parents, siblings may have to cope with a brother or sister with social and communication difficulties, and behaviour problems. Third, siblings of children with autism may themselves be at risk for social and communication difficulties, and behaviour problems, through a genetic predisposition to ASD characteristics, even though they might not meet the criteria for a full diagnosis of ASD; this is often referred to as the broader autism phenotype.

Between October 2005 and October 2008, researchers in the School of Psychology (Michael Petalas, Richard Hastings, Susie Nash, Alan Dowey, & Deirdre Reilly) at Bangor University carried out a series of four research studies focused on the psychological adjustment and experiences of siblings with a brother with autism spectrum disorder (ASD) (see Appendix). In this report, we summarise the main findings from this research and propose recommendations for policy and practice.

Research Findings
Study 1: Emotional and Behavioural Adjustment in Siblings of Children With Intellectual Disability With and Without Autism

Children with autism often present with an associated intellectual disability (ID) (approximately 70% according to the American Psychiatric Association). It is difficult therefore to know whether autism or the presence of intellectual disability explains the difficulties that some siblings of children with ASD experience. Mothers provided information on the emotional and behavioural adjustment of 25 siblings of children with ID and autism, and 24 siblings of children with ID without autism. Information was also available 18 months later for 15 siblings of children with ID and autism. The results showed that siblings of children with ID and autism had more emotional problems when compared with siblings of children with ID only, and also with data from other similarly aged children around the UK who did not have a sibling with a disability. Furthermore, the increasing age of the child with autism, having a brother with autism, coming from a family with more socioeconomic deprivation (such as low family income, low level of parent/caregiver education), and being younger than the child with autism were related with more emotional and behavioural problems in the siblings of children with ID and autism. The behavioural and emotional difficulties of siblings of children with ID and autism were still present after 18 months.

Study 2: “I like that he always shows who he is”: The Perceptions and Experiences of Siblings with a Brother with Autism Spectrum Disorder.

Eight typically developing siblings in middle-childhood (9 to 12 years of age) who had a brother with ASD were interviewed face to face. The interviews were analysed using a
qualitative method of analysis (Interpretative Phenomenological Analysis (IPA)). The analysis of the siblings’ accounts produced five main themes which are exemplified below with some extracts from the transcripts: (i) siblings’ perceptions of the impact of their brother's condition on their lives. Some siblings, for example, spoke about having to face physically and verbally aggressive behaviour from their brother with ASD in the home.

Leah - when like you play with something, Jack he comes along because he wants to put it in a little order; and he absolutely takes it off you. And say you just walk off and just go and sit in the sitting room and go and watch TV, he just comes in and starts chucking things at you, (...) he just chucks things at you, shouts at you, screams at you.

(ii) Siblings' perceptions of the attitudes of others. Kevin's feelings of embarrassment turned to frustration and anger as he talks about other peoples' reactions toward himself, his family, and his brother.

Kevin- (...) people look at us in funny ways (...) just because it’s a family with autism. (...) so if he starts swearing or starts kicking, you know, it’s quite embarrassing because people might think, oh, you know, their mother or father taught him to do that, so it’s quite embarrassing to me to think that people sort of disrespecting my family and me and my brother.

(iii) Siblings' tolerance and acceptance towards their brothers. Maddie expressed a clear wish for her brother to be normal.

Maddie - (...) It would be nice to have a nice, normal brother because I could do more with him, so that would be better.
Lizzy, on the other hand, welcomed having a brother with ASD.

*Lizzy* - (...) *I like him the way he is. He’s my brother. I’d never make him normal because I knew him like this. And I can’t imagine a brother any other way.*

(iv) Positive attitudes and experiences. Lizzy appreciated her brother's sincere and genuine nature.

*Lizzy* - *I like that he always shows who he is. He always shows that he does have a personality and he is someone. And also just so he can’t talk doesn’t mean he doesn’t have anything to say. He can sort of speak to you in a way.*

(v) Siblings' views on support for themselves and their brothers. Kevin drew support from interacting with others who shared his experiences and problems and from being able to confide in people who understood how he felt.

(...) *there's a group in [location name] that I go to which go swimming or wall climbing or different activities, (...) before I went there I didn't know anyone that's got brothers or sisters that are disabled, but when I went there, I found out there’s a whole range of children with problems worse, or not as bad as me. I felt more reassured on how you know, I’m not alone, there is people to speak to you know and there is other children with the same issues in the family as me.*

These results can be used to inform future research as well as the development of support packages for siblings of children with ASD.

Study 3: *The Perceptions and Experiences of Adolescent Siblings with a Brother with an* Autism Spectrum Disorder
Twelve typically developing adolescent siblings with a brother with ASD were interviewed face to face. The interviews were analysed using IPA. The analysis of the sibling's accounts produced six themes. Extracts from the sibling interviews are provided below to illustrate each theme.

i) Siblings expressed the difficulties and negative impact of their brother's condition. This is an extreme example:

Natalie - ...That incident with the knife was what tipped it over the edge. That’s when they decided that he couldn’t stay at home. ... at the end the police were being called almost every night. ...it has been quite hard.

ii) Siblings reflected on the reactions of others, and often compared their relationship with their brother with ASD to the sibling relationships of their peers. For example, Sophie found it difficult to watch other siblings interact.

Sophie - It's very hard sometimes, because you see other brothers and sisters all just acting like brothers and sisters, if you know what I mean, having good times together. But like it's different with me and Noah, we have like play-fights and that kind of thing but it's not the same as other people ...

In contrast to Sophie, Emily compared the relationship she had with her brother with ASD favourably to others.

Emily - ...siblings don’t seem to get on when they’re both in their teens, do they? They’re, like, trying and keep away from each other. So, in a way, I’m grateful, because we do spend a lot of time together, or as much as we can, and we do enjoy being with each other.
iii) The adolescents were able to look upon their present circumstances in the context of their past experiences with their brothers.

Natalie - Even though he’s had this awfully aggressive side, there’s been another side to him where he’s been absolutely lovely. There was a really loving side to him.

iv) Some siblings wished for things to be different, while others expressed positive acceptance and tolerance towards their brothers.

Rhiannon - If I had a magic wand, I’d take away the autism straightaway; and he’d go to a normal school and have friends round and things like that. That’s what I’d do, straightaway.

Emily - I wouldn’t want him to change, and I like him the way he is, and I wouldn’t want him normal. But then, that’s just the totally selfish option, isn’t it, and not thinking about him, and would his life be better...

v) Positive perceptions and experiences were present throughout the interviews with the siblings.

Daniel - ... he’s a very happy person. He’s always like just generally being happy and I always think to sort of learn from that, and take after him ...

Sophie - ...I’m glad that I’ve got Noah because it makes me appreciate stuff, like you shouldn’t judge people on what they are and what conditions they have ...

vi) Siblings also expressed thoughts and worries about the future.

Rhiannon - ...my mum’s obviously quite old; well, she’s not that old, don’t tell her I said that, but when she’s really old, am I going to have to look after him, which I wouldn’t mind doing, but is he going to be able to look after himself? That’s what worries me about it.
In addition to the implications that these results have in supporting siblings, they also show that adolescents may have different concerns and needs than younger siblings, which should be explored further.

Study 4: *Psychological Adjustment and Sibling Relationships in Siblings of Children With Autism Spectrum Disorders: The effects of environmental stressors and the broad autism phenotype*

Research focused on siblings of children with Autism Spectrum Disorders (ASD) shows that they may be at increased risk for behavioural and emotional problems as well as relatively poor relationships with their brother or sister with ASD. Because autism is a genetic disorder, some siblings display autistic characteristics themselves, even though they might not have, or qualify for, a full diagnosis of autism; researchers and clinicians call this the broad autism phenotype (BAP). It has been suggested that the difficulties that some siblings have may result as a combination of living and growing up in a family with a child with ASD, and the autistic characteristics found in the siblings themselves.

Mothers provided information on 168 siblings between five and 17 years of age, their child with ASD, and their own psychological well-being. The main results showed that sibling behavioral adjustment related to the behaviour problems in the child with ASD and with the extent of the sibling’s BAP. Sibling relationships were more negative when the child with ASD had more behaviour problems and when the family environment was more negative (high criticism toward the child with ASD or the sibling). Siblings with more BAP characteristics who had brothers or sisters with ASD with high levels of behaviour problems, had more behaviour problems themselves.
Siblings with more BAP characteristics who also had parents with mental health problems had more conflict in their relationships with their brothers or sisters with ASD.

**Implications for Policy and Practice**

1. Professionals working with siblings of children with ASD should be aware of the impact of such factors as being younger than the child with ASD, low family income, and having a brother, rather than a sister with ASD, which our research shows may mean more difficulties for the siblings.

2. While our research shows that autism and not associated intellectual disability somehow places siblings at risk for emotional problems, it is still not clear what it is about autism that places some siblings at risk. For example, given that some siblings present with increased autistic features, it is worth exploring whether that in itself is underlying some of the difficulties in siblings. In addition, research shows that parents of children with autism are also at risk for emotional problems such as depression. It is possible therefore that siblings are also being affected by their parents’ mental health problems.

3. Professionals working with young siblings who are experiencing difficulties in their relationships, need to recognise the importance of early intervention designed to improve and facilitate positive sibling relationships in early and middle childhood, in order to ensure good outcomes longer term for children with ASD and their siblings.
4. Professionals developing sibling support groups should be taking into consideration the developmental level (i.e. age, level of understanding) of the children they are targeting for support or intervention. Offering developmentally appropriate information can help siblings achieve a more mature understanding of their brother’s or sister’s autism. This may be particularly important in helping siblings to deal with their own as well as others’ reactions toward the child with ASD.

5. Our research showed that adolescent siblings expressed future care worries about their brother or sister with ASD. Parents and professionals need to acknowledge siblings' roles in their brother's or sister's future, and be able to support siblings in dealing with their concerns. One way of supporting siblings is by encouraging open discussion in the family.

6. There is much more that we need to understand about siblings' perceptions and experiences. Allowing siblings to be heard is important in ensuring that individual family members’ needs are understood. It also helps siblings achieve a sense of empowerment; siblings often find themselves surrounded by parents and professionals representing them and advocating for them and the child with ASD, but who may at times forget that siblings have a voice of their own.

7. The findings from our research suggest that siblings of children with ASD who have autistic features themselves may find it difficult to cope with stressful situations in the home, such as a brother or sister with ASD and behaviour problems, and a parent with
mental health problems. Furthermore, parental criticism may place siblings at risk for poorer relationships with their brother or sister with ASD. These results call for clinicians to be able to systematically measure autistic characteristics in the siblings in order to identify children at risk. In addition, developing social skills and stress coping skills, as well as an increased understanding of autism and associated difficulties (e.g., behaviour problems) may help siblings to cope more effectively.

8. Our results further stress the importance of examining siblings’ needs within the family context. Siblings are likely to benefit from interventions not only aimed directly at them. For example, improving the behaviour problems of the child with ASD, treating parental mental health problems such as anxiety or depression, and promoting positive parent-child interactions, might all benefit sibling well-being and sibling relationships.

Finally, as mentioned previously in this report, it is important to bear in mind that siblings are not necessarily negatively affected by having to grow up in a family with a child with ASD, in fact there may be many positive influences that arise from such an experience (as illustrated through the sibling’s accounts in studies 2 and 3). It is also important to be clear that our research does not point to the child with autism or the parents as causative factors in the development of behavioural and emotional difficulties in the siblings. Such problems arise from a complex mixture of genetic and environmental influences. Any child is a unique and intricate being, and must be viewed at his/her own developmental level and his /her own totality.
Appendix - Abstracts of research papers
Emotional and Behavioural Adjustment in Siblings of Children With Intellectual Disability With and Without Autism

Abstract

Siblings of children with autism may be at greater risk for psychological problems when compared with children with another disability or with typically developing (TD) children. However, it is difficult to establish whether autism or the presence of intellectual disability (ID) explains the findings in previous research. Mothers rated the emotional and behavioral adjustment of siblings of children with ID with (N = 25) or without (N = 24) autism. Data were also available 18 months later for siblings of children with autism and ID (N = 15). Siblings of children with autism and ID had more emotional problems when compared with siblings of children with ID only and also with normative data. Three variables had independent relationships with emotional problems in siblings of children with autism and ID, namely: The increasing age of the child with autism, having a brother with autism, and being younger than the child with autism. Behavioural and emotional difficulties of siblings of children with autism and ID were relatively stable over 18 months.

The full paper is published as:

“I like that he always shows who he is”: The Perceptions and Experiences of Siblings with a Brother with Autism Spectrum Disorder.

Abstract

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Psychological Adjustment and Sibling Relationships in Siblings of Children with Autism Spectrum Disorders: The Effects of Environmental Stressors and the Broad Autism Phenotype

Abstract

Primary caregivers provided data on 166 siblings (5-17 years of age), their child with an Autism Spectrum Disorder (ASD), and their own psychological well-being. Sibling adjustment was associated with the extent of behavior problems in the child with an ASD and with the extent of the sibling’s Broad Autism Phenotype (BAP) features. Sibling relationships were more negative when the child with an ASD had more behavior problems and when there was evidence of critical expressed emotion in the family environment. Siblings with more BAP features, who had brothers/sisters with an ASD with the more behavior problems had more behavior problems themselves. Siblings with more BAP features who had parents with mental health problems reported more sibling relationship conflict.

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