



So, your brother has autism...NOW WHAT?

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Since the 1950's, researchers have grown increasingly interested in how raising a child with special needs impacts the family, specifically the mother. However, siblings are frequently the focus of attention, especially when their brother or sister has autism. Autism occurs about four times more often in boys, so a sibling is more likely to have a brother with autism.

What is the impact of having a brother or sister with autism on siblings?

There was a long-standing belief that siblings of children with special needs would have behavioral or adjustment problems however, research does not prove this. Consider a study published in the *Journal of Child Psychology and Psychiatry* by Laurie Eisenberg, Bruce Baker and Jan Blacher in 1998. That study included three samples of children: School-aged siblings of children with severe special health needs (some with autism) living at home; school-aged siblings of children living elsewhere in a residential facility and a control group of siblings of children without special needs. There was no evidence of clinically significant adjustment problems in siblings of children with disabilities.

More recent studies yield some contradictory results. In a 2004 study by Tammy Pilowsky and her colleagues in Israel, also published in the *Journal of Child Psychology and Psychiatry*, the siblings studied all had brothers or sisters with autism. Given the now-known genetic liability that such siblings have,

Pilowsky and her team looked specifically to see if there were problems in social-emotional adjustment, behavior, and socialization in 30 siblings of children with autism, as compared to 28 siblings of children with intellectual disability of unknown origin and 30 siblings of children with developmental language disorders. While a small percentage of children from each group did ultimately receive another clinical diagnosis, the three groups as a whole did not differ significantly from each other in terms of socialization skills, behavior problems or emotional adjustment. Of course, this study did not have a typically developing control group, so we cannot say whether or not the overall incidence of problem behaviors was elevated in these three groups.

Findings within the autism sibling group were informative. Siblings whose brother or sister with autism was nonverbal tended to have lower socialization skills which makes sense, since their opportunities for sibling interaction were more limited. Also, the limited verbal ability of the brother with autism may present more daily challenges to the family unit that have negative implications for the siblings' adjustment. The researchers also found that the greater the family stress, as reported by parents, the greater the delays in sibling socialization skills.

In another recent study, Richard Hastings asked mothers to provide information about any behavior problems and also about specific pro-social behaviors of siblings of school age children with autism. Pro-social behaviors includ-

ed domains such as being kind to younger children, considerate of others' feelings, sharing and helpful to people who are hurt or upset. In this study, siblings of children with autism were found to have more behavior problems and also fewer pro-social behaviors when compared to typical British children. The sibling behavior problems, however, were not related to the siblings' gender, whether they were the same gender as their sibling with autism, whether they were older or younger, whether their mothers were experiencing stress or whether the sibling with autism had high levels of behavior problems. Thus, the heightened behavior problems experienced by siblings of children with autism remains unexplained. On the other hand, pro-social behaviors were related to the sibling's gender and age. Siblings who were girls, and those who were older than the child with autism, showed more pro-social behavior.

We need more research to help explain why some siblings of children with autism might have behavior problems and fewer pro-social behaviors overall. Whether causal factors turn out to be environmentally or genetically based, such information will enhance our ability to support siblings of children with autism.

What other aspects of family life might be affected?

There is still more to the question, "So your brother has autism...now what?" If your brother was recently diagnosed and

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is young, chances are there will be an intensive behavioral intervention program set up in your home. Many such programs are delivered for up to 40 hours a week and can involve the use of several tutors or therapists who maintain a rather prominent (some might say, intrusive) presence in the home. There have been suggestions that families may be negatively affected by the intensity of programs that involve 40-hours-per-week and the financial burden of this type of intervention. We know little about the impact of such home programs on family members other than the child with autism. However, Hastings and colleagues have made an initial attempt to do this by examining the experience of siblings in families with home programs.

Consistent with data also collected on mothers of the children in the programs, Hastings found no evidence of increased problems in these siblings, compared to a sample of British children at the same ages. This research also focused on the role of social support for families who had a child with autism, with the implication that social support would be a protective factor for the non-disabled sibling. Some social support is derived from those who deliver the home program, though ideally there are other external sources as well.

Family social support was found to protect the sibling from developing behavior problems in families where the child's autism was less severe. When the child's autism was severe, however, the sibling had an increased risk of behavior problems, and social support was not a protective factor.

This research suggests that siblings of children in intensive applied behavioral analysis home programs are generally not negatively affected. However, siblings at risk for subsequent problems are those in families with less available social support, and/or in families where the child receiving intervention has more severe autism. This type of information will be useful for identifying which

brothers or sisters of children with autism and intensive home programs are most at risk of developing behavior problems themselves.

What kinds of sibling involvement can be expected?

If your brother has autism, there will be many opportunities for you to help the family. This help can take many forms including being empathic, sharing material goods, providing nurturing and comfort, and giving advice and emotional support. Often, non-disabled siblings take on these responsibilities to lessen burden and demands on parents. Researchers have been interested in studying the types of help that siblings provide, and the impact of this involvement on the siblings themselves.

There are many studies attesting to the fact that siblings appear to be involved with some form of caretaking. Often, girls are found to be involved more than boys, and older siblings to help more than younger ones. Studies also indicate that siblings with younger brothers or sisters with a disability are more likely than siblings without a disabled brother or sister to be involved in caretaking responsibilities.

These general findings were born out in a 2005 study by Hannah and Midlarsky that was published in the *American Journal on Mental Retardation*. Researchers interviewed 50 mothers and siblings of children with intellectual disability (ID) and 50 mothers and siblings of children without an intellectual disability. Here, too, mothers reported that girls were more apt to engage in helping than were boys, and older siblings engaged in higher levels of care than did younger ones. Also, siblings were more likely to help if they perceived that their brother or sister required more care.

Overall, whether it was reported by mothers or by siblings themselves, siblings of children with ID were found to provide more help and support than children without a brother or sister with special needs. An area that has received

much less attention is the social role of the sibling, whose own public behavior with the child plays a role in normalizing interactions, explaining differences, and generally facilitating social acceptance of the family member with autism.

While sibling involvement clearly seems to be an asset for families, a relatively unexplored question is, "What do the sibs gain from this experience?" In the study by Hannah and Midlarsky, siblings who helped the most appeared themselves to have higher self-esteem. Of course, it is difficult to know from this study's design whether high levels of self-esteem led to more helping, or whether sibling helping behavior resulted in higher self-esteem.

Finally, few researchers have directly examined the elusive question of how the sibling positively impacts a brother or sister with autism. Here, the novelist says it best. Consider Natalie, a fictional book character who is 16 years of age and has autism. She has a 12-year-old brother, nicknamed Moose. Natalie's teacher confides in Moose: "And, Moose? There's something I wanted to tell you too, dear. When Natalie and I are working together and I see I'm starting to lose her, I always say, 'What do you think Moose is doing right now?' And lately, she's been able to stay with me. She talks about you at school or playing catch or talking with Theresa and she's able to keep herself with me that way. I thought you might want to know how important you are to her (*Al Capone Does My Shirts* by Gennifer Choldenko, 2004, pp- 200-201).

In closing, there is much to be learned about the impact of a child with autism on his brothers and sisters and vice versa. Fortunately, if you have a brother with autism, you have much to feel positive about. At the very least, read *Al Capone Does My Shirts*. Choldenko has a sister with autism and her fictional portrayal of Natalie captures the conflict and caring in sibling and peer relationship.

References provided upon request; please email epedit@aol.com

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