



Dual Familial Roles: An Asperger's Syndrome Case Story

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Abstract

Sibling interactions are challenges that all families face on a daily basis. These interactions are significantly more difficult when one child has autism. With the apparent increase in diagnoses of autism, there are more families each year who are dealing with issues of relationships. Children learn, as part of the growing up experience, how to relate to their brothers and sisters. They also acquire future parenting styles by watching their own parents and how they relate to children with and without disabilities. This case study explores one woman's childhood experiences with a sibling of undiagnosed Asperger's Syndrome and the effects of her experiences as a parent of a son with Asperger's Syndrome.

Keywords

Autism, siblings, parenting, Asperger's syndrome

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In any family parents have expectations for their children and likewise, children have expectations of their siblings. Parents expect the relationship between siblings to be warm and nurturing, lasting into adulthood. Children develop intimate relationships with each other through extensive time spent together engaged in play as well as through disagreement. It is through these experiences that children foster emotional understanding and develop conflict resolution skills (Orsmond & Seltzer, 2007). Parents also have expectations concerning projected outcomes for future development of their children. Research has shown that there is a positive correlation between parental expectations and future outcomes for children with disabilities (Ivey, 2004).

A major contributing factor to a familial relationship is the presence of an autism spectrum disorder (ASD), including, Asperger's Syndrome and pervasive developmental disorders (PDDs). Autism has been referred to as a "triad of impairments" (Wing, 1997) including difficulties in communication, social interactions and odd or unusual behaviors (Goldstein & Reynolds, 1999). Individuals with Asperger's often demonstrate characteristics similar to those of a nonverbal learning disability (Klin, Pauls, Schultz & Volkmar 2005) in that they demonstrate skills in areas such as vocabulary and verbal output but experience significant difficulties with nonverbal skills. Children with Asperger's also display significant inappropriate social interactions including a lack of social reciprocity, the inability to maintain a discussion on a topic of another person's interest, and the inability to interpret nuances and nonverbal cues (Charman & Baird, 2002). Of additional concern is the often inconsistent, inappropriate behaviors exhibited by children with an

ASD. Consequently, families of children with ASD typically engage in fewer recreational activities, experience higher rates of stress and have greater disruptions in the family (Macks and Reeve, 2007). Of particular interest in this case study is the impact of the behaviors of a sibling with Asperger's Syndrome, undiagnosed until adulthood, on the adjustment and parenting style of the typically developed sibling.

Of familial relationships, those of siblings last the longest (Orsmond & Seltzer, 2007). The quality and endurance of that relationship are rooted in childhood experiences (Ross & Cuskelly, 2006). It is during childhood play and intimacy that siblings form reciprocal friendships. For children with autism, social play and imagination is severely limited resulting in less interaction between children. The social inabilities of the child with autism limit the extent of the relationship between affected children and typically developing siblings (Orsmond & Seltzer, 2007). Often the typically developing child reports feelings of embarrassment regarding the be-

“Typically developing siblings report a less optimistic viewpoint of the future possibilities of a brother or sister with autism”

havior of the child with ASD. When questioned by researchers, typically developing siblings report a less optimistic viewpoint of the future possibilities of their brother or sister with autism (Orsmond & Seltzer, 2007). Interestingly and in contrast, when Stalker and Connors (2004) asked children to describe their disabled sibling, many, especially young children, did not mention the disability

at all. Most descriptions were based upon appearance. Many descriptions included the word “normal” indicating the sibling is viewed as part of the family with no differences than other siblings.

Parents play a role in the relationship developed among typical and affected children. In a study cited by Ross (2006), knowledge of the presence and condition of autism as well as open communication about the disorder and its manifestations had a significant impact on the well being of the child who is not affected with autism. Another factor impacting the social adjustment of typically developing children and adolescents was that of the perception of fairness felt between the siblings. These children felt they received more negative treatment from their parents and were unjustly treated tended to have more behavioral and emotional ramifications (Orsmond & Seltzer, 2007).

The literature on sibling relationships and outcomes with regard to one sibling having an ASD is limited. Given the above referenced data, one would expect research to yield highly negative effects on adult relationships and psychiatric outcomes for typically developed siblings. Unaffected adult siblings report a positive relationship with parents but a less affective relationship with the sibling with ASD (Orsmond & Seltzer, 2007). Additionally, Stalker and Connors (2004) report siblings of children with disabilities to have no difference in the feelings of self worth and competence. However, a meta-analysis conducted by Yirmiya et al. (2001) cited by Orsmond & Seltzer (2007) indicates there is insufficient data to make a speculation regarding an increased risk of adulthood psychiatric difficulties. Given the mixed results and unexpected reports, additional research is warranted on the outcomes of siblings of children with autism spectrum

disorders. This case study examines the life experiences of one woman in Texas, who is not only a sibling of a brother with Asperger’s Syndrome, but she is also a parent of a son with the same diagnosis. Of particular interest is the impact of living with a sibling with Asperger’s Syndrome, undiagnosed until adulthood, on the effects of parenting a child with ASD.

Method

Participants

Judy is a 38 year-old Caucasian woman. Her husband’s name is Robert and they have three biological children. Keith is their 13 year-old boy who was diagnosed with Asperger’s Syndrome during the third grade. His siblings are Heather, a 9 year-old girl, and Bill, a 6 year-old boy. Living in Texas, Judy is employed as a special education teacher and Robert is a university professor.

Joe, Judy’s only sibling, is a 40 year-old male who lives in Arizona. He is married and the father of a three year-old daughter. While not clinically diagnosed with Asperger’s Syndrome as a child, he has been labeled as having Asperger’s in adulthood by physicians and other professionals.

Procedure

The investigator conducted this semi-structured interview at Judy’s home in July of 2007. A comprehensive list of possible interview questions was provided two weeks prior to the interview date. During the interview session a video camera was positioned to record only the participant. The researcher and Judy’s husband, Robert, were graduate students at the same university (1999-2001). Therefore, the researcher is an acquaintance of the family. Robert and Judy, knowing about the researcher’s interests, volunteered to become participants in this study. This pro-

ject was approved by the Institutional Review Board at the university at which the investigator is employed.

Childhood Experiences

There are many interesting layers to this case study. Judy's parents were divorced during her childhood and she feels strongly that while her parents were married she experienced a "much divided" family unit. She attributes this "division" to having a mother who was and continues to be very protective of Joe. Discussions regarding her brother's differences were never allowed. Judy states, "The door that Joe was different could not be

"Judy indicated that her family was 'set up to ensure that her brother appeared normal'"

opened. If we wanted peace within the house, we had to leave that alone." She indicated that the same is still true today. Her relationship with her parents is still strained. Consistent with the research data, Judy also claims to have a minimal relationship with Joe except to see each other during holiday gatherings.

There was much confusion in Judy's mind during her childhood. There were behaviors exhibited by both her mother and father that she simply did not understand. She indicated that her family was "set-up to ensure that her brother appeared normal." Things that Joe was not capable of doing were minimized within the household. An example of this family dynamic emerged when Judy began to excel in athletics. Judy's father had valued and enjoyed athletics as long as she could remember. However, when her father realized that Joe did not exhibit great tal-

ent in sports, it was no longer important. Strengths that Joe exhibited, such as reading and singing, became "valued." Judy felt as if her strengths were "resented" during her childhood and adopted a "why-try" attitude. Judy reports that this disparity comprised a "huge dysfunctional component" in her family.

It wasn't until her ninth grade year that Judy realized Joe was different. She reported that it was hard to notice anything out of the ordinary since her parents stressed that he was good at the things that were important in life. She said the odd things had always been present but she did not realize how odd they really were. Until that point, Joe's idiosyncrasies were the accepted behaviors exhibited by children within the gifted population. At the age of 14 Judy came to realize her brother's behaviors were not typical of all sibling relationships. Since preschool Joe made up stories about Judy and told those stories to anyone willing to listen. Judy's teacher had heard one of the stories portraying her in an unfavorable manner. The teacher questioned Judy in front of her friend regarding the matter. When Judy denied the accusation, her best friend asked her, "Why does your brother keep doing that?" Judy could not answer and it was at that moment she realized that most siblings probably didn't have experiences like these.

Joe's Adult Life

When asked to describe her brother and what his life looks like today, Judy reported that her brother, Joe, is married and the father of a three year old daughter. She stressed that he is an intelligent individual. However, he is also described as "reclusive and socially inept." She reported that he has spent the majority of his life in higher education. He has earned four degrees in different

areas of study. She indicated that when he is interested in a topic, he is extremely focused. However, once his interest is gone, it is impossible to revitalize. This is evidenced by the fact that Joe has earned bachelor degrees in the areas of Petroleum Engineering, History, Political Science, and Electric Engineering. He is now considering law school. Judy states, "School is a safe environment for him. This is where he finds comfort." She elaborated by reporting that "the work world expectations are extremely stressful for him." Statistics indicate that only 12% of individuals with Asperger's Syndrome maintain full time employment status (Myles & Smith, 2007). Emotions of stress and anxiety felt by someone diagnosed with an autism spectrum disorder (ASD) are not uncommon (Barnhill, 2007).

Joe has an unusual fascination for objects that are not always age appropriate. Judy reports that Joe has collected extremely small toy soldiers since he was 14 years of age. At age 40, Joe continues to perform battles with his soldiers and has kept them under his bed since he was young. She imagines this is still the case today. Joe went to Thailand to further his interest in miniature toy soldiers and to have them painted. It was in Thailand that Joe met his wife.

Realization of Asperger's Syndrome

Remarkably, it was during a Tony Attwood conference Judy attended regarding her son Keith that she came to realize that her brother had the characteristics of a person with Asperger's. She describes it as "a light coming on" in her mind. It was during this enlightenment that she began to see her mother's views and understood why her mother went to such lengths to protect Joe. Judy stated, "My mom did this out of love for my brother. I wish I could go back and

change things." It was this profound realization that influenced the way Judy decided to parent her other two children regarding Keith's diagnosis of Asperger's Syndrome. Judy and her husband have chosen to be extremely forthcoming and honest about Keith's Asperger's disorder. Judy sought an explanation for Keith's "differences" early in his life and has been a voice for her son since that time. Judy educated her other children regarding Keith's needs and in turn her children are very accepting of Keith and seek his friendship. On many occasions Judy hears her other two children say "Hooray, Keith is coming to play!" Judy states, "As a parent, I do everything in my power to help Heather and Bill accept Keith. In return, they are his biggest advocates." Judy is very honest about Keith's disability and how it impacts the family unit. His younger sister, Heather, is the person Keith will turn to when he wants to talk or when he needs someone to lean on. This is extremely gratifying for her as a parent of a child with Asperger's. Judy also works hard to ensure that her other children feel valued as individuals with talents and gifts while also having a clear understanding of their brother.

Educational experience

Educational experiences for children with special needs, particularly those with ASD vary a great deal (Myles & Simpson, 2001). One would expect that an individual, who grew up with a sibling with ASD, would have an insight on academic opportunities and parental rights in the educational setting. However, this was not the case with Judy. Joe was never diagnosed with ASD as a child. He did very well in school academically and his social ineptness was disregarded. The family did not acknowledge any differences in an effort to seek help but rather accentuated the differences in such a way as to make them

appear normal. As a result, Judy did not have any school-related experiences upon which to draw when faced with the challenges of Keith in the public education system. Having Keith diagnosed was a challenge in itself. Often parents suspect developmental delays and differences in their child from very early years (Tway & Novak, 2007). Such was the case with Keith. In kindergarten Judy and her husband pressed his school administrators to test him for special education services. The school district insisted on waiting until the third grade to complete an assessment. Therefore, Judy and her husband paid out of pocket for an outside comprehensive evaluation. Keith was diagnosed with sensory integration disorder. It was later, during the third grade, when the school district consented to a full individual evaluation and diagnosed Keith with Asperger's Syndrome.

Keith's school encounters range from "excellent" to "horrible" according to his mother. She reports that during second grade, the district did not make the accommodations to which he was entitled per the Individual Education Plan (IEP). In addition, the district did not fulfill the written testing requests nor did they conduct the Admission, Review, and Dismissal (ARD) meetings in a professional manner. It was during this year that she learned of her legal rights as a parent of a child with special needs. Judy has since transferred her son from one elementary school to another in the same school district to avoid the frustrations between his teacher and other parents of children with special needs.

While exact relationships to neurobiological constructs are not clear, it is clear that autism is a neurobiological disorder (Lord & McGee, 2001). Many children with autism experience frustrations and anxiety out of their control (Chalfant, Rapee & Carroll, 2007). Judy states that many of Keith's teach-

ers felt as if he were "choosing" to behave the way he did. She has observed many teachers responding as if accommodations to address academic and behavioral needs are a special privilege and not a requirement of the student's individual education plan. As a mother and an advocate, Judy believes it is her responsibility to educate others that modifications and accommodations are not only a legal requirement of a child's education but are what some children with disabilities need in order to be successful in school.

Communication between teachers and parents is a critical component for students' academic success. Unfortunately, this is often an area of contention and frustration for parents (Ivey, 2007). Judy stresses the importance of receiving positive communication from educators along with concerns or failures. According to Judy, she needs phone calls from the school that say, "Wow your child did this amazing thing today!" That type of communication is often nonexistent. Parents want to be a part of the educational process as well as a team player (Spann, Kohler & Soenksen, 2003). As a parent of a child with a special need, Judy agrees.

Not only do parents communicate needs to teachers, children also communicate with their teachers on a daily basis. This type of communication is extremely important. Many children with autism spectrum disorders experience anxiety and sensory overload (Farrugia & Hudson, 2006). Keith exhibits many of these characteristics and possesses the cognitive ability and self monitoring skills (Lee, Simpson & Shogren, 2007) to recognize his anxiety and voice this to his teachers. There are times during the day that Keith becomes overloaded with stimuli and needs a break from the rigor of the classroom. To alleviate his anxiety, Keith needs frequent breaks. Judy stresses, "This accommodation

is not a special privilege.” It is her belief, evidenced by history, that Keith needs a break to ensure his success. This break can range from 10 minutes of computer time to a few minutes walking around the school. Often Keith’s teachers refused to allow him breaks which resulted in abhorrent behaviors. Judy has since transferred Keith to a private school for children with and without disabilities and is overall pleased with his current school setting. She reports that he has “supportive teachers that are willing to work with him and meet his needs.”

According to Judy, she was not prepared for the challenges that she faced for her son’s emotional needs. Even growing up with a brother who was socially isolated and who exhibited idiosyncrasies, she was not equipped to deal with the battles that were ahead. Judy reports that one of her biggest struggles is “letting him accept who he is as a person.” Keith’s feelings of low self-esteem and uncertainty about social relationships are similar to that of other children with Asperger’s (Winter-Messiers, Herr, Wood, Brooks, Gates, Houston & Tingstad, 2007). Judy reports, “He realizes that he is different and there is nothing I can do to change that.” On the contrary, when asked what she enjoys the most about her son, Judy expresses that he exhibits a “wonderful sense of humor, is witty, affectionate and a sweet person.” In addition, she appreciates his love for animals and wonderful imagination.

Discussion

Judy will continue to fight for her son’s rights and autonomy for the rest of her life. She has reflected upon her own experiences as a sibling of a child with Asperger’s. Her experiences made a tremendous impact on her parenting styles. Judy has elected to face her son’s disability head on as opposed

to denying its existence as her parents did with Joe. Judy also relishes and appreciates Keith’s idiosyncrasies and accepts them not as “normal” but as part of that which makes Keith unique. In addition, her past has also shaped in both positive and negative ways her values and beliefs. Hence, these beliefs have influenced her behaviors within her family system as she is extremely cognizant of her other children’s needs. Judy recognizes that each of her children possess unique personalities which must be celebrated. Each child has been taught to accept the other children and include them in daily activities. Judy strives to function as a typical mother in a family with a variety of needs and she has ever increasing yet realistic expectations for her children. Judy reports, “Mothers [of children with autism] are the mother tigers of the world. Whether you are born with this personality or not... you become one.”

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