



# **NASET's Autism Spectrum Disorder Series**

## **The Impact of Autism Spectrum Disorder on Family Dynamics: A Literature Review**

This issue of **NASET's Autism Spectrum Disorder series** was written by Erica Williams-Sanders from Florida International University. The literature review describes the effects of Autism Spectrum Disorder on families as a whole when a family member is diagnosed with Autism. Autism changes the dynamics of the family from diagnosis and for the rest of their lives. Everyone in the family: parents, siblings, grandparents and so on, deals with the effects of Autism in different ways. Counseling and other resources are needed for these families; however, they are limited for some depending on finances, culture, and demographics.

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### **Abstract**

This literature review describes the effects of Autism Spectrum Disorder on families as a whole when a family member is diagnosed with Autism. Autism changes the dynamics of the family from diagnosis and for the rest of their lives. Everyone in the family: parents, siblings, grandparents and so on, deals with the effects of Autism in different ways. Counseling and other resources are needed for these families; however, they are limited for some depending on finances, culture, and demographics.

### **The Impact of Autism Spectrum Disorder on Family Dynamics: A Literature Review**

One of the most frightening and devastating words parents can hear is their child/children has been diagnosed with Autism Spectrum Disorder (ASD). Autism Spectrum Disorder is a developmental disorder that has an array of conditions characterized by challenges with nonverbal communication, social skills, repetitive behaviors and speech. These challenges have

complex needs requiring a vast range of medical, educational, and social supports. In recent years ASD has become more prevalent as 1 in 45 children, ages 3 through 17, have been diagnosed with Autism Spectrum Disorder, according parent surveys (Rosanoff, 2015). This is remarkably higher than the official government estimate of 1 in 68 American children with Autism, by the Center for Disease Control and Prevention (CDC). Although more is known today about Autism, there is not any proven evidence of the cause or cure.

This topic has become important because of the alarming rate of children being diagnosed with ASD and the significant impact it has become on their family structure. Once the words, Autism Spectrum Disorder, are uttered, their lives are forever changed.

The first reaction for most parents is shock, denial, and disappointment followed by a plethora of questions from: How did this happen? Will my child ever be able to function like other children their age? What do we do next? How can we care for a child with autism? What will people think? Will our child need to go to a special school? Can we afford the intervention or therapy our child may require? etc. Those questions are just the beginning of what families ask after this diagnosis. It can become overwhelming. After, many of those questions have been addressed and the family has accepted the diagnosis, most parents go on a quest for finding what can help their child function in society. This search can be extremely stressful on parents and siblings because of the time and attention needed to find solutions, resources, help, and services for their child diagnosed with Autism. Siblings may feel sad, embarrassed, and even ignored.

Another stressor for the parents is that in certain parts of the country, help, and services are not readily available or affordable for most families or the school system is not able to provide the appropriate services for the child. When there is no access to help, the sole responsibility falls on the parents. Trying to support the family financially and emotionally can become problematic and many instances marriages are tested and result in divorce.

Milshtein et al. (2010) investigated resolution of the diagnosis among parents of children with autism spectrum disorder. The study included areas associated child (CA, gender, MA, adaptive behavior, diagnosis type, time elapsed since diagnosis) and parent characteristics (age, gender,

IQ broad autism phenotype index, special needs' impact on family). The participants in the study included 61 mothers and 60 fathers of 61 children with autism spectrum disorder aged 2-17 years. Resolution with diagnosis of one's child included coming to terms with and accepting the diagnosis and its implications. A letter was also published in newsletters and websites of parent organizations, parents that wanted to participate contacted those conducting the study. To measure for the assessments of child's diagnosis and functioning level, a variety of assessments such as an Autism Diagnostic Interview-Revised (ADI-R) to assess the areas of communication and language; reciprocal social interaction; and repetitive, restrictive and stereotyped behavior. Another assessment was Autism Diagnostic Observation Schedule (ADOS), it assessed the child's social interaction, communication, play, and imaginative utilization of materials. Parents were interviewed with the Vineland Adaptive Behavior Scales (VABS) assesses adaptive abilities in the domains of socialization, communication and daily living skills. Children were also assessed with a Developmental/IQ Test. There was a 15- minute interview of the parents, in the interview the parents were asked various questions such as when they began noticing that something had gone awry in their child's development ("when did you first realize that your child had a problem?"); how they felt at the time; whether those feelings changed over time; and, if so, in what way. The parents were also expected to ("Tell me exactly what happened when you learned of your child's diagnosis, where were you, who else was there, what were you thinking and feeling at that moment?"); and whether they had and/or have any thoughts about possible causes for their child's condition. There were other assessments for instance the WAIS III, which assessed the parents IQ, an Assessment of the BAP: Autism –Spectrum Quotient (AQ) is a self-report instrument for measuring the degree to which an adult with normal intelligence has traits associated with the autistic spectrum. Family Impact Questionnaire (FIQ) and a Demographic Questionnaire. These interviews were done over 4 in home visits. The results indicate that only about one-third of the mothers in our sample and half of the fathers were resolved to their children's ASD diagnosis. On the other hand, in only one-fifth of the families (20%) both parents were resolved, whereas in 33% of the families both parents were unresolved, and in close to half (47%) only one parent was resolved. The other hypothesis, regarding relation between resolution and the impact of raising a child with a disability on the family was confirmed for mothers only. Compared to resolved mothers, unresolved mothers reported a higher perceived negative impact of the diagnosed child on some facets of family life such as the family's social life and negative feelings about parenting and marriage. Parents who are unresolved with respect to the diagnosis of their child often present cognitive biases regarding

their child and her/his abilities and difficulties. Most are pre-occupied with feasible causes for the disability; they retain an unbalanced view regarding the effects that their child's condition has on them; they seem to lack the energy to move on with their lives; some may be detached from the experience and the feelings surrounding the diagnosis, etc. However, similar patterns were not found for resolved and unresolved fathers. When it comes to resolution with respect to the diagnosis it seems to be an attribute of the parent rather than the child. A little more than half of the parents in the sample (57%) were not resolved, and this lack of resolution was associated with more negative perceptions regarding their child and the influence that raising the child has on the family, among the mothers.

Wesis et al. (2014) conducted a study on the subjective experience of crisis in 155 mothers of children diagnosed with autism spectrum disorder. Understanding what crisis means to families of individuals with ASD could help inform effective preventative and crisis services. The revelation of the thematic analysis was characterized by factors influencing four main areas: demands, internal capabilities, external resources, and subjective appraisal. Mothers of children with ASD report greater emotional problems compared to mothers with intellectual disability without ASD and mothers of typically developing children (Totsika et al., 2011). Often parents of children with autism spectrum disorders report high levels of stress and mental health problems, related with challenges of caring for individuals with complex needs. The participants involved in the study were 155 mothers, aged 26–71 years ( $M = 44.96$ ,  $SD = 7.93$ ), whose children were 5–48 years old (82% male,  $M = 15.31$ ,  $SD = 7.43$ ), out of a larger survey sample of 186 mothers who participated in the quantitative aspect of the survey. The diagnoses were as follows: Asperger syndrome (28%), autism (50%), and pervasive developmental disorder–not otherwise specified (PDD-NOS; 20%). In all, 50% of parents noted that their children had below average intellectual functioning. The immense majority of individuals with ASD were living at home (94.8%). Socioeconomic status was estimated based on the average income related with the participants' forward sortation area of postal codes (first three digits) using Statistics Canada's 2006 Canadian Census ([Statistics Canada, 2008](#)). The thematic analysis was done on data collected from a prodigious, online survey of parents of individuals with developmental disabilities. Crisis arose for mothers when faced with chronic and acute demands stemming from diverse factors: child emotional issues, caregiving, multiple stressors, school stress, death, life changes, child behavior, and family problems. A timing aspect defined crisis, mainly utilizing

the words that depict a chronic experience (e.g. daily lives, regularly, frequent, ongoing, and persistent). The mothers in the survey reported experience crisis in different ways, some witnessing their child being impacted by significant emotional problems such as depression, inability to deal with life, thoughts of self-injury and suicidal tendencies. Crisis may also result from difficulties in the home, or family issues (n = 18), which mothers explain as marriage stress (n = 3), sibling difficulties (n = 3), disrupted dynamics (n = 3), and relationship breakdown (n = 9). Mothers described their crisis as an event that led to significant changes in the family's current way of life (n = 27). The responses falling under this theme were related to death (n = 8), life-course disruption (n = 5), loss of shelter (n = 7), and loss of employment (n = 7). Other mothers depict crisis as vital changes in their life like "change in the household (divorce, separation, death). Some mothers describe their crisis particularly as the cumulative impact stressors for instance in the areas of finance, housing, health, school, and emotional problems. While others associated experience of crisis with their internal capabilities, referring to failed coping (n=35) or functional impairment (n=24). Mothers reported experiencing difficulties getting support from extend family and describe having little support. Lack or loss of resource leads to challenges in the aspect of affordable childcare not to mention the high comorbidity of psychiatric and behavioral disorders in children with ASD results in higher medical cost compared to children without ASD ([McCarthy, 2007](#)). The results showed the four elements (demands, internal capabilities, external resources, and subjective appraisals) interact with each other during experiences of crisis. This study also provided insight to the experiences of mothers of children with ASD.

Horlin et al. (2014) analyzed the financial burden of autism on families and communities. The researchers sent out a registered based questionnaire covering families with a child with ASD in Western Australia. The participants were families with one or more children diagnoses with ASD; 317 records were included in the final analysis. Early diagnosis was less expensive than a delayed diagnosis. Children that were diagnosed early and had proper access to early intervention was known to improve a child's long-term outcomes and a decrease in lifetime cost to the individual, family and society. The Disabilities Services Commission (DSC) in Western Australia assisted with the distribution of the questionnaires to families. There were 3, 965 children registered with DSC with the DSC from 3,723 families. One packet was mailed out to 3, 494 families with one child with ASD, 217 packets were mailed to families with two diagnosed

children, 11 packets was sent to families with three diagnosed children and 1 packet sent out to a family with four diagnosed children. Out of 3,723 questionnaires were mail by the DSC, 521 questionnaires were restored, resulting in a response rate of 15%. Development of the full parent-report questionnaire was informed by anecdotal reports from clinical experts and families, the current research literature and insurance reports. The data analysis included the following treatment-related travel cost (medical, therapeutic and complimentary/alternative treatments), out of pocket cost, loss of income from employment reduction (loss associated with having a child diagnosed with ASD, cumulative cost of having a child diagnosed with ASD (direct and indirect cost), immediate versus delayed diagnosis. The results for the median family cost of ASD was estimated to be AUD \$34,900 per annum (IQR \$20,700- \$51,700; based on median income from wages), approximately 90% of the sum (\$29,200) due to loss of income from employment. The cumulative presence of ASD symptoms had a notable impact on the costs and a delay in diagnosis may indirectly boost the costs by disregarding symptoms that could respond to more immediate intervention. Families of children with ASD, the financial burden correlates with the existing societal financial safety net. In Australian, families could miss out on the most widely available financial support for early intervention if the diagnosis is received after the age of six. There could be detrimental consequences for the well-being of the child and their families, particularly low-income families, especially, if the families are expected to carry a considerable amount of the cost needed to support the development of children with ASD.

The effect of autism on sibling relationships and well-being was examined by Gold et al. (2012). The impact of autism on the family is of particular significance to school psychologists working with students and their families. Research confirms high rates of dysfunction in families with children who have disabilities, findings on the effects of autism on sibling relationships and well-being are commonly divided (Macks & Reeve, 2007; Rivers & Stoneman, 2003). There was both positive and negative effects on siblings of children with autism. The methodology included typically developing siblings and parent participation in the form of empirically based rating scales and questionnaires. Their finding revealed that siblings of children with autism do not exhibit at-risk levels of adjustment problems, feeling of loneliness, or social incompetence. Another study examined a negative perspective from mothers of one child with autism and another who was typically developing. The typically developing child was rated across four domains, involving emotional problems, conduct problems, hyperactivity, and peer problems.

Additionally, component of the questionnaire was a prosocial behavior scale. Rating were compared to a large-scale study of mental health in British children. Data suggested that siblings of children with autism exhibited increased rates of peer difficulties and overall poor adjustment levels. Other areas were analyzed such as the extent to which siblings of children with autism experienced feeling of depression and anxiety. The methodology included evidence-based rating scales and questionnaires that completed by the typically developing sibling and, in some cases, their mother. The finding revealed depression in typically developing siblings correlates with a family history of autism. There were methodological challenges with the study such as small sample sizes were at it limits generalization of results and the overall reliability and validity of the studies. Even with a large sample size and multiple informants, measuring the effect of autism on sibling relationships requires a mixed methodology approach. Another, challenge to studying sibling relationships is assessment of environmental factors and biological predictors (Meaden et al., 2009). Assessments of environmental factors included family size, life stressors, parenting styles, socioeconomic status, social supports and biological predictors associated to family, severity of autism, sex, and birth order. The data in this study was unable to clearly determine the effect of autism on sibling relationships and well-being despite consistently finding increased rates of dysfunction in families with children who have disabilities (Macks & Reeve, 2007; Rivers & Stoneman, 2003). There is not a single assessment tool that provides school psychologist with prediction of adjustment difficulties in siblings of children with autism. It is suggested, multiple evidence-based assessments that measure the quality of sibling relationship should be utilized. The level of support that schools provide siblings of children with autism is encouraged to be assessed by school psychologists. Schools should implement sibling support groups within schools as well as the community which allow siblings of children with autism and other pervasive developmental disabilities the opportunity to share experiences and coping methods. More and more awareness of potentially at-risk population heightens, evidence-based interventions emerges that could guide practitioners to deal with all potential difficulties in the family of a child with autism.

Vieira & Fernandes (2013) assessed the quality of life in siblings of children with autism spectrum disorder. The study was done through a self-response to the World Health Organization Quality of Life (WHOQOL)– BREF questionnaire. There were 77 children on the autism spectrum aged 3 to 16 years, 62 males and 15 females and 21 older siblings, aged 16 to 30 years,

15 females and 6 males, that participated in the study. The participants in the study all lived in the same residence. Many families with a child included on the autism spectrum faced difficulties, as they revealed a higher level of stress in the family system when compared to a control group of families with typically developing children. The family dynamics often suffer mobilization, ranging from financial strains to facets associated to physical, psychological as well as social quality of life (QoL) of caregivers. Seventy-seven autistic individuals, of whom 52 had siblings (68%) and 25 were only child (32%), were investigated. Of those who had siblings, 36 had older siblings (77%), 13 younger siblings (19%) and three both younger and older siblings (4%). Of all the patients investigated, 21 had older siblings who fit the inclusion criteria of the study (totaling 28 potential subjects to whom questionnaires were delivered). However, the siblings of only 17 patients participated in the study, totaling 21 subjects who completed the WHOQOL-BREF questionnaire. The results revealed, the comparison between the various domains identified differences between the Environment and the Psychological (45/33.62) and Physical (15/11.62) domains. The Pearson correlation showed a tendency toward linear correlation between Psychological and Physical domains and between Environment (55/37.62) and Personal Relationships (15/10.71) domains. Although, the study showed elevation in all domains, and the family faced many difficulties it also indicated that the siblings who responded to the questionnaire did not report notable impairment.

### **Conclusion**

All in all, the diagnosis of autism spectrum disorder can impact families in various ways, mostly because it's life changing for the family as a whole. Most families not only have a difficult time accepting the diagnosis, they have additional stressors such as learning how to care for their child or children with autism financially, emotionally and in some cases educationally. It's not only parents that are affected by autism, so are siblings. It is imperative for those diagnosed with autism to receive early interventions. It's just as important for siblings and family members to become a part of a support system.

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## About the Author

Erica Williams-Sanders is a wife and mother of four beautiful children, one of which is a young adult with Autism. She's been an advocate for Autism, for more than 15 years old. Erica is currently working as a Varying Exceptionalities teacher at Koa Elementary School, where she works with students with disabilities, grades K-2. She graduated from Columbia Southern University, Magna Cum Laude with a Bachelor's degree in Health Care Administration in 2015. After graduation, she worked at a private school with students with disabilities and problematic behaviors. She is currently seeking her Master's Degree in Special Education with an Autism Endorsement at Florida International University.