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# Autism and its Impact on Families

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Autism and its Impact on Families

Submitted by Ashley L. Hartmann

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MSW Clinical Research Paper

The Clinical Research Project is a graduation requirement for MSW students at St. Catherine University/University of St. Thomas School of Social Work in St. Paul, Minnesota and is conducted within a nine-month time frame to demonstrate facility with basic social research methods. Students must independently conceptualize a research problem, formulate a research design that is approved by a research committee and the university Institutional Review Board, implement the project, and publicly present their findings. This project is neither a Master's thesis nor a dissertation.

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# AUTISM AND ITS IMPACT ON FAMILIES

## **Abstract**

Autism Spectrum Disorder (ASD) is typically diagnosed in childhood and has a wide range of symptoms, some being more severe than others. The purpose of this research is to examine ASD and how it is impacting families. The empowerment theory, strengths perspective and family systems theory promote resiliency among families who are impacted by an ASD diagnosis. These theories strengthen the individual and family unit by allowing them to live a more fulfilling life. In this study, qualitative research was used. Qualitative research includes data collection, data analysis and drawing conclusions. This study is based off of eight interviews, four being the sibling perspective and four being the parent perspective. There were six primary themes found in the sibling interviews; knowledge of Autism, affect on relationships, feelings of sibling's autism diagnosis, future care for sibling, meaning, acceptance and advice and extended family. There were also six primary themes found in the parent's interviews, feelings around autism, knowledge around autism, life changes, affect on relationships, support systems and acceptance, meaning and advice. My overarching research question asks, what are the experiences of parents and siblings with a child diagnosed with autism? After reviewing the literature, my findings produce both similar and contradictory results which were discussed. This research produced both strengths and limitations. The implications of this research allow current and future social workers to relate and work with families who have a child or sibling with an autism diagnosis.

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### **Introduction**

Autism Spectrum Disorder (ASD) is typically diagnosed in childhood and has a wide range of symptoms, some being more severe than others. These symptoms consist of communication, socialization, behavioral and interest impairments, as well as minimal social skills (Weiss & Lunskey, 2011). Due to these symptoms, a child with ASD may have trouble relating to peers and forming meaningful relationships. Children diagnosed with autism communicate verbally, nonverbally or a combination of both. Due to this aspect of ASD, school curriculum and special education services may need to be modified in accordance to their communication style. Social workers may encounter children with autism who express restricted and repetitive motor mannerisms in order to self-stimulate such as rocking, banging on objects, biting themselves and spinning (Mays, Beal-Alvarez, & Jolivet, 2011). Children diagnosed with autism are often looked at by their peers as being socially awkward.

There has been an increase in the diagnosis of ASD over a short period of time. Approximately eleven years ago, the cases of autism ranged from five per 10,000 (American Psychiatric Association, 2000) to 60 per 10,000 (Altiere & Kluge, 2009). A recent study concluded that autism is affecting approximately 1 in every 110 children and is growing at a rate of 10% to 17% per year (Meadan, Halle, & Ebata, 2010). ASD is becoming more and more prevalent in today's society with males being affected 4.5 times higher by this diagnosis than females (Rice & Centers for Disease Control and Prevention, 2009). With that said, social workers with knowledge and experience in this are in high demand with this population as this diagnosis not only affects the individuals themselves, but it affects their families as well.

An autism diagnosis can be perceived as a loss for the family;

The grieving process associated with the birth of a child with disabilities is complicated by the parents' grieving the death of the 'expected' baby while at the same time trying to accept the 'imperfect' baby. Even though they have the joy of being able to hold and love their baby, their life is suddenly and drastically changed (Hooyman & Kramer, 2006, p. 200).

This in turn produces feelings of grief, stress and confusion. Immediately, with no warning or preparation, the family has to transform and adapt to a new lifestyle. Daily routines become much more complicated, family vacations become much harder to plan, and families find themselves no longer able to do some of the things they were once able to do. Mothers and fathers reported more stress when having a child diagnosed with autism as opposed to parents who have children with Down syndrome and parents of typically developing children (Meadan et al., 2010). With the causes of autism still unknown, parents experience blame for their child's autism. Some fathers may blame the autism on their wives (Barnes, Hall, Roberts, & Graff, 2011). This was once defined as a refrigerator mother. The term "refrigerator mother" was invented by Leo Kanner. It was used to describe a parent who was seen as cold and uncaring and as a result, traumatized their child causing them to retreat into autism (about.com). In addition to parents being affected by this diagnosis, the sibling(s) of a child diagnosed with autism are also impacted. Siblings are impacted in similar ways as their parents. Siblings may experience worry, anger, embarrassment and have an inability to understand the autism diagnosis. The sibling's dream of having a normal playmate or companion is no longer congruent with their past expectations (Naseef, 1989).

The initial autism diagnosis leaves parents and siblings confused and they may have a hard time accepting that the child/sibling they were anticipating is not the child/sibling they expected. This new transformation in their family impacts the relationships in the family, as feelings of fear and worry encompass the family system. It is important for social workers to have general knowledge and resources regarding this because social workers will encounter families in the school system or in other settings.

The purpose of this research is to examine ASD and how it is impacting families. The following research question is; what are the experiences of parents and siblings with a child diagnosed with autism? The goal of this research is to empower families whose children present with ASD as well as provide educational support and further knowledge and understanding for social workers and other professionals working in the field.

## **Literature Review**

### **Characteristics of Autism**

In 1943, Leo Kanner officially acknowledged the Autism Spectrum Diagnosis as a clinical disorder. At this time, autism was extremely rare with approximately 2-4 out of every 10,000 children being diagnosed. Prior to this acknowledgment, children were often classified as emotionally disturbed or mentally retarded (MacFarlane & Kanaya, 2009).

Autism Spectrum Disorder, also known as ASD, is extremely complex and has a wide range of symptoms. ASD is categorized in the *Diagnostic and Statistical Manual of Mental Disorders, IV ed.* (DSM-IV) as a pervasive developmental disorder. An individual diagnosed with autism may communicate verbally or nonverbally, they may follow



restricted and repetitive routines as well as exhibit restricted motor mannerisms (American Psychological Association [APA], 2000, p. 72). Children who are diagnosed with ASD are very interested in friendships but lack the social skills to develop these relationships and are unable to relate to peers. The population often displays atypical sensory related behaviors such as excessive rocking, spinning and twirling in order to self-stimulate. Another aspect of the autism diagnosis can be sound sensitivity. Children who are diagnosed with ASD may be observed covering their ears or wearing a headset to drown out unwanted sounds (Schaaf, Toth-Cohen, Johnson, Outten, & Benevides, 2011). Behavioral symptoms are also recognized in children diagnosed with autism including hyperactivity, short attention span, impulsivity, aggressiveness, self-injurious behaviors and temper tantrums (APA, 2000, p. 72).

The autism spectrum ranges from low to high with some symptoms being more extreme than others and because of the wide range of manifestations, this disorder varies greatly. ASD is typically diagnosed in children by the age of three where difficulties are recognized in the area(s) of social interaction, language for communication, and/or restricted, repetitive, and stereotyped patterns of behavior (MacFarlane & Kanaya, 2009).

ASD is one of the top three most expensive diagnoses in special education. Generally, students diagnosed with ASD are eligible to receive services for special education only if the child's impairment or behaviors are interfering with his or her academics (MacFarlane & Kanaya, 2009).

The development skills of a child with ASD could progress normally in the first years of life but then deteriorate or progress no further. It has been reported that up to

30% of children with ASD regressed in their development skills or completely lost these skills before the age of two and up to 11% of children who are diagnosed with ASD, prior to the age of two, had development skills that did not progress any further (Rice & CDC, 2009). If a child presents no eye contact or is not meeting developmental milestones, this may indicate an autism diagnosis and parents should seek out professionals to conduct appropriate assessments (Whelan, 2009).

### **Prevalence, Gender, and Ethnicity**

Autism is becoming more prevalent. It has been found that in children 18 years of age and under, the prevalence of autism ranges from five cases per 10,000 to 60 cases per 10,000 (Altiere & Kluge, 2009). Another study done by the Autism Developmental Disabilities Monitoring (ADDM) Network indicated an overall prevalence of ASD to be 9 in every 1,000 children (Rice & CDC, 2009). Findings from a recent study indicated that ASD is affecting 1 in every 110 children with a growing rate of 10% to 17% per year. Due to the growing prevalence of ASD, interest in autism and its affect on families is present (Meadan et al., 2010).

Gender plays a role in the prevalence of autism, with more boys being diagnosed than girls. A study was conducted showing the gender differences in the autism diagnosis. Findings indicated the prevalence of ASD in males ranged from 7.3% in Florida to 19.3% in Missouri whereas the ASD prevalence among females ranged from 1.0% in Florida to 4.9% in Arizona. This brought the overall prevalence ratio across all sites to 4.5:1 with males obtaining 4.5 and females obtaining 1 (Rice & CDC, 2009).

ADDM indicated the prevalence rate of ASD being 4.5 times higher in males than in females. This study also found that the ASD prevalence was 14.5 per 1,000 males and 3.2 per 1,000 females in children eight years of age (Rice & CDC, 2009). According to Rice & CDC, 2009, ADDM indicated that ASD increased across all sex, racial/ethnic, and cognitive functioning subgroups from 2002-2006. “Data from the 10 ADDM sites with results from multiple surveillance years (4, 12) indicate a significant average increase (57%) in identified ASD prevalence in 2006 compared with 2002 (range: 27%-95%)” (Rice & CDC, 2009).

In addition to gender being a factor in the ASD prevalence, ADDM indicated that ethnicity plays a role in the autism diagnosis. ASD is more prevalent in non-Hispanic white children than it is in non-Hispanic black children and Hispanic children. After combining data from all sites, non-Hispanic white children diagnosed with ASD ranged from 9.4%-10.4%, whereas non-Hispanic black children ranged from 6.6%-7.8% and Hispanic children from 5.3%-6.6% (Rice & CDC, 2009).

Early identification and interventions are important to examine among ASD as the prevalence of this diagnosis is growing significantly. Statistically, Non-Hispanic white males are most at risk for autism. Causes are still unknown.

### **Impact on Parents**

Parents whose child is diagnosed with ASD experience difficulties and it changes the dynamics of the family in that everyday activities need to be modified and the child with ASD will need extra attention from the parents. Learning that your child is autistic can result in scattered emotions for the parents. Each family handles the vision of their

child differently. Just as the spectrum varies, so does each family's experience. Upon hearing their child's diagnosis, one study found that in parents, "52% felt relieved, 43% felt grief and loss, 29% felt shock or surprise, and 10% felt self-blame" (Banach, Iudice, Conway, & Couse, 2010). Often, parents are relieved that they were given an answer in regards to their child's symptoms but this does not erase the stress that they endure while raising a child with autism. Parents often experience stressful situations upon the initial diagnosis that relate to their child's behavior, adapting to this new lifestyle and the complexity of finding access to the appropriate services useful to the family (Banach et al., 2010). Stressors from an ASD diagnosis can cause a strain on parent's marital relationship, increase financial burdens in the family and result in parents socially isolating themselves from others. Parents experienced stress as a result to modifying goals and activities for their child diagnosed with autism, having to implement different arrangements for the child's education as well as grief due to limited opportunities offered to their child (Naseef, 1989). Findings indicated that mothers reported having more stress than fathers related to their child diagnosed with autism as mothers are usually the primary care givers of these children and are more active in the child's education (Dabrowska & Pisula, 2010). In the following section, parental stress of receiving information that their child has autism will be explored (Autism Society, 2011).

### **Parental Stress**

One main stressor for a parent is their child's inability to express their basic needs. This produces frustration for both the parent and the child. The parent will experience difficulty clarifying the needs of their child diagnosed with autism while the child will experience difficulty expressing their own needs. This can often result in

aggressive behaviors for the child diagnosed with ASD as parents may be unaware if their child is hungry, sick, tired, hurt, sad or mad. This is especially stressful for the children who are non verbal. Extreme worry may also be present in parents as their child may be unable to report abuse or neglect in other settings. Parents experience worry and concern that their child may be potentially harmed because often, they cannot communicate verbally and are highly vulnerable (Autism Society, 2011).

Another stressor is parents taking their child diagnosed with autism out in the community. Persons out in the community may not understand or be sensitive to the behaviors that may occur. This also makes parents hesitant to take their kids over to friends or relatives houses because they feel as though they cannot socialize or relate. This sometimes leaves parents experiencing a sense of isolation from their friends, family and the community (Autism Society, 2011).

A third stressor parents experience is the concern for their child's future welfare. Parents provide the best care and understand their children. They may experience fear as they plan for their children's future and examine ways of proper care. Some children, depending on their developmental ability, may need toileting and bathing assistance. Future care giving presents stress in parents because in certain circumstances, there are no other family members capable of taking over when the parents are no longer able to care for their child (Autism Society, 2011).

A fourth stressor for parents is the financial aspect. A child diagnosed with autism needs several services to assist in their care and can often times be financially stressful for the parents. A child may need evaluations, home programs, and various therapies

which can be expensive. After the child turns eighteen and the parent wants to continue having custody of that child, court and a nominal guardianship fee is required. If one parent has to give up his/her job to help with caretaking, this can be financially stressful as it leaves one parent to support the entire family (Autism Society, 2011).

Finally, feelings of grief can be stressful on the parents. The 'typical' child parents were expecting is no longer reality. They are faced with the loss of lifestyle changes and drastic changes in their family dynamics that may be produced from an autism diagnosis. Parents grieve the loss of the child they expected for themselves and their family (Autism Society, 2011). These feelings of grief can occur throughout the parent's life as different events can trigger this grief. Some triggers include birthdays, holidays, continuous care giving, weddings and reproduction.

### **Routines in Autistic Children**

Children diagnosed with autism often follow specific routines in their everyday life. One study indicated that parents have to rearrange their daily routines to accommodate to the child as the child is unpredictable and often unable to regulate their behavior. Parents reported that routines were much easier to follow in familiar spaces such as their own home, however more difficult in unfamiliar places such as another relatives home or out in the community (Schaaf et al., 2011). The parent often feared that if the child became disregulated, the child would damage another's belongings. In unfamiliar places, parents often do not have the tools needed to prevent or cope with disturbances that could possibly set off the child. This resulted in parents taking less

family vacations, attending limited community outings and isolating themselves from family and friends (Schaaf et al., 2011).

Parents reported morning routines to be most difficult as most meltdowns occur during this time due to sensory issues, causing the child to be late for school and the parent to be late for work. Mealtime was challenging as a child diagnosed with autism can be sensitive to certain textures of food, often refusing to eat (Schaff et al., 2011).

Although raising a child diagnosed with autism can be extremely stressful and life changing, families may not have a negative experience. Parents are able to find resilience in their child's autism diagnosis and are able to recognize positive ways in which the autism has impacted their lives. A child diagnosed with autism allows the family to see life from a strengths based perspective. The child with autism helps the parents and siblings become more empathetic and compassionate to other kids who may be viewed as different (Neely-Barnes, Hall, Roberts, & Graff, 2011).

### **Informing Siblings of ASD**

In addition to the parents, siblings are also very much impacted by the autism diagnosis. Siblings, however, may not fully understand the diagnosis as they do not receive explanations from specialists and are still developing themselves.

One study indicated that siblings reacted adequately when informed by their parents about their sibling's autism diagnosis. They showed a more accepting attitude than expected as well as understanding and a desire to learn more about the diagnosis (Tanaka, Uchiyama, & Endo, 2011). It is important for siblings to be informed of their brother/sister's autism diagnosis so they are able to connect with peers who are

experiencing the same situations. Another study's findings indicated parents were more likely to inform their typically developing child when they were older than their sibling diagnosed with autism by two years or more. Typically, parents informed their children of a sibling's autism diagnosis followed by information which would allow them a further understanding of their sibling (Tanaka et al., 2011).

### **Sibling Stress**

There are several sources of stress that a sibling could experience when having a sister/brother with autism. The following paragraph will examine some of the main stressors found.

One stressor for siblings is the embarrassment around peers. In having a sibling with autism, they may say or do things that others find "weird" and/or exhibit aggressive behaviors. A sibling may feel awkward or nervous bringing friends around their brother/sister with the fear of the unknown (Autism Society, 2011). A study indicated siblings ages 7-20 who have a brother/sister diagnosed with ASD mentioned feelings of embarrassment. Another study confirmed these results with siblings reporting the negative aspect of having a brother/sister with autism is feelings of embarrassment (Orsmond & Seltzer, 2007).

Another stressor for siblings is the jealousy regarding the amount of time parents spend with their brother/sister diagnosed with autism. Due to the significant needs of children with autism, the sibling may feel as though he/she is being ignored. It may be hard for some parents to balance time with their other children if their child with autism is in high need. A child with high needs may require assistance with eating, toileting,



personal cares and behavior modification which can occupy the parents time. In some cases, the typically developing child may act out in hopes to intercept some of the parental attention (Autism Society, 2011).

A third stressor for siblings is the frustration over not being able to engage or receive a response from their brother/sister with autism. It can be hard for siblings, especially at a young age, to figure out how to engage with their brother/sister with autism. These siblings may also become the target of aggressive behaviors, pushing them away from wanting to engage and play with their brother/sister with autism (Autism Society, 2011). A study reported that in siblings ages 8-15, 84% reported aggression produced by their brother/sister with autism when trying to interact with them (Orsmond & Seltzer, 2007).

A fourth stressor for a sibling is the concern regarding their parent's grief and stress. A child is able to sense when a parent is stressed which in turn stresses out the child. Unconsciously, the parent may take their grief and stress out on the sibling. The sibling may also feel the pressure to have to make up for the deficit of their brother/sister with autism (Autism Society, 2011).

Finally, the concern over their role in future care giving of the child diagnosed with autism can be stressful for siblings. A study indicated siblings reported significant concern regarding the future of their brother/sister's autism (Orsmond & Seltzer, 2007). A sibling may feel obligated to take over for the parents when they are no longer able to care for the child diagnosed with autism. On the other hand, a sibling may be persistent about taking over for the parent, however, fear they will not be able to provide

appropriate care and financial stability by the time the care is needed. A sibling often worries about what will happen to their brother/sister with autism in the future (Autism Society, 2011).

### **Adjustment Problems in Siblings**

One study found siblings of children diagnosed with ASD are more likely to experience adjustment problems which are more prevalent in siblings of children with more severe ASD symptoms (Meyer, Ingersoll, & Hambrick, 2011). Another study found that 40% of siblings, reported by their mothers, were experiencing severe adjustment problems. This was followed by a finding that major depressive disorders in siblings of children with autism have increased (Ross & Cuskelly, 2006).

A more current study displayed contradictory results. Findings indicated that siblings do not experience increased depression symptoms due to their siblings ASD diagnosis. It has not been found to be a factor in these sibling relationships (Orsmond, Kuo, & Seltzer, 2009).

### **Adult versus Adolescent Sibling Relationships**

One study that examined adult sibling relationships and adolescent sibling relationships with a child diagnosed with autism indicated the following results (Orsmond et al., 2009). Adolescent siblings were more actively involved in shared activities than that of the adult sibling. Positive effects on the relationship as well as depressive symptoms in these two separate sibling age groups did not have any significant difference. In adult sibling relationships, it was found that adult women were more involved in shared activities with their sister who is diagnosed with autism than that

of the adult brother. Positive adult support was found to empower the sibling relationship in both adults and adolescents. Being from a larger family was also an aspect that had a positive influence on the adolescent sibling relationship with their brother/sister diagnosed with ASD (Orsmond et al., 2009). It was also found that if the sibling diagnosed with ASD was younger than the adult sibling, they were more likely to engage in activity with their brother/sister (Orsmond et al., 2009).

### **Positive Sibling Relationships**

Although having a sibling diagnosed with ASD can be a challenge, there have been reports of positive interactions. Siblings were able to gain a profound appreciation for their brother/sister with autism. After interviewing several siblings of children diagnosed with ASD, one study found that there were positive results within these relationships. One sibling reported that if given the chance, he would not want to take away his brother's ASD because he likes his brother the way he is. Another sibling reported playing and having fun was the best part of having a brother with autism. Several children interviewed in this study viewed their sibling's autism as a part of who they are (Petalas, Hastings, Nash, Dowey, & Reilly, 2009).

An observational study indicated that siblings reported spending a significant amount of time with their brother/sister with autism during childhood. It was reported that siblings ages 2-12, spent approximately 40 minutes out of every hour together when playing at home. Another study using sibling's self reports, found that siblings ages 7-12, typically endured in positive relationships with their brother/sister with autism. A third study had similar findings in a qualitative study with siblings ages 7-20. Almost half of

these siblings reported playing with their brother/sister with autism and having fun together. Siblings watched television, played together and spent time outside (Orsmond & Seltzer, 2007). Although the ASD diagnosis can produce stress within the sibling relationship, there have been positive interactions reported. Not every typically developing sibling views their brother/sister's autism as a negative experience.

### **Impact on Grandparents**

In addition to siblings and parents, grandparents are also very much impacted by their grandchild's autism diagnosis. Recent findings indicate that one in 166 grandparents have a chance of becoming a grandparent to a child diagnosed with autism (Hillman, 2007). It has been reported that grandparents of a child diagnosed with autism hurt twice, the first time for their child and the second time for their grandchild. ASD presents families with unique stressors, including grandparents. Grandparents, similar to parents, experience sadness, frustration, and disillusionment due to their grandchild's inability to express their feelings or needs. Grandparents also fear or avoid taking their grandchild out in public settings because of behaviors that are produced from the autism diagnosis. Studies have indicated that maternal grandparents are more supportive and involved than paternal grandparents. Maternal grandparents are more likely to rate the child's symptoms of ASD more positively than parents. Mothers and fathers of a child diagnosed with autism have both benefited from maternal and paternal grandparent involvement as it has helped reduce stress. Grandparents have been described as providing emotional, practical, and instrumental support as well as being emotionally supportive and providing the parents with empathy. A majority of grandparents are in need of social support as a

result of the stressors that are produced from their grandchild's autism diagnosis (Hillman, 2007).

### **Coping with an Autistic Child**

Coping is an important aspect in the grieving process when presented with an autism diagnosis. Coping compliments the family's acceptance process. "The grieving process associated with the birth of a child with disabilities is complicated by the parents' grieving the death of the "expected" baby while at the same time trying to accept the "imperfect" baby. Even though they have the joy of being able to hold and love their baby, their life is suddenly and drastically changed" (Hooyman & Kramer, 2006, p. 200). One way parents can cope with the stress of autism is by networking with other families who have been affected by the disorder. This provides parents with comfort in finding others who are experiencing similar situations as well as receive advice that will be useful in the parenting process (Autism Society, 2011). Some primary places in which parents can receive support include support groups, other parents of children with autism, social workers, occupational therapists, special education teachers and other mental health professionals. One study indicated that social support from friends, family and spouses reduced depression and increased the well-being in parents of children with autism. Spousal support was indicated as the most beneficial source of support as they provide respite, divide household responsibilities and share the disciplinary role for one another. Another study indicated respite care to be a significant support in coping with autism. Respite is a service in which another adult assumes the role of the parent for a child diagnosed with autism, giving the natural parents a break. This has been found to reduce stress levels in both parents (Meadan et al., 2010).

One study indicated formal supports as a coping mechanism for parents. This includes support groups, health and professional services and counseling. These services allow the parents to discuss current issues and gain knowledge of their child's ASD diagnosis (Meadan et al., 2010). Another study explored the effectiveness of support groups for siblings of children with autism. This study indicated siblings deepened their understanding and knowledge about the autism diagnosis (Meadan et al., 2010). Another study examined the effectiveness of support groups for parents of children with autism. The study indicated parents who were given the opportunity to connect with other parents of children with autism, may likely reduce stress and social isolation while allowing them to network and find appropriate resources (Meadan et al., 2010). Another study indicated parents utilized parent support groups and social support to cope with the stresses of an autism diagnosis. It was also found through several other studies that support from marital partners were helpful when coping with stress (Mancil, Boyd, & Bedesem, 2009). A different study found the high need for support groups. It was found that parents gained knowledge and were empowered to advocate in the community with other parents whose children were diagnosed with autism (Banach et al., 2011). Another study demonstrated the significance of social support when families are coping with an autism diagnosis (Altiere & Kluge, 2009).

Parents are able to adapt adequately when they receive support from others through networking. Information from health care providers and agencies is also helpful (Meadan et al., 2010). Further suggestions parents can utilize in order to cope with the stress of raising a child with autism include prayer, exercise, deep breathing/relaxation exercise, writing in a journal, keeping a daily schedule of things to accomplish, advocacy,

and individual, marital or family counseling. Coping with a loss is significant and will make it easier to find acceptance in that loss (Autism Society, 2011).

### **Coping Fathers**

One study indicated that fathers of children diagnosed with ASD put significant trust in their spouse to help support the family (Altiere & Kluge, 2009). The authors discuss how fathers rely on their marital relationship as a source of support by discussing concerns and building a closer relationship. This study also indicated that fathers found it helpful in coping with an ASD diagnosis by keeping family stability such as involving all members of the family in activities (Altiere & Kluge, 2009). Connecting with other parents who have a child diagnosed with ASD was helpful in coping for these fathers as well. In addition to the coping mechanisms used by fathers, this study indicated that mothers also reminded themselves of the things they are thankful for and continue to do things with their children in order to cope (Naseef, 1989). Another study indicated that fathers are less likely to seek out social support from friends and family as opposed to mothers whose child is autistic. Father's reported losing friends to a child's autism diagnosis because their friends could not relate to the challenges associated with ASD (Altiere & Kluge, 2009).

### **Types of Coping**

There are two types of coping, one being the approach and problem-focused strategies and the other being avoidant and emotion-focused strategies. Approach and problem-focused strategies define individuals who pay attention to a stressor and seek out

a solution. Avoidant and emotion-focused strategies define individuals who ignore, minimize and deny their stressor (Meadan et al., 2010).

One study indicated that those who utilize approach and problem-focused strategies adjust better whereas those who utilize avoidant and emotion-focused strategies resulted in higher stress levels and mental health issues (Meadan et al., 2010). Another study was conducted over an 8-10 year period in which parental coping strategies shifted. In the beginning of the study parents were more likely to use problem-focused strategies but later shifted towards emotion-focused strategies such as relying on their religious faith (Meadan et al., 2010). The authors found that families who utilize various methods of coping strategies enhanced their family bond and had decreased levels of stress (Meadan et al., 2010).

### **Interventions/Treatments**

There are several services and approaches to utilize when working with a child diagnosed with autism. One study found that parents of children diagnosed with ASD were in need of consistent therapy with their children as well as assistance from knowledgeable professionals (Siklos & Kerns, 2006). Another study indicated speech therapy being the most common service for children diagnosed with autism as 87.3% of families utilized this source followed by occupational therapy with 67.5% of families utilizing this source. This study also indicated 45.6% utilized behavioral management programs while 42.7% utilized learning strategies and study skills assistance (MacFarlane & Kanaya, 2009). Another study indicated that in school, 83% of families used speech and language therapy, 64% of families used occupational therapy, 28% used



social skills training, and 11% used physical therapy. Findings in this study indicated that outside of school, 57% of families used care from family or friends, 12% used special summer camp, 11% used respite care and only 1% used residential placement. Twenty-eight percent of these families used a case manager and only 8% used a behavioral specialist. Forty percent of these families used medication, 10% used supplements only and 8% used a combination of the two. Picture exchange communication was used by 23% of families outside of the home and 21% used sensory integration therapy outside the home. Thirty percent of families used parent support groups and only 4% used family counseling. Only 1% of siblings used support groups (Thomas, Morrissey, & McLaurin, 2007).

Another effective intervention is video modeling. Video modeling is used to target various behaviors in different aspects of functioning such as language, social behavior, play, academics, and adaptive skills in a child diagnosed with autism. The purpose of this intervention is to facilitate observational learning (Corbett & Abdullah, 2005). This intervention begins by determining the skill or behavior to target. Once the skill or behavior is identified, the facilitator will write a script that addresses that skill or behavior, prepare a video and repeatedly show the videotape to the learner. After the video is shown, the facilitator will attempt to perform the target behavior or skill and practice the behavior or skill with the learner until the learner can perform the skill or behavior on their own (Corbett & Abdullah, 2005). Video modeling has been demonstrated to increase appropriate social interactions, improve conversation skills, improve daily living skills, improve play skills, and reduce problem behavior. Video

modeling has been implemented alone or in combination with other strategies (Ganz, Earles-Vollrath, & Cook, 2011).

One study indicated social stories to be an effective tool when working with children diagnosed with autism. This showed improvement in classroom behavior for students following social stories (Chan et al., 2011). Social stories are short narratives used to promote positive behavior. The language used in social stories is simple and emphasizes what to do in certain situations after being provided with descriptions of the environment. Social stories allow children diagnosed with ASD to learn social skills, deplete bad behavior while improving communication skills and learn self-help skills. The study indicated that social stories resulted in mild to moderate improvement in target behaviors (Chan et al., 2011). Carol Gray is the originator and owner of social stories. Carol Gray has a reputation as an educator to individuals diagnosed with ASD as well as their parents and other professionals. Her social stories are used in the education of individuals with ASD and have been proven effective. Social stories written by Carol Gray can be found in published books by Future Horizons, Inc. and Jessica Kingsley Publishers. Her work can also be found in a variety of articles written for the morning news and the Jenison Autism Journal (Autism spectrum disorder, 2012).

Self-stimulating behaviors such as bouncing, rocking and covering the ears are all common upon children diagnosed with autism. Although these methods can be self-stimulating for them, they can also interfere with the child's ability to attend, communicate, learn and interact. It is important for sensory interventions to be implemented in order for the child to focus and learn new skills. Sensory interventions

also allow the child to register and regulate sensory stimuli responses which will prevent over reactive or under reactive behavioral responses to occur (Mays et al., 2011).

Another intervention used by occupational therapists is the weighted vest. The purpose of the weighted vest is to provide deep pressure stimulation to the child in order to calm the central nervous system. It is a sensory tool provided by the sensory integrative framework. In one study, 82% of occupational therapists in schools reported using this intervention (Morrison, 2007). These occupational therapists witnessed positive benefits of calming, increased attention and decreased self-stimulating behaviors. One study found moderate improvements in focus and decreased distractions by the students while wearing the weighted vest (Morrison, 2007). Another study found no improvements and for three students, negative outcomes occurred due to the weighted vest (Morrison, 2007). Another study in which the weighted vest was used with children diagnosed with autism in a school setting indicated decreased negative self-stimulating behaviors, and a small increase in positive behaviors such as staying on task and following instructions (Morrison, 2007).

Play therapy is an intervention often used by occupational therapists when working with a child diagnosed with ASD. Children are more apt to express themselves through play as it is a way professionals can enter the children's world. Play allows these children to problem solve by using toys as well as express any fears, anxieties, fantasies and guilt through objects. One researcher indicated that play has resulted in emotional, social and intellectual growth (Parker & O'Brien, 2011). Sand play is a technique often used in play therapy with children on the autism spectrum as it provides high sensory stimulation. Children diagnosed with ASD play with toys in a sand tray and shape the

sand. Sand play is categorized as an expressive therapy; children diagnosed with autism typically share inner thoughts and feelings with their toys that they would not normally verbalize. One study reported sand play to be the most favored therapeutic approach by children. Literature over many years indicated that play was effective in children experiencing several different issues, including autism (Parker & O'Brien, 2011).

Picture Exchange Communication System training (PECS) is also a commonly used intervention. The PECS training is typically used with the nonverbal children who are diagnosed with autism as it increases communication by using picture cards. One study indicated that PECS training enhanced speech as a means for communication as well as encouraged the students to use picture cards to communicate. PECS training teaches simple communicative words first, such as requesting for a drink or a toy. One study indicated a positive effect with this communicative function through PECS (Gordon et al., 2011). There are several interventions used when working with a child diagnosed with ASD, in which a few of the primary ones were identified. ASD has a wide spectrum so interventions are to be used per case as some children may communicate verbally and some may communicate non verbally. It is also important to identify their symptoms and presenting behaviors when choosing and intervention.

Applied behavior analysis (ABA) is commonly used when working with children diagnosed with autism. There are four ABA's that have been identified to be effective including video modeling, visual strategies, social script fading, and task analysis. Video modeling which has been described above, allows the student to observe a videotape of a model demonstrating a target behavior that the student will then imitate. Visual strategies which are very similar to PECS, use a visual cue large enough for the student to see. This

visual cue prompts the student to engage in a behavior. Social script fading is focused on social interaction through audiotape or a written script. Once the student masters the social skill that has been demonstrated, the script is reduced or faded out until the skill is performed without the script. Task analysis breaks down a difficult behavior into smaller parts or fewer steps then positively reinforces each small positive response. Task analysis is effective when teaching personal hygiene (Wofe, Condo & Hardaway, 2009). Another strategy of ABA is social stories which have been described above. Social stories are short stories developed to direct the attention towards a difficult social skill or situation. The concepts and principles of ABA are directed to compose meaningful and functional behavior change so the individual is able to live more independently (Szapacs, 2006).

### **Conclusion**

In conclusion, Autism is a complex disorder that is diagnosed in childhood and has a wide range of symptoms. ASD has become more prevalent with males at higher risk of the diagnosis than females. ASD impacts parents and siblings as it changes the dynamics of the family. It is significant for families to find coping mechanisms that work for them as they are needed to help find acceptance. There are several different approaches and services available to families of children diagnosed with ASD which help alleviate some of the stressors families' experience. Social workers are needed to educate these families and provide them with appropriate resources. In the following section, I will discuss the conceptual framework that guides this research project.

## **Conceptual Framework**

### **Introduction**

In this section, I will use the conceptual framework of empowerment perspective, strengths perspective and family systems theory as they all apply to this research. This researcher found these theories to be most effective when dealing with families who are presented with an ASD diagnosis.

### **Theories**

The first theory applicable to this research is the empowerment perspective. The empowerment perspective is important because the purpose of this research is to empower families who are impacted by an ASD diagnosis. The focus of the empowerment perspective is to help individuals and families gain control over their life situation. The empowerment perspective allows these families to emphasize their ability to survive in the most difficult situations. Social work professionals are needed to help empower families who are experiencing the difficulty of an ASD diagnosis. Social work professionals empower these families by connecting them with appropriate resources and providing them with useful information. Social work professionals use the empowerment perspective to help clients lead a more satisfying life by creating their own goals (DeJong & Berg, 2008).

Another theory that can be used with families who encounter an ASD diagnosis is the strengths perspective. The strengths perspective focuses on the strengths of the client rather than client problems and deficiencies. The strengths perspective is a collaborative exploration by the client and professional to identify client strengths. This allows social work professionals to emphasize the client's potential and success and move away from the client's dysfunctions. This prevents the discouragement of clients and promotes client

motivation. It is important to use strengths perspective when working with families who are impacted by an ASD diagnosis as it assists individuals, families and communities to apply their identified strengths in real life situations. This will in turn improve the overall quality of life. Social work professionals focus on client strengths which prevents the social work professional from judging or blaming the client. The overall focus of the strengths perspective is to help clients become more aware of their successes and strengths (DeJong & Berg, 2008).

Finally, family systems theory is useful when working with families who are impacted by an ASD diagnosis. Family is the most important support system for a child. The family systems theory focuses on the shift of an individual perspective to a family systems perspective. The family is looked at as a unit, therefore, by using the family systems theory, social work professionals are able to identify family influences on the individual client (Paylo, 2011). Family systems theory is especially important when working with families who are impacted by an ASD diagnosis because the family as a whole is coping with this disorder. The family system impacts a child's development as family members affect the thoughts, feelings, and behaviors of one another (Paylo, 2011).

### **Conclusion**

In conclusion, the empowerment theory, strengths perspective and family systems theory promote resiliency among families who are impacted by an ASD diagnosis. These theories strengthen the individual and family unit by allowing them to live a more fulfilling life. Being presented with an ASD diagnosis in the family can be a struggle

which is why this researcher identifies three theories that will allow these families to overcome this struggle in the hopes to strengthen the family bond.

## **Methodology**

### **Introduction**

In this section, the researcher will identify the methodology that was used in this study. This was a qualitative research project.

Qualitative research collects information by raw data through observation in the form of words, pictures, descriptions or narratives. Qualitative research includes data collection, data analysis and drawing conclusions. Qualitative research is more exploratory and descriptive and researchers are able to discover how individuals structure and give meaning to their everyday lives. Narrative interviews allow participants to better express their meanings and feelings on a specific research topic. In this study, the researcher used narrative interviews as a method of data collection. Qualitative research seeks appropriate answers to questions by investigating several different social settings involving a deeper understanding of people's lives and behavior (Monette, Sullivan, & DeJong, 2008).

### **Sampling**

This researcher recruited eight participants through convenience sampling. Convenience sampling can be defined as using samples that are readily available and convenient (Monette et al., 2008). This researcher seeked out four individuals obtaining a parental perspective on a child diagnosed with autism and four participants obtaining a



sibling perspective on a child diagnosed with autism. This researcher provided a ten dollar gift card to Target as an incentive for participants who were involved in this study.

Four participants were recruited through convenience sampling. The researcher identified these four participants that provided a parental perspective on autism and its impact on families. These participants all held a parental perspective on autism and its impact on families. Four participants were recruited through convenience sampling. The researcher identified these four participants that provided a sibling perspective on autism and its impact on families. These participants all held a sibling perspective on autism and its impact on families. Client confidentiality was protected by this researcher.

### **Data Collection**

In this research project, the researcher interviewed eight participants on autism and its impact on families. A semi-structured qualitative interview was conducted in order to collect data. This researcher emailed each participant an information sheet regarding the content of this research. Each participant was contacted by email during the month of January to coordinate a meeting time. Upon arriving to the interview, this researcher provided each participant with a consent form that was signed before conducting the interview. This researcher conducted interviews in a confidential, convenient place chosen by each individual participant. This researcher asked ten questions and did not need to use the follow up questions that were available for extra exploration on the topic. The questions were different in nature for parents and siblings as the same questions do not fit for both groups. The interviews took approximately forty-five minutes to one

hour. Each interview was audio-recorded by this researcher and each participant was informed.

### **Data Analysis**

This researcher used content analysis in this study. Content analysis is a method that is used to transform data from qualitative to quantitative. Coding was done in this study by categorizing the research into a limited number of categories (Monette et al., 2008). This allowed this researcher to identify the similarities and differences between families who are impacted by ASD through semi-structured interviews. Content analysis also enabled this researcher to identify the major themes presented in these families due to their personal experiences with ASD. This researcher transcribed each audio-recorded interview in order to obtain all important information for this study.

### **Protection of Human Subjects**

In order to protect all participants in this research study, client confidentiality was addressed. This researcher obtained the protection of each human subject by locking each audio tape in a locked filing cabinet in this researcher's home. No other persons had access to the audio tapes and only the researcher had access to them. This researcher was the only one listening to these tapes and transcribing them. The participants' names were not used in this study. The consent forms signed by each participant were kept in a locked filing cabinet. After the study was completed in May of 2012, this researcher destroyed each individual audio-recorded tape.

### **Strengths of the Study**

There is limited information regarding the experiences of family members who have been impacted by an autism diagnosis. This study contributed to the body of social work knowledge. This study represented the experiences of eight families, both siblings and parents, who have been impacted by an autism diagnosis. Social workers will benefit from this study as it will not only deepen their knowledge on the autism diagnosis but it will allow them to be more effective when working with families as well. This study makes a contribution to current and future families who are impacted by an autism diagnosis by better understanding the impact of a diagnosis on family. This study empowers families of those diagnosed with autism as it offers guidance, advice and resources to assist in the coping process.

### **Limitations**

This researcher has a sibling with autism which may produce personal biases. This researcher's personal biases regarding the impacts and experiences of a family member who is diagnosed with ASD was a limitation of this study. Another limitation was the limited number of questions. Due to the allotted time, there was only time for approximately ten questions to be asked which resulted in a limited amount of information. This was a small qualitative study with only eight participants so it does not represent generalizations to a larger population.

### **Conclusion**

In conclusion, eight participants were recruited through convenience sampling. The interviews were audio-recorded and took approximately forty-five minutes to one hour. These participants were asked approximately eight questions and received a ten

dollar gift card to Target for their participation in this study. This researcher kept all information confidential. This research provided some strengths and limitations with the overall goal to empower families who are impacted by an ASD diagnosis.

### **Findings**

The purpose of these interviews was to examine autism and its impact on families. The demographics of this research include six females and two males ranging in ages 19-63. Four of the participants are siblings of a child with autism and four of the participants are parents of a child with autism. All eight participants reside in Minnesota. For this section, I will refer to these participants as participants 1-8.

### **Siblings**

In the sibling interviews, six primary themes were found to be most prominent. (a) knowledge of Autism, (b) affect on relationships, (c) feelings of siblings autism diagnosis, (d) future care for sibling, (e) meaning, acceptance and advice and (f) extended family.

### **Knowledge of Autism**

Four participants from a sibling's perspective were asked how they learned of their sibling's autism diagnosis; three siblings reported finding out when their sibling was around age 2 or 3. The other interviewee was younger than their sibling so it was always known since this participant was born.

Two participants who were interviewed remember being informed about their sibling's autism diagnosis from their parents.

Participant 1 reported:

My parents explained it to me as best as they could. I was 10, so I was so young that I didn't really understand at the time. Autism wasn't very known back then and my sibling was the only one I knew at the time that had this diagnosis.

Participant 2, who recalls being informed by their parents stated:

Our family first learned about JJ's autism diagnosis when he was 3. There was always some suspicion that JJ had autism but we weren't quite sure. Once he was diagnosed, my mom informed me further as to what it was because I wasn't very familiar with the diagnosis, the doctors also helped in informing us a little better.

The other two siblings interviewed reported having no recollection regarding how they were informed of their sibling's autism diagnosis at the time. However, they recalled being informed later in life by their parents.

Participant 3 stated:

I don't remember how I learned about the diagnosis when I was growing up, or at the time of the diagnosis, I know as I got older and asked my mom questions she informed me further on the diagnosis.

Participant 4 does not recall but assumes that he was informed by his parents:

I honestly have no idea about when or how I learned cause as far as I remember, I knew she was always autistic being I am younger than her. I'm assuming my mom or dad told me, but like I said, as far as I can remember I just always knew.

The participants reported on their sibling experiences being different because of the diagnosis. The following report observations of participants 1-4:

Not at first but when he was around other babies I would notice that they were much more engaged and talkative. No one in the family not even my mom noticed any signs until after JJ's first birthday. A majority of the differences were lack of eye contact, nonverbal communication except for babbling, and repetitive actions.

We did notice that she was different from other kids. I guess the differences that stood out the most is the fact that she didn't make eye contact, she didn't communicate and meet the milestones like others did. She had tantrums often because of the lack of communication. When she became frustrated she would bite herself, drawing blood and leaving scars.

Yes, she didn't speak much at the age she should have and her development was behind the rest of her peers. She would also become frustrated and aggressive but unable to tell us why. Her aggressive behaviors stood out the most, throwing things, putting holes in the wall and screaming.

Yes I knew she was different because she would scratch me and others, pushed me, threw things at me, swore at me, and sometimes spit on things, all of these stood out because I never saw anyone else acting this way.

### **Affect on Relationships**

Participants were asked how their sibling's autism diagnosis affected their relationship with their parents and if they felt less attention was paid to them, they all had

similar answers. These siblings experienced the stress and challenges their parents experienced but they never felt ignored or neglected as a result of their siblings' autism diagnosis.

Participant 1 had the following response:

I don't think it really had much of an impact on my relationship with my parents. Of course they were stressed at times but they didn't punish me for it. My parents were very much involved and very equal, they managed their time very well so I never felt ignored or pushed aside because of my sibling's autism diagnosis.

Participant 2 reported the following:

I think it has actually brought me closer to my mom and family because we all rely on each other and understand how each other feels when it comes to JJ. I never felt jealous or like he received more than I did, JJ reminded me how blessed and thankful I am.

Participant 3 stated the following:

I think there were many challenges along the way but there are always challenges when raising kids. I don't remember ever feeling like I had less attention paid to me. I think my parents did a pretty good job of keeping the attention equal. I would say maybe more time was spent taking me and my siblings to all of our events so maybe my sister had less attention than we did?

Participant 4 had a very similar response regarding the affect of the relationship with his parents: "This really didn't have any effect on my relationship with my parents

and I feel like they paid just as much attention to me, especially with my baseball and hockey”.

The four participants were asked how the relationship between the participant and their sibling is now. They all seemed to display a positive response: “Now that we are older I have grown to accept JJ no matter what which makes our time together less stressful and more relaxing and fun. Just enjoying him for who he is has made our relationship stronger”.

Well, me and my siblings are all very close. Now that I am married and have kids of my own, I don't spend as much time with my sister as I would like to, but we are all very supportive of each other.

Excellent. AA and I are very close and I make it a point to see her often. She is also a lot more independent now which makes things a lot easier but she also attends a day program 5 days a week so she is busy with her own life as well.

It's good. HH has grown out of being aggressive with me, I'm not afraid of her anymore and don't mind being around her, watching her, taking her in public, you know, whatever.

The four participants were asked if their sibling's autism diagnosis strengthened or weakened the family bond, all participants reported that it strengthened their family bond. It appears from this research study, situations such as this cause a family to lean on one another and support one another.



Participant 1 also agreed that the family bond was strengthened rather than weakened: “I think it strengthened it because we had each other to talk to when things were tough”.

Participant 2 responded:

Definitely strengthened our family and brought us together more than before JJ was born. Even though everyone in our family is not understanding of JJ’s behaviors, like those who aren’t around him much, but our immediate family has definitely become closer.

Participant 3 also reported feeling as though their sibling’s autism diagnosis strengthened their family bond: “Definitely strengthened. AA has a lot to do with how close our family is, we learned to help each other out through everything”.

Participant 4 responded: “For sure strengthened it because our family has gone through way more trials than most will go through in their entire life”.

### **Feelings around Sibling with Autism**

My findings indicated that siblings’ feelings surrounding their siblings’ autism diagnosis were mostly positive. The areas of feelings that were examined include the affect of their relationship with their sibling and feelings of embarrassment regarding their sibling with autism. In regards to the affect of their relationship with their sibling who was diagnosed with autism, all siblings interviewed found it difficult at first and felt there was a separation between them and their sibling, however, the participants reported that they have found ways to connect and flourish the relationship in their own ways.

Because he is still fairly non-verbal it can be difficult to always understand what his needs/wants are. Also, people with autism including JJ tend to be not as emotionally aware of their own or others feelings which is what I feel can be the bridge between me and my brother. Although we have our own ways of connecting and having fun with each other which makes me feel closer to him and helps our relationship.

At first, it was very difficult because I felt like I couldn't relate to her but as time went on, our relationship developed in a different way. I was able to do things with my sister that interested her and I was able to recognize what set her off, what calmed her down, so all in all, it was hard in the beginning but developed into something unexplainable.

“If anything it made us all closer. The tragedy of her being sick and of us being told that she wouldn't survive made us stronger and know that God answered our prayers”.

Participant 4, being younger than their sibling with the autism diagnosis had a different response. Participant 4 felt victimized in the beginning years but still reported a positive outcome. Participant 4 reported:

I was definitely afraid of her when I was younger because she would scratch me, hit me, push me, throw things, swear but as I got older I was able to understand better. I didn't have any anger or resentment towards her but I knew she couldn't help it. Regardless of her problems, I knew she couldn't help it, so it didn't change the fact that she's my sister and I love her.

Each participant interviewed reported no feelings of embarrassment in regards to their sibling with autism. Each participant portrayed a deep level of care and support for their sibling diagnosed with autism.

Participants were asked if they were embarrassed of their sibling's behaviors growing up. Participant 1 reported that there were no major issues with embarrassment, just minor feelings around the opposite sex when in her adolescent years:

I never really had a problem bringing her around my friends. Everyone close to me knew her and if they didn't accept her, then they wouldn't be in my circle of friends. Each friend of mine who did know my sister, loved her and enjoyed being around her. The only time I can remember being a little embarrassed was when I started bringing boys around. It was awkward at first because they didn't really know her but once they were around her a little more, that embarrassment went away.

Participant 2 stated the following:

Because I am a lot older than JJ I never felt embarrassed growing up most of my friends were sympathetic and understanding of his behaviors. I could imagine if we were closer in age and attended the same school my feelings may be different. Today and watching JJ growing up I feel more frustrated and helpless than anything else, because I want him to progress more and be more independent.

Participant 3 also expressed experiencing no feelings of embarrassment surrounding her sibling's autism diagnosis:

I wouldn't say that I was ever embarrassed by my sister's behaviors. I know that when she would have meltdowns it would be exhausting for my parents, but I think we had a good support system around us. Our friends and other community members knew she was a part of our family. We didn't isolate ourselves from any activities or functions because of her. I also would take my sister in public and she likes to say hi to everyone and ask what their name is. It frustrates me to no end that people will just look at her like she is a crazy person and not respond. I think how hard it is to say hi back and is it going to hurt you to respond? I just explain to my sister that the people are rude and I will say hi back.

Participant 4, being younger than their sibling with autism, did not feel there were any feelings of embarrassment because he was born after his sibling and that is just the way it always was. Participant 4 reported:

I never was embarrassed at all about her behaviors because, since she was around before I was born; it was just the norm for me to have an autistic sister, so I was always used to it. I wasn't embarrassed to have friends over either because they all knew her from school usually otherwise if they thought anything of it then they could go to hell for all I cared. Now, I still don't feel embarrassed because that's life and she obviously can't help it, so if people have a problem with it in public, then that's their own fault. I could care less about what some random person thinks about it.

### **Future Care of Sibling**

Participants were asked about the future care of their siblings. These participants were asked once their parents are no longer able to care for the sibling with an autism diagnosis, where that sibling will go.

Participant 1 reported that this issue has not been discussed yet:

We haven't really discussed this issue since JJ is only 10 but I think that is really important and raises a good point what if something happens to our parents who would take care of JJ? To be completely honest I most likely would because I am the closest to JJ and understand him more than my other siblings do.

Participant 2 reported that this issue has been discussed a lot within the family and concludes that a group home placement is out of the question. This participant plans to take the responsibility and move the sibling in with them. This participant reported:

We have discussed this issue a lot. In my opinion, a group home placement is out of the question. I already said that AA would live with me in the future. Group home placements are beneficial for some people but I don't see them as being beneficial for AA. It would make me sad to know that she is sleeping in a house with strangers rather than her family who she knows and trusts. She wouldn't understand the concept of moving out and moving on in life, group home placements seem more beneficial to the more independent population. My sister would be more comfortable and function better in the home of her own family members.

Participant 3 and participant 4 reported that the issue has been talked about a little within the family and there would be shared responsibility between themselves and their other siblings.

My other siblings and I have talked about the fact that we will do whatever we have to to take care of her and keep her out of a home. She will most likely live with one of us and we will make sure that she is cared for if my parents become unable to care for her. I think that no matter what we will all contribute to making sure that she is taken care of. We all agree with that.

Either me or my other siblings will care for her. I have definitely thought about that and don't like the idea of her being in a home, especially since it would be hard for her to communicate with us if there were any problems. It has been talked about a little but the details haven't been set in stone.

Three out of the four participants reported that they are not open to group home placements for their sibling with autism.

### **Meaning, Acceptance and Advice**

Four participants were asked how they found meaning and acceptance in having a sibling with autism. Three out of the four participants reported not really needing to find meaning and acceptance and that their sibling was just born the way that they were born. Participant 1 did not feel they needed to find meaning or acceptance. This participant stated:

I honestly don't ever feel like I needed to find acceptance. I accepted my sister at birth and she was born the way that she was born, this is the only way I ever knew her. I guess if I had to say where I found meaning and acceptance; it would be in her unique personality. There is seriously nobody like her and I wouldn't change it for anything in the world. She definitely keeps us on our toes.

Participant 3 stated:

It was part of life, there was nothing we could do to change it, I think I just accepted it and moved on. I know I have talked with my family about what it would be like if she weren't born with autism, but she's healthy and loved and there's nothing else I would ask for.

Participant 4 stated: "I have always accepted it as far as I can remember because that's life, it isn't fair and I feel like everything happens for a reason, regardless if we know why or not".

Participant 2 found that finding meaning and acceptance was a slower process.

Participant 2 stated:

I feel it slowly happened slowly overtime with research and spending more time with JJ, but I have always been accepting. It was hard to find meaning and accepting that he may never verbally communicate. Believing that God makes no mistakes and every person on this planet has a divine purpose eases some of the worry and frustration that this diagnosis has brought about in me.

The following is the advice given by all four sibling participants to other siblings who may be experiencing similar situations.

Try and be understanding and sympathetic to a sibling with autism and become as knowledgeable as you can on autism and resources, the more you know the easier it is to relate and understand your sibling. Also although it may be difficult to connect to your sibling with autism try and connect with your sibling through ways that he/she can relate to or enjoy.

“Don’t be ashamed and embarrassed by it. Take it for what it is and continue doing the best you can for your sibling, take care of them and love them no matter what their differences are”.

“Love your sibling for who they are and put them before anyone else in your life. Don’t be embarrassed or ashamed of who they are because they make this world unique”.

Accept them for who they are and always remember that they can’t always control their actions and just try to not treat them differently than anyone else because they want to live a normal life, just like everyone else does.

### **Extended Family**

Four participants were asked if they were supported by extended family and how extended family reacted to the autism diagnosis, participant 2 had a cultural difference that resulted in a different response:

“Our family is Puerto Rican and not many people in and around that community are aware of autism and the exhibited behaviors”.



Participant 2 reported that extended family tends to ignore her sibling with autism because they do not understand why he does some of the actions and behaviors that he does. This participant also reported that her extended family was supportive just unfamiliar and that the older generations have a more difficult time with it than the younger generations.

Participant 1 and participant 4 talked about Grandparents being very supportive, however, they did not report on the experiences of aunts, uncles, and cousins who were supportive. These are the following statements from Participant 1 and participant 4: “My grandparents have always been there to help out in any way they can. We are all very close. There were no negative reactions to the diagnosis as far as I can remember”. “My Grandparents were always around to help out. Their support was very helpful and much needed for all of us”.

Participant 3 reported Grandparents being very supportive as well. Other extended family was reported to be accepting but not very much involved.

My Grandparents were always very helpful; they would watch me and my siblings. The rest of my extended family reacted just fine and are very accepting of my sister. I don't really remember them ever babysitting her but my grandparents definitely helped care for her and still do when it is needed.

After examining the primary themes in the sibling interviews, we will now explore the parent interviews.

## **Parents**

There were four parents interviewed regarding their child's autism diagnosis. Six primary themes were present including, (a) feelings around autism, (b) knowledge around autism, (c) life changes, (d) affect on relationships, (e) support systems and (f) acceptance, meaning and advice. In the following paragraph, the first theme, feelings around autism will be explored.

### **Feelings around Autism**

These four participants were asked about their initial reaction to their child's autism diagnosis, the findings displayed mixed emotions.

Participant 5 reported feeling relieved to know that her child had autism rather than being deaf, which is what her initial thought was. This participant stated: "I originally thought he was deaf so as weird as this may sound, I was actually relieved that it was autism and that he wasn't deaf".

Participant 6, participant 7 and participant 8 experienced more negative feelings surrounding their child's autism diagnosis. They all reported feelings of shock, grief and sadness. "I cried. I didn't really know what to make of all this information I just received".

The mixed feelings of these participants display how each parent in this situation reacted differently with some parents feeling a sense of relief finding an answer and other parents feeling sadness to find out that their child has a lifelong diagnosis. The following paragraph will examine the knowledge these parents have surrounding autism.

### **Knowledge around Autism**

Participants were asked if they were aware of what autism was at the time their child was diagnosed and if not, how they became aware. The results were as follows. Participant 6 reported having deep knowledge due to the fact that she was currently working for five child psychologists at the time. She had a great understanding of the diagnosis being that these psychologists she worked for had several clients in the practice that had autism. Participant 5 stated:

I had a very brief understanding of what autism was but I did not know the different levels of severity that came along with the diagnosis and that every case was different. I did lots of research online and took classes at Autism Society to inform myself.

Participant 7 and participant 8 had no knowledge of the diagnosis when their child was diagnosed. Participant 7 stated:

I really wasn't aware of what autism was. The physician that was involved in her testing informed us of what it was and we were given educational literature and resource numbers of people who could assist us with finding proper resources.

Participant 8 stated: "I never heard of it until my child was born since autism wasn't as prevalent then. I informed myself online and the doctors gave me some information".

Participants were asked what they have learned from raising their child with autism. Patience is a word that was used in all responses.

“Patience, um, tolerance, how both good and bad people, um, people are either great, wonderful, patient, kind people or they just really suck and they’re intolerant”. “Lots and lots of patience and understanding and appreciating the small things in life”. “Oh a lot, the most important thing I have learned is patience, patience, patience! This is one of the hardest diagnoses to deal with so you have to remember to be patient with your child and be calm”. “Oh definitely patience! It can be very challenging at times so you have to be patient. I also learned how much fun it can be to raise a child with autism”.

### **Life Changes**

Findings indicate that having a child with an autism diagnosis often produces several life changes. Four participants were asked how their child’s autism diagnosis changed their expectations for their child.

Participant 5 reported that she hadn’t really formed any expectations for her child yet as he was diagnosed before the age of two.

I guess I had not really thought about what I expected of him at this time. I was just new to motherhood, he was my first child and everything was new to me and that just threw things for a loop.

Participant 6, participant 7 and participant 8 reported that their expectations for their child had changed upon the initial autism diagnosis. Participant 7 reported expectations were pretty subtle with a simple realization that her child would lead a different way of life than that of the other siblings, however, still felt that her child would

live a fulfilling, rewarding life. Participant 6, however, reported that her expectations for her child changed drastically. The participant reported:

He was no longer going to be president of the United States or go to Harvard. Initially, I didn't rule that out for quite some time but the expectations changed drastically but it's a long process for that to happen, it doesn't happen overnight and the expectations change at first pretty frequently and then later on kind of an annual basis.

Participant 6 also reported that she was still holding out hope for more gains for her son until he was about thirteen years old. She then got to the point where she began to look at realistic, tangible goals for her son to achieve.

Participant 8 reported being so heartbroken over his child's autism diagnosis that he never really thought about expectations changing for his child. He was more focused on the current situation and things that he could do to allow his child to lead a successful life.

Participants were asked how their child's autism affected their daily routine. Participants 5-8 all began their response with humorous statements such as, 'what routine' or 'how did it not change my routine'. Participant 5 reported that she had no choice but to work full time to support her son and felt that her routine was affected for the better as her son made her grow up very fast. This participant reported:

Life was no longer about me, it was about DD and how I could help make his life as easy as possible. I had to find a job fast and needed to work a lot to make ends meet, working over 50 hours a week.

Participant 6 and participant 7 felt as though their career was definitely impacted the most. These two participants have more severe cases in which they have to get their children ready by bathing them, brushing their teeth, dressing them, etc. before getting themselves ready for the day. Participant 6 reported being fired from several jobs due to the care her son needed while participant 7 reported having to give up her career to care for her child at home.

I worked part time but had to give that up to care for her at home. I was also offered a full time supervisory position but it was too much so I had to decline. My daily routine was surrounded by her and I always had to get her ready before I could get myself ready.

I still have a two year old at home basically so I always have to be there and have to do things for him, I have to bathe him, I have to brush his teeth, I have to dress him, I have to do all those things. In the early years I could barely leave the house at all and I couldn't take him anywhere.

Participant 6 and participant 7 were able to land consistent careers and become successful after their children grew a little older and were in school full time. Participant 8 reported that his daily routine was impacted; however, he did not have significant problems with his career as he continued to work full time while his wife stayed at home and cared for their child with autism.

### **Affect on Relationships**

Findings indicate that children with autism diagnoses can have an effect on other familial relationships. Participants were asked how their child's autism diagnosis affects

their relationship with their other children. Only two of the four participants situations applied as two of the participants do not have any other children.

Participant 5 reported that her son's autism diagnosis has impacted her relationship with her other son due to her son with autism needing more attention.

Participant 5 reported:

Well as much as you don't want to give more attention to one child than the other, it doesn't always happen that way. DD definitely gets more attention than his brother, I try not to have it be that way but it is too hard. DD just needs more from me right now.

Participant 5 also reported that she hopes her younger son will understand once he is older and doesn't feel as though he was treated unfairly growing up. Participant 7 reported being grateful to have wonderful PCA's that allowed her and her husband to pay equal attention to their other children. Participant 7 reported her child's autism diagnosis having no negative affect on the relationship with her other children. Participants were asked about the affect their child's autism diagnosis had on their marital relationship. The findings were different in each case. Participant 7 and participant 8 reported that they were still currently married to the biological parent of their child. Participant 7 and participant 8 reported that their child's autism diagnosis caused extra stress on the marital relationship but were still able to stay strong and overcome the stress it caused. The participants reported:

"Yes it definitely caused extra stress on our marriage. My husband didn't have much patience and would yell at our daughter when she acted out, that would upset me

and result in us arguing”. “We were no longer able to go on vacations just the two of us; it would require so much planning that it was more stressful than it was to just stay home”.

Participant 5 reported not being married to the father of her son; however, they live in the same home and raise their son together. Participant 5 stated: “I think we stayed strong because we aren’t selfish people and we always put our child first”.

Participant 6 had a very different experience regarding the marital relationship. Participant 6 experienced two divorces. Participant 6 does not blame these divorces on her son’s autism diagnosis. However, participant 6 does believe that her son’s autism diagnosis was a factor in both divorces because of his high needs. Participant 6 reported that the first marriage lasted sixteen years and described marital discord. She reported how they blamed one another for their son’s autism, fought, and eventually caused a damaging strain on the marital relationship, ending in divorce. This participant’s second marriage ended in divorce due to the fact that her husband ended up giving her an ultimatum between himself and her son.

### **Support Systems**

Support systems play an important role in parents’ ability to cope and manage the stressors when having a child with autism.

Participants were asked about the outside sources their child with autism received. Participants 5-8 reported that their child received PCA services (personal care attendant), speech language services, occupational therapy and respite care. Participant 5 and participant 6 also reported that their child received early childhood services.



Participant 5 reported that her son received sleep therapy as her son was also diagnosed with insomnia on top of his autism diagnosis. These four participants were asked about the type of support they received from extended family. The responses were very mixed. Participant 6 reported that her extended family did not help at all. This participant's parents died right after her son was born; therefore, her sister was the only one left. This participant reported her sister helping out financially, but never any physical assistance with her son. Participant 6 also reported losing friendships.

Participant 6 stated the following:

Interesting things happen with your friends, when those things happen too. Some of the people that you think are going to be right there for you, are not. I think I lost a lot of friends, I think a lot of it was because of DD's diagnosis and people just didn't know what to do or say or how to act or how to do things with him.

Participant 5 reported the maternal grandparents being most supportive along with this participant's biological sisters. Participant 5 reported the paternal grandparents having no involvement. Participant 5 reported:

My mom let me move in with her when I needed the most support and helped me with my son. Besides my mom and sisters, my family won't help watch him because they're all too busy or in bad health.

Participant 7 reported being supported by extended family. Participant 7 reported: "Everybody in our extended family has always been more than willing to lend a helping hand in the care of our daughter when it is needed. They have always been upbeat and positive and extremely supportive".

Participant 8 had mixed feelings regarding support from extended family. This participant reported extended family has been great and supportive but feels when they need extended family to help care for their child the most, their families seemed to have other events going on.

### **Acceptance, Meaning and Advice**

Participants were asked how they found meaning and acceptance in their child's autism diagnosis. Some adapted easier than others. Participant 5 reported that after several years, she still has not fully accepted it. This participant reported being glad that her child is making improvements but still dwells on the things he is unable to do. The participant stated:

I still haven't found acceptance, at this point I don't know if I ever will because I feel that at every point in his life, I am going to think of how he would have been or what he would be doing if he weren't diagnosed with autism. I love my son to death but it is hard to live with the fact that he will never be "normal".

Participant 6 found meaning and acceptance to be a long and slow process. This participant reported that her son was the only child with autism in his classes; therefore, it was a teaching experience with other parents and school professionals. After years of crying at IEP meetings and school conferences, this participant told herself that it was time to advocate for her son. Participant 6 reported:

From that point forward I just said that's enough of that grieving thing, I guess I got a lot of work to do. So that was a big turning point for me. So then I became an advocate, I fought, I was a red flag parent.

Participant 6 has been working with children who are diagnosed with autism for more than twenty years as a speech language pathologist in the school system. The other two participants interviewed found meaning and acceptance quicker than the others.

Participant 7 reported finding meaning and acceptance in her child's unique personality.

Participant 7 stated:

I found meaning because she is the light in the room. I find meaning in seeing that when you don't have all the "normal" stresses in life, you can be truly happy. She is in her own little world, happy and friendly. She puts life into perspective and makes you think why can't we all just bypass the stresses in life and be happy with the simple things in life? She's content with what she has.

Participant 8 felt that finding meaning and acceptance immediately was important. Participant 8 stated:

Oh, right away. It's kind of hard not to accept that, I mean my child was drastically different from others. You always hold out hope for something different to happen but you still need to accept your child for who they are, no matter what the circumstances may be.

Finally, these participants were asked to give advice to other families who are raising a child with autism. All four participants stressed the importance of utilizing the appropriate help and support systems when raising a child with autism. The following will display all four participants' words of advice.

Participant 5 stated:

My advice to other parents is to ask for help, don't lose focus on yourself. You're no good to your child if you are run down. Put your child first and do what you have to do to make their life fulfilling

Participant 6 stated:

Well, I think it's important to get help early on, and not wait. I know it's hard with social services system that is set up currently, but I think whatever kind of help and whatever kind of support you can get in the beginning is vital.

This participant also stressed the importance of taking care of yourself first, such as having a hobby, going for walks and getting out of the house rather than focusing all of their time managing their child.

Participant 7 stated:

Take it one day at a time and don't be afraid to seek out services and help from anyone who offers it to you. It will change your family dynamics but it doesn't always mean in a negative way. They can teach you a lot about life, it can make you a stronger person.

Participant 8 stated:

It is life changing and can be hard at times but use your support systems and allow yourself to see the good spirits your child has. When you get frustrated, remember that their way of learning and thinking is different from your own.

## **Conclusion**

The purpose of this research was to examine autism and its impact on families. The interview questions were implemented in order to empower future and current families who are raising a child with autism as well as provide vital information that can be applied to their specific situation.

The next paragraph will include a discussion comparing my finding to most recent research.

### **Discussion**

In this project, the following research question was examined, what are the experiences of parents and siblings with a child diagnosed with autism? After reviewing the literature, my findings produce both similar and contradictory results.

#### **Siblings**

In regards to sibling's feelings of embarrassment around their sibling's autism diagnosis, a study indicated sibling's ages 7-20 who have a brother/sister diagnosed with ASD mentioned feelings of embarrassment. Another study confirmed these results with siblings reporting the negative aspect of having a brother/sister with autism is feelings of embarrassment (Orsmond & Seltzer, 2007). Findings in this study disagree with current literature. The four participants reported no feelings of embarrassment. The siblings interviewed felt comfortable bringing their siblings around others and had no issues of embarrassment surrounding their sibling's autism. The participants felt as though their sibling was born the way they were born and that was just who they were. One study supported these participant's results. One sibling reported that if given the chance, he would not want to take away his brother's ASD because he likes his brother the way he

is. Another sibling reported playing and having fun was the best part of having a brother with autism. Several children interviewed in this study viewed their sibling's autism as a part of who they are (Petalas, Hastings, Nash, Dowey, & Reilly, 2009).

Another interesting finding is that current literature communicates siblings feeling ignored by parents due to their siblings autism diagnosis. Due to the significant needs of children with autism, the sibling may feel as though he/she is being ignored. It may be hard for some parents to balance time with their other children if their child with autism is in high need (Autism Society, 2011). Findings in this study do not support current literature. Participants reported feeling as though their parents did an excellent job dividing their time between themselves and their sibling with autism. Participants did not report feeling neglected or ignored by their parents. Participants reported that if anything, they felt as though their sibling's autism brought them closer to their parent.

### **Grandparents**

Research shows that grandparents have been described as providing emotional, practical, and instrumental support as well as being emotionally supportive and providing the parents with empathy (Hillman, 2007). Findings in this study supported current literature. Participants reported grandparents always being around to help and providing a great deal of support. However, there was an interesting finding in this area regarding a cultural difference. One participant reported being Puerto Rican. This participant reported that extended family tends to ignore her brother with autism because not many people in the Puerto Rican community are familiar with autism and how to manage the behaviors it can produce. There was no research supporting or disagreeing with this finding.

**Parents**

One study found that upon hearing their child's diagnosis, parents felt the following, "52% felt relieved, 43% felt grief and loss, 29% felt shock or surprise, and 10% felt self-blame" (Banach et al., 2010). Findings indicated the above categories to be true as one parent felt relieved that her son had autism and was not deaf while the other three reported feelings of shock, grief and sadness.

One study indicated that parents have to rearrange their daily routines to accommodate their child with autism as the child is unpredictable and often unable to regulate their behavior (Schaaf et al., 2011). Parents reported that routines were much easier to follow in familiar spaces such as their own home, however more difficult in unfamiliar places such as another relatives home or out in the community (Schaaf et al., 2011). One study found parents morning routines to be most difficult as most meltdowns occur during this time due to sensory issues, causing the child to be late for school and the parent to be late for work (Schaff et al., 2011). Findings in this study are similar to current findings in the studies mentioned. Participants reported changing their daily routines significantly to support and accommodate their child with autism. One participant was forced to take a full time job in order to support her son. Two participants reported having to get their child ready before getting themselves ready each day and this often affected their professional life.

**Parental Perspective**

One finding reported a participant feeling as though she gives her son with autism far more attention than she is able to give her son who does not have an autism diagnosis.

This participant hopes that her typically developing son will understand when he is older; however, her son with autism needs more parental attention. On the contrary, one participant reported that her child's autism diagnosis had no negative impact on her relationship with her other children.

### **Future Research**

The research done in this study produced further topics of research surrounding ASD and its impact on families. One topic that should be considered for future research is the impact of autism on families with limited sources of income. This would include families who have children with autism but do not have access to extra financial support and their child utilizes free and reduced lunches at school. Another topic to consider in future research would be future living arrangements for children and young adults with an autism diagnosis since there is no current ASD waiver provided to these families. A third topic for future research that may be of interest is the correlation between ethnic and cultural backgrounds and autism. Specifically, how different cultures experience the autism diagnosis and their cultural beliefs regarding ASD. A list of national resources has been provided for families and professionals who are encountered with an autism diagnosis. These resources may be helpful, see Appendix F.

### **Conclusion**

Overall, findings indicated that siblings had no feelings of embarrassment towards their sibling with autism. Literature found studies that supported and disagreed with these findings. A study indicated siblings feeling ignored by their parents due to their siblings autism diagnosis. However, findings indicated that there were no feelings of being



ignored by their parents due to their sibling's autism diagnosis. It was found that grandparents are most supportive of the family. Findings indicated feelings of relief, shock, grief and sadness upon the discovery of their child's autism diagnosis. Findings indicated daily routines being a challenge and having to accommodate the child with autism, routines were no longer simplistic. Findings were different regarding the amount of parental attention given to their child with autism and their typically developing children. The research produced future research topics related to ASD that may be of interest to the general population. A list of National resources has been provided for current and future families experiencing an autism diagnosis.

### **Strengths**

The following include the strengths and limitations that were discovered with the findings.

My personal experience of having a sister with autism also provided me with a strength in this study as I have an inside perspective regarding autism and its impact on families. I know from my own personal experience, my parents' routine was definitely affected by my sister's autism diagnosis so I can relate to those experiencing the similar situations. It became difficult for my parents to leave the house, everything took so much planning. Regular childhood baby sitters were not trained to handle the behaviors that often came along with an autism diagnosis so there was the care taking aspect to plan for. My mom struggled in the mornings getting my sister ready and off to school on time. Autism definitely changes your entire family dynamics. We rarely went out to eat as a family; one of my parents had to stay home with my sister because crowded, loud spaces

made her very agitated. Life is no longer simple and spontaneous when you have a sibling or child with autism, there is a lot of planning that takes place.

Another strength of these findings is the empowerment and knowledge this study provided current and future families. Findings provide current and future families who are living with a child or sibling diagnosed with autism information on others personal encounters with this diagnosis. Findings also allow current and future families to see the thoughts, feelings and perspectives of those who have lived or are currently living with a child or sibling who has autism.

### **Limitations**

One limitation in these findings is the demographics. The female to male ratio of these participants was 6:2 with females representing the larger population. Participants considered in this study do not represent the general population of parents and siblings who have a child or sibling with autism. These findings are predominately viewed through the female lens. The information may be different if there was an equal amount of males and females being interviewed on their child and siblings autism diagnosis.

Another limitation is the ethnic backgrounds of these participants. Out of the eight participants, seven were of Caucasian descent and one was of Puerto Rican descent. Ethnicity plays a role in families, how they deal with certain situations, their knowledge of autism and what their cultural beliefs may be. The findings may have varied if these participants were from more diverse backgrounds. Seven participants were from the same ethnic background which limited findings on the perspectives of other ethnic backgrounds.

A third limitation is the small sample size which consisted of eight participants. Autism is more prevalent in the recent years with an increase in parents and siblings who are living with a child diagnosed with autism. Eight participants do not even make up a small fraction of those individuals. The findings may have varied if there were perspectives from a larger sample size.

My own personal biases regarding my sister's autism diagnosis provided a limitation in this study. This produced a limitation as I have a biased opinion which influences my understanding of how participants view their sibling with autism. In my own personal experience, I never felt as though my sister received more attention than I did. I never felt any feelings of embarrassment, I had no problem bringing her around my peers, bringing her out in the community and making it known that she was my sister. My grandparents, both maternal and paternal, were very supportive of my sister's autism diagnosis. They were continuously offering their support and helping my parents in every way possible.

Finally, because the researcher had a previous relationship with the participants, it may have skewed the results to be more positive. The results may have varied if the participants were unfamiliar with this researcher when asked personal questions about their family member with ASD.

## **Conclusion**

There are a few limitations and strengths in regards to these findings. The findings may have varied if participants were from a more diverse background, a larger sample size was obtained and the participants had no former relationship with me. My own

personal experience with autism produced both strengths and limitations. Findings also produced empowerment for current and future families experiencing a family member with autism.

### **Implications for Social Work**

The implications for this research help current and future social workers relate to families of children diagnosed with autism. The research gives social workers a stronger knowledge base on the autism diagnosis regarding the characteristics of ASD and its correlation with gender and ethnicity. This research allows social workers to develop strategies, provide resources and support families who are experiencing a child or sibling with autism.

This research provides social workers with personal experiences of parents and siblings who have a child or sibling with autism. Autism is becoming more prevalent in recent years with more social workers gaining clients and family members living with an autism diagnosis. This research helps educate current and future social workers as it provides insight in regards to clients and families they may encounter in their professional work.

The implications of this research educate social workers on how to support families and find resources available for coping with a child or sibling with an autism diagnosis. This research provides social workers with personal experiences of families' coping strategies in which social workers can reiterate to families they encounter in their professional work. These coping strategies include support groups, other parents of

children with autism, social workers, occupational therapists, special education teachers and other mental health professionals.

The research exhibits the stressors parents and siblings may experience which makes social workers aware of issues that can be addressed when working with these families. This research provides social workers with several aspects autism exhibits such as behaviors, routines, and needs of these children. This research provides social workers with the current interventions used to help support children with autism which may be passed along to families and siblings of a child diagnosed with autism. These interventions include speech therapy, occupational therapy, video modeling, PECS, social stories, play therapy and applied behavior analysis.

This research provides resources and programs available to children with autism such as PCA services, respite and early childhood. This enables social workers to support families by providing them with these resources and programs that have been used by previous families in similar situations.

### **Conclusion**

In conclusion, the implications of this research provide social workers with a deeper knowledge base and insight when working with families experiencing an autism diagnosis. The research allows social workers to gain personal experiences from families who have a child or sibling with autism. The research provides social workers with the appropriate resources needed to guide and support families who have a sibling or child with autism. All in all, the implications of this research allow social workers to empower future and current families who are faced with an autism diagnosis.

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**APPENDIX A: INFORMATION SHEET FOR THE STUDY**

My name is Ashley Hartmann and I am a MSW student under the direction of Professor Catherine Marrs Fuchsel, PhD in the School of Social Work, at St. Catherine University and the University of St. Thomas. I am conducting a research study to explore the impacts of an autism diagnosis on families. I am interested in empowering current and future families who are impacted by an autism diagnosis. I hope that what I learn from this study will help social workers and service providers understand the impact autism diagnoses have on families and how to help these families cope. I would like to interview siblings and parents who have been impacted by an autism diagnosis.

I am inviting the participation of parents and siblings who are willing to share their experiences. This study will involve one interview for approximately 45 minutes to 1 hour. I will be conducting the interviews at a confidential, convenient meeting space of your choosing. I will set up the time and day for the interview depending on what is best for you. If you agree to participate, I will ask you on tape if you understand the information letter, if you have any questions and if you agree to take part in the interview. This study is voluntary and you may choose to stop participating at any time. You may also choose not to answer any question.

In the interview, I will ask you about your personal experiences with autism spectrum disorder. I will ask you about the affects it had on family relationships, how it impacted your daily routine, what you learned, how you found meaning, and advice you may have for other families impacted by autism spectrum disorder.

There is one benefit directly to you for being in this study. You will receive a \$10.00 gift card to Target for your time and commitment. This study may help empower other families who are impacted by an autism diagnosis. The information from this study will be published in my clinical research project. Your name will not be used to identify you and information will be recorded anonymously.

The interviews will be tape-recorded and they will not be recorded without your permission. You will have the right to ask for the recording to be stopped. The audiotapes will be locked in a filing cabinet at this researcher's home and only I will have access to the confidential information. The data will be kept until May of 2012 and notes will be shredded. The tapes will be destroyed and discarded immediately after the study has been completed.

**Contact information:**

**Ashley Hartmann**

**Cell phone: 651-324-8619**

**E-mail: hart7174@stthomas.edu**

If you have any questions about your rights as a subject/participant in this research, or if you feel you have been placed at risk, you can contact Catherine Marris Fuchsel at 651-690-6146.

**APPENDIX B: RESEARCH INFORMATION AND CONSENT FORM****Introduction:**

You are invited to participate in a research study investigating autism and its impact on families. This study is being conducted by Ashley Hartmann under the supervision of Dr. Catherine Marrs Fuchsel in the MSW Program at St. Catherine University and the University of St. Thomas. You were selected as a possible participant in this research because of your personal experiences with a family member diagnosed with autism spectrum disorder (ASD). You were selected by convenience sampling which can be defined as this researcher seeking out participants personally that this researcher knows. Please read this form and ask questions before you decide whether to participate in the study.

**Background Information:**

The purpose of this study is to empower other families that are impacted by an ASD diagnosis in relation with your experiences. Approximately eight people are expected to participate in this research, four from the parent perspective and four from the sibling perspective.

**Procedures:**

If you decide to participate, you will be asked to meet with this researcher in a confidential space that is convenient to you. You will be asked approximately ten semi-structured interview questions regarding your child or sibling's autism diagnosis. These questions will be audio-recorded and only viewed by this researcher. This study will take approximately one hour and be completed in one session.

**Risks and Benefits:**

The study has minimal risks. First, there may be some discomforts when discussing negative impacts of your child or sibling's autism diagnosis. Second, you may become emotional when discussing experiences you have encountered due to an autism diagnosis.

Other families sharing experiences of the autism diagnosis may help empower future and current families.

**Compensation:**

If you participate, you will receive a ten dollar gift card to Target from this researcher on the day the interview is conducted.

**Confidentiality:**

Any information obtained in connection with this research study that could identify you will be kept confidential. In any written reports or publications, no one will be identified or identifiable and only group data will be presented. This researcher and Dr. Catherine Marrs Fuschel will be the only ones to transcribe and read the transcripts.

I will keep the research results in a locked file cabinet in my home and only I will have access to the records while I work on this project. I will finish analyzing the data by May 2012. I will then destroy all original audio tapes and identifying information that can be linked back to you. I will be the only individual who will have access to the audio-recordings of our interviews and I will destroy them after this research project is completed in May 2012.

The tapes will be erased.

**Voluntary nature of the study:**

Participation in this research study is voluntary. Your decision whether or not to participate will not affect your future relations with St. Catherine University in any way. You have the right to refuse any answers to questions that make you feel uncomfortable. If you decide to participate, you are free to stop at any time without affecting these relationships, and no further data will be collected.

**New Information:**

If during course of this research study I learn about new findings that might influence your willingness to continue participating in the study, I will inform you of these findings.

**Contacts and questions:**

If you have any questions, please feel free to contact me, Ashley Hartmann at 651-324-8619. You may ask questions now, or if you have any additional questions later, the faculty advisor, Catherine Marrs Fuschel, 651-690-6146, will be happy to answer them. If you have other questions or concerns regarding the study and would like to talk to someone other than the researcher, you may also contact John Schmitt, PhD, Chair of the College of St. Catherine Institutional Review Board, at (651) 690-7739.

You may keep a copy of this form for your records.

**Statement of Consent:**

You are making a decision whether or not to participate. Your signature indicates that you have read this information and your questions have been answered. Even after signing this form, please know that you may withdraw from the study at any time and no further data will be collected.

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I consent to participate in the study and be audio-recorded.

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Signature of Participant

Date

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Signature of Parent, Legal Guardian, or Witness

Date

(if applicable, otherwise delete this line)

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Signature of Researcher

Date

**APPENDIX C: IN-DEPTH SEMI-STRUCTURED INTERVIEW GUIDE  
(PARENTS)**

Theme: Impact of Parents

1. What was your initial reaction when you were informed of your child's autism diagnosis?
2. Were you aware of what autism was? If not, how did you inform yourself on the diagnosis?
3. How did this diagnosis change your expectations for your child?
4. What outside sources did your child with autism receive? i.e. occupational therapist, respite, speech language pathologist, PCA, etc.
5. How did having a child with autism affect your daily routine? Were you able to work full time or did you have to give up your career plans to care for him/her in the home?
6. How did your child's autism affect your relationship with your other children? (i.e. less attention towards them, more towards her)
7. How did your child's autism cause extra stress on your marital relationship? How were you two able to stay strong as a couple and help support one another through this?
8. How did you find meaning and acceptance in having a child with autism? (i.e. at what point did you accept that your child will be "different" than other children?)
9. What advice can you give other families who are raising a child with autism?
10. What have you learned from raising your child with autism?
11. How were you supported by extended family and how did they react to the diagnosis?



**APPENDIX D: IN-DEPTH SEMI-STRUCTURED INTERVIEW GUIDE  
(SIBLINGS)**

Theme: Impact of Siblings

1. How did you learn about your sibling's autism diagnosis?
2. When you were growing up, did you notice that your sibling was "different" from other kids? What differences stood out the most?
3. How did this affect your relationship with your sibling?
4. Growing up, did you feel embarrassed of your sibling's behaviors? Were you embarrassed to have friends over, bring them in public, etc? How about now?
5. How did this affect your relationship with your relationship with your parents? Do you feel they paid less attention to you or did they try to be equal?
6. How is your relationship with your sibling now?
7. Do you think having a sibling with autism strengthened your family bond or weakened it?
8. Once your parents cannot care for your sibling, where do you think he/she will go or who do you think will care for him/her? Have you thought about and discussed this with your family?
9. How did you find meaning and acceptance in having a sibling with autism? (i.e. at what point did you accept that your sibling will be "different" than other children?)
10. What advice can you give other siblings who have a sibling with autism?
11. How were you supported by extended family and how did they react to the diagnosis?

**APPENDIX E: ADDITIONAL QUESTIONS (PARENTS, SIBLINGS)**

1. What are or were the hardest years when living with your child/sibling who is diagnosed with ASD?
2. What are or were the best years when living with your child/sibling who is diagnosed with ASD?
3. How is your relationship with your child/sibling now?
4. What helped you the most to find meaning and acceptance with your child/sibling's autism diagnosis?
5. What are your thoughts regarding a group home placement for your child/sibling diagnosed with ASD?

**APPENDIX F: NATIONAL RESOURCES**

Autism Society of America [www.autism-society.org](http://www.autism-society.org)

Autism Speaks [www.autismspeaks.org](http://www.autismspeaks.org)

Center for Disease Control and Prevention [www.cdc.gov/ncbddd/autism/facts.html](http://www.cdc.gov/ncbddd/autism/facts.html)

Autism Society of Minnesota [www.ausm.org/index.asp](http://www.ausm.org/index.asp)