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# Autism and the Impact of the Siblings' Identities

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# Autism and the Impact of the Siblings' Identities

by

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MSW Clinical Research Paper

Presented to the Faculty of the  
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Master of Social Work

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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 research design that is approved by a research committee and the university Institutional Review Board, implement the project, and publicly present the findings of the study. This project is neither a Master's thesis nor a dissertation.

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### **Abstract**

Autism Spectrum Disorder (ASD) can be an overwhelming experience for the caregivers and families of those diagnosed. According to estimates from Centers for Disease Control's (CDC) Autism and Developmental Disabilities Monitoring (ADDM) Network, about 1 in 88 children have been identified with an autism spectrum disorder. This is a small, qualitative study that explores the impact ASD has on siblings and their identity development. Previous research regarding this subject has focused primarily on the sibling's stress and experiences when growing up with a child diagnosed with ASD. However, there is little to no literature on ASD impact on a sibling's identity. The purpose of this study was to explore the lived experience of siblings of individuals diagnosed with ASD and the potential impact this played on their identity development. Given the rate of ASD in children, it is a natural extension to explore how such diagnoses affect the siblings' and their own identity development. The goal of this study was to contribute to and expand upon the literature on the experiences of individuals who have a sibling with ASD and to hopefully develop a better understanding of the impact of ASD on siblings. In this study, qualitative research was used. Qualitative research includes data collection, data analysis, and drawing conclusions. There were five themes found in the sibling's interviews; 1) Definition of Self, 2) Family Dynamics, 3) Childhood, 4) Future Care, 5) and Reflection. This study is based on eight semi-structured interviews. The participants explored the sibling perspective and experience of having a sibling with ASD. The primary research question is the following: What is the impact on sibling's identity of a sibling diagnosed with autism? The research produced both strengths and limitations. The implications of this research will inform current and future social

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workers to relate to and work with individuals who have a sibling diagnosed with an autism spectrum diagnosis.

*Key Words: Autism, Identity, Siblings, Impact*

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### Autism and the Impact of the Siblings' Identities

In November 2011, U.S Census Bureau recorded that out of the 5.9 million school- aged children (5 to 17 years of age) in the U.S school system, about 2.8 million children have a form of disability<sup>1</sup>. Until recently there has been a minimal amount of research done to understand and explore the experience of siblings of children with an intellectual disability. The family of a child with an intellectual disability is at a higher risk of stress and psychological difficulties. Specifically, siblings of children with autism spectrum disorder (ASD) struggle with social, behavioral, and psychological adjustment (Moysen & Roeyers, 2011). Having a sibling with autism can be difficult and largely influence the development of one's sense of self. Formation and acceptance of one's self is a life long process. Researchers, such as Erikson and Garcia theorize that a majority of self-concept occurs within adolescence, which allows individuals to experiment and evaluate ideas to establish a firm sense of identity. Siblings of children with ASD are frequently confronted with additional challenges and factors that cause the self-identification process to be more intimidating and difficult. The following definitions describe ASD, sibling, family, and identity for the context of this paper.

ASD: Autism spectrum disorder is a group of developmental disabilities that can cause significant social, communication, and behavioral challenges (Center of Disease Control and Prevention, 2014).

Family: A committed relationship that progresses over time between individuals who are active in each other's emotional and spiritual daily life. This can include

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<sup>1</sup> Disability is measured in terms of a physical or mental condition that limits a person's movements, senses, or activities.

biological and no-biological relationships where the members share a commitment toward building a long term-sustainable, primary relationship with one another (Morrow, 2000).

Identity: “People’s concepts of whom they are, of what sort of people they are, and how they relate to others” (Hogg and Abrams 1988, pg. 2). In this context, identity will largely focus on the notion of Self- Concept.

Neurologically Typical (NT): An individual who does not have a mental/neurological/cognitive disorder.

Self-Concept: Beliefs about one’s characteristics (e.g., short, intelligent, attractive), roles and goals (e.g., future occupation, future ambitions), and interests, values, and beliefs (e.g., religious and political) (American Psychological Association, 2002).

Siblings of children with ASD are “at risk”. They struggle with the normal adolescent identity process with self-awareness and acceptance in addition to living with a sibling with special needs. ASD is prevalent in today’s society with males being affected 4.5 times more with this diagnosis than females (Rice & Centers for Disease Control and Prevention, 2009). With that, current literature invites further research to understand the lived experience of this population by analyzing their presenting difficulty in identity formation in their life span.

This literature review evaluates the experiences of individuals who have siblings with disabilities in regards to their overall support, difficulties, positive experiences, and role within the family. The following areas will be explored:



characteristics of ASD, the overall impact that an ASD diagnosis has on the family, the lived experiences of the siblings, and identity formation throughout adolescence.

A better understanding of the limited attention on siblings of children with ASD emphasizes the strain siblings experience and demonstrates the need for further exploration of ASD's impact on family members in order to increase the quality of life for these family members. The purpose of this study is to further investigate the lived experiences of children with siblings who have ASD and its effect on their identity formation.

### **Autism Spectrum Disorder**

Autism Spectrum Disorder, also known as ASD, is a neurodevelopmental disorder, characterized by impairments in social interactions, communication limitations (both in non-verbal and verbal interactions), and repetitive behaviors (Autism Speaks.org). Autism was first recognized and declared an official clinical disorder in 1943 by scientist, Leo Kenner. In the mid-twenties autism was considered a rare disorder with the prevalence of 2-4 out of 10,000 children diagnosed (MacFarlane & Kanaya 2009).

ASD is categorized in the Diagnostic and Statistical Manual of Mental Disorders, 5 ed, (DSM-5) as a neurodevelopmental disorder. A neurodevelopment disorder is impairment of growth and development of the brain or central nervous system. This term refers to a disorder of brain function that impairs emotion, learning comprehension, self-regulation, and communication. ASD typically develops around the age of 18-24 months. Some common symptoms or "red flags" that are associated with ASD are as follows: lack of response to their name by the age of 12 months, lack of pretend play by 18 months of

age, lack or delay of empathy for others, delay or loss of speech, obsessive behaviors, repetitive words or phrases, also known as echolalia, rapid movements such as flapping or rocking, and hypersensitivity to sensory stimuli such as, loud sounds, tastes, smells or textures (Center of Disease Control and Prevention, 2014). According to the recent changes in the DSM-5 (American Psychiatric Association, 2013), for a child to be diagnosed with ASD they must meet criteria A, B, C, and D, which are outlined in the Diagnostic and Statistical Manual of Mental Disorders, fifth addition (DSM-5). The criteria consist of deficits in social communication/interaction and restricted, repetitive patterns of behavior that must be present in early development and significantly impact social, occupation, and other important areas of functioning (American Psychiatric Association, 2013).

According to Center of Disease Control and Prevention (2009), an average of 1 in 100 children in the U.S. is diagnosed with Autism Spectrum Disorder (Tsao & Davenport, 2011). The CDC indicates that ASD is 4.5 times higher in males than in females, the statistic being, 1 in every 43 males and 1 in every 180 females. In addition to gender as a factor in predicting ASD, its prevalence also varied by race and ethnicity. According to the CDC (2012), Caucasian children (15.8 per 1,000) were significantly greater than that among African American (12.3 per 1,000) and Hispanic children (15.8 per 1,000).

The cause of ASD remains unknown and, as a result of the alarming statistics, ASD has become a nation-wide concern. According to O'Brian and Daggett (2006), both parents and professionals have opened an aggressive discussion to find the best possible interventions and strategies for children with ASD (Tsao et. al., 2012). In a study

conducted by Bittermam et. al., (2008), the authors explored the most commonly used intervention strategies used when working with children diagnosed with ASD. They identified speech therapy as the most common service for children with ASD (87.3%), followed by Occupational Therapy (45.6%), and lastly, study skills (42.7%), (MacFarlane & Kanaya 2009). On average students with ASD require 5.4 different services to assist and enhance their learning experience (MacFarlane & Kanaya, 2009). This is of particular concern because according to the Special Education Expenditure Project (2003), ASD is among the top 3 most expensive diagnostic expenditures in special education, costing \$18,790 per year (MacFarlane & Kanaya, 2009). A majority of the researchers agree that early identification and intervention are examining the prevalence and development of ASD among children (Tsao & Davenport, 2011).

### **What is the Impact on Families?**

Although there are many high stress situations and overwhelming demands experienced by family members, there are many rewards from having a family member with disabilities. Many families with a child who has a disability experience an increase in knowledge, spiritual growth, and personal growth (Scorgie & Sobsey, 2002). However, disabilities can have devastating effect for both the effected individual and the family members. Families impacted with an ASD diagnosis experience the typical stressors in family dynamics, however, they also endure additional unique stressors, which can include financial stress, family conflict, psychological and health stress, and uncertainty for the child's future (Kenny and McGilloway, 2007).

Raising a child with a disability has financial ramifications due to the high cost of services. On average, a child with disabilities receives six different services from various

agencies. And while most families receive some financial support from the government, the support is inadequate to fully encompass the cost of the needed services. According to Paulsson and Fash, (1990) and Sezebehely et al. (2001), the disability affects the family finances because in most cases the household functions on one income rather than two. The economic burden has a particular impact on mothers. Generally, the mother was the main caregiver for the child, thus resulting in limited employment opportunities outside the home (Dellve et al., 2006). Mothers tended to fulfill the role of main caregiver for the child because men are paid better in the job force. This division in job opportunities contributed to the unequal distribution of stress between parents.

The family relationship, especially between the parents, becomes very strenuous when raising a child with disabilities. The high demands for personal care, adaptive behavior deficits, and medical needs have been related to the negative impacts, stress, and burden upon the family (Neely-Burnes and Dia, 2006). Hutton and Caron (2005), examined the spousal stress experienced due to childhood disability. High spousal stress and neglect were reported due to a lack of “intimate time” the parents have because all effort and energies are typically focused on the child’s needs. According to a study done in 2001, researchers Feinber and Hetherington, found that siblings of a child with disabilities generally received less attention and differential parental treatment, which resulted in feelings of resentment and jealousy and was also linked to adjustment problems (Tsao et. al., 2011). In many cases, as described by Neely-Burnes and Dia (2006), families did not have the opportunity to deal with other family issues aside from the disability, which can potentially create a hostile and tense home environment.

Neely-Burnes and Dia (2006), also highlighted how poor family functioning affects the overall family relationship. According to Abbeduto et al. (2004), family functioning was far more important in predicting family stress and depression than the actual existence of a childhood disability (Neely-Burnes and Dia, 2006). For instance, Lustig (2002) found that families who had the ability to construct the disability in a positive outlook reported a successful family adjustment, acceptance process, and decrease in stress (Neely-Burnes and Dia, 2006). Research also indicated that the way in which each parent copes with the disability may impact the spousal coping. Hastings, Kovshoff, Ward, delgi Espinosa, Bowen, and Remington (2005) noted that spousal depression was a significant predictor of stress in both mothers and fathers.

Evidence suggested that caregiving for a child with disabilities was associated with poor emotional and physical health of caregivers. Caregivers who appeared most distressed were those who spent the most hours caring for the child. Children's behaviors and demands were found to significantly affect overall psychological and physical health of the caregiver as well. Dellve et al. (2006) reported that 88% of parents experience psychological strain. The psychological burden parents experience accounted for a majority of the stress on the caregivers. According to Dellve et. al. (2006), mothers tended to run at a high risk for poor mental health, especially susceptible to developing depression. Murphy et. al. (2006), reported that out of 40 caregivers in their study, 36 reported recurrent anxiety, depression, or guilt due to their child's disability. Parents also experienced physical strain. Murphy et. al. (2006) reported that, "most caregivers described one to more chronic physical ailments that they directly attribute to the long-term effects of caregiving" (p. 183). Parents reported back, shoulder, and arm pain due to

the constant physical labor (lifting, and restraining) of caring for children with disabilities.

Research identifies a particular concern among caregivers about their child's future. The high level of anxiety experienced by parents and siblings pertains to the uncertainty of the child's future and, specifically who will provide care once the parent is no longer able to provide services. Most long-term planning programs address the financial and living arrangement for the individual with disabilities. Programs, such as Planned Lifetime Advocacy Network (PLAN), provide information and step-by-step guidelines for caregivers. This program helps caregivers establish a plan for residential stability, guardianship, assists the persons with a disabilities learn to make healthy life choices and garner everyday skills needed to thrive in the community. Unfortunately, very few programs like PLAN are established and successful due to funding and lack of resources (Neely-Barnes and Dia, 2006).

### **The Siblings' Experience**

There is an absence of insight about a sibling's experience in a family with a child diagnosed with autism (Petalas et al., 2009). Siblings are affected when an ASD diagnosis occurs within the family. Sibling's experiences such as role confusion, negative peer perceptions, denied relationships, acceptance, and positive qualities all occur while growing up with a sibling with ASD (Petalas et al., 2009).

### **Sibling Role**

When analyzing and exploring the sibling's experiences, a majority of the research alluded to common factors that siblings encounter as they grow up with a child diagnosed with ASD. The sibling's role, or perceived role, is a common recurrence

within research. For example, in a study conducted by Seltzer and colleagues in 1991, findings showed that siblings, specifically sisters, often take on a caregiver role as well as an advocator role for the child with ASD (Davys, Mitchell & Haigh, 2011). When exploring the sibling's role, it is crucial to take into account the parental expectations of sibling's responsibilities. According to Weinberger's (1996) theory, the author suggests siblings tend to feel high levels of responsibility and obligation to help and assist the family as a whole to compensate for the challenges of having a child with ASD (Barak-Levy, Goldstein & Weinstock, 2010). One study indicated Weinberger's theory to be accurate when defining the sibling's role within the family. In 2010, Barak-Levy and colleagues conducted a Child Behavior Check List (CBCL; Achenback, 1991), with 12 control group participants and 12 research group participants. When analyzing the differences between the control and research groups, 60% of parents report a sibling as being 'helpful/responsible', in comparison to 15% of parents from the control group (Barak-Levy et., al 2010). Furthermore, when the siblings were asked to self-report, Weinberger's theory held true, as a majority of the siblings of children with ASD tend to 'go out of their way to do things for others' (Barak-Levy et al., 2010). The results also showed siblings of children with ASD have significantly lower rates of participation in social activities (56%) when compared to the 44% of siblings with typical developing children. The findings suggest that siblings with children with ASD feel a stronger sense of responsibility and obligation to care and assist the family that it restricts their independent and social interactions (Davys et al., 2011).

Along with the role of caregiver, research suggests that siblings play a pivotal role in the child with ASD's learning development. According to one study, siblings are

imposed to a teaching role for the child with ASD (Tsao et al., 2011). Neuro-typical (NT) siblings usually are the first and primary individuals who interact and socialize with the child with ASD. The siblings teach social skills, appropriate behavior, social competencies, and overall understanding of peer relationship through play interactions (Tsao et al., 2011). Again, a NT sibling may feel pressure or strong expectations from parents, to lead the interactions between the children and him/herself (Barak-Levy et al., 2010), thus imposing another role onto the TD sibling.

### **Peer Reaction and Tolerance**

Peer and community reactions to their siblings with ASD were a reoccurring conflict and dilemma for the TD sibling. Due to the presentation of ASD, the idea of invisible nature of the disorder had developed as a result of the lack of physical presentations of a disability. This invisibility can cause both siblings and peers to have a lack of understanding and even doubt the disability. Researchers Moyson and Royers (2011) found that children and adolescents recognize and acknowledge disabilities when the disability is associated or requires technical devices (e.g., a wheel chair or communication devices). Thus, learning disabilities such as ASD and other “invisible” disorders that require limited or no technical devices are treated with ignorance, doubt, prejudice, and perplexity (Moyson & Royers, 2011). The invisible nature of sibling’s conditions led to negative peer reactions and caused the sibling internal conflict of subsiding to peer ridicule for acceptance or confronting the mockery for justice (Petalas et al., 2012). The need for peer acceptance is crucial and very important for adolescents. Siblings reported feelings of embarrassment, frustration, and disappointment presented in



social situations involving their sibling with ASD. Siblings expressed the hesitation and difficulty to explain their sibling's condition out of fear of rejection (Petalas et al., 2012).

### **Sibling Relationships**

As the researchers examine the experience of siblings of a child with ASD, the perceptions of sibling relationship frequently emerged (Petalas et al., 2012). As in any sibling relationship, there are hardships and positive qualities that develop. For siblings with a child with ASD, the hardships tend to be more frequent than the positive experiences. In one particular study, researchers McHale, Sloan, and Simenson (1956) sought to gain a better understanding of sibling relationships. They interviewed 30 siblings of TD children and 30 siblings with autism between the ages of 6 and 15 years old and examined their perceptions of the sibling relationship. The researchers found an overall positive experience. However, when more closely analyzed, siblings of children with ASD had described many negative experiences (Petalas et al., 2009). The negative relationships were associated with disruption in daily life, parental favoritism, worries about the future, and deprived of a sibling relationship (Petalas et al., 2009).

Throughout the research, there is a strong correlation between negative sibling relationship and disruption in daily life. In one study, siblings report that aggressive, unpredictable, and annoying behavior were difficult to tolerate (Moysen & Roeyers, 2001). Siblings spoke of the constant disruption in their daily lives as a result of the child's behavior. Specifically, they reported behavior such as the unprovoked physical or verbal aggressive behavior (Petalas et al., 2009). Because of the unpredictable behaviors, having a child with ASD often times limits the families' ability to enjoy recreational activities due to said unexpected outbursts (Petalas et al., 2009).

A stressor and possible predictor for siblings with emotional and behavior issues is the amount of time spent with parents. Studies have reported that increased parental differential treatment occurs when there is a child diagnosed with ASD. Due to the substantial amount of necessary care for children with ASD, the TD sibling may feel ignored or unworthy of parental attention (Tsao et al., 2011). As a result, studies have shown that differential parental treatment of siblings demonstrates a strong association with adjustment problems (Feinber & Hetherington, 2001; as cited in Tsao et al., 2011). Some researchers have noted that individuals who have a sibling with ASD are at a greater risk to internalize their feelings and exhibit behavioral problems (Petalas et al., 2009). Typically, the need to internalize feelings stems from their perceived role of responsibility for the child with ASD, which can lead to repressed anger (Barak-Levy et al., 2010).

The typical developing siblings frequently reported fear and concern for the future for their family member with ASD. Orsmond & Seltzer, the authors conducted a study in 2007, regarding sibling concerns for the future. Due to the atypical role the sibling had acquired, siblings often feel an obligation to care for their sibling with ASD in the future. According to Autism Society (2011), it's very normal for siblings to develop anxiety about their sibling's future with regard to financial care, residential care, potential employment, managing the required services, and overall the sibling's confidence to provide adequate care.

Siblings of children with ASD quickly understand and notice the difference in sibling relationships when compared to TD sibling relationships. Researchers Kaminsky and Dewey (2001) explored the relational differences between siblings of children with

ASD and siblings of TD children. The results revealed that siblings of children with ASD reported lower levels of intimacy, prosocial behavior, and nurturance by their sibling with ASD (Moyson & Royers, 2011). The participants expressed their understanding of their sibling's lack of communication skill and emotion awareness, which left the sibling feeling restricted when it came to communicate with their sibling (Moyson & Royers, 2011). Along with the limitation of communication, siblings also reported the difficulties in observing typical developing sibling relationships because of their feelings of loss or denial of their own typical sibling relationship (Petalas, Hastings, Nask, Reilly & Dowey, 2012).

Although there are many challenges and difficulties of having a sibling with ASD, in a majority of the studies, many reported positive experiences and interactions. Several siblings of children with ASD found that there were positive results in the sibling relationships. In 2009, Petalas and colleagues explored the perception and experience of TD siblings growing up with a brother diagnosed with ASD. They found many siblings reported having fun with, feeling proud, protective, and even admired their brothers with ASD (Petalas et al., 2009).

According to Harris and Glasberg (2003), and Knott, Lewis & Williams, (1995), the stability, longevity, and quality of the sibling relationship is greatly influenced by the amount of time spent with one another. It was stated that on average, 40 minutes out of every hour in mutual interaction between siblings is a crucial stage for developing an emotional support network for both siblings, resulting in a better quality relationship (Petalas et al., 2009). In the same study, siblings also reflected on their positive views and experiences, such as, a sense of pride when the sibling with ASD had achieved a task, no

matter how big or small. One sibling stated his admiration for his sibling's ability to recall specific events, words, or facts (Petalas et al., 2009). Although adjusting to the behaviors of siblings with ASD can be difficult and strenuous, more often than not, siblings report positive experiences and appreciation for their 'bizarre ways'.

### **Family Support**

There are many interventions and approaches to utilize and explore when working with a child, siblings, and family with autism. In the Intellectual Disability community, it is generally agreed that early intervention programs for the child with autism is most effective and shows higher improvement rates. With that, a majority of research is on the intervention for the child with ASD. However, family intervention and support is equally important to consider.

Gold (1993) expressed the importance of open communication throughout the family regarding the disability as a driving support for all family members (Tsoa et al., 2011). Creating an open environment that welcomes questions, concerns, and thoughts about the disorder allows for all members, especially siblings, to express their perceptions and gain access to information regarding their sibling's disorder (Tsao et al., 2011).

Another advantage of creating an open and communicative environment is that siblings have indicated that they feel more support and understanding when learning to express their own emotions and personal needs (Tsao et al., 2011). In 2011, Researcher Ling –Land Tsao facilitated a class for siblings of children with ASD about, "How to play with children with ASD," which resulted in more observed positive play and behaviors between both the children, suggesting both siblings were socially and actively engaged (Tsao et al., 2011). Teaching siblings how to play allows for trial and error

experiences, safe environments, and social feedback, allowing TD children learn to adapt to their siblings erratic social behavior (Stoneman, 2001). Play creates a social context for both siblings to explore roles, power relationships, and familiarity of interaction with each other (Tsao et al., 2011).

Research also suggests that family support groups are a positive and beneficial approach for seeking outside support, acceptance, and guidance when raising a child with autism (Tsao et al., 2011). Support groups allow family members to relate to other individuals who are in similar situations, as well as allow for collaboration, emotional support, and building skills like coping mechanisms (Petalas et al., 2009).

### **Identity Formation**

The formation of self-identity is crucial for any young person regardless of race, age, nationality, or ethnicity. Identity development is a life long process. According to Levy-Warren (1996), the developmental stages during the adolescent period occur roughly between the ages of 10 and 22. Erik Erikson (1950-1968) proposed a theory of development throughout a life span that consists of eight stages. During each psychological stage individuals seek to adjust to the stressor and conflicts experienced. Erikson's fifth stage, identity versus role confusion, occurs in adolescence. During this stage in particular young people explore who they are, examine the various roles they play, and associate these roles with a perception of self, which in turn forms an identity (Zastro & Krist-Ashman, 2007).

A significant component of identity is the analysis of the major principles in a personal code of morality. Moral development involves a set of principles that guide an individual's ideas and beliefs of what is right and what is wrong (Zastro & Krist-Ashman,

2007). Lawrence Kohlberg (1963) classified moral development into three levels and six stages within which people evolve and develop their moral framework (Zastro & Krist-Ashman, 2007). According to Kohlberg's theory, adolescents experience the conventional level, better known as "role conformity". Within this level, opinions and reactions become important and influential (Zastro & Krist-Ashman, 2007). Stage three focuses on gaining the approval of others and stage four emphasizes the need to abide by the law (Zastro & Krist-Ashman, 2007).

A majority of the previous literature is congruent in addressing the adolescent stage, finding that one's self-concept is largely impacted by their peers and reactions of others (Zastro & Krist-Ashman, 2007). A common tenet of this labeling process is known as the *looking-glass self*, coined by Charles Cooley in 1902. This idea alludes to how we view ourselves, not who we are, but what we believe others see us as (Zastro & Krist-Ashman, 2007).

### **Conclusion**

In conclusion, Autism is a complex disorder that is diagnosed in early childhood. Recent public awareness has familiarized society with the symptoms and characteristics of the disorder. ASD not only affects the child who is diagnosed with the disorder but also the lives of their caregivers and family members. It is vital that social workers are educated and acknowledge the effects the disorder has on the family as a whole, especially on the siblings as they continue to develop and progress in their lives. In the following section I will address the conceptual framework that guides this research project.

### **Conceptual Framework**

In this section the researcher defines the conceptual framework that guides the understanding and design of the study. I will use the conceptual framework of family systems theory and strengths perspective, as they both apply to this research topic. This researcher found these two theories to be most applicable and appropriate when dealing with siblings and families who are presented with an ASD diagnosis.

The first theory related to this topic is the family systems theory. Dr. Murry Brown, a psychiatrist, introduced the family systems theory in the 1950s. The theory was formulated into eight interlocking concepts regarding human behavior and the idea that the family is an emotional unit (Kirst-Ashman & Hull, 2006). In situations with a child diagnosed with ASD, the family plays a major role in treatment and intervention and, as previously stated, the family is greatly impacted by the diagnosis. The family system theory focuses on the family as a unit rather than focusing and fixating on a particular member of the family. The theory emphasizes the interaction of various systems that include the individual, family members, groups, and communities in the current environment. In hindsight, the family operates as a system and all parts (family members) have relationships that affect one another (Kirst-Ashman & Hull, 2006). Family systems theory is particularly important when analyzing and working with families that are impacted with an autism spectrum diagnosis because the disorder influences and affects everyone within the family system. Social workers working with siblings of children with ASD would benefit from working within this approach because siblings tend to play a specific role within the family system (Kirst-Ashman & Hull, 2006).

Strengths perspective is another theory that applies to this study. The strengths perspective focuses on the positive assets of the client rather than concentrating on the adverse circumstances and negative attributes of the client (Kirst-Ashman & Hull, 2006). This perspective allows the client and the professional to collaborate and identify the strengths within the client's current situation.

Families impacted by an ASD diagnosis often struggle to focus on the positive aspect when the daily struggles and hardships are the primary focus. Identifying a client and their family's strengths can help in several ways, such as reinforcing a sense of self respect and values. Second, it provides a sense of hope. Third, it helps identify possible solutions by utilizing those strengths (Kirst-Ashman & Hull, 2006). Using strength-based approach with families that are impacted with an ASD diagnosis allows the social worker and client to promote the individual, family, and community strengths as they apply those strengths to their daily lives. Focusing on the strengths and applying those strengths will improve all individuals quality of life and improve the family system and function.

In conclusion, the family systems theory and strengths perspectives are strong and effective models when working with families with children diagnosed with autism spectrum disorder. Both theories empower, strengthen, and unify the family as a whole, thus increasing their quality of life. Families impacted with an ASD diagnosis encounter unique difficulties and hardships, which is why this research has identified the family systems theory and strength perspective as effective and applicable theories that enable families with an ASD diagnosis to adapt to the hardships and strengthen family relationships and overall quality of life.



## **Methodology**

### **Research Design**

In this section, this researcher will identify and describe the methodology that will be used to explore the experiences and identity development of siblings with children who have ASD. This researcher used qualitative and exploratory methods to complete this study. Qualitative research includes data collection, data analysis, and conclusions regarding the research topic (Monette et al., 2008). Qualitative interviews were used to explore the experiences of siblings of children with ASD and assess their identity development. In this study qualitative semi structured interviews were conducted with eight siblings of children with autism spectrum disorder. Semi structured interview questions (See Appendix, A) allowed the researcher to gain a deeper and ample understanding of how growing up with a child with ASD impacts the development of siblings identity (Monette et al., 2008). Grounded theory was used to analyze the collected data. Grounded theory is a method used to develop a possible theory based on the collected and transcribed data. Grounded theory is applicable to the current study because examining identity development of siblings with children with ASD is under researched and under explored (Monette et al., 2008). Thus allowing new theories and strategies to emerge to more effectively intervene.

### **Sample Population**

Participants in this study are young adults between the ages of 18 and 28 who have a sibling with ASD. Siblings whom have multiple siblings with a diagnosis are encouraged to participate due to their unique experience. Also, siblings were asked to disclose their sibling's diagnosis and the level of functioning to gain a better

understanding of their diagnosis and attain valuable information. Snowball sampling was used to recruit eight individuals to participate in the study. Snowball sampling is a subset of purposive sample, which is used in rare or limited populations, and achieved by asking a participant to recommend someone else who is willing and appropriate for the study (Monette et al., 2008). This researcher obtained participants by creating an informational flyer (See Appendix, B) outlining the details of research study and invite individuals to participate. The informational flyer was given to professional colleague asking to distribute to possible participants. All participants interested in contributing to the study were asked to contact the researcher directly via e-mail or phone to further discuss the details and interview process. When possible participants agreed to partake in the study, this researcher discussed possible meeting locations and times to complete a face-to-face interview. Individuals that choose to complete the study were given ten-dollar Target gift card as an incentive to participate in the study.

### **Protection of Human Subjects**

The informational flyer (Appendix, B) explains the intent and process of the interview, which include tape recording and storage of the tapes as well as how the data collected from the interview will be used for publication. In order to protect all participants involved in this research study, participants and data collected is kept confidential and protected. This researcher kept confidentiality of each human subject by securing all tapes and paper documentation locked in a filing cabinet in this researcher's home. No other individual has access to the audiotapes, as they are secure by lock and key, which only this researcher has. The interview tapes will be destroyed after they are

transcribed. The data will be kept until May 18, 2015 at which time all notes and reports will be shredded and destroyed.

Participants were asked to complete a consent form before the interview is conducted. Information about confidentiality was explained to each participant at the time of interview. Each participant was assigned a pseudo name, that they are known as on the tape and in data collection. All names and dates have been altered to protect the identity of the participants and their family members. The interviews were conducted at a time and semi-private public accommodate the participant. At the end of the interview, the researcher provided a list of counseling resources (See Appendix D) that the participant may access and receive services.

### **Data Collection**

In this research project, this researcher interviewed eight participants who are sibling to children with ASD. All interviews, that are semi-structured, were conducted in order to collect data. The Semi- structured interview allows flexibility for the researcher to gain more information. The semi-structured questions act as a guide for the interview process (Monette et al., 2008). Before the interview, participants receive an email regarding the interview and an information sheet regarding the interview questions (Appendix E). All interviews were taped recorded and transcribed following the interview. As stated before, all tapes and documents are stored in a filing cabinet at the researchers home and destroyed after May 18, 2015.

### **Data Analysis**

This researcher used content analysis in this study. Content analysis is a specific style of data analyses, which is used to transform data from quantitative to qualitative.

Using content analyses, this researcher hoped to find a deeper meaning and abundance of data that will emerge from the data when analyzed. Coding was completed in this study by separating and categorizing the research data into a limited number of themes (Monette et al., 2008). This allows for the researcher to identify the major themes that emerge in the lived experiences of typical developing children of siblings with ASD. This researcher transcribed each audio-recorded interview in order to obtain all vital and crucial information that pertain to this study.

### **Strengths and Limitations**

There is very limited information regarding the experience of individuals who have a sibling with ASD. This study provided contributions of valuable information to the literature on this subject especially when addressing the identity development of these siblings. This is an emerging area of study that is impacted by the lack of research regarding the experiences and development of siblings. This addition this is valuable information when addressing families who are impacted by an ASD diagnosis, as the clinician is able to assess the family's situations from new perspectives.

The limitations of this research study include the small sample sizes of eight siblings. The small sample size hinders the researchers ability to generalize the findings to a larger population. Another limitation is the diversity in the sample. The study only included individuals in the Midwest, Minnesota area. And, due to the IRB, this researcher was not be able to interview minors in the beginning stages of their identify development which would have examined the initial developmental processes of forming an identity. Lastly, there was a time limitation when interviewing which may cause a lack or complete understanding of the data.

### Findings

The author of this study analyzed data from a qualitative, semi-structured interview with eight individuals who have a sibling with Autism. The majority of the participants interviewed currently live in the Twin Cities or surrounding suburbs. Seven participants were woman and one was a male. The participants ranged in age from 18 to 28. Six of the participants identified as Caucasian and two participants identified as African American and Asian American. Seven of the participants were older than their sibling who is diagnosis with Autism while the remaining individual was the twin of an individual diagnosed with Autism. See table 1 for a summary of the participants' demographic background.

Table 1

*Summary of participant demographic information*

Sex	Age	Race	# of Siblings	Birth Order	Parents Relationship Status	Occupation	Religion Affiliation
Vanessa	18	Caucasian	2	Oldest	Married	Student	Christian
Tina	23	Asian-American	2	Oldest	Divorced	Business	Buddhism
Martha	25	Caucasian	3	Middle	Married	Business	Lutheran
Anna	27	Caucasian	7	Oldest	Divorced	Social Service	N/A
Bri	28	African-American	5	Oldest	Divorced	Business	Christian
Jess	28	Caucasian	3	Young est (Twin)	Married	Special Ed. Teacher	Protestant
Rachel	28	Caucasian	3	Oldest	Married	Teacher	Christian
Mack	28	Caucasian	4	Oldest	Married	Business	Christian

The purpose of these interviews was to examine autism and its impact on siblings' identities. In the interviews, five primary themes emerged along with multiple sub-themes regarding the participants' identities. Originally, the researcher identified ten themes. However, after further analysis, this research divided the information's into five themes with multiple subthemes. The five major themes with multiple subthemes that have emerged from the data analysis are the following: 1) Definition of Self 2) Family Dynamics 3) Childhood 4) Future Care 5) Reflection.

### **Definition of Self**

In the interviews, the participants were instructed to describe themselves. This researcher chose not to provide any specifics because the purpose of this question was to explore the participants' perception of self. In all eight of the interviews the participants described themselves in three areas such as personality traits, job or occupation, and social life.

**Personality Characteristics.** As the participants described themselves five out of the eight participants first described who they were by using identifiable traits. The most common traits that were identified by the participants identified with were compassionate, ambitious, and protective.

Martha reported:

I'm almost overly compassionate, I just feel hard. I think it started with my brother, like when he was feeling hurt I was feeling hurt. I think I'm naturally drawn to people who are feeling sad or disenfranchised or lonely. I just feel hard.

Jess, who identifies herself as compassionate stated:

I'm just in tune to others and have a deep feeling of compassion like if I see a little kid at a store walking on their tiptoes I know that's not an unruly toddler. I just know their home is a little bit different.

Tina, identified herself as ambitious and goes on further to state "I base a lot of who I am on my goals and achieving those goals. I set so many goals that it does get overwhelming but I know if I don't reach those goals I'm just cutting myself short". Tina is currently in school full time pursuing her masters in financing, she also is working full time at a fitness center. Throughout her interview Tina stated that she enjoyed the busyness of her life.

Mack also defines a lot of who he is based on his ambitions:

I know what I'm capable of. I know what I want in life and I know I can do it.

Sometimes I get frustrated that I can't do everything. I have so many paths I want to go down but I know that sometime I need to slow down and just allow myself to enjoy what I'm doing now.

Perhaps the most common and what seemed to be the strongest characteristic trait identified by all participants included an innate sense of protectiveness. Bri, who was the eldest of seven children stated, "I know I'm protective, I know that I can be overbearing but it's my job". Bri was not the only one to identify her need to protect others.

Martha described how she protected her brother:

I'm pretty sure my first memory of someone making fun of my brother; I think I clocked him and told him he was going to Hell. He went home with a bloody nose and got grounded. For me, I think it was from the get-go that you just DO NOT make fun of my brother.... Only I'm allowed to.

Tina described a time where she protected her brother:

People look at him differently because he does things a little differently. When people ask me what's wrong with my brother, I just say nothing is wrong with he he's just a bit different like how maybe someone wears glasses because they need help.

Mack, who described himself as pretty popular stated:

I knew everyone and everyone knew me. They knew that Sam was my brother and if anyone would mess with him they wouldn't only have to deal with me, they would have to deal with the whole football team. He is one of us and we protect our own.

An additional observation was made during the interviews. Many of the participants had a difficult time identifying personal characteristics. Many of the individuals would redirect their answers to their siblings.

**Job and Occupation.** Another major identifier for the participants was their job and occupation. Three of the participants described their job and occupations when describing themselves.

Vanessa stated:

Well I'm a student at the U of M and majoring in psychology with photography minor. Right now I'm working as a PCA for a young boy who has cerebral palsy (CP) and a traumatic brain injury. I love what I do; I basically just to get hangout with my little guy and I get paid for it.

Rachel stated:



Well I graduated from Duluth in 2010 and then I went right into the Peace Core. I absolutely loved it and really motivated me to go into teaching so I went back to school and now I teach in a inner city school and I've never been happier.

Anne also identified strongly with her occupation as an Education assistant:

I am currently working as an EA and to be honest when I was younger I did not want anything to do with kids or schools and well look at me now. I've been an EA for the past 9 years and I haven't thought or wanted anything different. I know this is what I'm supposed to be doing.

It is important to note that six of the participants are either in school or have a degree relating to social services. For the other two participants, they have worked as a personal care attendant (PCA) for a person with a disability.

**Social Life.** Many participants identified their social life as a contributing factor to who they are. Four of the participants disclosed to having more than one job and involved with two of more social activities.

Martha stated:

I'm a very social person. Like if I'm not with someone I feel weird. Like I just love being with my friends. And for me I have a lot of different friends in different groups so it's just nice to expand. For example, I'm in a running group, book club and I am starting to take an art class with a few of my girlfriends.

Tina described her busy life:

I'm always on the move. If I'm not working then I'm studying. If I'm not studying I'm with my friends most likely working out. I like being active and

doing things. Being around people is just important to me. Sometimes its nice to have a break from my family and just be.

### **Family Dynamics**

Throughout the interviews, participants were asked to describe themselves, which often resorted back to their family and specifically their role within the family. Three out of the eight participants came from a single parent household, while the remaining five came from a two-parent household. When asked about their families, the participants described their parents' relationship as a major impact in their life. Another significant family dynamic for the participants was the relationship between the siblings. Along with the sibling relationship, an interesting theme of the "other" sibling was identified. Two of the participants in this research had no other sibling other than the individual with autism and their family dynamics did have some differences when compared to the individuals who had multiple siblings.

**The role of parents.** Parental figures and caregivers are seen as the primary source of information and guidance in life. Parents are typically the ones who instruct their children how and who to be in the world. In the interviews, it became apparent to the researcher that parents had a major impact on the family dynamics. More specifically, the parents approach to the diagnosis and expectations of each family member formed the bases on which the family functioned.

Martha described her family as the Brady Bunch:

It's almost gross how close and cohesive my family is. We are always in each other's lives and well we just kind of stick together. I guess you could say we're the Minnesotan Brady Bunch. My dad and mom are defiantly one of the major

influences in my life in terms of growing into an adult. It just seems like they have it [life] figured out. If I could be anything like my parents when I'm a fully realized adult I'd be thrilled.

Jess told the interviewer:

I not only am extremely close to my family like relationship wise but I live down the road from them. My husband and I moved so close just to be near my family. We are all really close and I'd say my brother [Sibling with autism] is really the anchor of our family. We always felt respected and open with our parents, which kinda set the mood for the rest of our lives.

Many of the participants expressed admiration and appreciation for their parents. They spoke very highly of their parent's strengths and resilience through their childhood and adulthood that "guided" them into adulthood.

**Parental approach.** A subtheme that emerged from the interviews was the parents approach to dealing with an autism diagnosis in the family. This researcher found that parents who had a more pragmatic approach tend to have better relationships within the family and also impacted how the participant's attitudes were toward the diagnosis. For those who were more hesitant to accept the diagnosis tend to have strenuous relationships within the family.

Jess reported to the interviewer:

My parents really accepted him right away because he's God's child and it was their job to take care of him. I just wanted to help, I just loved my brother so much and my parents really taught me just to be accepting of all things no matter

their differences. My family is just so tight, we know we're a team and we deal with things as they come.

Martha goes on to describe her parent's acceptance of her brother:

I think I revered both my parents because I just did not want to disappoint them because of how accepting they were. They honestly are a great testament and role models in life. In any negative or adverse situation my parents would just accept it for what it was then worked together to find a solution or even just to make the best of it. When it comes to my brother and getting diagnosed, my parents just accepted my brother and loved my brother for who he is and what he has to offer.

In two of the interviews, the participants described their parents, specifically their father, hesitant to accept their child's diagnosis. In Tina's interview, she disclosed that her parents divorced at the age of 10 and she has very limited contact with her father.

Tina stated:

My mom was really the one who took charge of my brother and me. She was the one who made his appointments and went to the school meetings. My dad really never went or showed interest in his needs or like the services he had. My dad really never recognized the disability. He just would describe him as slower and wouldn't really interact with my brother. I honestly think its because he's scared and he doesn't want to deal with the fact that his son isn't going to be the quarter back of the football team or the son you can take out hunting. It's actually really sad.

Vanessa described her relationship with her parents to the interviewer:

My mom and I are really close and I really don't talk to my dad that much. My mom and I just get it. We understand where we are both coming from when it comes to my brother. We were both apart of his treatment. My dad really didn't take part in that stuff and dealt with his behavior. However, my dad and brother are close in the sense they bond over food and my dog. I think that's a way for my dad to accept my brother's disability and connecting with my brother.

Many of the participants identified their mother as the primary caregiver for the sibling diagnosed with autism. Many participants referred to their mother when asked about their sibling's services and diagnostic process.

**Parent expectations.** Along with parental relationships and parental approaches, parent's expectations of the siblings were very important and influential in the participant's lives. According to the findings, and contrary to what most people believe, individuals who have a sibling with autism do not receive any less attention from parents. In the interviews all eight participants explained their frustration with the stigma of parents attention and expectations of the neuro-typical developing siblings.

Rachael stated:

You know it's interesting. I never really thought about how growing up with my brother and how it affect me it just I don't know I think, in a good way, my parents didn't even make that a factor. Like it's just the way it is. He was never treated any differently or held to any different standards.

Mack discussed his experience:

The part the really annoys me with the diagnosis, is peoples assumptions of our family. Seriously though, people just assume I'm deprived of attention from my

parents. People just assume that my parents only pay attention to my brother, which totally isn't the case. I mean yeah my parents have to focus on my brother and what he needs but that doesn't mean I'm not a priority of theirs.

Martha responded:

My parents made it a point for all three of us kids to be super involved. I mean we all were involved with church but even besides that, my sister and I were in sports and my parents made my brother come to support us. But that goes both ways, my brother was in Special Olympics and my sister and I were always involved weather it was coaching or cheering on the sidelines.

**The sibling relationship.** These findings suggest that the participants in this study had a positive and strong relationship with their sibling who is diagnosed with autism. The areas of the sibling relationship include a “special” bond, the role of the sibling and feelings toward their sibling. The phrase “special” bond came up in many of the interviews. This “special” bond is often referred to by the in-tune feelings the participants have with their sibling. Vanessa reflected on her relationship with her sibling and stated, “I remember speaking for him a lot. Like him and I have this one mind kind of thing where I understood what he wanted or needed”. Again, another one of the participants in the study, Jess, reflected on her relationship with her brother. It is important to note that Jess is actually twins with her brother who is diagnosed with autism.

Jess stated:

My brother and I have a strong relationship. I mean even though he's non-verbal we just always had a connection. Like if my parents were struggling with him

they kind of depended on me to calm him down because... well I'm his twin and we're connected. My parents really listened to me when it came to my brother because we had a special bond. Like for example, even in school when he was acting out the teacher would come and get me and I would just go into his classroom and just sit down. No lie within three minutes of me being in there and not even saying anything he was calm.

Mack also refers to the concept of a special bond:

My brother and I just get each other. We have this special bond where I know what he's thinking and he knows what I'm thinking. My brother has limited language so I kind of took it upon myself to be his spokesman. At a young age I remember just looking in his eyes and just trying to get inside of his world, and I think I did.

Tina also commented on her bond with her brother:

Now according to my mom, I'm the only person my brother listens to. I think it's because I get it. I get his disability and I connect with him in a special way. Like I just play with him and I don't think he gets that a lot. Playing with my brother means just accepting his SpongeBob figures all over the floor and showing interest in what he has to show you. That's all he really wants is just someone to acknowledge him. We have a strong relationship, I think it's because my parents weren't really there for us emotionally so we were they for each other. And he does a lot for me too. Like I feel like he knows or can sense when I'm stressed or upset. Although I know he really can't empathize with me I know he cares, mainly because he'll let me be Mr. Krabs when playing.

In the interviews, several of the participants described their relationship with their sibling as strong and on a deeper level. Several of the participants even stated they believe their relationship is so strong because of their sibling's diagnosis.

**My role as a sibling.** Although not all participants had the same experiences while growing up, six out of the eight participants identified their role as a sibling in the interview. Three of the participants identified themselves as having a mothering or parental role with their sibling.

Bri, the eldest of five siblings described herself as “the other parent,” she elaborated.

I really did a lot with my brother and especially my little sisters. My dad wasn't around so it was just my mom. She needed to focus on my brother and his behaviors so I kind of took on that role of the other parent. I was the one doing the cooking, cleaning and putting my other siblings to bed. I know my brother didn't want to listen to me but I knew he respected me.

Rachael stated:

To be honest, I think my brother see my husband and I as another set of parents. My husband is really my brother's idol. He wants to do everything my husband is doing. I don't mind being in that role either. I feel like it just kind of fell into place. My sister is more of a typical sibling for my brother and I'm more of the parent or nurturing sibling.

Another theme that emerged in the interviews was the admiration and respect the individual diagnosed had for their siblings. It seems many of the participants are role models for their sibling, Tia stated, “I really don't know, but I think he sees me as a role



model or something”. Several of the other participants share this role as their sibling’s idol.

Mack responded:

I fee like my brother just wants to be like me. It makes me feel great. I feel like I have to succeed and do the right thing because I want to live up to his standards. I want him to be proud of the person he is looking up to.

Anne reported:

It’s funny even as a kid my brother would follow me around and do the things I did. I kind of feel like he was living his life through me and my accomplishments. Like for example he would come to all my soccer games and he had on the same jersey as I did and he would freak out when I scored. He was always experiencing life with me.

The findings suggest that the individuals value their sibling’s admiration and this only encourages the participants to live up to their full potential.

**Feeling toward the sibling.** In the interviews, the participants were asked to share a time they felt embarrassed and proud of their sibling. In all of the interviews the participants said they were not embarrassed or frustrated with their sibling but they were more frustrated with how others treated and interacted with their sibling. For example, Anne described her frustration with her father when he refused to listen to her regarding her brother’s mood.

He was obviously done with the day and ready to go home. He was giving me all the signals and I told my dad. He refused to listen to me. Once we got into the restaurant my brother just lost it he began flapping and screaming and all I could

say was I told ya so. So no I never felt embarrassed with my brother but I did get frustrated with others.

One of the participants, Jess, stated, "I just get sick of Autism. Not of my brother but just of autism. I don't like the disorder but I love my brother."

Many of the participants shared a sense of pride for their sibling. Martha reported:

The most proud I have ever been of my brother moved out of my parents house and into a group home. I'm proud of him because of his fearlessness. For him and kids on the spectrum or with a disability they feel some sort of trepidation or fearful of moving out, But my brother never had that. He was ready and confident to be on his own. Just watching him walk into the house up the stairs suitcase in hand he was just so proud of himself, which just made me cry because I saw that he was proud of himself.

Bri stated:

The most proud sister moment was when he graduated from school. My parents were alumni's of the school. He was always in a special education room which he didn't mind but I remember him saying " I'm graduating with my class I don't care if it kills me" He was so determined to graduate on time and with his fellow peers. And we always just thought ya know he is going to finish but he might have to do some extra years. But wouldn't you know it when 2010 rolled around, he graduated right along with his peers. It was really funny he actually the first one to throw his hat in the air and scream. I'm pretty sure I blubbered like a baby. You could just see the pride on his face.

In seven out of the eight interviews, the participants said they were never embarrassed of their sibling or the diagnosis. Many of the participants told the researcher that their sibling is their idol and role model because of the obstacles in their lives.

**The other sibling.** The siblings in this interview were asked about the make up of their family. Six out of the eight participants have non-disabled siblings in their family. Several of the participants talked about their other siblings and how important and helpful it was to have someone who grew up with them and sharing the experience of growing up with a child diagnosed with autism.

Martha responded:

My older sister was like perfect. She was the valedictorian and I always called her mother Mary. I sort of had projection because she was always the one to beat. But that only really pushed me to do better and go further. We are really close even though we are completely different. It was really great to have her as my older sister, it was nice to have someone to look up to and to connect with. Like not many people in my small town had a family member diagnosed with a disability. So it was nice knowing she was there to understand what was going on.

Jess reported:

My older brother is a real man's man and I'm really girly so I mean we didn't totally connect but we shared a lot of the same friends and we even went to the same college. I would say growing up my brother was a little more reserved than I was when it came to our brother. He was kind of embarrassed of him but I know that if I need him or if my brother need him he is always there. I'm really happy

to have an older brother, its nice knowing I'm not alone when it come to taking care of my twin when my parents can no long provide care.

For the other two participants who did not have another sibling, they described their childhood as lonely. In Tina's interview, she described her parent's divorce and her struggle in that period of her life, "I don't even think my brother really understood what was going on." She goes on to say how she longed for someone to talk to about her parents divorce; she wanted her brother to empathize with her and their loss. In Vanessa's interview, she also expressed a sense of loneliness in her life. She goes on to say, "Its hard. I'm upset and he doesn't get it. Sometimes I just want him to get it." Another factor in these participants attributed to their loneliness is the lack of communication with their sibling. Tina states, "we only talk about what he want to talk about, I can't tell him anything serious because he can't comprehend it."

The findings suggest that individuals who have multiple siblings when compared to individuals without other siblings have a higher feeling of support and acceptance from their parents and extended family members.

### **Childhood**

In the interviews, the participants were asked when and how they were told about their sibling's diagnosis. It's important to note that all the participants were older than their siblings with the diagnosis. Three of the participants reported to have early knowledge of their sibling's diagnosis. Many of the participants were under the age of six when they were told about their sibling.

Vanessa reported:

He was born right after me so I noticed something was off pretty young. I don't really remember my parents even sitting me down and talking to me about it. But I do remember having therapist in the house working with him all the time. To be honest I kinda thought they were family members because they were at my house all day.

Anne also spoke about her early understanding of her brother diagnosis. "It was pretty obvious, I mean no two year old is constantly flapping their arms and screaming at the top of their lungs."

One of the participants, Jess, had a very unique experience with understanding her brother's diagnosis. Bernard Rimland, who is the founder of Autism society of America, diagnosed Jess's brother in 1990 when they were four years old.

Jess reported:

I'm sure my brother is a little pioneer because Dr. Rimland referred him to Dr. Fingould who was another autism Doctor back then. I mean my parents never sugarcoated his diagnosis. But I really don't remember a time at they sat me down and explain what this was. I'm pretty sure they just said your brother has autism and his brain works a little differently. But a time that I really remember what going to his speech pathologist it was the first time I was my brother look at and communicate with other adult other than my parents. And that scared me too. Because he just looked like an unruly toddler and I will never forget I was so scared for him when he was with this lady and she got one on one time with him. After an hour they were best buds. And I'm pretty sure that lady is a pioneer in the field too. Her name is Phyllis Kupperman.

After the interview with Jess, this researcher did further investigation to find background information on Phyllis Kupperman. The research showed that Phyllis Kupperman is the founder of the Center of Speech and Language in Chicago Illinois.

Three of the participants reported that they had little knowledge of their sibling's diagnosis. One of the participants, Bri, told this researcher that it wasn't until her brother was fifteen years old that he was diagnosed. She further explained, "I mean we all knew he was slow and needed extra help, none of us really thought of him having autism". Bri also reported that she regrets not seeing his disability sooner, "He would have progressed a lot faster and further if he was diagnosed earlier".

Two of the participants had no recollection of how they specifically learned about their sibling's diagnosis. Both of these participants assumed that their parents did describe their sibling's differences but had little memory of the time.

Rachel reported:

I don't remember a conversation where I specifically asked about his developmental capacity of where he was. I don't remember asking about it or my parent explicitly saying "we need to talk" I think his developmental timeline was so slow and was not readily apparent in his interactions with him or any physical display. So I mean if I had questions I know I could or probably did ask my parents but it just never was laid out.

**A new normal.** In the interviews, a subtheme emerged when the participants were asked to describe their childhood. The phrase, "It was my normal," was a common reoccurrence in the interviews. Several of the participants share a common experience in their childhood that they realized not every household has a child diagnosed with autism.

Jess stated:

I didn't know anything was really different about my brother until I went to school. I didn't know anything was wrong until I met other peers. I didn't think anything was off with my brother because that's all I knew. So when we got to school and kids were talking about a funny looking kid who makes funny noises it clicked then I went "oh, oh that's my brother. Not everybody has a brother with autism? I didn't know that".

Vanessa also commented on the constant care and treatment teams involved in her family's life. Vanessa is only a year and a half older than her brother and very involved in his intervention plan. "I remember having people there all the time, just playing with him and teaching him stuff, it was just normal to me to have seven different people in my house". She goes on to further talk about her involvement with her brother's intervention, "The therapist would always have me just play with my brother. It was actually a lot of fun and the people were nice."

Mack shared a very similar experience as Vanessa, in that which he also had multiple therapists constantly in his home.

My childhood was a lot different than my friends, my friends didn't have to deal with having a brother who has autism and have to depend on these people coming to fix you brother. As a family, which included the paras and the therapist, we all had to work together to help my brother.

Tia, another participant also described her involvement with her brother's intervention.

My brother was born premature and had a feeding tube for a really long time. So like when he was hungry we would have to do the tube. I think I started changing it or at least help changing it when I was like seven? And he also had a nebulizer until he was ten so that what I grew up with it was pretty normal to me.

**Invisible disability.** Along with the subtheme of “normal” life, six of the participants commented on their sibling’s ambiguous diagnosis. Six of the participants reported that their sibling is on the higher functioning side of the autism spectrum and did not display any apparent physical facade of a disability. The idea of the invisible disability made it difficult for at least three of the participants to describe to their peers what was “wrong” with their sibling. Martha stated, “my brother doesn’t look any different or like he has a disability you can only really tell when he talks.”

Rachael stated:

My friends would always ask like what’s wrong with my brother. And it was hard to describe to them. I would say he has autism but I mean at ten years old you have no idea what that means. It made it even hard to describe because he didn’t look like he had a disability. He wasn’t in a wheelchair or had distinct physical features like Down syndrome so it wasn’t obvious.

Vanessa described one of her experiences of trying to describe her brother’s behaviors:

One time my friend asked me why he walked on his tippy toes and why he repeated thing from the T.V I just told her that he has autism and sometimes he does things different and doesn’t always know how to respond. My friend then said why doesn’t he look different. And I said. Why don’t you look different



because you wear glasses? I guess I just tried to put it into perspective that maybe they can understand?

Jess described her fear as a child when her brother would “act out” in public. She stated that her fear stems from her brother's invisible diagnosis:

My twin doesn't look any different he just acts different. I remember being scared going to the store with him because if he too overwhelmed or tired he would scream and start hitting himself. My dad or mom would then basically have to tackle him to make sure he was safe. It looks, to someone who doesn't know what's going on like my parents are abusing him or my brother is dangerous. But really it's just my brother communicating his discomfort.

Findings indicate that having a sibling with an autism diagnosis often produces many obstacles and hardships in their lives. Even more so, having a sibling with a disability that is not easily recognized presents even further challenges.

### **Future Care of Siblings**

Participants were asked about the future care of their siblings. These participants were asked how involved they see themselves in their sibling's future. All eight participants expressed having an active role in their sibling's future. However, when asked about guardianship over their sibling once their parents are no longer able to care for them the responses varied. Three of the participants reported that they will have sole guardianship, four of the participants will have joint guardianship with their other siblings, and only one participant expressed their reluctance to have guardianship over their sibling diagnosed with autism.

Two of the three participants who will obtain sole guardianship stated the issue has not been formally discussed, however it is the obvious plan. Tia stated, “My mom and I have yet to do the paper work but I’m really the only one who can do it”. Vanessa also has not had a formal conversation about her brother’s future, “My parents have guardianship now but I know once I’m out of college we’ll have that discussion but it’s just what is expected.” Mack will also take sole guardianship over his brother and stated, “I feel honored to be his legal guardian I never felt like it’s a burden or too much, I love my brother and he deserves the best life”.

Martha and Rachael, on the other hand, will share legal guardianship over their siblings and have already had a formal conversation about this process with their parents. Martha described, “It’s just obvious, I mean when my parents die my sister and I will take over.” Rachael also discussed the process, “my parents and my older brother sat down and just talked about my little brother future. My parents laid out the paper work and really went into detail what it means to be a guardian.”

Anne was the only participant who will not take over guardianship for their sibling. She is the oldest of seven children and expressed no interest in having guardianship. “All my life I was the second mother, I didn’t mind it but I need to live my own life. My sisters can help out now.” Anne reported that this topic of guardianship has been slowly and lightly discussed within her family, she reported that her family is aware of her current thoughts on the topic and are respecting her wishes.

While discussing the future of their siblings, five participants commented on their willingness to respect and take into account their siblings wishes. The five participants all stated, “I’ll listen to what he wants,” when discussing the future housing of the sibling

diagnosed with autism. It became clear that the participants prioritize their sibling's happiness and requests to improve their sibling's quality of life.

Martha stated:

I don't know how necessary it would be for us to live next door. But also I want to listen to what he needs and what he wants too. You know it's worth asking "what do you want?" and if that was important to him that would have to be taken into consideration. It really just depends on what will make my brother happy and most successful. That's really all that I care about.

Vanessa reported the following:

Even though we really haven't talked about it but I'm honored to be his guardian. He really doesn't need a lot of guidance or supervision. So I would be comfortable with him not living with me. Maybe in a group home or with a roommate, I would still stop in to check on him but not where I'm over controlling. I know when it comes to making those decisions I'll give him a lot of say in what he wants. I mean he's smart and really responsible plus it's his life and he deserves to be happy.

Many of the participants prioritize their sibling's happiness and wishes when deciding any major life changes. Having the opportunity to voice their siblings concerns is important to the siblings. One of the participants even stated, "My brother is the MVP in his life, he should have a say in what happens to him. It's his life and if he has a say in what happens he'll be more successful. I'm just a cheerleader on the sidelines"

**Reflection**

Several of the participants commented that before they agreed to participate in this study, they had not reflected on their experiences. Many of the participants offered gratitude to the researcher for encouraging them to ponder their experience of growing up with a sibling who is diagnosed with autism.

One of the participants stated:

Until you contacted me I never really sat down and pondered this and how it might have affected who I am and what I'm doing with my life. It was a really good exercise to just think about my experience and now I know I'll be more aware of it.

The participants were asked if they thought their sibling's diagnosis had an impact on who they are today and in what ways. All eight participants expressed the influence their sibling had on their lives. Tia suggested that without her brother she wouldn't be as "humble and compassionate".

Bri stated the following:

I think my brother and my childhood has defiantly impact on who I am today. I think it's made me more willing to interact with people who are different. Most people don't like interacting with people who has a disability but I love it. I think growing up with my brother and going through and see what he has overcome has made me more appreciative and accepting of others.

Rachael stated:

Without my brother I don't think I would be who I am today. My brother forced me to develop a level of empathy for people and to have an eye for people who

aren't like everyone else. I think I'm naturally drawn to people who are disenfranchised or different because that's all I knew growing up. I don't know if I would have that same intensity if I didn't have him growing up. I love my brother and I feel so lucky to be his sister.

Mack stated:

Growing up with my brother and seeing all the obstacles in his way that he just overcame with strength pretty much made me who I am today. Watching my brother and helping my brother absolutely made me who I am today. In any situation if I see someone mistreated or left out I take it upon myself to befriend them and to stick up for them. I'm protective, compassionate and accepting all because of my brother.

Three of the participants discussed how their sibling's diagnosis encouraged them to persevere in a specific occupation. Two of the participants are special education teachers in the inner city. Jess suggested that her career choice was completely based on her experience with her brother. She stated, "I know the struggle; I understand what my students families are going through. And I know I can provide some help or guidance"

Vanessa stated:

In high school we had to take those tests that suggest an occupation for you. I wasn't surprised when the test suggested a social service job or something in the medical field. Now I'm going to school for psychology I'm not sure what I want to do with the degree but I know I'm meant to help people. I'm pretty social, easy going and always willing to help people. I know that I have the ability to tune in

to peoples needs. So something defiantly with people and helping others, it's just an obvious choice.

### **Conclusion**

The purpose of this research was to explore autism and it's impact on the identities of siblings. The interview questions were asked in order to encourage future and current individuals who are siblings with a person diagnosed with autism as well as provide new information that can be applied to their specific situation. The findings in this study suggest that individuals with a sibling who has autism identify themselves in five major areas which include, 1) definition of self, 2) family dynamics, 3) childhood, 4) future care of their siblings and, 5) personal reflection. In the next section, we review the discussion and connection between the findings and pervious literature.

### **Discussion**

There is limited amount of research on the lived experiences of individuals with a sibling diagnosed with autism spectrum disorder (Kaminskey & Dewey, 2001). There is even less information on the impact an autism diagnosis has on the siblings' identity. After reviewing the pervious literature and analyzing the current findings, the family dynamic and roles within the family hold a great influence when exploring the identity development of individuals.

### **Family Dynamic**

Throughout the literature reviewed and the researcher's findings, there is general agreement and emerging evidence regarding the siblings' experience of growing up with a child diagnosed with autism. First, both previous research and the current study identified that the mothers in a family is the primary caregiver for the family and

especially for the child diagnosed with autism (Dellve et al., 2006). The findings of the current study indicated that the mothers in the participant's families were the primary caregiver and also had closer relationships with the children of the family. Another similarity between the current findings and the previous research is the time and outlook of the diagnosis. Lustig (2002), found that families who had the ability to construct the disability in a positive outlook reported a successful family adjustment, acceptance process, and decrease in stress. Many of the participants referred to their parents approach and acceptance of their sibling's diagnosis and the major impact on how they view their sibling's diagnosis. A family's cohesiveness and attitude of autism has a strong impact on the whole family (Tsao et al., 2011).

One major difference between the previous research and the current findings was the individual's feelings of the siblings. Researchers Feinber and Hetherington, (Tsao et al., 2011), found that siblings of a child with disabilities generally received less attention and differential parental treatment from the parents which resulted in feelings of resentment and jealousy and also linked to adjustment problems (Tsao et al., 2011). According to the current study's findings, it is suggest that the neuro typical developing siblings receive the same attention and expectations, as does the sibling diagnosed with ASD.

### **Family Support**

In congruence with previous studies found in the previous literature discussed, the findings convey the importance and the significant impact communication and intervention has on the family dynamic. Findings from several study expresses the importance of open communication regarding the disability, it suggests that an open and

welcoming environment that encourages questions, concerns and thoughts regarding the disorder can better support and strengthen relationships between family members (Tsao et al., 2011; Petalas et al.). The siblings interviewed generally coincided with the pervious findings. In many of the interviews, the siblings spoke to their families' open door policy where questions about their siblings were welcome and not ignored.

Another study suggested that when supporting the siblings, learning "how to play" and interact with their siblings is very important and will impact the individuals perceptions and relationship with their sibling who is diagnosed with autism. Involving the siblings with the early intervention will positively impact the sibling relationship, play between the siblings, creates a social context for both siblings to explore roles, power relationships, and familiarity of interaction with each other (Tsao et al., 2011). Many of the participants spoke to their involvement with their sibling's intervention; they reported that their involvement provided a better understanding of their sibling's diagnosis.

### **Feelings Toward the Siblings**

Although there are many challenges and difficulties of having a sibling with ASD, in a majority of the studies, many reported positive experiences and interactions. Several siblings of children with ASD found that there were positive results in the sibling relationships. In 2009, Petalas and colleagues explored the perception and experience of TD siblings growing up with a brother diagnosed with ASD. They found many siblings reported having fun with, feeling proud, protective and even admired their brothers with ASD (Petalas et al., 2009). The current study's findings are consistent with the research that indicates positive feelings toward siblings. For example, many of the participants



communicated their pride, admiration and respect of their sibling. This finding was consistent with previous research as researcher Petalas and colleagues found that although adjusting to the behaviors of siblings with ASD can be difficult and strenuous, more often than not, siblings report positive experiences and appreciation for their 'bizarre ways' (Petalas et al., 2009). Another study conflicts with both of these findings which suggest that the sibling reporting the negative aspect of living with a sibling who is diagnosed with autism is feelings of embarrassment (Osmond & Seltzer, 2007). The participants in the study were specifically asked if they have ever felt embarrassed by their siblings and 7 out of the 8 participants reported no feelings of embarrassment. The individuals felt comfortable and no shame regarding their sibling's autism. However, they did report their frustration with others who were "ignorant" when interacting with their siblings.

### **Identity Development**

The formation of self-identity is crucial for any young person regardless of race, age, nationality, economic status or ethnicity. Identity development is a life long process. For many of the participants in the study, the typical identity and moral development was influenced by their sibling's diagnosis. According to Erik Erikson and Lawrence Kohlberg, individuals encounter internal dilemmas at specific stages in their lives, which enhance and shape their identity, for example, in Erikson's fifth stage, identity versus role confusion occurs in adolescence (Rogers, 2010). During this stage young people explore who they are and examine the various roles they play and associate these roles with a perception of self, which form into an identity. The participants in this study were asked if their sibling's diagnosis had an impact on the person they are today. All the participants

agreed that their identity and self-concept is largely shaped and defined by their sibling and the diagnosis of autism. The findings in this study mirror another study's results that suggest families with a child who has a disability experience an increase in knowledge, spiritual growth, and personal growth (Scorgie & Sobsey, 2002).

Lawrence Kohlberg also proposed a theory of development throughout a lifespan.

Lawrence Kohlberg (1963), classified moral development into three levels and six stages which people evolve and develop their moral framework (Rogers, 2010).

According to Kohlberg's theory, individuals encounter the conventional level or "role conformity" during their adolescent years. During this stage, Kohlberg suggests that gaining the approval of others and acceptance of their peers is the most important experience. A majority of the previous literature is in congruence when addressing the adolescent stage and one's self-concept is largely impacted by one's peers and along with the reactions of others (Zastro & Krist-Ashman, 2007). However, the current findings in this study conflict with this conventional development of Kohlberg. According to the participants in the study, gaining the approval of their peers over their sibling's diagnosis was a non-issue. Many of the participants rejected the typical adolescent need to conform to be accepted. Many of the siblings even reported verbal and physical altercations with their peers as a result of taunting their siblings.

Despite the limited research on the impact of autism on siblings, when comparing the finding in this research and previous studies there are some significant impacts.

According to this paper the four main areas which impacts an individual who has a sibling with autism were, a) family dynamic b) family support c) feelings toward the

siblings and, d) Identity formation. Next, I will review the strengths and limitations of the study.

### **Strengths and Limitations**

Currently, there is an overall lack of research in the area of sibling relationships and autism (Hastings, 2003; Kaminisky & Dewy, 2001; Macks & Reeve 2006; Orsmond & Seltzer, 2009; Rivers & Stoneman, 2003; Roeyers & Buysse 2003; Verte et al., 2003). A major strength of this study is that it will add to the existing literature on the impact of autism on individuals who have a sibling diagnosed with autism. The impact on siblings and specifically the sibling's identity has not been thoroughly examined. This research will provide a new perspective and insight to clinicians who work with families who are impacted by an autism diagnosis. With the information provided in findings clinicians will have a better understanding the impact autism has on individual identities and will be encouraged to do further research on the impact of autism. This study offers a better and more specific knowledge to the challenges and influences faced by this population.

Another strength of this study is my personal experience with families who are impacted by an autism diagnosis. I have been a personal care attendant for families for the past seven years. I had the unique experience to observe and analyze the family dynamics, relationships and roles that occur when a family is impacted by an ASD diagnosis. More specifically, I have developed and maintained strong relationship ties with the neuro-typical siblings in among the families. My past experience has given me a unique insight to the lived experiences of individuals impacted by an autism diagnosis.

As in any study, this study includes limitations that should be taken into consideration. First, generalization beyond the participants in the study should be carried

out with caution due to the limited number of participants. This researcher was only able to recruit eight participants and seven out of the eight participants are female. The female to male ratio of the participants were 7:1 with females representing the larger population. Also the participants in this study all resided in the Greater Twin Cities area of Minnesota. Another limitation of this study is that all the participant's siblings were younger and male. To strength this study it would have been better to interview siblings who are both younger and older than their siblings diagnosed with autism. The findings may have been skewed because of the small sample size. The participants do not fairly represent the overall population. The individuals that part took in this study are a part of selective group. A random assignment and a controlled group of the participants would be ideal, however, due to the small number of families within the target population this would have been very difficult.

The lack of variation of subjects participating in the study also poses as a limitation. Along with the lack of males in this study, individuals with diverse cultural or ethnic background were not represented. Only two of the participants in this study identified themselves other than Caucasian. This study is limited by the lack of diverse backgrounds and understanding of cultural backgrounds in relation to the impact of autism.

Another limitation of this study was the researcher was not able to interview individuals who are currently forming their identity. Identity development is a life long process, it would be valuable to explore the impact on the beginnings stages of identity development that begins and sees major changes in late teens and early adulthood. Due to the Intuitional Review Board (IRB), it was not possible to individual individuals under

the age of 18 years old. Not being able to include individuals who are currently forming their identity does limit the findings and what the researcher was able to learn about impact of autism has on the early development of an individual's identity. Furthermore, another limitation is the researchers past experience of working with families who are impacted by an autism diagnosis. The findings may be skewed as a result of these researchers personal biases regarding the impact on individuals. The results may have varied if the participants were unfamiliar with this researcher.

### **Implications for Social Work Practice**

Over the past few years the awareness of childhood disability has been on the rise. A majority of the research has focused on the disability itself and the effects on the child, rather than the effects that caregivers and family members may experience. The increase of diagnoses of childhood disability must be further researched and understood to better provide effective treatments for not only the child but also for the caregivers. Raising a child with a diagnosis of autism spectrum disorder can be an overwhelming experience for the caregivers and families. Caring for a child with ASD presents a plethora of difficulties and challenges.

Due to the rising number of families impacted by an autism spectrum disorder, is it crucial to understand how each family member in the family system is affected by the diagnosis. The current research on the experiences of individuals with a sibling with an autism spectrum disorder is lacking, research exploring the impact on their identity is non-existent. The current research gives social workers a greater understanding of how individuals who have a sibling with ASD develop their identity.

The implications of this research educate providers on how to better provide support, intervention and also raise awareness to families. When working with an individual who has a sibling with ASD, social workers have a better understanding of how these individuals process and perceive life in a different way as a result of their siblings' experience. The research exhibits the unique experience of the typical developmental stages individuals who have a sibling with ASD. The research provides social workers with a basic outline of the nature of the individual's experiences and identified important factors that enhance value, moral and identity development.

### **Implications for Research**

In order to obtain more insight future research is necessary. Future studies should consider including a more diverse population. Future research should explore how different cultures and ethnicities may impact the identity formation of an individual. Along with diverse populations, further research should include various experiences from siblings in the same family system. In the current study all participants were from different family dyads, it might be helpful for future research to look at multiple siblings' experiences from the same family dyad. Further research could also explore the impact of the function level of the individual with ASD and how that may influence the siblings' identity development. It would also be valuable to know if the gender and birth order of the sibling with ASD had an impact on identity development.

### **Implication for Policy**

Additional research in the area of the impact of autism on siblings' identities will help social workers identify the needs of the individuals. Assessing the needs of the individuals will allow the social workers to effectively advocate for specific policies and

programs to support and work with individuals and families affected by an autism spectrum disorder diagnosis. The findings in this research projected positive experiences of growing up with a siblings' diagnosis of ASD. However, many of the siblings commented on their siblings "invisible" disability and how that became challenging to accept and explain to their peers. This is important and even crucial for social workers to advocate for programs that educate both students and educators of the characteristics of autism and also to increase tolerance and acceptance of people with disabilities.

A disadvantage of growing up with a sibling diagnosed with ASD mentioned by several of the participants was feelings of loneliness and loss. For this specific challenge, social workers can advocate for programs and support groups for individuals and families who are affected by ASD. Support groups allow for individuals to express their concerns and collaborate with others who are in a similar situation.

### **Conclusion**

The purpose of this study was to gain better insight on the lived experiences of individuals who have a sibling diagnosed with ASD and the impact on their identity. This research was possible by conducting eight semi structured interviews with individuals who have a siblings diagnosed with autism spectrum disorder. The findings exhibited positive and similar results regarding their upbringing with their siblings. All the participants expressed their pride and unconditional love for their siblings. Many of the siblings were able to articulate one common struggle of having a sibling with ASD was the lack of obvious presence of a disability, many of the participants referred to this as the "invisible diagnosis".

Despite the pervious research that suggests individuals who have a sibling with ASD will be negatively affected, the findings in this research exhibit positive impacts on the individual's identity. Many of the participants spoke to their appreciation and admiration for their sibling and how their siblings' diagnosis had a major influence on which they are today.

The implications of this research provide social work professionals with a deeper understandings and insight when working with individuals who have a sibling who is diagnosed with autism. The research allows social workers to have an in-depth view of the lived experiences of individuals who have a sibling with ASD. The research provides social workers with the ability to empathize and provide support for families and individuals impacted by an autism diagnosis.

This research should be extended to further explore the impact of an ASD diagnosis has on all members in a family. This research serves as a constant reminder that ASD not only affects the individual with the diagnosis but also all members in a family who provide support. As social work professionals it is our duties to empower and support all individuals who are experiencing struggle and adversities.

“I love my Brother and all that he is but, sometimes I just get sick of autism.”



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**Appendix A: Demographic Questions**

1. What culture, race or ethnic group do you identify as?
2. What is your age?
3. What is your sex?
4. Do you identify with any religion or spirituality? Is this a major support for you?
5. How many siblings do you have, what is the birth order?
6. Where on the Autism spectrum does your sibling(s) fall?

**Appendix B: In-Depth Semi-Structured Interview Guide**

1. Can you tell me a bit about yourself? (Hobbies, interests, what are your extracurricular activities? Friends? School?)
2. Tell me a bit about your family. FIRST NAMES ONLY (Weekend activities? Parent Relationships? Sibling relationships? A favorite memory or vacation?)
3. Please describe your relationship with your sibling? (Things you like, how you get along, things you don't like, things that annoy you?)
4. How was growing up? How did your sibling's behavior and disorder make you feel? In what situations and with whom?
5. Tell me about a time:
  - a. You were frustrated with your sibling./ You had fun with your sibling.
  - b. You were proud of your sibling./You were embarrassed by your sibling.
  - c. Have there been times when you had to cancel an activity because of your sibling's behaviors?
  - d. Does your sibling's autism change what you can or cannot do?
6. If you had to describe yourself in 5 words what would they be? Why?
7. Do you feel your sibling's diagnosis had an impact on the person you are today? How so?
8. What field do you intend to peruse?
9. How involved are or do you see yourself in your siblings future?

**Appendix C: Flyer for participants****Recruiting Siblings of Children with Autism Spectrum  
Diagnosis**

**Looking for Young Adults Ages from 18 to 28**  
For a One Time Interview

**Study Purpose:** To gain a better understanding of the lived experience of siblings with children with an ASD diagnosis.

Criteria for participation:

- 18 years or older
- Sibling of a child with ASD
- Mental and emotionally stable  
(for example you have no plans/ thoughts to harm yourself)

Commitment: 1 hour- one time interview

**Receive a \$10 Gift card to Target after interview  
for your time and commitment**

Please call Marya Dumke at 952-374-9984 if interested in participating or if you feel you have been placed at risk, you can contact the Chair of the Human Subjects Institutional Review Board, through St. Catherine University at  
(651) 690-7739



### **Appendix D: Information Sheet For The Study**

My name is Marya Dumke 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 lived experience of siblings of children with ASD. I am interested in hearing the experience from the typical sibling's perspective. I am specifically looking into the sibling's identity formation as they grew up in a household impacted by an ASD diagnosis. I hope to gain a comprehensive understanding of identity development and empower current and future siblings who are impacted by ASD. I hope that what I learn from this study will help social workers and providers in the social service field; to understand the impact an ASD diagnosis has on the family and specifically the sibling.

I am inviting the participation of siblings who are willing to share their experiences. This study will involve one interview for an hour. I will be conducting the interview in a confidential, convenient meeting space of your choosing. I will set up a time and date depending on what is best for you. If you agree to participate, I will ask you on tape if you comprehend the information letter, if you have any questions and if you agree to participate in the interview. This study is voluntary and you may choose to stop participating at any time and refuse to answer any questions.

There is one benefit to your participation in this study. You will receive a \$10.00 gift card to Target for your time and commitment. This study may also help empower other families and siblings who are impacted by an ASD diagnosis. The information from this study will be published in my clinical research project. Your name and all personal information will remain confidential.

#### **Contact Information:**

Marya Dumke

Cell Phone: XXX

E-mail: [Dumk0004@stthomas.edu](mailto:Dumk0004@stthomas.edu)

Please call Marya Dumke at XXX if interested in participating or if you feel you have been placed at risk, you can contact the Chair of the Human Subjects Institutional Review Board, through St. Catherine University at  
(651) 690-7739

## **Appendix E: Research Information and Consent Form**

### **Introduction:**

You are invited to participate in a research study investigating ASD and its impact on siblings. This study is being conducted by Marya Dumke under the supervision of Dr. Catherine Marris Fuchsel in the MSW program at St. Catharine University and the University of St. Thomas. You were selected as a possible participant in the research because of your personal experience with a family member diagnosed with ASD. You were selected by the purposive sampling. 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 siblings that are impacted by an ASD diagnosis in relation with your experiences. Approximately eight people are expected to participate in this research.

### **Procedures:**

If you decide to participate you will be asked to meet with this researcher in confidential space that is convenient to you. You will be asked 8 semi-structured interview questions regarding your sibling's ASD diagnosis. This interview will take one hour to be completed in one session.

### **Risks and Benefits:**

That study has minimal risks. First, there may be some discomfort when discussing negative impacts of your siblings ASD diagnosis. Second, you may become emotional when discussing your experiences you have encountered due to an ASD diagnosis.

### **Compensation:**

If you participate, you will receive a \$10.00 gift card to Target from this researcher on the day of 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 report or publications, no one will be identified or identifiable, and only group data will be presented. This researcher and I will be the only ones to transcribe and this researcher and Dr. Catherine Marris Fuchsel will be the only ones to 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 record while I work on this project. I will finish analyzing the data by May 2015. 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 recording of our interview and I will destroy them after this research project is completed in May 18, 2015.

The tapes will be erased.

**Voluntary Nature of the study:**

Participation in this research study is voluntary. Your decision whether or not to take part will not affect your future relations with St. Catherine's University in any way. You have the right to refuse any answer 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 future data will be collected.

**New Information:**

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

**Contacts and Questions:**

If you have any questions, please feel free to contact me, Marya Dumke at XXX. You may ask questions now, or if you have any additional questions later, the faculty advisor, Dr. Catherine Marrs Fuchsel, 651-690-6146, will be happy to answer them.

You will be given a copy of this form to keep for your records.

Statement of Agreement of Confidentiality:

I, \_\_\_\_\_, have read the above information and agree to confidentiality as stipulated above. I further agree not to disclose, publish or otherwise reveal any of the confidential information received from the researcher or interview participants.

\_\_\_\_\_  
Signature of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Researcher

\_\_\_\_\_  
Date

**Appendix F: Counseling Resources**

For further support services, I have provided a list of counseling resources to contact if needed.

- |  |              |
|--|--------------|
| 1. Children's Home and Family Services     | 651-222-0311 |
| 2. Fairview Counseling Services            | 612-672-6999 |
| 3. Family Restoration                      | 651-263-3035 |
| 4. Innerguidance Counseling                | 612-868-8678 |
| 5. Lakeville Family Therapy                | 612-750-0263 |
| 6. Minnesota Mental Health Clinics         | 651-454-0114 |
| 7. Northwest Youth and Family Services     | 651-486-3858 |
| 8. Therapy Place Service LLC               | 952-380-8515 |
| 9. White Bear Counseling Center            | 651-429-8544 |
| 10. Wilder Foundation, Children and Family | 651-280-2310 |

**Appendix G: Phone/Email Script**

“Thank you for responding to my flyer and showing interest in my study. As you saw on the flyer, I am studying the experiences of siblings who grew up with a children diagnosed with Autism. I am specifically looking into how your experiences impacted your identity development. I have a couple questions for you to start, to confirm your eligibility to participate. Do you have a sibling(s) who is diagnosed with Autism? If yes, where on the spectrum do they fall? Do you have any questions about the information sheet or anything else about the study? If you are still interested, the next step would be to set up an in person interview. The interview will last around 60 minutes and will be audio recorded. In the interview I will ask you six demographic types of questions and nine other questions including your experience growing up with a sibling with ASD. You have the right to back out of the study at any time. Are there particular days and times that tend to work better for you? For confidentiality, the interview will need to take place in a private location. I would like to find a location that is convenient for both of us. Please let me know if there is a location you prefer, otherwise I will contact you again within two days with potential meeting locations and times. Thank you, have a great day.”