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Sibling Relationships with an Autistic Sibling.

MSW Clinical Research Project

Submitted by Lori M. Kaplan

May, 2013

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

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Abstract

This study was conducted to determine how typically developing siblings feel about their sibling with Autism or another related disorder. The methods used were a combination of quantitative data and qualitative interviews. The quantitative data consisted of basic demographic data about the family such as the parent's marital status, household members, and the diagnosis of the Autistic child. The qualitative data consisted of interviews with one or two typical siblings from that family.

This study interviewed eight typical siblings from six different families with an Autistic child: two of the siblings were brothers and six were sisters of a child diagnosed with Autism, Asperger's Disorder or PDD-NOS. Two of the children with Autism were twins with a typical twin. Plus three out of the six Autistic children were girls, which is not typical of Autism. In this study, the typical siblings expressed moments of frustration and fun with their Autistic sibling. Overall, the siblings were mostly empathetic, supportive and loving towards their Autistic sibling.

Keywords: Autism, Asperger's Disorder, Asperger's, PDD-NOS, siblings

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Introduction

Anyone with a sibling understands the impact that they have had on one's life and development—whether that impact has been positive, negative or some combination of both. Siblings see one another's highs and lows throughout the lifetime: their challenges and their successes, too. A sibling relationship, in all likelihood, is the longest relationship a person will have. Sibling relationships can be emotionally powerful and a significant source of stability from childhood through adult life. Overall, siblings often play a critically impactful role in a person's social and emotional development (U.S. Department of Health and Human Services, 2012).

Siblings are not often considered when assessing families with a child with disabilities. In many families with a disabled child, the sibling relationship is very different from families with all typical children. The typical child can become a silent caretaker, teacher, advocate and protector of the disabled sibling (Caro & Derevensky, 1997; Knott, Lewis, & Williams, 2007). The disabled sibling frequently consumes the majority of the parental energy, and takes up a great deal of financial, emotional and time resources (Myers, Mackintosh, & Goin-Kochel, 2009). Rivalry is a given from time to time in any sibling relationship, but how do siblings relate to their disabled sibling in an unbalanced relationship? Additionally, how do they get along with any other siblings, who may also be developing typically?

This paper proposes the study of typical children who have a sibling diagnosed with Autistic Disorder, a cluster of developmental disabilities that manifest as impaired or unusual social interactions, communication difficulties, and limited repetitive patterns of behavior and interests. Impaired social interaction is the key component in all of the disorders on the Autism spectrum. Other terms which frequently tend to be used interchangeably with Autistic Disorder

are Autism and Autism Spectrum Disorders (ASD). In this paper I will use the term Autism or autistic sibling.

The large heading in the Diagnostic and Statistical Manual for Mental Disorders (DSM-IV-TR) is Pervasive Developmental Disorders. The specific disorders that are included under this heading are Autistic Disorder, Pervasive Development Disorder Not Otherwise Specified (PDD-NOS), Asperger's Disorder (sometimes called Asperger's Syndrome), and the two less commonly known disorders: Childhood Disintegration Disorder and Rett's Disorder. The term ASD was originally developed by the educational system, but it has become a commonly used definition that includes the diagnoses of Autistic Disorder, Asperger's Disorder and PDD-NOS.

The most clearly defined variation, autistic disorder, is used to describe children who have significant difficulties in social interaction, delayed or lack of verbal communication, and stereotypical and narrowed repetitive patterns of behavior, interests and activities. Asperger's Disorder describes those who have difficulty understanding nonverbal communication, developing peer relationships and have the restricted and repetitive patterns of behavior. People with Asperger's Disorder usually have no significant verbal or cognitive delays. Asperger's Disorder occurs much more frequently in males and is sometimes called "high functioning autism". PDD-NOS is defined as a person who has a severe and pervasive impairment in reciprocal social interaction and/or the stereotypical behaviors found in people with Autistic Disorder.

Rett's Disorder is categorized by the loss of head growth, hand skills, loss of social engagement, poor overall body coordination and impaired expressive and receptive language development with severe psychomotor retardation AFTER a period of normal development immediately after birth. Symptoms of Rett's Disorder usually appear between the ages of six

months and age four. Childhood Disintegrative Disorder (CDD) is characterized by normal development for at least the first two years of life, where there is later significant loss of language, social, motor and/or play skills. Another skill which may be lost is bowel or bladder control. CDD also has abnormal functioning in social interaction, communication and behavior patterns (American Psychiatric Association, 2000; Centers for Disease Control and Prevention, 2012).

According to the Centers for Disease Control and Prevention, (2013) recently there has been a dramatic increase in the number of children diagnosed with autism, which is alarming to both parents and professionals. Professionals do not know if this increase is due to broader diagnostic criteria or better efforts in recognizing and diagnosing autism. However, a true increase in the number of people with autism cannot be ruled out. This increase in autism diagnosis is likely due to a combination of these factors.

There has been a dramatic rise in the rates of children diagnosed with autism. In 1980, it was 1-2 cases of autism per 10,000 children. In 1990 it was 1 in 500 children. In 2000, it doubled to 1 in 250. In 2010, it was 1 in 110 (Centers for Disease Control and Prevention, 2013). In March of 2013, the CDC increased this number to 1 in 50 children in the United States that have been diagnosed with autism (Centers for Disease Control and Prevention, 2013). According to the 2010 census, there were over 8,800,000 families with two or more children. This corresponds to 689,211 households with a child diagnosed with autism (U.S. Census Bureau, 2012). Therefore, for every child diagnosed with autism, there is often at least one sibling that is affected by the autistic child's behavior as well.

In general terms, children with autism thrive on structure and predictability even more than normally developing children. Children diagnosed with autism have trouble with

communication and reciprocating social interactions. They also have stereotyped interests and behaviors (Lainhart, 1999). Autistic children generally are calmer and more cooperative when routine, predictability, and consistency is provided, and when they are prepared for changes in advance. If the autistic child's schedule gets interrupted, it can cause a major outburst that can last for hours, which may interrupt the routines of siblings, or quickly change or cancel errands or outings for the whole family.

People who have autism have difficulties with initiating and maintaining relationships. Children with autism want friendships but they do not know how to initiate, develop and maintain them. Some autistic children have extreme difficulty making and keeping friends because their behavior patterns make them appear too controlling (Centers for Disease Control and Prevention, 2012). The autistic child's difficulty in reciprocating relationships additionally impacts their siblings, who often spend the most amount of time with the autistic sibling – even more than the parents. Having to deal with the sibling's behaviors on a daily basis is most likely stressful for the typical sibling. "Clearly, the siblings of children with disabilities have needs of their own which require attention, understanding and support" from others (Dodd, 2004, p. 41).

Having an autistic sibling can be difficult for some siblings because the autistic child requires a lot of time, patience and understanding from everyone in the family. The siblings may find themselves embarrassed by their autistic sibling's behaviors and purposely limit their friendships to avoid this embarrassment. An autistic child has trouble respecting other people's boundaries and personal privacy, which can leave the siblings angry and feeling violated (Lainhart, 1999).

Siblings of autistic children may be asked to take on roles that they are not developmentally prepared for or that they do not want to partake in. For example, typical siblings

may have to keep an eye on a severely cognitively delayed older sibling with autism. Some siblings, especially females, may be asked to help with dressing or feeding their autistic brother or sister. Siblings may also become protectors of autistic siblings at school or in public. Autistic children are quite often the target for bullying because of their limited social abilities, their tendency to isolate themselves in social situations and their inability to understand norms in social situations (Centers for Disease Control and Prevention, 2012). This limited social ability will also make it more difficult for the autistic child to know what to do in a situation when/if they are bullied.

Meeting the complex needs of a person with autism can put families under a great deal of stress—emotionally, financially, and sometimes even physically (Centers for Disease Control and Prevention, 2012). Social workers have the ability and opportunity to improve the lives of every member of these families with an autistic child. Social workers are taught to be the advocates for those who do not have a voice or are afraid to speak up. Often, siblings of autistic children may not feel that they are being heard due to the parent's focus on the intense needs of the autistic child. This reinforces that the siblings need to be listened to in order to feel empowered and in control of their lives, despite having an autistic sibling (Naylor & Prescott, 2004). Social workers are also encouraged to be proactive instead of reactive. Professionals are often already working with the autistic sibling in a variety of roles—as Case Managers, Therapists and School Social Workers. Though often unrecognized, the typical sibling may have unmet emotional needs due to the extra roles they may need to take on with caring for their autistic sibling. Consequently, this may impact the typical child's own social, emotional and behavioral development. Professionals working with the autistic families need to monitor the

typical siblings and make referrals for them when needed to assure that the siblings are getting their needs met (Fisman, Wolf, Ellison, & Freeman, 2000).

As social workers, we also know that services are costly time-wise and with financial resources. During these tough economic times, these families especially need effective advocacy. The interventions these families with autistic children receive are crucial. Recent studies have estimated that the lifetime cost to care for an individual with autism is $3.2 million. Plus, individuals diagnosed with autism have average medical expenditures that are $4,110–$6,200 per year higher than those without autism (Centers for Disease Control and Prevention, 2012). However, having a child diagnosed with autism does not simply cost more in the pocketbook. Living with a person with autism affects the entire family system—parents, siblings, and in some families, grandparents, aunts, uncles, and cousins. To mitigate this effect the whole family, including the siblings, need to learn effective coping strategies and other skills in order to have effective relationships (Beyer, 2009).

The main purpose of this study is to ascertain how typical sibling(s) feel about their autistic sibling(s) and how the autistic siblings' behavior impacts them. A lot of research has been done on typical sibling(s) and their adjustment. The difficulty in comparing these results stems from not having clear definitions of adjustment and having a variety of different rating scales which focus on different aspects of the parents'—or autistic child's—behavior or feelings. Due to the growing number of children being diagnosed with autism each year, it is important to study the impacts autistic children have on their siblings.

Review of the Literature

Siblings

This study looks at the importance that siblings have with each other, and the impact that different variables and disabilities have on the sibling relationship. This study focuses on families that have a child with autism and the effect the autistic child has on the sibling relationship. The sibling relationship is one of the closest, longest lasting and most important relationships in one's life. In childhood, siblings often spend more time with each other than with their parents, especially if one or both parents work outside of the home. Siblings are a child's most available person to pick on, laugh with, hug, watch television or play tag with. Sometimes brothers or sisters will tease each other mercilessly one minute and will help each other with homework the next minute. But overall, sibling interactions are most often positive (Caro & Derevensky, 1997).

Siblings naturally take on different roles within the family based on their age, birth order and personality style. Some children are natural leaders or teachers, especially if they are older. Others—especially girls—will take on the "mothering" role. Still others automatically adopt the role of an "equal". Other roles that a child could assume include manager, helper and playmate (Caro & Derevensky, 1997). Furman and Buhrmester found that the four distinct factors in sibling relationships were warmth/closeness, relative status/power, conflict and rivalry. Children who were close in age and were of the same gender reported the most warmth and closeness (1985).

In childhood, siblings are the nearest and therefore the most available play partners for each other. As children grow and develop into adolescence and adulthood, the level of closeness with their sibling tends to naturally decrease as friendships take on a higher priority role. However, friendships and sibling relationships have one distinct difference, which is the

acceptable amount of conflict. Conflict is normally avoided in friendships and frequently engaged in between siblings (O'Brien, Slaughter, & Peterson, 2011).

There are many types of sibling pairs, including children that are a part of multiple births, different genders, siblings that are very close or very far apart in age, and children with one sibling or many siblings. Add to these differences all of the possible factors that make sibling dyads unique such as physical characteristics, abilities and disabilities. A lot of research has been done on families with a child with a disability. Some of the more common and commonly studied disabilities are Down syndrome, Attention Deficit Hyperactivity Disorder (ADHD), Intellectual Disabilities, Mental Retardation and Autism.

Disabilities

As one can imagine, adding a disability to a family can add another level of stress, conflict and challenge. Some families seem to struggle to survive, but other families seem to rise above all of the challenges. O'Brien et al's study didn't find the anticipated aggression and rivalry from the typical sibling towards the disabled sibling but instead discovered that the typical sibling had a great deal of sibling empathy towards their sibling with developmental difficulties (O'Brien, Slaughter, & Peterson, 2011). On a similar vein, some studies found that informing the typical sibling of their sibling's disability and how it affects the disabled sibling's behavior increased the typical sibling's empathy towards the disabled sibling and led to a closer sibling relationship (Beyer, 2009; Unal & Baran, 2011). "It can be suggested that in families informed about diagnosis of their child with mental disabilities, typically developing siblings care about their disabled siblings and have a synergy and feel empathy with their siblings more than others" (Unal & Baran, 2011, p. 557).

The disability of a sibling can significantly alter life for a typical sibling. The literature on this is mixed with both positive and negative results. Kaminsky & Dewey studied the typical

siblings of children with Down syndrome and autism. They found that the siblings of Down syndrome children reported "greater admiration of their [disabled] sibling than participating siblings of normally developing children…. They were also…less competitive with their sibling and quarreled less than participating siblings of normally developing children" (Kaminsky & Dewey, 2001, pp. 404-405).

Naylor and Prescott studied the typical siblings of children with a variety of disabilities that attended a sibling support group and found that the typical siblings reported that there were both positive and negative consequences of having a disabled sibling. Surprisingly, quite a few children reported that they felt that they received equal attention and treatment from their parents. The negative consequences the typical sibling reported more often stemmed from the typical siblings' worries and concern ABOUT the disabled sibling, not the results of the disabled sibling's behaviors (2004).

The overall parental stress level is probably the most significant factor in how the whole family functions. This is a sort of circular process. As the number of behavioral problems in the disabled child increases, so does the parent's stress level (Lecavalier, Leone, & Wiltz, 2006). Having a child with a disability not only increases the parental stress level, but may cause some depression in one or both parents. This increased depression and stress can decrease the overall functioning level of the family (Hastings et al., 2005; Rao & Beidel, 2009). Myers et al, study found that one-third of parents reported the conflict about the child led to their divorce (2009).

Autism and the Effects on Families

Autism is a group of developmental disabilities that can cause significant social, communication and behavioral challenges and alter each affected person in different ways. The symptoms can range from very mild and almost unnoticeable to severe. Children with autism

have some similar symptoms, such as problems with communication and social interaction. However there are wide differences in the number and severity of the symptoms. Autism occurs in all racial, ethnic, and socioeconomic groups yet occur on average 4 to 5 times more in boys than in girls (Centers for Disease Control and Prevention, 2012).

When thinking about autism and all of the deficits it entails, one is bound to assume that life for a typical sibling may be difficult. It may seem to the typical sibling that the entire family becomes centered on the autistic child, which may leave them feeling left out (Woo, 2008). In fact, a number of studies reported mixed results on the adjustment of siblings of children with autism. (Hastings, 2006; Kaminsky & Dewey, 2001; Moyson & Roeyers, 2011; Orsmond, Kuo, & Seltzer, 2009; Myers et al., 2009; Hastings et al., 2005; Hastings, 2003).

However, there is a lot of evidence suggesting that siblings of autistic children are better adjusted (Kaminsky & Dewey, 2002; Macks & Reeve, 2007; Myers et al, 2009). The typical siblings reported greater self-concept, less conflict and greater warmth in their relationship than siblings of typically developing individuals (Kaminsky & Dewey, 2001; Macks & Reeve, 2007). Another study concluded that siblings adjust and learn to communicate more effectively with their autistic sibling. They went on to say that the autistic sibling's behaviors had a profound influence on the typical sibling's responses to them and that both siblings were "actively involved and enjoyed the interaction" (Caro & Derevensky, 1997, p. 388).

Following along these same lines, Knott et al discovered that the sibling relationship provided the autistic sibling opportunities to develop the needed skills they lacked as a result of having autism. This demonstrates how children with autism show social interaction and imitation to their typical sibling and the special role that sibling interactions can play. "With their siblings

at least, children with autism appear to develop in line with other children, albeit more slowly" (Knott et al., 2007, p. 1994).

However, not all of the studies reported positive results; there were several studies that were able to identify risk factors to having a sibling with autism. The siblings of autistic children expressed more negative views of their autistic siblings (Dodd, 2004). The typical siblings of autistic children had poorer overall adjustment levels in addition to more problems with peer relationships (Hastings, 2003b; Petalas, Hastings, Nash, Lloyd, & Dowey, 2009).

Due to the many inside and outside factors that can impact the functioning of family members, some studies have focused on the impact of these factors. They looked at socio-economic status, gender, family size, ages of the siblings, birth order, and age difference between the siblings. A number of studies found no statistical significance in the birth order of the autistic sibling (Kaminsky & Dewey, 2001; Kaminsky & Dewey, 2002). Yet, some studies found that certain demographic variables placed the typical siblings at higher risk. These included: being male, being from a low income family, having only one sibling and being older than the autistic child (Macks & Reeve, 2007; Petalas et al, 2009). However, other studies concluded that older typical siblings were better adjusted (Hastings 2003b, Howlin, 1988).

Some studies found no significant differences in the adjustment of typical siblings around age differences between the siblings (Kaminsky & Dewey, 2002) and no differences in the typical sibling's adjustment based on the number of children in the household (Kaminsky & Dewey, 2002), nor did the number of children seem to affect the outcome of the family adjustment. However, a number of studies reported that better psychosocial adjustment in siblings of children with autism was associated with a greater number of siblings in the family (Kaminsky & Dewey, 2002; Macks & Reeve, 2007; Orsmond et al., 2009).

The majority of studies found a significant difference in the gender of the autistic sibling, meaning that more boys were diagnosed with autism between a 4:1 and a 6:1 ratio (Kaminsky & Dewey, 2001; Kaminsky & Dewey, 2002; Petalas et al., 2009). It is of interest to note; however, that sisters of children with autism had the highest average social competence scores, whereas brothers of children with autism had the lowest social competence scores (Kaminsky & Dewey, 2002; Macks & Reeve, 2007; Hastings, 2003b). These mixed results make it difficult to ascertain how the autistic child actually affects the sibling.

There are a limited number of studies done on the effect of sibling support groups. Most of these support groups have positive results. While a lot of other research shows mixed outcomes on the typical sibling's social and emotional functioning, these results are based on rating scales completed by adults; usually teachers and mothers. However, there is a significant lack of data from the typical sibling on how the typical sibling feels about having a sibling with autism. The best ones to provide information on the child's perspective and attitudes are children themselves (Dodd, 2004).

Social Work Role

The above results serve as a reminder to social workers everywhere that our jobs are not to just serve our primary clients—often autistic children—but that we need to assess the needs of the other family members and make referrals when needed. The results of Hastings (2003b) study showed that siblings of autistic children were rated as having poorer adjustment on a number of the domains compared to a normative sample. "These findings are useful in confirming that siblings are an important part of the family that should not be ignored by practitioners" (p. 102).

Hastings (2003a) measured the effectiveness of the use of intensive early intervention using Applied Behavior Analysis (ABA) and found that after using the ABA program, "mothers rated their [typical] child's hyperactivity and emotional, conduct, and peer problems lower than a large scale study of normal children" (p. 145). Naylor & Prescott (2004) studied the need and the results of a sibling support group and found several positive outcomes, including increased self-esteem, quality of life, social interaction, coping strategies within the family system and understanding of disability issues. "The children verbally communicated their pleasure at having the opportunity to speak to an adult on a one-to-one basis about their experiences and how they felt…listening to children…in a therapeutic way helps them to validate their experiences and raise their self-esteem" (p. 204). This further tells us the importance of social workers to assess and tend to the needs of the entire family.

Conceptual Framework

Social Work uses a broad perspective that encompasses the range of physical, emotional, and environmental factors that have an effect on the well-being of individuals and families. The Family Systems Theory Framework was used in this research project. Family Systems Theory was developed by Murray Bowen in the 1970s and states that a person's behavior is shaped by their social groups, but most importantly by their family (Crossno, 2011). The Family Systems approach has a philosophy that looks at and searches for the cause of behavior, not just in the individual, but in the interactions among the members of a group. The central idea is that family systems organize themselves to carry out the daily challenges and routines, as well as adjust to the developmental needs of the family members (The Gale Group, Inc, 2003; Cox, 2010). Family systems theory states that all of the members of a family are interrelated. Further, the family has

characteristics of its own that can be known only by looking at the relationships and interactions among all members (The Gale Group, Inc, 2003; Crossno, 2011). The family system attempts to remain in balance as a whole. There are established roles, rules and boundaries within each family system.

The Family Systems approach is constructed on four principle beliefs. The first one is that each family is unique because of the possible variations in the characteristics in each person, the cultural influences and the differences in philosophical and sociopolitical styles that shape the family. The second assumption is that the family is a system that interacts, despite the continually shifting boundaries and each person's level of resistance to change. The third is that the families must fulfill a variety of roles for each member, both collectively and individually, if each member is expected to grow and develop. The last belief is that families as a whole pass through progressive changes that produce varying levels of stress that affect all of the members. As these changes take place in the family system, every member of the family must readjust (Missouri Department of Social Services, 2011; Cox, 2010; Crossno, 2011).

The family develops its own set of limits and acceptable behaviors. They also set the tolerable level of deviation to these limits. Once these levels are set, the family system wants to maintain that stability. Family systems can be anywhere along the continuum of either open or closed. Closed systems do not easily allow other people or ideas inside their family boundaries. Open systems allow others and a lot of outside influences to cross over into their boundaries (The Gale Group, Inc, 2003).

The literature reviewed for this study appeared to use the Family Systems Perspective quite a bit. This would mean that the research was looking at the link between the autistic sibling

and their typical sibling. It was looking at the experience as a whole function of each sibling individually, the family system, the parent(s), the extended family, the school, and society and how all of these factors interplay over time and in each person's life developmental cycle. The literature also looked at the family rules and norms and how they interplay with the rules and norms of society, many of which children with autism would break due to their social deficits. The repeated reference to the typical sibling and their adjustment parallels the Family Systems Perspective; the family expects a certain level of behavior from a child at each developmental stage but the autistic sibling is unable to perform up to those expectations. This causes a lot of disruption in the family's norms. Since the autistic sibling is rigid and resistant to change, the rest of the family is forced to adjust.

While the existing literature mainly used quantitative figures comparing groups of children based on mostly parental questionnaires and rating scales, there is a lack of data directly from the children themselves. There is a plethora of research comparing normal, autistic and Down syndrome sibling relationships according to their age, birth order, etc., but there is a lack of telling us what that means to the sibling(s). The use of "qualitative research may provide a deeper and more comprehensive understanding of the experiences of siblings of children with ASD" (Moyson & Roeyers, 2011, p. 42). Research needs to include interviewing the siblings to get their point of view. This research attempted to find out how the siblings really feel about their autistic sibling to discover what they like and do not like about having a sibling with autism.

Because there is no single generally accepted instrument to measure siblings' adjustment, researchers have to choose an approach from existing measurements and methods or devise their own instruments. Each method conceivably measures a different aspect of siblings' adjustment,

so it is difficult to compare the results of all of the separate studies in the literature. Because of this ambiguous definition of adjustment, research cannot truly describe the experiences of the siblings of a child with autism (Moyson & Roeyers, 2011).

Using the Family Systems Perspective, this research will use a combination of open-ended interview questions and a brief survey to collect basic data about the family. The first step will be obtaining signatures on the required consent and assent forms. Then the researcher will answer any questions and the parent will fill out the questionnaire. The data will include the names and ages of all of the persons living in the household, parental marital status, diagnosis of the autistic child and any special language the family uses to describe their child with autism. See Appendices C and D for the survey and the interview questions. Then this researcher will interview one or two typical siblings of the autistic child.

Methodology

The main purpose of this study was to determine how the siblings of children with autism felt about their autistic sibling. The hypothesis was that the sibling relationship between the typical sibling and the sibling with autism would be more unequal and stressed; and that the typical sibling would have anger towards their autistic sibling.

Sampling

The inclusion criteria for this study included: being a family with at least two children, one of whom had a diagnosis of autistic disorder, Asperger's Disorder or PDD-NOS. This diagnosis had to be from a medical doctor or a Masters level licensed psychologist or social worker. Additionally, the typical sibling had to be between the ages of seven and twenty one. This age range was originally chosen so that the participating siblings would be able to read and

have a vocabulary large enough to describe their experiences. The child diagnosed with autism had to be between 5-17 years of age.

For the purposes of this research, a combination of convenience and snowball sampling was used. The participants were either known by the researcher, known by an acquaintance, or the researcher knew someone in their family. This was done to familiarize the researcher with the interviewing process with children and to attempt to gather more in-depth answers because the researcher was not always a complete stranger.

Protection of Human Subjects

The protection of the human subjects was assured through following the strict St. Catherine University Institutional Review Board (IRB) procedures and also by obtaining parental consent and child assent signatures prior to conducting any research. Before any interviews took place, the researcher described the purpose, criteria and time requirements of the research and interview process either in person or via email. Verbal or written consent was obtained by all of the parents before the interviews were scheduled. At the interview, the voluntary nature of the child's and the parent's participation was reiterated. All subjects were informed that they did not have to answer any questions that they felt uncomfortable with or did not want to answer.

Measurement

This study explored the experiences of the typical sibling and the relationship between the typical and autistic siblings. This researcher collected mostly qualitative data from the typical sibling. The sibling, because all were minors, were given the option to have their parent remain with them during the interview, or have the interview be private. Most of the questions were open-ended to allow for the sibling to discuss whatever issues or topics they felt were most important to them. Some of the topics that were covered include a description of themselves, their sibling(s) and their family, what activities they like to do as a family, and they told about

positive and frustrating experiences they've had with their autistic sibling. The approach used was retrospective and used a combination of both qualitative and quantitative data. The qualitative interview was exploratory and attempted to discover how the typical sibling viewed their disabled sibling and what aspects of his/her behavior that they like and dislike. Essentially, it revealed how the typical sibling really felt about their autistic sibling. Additionally, this enabled the researcher to hear the story from the sibling's point of view. The interviews were audio recorded and transcribed for data analysis.

The quantitative data collected was used for demographic information and was not the focus of the study. The focus was on the sibling's responses to the interview questions. The demographic data that was collected from the parent included names and ages of all family members, the diagnosis given to the autistic child, at what age the autistic child was diagnosed and any language that the family uses to describe the autistic child's illness.

The interviews took place either via phone (one family), in the child's home (three families) or a public place (two families). One of these two interviews took place in a church library and the other took place at a restaurant during a non-busy time of day where there were no tables occupied in the meeting room area. There was no time limit set for child interview process. The interviews ranged from eight minutes to 45 minutes in length. The audio recordings were transcribed verbatim.

Analysis

All of the interviews were audio recorded for transcription and the data was coded. Each transcript was read through by the researcher at least four times each to evaluate, identify themes and open code the data. Recoding happened as all of the interview transcriptions were

completed. This method of coding the data increased the credibility of this research because definitions were consistent and reliable.

Strengths and Limitations

Strengths. One of the major strengths of this research was that the interviews, transcription and analysis were all done by a single researcher. This allowed for high intracoder reliability and inductive coding of the data. This coded data provided an understanding of what it is like to have a sibling diagnosed with autism and all of the difficulties that living with a child with autism entails. This data was based on the sibling's own words and thoughts because the open-ended interview questions allowed for the child to focus on whatever topics were important to them. This rich data allowed the researcher to understand what it is like to be a sibling of an autistic child. The final strength of this research is that the data was collected in a relaxed and naturalistic setting and allowed the sibling to discuss his/her feelings more openly and freely.

This research is important to help Social Workers, Psychiatrists and other professionals understand what it's like to live with an autistic sibling. This provides the professionals the insight and empathy needed to understand the needs of the family and to develop appropriate services for these families. Once a family receives the right level of services, the family will have better overall functioning. This may reduce the use of long-term services in other areas.

Limitations. Since minor children were the subjects, the number of potential participants was limited because of the need to obtain parental consent prior to interviewing. Also because all but one of the families studied live in a large metropolitan area in the Midwest, the results will not be generalizable to other parts of the United States or world. The remaining family lived in a different Midwest state. Another limitation is that the families who chose to participate were

self-selective, which made this research a non-representative sample and might undermine its validity.

Another limitation of this study was the small sample size of eight participants, which will make it difficult to make large scale predictions of the needs of future families with an autistic child. Lastly, the results of this study could potentially be swayed based on the biases of the sole researcher.

More research is needed to explore the perceptions of the typical siblings whose siblings have specific diagnoses, such as PDD-NOS or Asperger's Disorder to ascertain if some of the themes found are specific to autism in general or in just the variants of autism. Not only more qualitative but also longitudinal research is needed to gain more insight into the sibling experience. The long-term repercussions of autism also need to be studied, so that the sibling relationship throughout the entire lifespan is taken in account. That way, Social Workers and all other professionals working with families of children with autism will be able to recognize the sibling's unique experience and at least let the sibling's voices be heard. The differing roles that adult siblings take on also need to be studied. Supporting all of the members of a family is the best way to assure that all of the children grow up to reach their potential.

Findings

This qualitative study sought to gain in-depth understanding of how having a sibling with autism affects the typical siblings and the family as a whole. Six families agreed to an interview with the typically developing siblings. Two of the families had two typical siblings that agreed to participate in this research project. All of the parental questionnaires were completed by the

mother. The siblings that responded included two brothers and six sisters. In two of the families, the autistic child was a twin and the other twin did not have an autism diagnosis. The autistic children ranged in age from 9-18. The autistic children were younger brothers in two families and an older brother in one family. They were older sisters in two of the families and a twin sister in the last. It is interesting to note that 50% of the respondents were discussing a female sibling with autism in this study because the rate of autism is 6:1 for boys. This is certainly not typical of the general population.

The family sizes ranged between two and five children: two families had two children, one family had three children, one family had four children (two of which were from the wife's previous marriage) and two families had five children. The most common diagnosis in these families was Asperger's Disorder, which was the case in three of the six families. The others were autism, mild Asperger's Disorder and PDD-NOS.

In order to provide the reader with an in-depth understanding of the data, a short description of each family will be given. In order to maintain confidentiality, all parents and children have been given fictitious names. After all of the family descriptions are provided, the themes that emerged will be discussed.

Family one: Smith family interview with Dylan

Jamie and Bill Smith are divorced and share custody of their three children: Dylan, 11, Darren, 9, and Damien, 7. The family has a unique arrangement, the children live at the house and the parents rotate different nights of staying there. Jamie is currently employed as a receptionist and Bill is a restaurant manager. Darren, the middle brother, was diagnosed with mild Asperger's Disorder when he was in kindergarten. The children are in fifth grade, third

grade and first grade. Darren was described as very emotional and has trouble with focus and concentration.

Family two: the Jerry family interview with Deanna

Charlene and Mark have been married for almost a dozen years. Charlene has two older children from a previous marriage, Dave, 22, and Mindy, 20. Charlene and Mark have nine-year-old twin girls named Deanna and Diane. This interview was done via phone because the family lives in a different state. Diane has been diagnosed with Asperger's Disorder along with visual impairments, learning disorder, sensory processing disorder and apraxia (neurological condition characterized by loss of the ability to perform activities that a person is physically able and willing to do). The family just received the Asperger's Disorder diagnosis in January 2013 after fighting with professionals for seven years to get further evaluations done. Diane is described as extremely outgoing and extra affectionate, but she has problems socializing and her mother states that her peers cannot relate to or understand her. She added that Diane tends to hang out with adults or by herself, has fine motor skill difficulties especially with handwriting and also has reading language and speech delays. She is good in math and science.

Family three: the Stewart family interview with Thomas

The Stewart family has two boys: Allen, 13 and Thomas, 10. The parents are married. Allen was diagnosed with PDD-NOS in first grade. Allen has been described as funny, hyper, smart, curious, controlling and as having high anxiety. In this case the parents decided that they would not inform their sons about the PDD-NOS diagnosis. Instead they told their children that Allen needs help with social skills, which is why he receives services at school.

Family four: the Marx family interviews with Jessica and Tara

The Marx family has five children. The oldest, Dennis, 19, is currently away at college. Jessica is 15, Tara is 13, Alex is 10 and Roxie is 4. Alex was diagnosed with Asperger's Disorder when he was six years old and he has been described as funny, sweet, smart, charming and affectionate.

Family five: the Holiday Family interview with Emily

Chuck and Marie Holiday have been married for several years. Chuck is a pharmacist and Marie is a pediatrician. They have two children Anna, 18 and Emily, 14. Anna has been diagnosed with PDD-NOS. However it should be noted that she did not receive this diagnosis until she was a senior in high school.

Family six: the Nelson family interviews with Rose and Deb

Jack and Isabel Nelson have five girls. Marly and Carly are 14-year-old twins, Rose is 11, Deb is 8 and Andrea is 5. Carly has been diagnosed with autism, developmental cognitive delay, and has hearing loss. Carly received the autism diagnosis in November 2011.

Parent's description of the autistic child

The parents had some very positive descriptions of their child with autism. The most common responses given were smart, sweet, funny and affectionate. The other positive descriptions used were: charming, curious, friendly, kind and outgoing. As expected, parents mentioned traits of their autistic child that were challenging such as: over emotional, has trouble socializing and making small talk, being a loner, anxious, perfectionistic, and lacking focus and concentration. Other terms that they used were controlling, hyper and difficulties with fine motor skills. Charlene [family 2] described her daughter Diane as "Extremely outgoing, extra affectionate, [has] problems socializing and [her] peers cannot relate or understand [her. She]

tends to hang out with adults or by herself. [She has] severe handwriting difficulties and [deficits in] fine motor skills. [She has] reading, language and speech delays. [She is] good in math and science that does not involve lots of reading."

Parent's description of the typical child/children

The typical children were described by the parents as Type A, high achiever, responsible, cooperative, empathetic, affectionate and able to reason with. Other terms they used were funny, sweet, sensitive and responsible. Marie [family 5] described her typically developing daughter as "bright, hyper-achiever and very organized. [She] doesn't want to be like her sister. [She is] friendly [and has] high energy." The parents described the other typical children in the family (if there were any) as easy going, sociable, talkative, normally developing, spoiled, liking attention and having normal to high academic achievement.

Parent's description of the diagnosis

The parents had a variety of different ways of discussing their child's diagnosis. The most common approach was to use the actual terms of Autism, Asperger's Disorder, or PDD-NOS. Charlene [family 2] stated "we were truthful. We are not ashamed or afraid of the diagnosis." The second most common way was to not actually use the term, but to describe how the autistic child's brain works differently. Some families found some unique and creative ways to explain it. The parents of the Marx family [family 4] stated that they told their children that their sibling with autism has a hard time staying "focused [and has a] harder time knowing what is expected socially." Jamie [family 1] put it this way "I refer to it as a difference that causes him to have outbursts, cry, shut down, and have trouble focusing. I stress that it's just different, not worse or less than anyone else."

The Stewart family chose to not inform their son that he had PDD-NOS, but told both sons that "he needs some help learning about reading other's spaces and emotions. He doesn't know his actual diagnosis." The reasoning for not telling them was to prevent him from being labeled and to prevent him from using his diagnosis as a crutch or an excuse.

Parent's reaction to the diagnosis

Almost all of the parents reported that they were relieved and were not surprised at the diagnosis. Tammy [family 4] described how they tried to get a diagnosis for a couple of years and how "we were frustrated that no one had been able to give us a diagnosis previously, and relieved to finally have a diagnosis. Now we [could start to] look for solutions to something defined." Charlene [family 2] described a similar battle and officially got a diagnosis in January of 2013. "We were relieved to finally get a diagnosis. We fought for seven years for a diagnosis. Professionals refused for many years to [send her for] further evaluation."

The Holiday's [family 5] struggled with their daughter's inability to complete tasks once she got into high school and finally received the diagnosis of PDD-NOS "in the beginning of 12th grade. [Our] reaction was relief. It explains the many things that were causing stress and frustration and the behaviors we didn't understand."

Barbara [family 3] said that they were shocked because she had thought her son had EBD (Emotional and Behavioral Disorder). The Smith family [family 1] that received the Asperger's Disorder diagnosis when their son was in kindergarten said that they were not surprised because they "thought there would be some sort of diagnosis."

Positives of having an autistic child

All of the parents had very positive things to say about how their autistic child has changed them for the better, and has allowed them to redefine success. Marie, a physician, [family 5] stated "[She's] made me appreciate nontraditional ways of judging my children's success, behavior and our family life." Barbara [family 3] said that one good thing that came out of her son's diagnosis was that she was able to meet lots of people; some of whom became very supportive friends. Jamie [family 1] said that "having a child with autism has helped [her] to be much more understanding and empathetic towards other parents in general but especially those with special needs children." Charlene [family 2] simply stated "We love her 'quirks' and who she is. We cannot picture her any other way!" Tammy [family 4] said of her son with Asperger's Disorder "he is somehow a purer soul he has no deceit. He is fundamentally honest and full of love."

Stressful parts of having a child with autism

Most of the parents brought up the stress and struggle of getting the diagnosis, and the length of time it took to finally receive a diagnosis. Tammy [family 4] stated "Most of the stress came from [the] lack of direction by the medical community. We knew something was different, but weren't getting direction." Charlene [family 2] said something similar and added the difficulties she has with dealing with extended family members. "The only stressful part was the seven year fight to get people to realize what we already saw. There are also family members who do not understand and choose to label her retarded." Marie [family 5] stated that she had a difficult time agreeing with her spouse on what approach they should take.

In addition to the time and effort needed to finally receive a diagnosis, parents discussed how much extra time and effort having a child with autism takes. One facet of this is the amount

of time it takes to travel to and partake in therapy, psychiatry, medical doctor and social skills group appointments. Add to this the emotional energy it takes to deal with the troublesome behaviors related to autism. Jamie [family 1] stated "[I] find it challenging to deal with the outbursts emotional meltdowns crying etc." Barbara [family 3] talked about both of these by stating "Therapies. [The] time [that it takes] to get places and the uncooperative behavior [from her son]." Tammy [family 4] talked about how it "takes longer to accomplish things which can be hard."

Isabel [family 6] discussed how she realized after her twin girls received their letter in eighth grade at school "that there are things that you kind of grieve over or know that I will never get to participate in…Yes they might but it's not the same as your regular kid. All of a sudden it was a big deal."

Advice for other families

The unanimous advice that these parents gave to any family just receiving an autism diagnosis was to get support. Tammy [family 4] said "Look for support. Most of the challenges can be mitigated by techniques the kids can learn." Charlene [family 2] summed it up by stating "It's not a death sentence. This is survivable. There's lots of help and support groups out there who help if you need it."

Sibling Responses

The siblings that took part in this research project included two fifth grade boys, Thomas and Dylan, who were ages 10 and 11 respectively. There were six girls who participated. This included two sibling pairs, 8-year-old Deb and 11-year-old Rose, and 13-year-old Tara and 15-year-old Jessica. The remaining respondents were 9-year-old Deanna (who has a twin sister named Diane), and 14-year-old Emily.

Activities

The siblings had a wide range of personal hobbies but the most common ones were reading, playing sports, writing, listening to or playing music and drawing. Other hobbies that were mentioned included sports, bowling, building things, cooking, playing outside, watching movies, hanging out with friends and crocheting. Math and art tied for the favorite subject in school. Other favorite subjects included social studies, biology, music and history.

The siblings reported participating in a wide range of family activities, but the most common responses were: eating supper together, playing board games, going bowling, and watching movies. Eleven-year-old Rose [family 6] stated "we always eat together" (Line 44). Other responses were visiting grandparents, playing outside, having bonfires, going camping and going on family vacations.

Definition of Autism

One parent requested that I did not use the word autism or ask their child about autism during the interview because she has never told her son that he has a diagnosis. But when the rest of the siblings were asked "what is autism?" They responded with a wide range in answers from Dylan's [family 1] honest and simple "I don't know" to Deanna's [family 2] "It's a dysfunction in the brain" (Deanna) to Emily's [family 5] very insightful answer:

> Well I know that it's more than… just a communication problem it is a social problem. It prevents someone from interacting socially what we would consider normal… And it comes in lots of different forms and is sometimes hard to figure out… It's hard because it's such a range. Sometimes she was weird I guess. She just didn't have a lot of friends and she didn't fit into the social norms of high school social stuff. So she really didn't have a ton of friends all the time and so that might have been part of that. And her inability to focus on her work even though she was extremely smart…she would freak herself out and worry about too many details at once instead of just getting it done.

A couple of the siblings were able to pick up on the aspect of how people with Asperger's [Disorder] truly WANT friends, but they just don't know how to make friends, or their efforts backfire and their behaviors actually drive people away. Jessica [family 4] expressed that by saying "I think that Asperger's [Disorder] is more like that you're not that quite normal. You're not really that socially tuned. You don't really need to be with people to be happy but [people with] Asperger's [Disorder] really want to have people around. [They] just don't really know how to act."

Her sibling Tara [family 4] discussed the wide range of symptoms displayed by her brother with Asperger's Disorder, from the meltdowns, to the lack of perspective of the other person, to the hyper focus on subjects. "I mostly think….Asperger's [Disorder] is different symptoms. They can be very loving at times and they have a harder time dealing with stress and they… don't really think about…how they will make other people feel. They are usually really good at one particular subject and [my brother] is really good at reading and math. Usually they're into one specific thing. [My brother] really likes polar bears."

Autistic Sibling's positive aspects

In the process of the interviews, the overall feeling I got from the siblings was a pretty positive vibe. They were able to tell stories about when they had fun together, like what would be expected of siblings. Emily [family 5] talked about how much fun she would have with her sister when they spent part of their summers on their grandparent's farm. I heard about fun trips to Disney World and waterparks in Florida and how much fun it was for another family to swim in the Gulf of Mexico.

There were stories of more simple everyday things, like helping a younger brother put together a Lego kit, or going bowling, or watching her autistic sister score a goal in adaptive soccer. The younger siblings look up to their older sibling with autism. Deb, age 8 [family 6] stated "I like it when she gets to play with us and stuff like that." Her older sister Rose talked about Carly's obsession with the television show 'Psych' and how Carly's frame of reference for everything in her real life is based upon this TV show. She went on to say how Carly constantly quoted lines from the show and how annoying she felt it was. Rose was really proud of Carly when she "went a whole month without quoting 'Psych'."

Then some of the siblings got into the more deep and philosophical parts of their autistic siblings. Deb [family 6] said of her sister "She has a good heart… I kind of have…a special bond [with her]…I have trouble [with dyslexia]… But it's kind of just like the same because she has troubles with other stuff and I have troubles with this." Rose [also family 6] went on to add "she is pretty much like every person; she is just mentally not as far ahead. Like most people they might be falling back in classes but [my sister] is just not as far ahead. It doesn't make her any different, she's just always been that way and we still love her."

Autistic Sibling's Negative Aspects

As with all sibling relationships, the siblings shared stories of frustration towards their autistic sibling. One of the most common annoyances was their autistic sibling's tendency to get stuck on a particular subject and constantly bring it up. A related issue was when the autistic sibling would say things at inappropriate times or out of the blue. Rose [family 6] told about the time that her Autistic sister Carly really embarrassed her, but can now look back at it and laugh. She said that on her very first day of junior high school she got on the special education bus with Carly and the other kids on the bus asked Carly 'who's that girl?' "Carly's response [to the

other kids] was 'she is my sister and she's very bossy, loud and annoying.' And…I know I'm all three of these things … [but] you just don't announce that to people, they learn that on their own." Other mentions were repeatedly asking 'why', their almost obsessive routines and rituals and not being able to agree on what activity to do. Tara, age 13 [family 4] touched on most of these "he doesn't really seem to think of things from other people's view. If you're doing something on the computer, he's like watching over your shoulder. Then I have to ask [him] would you like go away a little bit or go do something over there. He'll just be like 'why? Why can't I just watch you?' He doesn't get those things."

Another common complaint that the siblings mentioned were the autistic sibling's tendency to get angry more often. Deanna [family 2] summed this up by saying "She sometimes stomps up to her room or jumps on the couch and just pouts." Tara [family 4] described her 10-year-old brother with Asperger's Disorder as "he's never like fully together. He's not like perfectly patient… Sometimes he'll yell at others but other times he'll just kind of grumble to himself instead of doing the whole tensing up thing. He'll just stay quiet until someone comes along and drags [the 4-year-old sister] away because she keeps on him."

A unique complaint that Thomas [family 3] had was the amount of time his brother spent playing video games. "There's not much to him besides that he can be a little lazy—A lot. He spends most of his days on the weekends playing on the [video game system] for four hours and video chatting people."

Teased?

All eight of the respondents answered "no" when asked if they had ever been teased because of their autistic sibling. However, their friends had mixed things to say about the

autistic children. The most common response was that their friends said their autistic sibling was weird. Thomas's [family 3], somewhat humorous response was "They think he's lazy." Deb [family 6] simply said "I don't tell anybody out there." This implied that she tends to keep quiet about her older autistic sibling. On the other hand, some friends have commented that the autistic sibling is smart. Jessica's positive response was "my classmates all loved him [my brother with Asperger's Disorder]. They just thought he was the best thing ever. So whenever I… mention him. They always say something like…'I like that kid'."

Who do you talk to when you get frustrated with your autistic sibling?

The responses to this question were mixed. Four of the siblings said that they usually talk to their parent(s). Others added that they talked their grandma or another sibling. Two of them responded that they talked to themselves and then used their spirituality. Rose said "I tell my brain which then transfers it up to the God files and then [let it go]… I'm not much to hold grudges."

Probably the most troubling response was that three of the siblings said that they don't talk to anyone. Deanna's [family 2] response was a bit less troubling when she added "nobody really. I just keep it inside until I go to bed then I talk to myself."

Advice from the Siblings

The siblings had a lot of advice to give to other siblings who might have just found out that their sibling has autism. Rose's [family 6] down-to-earth advice was "Don't worry about it because… they probably have always been that way but now they've just finally realized it." Her viewpoint was that a diagnosis does not change who they are, they are still your sibling. Emily [family 5] thought along the same lines. "Kind of be flexible and take it as it comes. It's just kind of who they are, so you learn to live with that. Kind of like you would any other person in your

house. You get used to them and their behavior and their mood. Sometimes [you should] help them but at the same time [be] a sibling."

In the interview with sisters Jessica and Tara, [interview 4] they talked at length about how their brother with Asperger's Disorder would mirror the moods of other people.

> I think that you would want to keep [yourself] in a more cheerful mood and definitely not treat your sibling that's got Asperger's [Disorder] or autism like they're weird. But just kind of be a little bit happier when you're with them and try to be encouraging. Not in a babyish way, but in more serious way. Like you are treating them like they're a little bit older… yeah it's not like their brain is half gone.

Right after Jessica stated this, Tara added that she thought it was best to not give your sibling too many tasks to do at one time. She said that she found that giving him one small task to do at a time was the best, because it didn't stress him out.

Overall, the siblings had a lot of insight into their sibling's behavior and most have already adopted techniques for dealing with and avoiding any meltdowns. This reinforces the literature that states that siblings are very important in the life of a child with autism. Isabel [family 6], who is a mother of five girls, including Carly stated "the only serious connection [Carly] has is with her twin sister and that's another huge thing because she has a twin sister, she has a permanent friend. And her twin sister takes care of her."

Discussion

This research had a few themes that emerged between the families that included similar descriptions of the autistic child by both the parent and the typical sibling, the difficulties of getting the diagnosis and the importance of getting support. The siblings all admitted that they tend to get frustrated with their autistic sibling, but overall had a positive relationship with them.

The hypothesis at the beginning of this research project was that the sibling relationship between the autistic child and the typical sibling would be strained and that the typical sibling would feel anger towards their autistic sibling. This hypothesis was only supported by two families that participated in this study. The remainder of the siblings expressed an intense sense of love and empathy toward their autistic sibling.

It was stated in the literature that informing children about their sibling's autism "enables children to establish a more positive relationship with their disabled siblings…Accepting a disabled sibling is not easy for normally developing children, but children having knowledge about diagnosis of disability can create closer relations with their siblings" (Unal & Baran, 2011, pp. 557-559).

Implications

Practice. The findings from this study provide implications for clinical social workers in practice. Clinical social workers must be aware of the symptoms of Autism and how those symptoms impact family members. Allowing the siblings to discuss their feelings and frustrations is essential. "Encouraging typically developing siblings to share how they are feeling

and… [reassuring them that] their feelings are natural" (Beyer, 2009, p. 449) is an easy and effective way that social workers can help the typical sibling.

Research has shown that the typical siblings benefit from having their own therapy or support group to discuss the difficulties they're experiencing from living with a sibling with Autism. Making sure that there are resources (i.e. support groups) available for these siblings is another way to increase their ability to cope with the stressors of their Autistic sibling and assure that everybody achieves their potential. "Typically developing siblings need effective coping skills in order to effectively deal with the challenges that come with having a sibling with a disability and to develop a more positive relationship with their sibling with [autism]" (Beyer, 2009, p. 449). This research identified that all of the typical siblings had some level of frustration towards their Autistic sibling. Having enough support and effective coping strategies will make all family members feel empowered.

Early identification and intervention are key components of clinical social work in order to provide these families with the support and skills training needed to prevent life-long deficits. To promote early intervention, trainings could be provided to school teachers, daycare providers, law enforcement, doctors, and other workers in the community that may come into contact with Autistic children and their families. With this, it is necessary that social workers assist and advocate for other professionals, specifically those in early childhood education and community workers, to gain a further understanding of symptoms of Autism. Collaboration is needed between daycares/preschools, schools, parents, therapists, and other mental health professionals.

As described, children who have Autism have deficits in self-regulation, communication and reciprocating relationships. To support these children on a broader level, professionals in

other systems, such as childcares and schools could provide simple instruction and interventions such as identifying feelings, deep breathing techniques and work on identifying non-verbal communication cues. Though simple, these interventions could be a way to help children learn basic communication and self-calming techniques at an early age, which are valuable for everyone to have and can be utilized throughout their lifetime.

Policy. There are many implications that arose from this research. First, I believe that health insurance companies should look at the possibility of allowing more family-centered interventions in their policies. This could include support groups and individual therapy sessions for the siblings and the parents of children with Autism. The previous research has indicated that support for the entire family of an Autistic child has short-term and long-term benefits in adjustment. Hastings found that "formal social support moderated the impact of the severity of symptoms of the child with autism on their siblings' adjustment" (2003, p. 148).

Research. This study implies that further research is needed in order to gain more understanding of the best way to help families with Autistic children, especially the siblings. The Autistic children need extra help to learn social skills and effective communication techniques. Knott et al. discussed how important siblings are in developing these skills. "Children with autism demonstrate skills in interaction with their siblings which is rarely reported with their peers…Their ability to engage in collaborative interaction appears to be uniquely enhanced by the role reciprocity inherent in the sibling relationship" (Knott et al., 2007, p. 1994).

As described in this study and previous literature, it is clear that every member of a family with an Autistic child is important but that sometimes the typical child's needs take a back seat to their Autistic sibling's needs. This can strain the sibling relationship. Research has found four strategies for improving the sibling relationship are: to teach cooperative play skills to

both of the siblings, develop and strength the typical sibling's coping skills, arrange for the typical sibling to have private time with their parent(s) and avoid unnecessary emotional and physical pressure (Beyer, 2009). Further research is needed to further define and implement these strategies.

Conclusion

The purpose of this study was to determine how a typically developing sibling feels about their sibling with Autism. This study provided the reader with a unique look into the experiences of eight children from six different families from their perspective. The study intended to determine the personality and interests of the typical siblings, the typical sibling's view of Autism, and how the Autism impacts their sibling's behavior. The typical sibling was asked about all of their siblings if he/she had more than one, about typical family activities, about times when they were frustrated with and had fun with their Autistic sibling. The interviews found mixed results from the typical siblings, but mostly positively bonded relationships. All the siblings were able to articulate that they both got along with and fought with their Autistic sibling at times. They were able to list things that they enjoyed doing as a family and what the friends of the typical siblings stated about the Autistic sibling. All of the typical siblings stated though that they had not been teased because of having an Autistic sibling.

This study also sought, although in a lesser extent, to understand the parent's reaction to receiving the diagnosis, the similarities and differences they see between their children's personalities. Most of the parents stated that they had not been surprised by the official results from the professionals because they had noticed signs in their child that caused them to seek out

help. Several of the parents discussed the difficulties they went through to get professionals to diagnose their Autistic child. All of the parents had good things to say about how having a child with Autism has enriched their lives. The unanimous advice to other parents receiving an Autism diagnosis was to get help and support.

This research serves as a reminder to social workers that even though the Autistic child is the child with the actual diagnosis, every member of the family needs to be supported and heard. Teaching skills to all members of the family will have a greater impact on the whole family system to make it a more cohesive unit.

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Appendix A: Information Sheet for the Study

My name is Lori Kaplan and I am a Master of Social Work student under the direction of Professor Richa Dhanju, 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 sibling relationship between an autistic sibling and a typical sibling. I am interested in hearing the experience from the typical sibling's perspective. I hope to empower current and future families who are impacted by an autistic sibling. I hope that what I learn from this study will help social workers and service providers understand the impact autism has on the sibling and how to best help these families cope. I would like to interview siblings who have been impacted by an autism diagnosis.

I am inviting the participation of parents and siblings who are willing to share their experiences. This study will involve one interview for approximately30 minutes to 1 hour. I will be conducting the interviews at a confidential, convenient meeting space of your choosing. I will set up the time and day for the interview depending on what is best for you. If you agree to participate, I will ask you on tape if you understand the information letter, if you have any questions and if you agree to take part in the interview.

This study is voluntary and you may choose to stop participating at any time. You may also choose not to answer any question. In the interview, I will ask you about your personal experiences with autism. I will ask you about the affects it had on your relationship with your autistic sibling and other family members, how you have been impacted by your autistic sibling, your daily routine, how you cope with any behaviors that your autistic may exhibit, and any advice you may have for other families impacted by autism.

There is one benefit directly to you for being in this study. The information you provide may help empower other families who are impacted by an autism diagnosis. The information from this study will be published in my clinical research project. Your real name will not be used to identify you and you will be given a fictitious name in the report. The interviews will be tape-recorded and they will not be recorded without your permission. You will have the right to ask for the recording to be stopped. The recording will be locked in a briefcase at this

researcher's home and only I will have access to the confidential information. The data will be kept until May of 2013 and any handwritten notes will be shredded. The recordings will be destroyed and discarded immediately after the study has been completed.

Contact information: Lori Kaplan

Cell phone: 612-418-8907

Email: kapl7087@stthomas.edu

If you have any questions about your rights as a subject/participant in this research, or if you feel you have been placed at risk, you can contact Richa Dhanju at dhan6591@stthomas.edu or 651-690-8755.

Appendix B: Consent Template

Sibling Relationships with an Autistic Sibling

INFORMATION AND CONSENT FORM

Introduction:

You are invited to participate in a research study investigating the sibling relationship between a typically developing sibling and an autistic sibling. This study is being conducted by Lori Kaplan, a graduate student at the University of St. Thomas/St. Catherine University School of Social Work under the supervision of Richa Dhanju, a faculty member in the Department of Social Work. You were selected as a possible participant in this research because you have a sibling who has been diagnosed with autism or a related disorder. Please read this form and ask questions before you agree to be in the study.

Background Information:

The purpose of this study is to hear about the experience of having an autistic sibling from the typical sibling's perspective. Approximately eight to ten people are expected to participate in this research.

Procedures:

If you decide to participate, your parent will be asked to answer some demographic questions. Then I will interview you (the sibling). You will be asked about your personal experiences with autism. I will ask you about the affects it had on your relationship with your autistic sibling and other family members, how you have been impacted by your autistic sibling, your daily routine, how you cope with any behaviors that your autistic may exhibit, and any advice you may have for other families impacted by autism. The one-time interview will take approximately 30-60 minutes.

Risks and Benefits of being in the study:

The study has minimal risks. During the interview, the sibling may feel uncomfortable discussing the details of their family life to a person who may not be known to the typical sibling.

There are no direct benefits to you for participating in this research

Compensation:

There are no benefits for your participation. I will provide your family with a list of resources that you may access if you feel that they would be helpful.

Confidentiality:

Any information obtained in connection with this research study that can be identified with you will be disclosed only under a fictitious name; your results will be kept confidential. In any written reports or publications, all names will be changed to protect confidentiality.

I will keep the research results in a locked briefcase in my home and only I and my advisor will have access to the records while I work on this project. I will finish analyzing the data by May 30, 2013. I will then destroy all audio recordings, original reports and identifying information that can be linked back to you.

Voluntary nature of the study:

Participation in this research study is voluntary. Your decision whether or not to participate will not affect your future relations with myself or St. Catherine University in any way. If you decide to participate, you are free to stop at any time without affecting these relationships.

Contacts and questions:

If you have any questions, please feel free to contact me, Lori Kaplan, at 612-418-8907. You may ask questions now, or if you have any additional questions later, the faculty advisor, Richa Dhanju (dhan6591@stthomas.edu or 651-690-8755), will be happy to answer them. If you have other questions or concerns regarding the study and would like to talk to someone other than the researcher, you may also contact Dr. John Schmitt, Chair of the St. Catherine University Institutional Review Board, at (651) 690-7739.

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

Statement of Consent:

You are making a decision whether or not to participate. Your signature indicates that you have read this information, you agree to be audio-taped and your questions have been answered. Even after signing this form, please know that you may withdraw from the study at any time.

_____

_____

Signature of Participant Date

_____

Signature of Parent or Legal Guardian, if applicable Date

_____

Signature of Researcher Date

Appendix C: Parental Questionnaire

Please answer the following questions about your family and children

1. Please list the **first** names and ages of all people who live in the household

   _____ _____

   _____ _____

   _____ _____

2. What is your marital status:
   _____ Married _____ Living Together _____Separated
   _____ Divorced _____ Widowed _____ Single/Never Married
3. What is the primary diagnosis of your child (or children) with a disability?

   _____

4. When did your child receive the diagnosis? What was your reaction to the diagnosis? Why?

   _____

   _____

5. How would you describe your child with autism? _____

   _____

6. How would you describe your child that is typically developing? Do they have any special needs?_____

   _____

   Describe any other children: _____

   _____

7. What language do you use to describe your son or daughter's disability to them and the other child(ren) if any?_____

8. How has having a child with autism enriched your life?

   _____

   _____

9. How has having a child with autism made your life more challenging? _____

   _____

   _____

10. Is there any other information that you would like to share? _____

    _____

11. What advice would you give to other families who just discovered that they have a child with autism? _____

    _____

Appendix D: Child Interview Questions

1. Tell me about yourself. (What do you like to do? Hobbies? Favorite subject in school? Your best friend? What is your favorite part about school?)
2. Tell me about the people in your family. Only use first names. (What did you do this weekend? What activities do you like to do as a family? Tell me about your sibling(s). Family vacation.)
3. What are some things that you like about your sibling (name from demographic form). Something you dislike.
4. What is autism (or term used by parent)? How does it make him/her act?
5. Tell me about a time:

   You were frustrated with your sibling./ You had fun with your sibling.

   You were proud of your sibling./You were embarrassed by your sibling.

   Which happens more often?

   Have there been times when you had to cancel an activity because of your sibling's behaviors? Does your sibling's autism change what you can or cannot do?
6. Have you ever been teased because of your sibling's behavior? Have other kids said that your sibling is "cool"? Give an example
7. Who do you talk to about your sibling's disability?
8. What advice would you give to another person whose sibling had just received a diagnosis of autism?
9. Is there anything else you would like to add? Or feel that I need to know?

Appendix E: Recruitment Flyer



RESEARCH STUDY:

Examining the sibling relationship between a typically developing sibling and their sibling diagnosed with autism.

St. Catherine University and the University of St. Thomas
School of Social Work

DO YOU HAVE A BROTHER OR SISTER DIAGNOSED WITH AUTISM?
I would like to hear your perspective.

Currently Recruiting Research Participants!



This research aims to discover what life is like for typical children who have a sibling diagnosed with autism. This study will be conducted at either your home or at a public place of your choosing. This research is led by Lori Kaplan, masters of social work student, under the supervision of Richa Dhanju, PhD., MSW.

What am I looking for?

- You must be accompanied by a parent or have a parent sign consent forms prior to the interview if you are under age 18
- You must be typically developing (no diagnosis of autism) and be between 8-21 years of age
- Your sibling is between 5-17 years of age and has been diagnosed with Autism, Autism Spectrum Disorder, Asperger Syndrome, or Pervasive Development Disorder, Not Otherwise Specified
- You must be willing to participate in a brief interview. This should take about an hour or less of your time.

For more information contact Lori Kaplan at (612) 418-8907 or kapl7087@stthomas.edu

Appendix F: List of Resources

Resources that may help your family

Fraser Child & Family Center http://fraser.org/

Fraser provides a range of services for children, adolescents, adults, and families in the Twin Cities. Our offerings include early childhood services, autism evaluations and services, mental health services, neuropsychology, rehabilitation, products and information to serve more than 60 types of disabilities and disorders.

Mental Health Association of Minnesota http://www.mentalhealthmn.org/

The Mental Health Association of Minnesota (MHAM) enhances mental health, promotes individual empowerment, and increase access to treatment and services for persons with mental illnesses. This mental health non-profit serves the state of Minnesota and mental health issues, disorders, laws and employment.

Minnesota Association for Children's Mental Health http://www.macmh.org/

The Minnesota Association for Children's Mental Health (MACMH) was founded in 1989. MACMH's mission is to promote positive mental health for all infants, children, adolescents and their families.

Autism Society of Minnesota http://www.ausm.org/

The Autism Society of Minnesota exists to enhance the lives of individuals with autism spectrum disorders. AuSM seeks to realize its mission through education support, collaboration, and advocacy.

Minnesota Disability Law Center http://www.mndlc.org/

Mid-Minnesota Legal Assistance Provides Free Legal Aid to people with Low Income, Disabilities, and Seniors in 20 central Minnesota counties.

Washburn Center for Children http://washburn.org/

Washburn Center for Children is the leader in helping children with social, emotional and behavioral problems and their families. As a community mental health center focused on children's mental health, Washburn strives to integrate innovative research into program practice, implement meaningful evaluation methods and provide effective training and consultation for agency staff and community collaborators.