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The Experiences of Families with a Child Diagnosed with Autism

Lauren M. Snyder
St. Catherine University

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The Experiences of Families with a Child Diagnosed with Autism

MSW Clinical Research Paper
Submitted by Lauren M. Snyder
May 2014

School of Social Work
St. Catherine University & University of St. Thomas
St. Paul, Minnesota

Committee Members:
Catherine Marrs Fuchsel, Ph.D., LICSW (Chair)
Kathleen Caron, MSW, LICSW
Leanne Mairs, MSW, LICSW

This 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 publically present their findings. This project is neither a Master's thesis nor a dissertation.

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Abstract

This qualitative research study explored the experiences of families who have a child diagnosed with Autism Spectrum Disorder (ASD). Surveys were sent out to families at a local agency, and seven parents responded. The survey investigated the impact of the child's diagnosis on the parental relationship, stress levels, feelings of social support, and self-care techniques. The objective of this study was to gain a better understanding of the experiences of these families with an autistic child, and to gain insight into where they need more support from professionals in the field. The content of the surveys was transcribed, coded, and themes were drawn out to draw conclusions about common experiences.

The findings revealed five common themes: (a) positive impacts on the parent's relationship, (b) negative impacts on the parent's relationship, (c) increased overall stressors, (d) lack of social support, (e) and the importance of self-care. While previous research addresses effective intervention strategies for children and parents with autism, this project provides a framework for social workers to utilize in their therapeutic work with families who have a child with autism. These findings also uncover implications for future research. There is a need for more detailed research investigating what the experiences of having a child with autism are like for families. This includes gathering more information around the impact on parental relationships, stressors, self-care techniques, and need for more support.

Keywords: Autism, Families, Experiences, Stress, Coping Strategies

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The Experiences of Families with a Children Diagnosed with Autism

Autism Spectrum Disorder (ASD) is a pervasive developmental disorder that is rapidly growing in the United States (Bradford, 2010). Typically, the disorder can be diagnosed as early as age 3, and these children show deficits or abnormalities in the areas of social interaction, language for communication, and/or restrictive and repetitive patterns of behaviors (MacFarlane & Kanaya, 2009). Children diagnosed with autism also often experience unusual sensory experiences. In fact, nearly 90% of children diagnosed with Autism experience some sensory abnormality (Leekam, Nieto, Libby, Wing & Gould, 2007). Unfortunately, a definite cause of Autism has not yet been found. Many studies have looked at possible causes of Autism, including linking it to maternal health risk factors, genetic predispositions, or the attachment and parenting style of caretakers. However, there has been no conclusive evidence linking Autism to any one or combination of environmental or genetic causes, (Baxter, Lotspeich, Spiker, Martin, Gretcher, & Hallmayer, 2007). There has been much time and effort given to find therapeutic techniques to find ways to help children with ASD find ways to live in socially acceptable ways, and to help parents cope with their child's challenging diagnosis.

It is important to gain a better understanding of family's experiences with children diagnosed with Autism because of the increase prevalence of the disorder. Since it is rapidly growing, it would be beneficial to know what parents find are the greatest struggles, along with what therapeutic techniques they have found to be ineffective and most beneficial. Taking a closer look at family dynamics, including relationships between both parents, relationships with siblings, and social support systems for the family, can

give us a better understanding of the role of family members and how that affects the child with ASD.

Social workers today need to be greatly involved and concerned with this topic. Since autism now affects 1 in 68 children (Bernstein, 2014), the need for support and research on this topic is important. This research will help social workers assist children and families diagnosed with autism now, and give us a head start for the adult clients diagnosed with autism that will need support and assistance in the future. Understanding the views of parents and family dynamics may lead to more productive work.

The purpose of this research project is to explore the family dynamics of families who have a child diagnosed with Autism Spectrum Disorder. Specifically, the experiences of the child with autism will be looked at, as well as the relationship between parents, the sibling's experiences, and finally social support for the family. This research will answer the question, "What are the experiences of families who have a child diagnosed with Autism Spectrum Disorder?"

Literature Review

A close analysis of the literature concludes that despite current research and efforts to find a cause and a cure to Autism Spectrum Disorders (ASD), only slight correlations have been found. Although families with children who have ASD all look different, research reveals patterns of family dynamics and sibling relationships. Efforts to find effective early intervention programs are growing, and new alternative therapies are arising. The history of autism, correlations of cause in research, family dynamics, sibling relationships, and effective programs and interventions are explored below.

Definitions and History of Autism Spectrum Disorders

The DSMV-TR defines Autism as a developmental disability that exhibits a wide range of possible characteristics. One of these characteristics is having persistent deficits in social communication and interaction across a wide range of contexts (American Psychiatric Association, 2013). This could include difficulty with reciprocal emotional interactions, a lack or difficulty in exhibiting non-verbal communication skills, and difficulty initiating, maintaining, and fully understanding relationships with others. In order to meet a diagnosis of ASD, a person must exhibit all three of these symptoms on some level (American Psychiatric Association, 2013). A second characteristic of autism is having repetitive patterns of behavior or interests (American Psychiatric Association, 2013). In order to meet this particular diagnosis, a person would have to have two of the following characteristics: Stereotyped motor movements; ritualized patterns of verbal or non-verbal behavior or resistance to changes in daily routines; fixated interests abnormal in intensity; and sensory abnormalities (American Psychiatric Association, 2013). The symptoms of social communication and stereotyped patterns of behavior must be present in early development, and cannot be better explained by an intellectual disability. They also have to cause some impairment in daily functioning -either social, occupational, or other (American Psychiatric Association, 2013). Since individuals who have this disorder fall on all different levels on the spectrum, the research tends to use the term Autism and ASD interchangeably, (Ryan, Hughes, Katsiyannis, McDaniel, & Sprinkle, 2011).

The prevalence of Autism has vastly increased over the last 60 years. In 1943, Leo Kanner recognized Autism for the first time as a clinical disorder (Leekam et al., 2007). At this time, the population affected by the disorder was low – approximately 2-4

out of 10,000 children (Leekham et al., 2007). Over the last 40 years, however, the prevalence of ASD has multiplied by approximately 10-fold (King & Bearman, 2011). Today, Autism affects 1 in 68 children, and is five times more likely to be diagnosed in boys than girls (Bernstein, 2014).

Causes of Autism Spectrum Disorder

Since ASD has become such a rapidly growing developmental disability, much research has been dedicated to try to find a cause (Whittaker, 2011). When Kanner published his first paper, acknowledging Autism as a clinical disorder, he led the long journey in trying to find a cause. He noted first that there could be a possibility for a biological predisposition for the disorder (Whittaker, 2011). He then focuses specifically on the parenting styles and characteristics of the parents who have a child diagnosed with ASD. He describes these parents as “rejecting”, “obsessive”, and “emotionally cold” (Whittaker, 2011). This depiction of parents as lacking warmth would later help coin the term “refrigerator mothers” or “refrigerator parents” which puts the blame on the parents for raising a child who lacks social skills due to rejecting parents. After the publication of Kanner’s paper, researchers Schopler and Loftin investigated the topic more fully, and found no evidence of parental thought disorders causing them to be cold parents (Whittaker, 2011).

Over the years, a number of hypotheses and studies have been conducted to try and find correlations, linking Autism to any biological, psychological, or social cause. Many studies have looked at maternal and paternal age as a risk factor for the developing child to have autism. However, there has been no conclusive evidence that maternal age effects severity of autism in a child (Baxter et al., 2007). Research has stated that

advanced maternal age would play a larger risk factor than paternal age (King, Fountain, Dakhllallah, & Bearman, 2011). Other possible causes that have been looked at included socioeconomic status of families – and therefore exposure to risk factors such as environmental toxins or lack of general health of the parents. The results from these studies have also not been able to find any statistical significance linking autism to any one cause (King et al., 2011). Although much research has been done on trying to find correlations between autism and many different causes, the genetic and environmental factors related to autism remain unknown (Baxter et al., 2007). Therefore, it is important to find effective therapeutic techniques to help families and children diagnosed with autism manage the best way they can.

Impact on Family

Families of children diagnosed with ASD have many struggles in addition to the typical stressors of having a child. When looking into the lives of these families, research has found many common themes in relation to emotional well-being of parents, the relationship between the parents, the relationship between the parent and other siblings in the house who aren't diagnosed with ASD, and finally social support for the family.

Stress. One of the common themes within the literature appears to be that families who have a child diagnosed with autism tend to have higher levels of stress (Neely-Barnes, Hall, Roberts, & Graff, 2011). These stressors include an intense sense of loss or separation after their child has been diagnosed, feelings of making personal or professional sacrifices for their child and family, and finally, stress from relationship changes both within and outside their immediate family (Nealy, O'Hare, Powers, & Swick, 2012). Research has found that because of this added stress, parents of children

with ASD are more likely than other parents to experience depression, adjustment problems, and lower levels of well being (Neely-Barnes et al., 2013; Tobling & Glenwick, 2007). This stress that parents or caregivers experience affects their well being both physically and mentally (Johnson, 2012). Mothers are more likely than fathers to seek help for the stress they are experiencing – by reaching out to social support systems such as extended family or community ties (Altiere & Von Kluge, 2009).

Parental relationships. The relationship between parents is greatly affected by their child's diagnosis of autism. Research has found two main different scenarios that have played out in the couple's relationship over time. Some research has supported that parents tend to experience an initial drop in relationship satisfaction immediately following their child's diagnosis, but after time develop a healthier relationship and are able to bond in novel ways (Johnson, 2012). It was also concluded from another study that families of children with ASD don't differ significantly from those without an ASD child in terms of cohesion and feelings of closeness (Altiere et al., 2009). This suggests that couples sense of closeness may not be greatly affected by their child's diagnosis. Other research has found a real negative impact on the parents and their relationship with each other. The struggles that come with having a child with autism can cause some couples to draw further away from one another, and experience lower levels of satisfaction in their relationship (Johnson, 2012). This can be because there is increased conflict within the home, and an increased weight of responsibility for spouses (Nealy et al., 2012). The increased financial costs associated with a child with ASD also add more stress to the couple's relationship leading to dissatisfaction (Nealy et al., 2012).

Siblings. The parent's relationship with other children in the family not diagnosed with ASD is also a common theme within the literature. Mothers specifically have reported a lower quality of a relationship with her other children (Nealy et al., 2012). Reasons for a change in the relationship include not having enough time to spend or spending an unequal amount of time with each child, not scheduling outside activities for the other child to participate in, and forcing the other child to grow up faster than they are ready to (Nealy et al., 2012). Sibling's cognitive and social impact of having a brother or sister diagnosed with ASD has also been researched. A study was done that compared the cognitive, adaptive, social, imitation, play, and language skills of children in a family with an ASD child and children in a family with no ASD child. The results of the study concluded that children (ages 18-27 months) who grow up in a household with a child with ASD had lower expressive and receptive language skills, lower communication skills, and lower adaptive behaviors than the children without an ASD sibling (Toth, Dawson, Meltzoff, Greenon, & Fein, 2007). Another similar study concluded that despite initial drops in language and cognitive skills, these siblings were back on track with their peers by 54 months of age (Gamliel, Yirmiya, & Sigman, 2007). Ferraioli and Harris, (2010) also concluded that the siblings of children with ASD function as well as their peers when they are children, adolescents, and adults. The relationship between siblings and the child with ASD is another important factor to consider. The sibling's cognitive and emotional development influences how they view and perceive the behaviors of their sibling with ASD (Ferraioli et al., 2010). Another strong influence on the relationship between the two siblings is the responses of parents to both of the

children (Ferraioli et al., 2010). Overall, siblings experience an ongoing sense of responsibility for their sibling with ASD (Ferraioli et al., 2010).

Social support. Finally, the social support systems of families who have a child with ASD seem to be a reoccurring theme within the literature. Many families report a feeling of not being understood by society and professionals in the field – using words like feeling hidden, ignored, and discounted for (Altiere et al., 2009). In general, many families experience that their child’s diagnosis has negatively affected their social lives. One of the main reasons for this is that they no longer feel like they have any social ties left, that many of their previous relationships have disappeared because they are no longer able to relate to old friends (Nealy et al., 2012). Social support out in the community is also compromised for families. Many parents feel worried about taking their child with ASD out in public anywhere because of feeling embarrassed by their child’s behaviors (Neely-Barnes et al., 2013). Parents report feeling shamed, embarrassed and judged by others when they take their child out in public (Nealy et al., 2012 & Neely-Barnes et al., 2013).

Effective Programs and Interventions

Behavior therapy interventions: ABA services. Many different programs and interventions are aimed to help children with autism develop greater language skills, decrease their disruptive behaviors, and increase cognitive ability (Epp, 2008; Smith & Eikeseth, 2011). One of the leading programs in early intervention for autism is Applied Behavior Analysis (ABA). This research paper used participants who were currently utilizing ABA services, and so the majority of the previous research included in this

research paper incorporates ABA services as part of their intervention strategies. An overview of other important intervention strategies will also be discussed.

O.Iver Lovass is the first person to use ABA services to try to help young children under the age of four with autism to decrease their disruptive behaviors and increase effective communication (Smith et al., 2011). ABA uses B.F Skinner's science behind behaviorism in that it rewards positive behaviors with verbal recognition (Ryan, et al., 2011). Behavior therapy was a technique used by professionals outside of the home, but Lovass found that ABA services were most beneficial when brought into the home to pair with family interventions (Smith et al., 2011). Over the past 30 years, ABA services have been widely effective in dramatically improving disruptive behaviors and overall functioning of children with autism (Fortunato, Sigafos, & Morsillo-searls, 2007). Two key aspects of the therapy are "1) the effectiveness of early intervention techniques" and "2) the importance of peer and parent involvement in the process" (Fortunato et al., 2007, p. 87).

ABA has also been found to be effective in community and school settings. In a recent study, ABA techniques were used in one classroom with autistic children, while other classes resumed with "education as usual" with autistic children (Grindle, Hastings, Saville, Hughes, Huxley, Kovshoff, & Remington, 2012). Results of the study found statistically significant effects that were in favor of the ABA services. Children using this intervention experienced an increase in language skills and learning skills, which also led to an overall increase in their standardized testing scores (Grindle et al., 2012). Another study looked at a comparison of early intensive behavior interventions (EIBI) that utilize ABA techniques and autism-specific nursery provision. This study did not find a

significant difference in outcomes between the two interventions. However, both forms of interventions lead to significant gains in cognitive ability, language skills, and play skills at similar rates (Iliana, 2007). Since different interventions appear to be more effective than no interventions at all, it is also important to explore literature of alternative techniques to see if new age interventions can also be effective in treating autism.

Parent training and family therapy. Raising a child diagnosed with ASD comes with many challenges, as the children are likely to exhibit problems such as aggression, inattention, and impulsivity (Kaminski, Valle, Filene, & Boyle, 2008). Research has looked at the effects of parent or family training as an intervention for children with autism. Parental training is a way for parents to gain skills such as encouraging appropriate social interactions with their child, and reinforcing milestones in development of cognitive ability or academics (Kaminski et al., 2008). Parental training has also been found to help decrease the non-compliant behaviors of children with autism (Estrada, 1996), and increase appropriate social communication skills (McConachie and Diggle, 2006). Family interventions have also been found to be effective therapeutic techniques for children with ASD. These interventions include incorporating all family members in training techniques to gain knowledge, improve child management skills, and adjust attitudes regarding the child with ASD (Estrada, 1996). These family interventions have been found to improve the child's functioning and in some cases, the functioning of the parents (Estrada, 1996).

Alternative interventions. Alternative intervention programs used in the last decade have been found to be useful in treating children with autism. Art therapy, for

example, has been found to be effective to increase social skills and improve behavior problems in children with autism (Epp, 2008). This particular format utilizes cognitive behavior techniques paired with art therapy in the community or school in a group therapy format (Epp, 2008). Another effective intervention highlighted in the research is Response Interruption and Redirection (RIR) (Neitzel, 2009). This therapy has two main components. First, the child is interrupted when engaging in undesired behaviors. Then, teachers or therapists redirect the child and model for them how to engage in a more appropriate behavior. This behavior technique provides the child with autism a way to learn what kinds of behaviors that are either accepted or not by society. Technology has also been a leader in new intervention techniques. One study looked at using an IPOD touch to help autistic children learn to utilize activity schedules appropriately. Findings suggested that this intervention lead to an increase in the quality of engagement of the child when independently utilizing schedules and stay on task (Carlile, Reeve, Reeve, & Debar, 2013). Finally, another study looked at video prompting and video modeling techniques as a way of teaching children with autism daily living skills. This study found that video prompting was more effective than video modeling in teaching these skills, but both were found to be effective intervention strategies (Gardner & Wolfe, 2013).

Role of Social Work

Social workers play a large role in the movement to find effective therapeutic techniques that work with children with autism. Social workers can look at this issue from a micro, mezzo, and macro lens. On a micro level, individual skills work with the child lays the foundation for expectations of the caregivers and community members working with the child. On a mezzo level, studies have found that social workers play an

important role in integrating the family into therapy (Herman, 2007). This would entail social workers empowering families by giving them a say in decisions for how intervention should play out in the home or community, and then encouraging them to advocate for services for their child (Herman, 2007). Interventions and support are also needed within the school setting.

Social workers have a responsibility to advocate for these families to ensure their access to paraprofessionals and effective interventions within the school setting. As learned previously, students with autism show increases in cognitive ability and test scores as well as a decrease in behaviors when early intensive behavioral interventions are brought into the school setting (Iliana, 2007). Therefore, advocacy and support are needed to ensure adequate care of the special needs of children with ASD. Finally, social workers also have a role to play in the macro level of intervention. Evidence shows that the community and general public has little knowledge on what it means to be autistic and what the characteristics and special needs are of children who have ASD (Moroz, 1989). Therefore, education for community members would be a large part of the role of social workers. Advocacy to professional agencies about autism would also be an essential role. Families who have a child diagnosed with ASD have reported feeling neglected and hidden and sometimes misled by the helping professionals they thought would assist them (Altiere et al., 2009). It is clear then that even social workers in the field may have limited knowledge on ASD, and may need special trainings or conferences to create a better understanding of these families needs.

Conclusion

The current research on autism focuses heavily on effective interventions that are available to children and families struggling with autism. There is a gap in the literature when it comes to the experiences of these families who have a child with ASD. Although there has been some research done on the effects of autism on family functioning, the true experiences of these families in their relationships is not captured in the literature. The purpose of this paper is to grasp a clearer understanding of what the experiences of these families are in regards to changes in marital relationships, impact on other siblings in the household, and how social support has changed since their child was diagnosed. The research question that will be answered through this paper is, “What are the experiences of families who have a child diagnosed with autism?”

Conceptual Framework

This research question was examined using the family systems perspective and strengths perspective, both of which are widely used throughout the social work profession. The theoretical framework of this paper focuses heavily on the Systems Theory, with particular emphasis on the family system as a whole unit. “A systems perspective sees the human behavior as the outcome of reciprocal interactions of persons operating within organized and integrated social systems” (Hutchinson, 2003, p. 51). Since the experiences of families of children with autism are explored in the paper, it is important to look at all members of the family, including the child with autism, siblings, parents or caregivers, and finally social support systems for the family including friends and community support. This writer believes that each part of the family system serves a purpose and affects the system as a whole.

Taking a closer look into the experiences of families who have a child with autism, we can see that multiple aspects of relationships within the family are affected. Children with Autism experience a wide variety of symptoms that make it difficult to engage in family dynamics in a typical fashion. These include restrictive and repetitive disruptive behaviors, difficulty with verbal and non-verbal communication, limited emotional regulation techniques, and unusual sensory experiences (Leekman, et al., 2006 & Garcia, 2012). The symptoms that the children experience greatly impact how the family as a unit functions. The parental relationship is greatly affected by the child's unique experiences. Parents of children with autism often experience an initial decline in their relationship satisfaction when their child is diagnosed (Johnson, 2012). Many families opt to seek social services for their child. These services can be time consuming, expensive, and invasive – creating more stress on the parents. The new increased amount of time spent on the ASD child can take away time spent with other siblings in the household. Often, parents and specifically mothers, feel like the quality of their relationship with their other children decreases due to the amount of time needing to be spent with their ASD child (Nealy et al., 2012). Finally, the social support systems for families are also affected as a result in family dynamic changes. The added commitments of having a child with ASD makes it difficult for parents to reach out to friends and support in the community. This is often because parents feel as if they are not understood by old friends and can no longer relate to them (Nealy et al., 2012).

A strengths based perspective can also be beneficial to use when looking at the experiences of families who have a child with autism. The purpose of a strengths perspective is to help families become more aware of their successes and strengths

(DeJong & Berg, 2008). This research encourages parents and caregivers to explore positive outcomes of having a child diagnosed with ASD, and ways their family has overcome negative outcomes such as increased stress personally and in their relationships with others. Social workers utilize the strengths perspective framework to acknowledge resiliency in clients, identify protective factors, and eliminate judgment or blame towards clients.

The strengths perspective can be utilized when looking at multiple aspects of family dynamics in families who have a child with ASD. Although marital relationships often suffer an initial drop in satisfaction upon a child's diagnosis of autism, research has shown that some families report a later increase in relationship satisfaction and a new found bond between parents or care givers (Johnson, 2012). Research has looked at the cognitive abilities of siblings of children with ASD, and found that despite some initial delays in expressive and receptive communication skills, these siblings develop intellectually, physically, and emotionally in accordance to their peers (Ferraioli et al., 2010). Finally, although having a child with ASD makes parents more likely to exhibit symptoms of depression and higher levels of stress, many parents and especially mothers are still able to utilize social support from family or community members in times of need (Altieri et al., 2009).

In summary, both a family systems perspective and a strengths perspective play an essential role in understanding the experiences of families who have a child diagnosed with Autism. The family systems perspective emphasizes the importance how each unit in the family impacts the family as a whole. While the child with autism plays an essential role in family dynamics, other aspects of the family impact one another as well.

The strengths perspective acknowledges that many families are resilient to the negative impacts that can come with having a child diagnosed with Autism. Therefore, the foundation of this research study is to look at family dynamics and experiences of families who have a child with autism from a family systems and strengths perspective.

Method

The purpose of this study was to gain a better understanding of how each family unit is affected by a child who has autism. This study answered the question, “What are the experiences of families who have a child diagnosed with Autism Spectrum Disorder?” This qualitative study explored the experiences of all family units, including the impact on the child with autism, the impact on parental relationships with their spouse and other children, and the impact of social support and outreach for the family. Previous research has focused on effective interventions for families, however, this research provided an important framework of understanding families experiences in order to determine effective intervention strategies for the future of autism.

Research Design

This research had a qualitative design, meaning that it is inductive in nature. The qualitative research explored the experiences of families who have a child with autism in words, rather than gaining data in number form. It created a new theory rather than proving or disproving an existing theory. A survey was created that included qualitative questions that provoked thoughts of overall experiences of families with a child with ASD. The survey consisted of ten questions, including two basic demographic questions.

Sample

The participants in this exploratory study were parents of children diagnosed with ASD who are currently utilizing services at an agency in the Twin Cities. This company provides in-home, group, and outpatient services under the model of Applied Behavior Analysis (ABA) to families and children with developmental disabilities including Autism. A letter of cooperation from the agency was obtained, verifying their agreement to allow this researcher to distribute surveys to families using the agency for services. In order to obtain the sample, this researcher gave the program director of the agency an initial information sheet (see Appendix A) to send to each family who has a child diagnosed with autism within the agency, which described to them what the study is about and who is conducting it. It explained that in the next week, a copy of a qualitative survey will be sent out to the families, and if they do not want to participate, they can choose to discard the survey. Finally, this information sheet explained the purpose of the study, and confidentiality of information given to researcher. A week after the information sheet was given out, a copy of the a new information sheet (see Appendix B), informed consent form (see Appendix C), and survey (see Appendix D), were sent out to families, along with a pre-stamped 11' by 13' returning envelope. The new information sheet provided similar information as the initial one did. The informed consent form gave some background information on the study, how the procedure of the study will work, and risks/benefits of the study. It also discussed confidentiality and the voluntary nature of the study. Finally, the survey itself asked basic demographic questions such as age of the child with autism and number of siblings within the house. It then asked qualitative questions inquiring about experiences of stress, marital satisfaction, relationship with siblings, and social support.

If the families chose to participate, they filled out the 10-question survey asking them questions of their experiences of having a child diagnosed with autism. After they completed the survey, they put the signed informed consent form and the completed survey in the returning envelope, and sent it back to the address for the agency provided. The packets were received by the program director, and stored in a mailbox for this researcher to collect. The program director and all other staff at the agency used were instructed not to open any of the envelopes that were sent back to the agency. Participants were permitted to contact the researcher at any time throughout this process if they have any questions or concerns.

Protection of Human Subjects

To protect each human subject, a proposal was submitted to this researcher's MSW Clinical Research Committee. Upon the approval of the committee, the application of the proposal was sent to St. Catherine University Institutional Review Board (IRB). The IRB reviewed the application to ensure the protection of human subjects. In addition, the informed consent form was given to each participant before they completed the survey. This consent form clearly explained the purpose of the study, ensured the participant's anonymity, explained that the study was optional and they have the option to decline at any time. By signing the form, potential participants agreed to participate in the study.

Steps were taken to ensure anonymity and confidentiality of the subjects who chose to participate in the study. After the participants completed the study, they sent it back the agency. They were provided with an envelope that has been stamped and addressed to this researcher at the agency used. The program director, who received the

mail at the agency, was instructed to put all incoming mail addressed to the researcher in an enclosed box located in her private office. The program director and all other staff at the agency were instructed not to open any of the envelopes that were sent back to the agency. The research assistant divided the survey and the consent forms with signatures to ensure anonymity of participants to this researcher. The purpose of having a research assistant who has access to identifying information was so that the researcher could remain unbiased to identifying names that correlate with certain surveys.

Data Collection

This data was collected through the completion of surveys distributed to families who have a child diagnosed with ASD over a one-month period. The surveys contained qualitative questions related to experiences of having a child diagnosed with ASD. The questions ranged from topics such as stressors, relationships with spouses, relationships with other children in the family, social support, and effectiveness of therapeutic interventions.

Data Analysis

This researcher used content analysis to analyze the data that was collected through the qualitative surveys. Content analysis is, “a carefully, detailed, systematic examination and interpretation of a particular body of material in an effort to identify patterns, themes, biases, and meanings” (Leedy & ORMrod, 2005; Neuendorf, 2002 as cited in Berg, 2007 p. 303-304). The researcher started with a research question, and transcribed the survey results into themes based on common themes already found in the literature, and new themes that were found. The researcher encoded the data into the

different themes and categories that were predetermined. Finally, the findings of common theses were reported in the findings section of this paper.

Strengths and Limitations

There are several strengths of this research. First, having a qualitative design ensured that overall experiences were reported from families, instead of just using numbers to rate an intensity of an experience. Another strength of this study is that it incorporated families from a variety of different ethnic backgrounds, culture, socioeconomic statuses, and severity of the autism diagnosis. A final strength of the study is that it highlighted the greatest struggles of families who have a child diagnosed with autism, identifying where therapeutic services could improve their support in.

There are also limitations to this study. This sample only incorporated families who were utilizing services at one particular agency in the Twin Cities. Therefore, these parents and children are only experiencing the interventions of Applied Behavior Analysis. Another limitation is that since the responses of the surveys were written instead of vocalized to the researcher, non-verbal signals and emotions such as frustration, sadness, or hopelessness are harder to observe. Finally, the company BTS is small in relation to other in-home ABA service providers, and so the total number of families being asked to participate in the survey was relatively small.

Conclusion

The research question “What are the experiences of families who have a child diagnosed with Autism?” was investigated in this paper. This study used a qualitative survey to gather data. Participants of this survey were the parents of children receiving ABA services from an agency in the Twin Cities. The Program Director at the agency

distributed informed consent forms and surveys to the families they serve in order to recruit families for this study. Submitting the proposal to the IRB and gaining permission to conduct this study ensured the protection of human subjects. All documents were locked up, and all surveys will be destroyed by June 1st, 2014. The data gained through these surveys were analyzed using content analysis. Finally, results of this study were discussed in the findings section of this paper.

Findings

This research project was designed to gain a better understanding of the experiences of families who have a child diagnosed with Autism Spectrum Disorder. The researcher distributed thirty-six surveys to families who were seeking behavior therapy from a local agency. Of the surveys distributed, the researcher received seven total responses. The children discussed in the responses ranged from ages three to fifteen. Two of the families that responded had two children in the family who were diagnosed with autism. Of the people who responded, four of them were the mothers of the child who was diagnosed with autism, two were the fathers, and one was unknown. Finally, of the respondents, five of them reported that they were in a committed partnership or married, and that their partner was the father or mother of the child with autism. The other two participants reported that they are no longer in a relationship with the father or mother of their child with autism.

After the surveys were collected, the researcher then transcribed every word of each response onto a separate document. After all the surveys had been transcribed, certain words or phrases were highlighted that appeared to follow general themes throughout the research. Each of these words or phrases was then put into sub-categories

to better highlight more detailed themes throughout the survey. From the data analysis that was completed, five themes emerged. These themes consist of the following: (a) positive impacts on the parent's relationship, (b) negative impacts on the parent's relationship, (c) increased overall stressors, (d) lack of social support, (e) and the importance of self-care. Throughout this paper, the researcher will highlight certain words or phrases that each participant used. To ensure full anonymity, this researcher will refer to the respondents as "participant one, two, three, etc."

Positive Impacts on the Parent's Relationship

From the data collected, a number of participants discussed positive impacts that having a child with ASD brought to their relationship with their spouse. One clear finding is that parents feel they need to rely on each other more which brings them closer as a couple. Participant one said, "We are more patient, and also depend on each other more". Participant two said, "We need to rely on each other a lot more". Finally, participant three said, "Definitely makes us communicate about our kids more than the average people". Participant five also shared this experience, and reported, "It takes a lot of communication to deal with all of it." These four participants shared the experience of increasing communication, and relying on one another, especially when it comes to their child. Participant four also had a similar experience, finding that the family as a whole unit was brought closer together as a result of their child's diagnosis. Participant four stated, "It's brought us closer as a family. I've always accepted challenges head on. This is no different. She is a child with special needs, and is a blessing". The time and attention given to the autistic child made participant five grateful for the time she has with her husband. She responded, "I really try to get my husband to discuss all the

decisions with me regarding the kids so that helps. It makes us enjoy any time away together that much more.”

Negative Impacts on the Parent’s Relationship

The data collected also revealed some negative effects that having a child with autism brought onto their relationship with their partner or spouse. One stressor reported by some respondents is that they don’t get as much time together as they used to. Participant four reported, “We don’t have as much time together to enjoy personal activities like before.” Participant two discussed how hopes and dreams were disappearing as a couple. Participant two stated, “We’ve had to give up some of our dreams and goals to raise two autistic children.” Financial stress was also reported as a negative impact for the family. Participant one reported, “It has brought incredible stress and challenges. Also, it has been tough financially.” Participant five also reported “financial stress” as a negative impact. Finally, some couples found that the stress of having a child with autism weighed too heavily on their relationship, and so they are no longer together. Participant two shared, “We had to leave our home. My wife moved away with the children and we lived apart for three years.” Participant three also reported that their current relationship status is “Divorced – lives away from children”. It should also be noted here that two of the respondents reported that they are no longer in a relationship with the mother or father of their child with autism. These participants were originally with their spouse when their child with autism was born. For example, participant three, who is now divorced and their spouse lives away from their children, reported that the beginning of their relationship was, “good, very healthy”. Participant one also shared this experience. The beginning of their relationship was described as

“happy [heart sign]”, but after their child with autism was born, their “wife moved away”.

Increased Overall Stressors

Of the seven respondents, six of them reported that their overall stress levels have increased since having a child diagnosed with autism. The participants who described their children as having another sibling who is not diagnosed with autism reported that it has caused increased stressors on their relationship with the other child. Participant one reported that it has “taken attention away from the other child.” Participant two also reported a negative impact saying that their other daughter was “pulled along for the ride” and that “dealing with his [son with autism] behaviors took a lot of time an energy she didn’t get from us.”

Personal stress also seems to be impacted from having a child with autism. Participant one reported, “I am not the happy-go-lucky person I used to be, yes my stress level has increased.” Participant two responded, “dealing with their [children with autism] behaviors causes us individual stress.” Participant’s three, four, and six all reported that their overall stress levels have “increased”.

It is also evident that the families who have more than one child with autism experience a great amount of stress after their second has been diagnosed. Participant three reports that stress levels have,

Increased!! When he was first diagnosed it actually got better. He went to an ABA center all day and I could finally spend some time with my baby girl. Then she was diagnosed and it got crazy! Now there is too much to explain!

Participant five reported an increase in stress in her relationship with her spouse after having two kids with ASD. She reported, "I think our relationship is strained by having two kiddos with autism". Participant one also shares this experience, and stated, "We've had to give up some of our dreams and goals to raise two autistic children." Participant three also expressed some distress over needing to get her second child evaluated for autism after her first child was diagnosed. She reported, "We knew to have her evaluated sooner because of his diagnosis."

The new hindered social life and impact of future plans appears to be a large stressor for families. Many participants worry about what will become of their children after they are no longer able to help them. Participant two reported, "Parents have goals and dreams of what they will do when their children are grown and move away. We are feeling those dreams slip away. We also worry what will become of our children if/when we are gone." Participant seven reported that stress levels have "increased, giving up one's dreams, goals, desires, social life, so we can focus on treatment plans, so she can blend into society and live an independent life in the future."

There appears to be significant stress around taking a child with autism into the community or public. Participant one reported,

It is very hard to be out in public, as we never know what will trigger her outburst. The looks, comments, and eye rolls from the general public has been a way of life. Everybody (almost) just assumes you are a bad parent.

Participant three stated that they "avoid certain activities or outings because it is just too hard". Finally, participant seven experiences the same feeling and reported,

People stare and make rude comments; you need to learn to tune everyone out, even though it can be extremely embarrassing. It's a horrible feeling and I feel like I am constantly defending myself, when in reality, it's no one's business.

Lack of Social Support

The findings suggest that many families experience a lack of social support when it comes to their child with autism. Some participants experience a lack of understanding and support from their family members. Participant one reported,

We have had very little support and understanding from friends and/or family. I personally, have lost friends from it. A lot of people think they can fix your child but nobody really knows what it is like 24 hours a day.

When asked where they need more social support, participant three responded, "family involvement". It seems that it is difficult for families to be supportive because of a lack of understanding of autism. Participant six said, "We have supportive parents and family, but they don't really get it." Participant five reported, "It's hard to get grandparents to help with babysitting all the time to run errands or go to appointments."

Another clear finding is that families who have a child with autism need more support from the general community. It is important to families that the general public becomes more educated on the topic of autism. Participant two wants "more education for the medical field for families affected by this disorder." Participant seven also shares this wish. When asked how they could use more support, they responded, "They [community members] become more educated, research autism!" Participant three would want "more social experiences for children". Participant two felt that the public tends to automatically assume that they are just bad parents. When asked how they could be more

supported, they reported, “To believe that they ARE autistic, and that we are not just bad parents, and to believe that we are doing the best we can for them.”

Finally, families reported the need for additional assistance and help with their child. Participant one reported that she would ideally want, “A caregiver that you can trust, so I can spend more time away with my husband.” Participant four would want “respite care” to better help support their child with autism and to give more time and space for personal time. Participant five responded that they want a “secondary caregiver”. Finally, participant six reported, “It would be great to have a PCA [Personal Care Assistant] or someone to come with us to the store”.

Importance of Self-Care Strategies

The research studies highlight the importance of self-care strategies for families who have a child diagnosed with autism. There seem to be a variety of techniques or rituals that parents utilize in order to better manage the stress of having a child with ASD. Participant one reported that they need a “long, hot shower” to unwind. Participant two stated that they “occasionally get a babysitter to watch them [children with autism] so we can have a date night.” Participant three stated that for self-care strategies, they utilize “bible studies.” Participant four reported that ,“exercise, friends, relaxation, and therapy work for them”. Finally, participant five reported, “My art, being creative, and networking. My art allows me to do as I please and be professional again.”

Distraction techniques are also popular. Many families engage in activities to help take their mind off of the everyday stress they are experiencing. Participant five stated, “Continue to do activities we like. Golfing, running, movies. In the early stages of her autism we neglected these things and that was detrimental to our well-being as parents.”

Participant six reported, “Trying to sit down before bed and watch TV or a DVD or just going to bed early enough, getting enough sleep equals a happy mommy!” Finally, participant seven also uses these strategies. When asked what they do for self-care, they reported, “Going to a therapist, joining the gym, and taking different classes. Trying to set aside me time”. Participant four tries to escape and clear her mind. She reports, “I am not much of a people person because I am constantly being asked about my kid when I am trying to mind escape and forget.”

Finally, participants felt less stress when they felt supported by family members, caregivers, or friends. Participant two found support through, “some friends from church and our PCA.” Participant four reported that they found comfort in talking with, “other parents of children affected with autism.” Participant five reported they felt supported by, “my immediate family. Father, mother, and siblings have been very helpful.” This participant also noted that they are receiving a, “secondary caregiver. My wife’s mother is coming in April to help care for our daughter.” Participant six reported that the most support they have received has been, “therapists we have had.” Participant seven found that outside support systems have helped her and her daughter. She replied, “places that have helped us include: Scottish Rite Clinic (provided parent groups on tips for parenting autism, besides speech); Courage Center in Duluth (offered classes one-on-one).”

Summary of Findings

This research has gathered qualitative data on the experiences of families who have a child diagnosed with autism. Seven people responded to the survey, and the data was coded and analyzed to depict themes. The five themes that emerged from this research were: (a) positive impacts on the parent’s relationship, (b) negative impacts on

the parent's relationship, (c) increased overall stressors, (d) lack of social support, (e) and the importance of self-care.

The positive impacts on the parental relationship that were reported included feelings of closeness with their partner, an increase in the amount of communication between partners, and feelings of being more dependent on their spouse. Negative impacts on the parental relationship included both emotional and physical distance between partners, financial stress causing tension on the relationship, and no longer participating in bonding activities that couples once found joyful to do together.

Respondents reported that overall, their stress levels have increased. Common stressors included distress over lack of time spent with other children in the family, personal stress over feeling less happy and active, financial stress, and stress over taking their autistic child out into the community. Families felt an overall lack of support. Some respondents stated that they needed more support from family and friends, while others were concerned about the public awareness and education on autism. Most respondents felt judged in some way by community members, or misunderstood by professionals in the field. Finally, this project demonstrates that there is strong importance of self-care for the families who have a child diagnosed with autism. Respondents reported a wide range of self-care skills that they use, including church, exercise, time alone, time with friends or family, therapy, and relaxation techniques.

Discussion

A limited amount of research has looked at the experiences of families who have a child diagnosed with autism. The surveys that were completed for this study offer perspectives from parents who have a child with autism. This section of the research will

discuss and interpret the findings from the surveys, as well as compare and contrast it to the previous research discussed earlier. The strengths and limitations of the study will also be discussed, as well as the implications for future social work practice.

Impact on Parental Relationship

Similar to the previous studies conducted, this research shows that there are both positive and negative impacts of having a child diagnosed with autism in regards to the parental relationship. Johnson's (2012) finding that couples experiences a decrease in satisfaction with their relationship and an increase in isolation from one another seems to correspond with what this research found. Couples in this study reported financial stress as being a strong impact on their relationship, as well as feeling distant from one another. Nealy (2012) confirms that financial stress seems to be a real burden on families.

Previous research shows that there also seems to be some positive impacts on the parental relationship. Johnson's (2012) finding that parents experience an initial drop in satisfaction, but then are able to bond in new novel ways appears to also be a trend in this research. Respondents reported an increase in their communication with their partner, as well as feeling closer as a family system. Altieri (2009) concluded that the parental relationship is not impacted significantly in regards to feelings of closeness. This confirms the findings that some participants do not experience a significant decrease in the satisfaction of their relationships.

Both previous research and this study found that parents who have a child diagnosed with autism experience a wide range of impacts on their relationship. Some parents experience an initial or long term drop in their satisfaction of the relationship, and distance themselves from their partner. This could be due to a variety of reasons,

including an increased amount of stress, and lack of social support or understanding. On the other hand, some couples seem to experience an increase in their relationship satisfaction and report feeling closer to their spouse, depending more on them, and increasing their communication skills. This overall finding could be because their spouse is one of the only people who truly understand what they are going through. The increased communication might be a result of needing to discuss new and important medical decisions around their child's diagnosis or managing disruptive behaviors common in autism.

Increase in Overall Stress

Similar to Neely-Barnes (2013), this study found that parents who have a child diagnosed with autism experience an increase in their amount of overall stress. Six of the seven respondents replied that their overall stress has increased since the diagnosis. The families in this study reported stress around their relationship with other siblings in the household. Nealy (2012) also found that the relationship with other siblings seems to be negatively impacted by the diagnosis. This could be because more time and attention needs to be given to the child with autism, and the child without autism may have to develop a sense of independence and autonomy faster than they may originally have.

This research states that personal stress also tends to increase, and parents are finding that they aren't as happy or carefree as they used to be. Previous research found something similar, that parents feel that they have to make personal and financial sacrifices to compensate for their child's diagnosis (Nealy, 2012). Again, it is possible that so much time and attention is now drawn to the child with autism, that parents

neglect self-care and things that were once important to them in order to meet their child's unique needs.

Finally, families also reported stress around their new hindered social life and a lack of understanding and support from the community. Nealy (2012) also found that families experience a change in their relationships inside and outside of the home. Altieri's (2009) finding that parents feel hidden, ignored, and discounted for by professionals in the community seems to correlate with this studies findings as well. One of the possible reasons for these findings could be the lack of understanding of autism. A few parents in this study reported feeling misunderstood by both the community and professionals, and feeling judged by others. One person suggested that an increase in education and research needs to be completed so that greater advocacies can occur. This lack of understanding causes stress to families, probably because they feel that no one truly understands what they are going through.

Needing More Support

A theme for many families in this research project is needing more support in general. Families reported feeling unsupported by friends and family because of a lack of understanding about their child's autism. This is similar to Nealy's (2012) finding that previous relationships or friendships tend to disappear because of a lack of ability to relate to others. A possible reason that families are looking for more support from friends and family members could be because these are the relationships that people value the most. It could also be because friends and family offer assistance and support in ways that PCA's or babysitters may not be able to, such as watching the child with autism for a weekend while the parents have some time for themselves.

Similar to Nealy-Barnes (2013), this research found that families also are seeking more understanding and support from the community and general public. Many participants felt judged by others in the community, and felt that no one understood why their child was behaving the way they were. Nealy-Barnes (2013) reports that families experience a large amount of embarrassment when taking their autistic child out in public. Families are most likely looking for more support from the community so that they no longer feel embarrassed when they need to bring their child with autism out in public. If the community were more educated on the topic, and were more supportive, parents might feel more empowered and eager to work on behaviors in the community instead of avoiding outings all together.

Finally, this research found that many parents are also looking for more support inside of the home, such as babysitters, personal care assistants, or behavior therapists. Other research articles did not highlight this as a need reported by families, however, it did discuss the benefits of having supportive therapists and PCA's as part of the work with autism. It is possible that parents are just recently starting to become aware of the services available, since in earlier years behavior services such as Applied Behavioral Analysis were not yet implemented. It is also likely that because of the increased prevalence in autism, more services are becoming available, and advertisement and discussion around these services is becoming more frequent.

Importance of Self-Care Strategies

Families reported a wide range of self-care strategies that they use to help cope with the increased stress they are experiencing of having a child with autism. These included church/bible studies, seeing a therapist, having personal time to do activities or

just relax, seeing friends, and exercising. Previous research has discussed the increased amount of both physical and emotional stress that parent's experience (Johnson, 2012), but neglect to uncover how parents are coping with this stress. The recent change in how society is viewing autism may be a reason why previous research has not touched this topic. Since autism is becoming more prevalent, and more families are experiencing the impact this has on personal well being, it is possible that more focus is being put towards how to cope with it.

There has been a lot of previous research on intervention strategies that are beneficial for children with autism. The previous research seems more focused on finding out what is beneficial for the children with the autism, and less concerned about stress management techniques for family members coping with this difficult diagnosis. This could be because our society tends to be very focused on "fixing" things. The issue here, however, is that there is no cure for autism. Where behaviors and symptoms can be better managed through intervention strategies, it is still important for research to discover what techniques are helpful for parents to utilize in order to manage this new and difficult way of life.

Strengths and Limitations

There are several strengths of this research. First, having a qualitative design ensured that overall experiences were reported from families, instead of just using numbers to rate an intensity of an experience. Another strength of this study is that it incorporated families from a variety of different ethnic backgrounds, culture, socioeconomic statuses, and severity of the autism diagnosis. A final strength of the study

is that it highlighted the greatest struggles of families who have a child diagnosed with autism, identifying where therapeutic services could improve their support in.

There are also limitations to this study. This sample only incorporated families who were utilizing services at one particular agency in the Twin Cities. Therefore, these parents and children are only experiencing the interventions of Applied Behavior Analysis. Another limitation is that since the responses of the surveys were written instead of vocalized to the researcher, non-verbal signals and emotions such as frustration, sadness, or hopelessness are harder to observe. Finally, the company BTS is small in relation to other in-home ABA service providers, and so the total number of families being asked to participate in the survey was relatively small.

Implications for Social Work Practice

The findings of this study offer a variety of implications for social work practitioners and professionals working with families who have a child diagnosed with autism. While previous research has thoroughly investigated intervention techniques and programs that are beneficial for ASD children, little research has covered the wide range of experiences of families who have a child diagnosed with autism. Research in this area would provide insight into what the stressors of parents and families are, as well as where they feel like they need support. Many respondents reported feeling misunderstood by both the general public, and practitioners in the field. On a macro level, it would be beneficial for social workers to become more involved in advocating for education in autism. This would help both professionals and community members to understand what it means to have autism and how to appropriately respond. Understanding where

families are struggling can help future social workers become more involved in the therapeutic process of helping families cope with this difficult diagnosis.

Implications for Policy

Based on the findings of this research project, it is evident that there are both policy changes and future research implications that need to be considered. While previous research has highlighted intervention strategies that are effective, this research has suggested that parents who have a child with autism are looking for more ways to gain support. Participants are looking for more personal care assistants or respite care to support them and give them some time and space away to enjoy personal time alone or with their spouse. It is evident that many of these families do not readily have access to PCA's, babysitters, or respite care through medical assistance, and are financially struggling and therefore cannot afford privately paying for these services. Research reveals that the stress that these parents are experiencing have impacted their self-esteem, relationships with others, and own mental health status. Therefore, it would be beneficial for policies to implement changes geared toward provided assistance to all families who have a child diagnosed with autism, and giving them the option of having personal care assistance, or other supports readily available, should they need it.

Implications for Future Research

Future research needs to be completed to access where else more intervention strategies or support systems can be put in place for families. By further researching what families find the most stressful about having a child with autism, future clinicians will have a clear idea of where to support families, and what possible triggers will be in their work together. Future research on support systems will provide clinicians a clear

understanding of where clients already feel supported, and where they are looking for more support. For example, if more research was completed on family's feelings of misunderstanding and judgment from the general public, more intervention strategies could be implemented aimed at addressing this issue. By researching the experiences of these families in depth, and uncovering stressors, support systems, needs, and difficulties, future social workers will be better able to meet the needs of families who have a child diagnosed with autism.

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Appendix A: INITIAL INFORMATION SHEET FOR THE STUDY

My name is Lauren Snyder and I am a Masters of social work 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 experiences of families who have a child between the ages of 3-18 diagnosed with Autism Spectrum Disorder (ASD). I am interested in gaining a clearer understanding on the impact on emotional well-being, marital relationships, siblings, and social support. I would like to submit surveys to parents or caregivers who have a child with ASD.

I am inviting the participation of parents or caregivers who are willing to share their experiences of having a child diagnosed with autism. This study will involve filling out a 10-question survey that will take approximately 20-30 minutes. The survey will ask about personal experiences of the impact of having a child with ASD, including effects on marriage, relationships with other siblings, social support, and overall stress levels. If the participants agree to participate in the survey, they will be given a stamped envelope to send the completed survey back to me at the location provided.

Any identifying information will be kept in a locked box at my home, where only my Research Assistant and myself will have access. Any electronic information will be kept on a password-protected computer. All identifying information within this study will be destroyed May 2014.

In one week, you will receive a packet of information, including an informed consent form, a copy of my survey, and a returning stamped envelope. If you are interested in taking the survey, please read and sign the informed consent form and return it with your completed survey. If you are not interested in participating, you can discard the packet, and do not have to respond.

Contact Information: Please feel free to call or email me with any questions or concerns regarding this survey.

Lauren Snyder
610-***-****
*****@stthomas.edu

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

APPENDIX B: INFORMATION SHEET FOR THE STUDY

My name is Lauren Snyder and I am a MSW student under the direction of Professor Catherine Marris 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 experiences of families who have a child diagnosed with Autism Spectrum Disorder (ASD). I am interested in gaining a clearer understanding on the impact on emotional well-being, marital relationships, siblings, and social support. I would like to submit surveys parents or caregivers who have a child with ASD.

I am inviting the participation of parents or caregivers who are willing to share their experiences of having a child diagnosed with autism. This study will involve filling out a 10-question survey that will take approximately 20-30 minutes. The survey will ask about personal experiences of the impact of having a child with ASD, including effects on marriage, relationships with other siblings, social support, and overall stress levels. If the participants agree to participate in the survey, they will be given a stamped envelope to send the completed survey back to me at the location provided.

Any identifying information will be kept in a locked box at my home, where only my Research Assistant and myself will have access. Any electronic information will be kept on a password-protected computer. All identifying information within this study will be destroyed May 2014.

Contact Information:

Lauren Snyder
610-***-****
****@stthomas.edu

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

APPENXIX C

The Experiences of Families with a Child Diagnosed with Autism RESEARCH INFORMATION AND CONSENT FORM

You are invited to participate in a research study investigating the experiences of families who have a child diagnosed with Autism Spectrum Disorder (ASD). Lauren Snyder, a student in Master's of Social Work Program at St. Catherine University, is conducting this study. You were selected as a possible participant in this research because you are the parent or caregiver or a child diagnosed with autism. Please read this form and ask questions before you agree to participate in this study.

Background Information

The purpose of this study is to gain an understanding of the experiences of families who have a child diagnosed with autism. Specifically, this study is aimed at expanding the research in understanding the impact of having a child diagnosed with ASD in regards to marital relationships, relationships with other siblings in the home, and the impact on social support. Approximately 15-20 people are expected to participate in this study.

Procedures

If you decide to participate in this study, you will be asked to complete a survey consisting of 10 questions, which will take 20-30 minutes to complete. Upon completing the survey, you will send it back, along with the consent form, to the address given in the provided stamped envelope.

Risks and Benefits of Being in the Study

This study has minimal risks. You will be answering questions about your experiences of having a child diagnosed with autism in regards to impact on marital relationships, siblings, and social support. You may experience an emotional response.

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

Confidentiality

Any information obtained in connection with this research study that could identify you will be kept confidential. In the written and oral report of the research, no one will be identified, only group data will be presented. No one at the agency will know of your results.

My research assistant and myself will keep all of the surveys and consent forms in a locked cabinet in my home. Any electronic data will be kept on a password protected computer that only my Research Assistant and I will have access to. Analyzing this data will be finished May 2014. At this time, all original reports and identifying information will be destroyed.

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 the agency or St. Catherine University. If you decide to participate, you are free to stop at any time without affecting these relationships. You may also skip questions you don't wish to answer. If you do not wish to participate in this study, discard of the survey. Return of a completed survey implies your consent to participate in this research.

Contacts and Questions

If you have any questions, please feel free to contact me at, ****@stthomas.edu. If you have any additional questions later, the faculty advisor, Dr. Catherine Marrs Fuchsel at 651-690-6146, will be happy to answer them. If you have other questions or concerns regarding the study, and would like to talk to someone other than the researcher, you may also contact the University of St. Thomas Review Board at 651-962-5341.

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 you have read this information, and your questions or concerns have been answered. Even after signing this form, please know that you may withdraw from the study at any time and no further data will be collected.

I consent to participate in this study.

Signature of Participant

Date

Signature of Researcher

Date

APPENDIX D
SURVEY QUESTIONS

- 1) Age of child diagnosed with Autism _____
- 2) Relationship to child

- 3) Are you currently married or in a committed relationship?
Please circle: YES or NO
 - a. How is your spouse related to your child diagnosed with autism?
Please circle: Father Mother Not related
- 4) Describe your relationship with your current spouse before you had a child diagnosed with autism.
 - a. How has your child's diagnosis affected your relationship with your spouse negatively, if any?
 - b. How has your child's diagnosis affected your relationship with your spouse positively, if any?
- 5) How many siblings does your child with Autism have?
 - a. Please circle: None 1 2 3 4 More than 4 siblings
 - b. How many siblings are older? _____
 - c. How many siblings are younger? _____
 - d. Has your relationship with your other children been affected by your child's diagnosis of Autism? If so, in what ways?

- 6) Who or what has been your greatest outside social support for you and your family in regards to your child's autism?
- 7) In what ways do you need more support for your family in regards to your child's autism?
- 8) Since your child was diagnosed with autism, has your stress level increased, decreased, or stayed about the same? Please describe in what ways it has changed or stayed the same.
- 9) What strategies have you used, if any, for self care and/or stress reduction?
- 10) Other: Please discuss any other relevant information you feel comfortable disclosing that could be helpful in gaining a better understanding of the experiences of families who have a child diagnosed with autism.