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Autism Spectrum Disorder: How Parents use Behavior Modification With Their Children

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Autism Spectrum Disorder: How Parents use Behavior Modification With Their
Children

by

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MSW Clinical Research Paper

Presented to the Faculty of the
School of Social Work
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Master of Social Work

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

Abstract

This qualitative research study explores how parents use behavior modifications with their children diagnosed with autism spectrum disorder. Seven participants, who are mothers of children diagnosed with autism, were interviewed for this study. This research found that essentially, parents use different techniques applied in various ways in specific situations based on the uniqueness of their child and the behaviors displayed. Several themes emerged from this study which includes: challenging behaviors, behavior modifications used, behavior modification becomes a way of life, the need to individualize behavior modifications, behavior modifications will change as the child changes, challenges of having a child with autism, coping strategies, advice to professionals, and finding the joys.

The respondents displayed creativity and resiliency in their use of behavior modifications for their children. The challenging behaviors displayed varied among different types of behaviors such as sensory-related, verbally and physically aggressive conduct, lack of social skills, and obsessive behaviors. Additionally, each child had unique characteristics which required techniques to be tailored to him/her.

This research study provides further implications to social work practice, in that autism spectrum disorder affects the entire family and supports and resources should encompass the system as a whole. Additionally, social workers must stay abreast on the newest research regarding autism spectrum disorder to provide the best practices.

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Dedication

This paper is dedicated to my nephew Benji. May you always feel and know love.

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Autism Spectrum Disorder: How Parents use Behavior Modification With Their Children

Autism spectrum disorder is a complicated and comprehensive neurological disorder that is prevalent among children, especially boys. There is no known cause or cure for autism, only speculation to the cause(s). Treatments and interventions for this disorder exist rather than a cure. Studies regarding this spectrum disorder are happening continuously, as there are still many questions regarding how autism affects each individual and which treatment approach is best under which circumstance.

New research has led to revisions of the way autism spectrum disorder is diagnosed as well as treated. Symptoms usually present at an early age, providing for early intervention. In addition to early intervention, ongoing intervention is a key component to managing the symptoms of autism.

Autism Spectrum Disorder is now an epidemic in the United States, with an increasing number of diagnoses each year. In fact, the Chief Science Officer of Autism Speaks, Geraldine Dawson was quoted as saying, "The CDC's new estimates of autism prevalence demand that we recognize autism as a public health emergency warranting immediate attention" (Autism Speaks, 2012, p.3). In March 2012, the Centers for Disease Control and Prevention revised the estimate of the prevalence of autism spectrum disorder and reported that one in 88 children is diagnosed with autism spectrum disorder each year (Autism Speaks). This is a 23% increase from the previous estimate in 2009 which was one in every 110 children; now affecting one in 54 boys and one in every 252 girls. On a global level, it is estimated that one in every 500 births each year is affected by autism spectrum disorder (Grindle, et al., 2012). Autism spectrum disorder has

become the second most common childhood developmental disorder, with intellectual disabilities being the most common (Zeman, Swanke & Doktor, 2011).

A child with autism and his/her family face many challenges during life related specifically to the disorder. One of the challenges many individuals diagnosed with autism are medical conditions. For example, gastrological related conditions, and complications related to sleep deprivation, often co-occur with autism (Tarkin, 2013). Parents also face numerous barriers from pre-diagnosis, the diagnosis itself, dealing with professionals, to navigating treatment options and interventions for their child.

Given the fact that there are many behavior modification treatments used for children with autism, this research explores how parents use behavior modifications with their child diagnosed with autism, specifically in the home. Much of the existing research has been done in a quantitative form based on intensive models provided in either community-based programs, school-based programs, or in-home programs with professionals guiding treatments. This particular study will explore the following in a qualitative fashion; how parents implement behavior modification at home with their child as well as what techniques they find to be helpful, and experiences related to challenges and barriers of having a child diagnosed with autism.

Parental Involvement in Treatment

Parent involvement is pivotal during the intervention for children with autism (Boettcher et al., 2013). Specifically, parental involvement in treatments and interventions can improve the child's overall success and provide a sense of empowerment (Boettcher et al.) Because the symptoms of autism relate heavily around behaviors, behavior modification is one of the primary interventions of this disorder.

Many different variations of behavior modification exist. However, parents many times feel at a loss or overwhelmed by the amount of options for treatment interventions that are available, or not available, to their child to help the child succeed and cope in life.

Research shows that parents' involvement in their child's treatment has led to improved functioning and better generalized skills than children whose parents are not involved in treatment (Boettcher et al., 2013). Research also shows that parents who feel empowered are more likely to be involved in a supportive, effective way and are able to navigate the system of professionals in a more effective manner (Boettcher et al.).

Additionally, the inclusion of parents in the treatment of their children is now an essential piece of the puzzle of intervention of autism spectrum disorder (Vismara, Colombi & Rogers, 2009). The revised legislation of the IDEA act in 2004 afforded parents the right to have an important role in the educational planning for their child (Zeman et al., 2011). Additionally, as educational systems adapt to the needs of this growing group of children, it is beneficial to incorporate the parents' understanding and assistance with resources and policy regarding program planning for autism (Zeman et al.). After receiving training in Applied Behavior Analysis intervention techniques, parents stated that they felt empowered and that the training had a positive impact on the family as a whole (Dillenburger et al., 2002). Furthermore, parents reported that when they were involved in their child's program development and implementation, they felt they had gotten their control back.

Conceptual Framework

The purpose of this section is to define theoretical ideologies that the researcher identifies with for this study and will apply throughout the research. The strengths perspective and empowerment-based practices were used as theoretical frameworks for this study. Specifically, the use of both of the described theoretical frameworks guided the research as well as how the qualitative interviews and questions were written and conducted. Additionally, many of the behavior modifications used for children diagnosed with autism are strengths-based, building on what the child is good at and making progress in those areas. This study found that positive reinforcements for behavior modification were a key component to the child's success. Verbal praise, token systems, and reinforcers are all examples of strengths-based techniques. Five of the seven participants discussed learning the majority of the techniques they use with their child from ABA therapy, as well as other professionals working with the child.

Strengths-Based Approach

Using a strengths-based approach influences how the social worker views the client and uses the involvement of the client throughout the process (Miley, O'Melia & DuBois, 2011). The social worker can help the client identify and build on strengths during problem solving. Strengths are viewed and used as resources (Miley et al.), and the social worker and client both work together to tap into these resources as a collaborative effort. The future is more important than the past in the strengths-based approach. How to use the client's strengths in the present situation and future will help guide the change process. While the social worker focuses on the client's strengths and vision for the future, he/she does not discount the challenges and difficulties that the

client faces (Miley et al.). The social worker is more concerned with mastery and competence of strengths rather than correcting areas in which the client may be lacking (Miley et al.). The social worker acknowledges challenges and difficulties by using empathic techniques while also using techniques to help guide the client to continue to move forward.

Empowerment Based Approach

Strengths and empowerment-based approaches are both similar in that they use the client's strengths as resources. Each perspective also views the working relationship as a collaborative effort. The empowerment approach goes a step further and recognizes the power imbalances that are evident in relationships (Miley et al., 2011). Using the empowerment-based approach in social work consists of the social worker assisting clients to access and exercise power in relationships as well as on a macro level (Miley et al.) When the client is feeling powerless, oppressed and blamed as a victim, the empowerment-based approach can be very useful, in that the social worker uses the framework as a concept and a process (Miley et al.). In other words, empowerment offers a perspective as well as a proactive movement (Miley et al.) The social worker will help the client identify why he/she is feeling powerless and then help to make steps towards gaining and obtaining power in these relationships where power is lacking. Additionally, the social worker must understand how the client is being affected by the system he/she is involved in by applying the ecosystems perspective, as well as learning the client's strengths and applying the strengths perspective (Miley et al.).

Review of the Literature

The literature covers many different aspects of autism spectrum disorder. Researchers are continually learning new information about autism spectrum disorder in relation to prevalence, how it is diagnosed, how symptoms can affect each child, medical conditions that tend to occur along with the disorder, barriers related to autism, how parental involvement can benefit the child, and, lastly, behavioral interventions. All of these different aspects of autism spectrum disorder are important to keep in mind when working with families with children who have autism as one aspect can affect the others.

Symptoms of Autism Spectrum Disorder

Autism spectrum disorder is a neurological disorder that affects brain functioning, as well as causing social-interaction difficulties, communication challenges and a tendency to engage in repetitive behaviors (Autism Speaks, 2013; Neely et al., 2012). Research of the disorder has also described the brains of individuals who are diagnosed as showing “pervasive network under connectivity that limits response flexibility. In other words, individuals with autism spectrum disorder have difficulties in the guided participation relationship and dynamic intelligence such as anticipating, inferring, reflecting and expanding” (Solomon & Chung, 2012, p.252).

Autism spectrum disorder symptoms fall on a continuum, hence the spectrum, with some individuals showing mild symptoms and some more severe. Symptoms of autism spectrum disorder include communication deficits such as misreading or misunderstanding verbal and nonverbal communication such as not being able to interpret gestures and facial expressions. For example, a smile can have little meaning for some children diagnosed with autism (Autism Speaks, 2013). Additionally, some

children respond inappropriately in conversations, and have difficulty establishing appropriate friendships (American Psychiatric Association, 2013). Many children with autism do not begin to speak until they are older causing them to have less language and communication skills compared to peers their own age without autism (Autism Speaks). Children with autism fall behind in these skills and have difficulty catching up, or may never catch up to children their own age without the diagnosis. Additionally, when language begins to develop, speech may be used in unusual ways. Examples of unusual speech are repeating words or phrases, and even repeating every word verbatim that the child hears. Some children affected only mildly on the spectrum will display a large vocabulary yet be unable to carry on a conversation (Autism Speaks).

Children diagnosed with autism spectrum disorder also display ritualistic and self-stimulatory behaviors as well as more severe and maladaptive self-injurious and disruptive behaviors (LaBelle, Charlop-Christy, 2002). Examples of common repetitive behaviors include hand-flapping, rocking, jumping, twirling, repeating sounds or phrases, and lining up toys in an organized way rather than using toys for symbolic play. Other examples are categorizing, imitating and computing (Solomon & Chung, 2012). Children with autism need extreme consistency and order in their environment and daily routines and even the slightest variation can lead to outbursts and self-injurious behaviors (Autism Speaks, 2013). It is difficult for children with autism to convey their thoughts and emotions, which makes it difficult to regulate and control these emotions. This can also lead to self-injurious behaviors. Examples of physically aggressive and self-injurious behaviors are head banging, hair pulling or biting (Autism Speaks). Children who

become overwhelmed or frustrated may also hit, kick, shove others or throw toys or other objects.

As infants, many who develop autism showed symptoms of failure to respond to their names, reduced interest in people and delayed babbling at eight to ten months of age (Autism Speaks, 2013). As toddlers, many showed difficulty with playing social games, demonstrated an inability to imitate the actions of others, and the preferred to play alone (Autism Speaks). Additionally, children with autism spectrum disorder often present with sensory problems such as having a high pain tolerance, auditory hypersensitivity and tactile defensiveness. Tags on shirts and sand on the skin are some examples of sensory sensitivities that may be bothersome to some children with autism. Some may also exhibit sensory seeking behaviors such as crashing, squeezing, spinning and flapping (Solomon & Chung, 2012). Children with autism spectrum disorder, however, often have strengths in memory and the ability to use visual information (Schneider & Goldstein, 2009). They may be able to remember information for a long period of time, which is a strength used in interventions. However, children with autism generally do not have the ability to transfer what they have learned to new settings (Wong, Kasari, Freeman & Paparella, 2007), which can complicate interventions.

Changes in Categorization of Autism Spectrum Disorder

The fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), has categorized all autistic disorders under one single umbrella which is now autism spectrum disorder, or ASD (American Psychiatric Association, 2013). The previous diagnoses related to autism spectrum disorder were four separate disorders; autistic disorder, Asperger's disorder, childhood disintegrative disorder, or pervasive

developmental disorder. The single diagnosis of autistic spectrum disorder is believed to be a better reflection of what is currently known about autism (American Psychiatric Association). This DSM-5 change also encourages earlier diagnosis because individuals with ASD must show symptoms at an early age in childhood even if the symptoms are not recognized until later. As an example, a toddler may be very quiet and not interested socially in others, but this may not be addressed at a professional level until the child begins school. Under the current diagnosis, this child can be diagnosed with ASD once symptoms start showing, or when parents review previous symptom-like behavior to a professional. The criteria of the previous edition of the DSM (DSM-IV) were not as useful in diagnosing younger children, but were more focused on school-aged children (American Psychiatric Association). In addition, children who are higher functioning on the autism spectrum may be much more difficult to diagnose because their symptoms may not be identified until they are much older (Neely, Amatea, Echevarria-Doan & Tannen, 2012). Additionally, Autism Speaks Chief Science Officer Geraldine Dawson had this to say about the DSM-5 changes; “The changes have a strong scientific rationale, however; they are more than an academic exercise. They will impact how ASD is diagnosed, can affect access to services and will influence how the prevalence of ASD is measured” (Autism Speaks, 2012, p.6).

Medical Conditions Associated with Autism Spectrum Disorder

In addition to the symptoms of autism spectrum disorder, many children suffer from other medical conditions. Genetic disorders affect fifteen to twenty percent of those with autism spectrum disorder (Autism Speaks, 2013). Eighty-five percent of children with ASD are affected by gastrointestinal disorders such as chronic constipation, diarrhea

and inflammatory bowel disease (Autism Speaks). These symptoms can also range on a spectrum of mild to severe and the pain caused by these symptoms can lead to typical autistic symptoms such as self-soothing or self-injurious behaviors. These gastrointestinal disorders are many times, linked to the suspicion of gluten and casein being problematic for children with autism (Seitler, 2011). Seizure disorders, sleep dysfunction, and pica, the tendency to eat things that are not edible are all conditions associated with autism spectrum disorder (Autism Speaks, 2013).

All of the above conditions, as well as anxiety, restless leg syndrome, and medication can contribute to disrupted sleep (Tarkan, 2013). In fact, according to Tarkan, two thirds of children with autism suffer from disrupted sleep. Disrupted sleep can lead to behavioral issues at home, school, and in therapy (2013).

Some children with autism are medicated for various reasons, some to help control the behavioral outbursts and some to control these other medical conditions. However, the side effects for treating some of these other medical conditions many times interact with the other drugs that the children are already taking (Tarkin). In fact, Dr. Malow, a doctor on the Autism Speaks Treatment Network team, prefers to educate parents on behavioral strategies rather than prescribe medications for other medical conditions due to the side effects of the medications (Tarkin).

Contributing Factors to Autism Spectrum Disorder

It is known that genetics and heredity are strong components and factors to autism. Some researchers now believe that each feature of autism, (social deficiencies, communicative deficiencies and stereotypic behavior and restricted interests) is distinctive in its own genetic components and a separate issue; therefore inhibiting a

global explanation of autism spectrum disorder and its treatment (Neely et al., 2012). On the other hand, some researchers believe that due to the “exponential rise in cases, autism cannot be strictly genetic as our gene pool cannot shift that quickly,” (as cited in Jepson, 2007; Solomon & Chung, 2012, p.253). Environmental agents such as vaccinations and toxic substances are cited as potential causes of autism, which are viewed as controversial causes as there is no clear evidence based on the causes of autism (Seitler, 2011; Solomon & Chung). The cause of autism is believed to be a combination of multi-systemic complexities of both environment and biology, resulting in an ongoing biological process rather than hardwired in the brain (Solomon & Chung).

Barriers and Stressors Related to Diagnosis/Treatment of Autism Spectrum Disorder

Families of children with autism face a significant amount of stress and barriers to effective treatment for their children. The diagnosis process itself has been reported as a tremendous cause of stress in families (Dillenburger, Keenan, Gallagher & McElhinney, 2002; Neely et al., 2012; Solomon & Chung, 2012). In fact, families report that their stress of the diagnosis process is related to the lack of knowledge of autism spectrum disorder, ambiguity of the diagnosis, the nature of their child’s disability, and/or lack of consensus on treatments and interventions (Neely et al.). Stress is also related to the decision-making process (Dillenburger et al.) and lack of support and information regarding the diagnosis (Solomon & Chung). In a survey of 146 caregivers, only forty percent reported that the diagnosing professional provided information about autism resources (Solomon & Chung). Most parents also report feeling powerless during the lengthy process of the diagnosis of their children (Dillenburger et al.), and that the

process is specifically chaotic and poorly handled (Neely et al.). The new guidelines for the DSM-5 diagnosis of autism now allows for early diagnosis, which may shorten the time of the diagnosis process. Neely also reports that before the problem is clearly defined, parents of children with autism can have negative experiences with professionals that can generate strong emotions such as anger, guilt and anxiety (2012). Knowing that something is wrong with their child but not having a clear diagnosis or answers can be very frustrating and stressful for parents. Often times parent's concerns for their child were dismissed, also adding to these strong emotions.

The added stress of an autism diagnosis made it difficult for some families to manage their household in a way that promotes flexibility and smooth transitions. Families with children with autism also report lower family functioning such as adaptability and cohesion, as well as lower marital happiness and are twice as likely to divorce as parents without a child with autism (Solomon & Chung, 2012). Parents of children with autism face dilemmas that many without this diagnosis do not have to think of. For example, parents with a child who has autism may choose to decline social outings due to unexpected outbursts or they may allow some of the family to either stay or leave, and may have to travel in separate vehicles to the outing if necessary. Parents may even make special requests of the host and guests that accommodate their child such as to snap fingers rather than loud clapping (Solomon & Chung) or turn off background music to lower the noise level.

Significant amount of evidence shows that parenting a child with a developmental disability, including autism, is more demanding and stressful than parenting a typically developing child, and that parents of children with autism display higher levels of

depression, anxiety and sleep disorders (Boettcher, Minjarez, Mercier, Williams & Hardan, 2013). The presence of autism can have significant negative impacts on the family as a whole, including siblings who do not have the diagnosis (Preece & Jordan, 2006). While having a child with autism is challenging, research has indicated that many families with autism have become stronger as a result of the disorder and have shown to be resilient (Solomon & Chung, 2012).

Autism spectrum disorder is very costly (Autism Speaks, 2012; Leaf, Taubman, McEachin, Leaf & Tsuji, 2011; Moore & Symons, 2011; Zeman et al., 2011). Specifically, the cost to society is \$137 billion per year nationally, (Autism Speaks) and in 2006, it was reported that the average annual medical costs for children with autism exceed \$6000 compared to \$900 for other children (Moore & Symons). The estimated educational costs associated with children with autism are \$15,000 per year while additional therapies may cost families on average \$22,000 annually which is \$660,000 over the duration of the first eighteen years (Zeman et al).

Interventions and Treatments

Applied Behavior Analysis

Most behavioral treatments for autism spectrum disorder derive from Applied Behavior Analysis (Seitler, 2011). Applied Behavior Analysis (ABA) was developed by behaviorist psychologist O. Ivar Lovaas in 1970 and is a highly intensive and structured behaviorally oriented intervention program done on a one-to-one basis, usually in the child's home (Seitler). As originally described, it involves discrete-trial reinforcement-based teaching method for forty hours a week over a three-year time period (Reed, Osborne & Corness, 2006). Applied Behavior Analysis teaches children a standardized

skill set using behaviorist principles of stimulus/response and differential treatment while following an established pattern (Glynne-Owen, 2010). This form of intervention has been shown to improve socially meaningful behaviors (Steege, Mace, Perry, & Longencker, 2007).

ABA methodologies are used to support children with autism and other developmental disorders in at least five ways: to teach new skills, to reinforce and maintain previously acquired skills, to generalize the behavior from one situation to another, to restrict or narrow conditions under which interfering behaviors occur, and to reduce interfering behaviors by discontinuing their reinforcement and reinforcing competing behaviors (Steege et. al.). Assessment is an ongoing process in ABA, and occurs before the intervention to identify behaviors, needs, and to evaluate the environment. Assessment during intervention monitors, evaluates and analyzes progress (Steege et. al.).

The research literature regarding ABA suggests that effectiveness and efficiency of autism interventions are maximized when interventions are matched to the uniqueness of the learner (Steege et al., 2007). Therefore, practitioners should consider a broad range of interventions that are multifaceted to ensure individualized programs and durable behavior change (Steege et al.). In the original study conducted by Lovaas, the children who participated increased their IQ levels of up to 30 points (Reed et al., 2006). However, there are a number of critiques regarding the validity of the Lovaas study. One being that IQ is not necessarily the main problem or even focus in autism spectrum disorder (Reed et al.). Another critique is that many other studies have not been able to achieve the results obtained by Lovaas and no study has been able to replicate these

dramatic results (Seitler, 2011). In fact, when a 2002 study was performed that measured behavioral change rather than IQ, there were no gains at all after one year of home-based intervention (Reed et al.).

The literature discussed two main methodologies of ABA, which are Intensive Behavioral Intervention and Discrete Trial Training. Intensive Behavioral Intervention (IBI) has repeatedly been shown to be effective in improving functional skills and intellectual scores, as well as, minimizing problem behaviors in individuals diagnosed with autism spectrum disorder (Leaf et al., 2011). IBI treatment in its original form is behavioral intervention for forty hours per week for two years or longer and can be done in the child's home (Leaf et al.). Discrete Trial Training is also intensive behavioral training that focuses on four components, which are, presentation of a discriminative stimulus, occurrence or approximation of the targeted response, delivery of a reinforcing consequence, and specified inter-trial interval (Steege, et al., 2007). For example, a teacher might use Discrete Trial Training when teaching a child to identify objects such as a cup. The teacher would set these items on a table while sitting at the table with the child and ask the child to touch the cup. If the child did not touch the cup, the teacher would guide the child's hand to the cup. If the child did touch the cup, social and verbal praise would be used as reinforcement (Steege, et al.).

Discrete Trial Training is intended to be used for twenty-five to forty hours per week, and some studies were not following this instruction. Some researchers believe that not following the intended instructions leads to misapplication. Misapplication of DTT may not be as effective and may lead to children engaging in low levels of escape-motivated behaviors such as pushing away materials, turning away from instructor,

telling the instructor “no” and could also be followed by more extreme behaviors (Steege et al.) Discrete Trial Training is most effective when used in addition to other components of ABA therapy, therefore, if other methods have shown to be effective in addition to DTT, and are not being used in behavioral modification for children with autism, it reduces the probability of generalization of skills (Steege et al.).

The literature disagrees in applications of Applied Behavior Analysis. Some researchers have stated that Applied Behavior Analysis was intended to be used with several methodologies at the same time, and not just one specific methodology (Steege, et. al., 2007). Other researchers have modified behavioral applications for several reasons, which included, the large number of instructors needed to implement treatment as well as financial resources to pay for instructors (Thiessen, Fazzio, Arnal, Martin, Yu & Keilback, 2009

Other Behavioral Interventions Derived From Applied Behavior Analysis

In addition to Applied Behavior Analysis, there are several program models for intervention and treatment for children with autism. Treatment & Education of Autistic And Related Communication Handicapped Children (TEACCH), Learning Experiences: An Alternative Program for Preschoolers & Parents (LEAP), and Early Start Denver Model (ESDM) are a few models that are used to assist in behavior modification and all are derived in some way from Applied Behavior Analysis. Each is unique in its own way and specializes in specific areas. For example, TEACCH emphasizes working with each child on whatever developmental, cognitive, educational and social level that the child is on while using a strengths-based approach to enhance skills (Seitler, 2011). LEAP

focuses on training parents how to use play and social skills through peer modeling for children with autism (Seitler, 2011).

ESDM uses key techniques from Applied Behavior Analysis for toddlers and has been shown to improve brain activity related to social responsiveness in children with autism (Autism Speaks, 2012). In fact, Tom Insel, Director of the National Institute of Mental Health had this to say about this model, “This may be the first demonstration that a behavioral intervention for autism is associated with changes in brain function as well as positive changes in behavior” (Autism Speaks, 2012, p.18). ESDM was developed in the 1990’s, and the results of the first clinical trial showed that the group of toddlers that randomly received the ESDM therapy showed greater increases in IQ, language, and adaptive behavior than the group of toddlers who received early intervention services routinely available in their communities (Autism Speaks). Additionally, the children in the ESDM group showed greater brain responses to social information compared to the group that received the early intervention services while the children who received the early intervention services showed greater brain activity when viewing objects rather than faces (Autism Speaks).

Additional Models Used for Intervention

In addition to these behavioral intervention models for children with autism spectrum disorder, there are a plethora of less comprehensive methodologies, which include behavior analytic procedures, social stories, incidental teaching, task analysis prompting, functional analysis, naturalistic observation, peer modeling and joint attention. Each of these interventions focuses on specific characteristics of autism. For example, behavior analytic procedures teach children new skills to reduce problematic

behaviors (Grindle et al., 2012) while social stories use story telling as a way to address challenging behaviors and have been shown to improve on-task behaviors but do not typically address social interaction skills (Schneider & Goldstein, 2009). Incidental teaching focuses on the child's naturally occurring motivation for objects and reinforces the child to build on his or her skills regarding what they already know about the object (Steege et al., 2007). Task analysis prompting helps children learn more complex tasks such as brushing teeth, which requires a sequential chain of tasks (Steege et al.). Functional analysis matches the function of the target behavior with appropriate treatment for that behavior (LaBelle & Charlop-Christy, 2002) while naturalistic observation records problematic behaviors and the causes throughout the day (LaBelle & Charlop-Christy). Finally, joint attention refers to the ability to share attention between objects and people (Wong et al., 2007).

Barriers

Lack of Comprehensive Research

The main issue with treatment and intervention for children with autism spectrum disorder is that symptoms fall on a continuum, and, given this nature of this disorder, the consensus is that there is no single treatment that works for all children. Callahan et al. (2010) believe that having the philosophy that only one treatment model works for all children with ASD is questionable and unreasonably restrictive. One may also argue that this one treatment philosophy is also irresponsible and could limit further research into other options. Glynne-Owen (2010) explained further and argues that autism is not entirely measurable in each individual it affects and should not be characterized as a fixed category within research. Gaining a true baseline of what it means to be autistic is highly

unlikely regardless of what form of testing or observation is being used (Glynne-Owen). Another researcher described attempting to perform reliable in-depth treatment research due to the unpredictable nature of many children with autism to attempting to study a bullet in flight (Seitler, 2011). Additionally, children are believed to be tested, experimented on and retested to fit them into an established educational system when autism is not clearly defined nor presented identically (Glynne-Owen).

Many researchers have discussed the limitations in research of the treatments for autism spectrum disorder as being that there are not enough qualitative studies to have a true understanding of effective treatments (Callahan et al., 2010; Glynne-Owen, 2010; Seitler, 2011). In his opinion, Seitler believes that before quantitative studies are performed, they need to have a qualitative basis. Science should move from qualitative to quantitative information (Seitler).

All of the treatment approaches for autism spectrum disorder have some shortcomings (Seitler, 2011). Applied Behavior Analysis has been criticized because studies have not been able to replicate the outcomes from the original study by Lovaas (Seitler). Other behavioral interventions have been criticized because they are not true to ABA in its original form, yet derive from this intervention. Additionally, those affected by autism desperately need to know which components of which models work, how and why they work, and how to evaluate exactly how well the interventions are working, and the research does not clearly address these issues (Callahan et al., 2010). Furthermore, the current treatment models do not fully address all of the needs of each child (Callahan et al.)

Psychoanalytic treatments have also been criticized (Seitler) because they cannot be applied to every child with autism spectrum disorder due to cognitive reasons. There is also considerable variation in the types of assessments and interventions used in school-based programs that claim and appear to be an Applied Behavior Analysis program, but many are limited in scope and do not offer the full array of methodologies of this intervention that have shown to be effective (Steege et al., 2007).

Barriers Parents Face While Implementing Recommendations

Parents face many different types of barriers while implementing treatment interventions for their children. Navigating the system of services can be challenging for many parents (Boettcher et al., 2013). For example, there are many barriers dealing with teams of professionals and the treatment interventions. Many parents report that they are not included in the treatment interventions by the school staff and that available supportive links to schools and other behavior accommodations into learning plans for their children are limited (Zeman et al., 2011). However, parents do need to be informed of what they can do at home with their children based on what is being done in the professional areas.

Additionally, many behavioral interventions require extreme amounts of time, not to mention the effort, in implementing treatments. Many Applied Behavior Analysis programs require that parents apply the early intervention with their child for ten hours per week at home, in addition to, attending supervisory and instructional meetings (Granger, Rivieres-Pigeon, Sabourin & Forget, 2010). While parents can be trained effectively in implementing behavioral modification treatments for their children, the overall prevalence of non-adherence to physician recommendations is between twenty-

four and fifty percent (Moore & Symons, 2011). There is limited research regarding parental adherence to interventions for their children as well as barriers related to facilitating factors for intensive home-based behavioral interventions (Moore & Symons, 2011; Johnson & Hastings, 2001). Johnson and Hastings conducted their own study and found that barriers to implementing at-home treatments were establishing and sustaining an effective team of professionals, as well as the financial cost of treatments (2001).

Finally, another common theme regarding adherence is the correlation between the patient/client and provider relationship (Moore & Symons). The more cohesive the entire team was, including the parents, the better the services were for the child and the family. Families reported satisfaction of services when they felt they had a good working relationship with their child's providers.

Barriers Within Schools

There is a disconnection between research and practice within public schools and autism intervention. One reason could be because the lack of empirically validated comprehensive treatment models and the variance of validity and sources (Callahan et al. 2010). People are concerned with numbers and hard facts, but first there needs to be more qualitative studies in this area. It is not surprising, then, why the literature reflects that there is a need for studies that better define what treatments are best for what children under what conditions (Matson, Matson & Rivet, 2007). The literature also reflects that an eclectic style of interventions for children with autism might be appropriate. While it would be very difficult to explore information from very young children, the information is needed and beneficial to the research of autism intervention (Glynne-Owen, 2010).

Those that provide autism interventions in public schools have been mandated by law to deliver interventions based on research evidence, however; many teachers, parents and administrators, have reported concerns that the schools do not provide high quality autism programming (Callahan et al., 2010). Typically all children with or without a diagnosis of any sort should receive social skills training before the age of five, however; many times early intervention programs for children with autism start at the age of two or three but do not focus on social skills training. Research suggests that deficits in this skill set could be due to the lack of or ineffective early intervention specifically in social skills (Matson et al., 2007). Essentially, the children diagnosed with autism are missing out on the social skills training at a time when they need it the most. Early intervention programs for autism spectrum disorder are not typically linked to the school system, causing a gap in the child's intervention as well as a professional team because the early intervention team is not the same team that the child would receive services from when he/she is school aged (Matson et al.).

Implications for Further Research

With so many behavioral interventions for children with autism spectrum disorder, as well as many differing opinions, it is no wonder why parents may feel overwhelmed and lost when it comes to best practices for their child. Using behavior modification in the home may seem like an impossible task. Not to mention, studies have shown that even social workers do not fully understand autism spectrum disorder. Therefore, implementing treatments and interventions may be difficult, ineffective or inappropriate (Preece & Jordan, 2006). Given the lack of information regarding the ways

parents help their children, the purpose of this study is to explore how parents use behavioral modification with children with autism.

Method

Design

This research study addressed the question, “how do parents use behavior modification with children with autism?” and was of a qualitative approach. A qualitative approach was chosen for this study because, as the literature stated, more qualitative studies are needed to understand autism spectrum disorder and effective interventions. Additionally, qualitative methods can allow access to more personal and subjective information (Monette, Sullivan & DeJong, 2011) which can be useful especially in areas that quantitative research does not explore. For this study, qualitative interviews were done to gather information related to this research question.

Sample

Participants of a support group for caregivers of children with autism were initially used for this study, which also lead to a snowball sample. For example, some participants from the support group who were interviewed contacted their friends from other support groups, creating a snowball sample (Monette et al., 2011). Permission from the facilitator of the support group was given to the researcher to recruit caregivers for interviews. The researcher was invited to an open forum group to introduce herself and explain the research topic and also provided contact information for the members of the group to contact her for interviews. Some members of the support group volunteered for this study and also referred their friends who are a part of a different support group to participate in this study.

There were seven participants total for this research, all of whom are mothers of a child diagnosed with autism. The original support group is made up of males and females, however, only mothers volunteered for this study. All participants identified as Caucasian as their racial background. One participant had just one child, and the others were caring for at least a total of two children. Specifically, two out of the seven participants had two children, three participants out of the seven had three children, and one participant had six children and was expecting a seventh. Six out of seven participants were married and one participant was a single mother.

Measurement

The researcher developed the following questions to ask each of the respondents during the audio-recorded interviews. The interview questions are reliable and valid because each question asks only one question at a time, provides for open-ended responses, and relates directly to the research question. Specifically, each participant was asked the same questions in the same order, providing a reliable source of measurement (Monette et al., 2011). Due to the nature of the qualitative study, interview questions were designed in an open-ended manner to provide for a little or as much information as the participant wanted to share.

Interview Questions

1. Can you tell me about your child who is diagnosed with autism?
2. How old is your child who is diagnosed with autism? At what age was your child diagnosed?
3. How many children are you caring for?

4. Can you identify your support system, whether they are living in the home or not, such as family members or friends?
5. What ethnic culture do you identify with?
6. What types of challenging behavior does your child display when you feel you need to modify his behavior?
7. Give an example on how you use a behavioral modification technique with your child. What steps do you take to stop or redirect unwanted behavior?
8. How has this technique been helpful?
9. Explain how your support system helps your child with modifying his behavior. Do you all use the same techniques?
10. How much time a day or a week do you spend doing behavior modification with your child?
11. How much time each week do you spend taking your child to appointments related to his diagnosis?
12. What recommendations have been given to you by mental health or other professionals such as doctors, etc. to manage your child's behavior?
13. Have you received training on how to use behavior modifications? If yes, describe the training process and where it took place.
14. What kind of supports do you have to take care of yourself emotionally besides the help of your support system? (such as therapy, mini vacations etc).
15. What advice do you have for other parents or caregivers of a child with autism?
16. What advice do you have for social workers or other professionals working with children and families with autism?

17. What is your favorite thing about your child?

The researcher explained the definition of behavior modification to ensure everyone had an understanding of the term at the beginning of each interview. Behavior modification was defined as doing something to change your child's behavior by using a reward system to stop unwanted behavior and reward desired behavior.

Human Subjects Safeguard

The researcher explained all aspects of the study to the participants and asked them if they were interested in participating before interviews were conducted. After obtaining their interest in participating in this study, the researcher provided all participants a consent form to sign (see Appendix B). The interview questions were emailed to each participant before the interview was conducted to provide an opportunity to view questions and generate thought about the answers prior to the interview. This research study was also reviewed and approved by the Institutional Review Board before conducting interviews. Each participant was informed of the potential risks at the onset of the interview and participants were also informed that they could withdraw from the study at any point in time if she should request. The researcher also explained that questions may be answered at the comfort level of the participant and that questions may be skipped if participant did not feel comfortable sharing. All seven participants committed to the study and did not request to have any information removed from the study.

One risk that may be associated with this study was emotional discomfort of the participants in the unlikely event that the interview questions triggered an emotional response. The researcher is trained to provide empathic responses and was sensitive to

the material discussed. The researcher also provided contact numbers to resources and supports that the participant could utilize if the interview caused emotional distress. The researcher audio recorded all interviews for coding purposes and destroyed all audio recordings and notes after data had been analyzed. To protect the participants, no identifying information was used in this study. Thank you cards were issued to each participant after the interview was completed, to provide a sense of gratitude from researcher and closure of the study.

Data Analysis

Coding is a form of qualitative data analysis and was used to analyze each interview for this study. Specifically, open coding provided numerous possibilities of data and was done in stages to clarify and condense data into appropriate categories by using patterns and concepts (Monette, Sullivan & DeJong, 2011). The researcher transcribed all of the interviews and then identified themes within the data. Many initial themes were broken down to create sub-themes, linking ideas together. Direct quotes from the interviews were used to illustrate the codes and themes.

Findings

How do parents use behavior modification with their children with autism? For the purpose of this study, behavior modification was defined as doing something to change a child's behavior by using a reward system to stop unwanted behavior and reward desired behavior. Behavior modifications are applied in various types of ways, in different types of situations, for each child, and specific to in-the-moment behavior. Most of the behavior modifications that each parent used with her children originally came from ABA therapy. Other behavior modifications came from forms of education

such as seminars, prior education on child development, teachers and other professionals such as physical therapists, social workers, occupational therapists, pediatricians, behavior therapists, and other doctors. Behavior modifications were applied by parents in an eclectic way, using the resources that were available to them. Examples of behavior modifications mentioned in this study were the use of rewards, redirection, and removing attention. These behavior modifications will be described in detail under the heading, “behavior modifications used.”

Challenging Behaviors

Several distinct types of challenging behaviors emerged from the data. One was sensory related behaviors such as a child being sensitive towards bright lights, loud noises and touch. Another challenging behavior that emerged from the data was aggression, either displayed in verbal outbursts or physically. Lack of social skills was also identified as a challenging behavior. Four of the seven participants also stated that obsession about a particular object or occurrence in the child’s life as a challenging behavior. All of these challenging behaviors could be linked to one another; as one behavior, such as a sensory related behavior, could progress into aggression. The data showed sensory related behaviors seemed to be less challenging for parents to attend to, while aggression and social issues seemed to be more challenging for parents to address.

Sensory-Related Behaviors

Sensory-related behaviors that emerged from the data were children feeling uncomfortable getting their hair cut, finger nails being clipped, being hugged by family members, and not having enough personal space. Additionally, that data revealed some discomfort with loud settings and/or bright lights. If a child was focused on a task and

was interrupted by loud noises, the child became irritable. One participant explained, “Even then, if he’s focused on something he can get irritable pretty easily. If someone is making noise around him, he really has a low threshold of things bothering him.” Three participants reported that their children were picky eaters, usually due to the texture of foods. Three participants reported that different types of clothing bothered their children, as well.

Verbal and Physical Aggression

Examples of verbal and physical aggression given by participants were screaming and yelling, outbursts of foul language, fighting and playing rough with siblings and other children, hitting, kicking, throwing objects, and temper tantrums. All seven participants reported that their child displayed verbal and physical aggression to varied degrees. Many of these behaviors were described as impulsive and reflexive. As one participant describes, “...a lot of yelling, sometimes physically being aggressive, sometimes it’s almost like a reflex. If someone gets too close to him, he’ll push him, and he’s the oldest; he’s the strongest so that little push can be a big deal. He’s kind of impulsive.” Another participant describes how her daughter’s challenging behaviors changed over time and how her child went from being physically aggressive to displaying verbal outbursts, “When she was younger it was that explosive anger and when it’s okay for that. Maybe it’s more appropriate for her to express that anger in our home as it is opposed to than it is out in a store. As she’s now gotten into the teenage years, she’s gotten a little more lippy if you will.”

Lack of Social Skills

Examples of lack of social skills that data revealed were that children were described as being bossy, obnoxious, and engaged in rough play with peers. Children also displayed socially unacceptable behaviors, the inability to join in and play or have conversations with peers. Children also lacked eye contact, ran away in public places, did not follow rules, and displayed very intense emotions in public. Social issues were an area of concern for all seven participants, to varying degrees. One participant reported, “The reason we took him to get assessed was because he had a lot of social issues. He just didn’t know how to join in with other kids and cooperate with other kids a lot of the time.” Additionally, three participants reported concern for their child running away in public spaces. One participant stated, “He kinda seemed to just run away without regard to safety.” Another parent reported, “He would take off and he wouldn’t really run very far because we’re kinda new to this neighborhood, but he would just go down the road or go down here to the yard and stand there.”

Obsessive Behavior

“Obsessive,” “addicted,” “fixated,” and “overzealous” were all words used to describe the challenging behaviors among the children diagnosed with autism for this study. These “obsessive” behaviors seemed to be challenging for parents to address, as sometimes safety and health were issues as well. For example, one participant reported, “he also gets overzealous about certain things like if there’s something that he enjoys eating, he will want to keep eating it and eating it and eating it until he gets sick. He’s almost obsessed with it.” Another participant explained, “He will also get very stuck on

something. If he wants something he'll just push and push and push and he won't take no for an answer."

Behavior Modifications Used

There are many different types of behavior modifications that the participants of this research used. Three distinct themes within these behavior modifications were rewards, removing attention, and redirection.

Rewards

Examples given of rewards included the token system using charts and incentives, and positive reinforcements using verbal praise and reinforcers from ABA therapy. Five out of the seven parents reported that they created behavior charts for their children specific to their child and preferred behaviors. One respondent explained, "He has to behave real well to earn what he wants." Parents also set up rewards systems so that the child knows what he/she is working towards. As an example one participant explained, "Every time he uses gentle hands or uses his words or whatever instead of pushing he gets a token and those add up to, like right now he's getting ipad time." Four participants stated that they were purposeful about using verbal praise. For example, one participant stated, "If I give him some independent play time while I'm trying to make dinner, I'll set up a bunch of his toys and every 3 minutes I'll go in and just say "M, you're doing such a great job playing with your toys, and then I'll go back to cooking."

Removing Attention

Applying extinction of an item that is causing conflict and implementing time-outs to allow for child to "restart" or for parents to have a break are examples of removing attention. Extinction is a way to remove attention from the problem behavior

by not focusing on a particular item or behavior causing conflict. For example, one participant explained, “behavior that’s like, I want to keep watching my ipad, we’ll take it away from him and he’ll have a huge tantrum and a fit so that’s different. One behavior technique that we use a lot is extinction, so if he starts to throw a tantrum, you know, I’m not going to respond to that or give it back to him because then I’m just reinforcing the idea that if you cry and give a tantrum you get what you want.”

Five of the seven participants mentioned time-outs as a form of behavior modification that removes attention from the challenging behavior. Time-outs were also used for a child to have his/her own space. One parent explained, “We did the strong stand and strong sit which is basically another word for time out. Just to give him a time and space where no one else is where he can sit and sort through his thoughts and come back and let us know what he’s thinking or feeling.” Another parent explained further stating she felt she wished her son would choose a time-out for himself rather than her sending him to his room as a consequence. Later in the interview, she explained that the time-out is for everyone including her and her husband. “A lot of times if he’s not dealing well with people around him I’ll send him to his room. It’s like a consequence to him because of the way he’s handling something, which, I wish it could be something where he would just choose to go there if he needs a break from people, but I kind of feel like we’ve never set it up that way.”

Redirection

Redirection was a theme within the behavior modifications that parents used with their children. Essentially, redirection is a way to refocus the attention on something

else, changing the path or direction of something that is happening. All seven parents discussed how they had to be creative in the ways they used redirection.

Deep Breathing and Counting

Asking a child to take deep breaths and count to ten in order to calm down to think and process what is happening was mentioned by participants. Three of the seven participants discussed the importance of stopping to ask their child to take a few deep breaths; “Sometimes, because he’s got a delay in processing what people say we give him five or ten seconds to calm down. We say, take three deep breaths, and calm down and think about it.” Another participant explained, “We would put our hands on his shoulders and tell him, you know, look at my nose or look at my eyes and you need to listen, calm down, take a breath.”

Feelings Scale

Additionally, a scale from one to five was mentioned for child to identify emotions at the moment as a way to stop, redirect and assess emotions and aggression. One mother explained how this scale has had a significant impact on her daughter’s behavior and how it empowered her daughter to take ownership of her own feelings and reactions. “It’s the 5, 4, 3, 2, 1, it’s the scale on how she’s feeling, is she a 5, is she a 4. When she was younger we had a scale on the refrigerator so we could go over to the scale and she would point. I used to carry one in my purse. I used to have one on my badge so I would have it with me everywhere. She would show us as we were going through the store and if she was starting to get ramped up and she would point to a number to how she was feeling, and if it was starting to get high, we left, we walked out of the store.”

Social Stories

Social stories were also mentioned by two participants as a way to redirect behavior by mapping out and making sense of the pieces of the story that did not make sense, to try and gain a perspective of what the child is attempting to explain. One mother discussed how she used social stories. “If there was an incident that caused a conflict, (I would) have him map out what happened, and write down what happened, and talk about parts that don’t make sense. (We would) Try to go back and figure it out, and just help him think through what went wrong.” Another participant explained her use of social stories; “if I notice he’s really struggling, I can pull him back with a social story or something and we’ll have to revisit and talk about things but then we try to figure it out.”

Desensitization/Exposure

Desensitizing and exposure were other forms of redirection used in behavior modification, especially in situations that trigger anxiety. Two participants spoke of desensitization in the case of alleviating anxiety. One participant discussed how it took time and patience for her four year old son to become comfortable to have his hair cut. “An example is a couple months ago J had his first haircut ever and it took us a long time to build up to that and I think you take that as little baby steps. ABA does that, you break things down into smaller segments, and we kind of do that with sensory too by desensitizing things.” One mother shared that she learned about desensitization as an intervention to address her son’s anxiety from her child’s therapist. “He has so much anxiety about new things, one of the times we wanted to put him in baseball; he was not wanting to do it at all. One of the things she recommended was for someone to take him to the field where he would be playing or practicing. With one adult, and do things that

he would be doing so he could get familiar with it and what he would be doing so I thought that was really good advice.”

Sensitive to Sensory Needs

Attending to children’s sensory needs were also forms of redirecting behavior. Specifically, applying pressure on certain pressure points such as the head, hands, arms, legs and feet was mentioned by four of the seven participants as ways to redirect and modify behavior. One mother discussed how applying pressure to her daughter’s pressure points has been effective in modifying her child’s behavior. “What’s really worked really great and has been very helpful is that she’s very much a kid who needs the force on the pressure points, so the weighted vest. She likes to have her hands and her feet squeezed and there’s certain ways and techniques to do it. I mean for me that would be painful but to her it feels really good. Then also there are certain pressure points on her head that we hit. You know just like a little fingernail or massage on her head and that seems to have worked really well and that’s all come from physical therapy.”

Another mother discussed how the Willaburger brush has been helpful for her son and how using this brush on her son’s body can replace physical activity if physical activity is not accessible at the moment. “After you brush them it stimulates all of the cells on the arms and legs and then you give them compressions on their joints. If your child can’t get outside because of winter, you can brush them and do the compressions and it would give them just as much deep pressure as it would if they went and climbed four foot pile of snow. Basically, you’re imputing sensory for them.”

Additionally, the data revealed using a box of sensory items was another way of redirecting behavior by attending to the child’s sensory needs. For example, one parent

explained how she had various sensory items in a box for her son such as koosh balls, teething rings, bubbles, and play-doh. He could retrieve the box on his own when he was feeling overwhelmed or upset. “When he was upset he would go through the sensory box and keep himself occupied. He kind of outgrew that himself but otherwise it did work well when he was younger.”

Dietary Changes

Lastly, two participants reported that they made dietary changes for their children, which had a positive impact on challenging behaviors and overall health of the child. One mother felt very strongly about the dietary changes she made for her son and how his behavior and other co-occurring ailments dramatically improved. “Once dairy was removed we saw an improvement very quickly. It was amazing. His aggression was significantly reduced. His eye contact was better. He was more alert. He had a terrible diaper rash that I had prescriptions and ointments for and it went away.” This mother went on to explain that after dairy was removed from his diet, “his bowel movements improved. His daycare approached me and said we had no idea J knew so much. He is talking, not a lot, but he’s alert, he’s much more pleasant. So I really do think that there was something in the dairy that really was not good for my child. Removing the dairy made significant improvements.”

Clearly, there are many different types of behavior modifications that parents use for their children, and in different situations. One participant explained that because her child was really interested in bowling and mathematics, she uses bowling terms and math as a way to modify and redirect her son’s behavior. “If we’re in a shopping mall and C is having a meltdown, I will compare how many steps it is to get out the door to how many

bowling pins there are in a bowling alley. I'll say, it will take us 58 pins to get out of here. That gives him an idea, you know, of what he can connect. It's mathematical, it fits into his world, it sounds weird to you and I maybe but it makes sense to him."

Behavior Modification Becomes a Way of Life

Four of the seven participants reported that they were constantly using behavior modification with their child diagnosed with autism. Two other participants reported that, in the beginning, their child needed constant behavior modification; however, the need has decreased over time. The data revealed that the use of behavior modification becomes such a routine that it is simply just a natural way of running a household, as four participants specifically mentioned this natural occurrence. When asked how much time is spent using behavior modifications at home, one participant responded, "Oh every day (laugh) every day! Every day!" Another participant responded, "For me it's not really a certain amount of time, it's just a way that we do things." Finally, another participant reported, "It's hard to say because it's just so interwoven into what we do." Three of the seven parents reported using behavior modifications with their other children because the techniques are effective and relevant. All of the parents mentioned that professionals working with their child use behavior modification techniques which help the parents and child become accustomed to these techniques.

Need to Individualize Behavior Modifications

One theme that emerged from the findings that speaks volumes to the research question is that each child is unique and will need specific behavior modifications related to him/her in that particular moment. There is no special behavior modification that works at all times for all children under all circumstances. Three of the seven

participants also noted a difference among the use of behavior modifications and challenging behaviors when challenging behaviors were either sensory related or when aggression was an issue. In other words, parents applied behavior modifications in a different way when challenging behaviors were related to sensory issues rather than aggression, verbal outbursts, or an unwillingness to do the preferred activity. A parent explained that a sensory-related behavior such as a child becoming agitated with the tag on his t-shirt would be treated differently than if the child becomes physically aggressive toward his sibling. It is not uncommon for children with autism to have physical irritation to the tag on the inside of the t-shirt, as it may scratch and bother the child, causing him/her to then become emotionally irritated by this. This parent explained that simply allowing her child to remove his shirt may be appropriate to alleviate the agitation; however, this would not make sense in a situation where he is physically aggressive towards his sibling. In situations where aggressiveness needs to be addressed, attention such as verbal praise and reinforcements are given to the child when he uses gentle hands and is nice to his sibling. One respondent explained the difference between approaching different challenging behaviors with her child, "I would approach those two differently. It can be helpful to use some type of incentive to get to the goal or have a distraction but also you need to be realistic. The sensory issues are very very different from other behavioral issues."

Waiting it out

Waiting out the child's behavior was also mentioned by three of the respondents as a way to deal with challenging behaviors. Waiting out challenging behavior was only done in situations where behavior could not be modified in a particular situation such as

in a grocery store or other public places in which a child was having a temper tantrum. These parents reported that, in these situations, there was not much they could do but either remove the child or just let the child finish out the temper tantrum, which would cause the child to become tired physically and emotionally and then he can regulate him/herself. Parents also chose to not follow through with modifying the child's behavior under these conditions due to the parents' emotional state. These parents reported that sometimes it is not worth the fight or their sanity to continue with a modification.

Behavior Modifications Will Change as the Child Changes

Four participants reported that many times their child will become bored of a particular behavior modification such as a reward chart and the chart will no longer be effective for modifying behavior. Additionally, the child's interests may change, causing the incentive to no longer be motivating for the child. One participant had this to say about the reward chart, "The one thing that's hard with the charts is that I kind of feel like they wear off after a while and you kind of have to think of a new thing. It can't be something that you're doing all the time and that's hard to think of something." Also, these participants explained that as the child becomes older, many of the behavior modifications that were effective when the child was young are no longer effective because the child simply grows out of a particular behavior. In some cases, the modification needs to be adjusted to reflect the child's development. Also, four participants explained that sometimes when a behavior modification became the norm of the family's household, and incorporated into the daily routine, it no longer needed to be applied with as much emphasis because it has been proven effective for the child and was a natural occurrence.

Challenges of Having a Child with Autism

Limited Support System

All participants were able to identify some support system, but five recognized that they had limited supports. Spouses were sometimes named as a support system, as well as family and some friends, teachers and other professionals. Five participants listed their parents as support systems and were involved with helping out the family as a whole, but not with applying behavior modification.

Lack of Self-Care

Four of the seven participants laughed when asked how they take care of themselves emotionally. Three participants could not think of an answer or simply said there was nothing they do for emotional support. Specifically, one participant responded, “My support system would be the teachers that I work with. That would be my support system. That’s it! (laugh) There isn’t anything. If there is I’m not aware of it.” Five participants said that it was a good question and one stated that it was an area to be addressed. All participants, however, agreed that healthy supports are necessary.

Two of the seven participants mentioned a healthy lifestyle such as getting regular exercise and eating healthy foods as ways for them to have outlets and take care of themselves. For example, one participant reported, “The other thing for me personally is that I practice yoga. Practicing yoga and maintaining a healthy lifestyle. Working on things that I can control, because there’s a lot of things I can’t control and that’s really scary and really hard. It feels really good to be able to have something that you can control. Having a healthy exercise program for me and eating healthy and taking care of myself has really helped.” Another participant responded, “My husband’s at the gym

now, I went running this afternoon. We do that kind of stuff during naps and have one of us sneak out while the twins are napping.”

Lack of Available Child Care

Five participants felt as though they had limited support systems in the sense of people who could care for their children. These participants reported that they felt uncomfortable leaving their children with others due to the special needs of their children. These participants also stated that they do not go on vacation or out of town because they do not have anyone who could watch their children for an extended period of time. Six out of seven participants had more than one child. Even though the children diagnosed with autism discussed in this study were on varying levels of the spectrum, some being very high functioning, parents still did not feel comfortable asking others to watch their children. One participant had this to say, “It’s hard to have someone watch your children. It’s hard enough to ask someone when your children are typical developing, normal children and there’s nothing wrong. It’s even harder when you want to have someone come in and watch your children when they are special needs. It’s almost impossible to find someone to watch three children with special needs that are three different sets of needs that people don’t understand.” Another participant responded, “I just don’t see anyone being able to take care of our kids for more than a day.”

Lack of Social Support Systems

All of the participants reported that they have some friends but that it was difficult to maintain friendships. According to two of the participants, the friendships that they do have, many are also parents of a child with special needs. One participant said that her

friends “fell by the wayside” after her child was diagnosed with autism and that she was spending much time attending to his needs. Six of the participants mentioned that they had to make many sacrifices and having friends and a social life was one of those sacrifices.

Coping Strategies

Social Media

Three participants mentioned social media as the main support system. One participant discussed how her social media support group was important, “There are also facebook support groups and you feel an incredible bond with other autism parents.” These participants felt that the internet was their main or only outlet as far as coping with their child’s diagnosis, as one participant describes, “There’s facebook groups. I would say that’s mostly it, the internet. I’m able to go on certain sites and ask questions and say, ‘okay, is anyone else going through this and how are you dealing with it?’ That helps.” Lastly, one participant described how her life was not how she had planned, but she finds support in the camaraderie of the social media groups she plays an active part in, “It’s a club I never wanted to belong to, but within that club there’s very strong support.”

Decreasing/Modifying Therapies

Four of the seven parents reported that at the beginning of the diagnosis they felt overwhelmed with the number of services their child needed and they had to later modify decisions based on what was best for the family as a whole. For example, one family went from a center-based ABA therapy to in-home therapy to save time commuting to and from the center. This family felt that though the center-based ABA therapy was

beneficial for their child, in-home therapy worked best for the entire family due to the amount of time it saved. Three participants reported that they were able to curtail some of their child's therapies and appointments because it was just too much going on all at once, causing more stress than what it was worth.

Advocacy

All of the participants reported the importance of advocating for their child and being proactive about the entire process of obtaining a diagnosis, to getting services in place, to behavior modification and ongoing education, and researching ways to help their child. All seven parents felt at some point that they were not being heard by the professionals, which caused them to advocate for their child even more. Four parents voiced frustrations with either the school system, obtaining a diagnosis, and lack of resources available to them. This caused them to take charge of their situation and not only be an advocate for their child, but they also helped other parents advocate for their children by providing support and advice. Much of the advice the participants had for other parents of children diagnosed with autism was to be persistent and obtain as much information as possible to help their child.

Six participants voiced concerns about their child to professionals and two participants reported that their concerns were dismissed, causing the parents to be persistent with getting help for their child. One participant discussed how she pulled her child from his school because the school was not following his behavior plan in his Individualized Educational Plan and instead suspended the child from school. This respondent became very frustrated and decided to provide home-schooling her child. She reported that she can attend to his needs better than the school could. She advocated for

her son as well as for other parents, as she said that she “was not being heard by the school system.” As advice to parents, she reported, “If they feel something isn’t right or if something else needs to be done, to follow through and actually be the one that’s doing it.” Another participant responded, “Prepare to advocate on several fronts for your kid because that’s how you get what you want, and that’s how they get what they need really, which is what you want.” Lastly, another participant reported, “Educate yourself I guess, try to figure out what’s best for your child. I always tell parents to go with their gut feeling.”

Advice to Professionals

More Support and Resources

All of the parents stated at some point during the interview that wanted to be heard and they wanted more support and resources from the professionals for their child and family. Five parents reported that they had to figure things out on their own and that it would have been helpful for the professionals to provide more resources and supports for them in dealing with the diagnosis of autism for their child. They also wanted supports and resources for the entire family. One participant said she was devastated when she was told that her child has autism and that she and her husband were left to “fend for” themselves. She reports, “You know you’re really putting all your resources into your child and you can’t even contemplate thinking to go get counseling for yourself. I know being involved with parents; we are all grappling with emotional stress on us, and the grief is very real and most families are probably not getting any support for those things. The pressures take a serious toll.” When asked about advice for social workers, another participant responded, “Being able to give them outlets and places and websites

to connect them to other parents. I think that's a big one; just being able to connect them to other people, realize you're not the only one and things that you're dealing with other people have dealt with and have survived." Another participant stated, "Social workers should have empathy for the parents in regards to lack of sleep and to understand that most parents are doing everything they can to help their child."

Parents are the Expert on Their Child

Two respondents reported that while they respect what the experts had to offer, that they were truly an expert on their child. One participant stated, "First and foremost I guess just listen to the parents. We kinda know what's best for our kids in some way, I mean they're our child and we will see things that maybe they don't pick up. I think that that's a big thing is when you're talking to people and you say, 'well this is what I'm seeing, this is what I'm dealing with' and they're like, 'well I don't see it.' Well, because you're not here twenty-four-seven." Additionally, another participant reported, "So I think just take your time to actually get to know the child and understand that as a social worker, you really need to listen to the parent who has the child because they are going to be the expert. I think a lot of social workers feel that they are the expert because they are social workers, but you can't be an expert on my child when you don't even know my child."

Continue to be Patient and Helpful

While all seven participants stated that they wanted more resources from the experts, they all identified recommendations and supports provided by professionals that have made a positive impact on their child. For example, one participant said that the behavior therapist for her child came to her son's school during his recess for almost two

years. This mother believed that this therapist played a “huge role” in her son’s improved social skills because the therapist came to his setting and into his life rather than him going to her office. This participant stated, “What has helped by far for me and my son is that the people working with him work with him in his setting. In the setting where he lives or in the setting where he goes to school, it’s his everyday life.” Another participant responded, “I don’t think I could give them any advice (laugh) they keep giving us advice. They’ve been so good and so patient and so helpful. I guess because they are such great listeners. So I guess that would be the only advice I could give is to be a good listener.”

Finding the Joys

Each participant talked about stressful and frustrating situations, though; exhibited positive attitudes and reported being grateful and thankful for what they have. The following quotes illustrate this positive attitude: “It could be worse though (laugh),” “we’ve been very blessed to have such a good group,” “He’s just brought so many wonderful things to our life,” “My favorite thing about C is his smile; it can light up the world if he wants it to,” “I mean anyone who’s ever met her; they tell me what a great kid she is and what a good heart she has, and she has a great sense of humor. They just adore her and I love that about her,” “He’s very sincere (laugh). He always says what he thinks. He doesn’t care what people think,” “I just love him to pieces. He’s a sweetheart, real gentle and he’s a good kid,” “He is funny. He’s a great little guy, super smart, but I would say my favorite thing is just the intensity at which he loves, loves life. Like I said when he loves you, he loves you so much, and that feeling is just so big,” “He is probably one of the most interesting and funny little people, person I’ve ever met. I mean just the

way he sees things and the world and the questions he asks, he's just, while still being a very fun little kid, and he's just a very intriguing person.”

Discussion

As the review of the literature suggested an eclectic approach of behavior modification is appropriate for children with autism based on the varying needs and the uniqueness of the child (Glynne-Owen, 2010). Four out of the participants of this study are using Applied Behavior Analysis therapy for their child. As discussed in the literature review, many behavior modifications were derived from ABA therapy (Seitler, 2011). This study showed that ABA therapy did not have to be applied in its original form of forty hours per week for the behavior modifications to be effective. In fact, parents use the ABA therapy skill set and modified to fit the needs of their child in order to help their child. Participants that did not have ABA therapy for their child were able to learn ABA-like behavior modifications from other professionals such as occupational therapists, physical therapists, behavioral therapists, and teachers. Additionally, all of the participants reported that the techniques they use are effective for their child. If the technique were no longer effective, the parent would modify or use a different approach, but each parent reported that they were able to be effective in modifying their child's behavior at home at least some of the time.

Not all of the behavior modifications that the participants used with their children were derived from ABA. Five participants mentioned sensory related interventions such as applying pressure to certain parts of the child's body for emotional regulation and comfort, as well as using sensory items to redirect behavior. Additionally, the use of social stories was mentioned by a few participants to gather more information and help

the child understand the situation he/she is explaining. A social story helps fill in the gaps and helps the child with addressing challenging behaviors (Schneider & Goldstein, 2009).

Three of the seven participants discussed how the diagnosis process was very frustrating for them; however, after their child had received a diagnosis they were able to get services in place without too many obstacles. This was unlike much of the literature review (Boettcher et al., 2013), in that the participants of this study did not report as much frustration and complaints as the studies reviewed in the literature. The literature also revealed that parents were very frustrated with the school systems and could not provide the learning environment their child needed (Boettcher et al.) Granted, one participant of this study did discuss that school services were not what they should be in her community. For example, this participant pulled her son from the public school and decided to home-school him instead. This study did not, however, focus specifically on barriers families faced within the school system, which may have produced more frustration within the schools as the review of the literature described.

As discussed in the literature review (Solomon & Chung, 2012), many parents believe they do not receive enough resources and supports from professionals to help their child and their family with a diagnosis of autism. This concern was raised by the participants of this study as well, in that all parents felt they wanted more from the professionals. Participants took matters into their own hands by doing what they felt was right for their child in the moment. Internet research was mentioned by six of the participants, and social networking was mentioned as a resource and support by three participants.

Advocacy took on the role of its own by parents supporting other parents and linking resources for their children. Advocacy is essential in order to gain knowledge and support. All the parents spoke of how they advocate for their child on several levels and how they thought it was important.

Parental involvement was a significant component to the review of the literature (Boettcher et al., 2013), and was identified as essential for success in the child's treatment and intervention. This study found that parental involvement is necessary for the child and family to succeed. All participants were heavily involved with their child and implementing effective behavior modifications. Additionally, all participants were able to identify how they use behavior modifications with their child as well as provided additional information on how they help their child succeed with goals and life's challenges. Parental involvement is essential for meeting the needs of children with autism spectrum disorder.

The conceptual framework of strengths-based and empowerment approaches were prevalent throughout this study, in that behavior modifications for children with autism are strengths-based in and of themselves. For example, respondents said that building on the positive attributes of the child is essential in order to be effective in modifying behavior. Focusing on what the child can do is more important than focusing on what the child cannot do. All participants reported that their child made progress in the areas in which his/her strengths were applied. Additionally, the conceptual framework of a strengths-based and empowerment-based approach was also prevalent in the participants themselves. All the participants of this study reported being thankful and grateful for their child and the life they have, as well as having learned new things from their child.

These participants displayed resilience and empowerment for their children. All participants made positive statements about their child and how their child is unique and special.

Strengths

This study was a qualitative approach, which the review of the literature suggests would provide more information than a quantitative study (Seitler, 2011). This study was able to answer the intended research question of how parents use behavior modification with their children diagnosed with autism, and found that parents use an eclectic approach. This study also found that parents adapt and modify to the uniqueness of their child. Data were gathered from a total of seven participants, which is appropriate for the scope of this research. The data were relevant and important to this study and research question, and also contributed to the research on autism spectrum disorder as a whole. As a result of this study, data gathered and analyzed will be used to educate the field of social work when working with children and families diagnosed with autism spectrum disorder.

Limitations

One limitation to this study is that it is missing a multi-cultural component. All of the participants identify as Caucasian. The lack of cultural diversity among the participants does not provide any information as to a possible cultural component of how parents use behavior modification with their child. It may be possible, for example, that Latinos, East Africans, or Asians approach the diagnosis of autism and interventions in a much different way than Caucasians do. A spiritual component was not addressed in this study, which may have left out important data, as well. Another limitation is that while

valuable, data was gathered from only seven participants. Autism spectrum disorder is prevalent enough that seven participants may not be enough to gather the necessary information. This small sample size also cannot be generalized to the larger population. Additionally, the socioeconomic level of the families was not specifically addressed in this research, which may have limited the data, leaving out some relevant information. The age of the participants is unknown, which may also have limited the data. Finally, all of the participants were female, causing a lack of the male voice.

Implications for Further Research

As discussed in the limitations, there is a need to have a multi-cultural perspective as a way to discover other effective behavior modification approaches. Additionally, because the participants of this study discussed limited support systems and resources for their families, it would be beneficial to research this in detail in an effort to provide more support in the future. Finally, as discussed in the findings, this study did not go into detail with the barriers families face with a child diagnosed with autism, specifically in the school system, which would also be useful to explore.

Application for Practice

An important finding from this study is that practitioners need to strengthen their efforts in providing and connecting families with supports and resources in regards to the diagnosis of autism. Autism spectrum disorder affects the entire family and the family as a whole needs to be supported. Professionals who are working with the family need to communicate with the family and collaborate with the child's team of professionals in order to "cover all the bases." A child should not have to be pulled out of a public school due to lack of resources, communication and support for the family. To decrease feelings

of isolation, parents in this study emphasized the need for education and support. Collaboration and consultation are essential in order to ensure the family's needs are being met. Lastly, due to the prevalence of autism spectrum disorder, it is imperative that professionals working with families with autism are well informed and educated about the diagnosis and treatments and intervention methods.

Conclusion

Autism spectrum disorder is a prevalent and pervasive disorder that affects not only the child diagnosed, but the family as a whole. The use of behavior modifications at home decreases the symptoms associated with autism spectrum disorder. Effective behavior modification tends to be consistent and constant thus, becoming a way of life for the family. Many behavior modifications have a foundation in Applied Behavior Analysis, however, not all. Due to the uniqueness of the child, level of development, and specific in-the-moment situations, behavior modifications are also unique to the child in the way that they are applied. Further research is recommended to explore cultural components of behavior modifications as well as providing more valuable information as a whole especially to professionals working with families with autism.

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Appendix A**CONSENT FORM****UNIVERSITY OF ST. THOMAS****Autism Spectrum Disorder: How Parents Use Behavior Modification With Their Children With Autism**

UST IRB# 534476-1

I am conducting a study about Autism Spectrum Disorder and how parents use behavior modification with their children with autism. I invite you to participate in this research. You were selected as a possible participant because you are a member of a support group for parents with children with autism, or know someone who referred you to me. Please read this form and ask any questions you may have before agreeing to be in the study.

This study is being conducted by: Jessica Boner, MSW graduate student; Kendra Garrett, Research Advisor & LICSW, University of Saint Thomas/Saint Catherine University School of Social Work.

Background Information:

The purpose of this study is: to explore how parents use behavioral modification with children with autism. Specifically to explore what is working and why, and what may not be working. Additionally, this research will also provide beneficial information in the field of social work when working with families who have children with autism.

Procedures:

If you agree to be in this study, I will ask you to do the following things: will have you answer a series of interview questions in which you will answer to your comfort level. The expected commitment time is approximately 30-45 minutes which is the estimated time for the interview. I will audio record the interview and data collection will take place at my home and will be stored in a locked filing cabinet and electronic data will be stored on a password protected computer located at my home.

Risks and Benefits of Being in the Study:

The study has a couple risks. There is a possible risk of emotional discomfort, as well as the feeling of discomfort in regard to privacy of self and family.

To minimize the risk of emotional discomfort in the unlikely event that the interview questions trigger an emotional response, and the potential of personal responses, I will use some precautions. I will tell you that you do not have to answer all of the interview questions and you can share information based on your comfort level. In the unlikely

event that the interview questions trigger an emotional response, I will listen to the you with empathy and provide you with information of contact numbers of therapists in your area that you can call.

Compensation:

There is no compensation for this study.

Confidentiality:

The records of this study will be kept confidential. In any sort of report I publish, I will not include information that will make it possible to identify you in any way. The types of records I will create include recordings, written notes, transcripts, and master list and computer records. Consent forms will be kept at home in a locked filing cabinet, as well as written notes and audio recordings. Transcripts will be kept electronically on a password protected computer/hard drive. The only people that will have access to this information is myself and my research advisor. All documents stored will be destroyed on or before May 19th, 2014.

Voluntary Nature of the Study:

Your participation in this study is entirely voluntary. Your decision whether or not to participate will not affect your current or future relations with the support group or the University of St. Thomas. If you decide to participate, you are free to withdraw at any time up to and until one week after the interview. Should you decide to withdraw data collected about you will not be used if you withdraw within one week from your interview. If you withdraw from the study anytime after one week following your interview, your data will be used in the study. You are also free to skip any questions I may ask.

Contacts and Questions

My name is Jessica Boner. You may ask any questions you have now. If you have questions later, you may contact me by phone or email. You may also contact my research advisor. You may also contact the University of St. Thomas Institutional Review Board at 651-962-5341 with any questions or concerns.

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

Statement of Consent:

I have read the above information. My questions have been answered to my satisfaction. I consent to participate in the study. I am at least 18 years of age. I also consent to an audio recording of the interview.

Signature of Study Participant

Date

Print Name of Study Participant

Date

Signature of Researcher

Date

Appendix B

Agency Consent Form

Researcher: Please provide your agency with the information about your project and have your agency contact complete this form.

Agency: Please read this form and ask any questions you may have before agreeing to allow this study to take place at your agency. Please keep a copy of this form for your records.

Project Name	Autism Spectrum Disorder: How Parents Use Behavior Modification With Their Children With Autism	IRB Tracking Number	534476-1
General Information Statement about the study:			
This research study will address the question, “how do parents use behavior modification with children with autism” and will be of a qualitative approach.			
Your agency is invited to participate in this research. The agency was selected as a host for this study because:			
You facilitate a support group for parents and caregivers of children with Autism.			
Study is being conducted by:	Jessica Boner		
Research Advisor (if applicable):	Kendra Garrett		
Department Affiliation:	Social Work		
Background Information The purpose of the study is:			
The purpose of this study is to explore how parents use behavioral modification with children with autism. Specifically to explore what is working and why, and			

<p>what may not be working. Additionally, this research will also provide beneficial information in the field of social work when working with families who have children with autism.</p>
<p>Procedures</p> <p>Study participants will be asked to do the following:</p> <p><i>State specifically what the subjects will be doing, including if they will be performing any tasks. Include any information about assignment to study groups, length of time for participation, frequency of procedures, audio taping, etc.</i></p>
<p>The study participants will be asked a series of interview questions that will be available prior to interview. The interview will take approximately 30-45 minutes and will be audio recorded. The participants will be notified that the answers they give are based on their comfort level and they can choose to not answer questions if they do not feel comfortable. After interview, participants will be given one week to decide if they do not want their information used for the study. If they should choose to withdraw from the study within one week from interview, their data will not be recorded and will be disposed of.</p>
<p>Risks and Benefits of being in the study</p>
<p>The risks involved for subjects participating in the study are:</p>
<p>One risk that may be associated with this study is emotional discomfort of the participants in the unlikely event that the interview questions trigger an emotional response. Another risk is that the content of the information discussed in answering the interview questions may be personal.</p>
<p>The direct benefits the agency will receive for allowing the study are:</p>
<p>N/A</p>
<p>Compensation</p> <p>Details of compensation (if and when disbursement will occur and conditions of compensation) include:</p>
<p>N/A</p>
<p>Confidentiality</p>

<p>The records of this study will be kept confidential. The types of records, who will have access to records and when they will be destroyed as a result of this study include:</p>	
<p>The records of this study will be kept confidential and those that will or may have access to these records are myself, and my chair research advisor.</p>	
<p>Voluntary Nature</p> <p>Allowing the study to be conducted at your agency is entirely voluntary. By agreeing to allow the study, you confirm that you understand the nature of the study and who the participants will be and their roles. You understand the study methods and that the researcher will not proceed with the study until receiving approval from the UST Institutional Review Board. If this study is intended to be published, you agree to that. You understand the risks and benefits to your organization.</p>	
<p>Should you decide to withdraw, data collected about you</p>	
<p>Will be used in the study, however, if you withdraw after one week after interview, data collected about you will not be used.</p>	
<p>Contacts and Questions</p> <p>You may contact any of the resources listed below with questions or concerns about the study.</p>	
<p>Researcher name</p>	<p>Jessica Boner</p>
<p>Researcher email</p>	
<p>Researcher phone</p>	
<p>Research Advisor name</p>	<p>Kendra Garrett</p>
<p>Research Advisor email</p>	
<p>Research Advisor phone</p>	
<p>UST IRB Office</p>	<p>651.962.5341</p>

Statement of Consent			
I have read the above information. My questions have been answered to my satisfaction and I consent to allow the study to be conducted at the agency I represent. By checking the electronic signature box, I am stating that I understand what is being asked of me and I give my full consent.			
Signature of Agency Representative <input checked="" type="checkbox"/> <i>Electronic signature</i>		Date	10/26/13
Print Name of Agency Representative			
Signature of Researcher <input checked="" type="checkbox"/> <i>Electronic signature*</i>	Jessica Boner	Date	10/26/13
Print Name of Researcher	Jessica Boner		

*Electronic signatures certify that::

The signatory agrees that he or she is aware of the polities on research involving participants of the University of St. Thomas and will safeguard the rights, dignity and privacy of all participants.

- The information provided in this form is true and accurate.
- The principal investigator will seek and obtain prior approval from the UST IRB office for any substantive modification in the proposal, including but not limited to changes in cooperating investigators/agencies as well as changes in procedures.
- Unexpected or otherwise significant adverse events in the course of this study which may affect the risks and benefits to participation will be reported in writing to the UST IRB office and to the subjects.
- The research will not be initiated and subjects cannot be recruited until final approval is granted.