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## Parental Involvement in Early Intervention Programs for Children with Autism

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Parental Involvement in Early Intervention Programs for Children with Autism

MSW Clinical Research Paper  
Submitted by Alexis M. Bennett  
May, 2012

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

School of Social Work  
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**Abstract**

This qualitative study explored the perceptions of mental health professionals and practitioners of parental involvement in early intervention programs for children with autism. Interviews were completed with eight mental health professionals and practitioners to better understand the importance of parental involvement, the role parents play within an early intervention program, and the impact parental involvement or lack thereof can have on the child's success developmentally and their success in the early intervention program. The objective of this study was to gain insight into mental health professionals and practitioners' perceptions in order to learn ways for social workers and professionals alike to be more effective in supporting children with autism and their parental figures. The content of the interviews were analyzed to identify categories and subsequent themes expressed by the participants.

The findings indicated lack of parental involvement is detrimental to the child's development and progress within an early intervention program. There is ample research on the positive effects of children with autism who have parental involvement, such as increased developmental skills and progress in an autism early intervention program. The effects lack of parental involvement could have on a child are the inability to support the child's needs, the child's ability to generalize skills across environments, and lack of developmental progress. The findings also present several implications that can be taken from this study, including the need for both the social work profession and parents to have an understanding of the benefits parental involvement provide as well as the harmful effects it could have on a child with autism. Other implications include the need

## PARENTAL INVOLVEMENT: AUTISM EARLY INTERVENTION

to be culturally aware of the parents, and the need to provide a variety of services to reach each individual family.

### **Acknowledgements**

First and foremost I would like to thank the Lord Jesus for giving me the strength and courage to get to where I am today. Without His guidance and constant signs of the spectacular gift He has given me to serve the less fortunate and fight for social justice, I am not sure I would be on this path in life. I owe my passion for special needs and the strive to want to make a difference to Him! I want to acknowledge and thank my husband and family for their encouragement and uplifting support since I started the program in 2007. Their belief in me is what got me into the MSW program, which eventually led me here today, writing this research paper. I would like to thank my husband, sister, mother and father for their encouragement, understanding, patience, and consistent prayer throughout the year. The endless phone calls, dinners out, shoulders to lean on, and agape love are things and moments that I will cherish forever. Thank you for being a light through times where I wanted to throw in the towel and loving me through the many personalities I am sure I had throughout the year.

To my committee chair, where do I even begin? Thank you for your unconditional support through the year, professionally and personally. Your passion for research and your dedication to this project is admirable. Without your wisdom and consistent check-ins I would still be on page one of this project with a blank piece of paper. I look up to the work that you do in the field and on paper and I pray that one day I will be able to make a difference in this world and in our communities as you have done in your lifetime. Thank you for believing in me. It is a rare blessing to receive and I am honored to be on the receiving end.

## PARENTAL INVOLVEMENT: AUTISM EARLY INTERVENTION

To my committee members, thank you for your dedication to this project and your interest in the field of Social Work. I knew that the two of you would give me the encouragement and feedback needed to survive this project. Your expertise in the field has enhanced my paper more than you will ever know. Thank you for being willing to help me through this year by giving your time and energy into this research paper and me. I admire you both for the work you have done and are currently doing. You have been mentors to me in a field that mentorship is desperately needed. Thank you for paving the way!

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## **Introduction**

### Parental Involvement in Early Intervention Programs of Children with Autism

Autism is a developmental disability on a spectrum that reflects differences in the way children develop early on and into adulthood (Lord, 2007). Autism is considered a spectrum disorder because there are a number of subtypes within the disorder that are connected with different levels of severity (Lord, 2007). The Center for Disease Control (CDC) previously estimated in 2007 that 2-6 per 1,000 children had an autism spectrum disorder (ASD), but as of 2012, one child in 88 identify as having an ASD (National Institute of Mental Health, 2004). This is a 78% increase in five years (National Institute of Mental Health, 2004). When compared to other childhood diagnoses, ASD is lower than the rate of mental retardation, but higher than cerebral palsy, hearing loss, and vision impairment (National Institute of Mental Health, 2004). With the rise in ASD diagnoses and its lifelong duration, early intervention is important and research has shown most children with ASD respond well to highly structured programs (National Institute of Mental Health, 2004; Ozonoff & Cathcart, 1998). Research has also shown that early intervention programs can lead to considerable gains in cognitive, social, emotional, and motor functioning (Dillenburger, Keenan, Gallagher, & McElhinney, 2004).

It was not until 1990 that Congress amended the education for All Handicapped Children Act to expand the number of disability categories to include autism as a population eligible to receive special education services (Ryan, Hughes, Katsiyannis, McDaniel, & Sprinkle, 2011). The services offered now reach a quarter million students with autism, which accounts for 4.97 % of all students with disabilities since last counted (Ryan et al., 2011). Some commonalities across all programs, regardless of belief, are: 1)

the use of structured behavioral and educational methods; 2) providing parents with training to implement strategies within the home environment; and 3) enrollment prior to age five (Ozonoff & Cathcart, 1998). Since every child falls somewhere different on the spectrum there is no single best treatment for children with ASD, but each program has one thing in common, which is the need for parental involvement (National Institute of Mental Health, 2004). Parental involvement is the one invariable factor and an integral part of the success of early intervention programs for children with autism. The collaboration between the parent and the professional working with the child in the program is critical to the effectiveness of programs (Ozonoff & Cathcart, 1998).

The programs point out how parent involvement helps ensure the behaviors learned in the structured program can be generalized to the home environment (Ryan et al., 2011). Due to the parents being the child's earliest teacher, many specialized early intervention programs offer training for parents to continue therapy within the home (National Institute of Mental Health, 2004). Some children attend a structured day treatment program and return home to their involved parents who have training in how to continue the learned behaviors from school to the home environment. Others come home to lack of parental involvement. Lack of parental involvement could be a result of many different variables. Parents of children with ASD experience varying levels of motivation, stress, depression, and different socioeconomic levels, which could impact their availability to resources and education (Ozonoff & Cathcart, 1998; Mancil, Conroy, & Nakao, 2006).

Research has shown the importance and effectiveness of parental involvement in early intervention programs. There is lack of research showing the effectiveness of

programs when there is lack of parental involvement and the impact it can have on the child's development within the program. When there is lack of parental involvement and the program is ineffective there is potential for impact on the child. Current research on autism includes topics such as assessment and diagnosis, class and in home services for children with autism, training and support services for parents and families (Lord, 2007; National Institute of Mental Health, 2004). Social Workers are an integral part of the assessment, diagnosis and treatment plan of a child with ASD. They also promote parental involvement and provide training and support to parents of children with ASD. In order for early intervention programs to be effective and the child to make improvements the parents need to be involved, but this responsibility ultimately lies on the parents themselves. Once the child leaves the hands of the social worker and the structured intervention program, it is out of the social workers hands and up to the parent to utilize the services offered.

The purpose of this project is to examine the importance of parental involvement in the effectiveness of early intervention programs and the role it plays on a child with autism. In this project, I will explore the history of autism and where the spectrum disorder currently stands today from a treatment perspective. I will also explore the main early intervention programs offered, the importance of parental involvement within the programs, and the potential causes of lack of parental involvement. There is existing literature stating the important role parents' play in the success of early intervention programs for their children with autism. There is a lack of research in regards to what happens to the early intervention program and the child enrolled if the parents are not involved. In this study, I will be adding to existing research by looking at professionals'

perceptions of parental involvement and the impact lack of parental involvement can have on an early intervention program and the child enrolled. The following research question will be examined: What are professionals' perceptions on children with autism enrolled in early intervention programs that do not have consistent parental involvement?

### **Literature Review**

Analysis of the literature reveals the history of autism and the importance of early diagnosis to ensure a child with autism is set up appropriately to receive adequate care through an early intervention program. In the literature, several early intervention programs are examined and within the programs the importance of parental involvement is revealed alongside the success of each program. The extent to which parents are involved is different for each family, therefore analysis of the literature reveals the importance of parent training, the option for home based early intervention programs, and factors contributing to the lack of parent involvement. The history of autism, early intervention programs and parental involvement, parent training, home based intervention and factors contributing to lack of parental involvement are explored below.

### **Definition and History of Autism**

Autism Spectrum Disorders (ASD) are defined by having deficits in three behavior areas: 1) social interaction; 2) verbal and non-verbal communication; and 3) repetition (Lord, 2007; National Institute of Mental Health [NIMH], 2004). According to section 300.8 (c) (1) (i) of IDEA 2004:

Autism is a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age three, that adversely affects a child's educational performance. Other

characteristics often associated with autism are engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences.

(Building the Legacy: IDEA 2004, 2009)

Due to the disorder being a spectrum disorder professionals and families use the terms ASD and autism interchangeably (Ryan et al., 2011). The cause of autism and these deficits is still unknown, but the initial introduction started in 1943 by Leo Kanner of the Johns Hopkins Hospital. Kanner conducted a study on 11 children and introduced the label “early infantile autism” for the first time initially relating the cause to cold, unloving mothers (NIMH, 2004; autismspeaks.org, 2011). Bruno Bettelheim continued this belief and it was not until the 1960’s and 70’s that Dr. Bernard Rimland put this myth to rest when he founded the Autism Society of America and the Autism Research Institute. He discovered that autism is a biological disorder (autismspeaks.org, 2011). Regardless of the potential causes of autism it is important to receive a diagnosis and begin effective intervention strategies for the child to work on their development. Autism can be diagnosed by the age of three and in some cases as early as 12 months of age (Lord, 2007; NIMH, 2004). The earlier a child is diagnosed the sooner they are able to enter an early intervention program to reduce symptoms and make an impact on their ability to learn and grow (NIMH, 2004).

### **Early Intervention Programs and Parental Involvement**

The purpose of reviewing early intervention programs is to gain an understanding of the components of the program and what the contributing factors are; most importantly taking a deeper analysis into how parents are a large part of the contributing factors to

making the program effective. Early intervention programs are available in every state for children under the age of three (NIMH, 2004). Current literature suggests that early intervention is the most effective educational program to increase behavioral outcomes and the overall development of the child (Panerai, Zingale, Trubia, Finocchiaro, Zuccarello, Ferri, & Elia, 2009; Dillenburger, Keenan, Gallagher, & McElhinney, 2004; Boyd, Odom, Humphreys, & Sam, 2010; Solomon, Necheles, Ferch, & Bruckman, 2007). Research varies in terms of the amount of hours needed to have successful intervention, as each child, developmentally, lies somewhere different on the spectrum. Roberts, Williams, Carter, Evans, Parmenter, Silove, Clark, and Warren (2011) recommended 15 to 25 hours a week as the amount needed for an effective early intervention program. In contrast, McConachie and Diggle (2006) found some programs have claimed 40 hours a week to be most effective. It is also important to look into the quality amongst the quantity of treatment that the child is receiving (Roberts et al., 2011). Part of the quality of an early intervention program includes the program components and whether or not it requires parental involvement.

To encompass both quality and quantity within a program to support children with ASD, two documents are provided to establish a plan for the development and care of the child (McConachie & Robinson, 2006). These two documents are the following: (1) the Autistic Spectrum Disorders Good Practice Guidance (GPG); and (2) the National Autism Plan for Children (NAP-C 2003). The GPG provides guidance on how to care for children with autism. The NAP-C was created in regards to early intervention programs with identification and assessment of the child in mind. Out of the documents came three recommendations for care of the child, which are the following: (1) a multidisciplinary

team of professionals; (2) an identified worker to support the family; and (3) access to programs with trained staff (McConachie & Robinson, 2006). Research literature has shown linkage to parental involvement within these three areas helping with the effectiveness of early intervention programs (Wieder & Greenspan, 2003).

Results from a study of 56 children and their parents over a 2 year period conducted by McConachie and Robinson (2006) indicated that contact with a multidisciplinary team decreased as the child aged, while only 39% of parents reported contact with an identified worker, and less than one third received access to a program with trained staff. These results showed lack of adherence to the three recommendations made by the GPG and NAP-C. It is important to review the early intervention programs, the components of the program, and the role parents play within the program.

According to Boyd et al. (2009) there are two types of early intervention programs available to children with ASD based on the literature. A focused intervention practice is used to promote a child's learning and development to decrease challenging or problem behaviors whereas a comprehensive treatment model (CTM) has a focus on promoting positive behaviors in children. Although the methods vary, they share core characteristics: early, intensive, one-on-one intervention (Solomon et al., 2007). When reviewing the literature on the different kinds of early intervention programs available, parental involvement was a contributing aspect of each program and a key factor to success. For the comprehensive programs, parents are involved in implementation (McConachie & Diggle, 2006). The intervention approaches involve parents in the behavior and communication change management strategies (McConachie & Diggle, 2006). Of the available programs offered for children with ASD the following early

intervention programs were reviewed: Developmental, Individual-Difference, Relationship-Based model (DIR/Floortime), Functional Communication Training (FCT), Social Communication, Emotional Regulation, and Transactional Support model (SCERTS), Treatment and Education of Autistic and Communication related handicapped Children (TEACCH), and Applied Behavior Analysis (ABA).

### **Developmental, Individual-Difference, Relationship-Based model**

Stanley Greenspan MD invented the Developmental, Individual-Difference, Relationship-Based model (DIR) model with a design to increase socialization, improve language and decrease repetition of behavior. Through unstructured Floortime play sessions the adult follows the child's lead through gestures and words by establishing a shared attention to engage with the child and then problem solve through play interaction (Wieder & Greenspan, 2003). Greenspan's initial case study had no control group and is considered an observational study, but is viewed successful as 58% of the 200 treated children no longer met the autistic criteria for the diagnosis of autism after a 2 year intervention (Solomon et al., 2007). This model of friendly play is experienced between child and clinician, educator or parent. The generalizability plays a key factor to the success of the DIR model due to the ease of a parent's ability to engage in the DIR model at home.

A 3-year case study was performed between a father and his young child (Wieder & Greenspan, 2003). The results concluded Floortime was central to the progression in his development over the 3-year period as he was able to take toys and make them into symbolic ideas and words and convey emotions and empathy as well as think logically and abstractly. Wieder & Greenspan (2003) noted this case study cannot provide the

effectiveness of one intervention, but the observation suggested the reason for the child's significant improvement in development. The improvement could not have taken place if it were not for the parental involvement and active participation along the way.

Furthermore, the PLAY Project Home Consultation (PPHC) program trains parents to use the DIR/Floortime model. Solomon et al. (2007) completed a study of 68 children who participated in an 8-12 month program with parents conducting 15 hours per week of play therapy. Parents received intense training such as, modeling, coaching, and video assessment. Results indicated 45.5% of children made good to very good functional developmental progress at completion of the program, similar to Wieder & Greenspan's (2003) case study. Results also indicated that there was a statistically significant trend that suggested that parents who did not spend as much time in play therapy had children who did not make as much progress. This research confirms the importance of parental involvement in an early intervention program and the impact lack of parental involvement can have on a child's development.

### **Functional Communication Training**

Functional communication training (FCT) was developed in the 1980's as an evidence-based practice with potential to impact the communication skills and problem behaviors of children with ASD (Mancil, Conroy, & Nakao, 2006). The process of FCT involves replacing the problem behavior with a communicative response. The behaviors of the child are found through a functional analysis process consisting of interviews, observations and assessments. Picture communication, verbal language, or gestures are some of the examples of the communicative responses used to replace the problem behaviors through the FCT model. Mancil et al. (2006) suggest limited research has been

conducted on training parents and caregivers on how to use FCT and stated most research has been done in structured clinical settings. Moes and Frea (2002) agree that most research has been conducted in clinical trials. However, the success of FCT relies on the parents' ability to integrate their training into the home environment once the problem behaviors arise.

Mancil et al. (2006) noted one case study of a 4-year old child and his mother, which provided literature on the effectiveness of training FCT in a home environment. The study included the importance of parental involvement in the program. In the study, the child was receiving speech, language and ABA therapy in a clinical setting outside of the home, but his mother expressed concern of the skills not generalizing to the home environment. Results indicated that the child's problem behaviors in the home decreased and as a result communication increased. The literature suggested providing training in the home greatly increased the child's ability to generalize into other areas and people, such as parents and teachers (Mancil et al., 2006). Furthermore a study of a 3-year old whose parents conducted the FCT program within their home experienced similar results to Mancil's et al. (2006) study, with increased communication skills and decreased problem behaviors in their child (Boyd et al., 2010). Similar to the DIR/Floortime model of Wieder and Greenspan (2003), the generalizability of FCT gave parents the ability to bring a structured setting into their home environment.

Three families participated in a training and implementation of an adapted FCT program with their children with autism (Moes & Frea, 2002). The three children ranged in age from 3 to 5 years old. The goal was to adapt an already existing FCT program within a family to meet their individual and family needs. After observations, interviews

and surveys, the results indicated the already existing FCT program can be changed to meet their needs and the family appreciated and welcomed the changes. Prior research literature has shown the importance of parental involvement and the need for collaboration between parents and professionals. Moes and Frea (2002) created an environment during the study within the home that closely resembled their current environment. This environment made the utilization of FCT after the study was completed easier to continue. Prior research has set up an environment that is hard for parents to replicate, making it difficult for parents and families to continue with intervention services after studies are complete. When asked about the sustainability of the adapted FCT program for her family after implementation, one mother went from stating, “can’t tell” to “much” (Moes & Frea, 2002, p.529). This research lends truth to the importance of parental involvement in an early intervention program and the effectiveness of its outcome.

### **Social Communication, Emotional Regulation, and Transactional Support**

Research has shown current programs either adheres to one or two approaches. One approach has little integration of numerous programs or in contrast they borrow from many different programs, even when not easily integrated. For example, the latter has potential to create confusion for a child who receives highly structured treatment during the day and loosely structured treatment in the home. As a result, the Social Communication, Emotional Regulation, and Transactional Support (SCERTS) model was created from a need seen in research for consistency across approaches in early intervention programs (Prizant, Wetherby, Rubin, & Laurent, 2003). Research suggested the SCERTS model is based on the most current research in ASD and is projected to be

the most widely used treatment of early intervention programs (Prizant et al., 2003; Walworth, 2007). It is derived from a theoretical and empirically based foundation. The components of the SCERTS model consists of a multidisciplinary team working towards three education and treatment goals which are the following: 1) enhancing capacities for joint attention and symbol use through social communication; 2) enhancing capacities for self and mutual regulation as well as the ability to recover from dysregulation through emotional regulation; and 3) educational, learning, interpersonal, family, and professional support through transactional support (Prizant et al., 2003).

Tying the research back to the importance of parental involvement in the success of early intervention programs, the SCERTS model emphasizes the importance of clinicians and educators understanding the possible reactions that families and parents might experience when raising a child with ASD (Prizant et al., 2003). Parents are encouraged to discuss their strengths and limitations in their communicative interactions with their child in order to develop the best treatment goals. The SCERTS model stresses the importance of clinicians and educators understanding various family structures, cultures and beliefs in order to design an appropriate treatment plan that is best for the family and child, as each program is not a one size fits all approach. This model places ownership of decisions on the parents and child, which emphasizes the importance in their involvement and impact on the child's developmental progression. After an extensive review of current literature no case studies exist to date regarding the effectiveness of the SCERTS model. Research has shown how other early intervention programs, such as music therapy, have similar goals to the SCERTS model and provides suggestions for providers of the therapy to adapt to the SCERTS model.

## **Treatment and Education of Autistic and Communication related handicapped Children**

Treatment and Education of Autistic and Communication related handicapped Children (TEACCH) is a clinical evidence based program that started at the University of North Carolina at Chapel Hill by Eric Schopler, PhD in 1972 (Mesibov & Shea, 2010). The program is centered on a “structured teaching” approach that is structured by time, space and sequences of events (Mesibov & Shea, 2010). TEACCH suggests four kinds of structure: 1) physical; 2) sequence of events; 3) organization of tasks; and 4) work/activity system. Schopler conducted the earliest intervention study on the benefits of structure within an early intervention program. The participants consisted of five children with autism, ranging from four to eight years of age. Schopler rotated the five children from structured to unstructured sessions. Within the structured sessions the adult working with the child chose the materials to be used, while in contrast the child chose the materials during the unstructured sessions. The results indicated the child responded better to the structured session and the children became more disorganized the less structure they had.

In addition to Wieder and Greenspan’s (2003) DIR/Floortime and Mancil’s et al. (2006) FCT, TEACCH also stresses the importance of parent involvement and has shown, through research, the effectiveness of the TEACCH program when parents interact and play an integral role in the development of their child through the programs structure. Furthermore, another study used behavioral observations and interviews of 15 children and their parents to evaluate changes during a TEACCH program. The changes happening within the program were compared to any changes that might happen during a

waiting period prior to starting the program (Mesibov & Shea, 2010). Observations indicated significant improvement in engagement with materials and the parent's ability to help guide behavior and parent involvement within the home. Parents rated the effectiveness of the TEACCH program very positively (Mesibov & Shea, 2010). This study further supports success of an early intervention program when parents are involved.

A three-year study at Oasi Maria Scientific Institute for Mental Retardation and Brain Aging compared the effectiveness of three different early intervention education programs for children with autism (Panerai, Zingale, Trubia, Finocchiaro, Zuccarello, Ferri, & Elia, 2009). This was the first comparison study with a long-term follow up. The first intervention program was a TEACCH program in a residential center. The sample consisted of 13 children. They resided in an institute and worked in groups of three or four and went home for regular intervals and did not attend regular school. Parents continued the same program at home after they completed a training program. Integration activities outside the institute and home were also carried out (Panerai et al., 2009). The second intervention program was a TEACCH program carried out in a mainstream school where there were 20 regular education students and one child with autism and the TEACCH program was also implemented at home after parent psycho-educational training. The sample consisted of 11 children (Panerai et al., 2009). The third intervention was inclusive education in mainstream schools where a nonspecific approach was used. The sample consisted of 10 children. The objectives were to diagnosis the children with autism and monitor the development. There was no education support program and the diagnosis was only given to the parents. The child was mainstreamed with 20 children

and had training from a support teacher. An Individual Education Plan (IEP) was developed, with more emphasis on academics. There were no structured teaching methods for children with autism and no classroom adaptations (Panerai et al., 2009).

The results indicated a higher effectiveness of the TEACCH program than the inclusive education approach for children with autism. Results obtained in the first and second study are greater than the third study (Panerai et al., 2009). In TEACCH there is collaboration between parents and support and regular education teachers; coordination between home and regular school-based programs; and shared objectives and the same work system. The differences were small and the program became a natural part of the child's life. This study shows the importance of parental involvement in the effectiveness of the TEACCH program. The parents took on the role of co-therapists throughout the study and implemented strategies of the TEACCH program within the home environment in both the first and second study. Research has shown the effectiveness of the first two studies with parental involvement. Research has also shown the third program to be ineffective with no parental involvement, thus contributing to the impact lack of parental involvement can have on a child with autism and their development (Panerai et al., 2009).

### **Applied Behavior Analysis**

B. F. Skinner created the science behind Applied Behavior Analysis (ABA) in 1957 under the theory of rewarding positive behavior with verbal recognition (Ryan et al., 2011). ABA has evolved from 100 years of research and is not autism specific, but has been shown to address the development of behaviors seen in children with autism (Dillenburger and Keenan, 2009). Ivar Lovaas was the first to study the effectiveness of an ABA program with a group of children under the age of four over 2 to 3 years through

Discrete Trial Training (DTT), which is a technique within ABA commonly used. DTT is taught by using a specific task repeatedly until the student has completed the task. Results indicated 47% reported higher functioning than the control group not receiving ABA treatment, at only 2% (Ryan et al., 2011). In the beginning of an ABA program, one-on-one instruction by a parent is usually recommended. This recommendation comes from parental involvement being a key element to helping the behaviors learned generalize into the home environment. Parents who are trained on ABA techniques have reported lower levels of stress and higher satisfaction levels when compared to other early intervention programs (Dillenburger, Keenan, Doherty, Byrne, & Gallagher, 2010). Other techniques are used within DTT and ABA, such as Picture Exchange Communication System (PECS), Verbal Behavior Analysis (VBA) and Pivotal Response Training (PRT) among many others (Dillenburger & Keenan, 2009).

ABA has often been compared to TEACCH as the two most widely known CTM's for children with autism (Callahan, Shukla-Mehta, Magee, & Wie, 2010). Callahan et al. (2010) compiled a list of components from both ABA and TEACCH models to determine the comprehensiveness and social validation of each model by the consumers of the model, which are teachers, parents and administrators. Results indicated that no preference was given for either model and consumers would rather use a combination of components from both models rather than adhering to one model over the other. When reviewing overlapping components for both models, parental involvement was highlighted as a key element to the structure of each CTM. Reporting on student progress, training parents to be providers to increase generalization, and direct involvement of parents and family in the program were common between both CTM's

(Callahan et al., 2010).

Reed, Osborne and Corness (2007) conducted a study on 53 participants involved in a home-based ABA, portage and specialized nursery program. Portage is a home-based, parent taught, early intervention group program typically seen in the United Kingdom. The goal of the study was to see if ABA had the same outcome from a clinic-based setting in the home-based setting. Results indicated intellectual and educational gains in the children with very little adaptive behavior gains. Adaptive behavior gains were seen in the nursery and portage program due to the group socialization of the program rather than the one-on-one setting such as the ABA home-based program. The ABA program was tutor taught and there was no mention of parental involvement within the ABA study. There was a focus on parental involvement with the portage program as it is parent led. In contrast, other research on home-based studies has been parent led after extensive parent training on FCT, TEACCH or ABA or has been effective and successful as a result of parental involvement (Dillenburger et al., 2004; Roberts et al., 2011; Ozonoff & Cathcart, 1998).

A study of 22 parents of children with autism involved a parent questionnaire to understand their satisfaction with home-based ABA programs in Northern Ireland (Dillenburger, Keenan, Gallagher, McElhinney, 2002). Results indicated parents' felt satisfied with the training they received and felt they were involved in the development and implementation of the program. Overall, parents felt empowered by the program and felt as though they were in control of their family and had a more structured environment within the home as a result of the home-based ABA program. A similar questionnaire was given to parents on the satisfaction of a home-based TEACCH program and the

results indicated TEACCH did not promote parental empowerment the way the ABA program did (Dillenburger et al., 2002). These two studies differ from previous research literature in that these results are from a parent's perspective and provide no cognitive, social or behavior statistics from the child's perspective on improvement levels within the program (Mesibov & Shea, 2010; Panerai et al., 2009). The parents were involved and felt satisfied, which is important and lends to the hypothesis about the importance of parental involvement. However, without information about the effectiveness of the child within the program alongside parental involvement it is hard to say if a parent's perspective is enough information. Parental empowerment is important when parents are in control of their child's learning and development. It is imperative for a parent to be well educated and trained in order to implement and carry out an early intervention program to the best of their ability.

### **Importance of Parent Training**

Raising a child without a developmental disability has its own challenges and problem behaviors play a role in the normal development of children. Some of these problems consist of inattention, aggression, and impulsions (Kaminski, Valle, Filene, & Boyle, 2008). Kaminski et al. (2008) conducted a study on the effectiveness of training programs for parents of children with problem behaviors. Some of the examples of skills learned in the programs include teaching parents to encourage their children's social interactions, cognitive abilities, and academics (Kaminski et al., 2008). Kaminski et al. (2008) reviewed 77 published evaluations of parent training programs and found parent-training programs to have a positive effect on parenting behavior and impacting the behavior of their children. Raising a child with ASD has a different set of challenges and

it is important for parents to be well educated to understand if they are able to provide the support and services needed for their child to develop and establish a healthy relationship with them (Schultz, Schmidt, & Stichter, 2011).

McConachie and Diggle (2006) conducted an extensive search of research literature and found 15,000 articles, of which 71 were reviewed and used for their study. McConachie and Diggle (2006) examined the effectiveness of parent implemented intervention programs for children with autism and found evidence that parent training is effective as a result of improved social communication skills in children with autism. Knowledge, skills and performance increased in the parents after partaking in a parent-training program (McConachie & Diggle, 2006). McConachie and Diggle (2006) also found parent training to have a positive effect on the parent and child relationship.

Furthermore, Schultz et al. (2011) reviewed and analyzed 30 research articles across a 20-year period related to parent education of children with autism. In contrast to McConachie and Diggle's (2006) review, Schultz et al. (2011) focused on how the trainings were carried out, while McConachie and Diggle (2006) focused on the skill enhancements of parents and child. In Schultz's et al. (2011) study the child was present for 80% of the trainings, which research has shown to be common practice. Only 10% of the parent education programs used curriculum based training, which means the literature referred to the training as curriculum or a citation was included in the literature for a published curriculum. A total of 43% of parent education programs used manuals to train the parents, meaning they taught out of a manual or provided them a manual to follow along. The remaining 47% did not use a curriculum or manual in their parent training. In regards to frequency and duration of parent training 40% of the research articles

contained no information and 23% contained information on either one or the other, but not both. When reviewing the frequency of training the range varied from 25 hours per week to one hour per week. Similar to frequency, the duration had a wide range of one year to only one week. Parental involvement is important in the effectiveness of early intervention programs and parent training is a contributing factor. It is important to conduct research on the effectiveness of parent training. Studies have shown the impact of parental involvement on early intervention programs conducted in homes (Dillenburger et al., 2004; Ozonoff & Cathcart, 1998).

### **Home Based Early Intervention Programs**

Effective parent training is important to the effectiveness of home-based early intervention programs to ensure parental involvement adheres to the child's educational and developmental needs. Roberts et al. (2011) conducted a randomized controlled trial of two early intervention programs. The first program was an individual home-based program and the other one was a small group centre-based program for children along with a support group for parents. Both programs fall into a low intensity category, only receiving a weekly session of two to three hours, compared to the recommended 15 to 25 or sometimes 40 hours a week of other intervention programs (Roberts et al., 2011; McConachie and Diggle, 2006). Eighty-four participants in the study were enrolled in other intervention programs outside of this study, which accounted for higher intensity and more hours. The results indicated that the centre-based program along with the support group for parents provided a better outcome when compared to the home-based and control group. Furthermore, the results indicated support for the child and parent combined to develop an effective intervention. Similar to McConachie and Diggle

(2006), providing information and support for parents was highlighted as an integral piece to improving social communication skills of a child with autism in increasing the effectiveness of an intervention program (Roberts et al., 2011). The results of Roberts et al. (2011) study contribute to the hypothesis that parental involvement is key to the effectiveness of early intervention programs, whether or not the program is centre or home based.

One of the guiding principles of the TEACCH model is the involvement of parents as change agents to the success of children with autism (Ozonoff & Cathcart, 1998). The TEACCH model can be used in a centre based setting, but also in a home based setting, which increases the duration of treatment the child is receiving. Parents involved in home-based settings can become advocates and liaisons for the centre-based programs based on their increased skill sets. Decreased feelings of stress and depression have also been shown after completion of a home-based program, such as the TEACCH model (Ozonoff & Cathcart, 1998). Ozonoff & Cathcart (1998) conducted a study of 22 children with autism and their parents who were enrolled in an unspecified day treatment setting.

In contrast to Roberts et al. (2011) where there was no control group or dual enrollment, in this study 11 were dually enrolled in a home-based program taught by their parents after an intense training program and the remaining 11 children were in the control group. Results indicated significant improvement in the treatment group in comparison to the control group with increased cognitive and developmental skills in the children (Ozonoff & Cathcart, 1998). Over the 4-month treatment period, the treatment group gained 9.6 months of development in relation to the control group (Ozonoff &

Cathcart, 1998). Evidence also showed children who simultaneously received different treatment methods during the study still benefited from the home-based treatment program based on the developmental gains. These results have shown that using a variety of methods in the treatment of children with autism both during the day and at home is more effective than just attending a day treatment program. These results have also shown that structured teaching, such as the TEACCH model during the day, alongside parent involvement in a home based setting in the afternoon and evening produced developmental gains in the child. Such results further the hypothesis of the importance of parental involvement alongside an early intervention program.

Furthermore, Dillenburger's et al. (2004) study, in contrast to Ozonoff and Cathcart's, (1998) were solely enrolled in a home based program with no participants receiving day treatment and followed a long-term and short-term group with no control group. The parent training in this program followed ABA principles, however gave the 25 parents involved the opportunity to tailor the methods and skills to their child's needs. Results indicated that parents found ABA to be effective in the development of their child with autism. Parents noted raised confidence and overall increased family wellbeing. This study's approach was to work with the child for as long as needed in order to reach the targeted goals of the child, whereas in previous research, duration lasted anywhere from one week to one year and there was no mention to duration lasting as long as needed for the child (Dillenburger et al., 2004; Schultz et al., 2011).

In contrast to Ozonoff and Cathcart's (1998) study, Dillenburger et al. (2004) focused on parent perceptions of their satisfaction with the parent training and home-based program rather than the improvement in child development. This study has shown

the importance of parental perception in the training and their involvement within a program, specifically a home-based program. Research has shown some children are enrolled in center-based early intervention programs, home-based programs or both and each unique setting plays a role into how involved a parent is alongside the program. Parental involvement or the lack of involvement causes stress on a parent, let alone caring for a child with autism in general.

### **Factors Contributing to Lack of Parental Involvement**

Parental involvement is considered to be a key element in the success of early intervention programs, yet there is limited research on the actual role that parents play in the early intervention of children with autism (National Institute of Mental Health, 2004; Benson, Karlof, & Siperstein, 2008). Research has shown the impact parental involvement can have on the success of an early intervention program, yet Benson et al. (2008) has found there is no research contributing to the factors that play a role in how involved parents are in their child's autism early intervention plan. Research has shown levels of stress to be higher in parents of children with ASD than most other children with developmental disabilities (Ozonoff & Cathcart, 1998; Mancil, Conroy, & Nakao, 2006; Osborne & Reed, 2010; Tehee, Honan, & Hevey, 2009). Stress is the main reason for lack of parental involvement alongside a child who is enrolled in an early intervention program. Lack of support, time, and socioeconomic status are also contributing factors to the lack of parental involvement (Benson et al., 2008).

### **Stress**

Research has shown the high amount of stress experienced by parents of children with ASD, particularly those who express behavior problems or language barriers at

home (Benson et al., 2008; Lecavalier et al., 2006). A Developmental Behavior Checklist was conducted by teachers for 18 children with autism to assess the level of stress, anxiety and depression in parents of the children. The correlations between the Developmental Behavior Checklist and stress scores indicated a level of 0.58 for mothers and 0.49 for fathers (Lecavalier et al., 2006). Osborne & Reed (2010) found the high amount of stress in mothers was correlated to lack of expression in emotions and feelings from a child to their mother. A study of 293 teachers and parents who care for children with autism showed parents had more stress in relation to child problem behaviors than teachers (Lecavalier et al., 2006). Lecavalier et al. (2006) believed this to be a result of teachers being better equipped with education and training resources to handle problem behaviors. Osborne and Reed (2010) found similar results in their study of 65 parents of children with autism in that stress is a direct result of problem behaviors within the child.

Benson et al. (2008) conducted a study of 95 mothers to assess their involvement in their child's development with the goal to determine what factors contributed to their involvement. Results indicated mothers engage in program-based resources when available as well as home-based interventions, such as DTT during meals and or car rides. Mothers reported trying to combine as many activities as possible to generalize program-based activities into daily routines. Some mothers reported they did not have the time or energy to be involved in their child's education at home (Benson et al., 2008).

Benson et al. (2008) stated:

Use of verbal language was also found to be significantly and positively related to intensity of mothers' home-based (but not school-based) involvement, suggesting that educational interactions between parent and

child may be hindered in situations where the child with ASD demonstrates limited language ability. (p.58)

This research supports the hypothesis that lack of parental involvement may have an impact on a child with ASD who is enrolled in an early intervention program, while parental involvement supports the success of programs.

Mothers have reported poor to fair in their mental health rating when compared to mothers of children without developmental disabilities (Schultz et al., 2011). Moes and Frea (2010) found the daily routine at home to be stressful on parents with a child with autism. Schultz et al. (2011) found mothers who received parent training felt more knowledgeable about their parenting skills. McConachie and Diggle (2006) found stress and maternal depression to be reduced amongst parents when they are involved in a parent-training program. Similarly, Moes and Frea (2010) found parent training in FCT to improve the stress that comes along with the rigor in the daily routine of taking care of a child with autism.

### **Overall Support**

Support from school staff also plays a key role in the involvement of parents. Benson et al. (2008) reported only 40% of mothers received parent training and 43% were asked to observe or volunteer in their child's classroom. Benson et al. (2008) reported mothers' felt how school's involve parents determines their involvement. Seeking out information can be hard, however research has shown when conducted, parents have adjusted better emotionally (Tehee et al., 2009). Parents feel a sense of hopelessness when they have do not have enough information provided by schools or support systems (Tehee et al., 2009). In regards to support, Tehee et al. (2009) found in

their study that parents of children ages 11-14 felt they had more support and received more information on education from school staff than parents of children ages three to six years old.

### **Time and Socioeconomic Status**

Research has shown working parents, particularly mothers, have a hard time caring for their child with ASD when they need to balance out work and child care commitments (Benson et al., 2008). Mothers tend to take on more domestic concerns where fathers are more anxious about the financial aspect of how raising a child with autism will affect the family (Tehee et al., 2009). Socioeconomic status plays a significant role in parental involvement. Benson et al. (2008) found a significant positive effect on mothers' home-based involvement and higher SES status. Mothers felt they knew more about educating their child than a school-based program would. Support, time and SES are factors that contribute to the stress parents feel when taking care of a child with autism. McConachie and Diggle (2006) summarized the theme of parental involvement when they stated:

Measurement of the efficacy and effectiveness of the involvement of parents in programmes to help their children's development should include a range of outcomes: child developmental progress, parent-child interaction patterns, parents' knowledge, attitudes and stress levels, family functioning, and cost-benefit analysis. (p.121)

The review of the literature gives insight into the current early intervention programs available and reveals the importance of parental involvement to the effectiveness of the programs. The review of the literature also reveals the importance of

parent training and how that generalizes to home-based interventions, along with contributing factors into potential lack of parental involvement as a result of the stress involved with taking care of a child with autism. There is a gap in the literature with regards to what happens to children enrolled in an early intervention program when parents are not involved. Literature reveals the success of programs when parents are involved; however there is lack of research on the success of programs and the impact on the child when parents are not involved. The purpose of this study is to explore children with autism enrolled in early intervention programs that do not have consistent parental involvement from the perspective of social workers. The researcher hopes to add to existing research by looking at professionals' perceptions of parental involvement and the impact lack of parental involvement can have on an early intervention program and the child enrolled. The data analysis will compare the findings to the research literature and identify implications for professionals that provide early intervention services.

### **Conceptual Framework**

This research will examine parental involvement alongside early intervention programs for children with autism through a family systems perspective. As a result of this perspective, the theoretical framework that this research study is based on is Systems Theory with attention on the family system as a whole. "A systems perspective sees the human behavior as the outcome of reciprocal interactions of persons operating within organized and integrated social systems" (Hutchinson, 2003, p.51). Therefore, the Systems Theory focuses on the interactions within a family working together and their environment and not just the individual at hand. Research has shown the effectiveness of early intervention programs for children with autism when their parents are involved. The

Systems Theory sees parental involvement in a child's success rate within an early intervention program as family working together rather than the child developing all on its own. According to research, early intervention programs are successful if parents are involved; therefore it is important to view the parents and child from a Family Systems theoretical framework.

Research has shown that a family is an "open, ongoing, goal-seeking, self-regulating, social" system (Broderick, 1993, p.37). An open and ongoing system involves changes over time where input and output are exchanged through itself and its environment. When referring to an open and ongoing system there is a strong correlation between change and its relationship to time, for example, the past, present and future (Broderick, 1993). The family unit sets and achieves goals by organizing their goals into hierarchies. Within the hierarchy the family places their most essential goals at the top as these goals have been found to be of utmost priority and less likely to change (Broderick, 1993).

Self-regulation helps families set and achieve these goals. The family assess' their goals and current status of each goal to determine if they are on track to complete these goals, which is essentially an evaluation process (Broderick, 1993). Therefore, families need self-regulation in order to determine their course of action when their goals and current status are inconsistent. Social systems share a same set of meanings among each other through communication. The meanings within the shared communication have an informational and relationship-defining component, which make up the family system (Broderick, 1993).

In summary, a family systems perspective focuses on the family system as an “open, ongoing, goal-seeking, self-regulating, social” system (Broderick, 1993, p.37). The interactions within a family play a vital role into how an individual coexists within their natural environment and family system. Parental involvement alongside a child with autism who is enrolled in an early intervention program is vital to the success of the program. Parental involvement in a child’s life with autism greatly impacts the family unit; therefore the foundation of this research study is to view parental involvement and the child with autism from a family systems theoretical perspective.

### **Methods**

As a result of a gap in the research literature regarding the impact lack of parental involvement can have on a child with autism enrolled in an early intervention program a qualitative exploratory research study has been completed through the use of unstructured interviews. The researcher chose qualitative research to gain a deeper understanding of the topic under consideration from a person’s perspective in words, rather than gaining data in number form. Under this natural environment the researcher wanted to understand the problem of lack of parental involvement through professionals. Through this form, the researcher entered the person’s natural environment and conducted an in-depth interview containing descriptive data, such as words, quotes and audio recordings. Qualitative research is inductive in nature, meaning this researcher has taken the research and created a new theory, rather than proving an existing theory right or wrong.

The purpose of this study was to explore professionals’ perceptions of parental involvement of children with autism enrolled in early intervention programs. This study answered the question, “What are professionals’ perceptions on children with autism

enrolled in early intervention programs that do not have consistent parental involvement?" This qualitative study explored the perceptions of professionals who work in an early intervention program for children with autism on parental involvement alongside the program.

### **Research Design**

For this qualitative exploratory study eight in-depth unstructured interviews have been conducted. The interviews lasted approximately 45 minutes to one-hour each. Mental health practitioners and mental health professionals were asked to participate in the interview. These practitioners and professionals provide one on one therapy and family services in an Autism Day Treatment Program to children with autism ages two to six years old. The Autism Day Treatment Program provides a classroom setting with one on one support and services including guiding principles from the TEACCH, DIR/Floortime, and SCERTS models with some ABA strategies instilled throughout, although they do not follow the ABA theory. The Autism Day Treatment Program focuses on social interaction, play, emotional regulation, cognitive functioning, fine and gross motor skills, speech, language, and communication. The Autism Day Treatment Program also emphasizes the importance of parent involvement by offering education, parent support groups and in-home support services. The Autism Day Treatment Program communicates with parents on a daily basis informally and formally through treatment plan updates and further progress and barrier updates as needed.

### **Sample**

The participants in this exploratory study were eight mental health practitioners and mental health professionals currently working within an Autism Day Treatment

Program. In order to obtain the sample, the researcher received a listing of names and email address from a mental health professional of all practitioners' and professional's working in an Autism Day Treatment Program. This email invited the eight Practitioners' and Professional's to participate in the exploratory unstructured interview as well as provide information explained the purpose of the study. The researcher provided a consent form, which included information on the background of the study, procedures, risks and benefits of the study, information about confidentiality, and a \$10 compensation payment to a coffee house. If they chose to participate they responded to the researchers email to set up a time to complete the interview.

The interviews were conducted in a closed private room at the agency where the Autism Day Treatment Program is located. During the interview, a verbal consent was tape-recorded and issues pertaining to confidentiality were explained. The researcher used an interview guide with the same eight questions for each participant. The researcher had the right to ask clarifying questions if need be. The researcher maintained a journal to write notes after each interview to reflect on the experience as a way to prepare for future interviews during the study as well as expand on ideas in the process of developing a theory.

### **Protection of Human Subjects**

To protect each human subject, a proposal was submitted to this researcher's MSW Clinical Research Committee. Upon the committee's approval, an application was sent to the St. Catherine University Institutional Review Board (IRB). This Board evaluated the content and procedures to ensure that the research upheld the participant's rights. In addition to this review process, a consent form (see Appendix A) was handed

to participants in the beginning of the interview that clearly defined the purpose of this research. The consent form explained that participation in the research study is voluntary, and that signing the consent form denotes their participation. As stated above, a letter was obtained from a mental health professional at the agency where the Autism Day Treatment Program is located to ensure the authorization of a sample containing practitioner's and professionals from the agency that were eligible to participate. The letter indicated that involvement in this study would in no way affect the participant's status with the agency now or in the future.

All necessary steps were taken to ensure confidentiality and to protect the privacy of the participants. The interviews were audio taped and transcribed with the help of the researcher's research assistant. Only the researcher and research assistant had access to the audiotapes and transcriptions. The audiotapes were secured in a locked filing cabinet in Edina, MN. The transcripts were kept on a password-protected computer. The participants were asked to give a verbal consent on tape as required by the IRB.

### **Data Collection**

The data was collected through the completion of eight unstructured interviews within a two-month period. The researcher conducted the interviews and asked questions of the mental health practitioners and mental health professionals who work at the agency. Each interview consisted of eight open ended questions (see Appendix B). The questions ranged from topics such as practitioners and professionals definition of parental involvement, what their experience has been with parents involved in the autism day treatment program, their ability to see an impact in children who have parental

involvement compared to those who lack parental involvement, and the success of children in the program with parental involvement.

### **Data Analysis**

The researcher and research assistant transcribed the audiotapes immediately after each interview. The researcher used content analysis to analyze the data collected, which is, “a carefully, detailed, systematic examination and interpretation of a particular body of material in an effort to identify patterns, themes, biases, and meanings” (Leedy & Ormrod, 2005; Neuendorf, 2002 as cited in Berg, 2007 p.303-304). The researcher began with the research question and sorted the content into themes by taking a look at previous literature and the interview questions. The researcher then read through the data within the transcription and took notes on themes that were found in relation to the research question. The researcher then selected coding rules for each category previously determined. Different color codes were used to distinguish the categories from one another. After separating the categories to the actual questions the researcher looked for patterns and took note of the patterns seen to include in the findings section.

### **Strengths and Limitations**

There were several strengths in this study. Gaining perceptions and in-depth information from mental health practitioners and professionals provided theory to existing literature and strengthened the researcher’s current study. Another strength of this study was the number of participants interviewed. Practitioners and professionals are part of the success to the early intervention programs and they understand the importance of parental involvement. An interview hopefully gave the practitioners and professionals the feeling that they had the opportunity to provide their experiences to the existing body

of knowledge in order to enhance the success rate of an early intervention program, such as the Autism Day Treatment Program at the participant's agency. By exploring their perceptions the researcher provided confirmation to the current body of knowledge on the importance of parental involvement and new information on the effects lack of parental involvement could have on a child to research and agencies that provide early intervention services.

There are also limitations to this study. There was a significant gap in research literature regarding lack of information on the success of early intervention programs for children with autism when parents are not involved. As a result of this gap the researcher had to be self-aware throughout the interview to not have an "investigator effect" or probe in a way that would steer the interviewee in a certain direction. The researcher needed to ensure there were no biases within the interview and remain neutral throughout the interview.

The sample consisted of practitioners and professionals from one agency, which resulted in the sample not being diversified regarding perceptions, age of the children and interventions used. Another limitation to this study was interviewing mental health practitioners and professionals. The researcher wanted to know their perceptions, however the thought regarding what would limit parental involvement had crossed the researchers mind and if interviewing parents would be beneficial to the study or not. The researcher was able to find information in previous studies on parental stress as a result of raising a child with autism, therefore did not feel it necessary to add parents to the interview list. However, this could be considered a limitation to the study. In the following section, the researcher provides implications and directions for future research.

## **Findings**

This research was designed to explore the perceptions of mental health professionals and practitioners on children with autism enrolled in early intervention programs that do not have consistent parental involvement. This portion of the study begins with a brief overview of the participants who were interviewed. This is followed by eight themes that emerged from the data. These themes consist of the following: definition of parental involvement, parents contribution to the success of the program, experiences with parental involvement, effect parental involvement has on a child or lack thereof, effect parental involvement has on a child and their success in the program, ability to tell the difference in children with parental involvement and children without, the role of education and socioeconomic status in parental involvement, desired changes for an early intervention program. Subsequent themes emerged from the primary eight themes, which are organized throughout this section. The mental health professionals and practitioners interviewed play a vital role in the autism day treatment room. Each participant works with the parents of children enrolled in the early intervention program.

### **Definition of Parental Involvement**

A number will refer to the professionals and practitioners that took part in the interview as participants in order to maintain anonymity of each participant. All of the participants touched on the following areas as important to the success of a child in an early intervention program when asked to describe parental involvement: 1) what is going on in the treatment room, 2) connecting with mental health professionals and practitioners on a regular basis, 3) attending meetings, 4) participating in in-home therapy; 5) working actively with the mental health family practitioner, 6) professionals

and practitioners being available for questions, 7) parents wanting to learn the techniques that are used in the treatment room so they can do them at home, 8) getting to know other parents in the program, and 9) getting to know the people working with their children by building a relationship with them. Within these definitions core themes arose as integral to the definition of parental involvement, such as, (a) contributing to success of the program and the child, (b) the importance of communication, and (c) the ability to generalize skills.

### **Contribution to the Success of the Program**

Most importantly, the theme of parental involvement contributing to the success of the program and the child was stated by many of the participants. Participant one, a mental health professional, stated, “I know research shows that parental involvement and family involvement is one of the biggest indicators of success”. Participant four, a Mental Health professional similarly stated, “I think any way that they [parents] can get involved and how they feel comfortable will really benefit their child overall”. Further, participant six, a Mental Health Practitioner emphasized the importance of parental involvement with the following statement, “Parental involvement is key because without the parental involvement you may never do early intervention”. This participant expressed, along with participant four, that parents are the experts on their children and the starting point to their treatment. These two participants believe that they have a lot of schooling and knowledge, however the parents know their child and they know what works and what they are able to do. Participant five shared feelings in regards to the importance of parental involvement within an early intervention program, “children who are this young, the more we can get parents involved and on board with what we are

doing in the treatment rooms the more they can benefit with the treatment we are doing overall”. Parents not only are the starting point to their children’s treatment, but also need to be involved once their children begin treatment. Parental involvement is a process that happens over time and it multi-faceted, not just limited to a one-time experience.

### **Importance of Communication**

The parent’s ability to convey information effectively to staff is important because then parents and staff are in agreement with the quality of care of their children will receive. Participant two found that relationships built between the professional or practitioner and parents result in more parental involvement when they stated, “The more parents are connected to professionals and practitioners here, [the agency] they are more involved and more connected to what is going on in the program and at home as well.” Daily communication from parents to the professional or practitioner as well as communication to the parents from the professional or practitioner is one way participant four reported everyone can be connected. Participants expressed when parents are involved communication seems to flow easier between the professional or practitioner and parents. It was noted that some parents are more open to communicating than others. Participants four, five and eight shared their feelings around the program not being a one size fits all type of program and that parental involvement can look different for each family. Participant eight stated, “I tend to look at involvement in what is realistic for them, but I also tend to look at what is optimal and has potential to be more involved”. This participant emphasized that involvement varies from family to family and noted that some families might want or need more involvement and support and others may be more

hesitant to being involved or requesting support, therefore, finding the optimal solution is important to the level of involvement parents can give. The same participant, "...looks at body language and non-verbal communication to see how engaged they [parents] are and how much interest they have in being involved". Participant eight was the only one to discuss body language as a sign of engagement.

Participant four discussed the requirement of parental involvement and how the agency used to stress the importance of parental involvement; however they are steering in the direction of certain aspects of parental involvement to be a requirement, such as the in-home piece. In regards to setting expectations early, the parents need to commit to their involvement, otherwise the program might not be the right fit for them. Participant four shared what a conversation with an incoming parent might look like and stated, "Really emphasizing how important overall their involvement is and now it is essentially a requirement for there to be some in home piece for all incoming kids in the program". Communication involved both parents and staff agreeing on the treatment plan of the child. Participant seven stressed this point when they stated:

Parental involvement is working with us hopefully as much as possible as a team, not just following through with suggestions that we might have for their child or them trying to replicate activities, and therapy ideas that we have here, but it is more being on the same page of what is important.

Professionals, practitioners and parents being involved in the child's life and working together as a team gives the child the most opportunity to generalize their skills across environments and into the community.

### **Importance of Generalization of Skills**

All eight participants discussed the importance of generalizing skills, which is the ability to carry learned skills across different environments, and expressed that active engagement with the child in the home allows the ability to generalize skills from the program to the home and then back to the program. Participant seven stated in regards to the overall goal of the program, “It is very important for this population [Autism] to generalize and it is very common for kids to do well here [in program] and not so well at home or they have things that they do at home that they do not do here [in program] and it is all very categorized in their minds and becomes very rigid as something that they only do or not do at home”. These rigid patterns can deter their success in the program because:

The overall goal is to function overall and for their skills to be generalized across people and settings and have it be okay that mom and dad might do this a little differently than I [child with Autism] do at school, but I still know what to do, or I can roll with the punches and adapt”.

In addition, participant four stated the following, “It is so important for your child to learn skills across environments because it is hard for children to generalize skills and it is really important for us to help them generalize the skills from school to the community”. In order to help with the generalizing of skills, the in-home therapy that is offered by the professionals and practitioners is key to helping the children succeed in generalizing their skills. Participant four stated:

Since the home setting is so different than the treatment room setting...I think that is one of the biggest pieces, but I think that can be really intimidating to let a

professional into your home and kind of be open to feedback and be vulnerable in saying, you know, this is what is hard for us and can you help us?"

The theme of generalization of skills was prominent across the eight interviews.

Generalizing skills is important to the child's success developmentally and without parental involvement, the ability to generalize skills can be difficult.

### **Experiences of Parental Involvement in the Autism Day Treatment Program**

The professionals and practitioners expressed parental involvement is different with each family and their experiences have varied from one extreme to the next, except for participant six, who expressed that their experience has been really good and all the parents in their treatment room are involved and invested in seeing their children succeed. Participant two expressed the variation of parental involvement in working with children when they stated:

I have some parents that are fantastic, when you mention something or a different way to follow through and they try it and they will update you on how it went and then I have worked with families where there is limited involvement and that's their choice.

Similar to participant two's experience, participant three, a mental health practitioner, has seen, "Some parents who are not involved really at all and basically will attend the meetings they have to and then will drop off and pick up and that's about it". However, conversely, participant three has also seen, "Parents who are very involved and always asking questions, making phone calls, and letting us come do in-home to work on their [child] skills in the home and carrying things over". Having seen the two extremes, participant three shared how her experience has been different with every family,

however participant two can “definitely see a difference in the kids who have had it and not had it”. Participant five has seen, “the whole spectrum of involvement with parents”, with some families not wanting support and some families, “who come to me [practitioner] every day with questions, who call me on the phone to learn as much as they can about the diagnosis, treatment, and research”. Within the experiences of parental involvement, positive experiences and experiences with lack of parental involvement were shared by the professionals and practitioners.

### **Positive Experiences with Parental Involvement**

In regards to parental involvement varying with each family, the participants were able to discuss some of the good experiences they had with parents. Participant six discussed this program being one that parents have to work hard to get into, such as being placed on a wait list, participating in various forms of assessments, and attending a variety of meetings with staff. Participant six stated:

It is not a court-mandated program; it’s their choice so they come seeking help whether they get referred by their pediatrician or other resources. They are looking for someone to understand autism and how to help their children so the parents here are very good and willing to use the family practitioner and to have them in their home and help them that way.

Participant one expressed that their experience with parental involvement has been good. Participant one stated, “It’s something within the last year that we have really put a focus on, the importance of it, what we are able to offer families, so that has been really exciting”. Participant eight shared the same experience as participant one. For example, participant eight expressed that parental involvement is evident from the start that they

would be able to be involved. Participant eight expressed that a big part of this was based on the relationship that was built early on with the family. Participant one also discussed the importance of building a relationship when they stated the following:

The families that are involved and reaching out and really utilizing the resources, I mean, there is such a big difference in just developing that relationship with the family, those are the kids that, regardless of their functioning and abilities, I just feel like children have more success in different areas when there is family involvement.

Participant seven believed that parents of children with autism are not that different than any other parent in regards to wanting the best for their child and loving their children.

Participant seven discussed the overwhelming piece for a parent of children with autism is that their child has autism, in contrast to a typical developing child.

### **Experiences with Lack of Parental Involvement**

Participants reported on the level of parental involvement among parents.

Participant four stated, "Some [parents] are really accepting and are OK what can I do? And some people are still in the stages of grief and loss and are not really sure".

Participant one stated, "I know for families it's challenging to participate, there is a desire for it and they want to do it, but families are under a lot of stress and time constraints".

Participant two stated, "I've had families look at me and say, 'well you fix the child' and they would prefer or are not interested in involvement because they think it's your job to do that." The "fix it" way of thinking became a theme in the research when participant three stated their experience with parents has fallen under this category. For example, participant three stated that a couple of years ago, prior to the in-home therapy being a

requirement in the program, the mindset of parents was very, “drop my child off, you guys are going to work with him or her and fix her so to speak”.

Contrary to participant three’s experience, participant seven reported the “fix it” mentality in a different way. Participant seven has seen parents who want to “fix” their child in regards to their diagnosis, and have a tendency to over involve themselves and tend to always be working on something, which can have a negative impact on the relationship with their child. Participant five has some families that have been in the program for a couple years and will be done with programming soon. According to participant five, these families expressed they were ready to move on as a result of having learned enough and not needing as much support at that time. This is different than the over involvement and both experiences can be seen as lack of involvement from a relationship standpoint because there is either too much focus on the diagnosis or not enough.

Participant two has worked with families who would not be classified as uninvolved based on their wants and needs; however they “lack the knowledge base of what parental and family involvement is”. Participant two worked with a family in which the father had mild retardation and it was hard for him to understand the diagnosis and how he should be involved. Participant two worked with them by teaching them about involvement and had more of a teaching approach, rather than informative. Similarly, participant four has taken the teaching approach with families as a result of, “Still grappling with the diagnosis and still trying to figure out what their role is”. From a teaching perspective, participant four tries to, “guide them to have confidence that they

play a really important role”. Participant seven also discussed the grieving parent when they stated the following:

Parents are depressed, grieving, exhausted, and totally overwhelmed and or confused, and a lot of anxiety about what does this mean in terms of a lot of denial about the diagnosis and they are not really understanding why their kid was diagnosed.

Similar to the lack of knowledge base is the cultural differences that play a role in the lack of parental involvement. Participant seven discussed the cultural differences in terms of how to talk about families and how much families want the professional or practitioner to be involved, such as coming into the home. Participant seven stated, “language barriers in terms of even understanding and having good communication” plays a role in the lack of parental involvement.

### **Effect Parental Involvement or Lack Thereof has on a Child**

Most of the participants discussed the effect lack of parental involvement has on a child, rather than the effects that parental involvement has on a child. Almost all of the participants expressed that a lack of parental involvement results in less success for the child developmentally and in the program. An important theme found by the researcher was the disconnection between what the participants are doing while the child is in treatment and what the parents are doing while the child is home.

### **Disconnect between Treatment Room and Home Setting**

To illustrate the disconnect that is seen between the treatment room and what goes on in the child’s home, participant two shared that lack of parental involvement has a significant effect on the child and their success in the program. Participant two stated:

I just think that with more parental involvement the more the communication is open between each other so we are more apt to hear what's not going well in the home so we are more open to trying to work on those things where the other families, if they are not very open to that parental involvement piece and they don't open those doors we don't know what's going on at home and we don't know the lack, we don't know what's missing or we don't know how to make it stronger, or how we can work on the follow through piece.

Participant two reported that consistency in the home would impact the child in a positive manner and their success in the program. Participant four expressed similar challenges with the same disconnect that participant two described. Participant four stated:

If professionals and parents cannot be working together on the same page...it's confusing for them because sometimes it works and sometimes it doesn't [depending on the setting]. If parents handle something at home and we are handling it a different way here; we don't want to teach a child that they can do something here that's a problem at home if they do that. So, if there were not that communication it would definitely be confusing for the child and delay their learning.

This concept of consistency of skills is known as generalizing, which is something that participant five stressed the importance of when she stated the following:

A lot of our kids have difficulty generalizing across different environments, so while we may be doing everything we can during the four hours a day they are here, the child is not going to gain as much progress if they go home or to school in a different environment and are not able to continue working on these skills.

Participant six also identified with the generalization of skills in regards to parents being consistent in the home setting with what is occurring in the treatment room. Participant six stated:

I don't believe the child would be successful without parental involvement because it doesn't matter what you do in the classroom or what you do in the treatment room or in OT [occupational therapy] or ST [speech therapy] if it's not also being done at home in some way. The children need the support of the people here as well as their parents at home because kids spend the majority of their time at home.

In regards to the amount of time the children spend in treatment, participant seven stated the following:

Their [parents] kids are with us for four hours, of a 24-hour day. In order for early intervention to have the best shot at making good progress toward a child being more functional in their world, it should be more than that and so there's kind of always the feeling of being discouraged or thinking how can we get them more on board with this or that.

Participant three shared an example of a family that initially experienced minimal involvement towards involvement in treatment:

An aftercare kid whose family was not involved and so then they panicked when she was discharged and went back home. They felt like she regressed back to before when she started. They feel she was in a good place when she left so then they were open to the resources we provided and they accepted the in-home services and we've been working on it.

This example showed participant two that, “parents not following through with the techniques and things that we have done with their daughter has shown she is not sustaining those skills”.

Within the theme of consistency, participant two has had experience with divorced or separated parents, which has made it difficult for the child to have consistency at home. Participant one has had experience with one parent being very involved and the other parent being less involved. This has even been seen with the diet of the child when the child stays at one parent’s house the diet is followed strictly, however when the child is at the other parent’s house the diet is not followed.

### **Effect Parental Involvement has on a Child and their Success in the Program**

Participant three, as noted above, has seen the effect lack of parental involvement had on a child and their success in the program. On the contrary has seen families who are very involved and follow through and seems, to this participant, to show progress for those kids. Participant four expressed how children benefit when parents and professionals are in agreement with his/her treatment (i.e., evaluating the success of the techniques and interventions in the home and treatment room). Participant one expressed an idea of what makes a difference when there is parental involvement when they stated the following:

Regardless of functioning level it’s not about working towards not having a diagnosis, it’s just increasing the support that that child and understanding the child, and I feel that’s what makes a difference when there is a lot of parental involvement in families...that investment in the child...they gain a better

understanding and they are able to access resources and get the support for themselves and their child.

Participant eight views parental involvement as what is optimal for the parents, such as, “showing a lot of engagement, a lot of interest, and asking questions shows high involvement. That equals greater success”. Although participant eight expressed that an optimal setting equals greater success, participant eight also comes from the perspective that, “It takes a village to raise a child”. Participant eight reported how children’s needs might not be met at home. And, how professionals or practitioners can help the child be successful in that environment. All of the participants agreed that a connection between the treatment room and the home needs to be consistent. The participants also agreed that professionals, practitioners, and parents need to work together in order to have the most success.

### **The Role Cultural Differences Play in a Child and their Success in the Program**

Culture was mentioned twice as playing a role in the effect it has on a child and their success in the program. Participant two expressed the importance of awareness to culture and working with families in the moment regarding parental involvement. Participant two stated, “with different cultures I know it’s always a little different in how we can be as open and welcoming as we can, without us appearing forceful”. Participant two discussed the change of requiring therapy within the home with families now, but in years past it has not been a requirement. Participant two currently has a family that will meet with them; however is still uncomfortable meeting at the agency or having the professional come into their home. Participant two noted that this family does not participate in therapy within the home, which could be a cultural difference. Similar to

participant two, participant three discussed letting people into your home as an important cultural component. Participant three stated, “There are different respect levels for people working with your children.” Culture plays a role in the success of a child in the program, specifically when the in-home requirement is not met, as seen in the previous discussion on the connection between what is happening in the home and the treatment room and the ability to generalize skills across environments.

### **Ability to Tell the Difference in Children with Parental Involvement**

Participant one was able to tell the difference in children who have parental involvement, although she stated the difference was not necessarily in their abilities or progress on treatment goals, although she did see that to be true. The difference she saw in the parents who were involved was a stronger, “connection with their child, happiness, and fulfillment in the relationship”. Similar to participant one, participant two also reported the ability to tell a difference in children who have parental involvement versus children who do not based on the type of relationship the parents have with their child. Participant eight reported that the relationship between the child and the parent started when the child was young and referenced attachment theory. She reported on attachment research that has shown:

The early relationships we have with our main caregivers are lifelong patterns with how we interact with others. So, if we see kids struggling in the center [the agency] interacting with others, even though that’s part of the diagnosis, it does make you wonder about that relationship with their main person being another indicator of a potential difference [that is seen].

Each of the eight participants reported being able to tell the difference between children who have parental involvement and children who do not, however participants varied in their responses based on the type of difference they have seen, such as the type of relationship discussed above, amount of progress in the program, and ability to generalize skills across environments.

### **Lack of Success in Children who do not have Parental Involvement**

Participant four reported expressed her frustration with parents who are not involved, she reported, “when there isn’t [parental involvement] it is frustrating and it’s hard to sometimes, as a professional, withhold judgment”. Participant four understands having to withhold judgment based on her position as a professional; however, she has tried to encourage parents to see other ways of doing things that can improve themselves or their lives. Participant four also reported:

It can be hard when we have such invested interest in the child and the parent might be doing things that I personally feel like may not be helpful for them to gain skills and that will help them in the future.

Participant four reported learning about these feelings and to be okay with having these feelings, the participant continues to work with the parents. Participant three reported her frustration when she stated:

It’s more frustrating when they are not involved because we keep trying to do one thing and they do something different at home and the child takes longer to learn skills because they do something here [the agency], they are expected to do something different when they walk out the door.

Participant three reported the difficulty children have when trying to generalize skills and stated:

How they cannot usually generalize their skills from one place to the next...they learn them here [the agency] sometimes and they do them here and then they go home and they don't and it leaves it up to the parents to do that.

Participant seven described a current family who lacks parental involvement and the undesired result she has witnessed:

One little boy in our room right now who does very well with the structure that our program has and parents report that he is extremely active and extremely destructive at home so he has this split life.

Participant seven reported that this is what happens to children when they have a structured schedule in the program and then it is different at home. She reported, "children on the spectrum are drawn to sameness and rules and that helps the children understand the world to organize it in their own way, with categories". The children have patterns that they do in the program and patterns that they do at home, and participant seven reported:

When those things are just extremely different there are kids who develop patterns and I don't feel that's helpful. It feeds into something that's problematic about the diagnosis in the first place, and then the more that gets repeated the more rigid those patterns and those categories become. And so, it's almost a set up for the child to not have the opportunity to learn how to be flexible or learn how to generalize skills.

As a result, participant seven stated, “I do think the kids who have less parental involvement their behaviors over time can become worse and sometimes that spills over into everywhere that they are”. In contrast, participants reported the children’s ability to generalize their skills a result of parental involvement. In addition to these reports, successes of children whose parents are involved are described below.

### **Success in Children who have Parental Involvement**

Many participants stated that they could tell a difference in the children who have parental involvement when compared to children who lack parental involvement.

Participant three reported, “Overall most of the kids who have a lot of parental involvement and the in-home services and follow through with things, their children seemed to progress quicker”. Participant six stated, “children who have high parental involvement are much more successful than children who don’t”. Participant five provided detail to the success that she has seen when she reported what it has been like to see the parents involved, she stated:

It is really fun to see when you do have parents who are seeking information and are practicing the games we are doing or use the words or gestures that we use with their child and we are able to see if their kids pick things up faster in the program and within the home too.

Participant four similarly stated, “you know what you are working on has come full circle” on what it has been like to have parental involvement. Participant five reported on the success of children where she has seen parental involvement. For example, parents taking as much information in as they can and working on things at home has shown faster progress for children. This has been shown through, “simple

things like transitions. For kids who struggle to make transitions from one room to another...if I have a parent who is really willing to work through that with them it makes the process go much quicker”, when the parents help support the process at drop off and pick up times within the program. Participant eight also discussed transitions and the ability to see a difference in the children, the participant stated, “when a child is so excited to see their parent at pick up [end of day] and the parent is also, to me that shows involvement, coming from a place of care and attachment”. Parental involvement has attributed to the success of children in the program in the following ways: immediate progress in the program, parents who seek out information and try things at home, and through the type of relationship between the child and parent or primary caregiver.

### **Over Involved Parents**

Participant one reported the temptation for parents to schedule every minute of their child’s life and be over involved. Participant one struggled to say the words over involved, because many parents want to do everything they can for their child. Even though the family was well intentioned, participant one stated, “the child is programmed every minute of their day and that can be overwhelming and cause anxiety for the child”. Participant one reported letting parents know that it is okay to for the child to have some downtime. Participant three reported her experience with a parent who was over involved in regards to wanting to manage the treatment room and wanted everyone revolved around her child. This was difficult for participant three because she wanted to make the parent happy, but at the same time needed to respect every other child in the treatment room. Similar to participant one, participant three reported the parents over

involvement coming out of a good place of wanting the best for their child. Participant four reported on one parent's over involvement:

I [parent] am going to fix this and I am going to work with my child and I am going to do therapy at home and I am going to take the treatment plan and make my own for my child at home.

Participant four stated she knew this parent wanted the best for their child and their heart was in the right place, however, participant four worried how accepting that parent was of the child and where they were at. Participant four stated her intent was for parents to keep teaching their kids skills, however, it is a balance between teaching and, "accepting what their child's strengths are and what's very hard for them and when to know when to push and when to not".

Participant four stated she could tell that the parents are not taking time for themselves when parents are in the "fix my child" mode, which can negatively impact the child and their relationship with them. Similar to not allowing children downtime, participant six reported this type of parenting as the "helicopter type". Participant six reported that parents who are the helicopter type are "so enmeshed with their child and they don't allow their child the independence to succeed on their own". In contrast, the participants reported experiences with under involved parents and the effects it could have on the child.

### **Under Involved Parents**

Participant one reported that parents do not receive manuals when their children are born, especially when they are diagnosed with autism. Parents respond differently to their children's needs, especially when they have a disability. Participant one reported:

Families really struggle in accessing resources, making use of them, and just having so much, whether its mental illness, or poverty, and for most families, when it's multiplied you see less involvement from the family because they are just trying to make ends meet in whatever way they can and that can really affect the child.

Participant one reported the high levels of stress that parents feel as a result of under involvement. Participant one reported:

This can be really difficult for the child because what happens, from what I have seen, is then that piece in the home, they are just not able to give the support the child needs or provide the interventions or have the energy or the piece to really follow through with what we are recommending because they are just trying to get basic needs met.

Participant five reported difficulties with under involved parents. The participant reported:

I think the under involved is personally more difficult for me. Those who you just really want to find out what's going on at home, wanting to get additional information such as how they are sleeping or how school is going. So, I think it's probably more frustrating to have a parent where you are really trying to figure out all that information so you can have a holistic approach to their child and you just aren't able to get that.

Participant five would rather work with over involved parents than under involved parents because she reported having a starting point where she can teach from there. The participant expressed frustration when trying to teach parents who have the mentality of

“fix my child”. Participant three has experienced parents who sent their children to the program and did not want to be involved and now want to be involved; however they struggle to make the necessary changes. Participant three reported, “being under involved in this way just isn’t serving them [children] to their potential”. Participant four stated that it is, “really great when the child can learn something in program, but if they’re not doing it at home they are probably not going to do it when they move to kindergarten”. This statement reinforces the need for a balance between school and home performance.

### **The Right Amount of Parental Involvement**

Each participant reported on what they think is the right amount of parental involvement. The participants stated the difficulties of determining what the right amount of parent involvement is as a result of each family being different and their children needing different things; however there was a theme of “balance” when participants referred to the right amount of parental involvement. Participant six would like to see a parent involved in:

All aspects of medical interventions and mental health interventions, and also give the child some space to learn and develop on their own naturally because kids do learn through play and if a child isn’t given some form of independence it can really negatively impact their self-esteem and their ability to grow as people.

Participant seven described her optimal balance of parental involvement, she stated:

What I think would be optimal for children in an early intervention program is for parents to really have a balance between being able to understand their child’s

diagnosis, being able to work with people in the school district or the people here in our program to be all on the same page and working on the same things.

A balance between understanding the diagnosis and, “being able to have fun with our child and do every day family activities with your child” was reported by participant six in regards to what balance would be like for parents and their involvement. Participant six stated her goal of balance, she stated:

To have a balance between feeling that your child has this diagnosis that you need to fix and that you need to make them better and have a balance of enjoying your child for who they are because there’s much in autistic children and much about them that is absolutely delightful and that typical children might not be doing, that could be channeled as a strength or could be something that you really enjoy about your kid.

Participant eight reported the difficulties in finding a balance between over involved or under involved parents. Participant eight related her experience to the attachment and relationship that a parent has with a child when she reported the parent’s ability to:

Read their child’s cues. So, a couple of our kiddos that I am thinking of in our classroom are starting to show desire for independence. For a parent to pick up on that and foster that, rather than “I’m not needed as much anymore. I don’t like that. I’m going to still hover over you so to speak”.

Having the ability, as a parent, to read those cues and support the child when they need more independence and in contrast, more support from the professional, is the optimal balance for participant eight. In summary, the participants expressed there is no right

amount of parental involvement because every family has different needs; however there is a balance of over and under involved that is desired.

### **Socioeconomic Status and Level of Parental Involvement**

The participants in this study had different experiences to report in regards to socioeconomic status and the level of parental involvement. Some expressed socioeconomic status playing a role in involvement while some expressed socioeconomic status not being a factor in the level of involvement. Participant two expressed the mentality of the parent playing a role in the level of involvement rather than their socioeconomic status. The participant has worked with families who identify as low socioeconomic status and who are highly engaged and in contrast, families who identify as high socioeconomic status being less engaged.

Participant one worked with family who identified as low socioeconomic status and with one of the parents diagnosed with mild mental retardation. The participant expressed the need to teach this family about the resources, as they were not aware of what was available due to the diagnosis of mild mental retardation. Participant three does not always associate low socioeconomic status with low involvement. The participant stated:

I had one family I worked with where I was so pleased because they were from a lower socioeconomic status, they really struggled financially, they had their own mental and developmental challenges as well and they actually succeeded far more than many other parents I saw who didn't have those same challenges that they had.

Even though participant three expressed little correlation between socioeconomic status and level of involvement, the participant stated, “I think sometimes it might”.

Furthermore, participant three reported:

I do think that sometimes our families who are a little less educated or have a lower socioeconomic status might struggle a bit more, but again, it depends on how determined they are to make it work. We always meet them where they are at as far as their understanding is and if they are willing and wanting to work on it, it works.

Similar to other participants expressions of socioeconomic status not always playing a role or sometimes playing a role in level of involvement, participant four stated:

I definitely think a family who is struggling to make ends meet financially, who don't have a car, so their child is brought by transportation, and they are not having daily communication with the practitioners or professionals working with their children. That can pose obstacles for them.

Participant six agrees with participant three in regards to families who have financial hardships. The participant reported, “Families who are worried about meeting their basic needs are less involved than parents who have the ability to meet all their needs”.

Participant six discussed the hierarchy of needs when she stated:

If you are worried about how you are going to pay bills and put food on the table you aren't going to be as worried about your child making eye contact that day. Once your survival needs are met then you can start worrying about other things.

Participant three works with a family who has very limited financial means, in contrast, the family is one of the most involved families in the treatment room. The

participant reported the family is involved through communication on the phone, however; certain behavior concepts or strategies that are done in treatment are hard to understand because it can be:

Counterintuitive if she [child] is yelling and screaming and we [professionals and practitioners] say to ignore it because she [child] is trying to get negative attention. That can be hard for them because it's so intuitive to say stop yelling so that can be where there are challenges if they have less education and both of them for this particular client have learning challenges themselves so it does make it hard.

This family is an example of a lower socioeconomic status with high involvement; however, the education of the parents played a role in their ability to be involved in regards to accessing resources and understanding them.

### **Education and Level of Parental Involvement**

Participant one reported having an education provides parents the ability to research and access resources. The ability to access resources is important for parents, according to participant one. Participant one reported, "There are a lot of systems that are hard to understand". For families that do not have the educational background to help them understand the systems available and access resources, the mental health professionals provide the support needed. For example, participant one stated, "trying to call medical assistance and get an answer can be very difficult or setting up transportation". The mental health professionals make these phone calls for families who struggle to understand the system.

Participant one expressed the level of involvement increasing for families who have an education as a result of easy access to resources. Participant one has experienced educated parents ask very educated questions of the professionals and practitioners. These questions are a result of books and articles they have read and different techniques they are trying in the home or questions related to the diagnosis of Autism. The participant stated it is much more difficult for families who do not have the ability to research and ask educated questions. An example of this was reported from participant eight, she stated, “maybe high school education is the highest, with that you typically have, or you make less per hour so then you might be picking up two shifts, which is more strenuous”. In contrary, the participant also stated, “on the opposite side a parent who has their PhD could be working just as many hours, coming home really tired, and not involved”. This example shows parents with less involvement, regardless of their socioeconomic status.

Participant five expressed that type of involvement impacts the level of education, rather than the level of involvement. The participant reported her work with very highly educated parents, a college degree or higher, who already know a lot about autism and have done their research. These parents have looked at different treatment modalities and are well informed. As a result, these parents access resources and have knowledge about autism. Participant five stated, “Involvement for them [educated parents] is about helping them be able to relate that knowledge to their child and about what they can do whereas with less educated parents there is more of an education component”.

Similar to socioeconomic status, the education level of parents has an impact on their ability to access resources, such as transportation and knowledge of the diagnosis.

However, a lower level of education does not always correlate to the higher involvement. This study shows level of education does correlate to the level of parental involvement; however it is not always the case and is different for each family.

### **Desired Changes for the Autism Day Treatment Program**

The interviewer asked the participants if there were anything they would change or like to see different in the early intervention program. The themes from this question revolved around family and ways to better support and involve them. Providing family support groups for parents to attend and have the ability to relate to each other was a consistent response from each participant. Participant one reported a desire to support the siblings within the family of a child with autism. An idea from participant one to support the siblings is to provide childcare for parent support groups so families can attend.

Participant one stated:

I think families need to be able to connect with each other and that's something we have struggled with trying to do family round tables and parent support groups, having them at times when their children are in programming so they can come, but it's just so difficult, they are balancing so much in their lives so just ways that we can support them more, more family nights. We have done the parents' night out where we watch the kids and siblings and they can go out. I just think those things where they can connect with other families and people that are going through or have gone through similar situations.

Participant five expressed her desire to support the siblings of children with autism by, "educating an older sibling about the diagnosis and what that means, or if they are younger just teaching them how they can play and interact with their sibling". Another

idea from participant five is to provide a fun group for the sibling that is special and just for them, because, “it has to be tough to have a younger sibling with autism who is taking more of their parents attention”.

Another desire from participant one is to have families take advantage of the in-home therapy that is offered as well as therapy in the community, where professionals and practitioners work with the child and family in a community setting. Participant one expressed, “I just feel that early intervention and family involvement is so important, it’s just crucial for these kids and their success”. Participant one would like to see families take advantage of what is offered, as well as have the program increase the frequency of the services offered.

Participant two sets family expectations early on to ensure the family is aware that the professionals and practitioners are available. Participant two also sets the expectation that they will be meeting regularly to discuss treatment goals and the child’s progress in the program. This is something that participant two would like to continue to do. Similar to participant two setting expectations early on, participant three would like to provide the benefits, during the expectation setting, of using the services provided. Participant three stated:

Instead of us giving a quick blurb on providing services, but actually being able to say these are the ways it can benefit you and benefit your child. These are some things we can do. Just making it more of an emphasis.

One way to show the benefits would be to have parents observe their child in the classroom. Participant four stated, “I would love to have parents scheduled more regularly to come observe in the classroom”. Participant four reported only one

classroom having an observation window to make this possible. Participant four has videotaped children in her classroom to show parents. The participant provided an example of videotaping when she stated:

Sometimes parents say, “Wow my child can do that? That’s amazing”. I just showed a video of one of our kids coming in from outside successfully and we watched it together, the child as well, and he was excited to watch himself and his parents said, “Wow, you did such a great job”. It’s almost kind of like video modeling for them and he [child] felt proud of himself and his parents felt proud of him that he can do certain things that they didn’t necessarily think he could.

According to the participant, “sharing videos with the parents helps the parent not be surprised to see that there child is doing something in the treatment room that they are not doing at home or vice versa”. Similar to the concept of video modeling, participant four expressed the idea of parent child interaction therapy. Participant four stated:

I just think it would be so cool to set up something where the parent has a bug in their ear and we [professional or practitioner] can provide them with things that might help if they are really struggling with how to play with their child”.

Participant four expressed the results of this idea would help the parents feel successful with their child.

Participant seven and participant eight both reported the desire to offer education to families. The education could be centered on what parents are currently struggling with or geared towards new families entering the autism day treatment program.

Participant seven stated:

I think there is a lot of information and a lot of topics that particularly new families to our program could probably benefit from having. And we just need to figure out what's going on in the family's lives and what it is that they want.

Participant eight would like the program to include a professional with a medical background to the existing multidisciplinary team. Participant eight stated:

There are things that come up that we may have ideas about, but more than that, that's out of our competency. We can make referrals, but just to be able to get that perspective also, and for families, so that the autism day treatment program is more of a one-stop shop. It's so great that we offer the speech and language therapy, the occupational therapy and mental health services, but how amazing would for families to also be able to have their dentist or doctor visit here too.

In summary, the autism day treatment program currently offers support to families in many different ways; however, the professionals and practitioners would like to see additional services provided, such as childcare, a sibling play group, video modeling, and medical services to make the agency a one-stop shop for families.

In conclusion, the eight participants provided data on the following themes: definition of parental involvement, parents contribution to the success of the program, experiences with parental involvement, effect parental involvement has on a child or lack thereof, effect parental involvement has on a child and their success in the program, ability to tell the difference in children with parental involvement and children without, the role of education and socioeconomic status in parental involvement, desired changes for an early intervention program. The themes expressed by the participants perceptions

provided data to the effect lack of parental involvement has on a child enrolled in an early intervention program.

### **Discussion**

A limited amount of research has been conducted on the perceptions of mental health professionals and practitioners on the effect lack of parental involvement could have on children with autism enrolled in an early intervention program. The interviews completed for this study offer perspectives of professionals and practitioners experiences. This section of the study interprets the interview findings and compares and contrasts the data with previous findings reviewed. This section also includes the strengths and limitations of this study. Finally, implications for social work practice and future research will be identified.

#### **Parental Involvement's Contribution to the Success of the Program**

Similar to Wieder & Greenspan's (2003) study that showed a statistically significant trend between uninvolved parents and children who did not make as much progress, the participants expressed the importance of parental involvement. The participants reported the difference in children whose parents are involved when compared to children whose parents are not involved. Wieder & Greenspan's (2003) study was the only study in the previous findings that showed the effect lack of parental involvement could have on a child with autism. Several studies indicated the importance of parental involvement within an early intervention program; however, several studies did not provide information on the success of a child and their success in the program when there is lack of parental involvement (Mancil et al. 2006; Moes and Frea, 2002;

Prizant et al., 2003; Mesibov & Shea, 2010; Panerai et al., 2009; Dillenburger and Keenan, 2009; Ozonoff & Cathcart, 1998).

A study conducted by Roberts et al., (2011) has shown that part of the quality of an early intervention program includes whether or not it requires parental involvement. Similar to Roberts et al., (2011) study, the participants expressed the importance of parental involvement within an early intervention program and reported the requirement of parental involvement in the early intervention program. Not only is it a requirement, but also the expectations of parental involvement are discussed in the beginning of treatment with parents who have children enrolled in the early intervention program. Roberts et al., (2011) study did report parental involvement being part of the quality of a program; however, the different treatment methods reviewed only suggested parental involvement as a component, not a requirement. The models only suggested that parents be involved and expressed the progress children made when they were (Mancil et al., 2006; Moes & Frea, 2002; Prizant et al., 2003; Walworth, 2007; Mesibov & Shea, 2010; Panerai et al., 2009; Dillenburger and Keenan, 2009; Ryan et al., 2011; Callahan et al., 2010; Ozonoff & Cathcart, 1998; Dillenburger et al., 2002). The participants reported parental involvement to be the key to the success of the program and expressed the lack of progress in the child and their development when the parents are not involved alongside an early intervention program. Previous studies did not report on the effects lack of parental involvement can have on the child, therefore the previous studies do not support the findings (Mancil et al., 2006; Moes & Frea, 2002; Prizant et al., 2003; Walworth, 2007; Mesibov & Shea, 2010; Panerai et al., 2009; Dillenburger and Keenan,

2009; Ryan et al., 2011; Callahan et al., 2010; Ozonoff & Cathcart, 1998; Dillenburger et al., 2002).

### **Child's Ability to Generalize Skills**

The findings showed the requirement of parental involvement being the key component to children's ability to progress in the program and generalize their learned skills across environments, such as the treatment room and within the home. One study conducted by Ryan et al. (2011) examining the effectiveness of a child's ability to generalize when parents are involved supports the findings in this study, which showed how parent involvement helps ensure the behaviors learned in the structured program can be generalized to the home environment. Furthermore, a study conducted by Ozonoff & Cathcart (1998) reported parental involvement as the one invariable factor and an integral part of the success of early intervention programs for children with autism. Participants and previous studies both reported an increase in progress and ability to generalize when parents were involved in the home using techniques taught in an early intervention program (Ozonoff & Cathcart, 1998; Ryan et al., 2011).

The participants' expressed active engagement with the child allows the ability to generalize skills from the program to the home and then back to the program. The participants offer in-home therapy to help with the goal of generalizing skills. Similar to in-home therapy, Wieder & Greenspan's (2003) Floortime model case study suggested that the reason for the child's significant improvement in development was a result of active parent involvement. The child was able to take toys and make them into symbolic ideas and words and convey emotions and empathy as well as think logically and abstractly.

Mancil et al. (2006) conducted a case study that examined a child's problem behaviors in the home and the decreased behaviors as a result of parent trainings. Similarly, findings suggested providing training in the home greatly increased the child's ability to generalize. Benson et al. 2008 reported mothers implementing as many activities as possible outside of programming to generalize program-based activities into daily routines. Similar to the study conducted by Benson et al. (2008), one participant expressed satisfaction when she has parents who are seeking information and practicing games, words, and gestures used in programming with their child. This participant was able to see the kids pick things up faster in the program and within the home. Furthermore, the participants reported the in-home therapy as a key component to engage the parents and show them techniques used in the treatment room. Participants also reported generalizing skills as the overall goal of the early intervention program, which is done in the home and community with parental involvement. Previous studies and findings agree that parental involvement is integral to the success of a child's ability to generalize their skills and increase their development in an early intervention program (Mancil et al., 2006; Benson et al., 2008).

### **Experiences with Parental Involvement**

Previous studies reported on numerous early intervention programs and the success of the children when their parents were involved in their treatment as well as involved at home (Mancil et al., 2006; Moes & Frea, 2002; Prizant et al., 2003; Walworth, 2007; Mesibov & Shea, 2010; Panerai et al., 2009; Dillenburger and Keenan, 2009; Ryan et al., 2011; Callahan et al., 2010; Ozonoff & Cathcart, 1998; Dillenburger et al., 2002). The studies did not report on experiences with children who do not have parental involvement

in their early intervention programs. The studies also did not report the effect lack of parental involvement could have on a child. The focus of the studies was the progress and changes seen in a child when their parents are involved. In contrary, when asked about the effect parental involvement can have on a child, the participants reported more information on the lack of parental involvement and the harmful effects rather than the benefits of parental involvement. Contrary to previous studies, the participants reported lack of parental involvement results in less success for the child developmentally and in the program (Mancil et al., 2006; Moes & Frea, 2002; Prizant et al., 2003; Walworth, 2007; Mesibov & Shea, 2010; Panerai et al., 2009; Dillenburger and Keenan, 2009; Ryan et al., 2011; Callahan et al., 2010; Ozonoff & Cathcart, 1998; Dillenburger et al., 2002).

The participants reported a lack of consistency amongst settings. For example, a child has a very structured setting in an early intervention program; however, the child could go home to less structure or no structure at all. This lack of consistency inhibits the child's ability to continually learn and be consistent in their behavior and abilities across environments. Similar to the findings, previous studies have shown the benefits of structure in an early intervention program as well as within the home (Moes & Frea, 2002; Mesibov & Shea, 2010; Ryan et al., 2011). In contrast, these studies have not shown the difficulties experienced when the child's environments are different, therefore resulting in a decrease in behavior and progress. The participants in the study expressed their beliefs as well as experiences with children not being successful as a result of the children spending most of their time at home, in an unstructured environment with little parent involvement, and only 4 to 5 hours in treatment each day.

The participants reported the child is unable to sustain the skills learned when

parents do not follow through with techniques shown to them by professionals or practitioners. The professionals, practitioners, and parents saw this lack of development in the child. In contrary, most of the literature did not report case studies on lack of development in a child as a result of inconsistency and lack of parental involvement. Only Ozonoff & Cathcart, (1998) reported significant progress in increased cognitive and developmental skills by children dually enrolled in an early intervention program and parent taught program at home. Ozonoff & Cathcart, (1998) study contributes to the participants' experiences with parent involvement within the home; resulting in increased skills for the child and progress within the program.

The theme that emerged from the data collected and was supported by previous findings is the positive effect parental involvement has on children enrolled in an early intervention program. Participants reported the positive effect parental involvement has on a child enrolled in an early intervention program. Previous findings supported this positive effect with many case studies done on children enrolled in early intervention programs who have parents involved in their treatment (Mancil et al., 2006; Moes & Frea, 2002; Prizant et al., 2003; Walworth, 2007; Mesibov & Shea, 2010; Panerai et al., 2009; Dillenburger and Keenan, 2009; Ryan et al., 2011; Callahan et al., 2010; Ozonoff & Cathcart, 1998; Dillenburger et al., 2002). The participants stated parents have a better understanding of their child and the diagnosis of autism as a result of their involvement. As a result of this better understanding, the participants and previous studies reported a correlation between the belief parents have in themselves as effective change agents and the level involvement in their child's program and at home (Ozonoff & Cathcart, 1998; Schultz et al. 2011).

### **Factors Contributing to Lack of Parental Involvement**

There are limited studies in the body of literature on the role parents' play in their involvement within early intervention for children with autism (National Institute of Mental Health, 2004; Benson, Karlof, & Siperstein, 2008). Previous studies reported parents' involvement through case studies; however, the case studies did not report the specific roles parents' play in order for their child to be successful (Lecavalier et al., 2006; Ozonoff & Cathcart, 1998; Mancil et al., 2006; Osborne & Reed, 2010; Tehee et al., 2009; Benson et al., 2008; McConachie and Diggle, 2006). Contrary to previous studies, all of the participants reported on the following areas as important to the success of a child in an early intervention program when asked to describe parental involvement: 1) what is going on in the treatment room, 2) connecting with mental health professionals and practitioners on a regular basis, 3) attending meetings, 4) participating in in-home therapy; 5) working actively with the mental health family practitioner, 6) professionals and practitioners being available for questions, 7) parents wanting to learn the techniques that are used in the treatment room so they can do them at home, 8) getting to know other parents in the program, and 9) getting to know the people working with their children by building a relationship with them.

In contrast to the above areas being positive components to parental involvement, there are also factors that contribute to the lack of parental involvement. Some of the factors found in previous studies were consistent with the findings and some new information was reported in the findings that were not found in previous studies (Lecavalier et al., 2006; Ozonoff & Cathcart, 1998; Mancil et al., 2006; Osborne & Reed, 2010; Tehee et al., 2009; Benson et al., 2008; McConachie and Diggle, 2006).

Several studies examined the correlation between high levels of stress and parents who have a child with autism (Benson et al., 2008; Lecavalier et al., 2006). Similar to these findings, the participants expressed parental stress as a factor contributing to their lack of involvement. One participant stated:

This can be really difficult for the child because what happens, from what I have seen, is then that piece in the home, they are just not able to give the support the child needs or provide the interventions or have the energy or the piece to really follow through with what we are recommending because they are just trying to get basic needs met.

Participants reported socioeconomic status (SES) as a factor contributing to the level of involvement by parents; however, some participants also reported SES as a non-factor. The participants expressed experience with families who have a low SES and were highly involved in their child's life and early intervention program. The participants also expressed low SES resulting in lack of involvement due to some families trying to meet their basic needs and not worrying about whether or not their child made eye contact that day. Similar to the findings, Benson et al. (2008) found SES plays a significant role in parental involvement. Benson et al. (2008) found a significant positive effect on mothers' home-based involvement and higher SES. Similar to Benson et al. (2008) study, the participants expressed a correlation between families with a high SES and a high amount of involvement. This correlation was as a result of more access to resources and support.

The participants expressed experiences with families who had a higher SES and a lower level of involvement. Factors contributing to this lower level of involvement are

long working hours, not enough time at home, and exhaustion once at home. The participants also expressed experiences with families who had a lower SES and a lower level of involvement. Factors contributing to this lower level of involvement are less education and lower salary. Less education and a lower salary result in longer working hours and working numerous jobs. These longer working hours and numerous jobs left parents not spending time at home with their children and exhausted once at home. These findings support Benson et al. (2008) study of working parents, particularly mothers, having a hard time caring for their child with autism when they need to balance out work and child care commitments. The findings and previous studies indicate the level of SES having an effect on parental involvement (Benson et al., 2008). However, a higher SES does not result in more involvement and a lower SES does not result in less involvement.

Contrary to previous studies, which reported stress, time and SES as factors contributing to lack of parental involvement, the participants expressed education and culture as two factors contributing to the lack of parental involvement (Ozonoff & Cathcart, 1998; Mancilet al., 2006; Osborne & Reed, 2010; Tehee et al., 2009; Benson et al., 2008; McConachie and Diggle, 2006). The participants expressed the parent's level of education playing a role in parental involvement. Parents with a higher education, for example a 4 yr college degree or graduate degrees, resulted in the ability to access resources and understand the diagnosis. Parents with not as much education, high school diploma or less might not be able to access certain resources, such as transportation to and from programming.

The participants discussed culture as a contributing factor in lack of parental involvement; however, previous findings did not report culture as a factor in lack of parental involvement through case studies. The participants expressed the importance of awareness to culture when working with families. One participant currently has a family that is only comfortable meeting with her. This parent is uncomfortable meeting at the agency with the multidisciplinary team or having the professional come into their home. The participant expressed this uncomfortable feeling from the parent as a cultural difference. Not only does culture play a role in the in-home therapy, but also in understanding the diagnosis. A parent's difficulty in understanding the diagnosis is a result of language barriers between the professional or practitioner and the parent. Interpreting services are provided; however, participants expressed language barriers still play a role in their struggle to understand the diagnosis. Participants expressed the importance of being culturally considerate when working with families and children enrolled in an early intervention program. In conclusion, the results of this study reveal the professionals and practitioners' perceptions of parental involvement and the impact lack of parental involvement could have on a child and their development in an early intervention program.

### **Strengths and Limitations**

There were several strengths in this study. Gaining perceptions and in-depth information from mental health practitioners and professionals provided theory to existing literature and strengthened the researcher's current study. Another strength of this study was the number of participants interviewed. Practitioners and professionals are part of the success to the early intervention programs and they understand the importance

of parental involvement. An interview hopefully gave the practitioners and professionals the feeling that they had the opportunity to provide their experiences to the existing body of knowledge in order to enhance the success rate of an early intervention program, such as the Autism Day Treatment Program at the participant's agency. By exploring their perceptions the researcher provided confirmation to the current body of knowledge on the importance of parental involvement and new information on the effects lack of parental involvement could have on a child to research and agencies that provide early intervention services.

There are also limitations to this study. There was a significant gap in research literature regarding lack of information on the success of early intervention programs for children with autism when parents are not involved. As a result of this gap the researcher had to be self-aware throughout the interview to not have an "investigator effect" or probe in a way that would steer the interviewee in a certain direction. The researcher needed to ensure there were no biases within the interview and remain neutral throughout the interview.

The sample consisted of practitioners and professionals from one agency, which resulted in the sample not being diversified regarding perceptions, age group and interventions used. Another limitation to this study was interviewing mental health practitioners and professionals. The researcher wanted to know their perceptions, however the thought regarding what would limit parental involvement had crossed the researchers mind and if interviewing parents would be beneficial to the study or not. The researcher was able to find information in previous studies on parental stress as a result of

raising a child with autism, therefore did not feel it necessary to add parents to the interview list. However, this could be considered a limitation to the study.

In the following section, the researcher provides implications and directions for future research.

### **Implications for Social Work Practice and Future Research**

#### **Implications for Practice**

The findings of this study offer various implications for social workers, professionals, and practitioners working with parents of children with autism enrolled in an early intervention program. One of the most important implications is the need for further research on the effects lack of parental involvement could have on children with autism enrolled in an early intervention program. The investigation into the perceptions of professionals and practitioners is relatively new and is not something that is often recognized and/or discussed in the social work community. Previous studies have shown the importance of parental involvement; however, these studies have not shown the effects lack of parental involvement could have on a child with autism (Mancil et al., 2006; Moes & Frea, 2002; Prizant et al., 2003; Walworth, 2007; Mesibov & Shea, 2010; Panerai et al., 2009; Dillenburger and Keenan, 2009; Ryan et al., 2011; Callahan et al., 2010; Ozonoff & Cathcart, 1998; Dillenburger et al., 2002). Educating professionals, practitioners, and parents on this topic may help parents be more involved in their child's treatment and assist social workers in finding the most beneficial ways to support the parents and their involvement.

As both previous studies and the results of this study suggest, parental involvement is a factor to the success of a child with autism enrolled in an early

intervention program (Mancil et al., 2006; Moes & Frea, 2002; Prizant et al., 2003; Walworth, 2007; Mesibov & Shea, 2010; Panerai et al., 2009; Dillenburger and Keenan, 2009; Ryan et al., 2011; Callahan et al., 2010; Ozonoff & Cathcart, 1998; Dillenburger et al., 2002). It is important that parents have knowledge of the diagnosis and the benefits they and their child will receive by their involvement as well as the detrimental effects they can have by lack of involvement. It is important for parents to understand and recognize their role as a parent.

One of the challenges the professionals and practitioners expressed for parents was the difficulty in accessing resources and factors hindering their involvement, such as stress, socioeconomic status and level of education. Findings in this study suggest that some parents are involved in the in-home services while others are not. The findings indicated in-home services as a requirement for parents who have children enrolled in an early intervention program; however, not everyone is utilizing the service. This information suggests the in-home services may need to be modified to fit the family's needs. An example of this modification is the concept of cultural consideration and whether or not diverse families would welcome the service or understand the benefits.

The findings suggested an opportunity to utilize the observation window as a means to educate parents on techniques that are being used in the classroom as well as show parents progress their children are making. The additional education to parents would further the goal of a child's ability to generalize their skills as a result of parents observing what is done in the treatment room and then trying the same interventions within the home. There is only one observation window in one of the treatment rooms, which has resulted in this opportunity not being used as often as it could. Furthermore,

findings also expressed parents' positive reaction to videotapes of their child in programming in addition to obtaining education. Parents expressed excitement and astonishment to the skills observed by their child. The video recorder may cause distraction to some children, whereas an observation window allows the parents to observe a live therapy session with little to no distraction.

### **Future Research**

The findings also suggest the need to modify certain services offered to meet the needs of all families. A family support group had been offered in the past; however, attendance had been low. Further research is needed to investigate parents' wants and needs in order to best accommodate each family. Suggestions in the findings indicate offering a family support group during the day for single parent families who work evenings or two jobs. Another suggestion was to offer childcare during the support group so parents are able to attend. In regards to supporting the whole family, suggestions were made on how to best support the siblings of children with autism. A sibling support group or sibling gathering was expressed as a way to have the whole family involved. The participants expressed that siblings can easily be seen as an afterthought; however, it is the social workers responsibility to meet the needs of the entire family and work to explore what works and what does not when supporting this unique population. Since the initial interviews were conducted the parent support group has started again within the participating agency. In order to support the entire family childcare services and a sibling support group are offered at the time of the parent support group to ensure the whole family is supported.

Cultural considerations were a prominent theme in this study. The need to meet families where they are at and offer modifications for in-home therapy if the family is not open to the service from a cultural standpoint is apparent. Cultural considerations is discussed during the intake assessment of a child when they enter an early intervention program; however, the benefit to understanding their culture and being culturally aware might allow families to discuss their needs and how everyone can work together to find a solution. Further research is needed on the benefits of being culturally aware. Further research is also needed to determine the needs of each culture present in an early intervention program.

### **Conclusion**

The findings of this study offer a challenge to the social work profession by way of the need to engage in additional research on the perceptions of professionals and practitioners on the effects lack of parental involvement could have on a child with autism. There is ample research on the positive effects of children with autism who have parental involvement, such as increased developmental skills and progress in an autism early intervention program. Other benefits include the child's ability to generalize skills across environments, a strong relationship between the parent and child, and a better understanding of the diagnosis and access to resources. The effects lack of parental involvement can have on a child are the inability to support the child's needs, the child's inability to generalize skills across environments, and lack of development and progress within the program.

A 78% increase in identification of children with autism over a five-year period indicates the growing number of children who need early intervention services and

parental involvement. With such a high percentage increase in five years, the diagnosis rate is trending against our favor. The findings of this research not only suggest the high importance of parental involvement for children with autism, they also suggest the need for early intervention program staff to encourage parental involvement and ensure involvement is a requirement of the program. Based on the findings of this study it is clear that children whose parents were involved made more progress developmentally and in the program. These new findings should be shared with not only incoming families who enroll their child in an early intervention program, but also to parents whose children are currently enrolled. These findings indicate the high level of power parents have in their ability to make a positive difference in their child. These findings provide hope for parents to feel empowered to get involved and make a difference.

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**APPENDIX A****Parental Involvement alongside Early Intervention Programs  
RESEARCH INFORMATION AND CONSENT FORM****Introduction:**

You are invited to participate in a research study investigating professionals' perceptions on children with autism enrolled in early intervention programs that do not have consistent parental involvement. Alexis Bennett, a student in Master's of Social Work Program at St. Catherine University, is conducting this study. You were selected as a possible participant in this research because you are a professional of an early intervention program. Please read this form and ask questions before you decide whether to participate in the study.

**Background Information:**

The purpose of this study is to establish the importance of parental involvement alongside the effectiveness of early intervention programs for children with autism. Approximately 8-10 people are expected to participate in this research.

**Procedures:**

If you decide to participate, you will be asked to participate in an unstructured interview. This interview will take place at the Autism Day Treatment Program agency in a closed private room. This study will take approximately 45 minutes to one hour over one interview session.

**Risks and Benefits:**

The study has minimal risks. You will be answering questions about your experience within the Autism Day Treatment Program in regards to parental involvement. You may experience an emotional response.

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

**Compensation:**

If you participate, you will receive a \$10 compensation payment to a coffee house for your participation in this study. You will receive this compensation at the completion of the interview.

**Confidentiality:**

Any information obtained in connection with this research study that could identify you will be kept confidential. In any written reports or publications, no one will be identified or identifiable and only group data will be presented. No one in the day treatment program will know your results.

My Research Assistant and myself will keep the audio tapings and research results in a password protected computer and a locked file cabinet in my home and only my Research Assistant and I will have access to the audio tapings and research results while we work

on this project. Analyzing the data will be finished by May 2012. All original reports and identifying information that can be linked back to you will be destroyed by May 2012.

**Voluntary nature of the study:**

Participation in this research study is voluntary. Your decision whether or not to participate will not affect your future relations with the agency or St. Catherine University in any way. Participants can refuse to answer any questions in the interview if you choose. If you decide to participate, you are free to stop at any time without affecting these relationships, and no further data will be collected. The \$10 compensation will not be received unless completion of the interview is successful.

**New Information:**

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

**Contacts and questions:**

If you have any questions, please feel free to contact me at, [benn9469@stthomas.edu](mailto:benn9469@stthomas.edu). You may ask questions now, or if you have any additional questions later, the faculty advisor, Dr. Catherine Marrs Fuchsel at 651-690-6146, will be happy to answer them. If you have other questions or concerns regarding the study and would like to talk to someone other than the researcher, you may also contact John Schmitt, PhD, Chair of the College of St. Catherine Institutional Review Board, at (651) 690-7739.

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

**Statement of Consent:**

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

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I consent to participate in the study and to be audio taped.

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Signature of Participant

Date

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Signature of Researcher

Date

**APPENDIX B****INTERVIEW QUESTIONS**

- 1) How would you define parental involvement?
- 2) What has your experience been like with parental involvement in the Autism Day Treatment Program (ADT)?
- 3) As a Practitioner or Professional how do you feel parental involvement or lack thereof affects the child and their success in the program?
- 4) As a Practitioner or Professional are you able to tell the difference between children who have parental involvement and children who lack parental involvement?
  - a. If so, what is this like for you?
- 5) Is there such a thing as under or over involved parents in your mind?
  - a. Probing question: is there a “right amount” of parental involvement?
- 6) What role do you play in terms of parental involvement within the ADT program?
- 7) As a Practitioner or Professional do you feel there is a correlation between the Socioeconomic Status and level of education of parents and their involvement in their child’s life or the program?
- 8) Is there anything you would change regarding parental involvement within an early intervention program?
  - a. If so, what would this be and why?

**APPENDIX C**

**EMAIL FLYER**

**Recruiting Mental Health Practitioners and  
Professionals for a research study!!**

**Looking for 8 people to participate in a 45 minute to one-hour  
interview!**

**Study purpose: To evaluate the importance of parental  
involvement alongside a child with autism enrolled in an early  
invention program.**

**TOPICS:** your definition of parental involvement, what your experience has been with  
parents involved in the autism day treatment program, your ability to see an impact in  
children who have parental involvement compared to those who lack parental  
involvement, and the success of children in the program with parental involvement

\*Commitment: one 45 minute to one-hour interview

**Receive a \$10.00 gift card to a coffee house for your time and  
commitment.**

Please email me, Alexis Bennett, at [benn9469@stthomas.edu](mailto:benn9469@stthomas.edu) to discuss or sign up for an  
interview!

If you have any questions about your rights as a subject/participant in this research, or if  
you feel you have been placed at risk, you can contact the Chair of the Human Subjects  
Institutional Review Board, through St. Catherine University at  
(651) 690-7739