

EFFECT OF DEMOGRAPHIC FACTORS ON EMPOWERMENT
ATTRIBUTIONS OF PARENTS OF CHILDREN
WITH AUTISM SPECTRUM DISORDERS

by

ASHLEY H. PERRY

KAGENDO MUTUA, CHAIR
JIM SIDERS
SANDRA NICHOLS
MARY CURTNER-SMITH
DHEERAJ RAJU

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ABSTRACT

The purpose of this study was to investigate the effect of demographic factors on empowerment attributions of parents of children with Autism Spectrum Disorder (ASD). Data were collected to determine differences between demographic factors of participants and self-reported empowerment attributions.

A quantitative research design was employed in this study. Parents of children with ASD completed the 32-item Psychological Empowerment Scale (PES), which included a demographic questionnaire. Analyses were performed to measure the effects of specified demographic factors on parents' self-reported responses on the three dimensions of the Psychological Empowerment Scale (PES), namely attitude, formal participatory behaviors, informal participatory behaviors and skills and knowledge (Zimmerman, 1995). Demographic factors included marital status, parent gender, parent education level and perceived severity of child's ASD.

The findings of the current study suggest that there are some relationships between demographic factors and parent empowerment attributes for parents of children with ASD. Parents who were married did not report a significant difference in perceived empowerment based on their own formal or informal education or support participatory behaviors than parents who were not married or parents who reported being in a partnership. Gender played a more significant role in the empowerment outcomes for parents of children with ASD. Mothers reported higher levels of empowerment than fathers in regard to informal participatory behaviors regarding parenting a child with ASD. Parents who had attended college reported higher levels of empowerment in regard to the empowerment attribute of skills and knowledge. Parents of children with ASD who participated in this study did not indicate that the severity of their child's

ASD had an effect on their empowerment attribute of attitude. In addition to demographic differences, results indicated that there was a strong, positive correlation between formal participatory behavior and skills and knowledge and informal participatory behavior and skills and knowledge for parents of children with ASD.

This study has begun to provide important information on the interaction effects of demographics on parent empowerment and the benefits of parent education and support for parents of children with ASD. Parents of children with ASD defined themselves as unique subgroup of parents of children with disabilities who have different strengths and needs in regard to empowerment. Outcomes of the study can be used to develop practice, programs, and policy in regard to education and support opportunities for parents of children with ASD from a more individualized, diverse or culturally sensitive perspective.

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“Two roads diverged in a wood, and I, I took the one less traveled by, and that has made all the difference.” (Robert Frost)

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CHAPTER I:

INTRODUCTION

Background of the Problem

Autism

According to estimates from the Center for Disease Control's (CDC) Autism and Developmental Disabilities Monitoring (ADDM) Network, 1 out of every 88 children in the U.S. are being diagnosed with an autism spectrum disorder (ASD)(CDC, 2012). A standardized criterion defining ASD is provided by the American Psychiatric Association's Diagnostic and Statistical Manual-IV, Text Revision (DSM-IV-TR) (American Psychiatric Association, 2000). The DSM-IV-TR currently refers to ASD as Autistic Disorder but for the purposes of this study, Autistic Disorder will be referred to as ASD.

The three most common and diagnosed types of ASD include autism, Asperger syndrome, and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS). For the purpose of this study, all three types of autism will be referred to as ASD. The DSM-IV-TR describes the characteristics of ASD as: 1) deficits in social interaction, developing peer relationships, seeking or sharing interests with others, a lack of social reciprocity; 2) impairments in communication which includes delay or lack of spoken language, a marked impairment in the ability to initiate or sustain a conversation with others, repetitive use of language, and lack of spontaneous social play appropriate to developmental level; 3) and repetitive and stereotyped patterns of behavior, interests, and activities which can include the preoccupation with one or more topic and restricted patterns of interest that is abnormal either in intensity or focus,

inflexibility with routines or rituals, repetitive motor manners, for example, hand or finger flapping, and a persistent preoccupation with parts of objects. Asperger syndrome includes the same characteristics as ASD but the individual must not demonstrate 1) clinically significant impairment in social, occupational, or other important areas of functioning; 2) no clinically significant general delay in language; and 3) no clinically significant delay in cognitive development or in the development of age-appropriate skills. PDD-NOS criteria include presentations that do not meet the criteria for Autistic Disorder because of late age at onset or demonstrating symptoms of ASD that are mild or not in all areas of criteria. ASD is a spectrum disorder that affects individuals differently and to varying degrees.

Prevalence of ASD in Alabama

For the purpose of this study, it is important to note the most current reported prevalence of children identified with ASD in Alabama. The Alabama Autism Surveillance Program (AASP), an autism-monitoring program through the Centers for Disease Control and Prevention (CDC), reported 174 children diagnosed with ASD in the state of Alabama in 2008. Through an analysis of information from 32 counties across the state of Alabama, a total of 3,000 students of 742,789 were reported to be receiving special education services for a diagnosis of ASD during the 2007 - 2008 school year (CDC, 2012). The results from the 2010 and 2012 surveillance have yet to be released for public access. Results of the 2006 surveillance indicated an 82% increase in ASD prevalence in Alabama over a four-year period. Figure 1 details the increase in the prevalence of ASD in Alabama.

Identified Prevalence of Autism Spectrum Disorders				
ADDM Network 2000-2008				
Combining Data from All Sites				
Surveillance Year	Birth Year	Number of ADDM Sites Reporting	Prevalence per 1,000 Children (Range)	This is about 1 in X children...
2000	1992	6	6.7 (4.5-9.9)	1 in 150
2002	1994	14	6.6 (3.3-10.6)	1 in 150
2004	1996	8	8.0 (4.6-9.8)	1 in 125
2006	1998	11	9.0 (4.2-12.1)	1 in 110
2008	2000	14	11.3 (4.8-21.2)	1 in 88

Figure 1. Identified Prevalence of Autism Spectrum Disorders in Alabama. Source: Center for Disease Control and Prevention. (n.d.). Identified Prevalence of Autism Spectrum Disorders. [Photo]. Retrieved from <http://www.cdc.gov/ncbddd/autism/data.html>

Proposed Changes to ASD Diagnostic Criteria

According to American Psychological Association (APA), proposed changes to the current diagnostic criteria for ASD in next series of the DSM, the DSM-V (American Psychiatric Association, 2013), are currently being considered. The APA has projected revisions for the diagnostic criteria of ASD. The new name for the category is autism spectrum disorder, which includes autistic disorder (autism), Asperger’s disorder, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified (APA, 2013). Based on the new proposed changes, there will no longer be separate categories under the umbrella of ASD. Instead, all categories will be grouped together as ASD. Under the proposed new classification, clinicians would rate the severity of clinical presentation of ASD as severe, moderate, or mild.

This proposed change is important to note in regard to the empowerment of parents of children with ASD because the proposal to eliminate Asperger’s syndrome as a separate disorder and instead merge it under ASD has become quite controversial amongst individuals with

Asperger's syndrome and their families. The major changes that will affect most individuals with ASD will be removing Asperger's syndrome and Pervasive Developmental Disorder-Not Otherwise Specified (PPD-NOS) from the autism spectrum, making it more difficult to be diagnosed with autism. A team of researchers from Yale who analyzed data from a 1994 study testing the criteria used in the DSM-IV found that half of the people diagnosed with autism in that trial would no longer qualify for a diagnosis under the new proposed DSM-V criteria (Volkmar, 2011). Previously there were 12 criteria for an autism diagnosis and a child only has to exhibit six of them. The proposed changes suggest three criteria and the child has to exhibit two of those three. Individuals diagnosed with Asperger's syndrome and PPD-NOS may lose services that are needed at school to help them in their education. These changes are important to note for this study because of the impact it may have on the overall stress, coping, and empowerment attributes of parents of children currently diagnosed with ASD. Parents may find the changes confusing and leave them with a sense of uncertainty for their child. Another concern for parents may be the concern for their children and adult children who identify strongly with their diagnosis (American Psychiatric Association, 2013).

History of Autism

In 1912, a Swiss psychiatrist named Eugene Bleuler was the first doctor to use the term autism to describe individuals with mental illness who appeared to be self-absorbed and withdrawn. Leo Kanner, a doctor from Johns-Hopkins University, in 1940, was one of the first doctors to use the term autism to describe children who demonstrated withdrawn and anti-social behavior (Fischbach, 2007). For years, Kanner associated autism with mental illness. Kanner was also responsible for supporting the theory that children with autism had the condition due to mothers not bonding with their child by turning away when the child would seek comfort or

interaction (Kanner, 1943). Throughout the years, autism researchers began to understand more about the characteristics of ASD and how it differed from what was once thought to be a mental illness or intellectual disability (CDC, 2012). Studies also began to explore the specific causes of ASD. Since the 1970s, research has thoroughly supported a genetic link to ASD (Fischbach, 2007). With the increase of investigations into the causes of ASD and the restructuring of the diagnostic criteria for ASD, the true origin of the condition has begun to take shape.

Over the past decade, the number of children diagnosed with ASD has been on the rise. The results of a study concerning the increase in the prevalence of ASD conducted by the Centers for Disease Control and Prevention (CDC, 2012) were revealed in 2009. The study conducted by the CDC funded program called the Autism and Developmental Disability Monitoring Network (ADDM) indicated 1% of children in the U.S. now have ASD. In 2007, it was estimated that 1 in 150 children had ASD. The newest rate has 1 in 88 children being diagnosed with ASD. CDC noted that this is a 23% increase since their last report in 2009 and a 78% increase since 2007. The CDC initially thought the increase in prevalence was due to changes in the way ASD is diagnosed. However, with the increasing rates of ASD being diagnosed the CDC has disclosed that the increase may be more than just better diagnosing. At this time, researchers have yet to find the cause of ASD and are unable to accurately pinpoint why ASD prevalence continues to increase.

Increase in ASD Prevalence

Shattuck (2006) examined the relationship between the increase in prevalence of ASD and changes in the use of other categories of classification. Shattuck found significant changes in ASD prevalence had occurred, however the changes varied greatly across different states. The concern with the significant differences was each state was under federal mandate to create a

separate special education category for children with ASD. The study further revealed that children diagnosed with ASD were significantly underestimated in the early 1990s. Therefore, the prevalence was likely to increase. Shattuck noted that the same increase occurred when the categories of developmental delay (DD) and traumatic-brain disorder (TBI) were introduced. Upon initial introduction, the prevalence in the two categories remained low. Over the years, states began to use the diagnostic areas more frequently and the prevalence increased. This study made the assumption that the same trend has occurred with ASD prevalence. The study also sought to determine if the increase in the prevalence of ASD was due to diagnostic substitution. The premise of diagnostic substitution is that a child with ASD may have been diagnosed differently before the shifts in referral and diagnostic criteria. Therefore, there may be decreases in the diagnosis of other disability areas as the increase in ASD occurs.

Children with ASD have deficits in verbal and nonverbal communication, stereotyped behaviors, restricted interests, and learning disabilities and have difficulties in social situations and daily functioning (Larson, 2006; Skinner, Correa, & Rodriguez, 1999). The disorder has an impact on the individual, the family, and society. Support for individuals with ASD should begin within the family (Turnbull &Turnbull, 2001). Families of children with ASD, more specifically the parents, are often responsible for seeking out information about their child's disorder, finding treatments to address the different characteristics of the disorder, and implementing interventions to help address the child's deficits.

Baker-Ericzen, Brookman-Fraee, and Stahmer (2005) examined parent stress before and after participation in an inclusive toddler program for parents of children with ASD and typically developing children. Parents of children with ASD reported higher levels of stress related to raising a child with ASD. Results of a study by Bromley, Hare, Davison, and Emerson (2004)

revealed that mothers of children with ASD disclosed high levels of psychological distress due to high levels of challenging behaviors from the child. The mothers also noted low levels of family support. Parents of children with ASD who participated in a study by Gray (2002) on the psychosocial adaptation of parents of children with ASD reported substantial amounts of stress, anxiety and depression. The parents who reported the greatest levels of distress also reported having a child with significant behavioral problems. Other challenges indicated by the parents were social stigma and rejection by other parents or family members. Higgins, Bailey, and Pierce (2005) examined the perceptions and experiences of parents of a school-aged child with ASD and the impact of the behaviors and characteristics of the child's ASD on the family. The study revealed high levels of stress related to parenting a child with ASD, specifically in the areas of physical, emotional, financial, or marital stress. The parents' primary concern regarding the behavior was the demonstration of aggressive behavior by the child, more specifically behavioral outbursts in public or aggressive behavior from older children with ASD. The parents indicated they felt they were being judged in public when their child misbehaved. In this study, Higgins and colleagues did not find that coping style added to the prediction of marital happiness, family adaptability, family cohesion, or self-esteem.

The results of these studies provide an overview of the negative effects parenting a child with ASD can have on the well-being, marital satisfaction, and overall caregiving experience for a parent of a child with ASD. These studies provide an adequate base for the need of supports aimed to enhance the overall empowerment of parenting a child with ASD.

Statement of the Problem

The Autism Society of America (ASA) has identified factors that play a role in the parenting stress of raising a child with ASD: 1) deficits and behaviors of ASD; 2) reactions from

society and feelings of isolation; 3) concerns over future care giving; 4) finances; and 5) feelings of grief (ASA, 2013). Children with ASD have difficulty communicating basic wants and needs and may demonstrate behaviors that are repetitive or disruptive which may in turn draw negative attention from others who do not understand the disorder. ASD is a lifelong disorder (CDC, 2012). Parents should plan ahead to ensure their child is prepared for a future and that the future is prepared for their child. Treatment, intervention, services, therapy, and future financial planning regarding the disorder can be costly and overwhelming. Without a support system in place and the tools to serve as a support system for their child with ASD, parents of children with ASD can easily become isolated, overwhelmed, and depressed (Hastings et al., 2005).

Research indicates parents who participate in formal and informal support systems gain a greater sense of empowerment and improved psychological well being (Cook, Heller, & Pickett-Schenk, 1999). Empowerment, defined as a multi-dimensional process, helps people gain control over their own lives (Zimmerman, 1995). Little research has focused on the correlation between support and empowerment for parents of children with ASD. To help provide insight into this notion, this study investigated the effect of demographic factors on empowerment attributions of parents of children with ASD.

Significance of the Study

The study focused on the empowerment of parents of children with ASD and furthermore provides a better understanding than currently exists of the understudied influence of demographic factors on the empowerment of parents of children with ASD. Given that the prevalence of ASD is on the rise, the outcomes of this study potentially have significant implications for both parents of children with ASD and professionals who work to provide support to those parents. The findings of this study may be informative to the design of support

programs, policies, and practices that seek to encourage parent empowerment. Because there are only a few studies on the relationship between demographic factors and parent empowerment attributes specific to parents of children with ASD, this study explicitly focused on this understudied area.

Research that documents the value of empowerment for parents of children with ASD is important to support initiatives that are already in place in some locations. This study searched for positive outcomes of empowerment and strived to understand the processes that assist in creating or deterring such outcomes.

Scope of the Study

This study was undertaken to provide information about the effect of demographic factors on empowerment attributions of parents of children with ASD. It was intended to address two sets of questions. First, do the demographic factors of parents of children with ASD contribute to parent empowerment? Secondly, is there a relationship between participatory behavior in formal and informal supports and the skills and knowledge parents of children with ASD have about the condition.

Purpose of the Study

The purpose of this study was to examine the effect of demographic factors that may contribute to perceived empowerment for parents of children with ASD. Specifically, the demographic factors included (a) marital status; (b) gender; (c) parent level of education; and (d) severity of child's ASD. The relationship between demographic factors and the empowerment of parents of children with ASD will be explored.

Theoretical Framework

The theoretical frameworks guiding this study are the family systems theory by Turnbull and Turnbull and the empowerment theory by Zimmerman. Turnbull and Turnbull's (2001) framework for understanding the emotions, dynamics, and elements of family systems has allowed professionals to work more effectively with these families. The four elements of this framework are 1) family resources; 2) daily interactions among family members; 3) different individual family needs; and 4) changes that occur over time which affect family members. Most literature defines empowerment as a multi-dimensional, social process (Rapport, 1984; Zimmerman, 1984; Zimmerman, 1995). Empowerment is a process that is similar to a path or journey. It develops as it is worked through. Empowerment occurs within different sociological, psychological, and economic dimensions. Empowerment can occur within individuals, groups, or communities. Empowerment is a social process since it occurs in relationship to others. Theoretical speculations about empowerment have evolved throughout the years.

Family Systems Theory

A key shift in support for parents of children with disabilities has taken place over the past several years. In the past, the focus was educating and supporting the child with disabilities with the assumption it would help the family. Best practice now is to focus on the family and the child with a disability, known as a family-centered approach. Professionals in the field of special education acknowledge the importance of understanding the functioning of a family and how it is impacted by a child with disabilities. This concept is referred to as the family systems theory (Turnbull & Turnbull, 1990). A major premise of family systems theory is that what affects the individual with a disability affects the whole family. In addition Turnbull and Turnbull et al. suggest that individuals within a family cannot be understood in isolation from one another, but

rather as a part of their family. Families are systems of interconnected and interdependent individuals. An impact on one member of the family will in turn have an impact on the entire family system. The family systems theory is built upon the premise that by understanding and identifying the basic characteristics, interactions and functions of families, professionals can build better partnerships and support systems for families and children with disabilities. A practice more commonly referred to as family-centered practice. According to the literature on family-centered approach, Turnbull and Turnbull (2001) determined four major characteristics to define practices as family-centered: (a) include families in decision making, planning, assessment, and service delivery at family, agency, and system levels; (b) develop services for the whole family and not just the child; (c) are guided by families' priorities for goals and services; and (d) offer and respect families' choices regarding the level of their participation. The foundation of family-centered approach is the recognition that the family is the constant in a child's life. For this reason, family-centered approach is built on partnerships between families and professionals. Family-centered professionals acknowledge and respect family diversity. Family-centered approach can help improve and enhance outcomes for children with special needs and provide more support for their parents as they deal with the challenges and joys of raising a child with special needs. In turn, parents may become more empowered.

Empowerment Theory

Zimmerman (1995) defines empowerment as "processes where people create or are given opportunities to control their own destiny and influence the decisions that affect their lives" (p. 583). Empowerment helps people gain control over their own lives and take action to get what they need (Akey, Marquis, & Ross, 2000). For parents of children with ASD, this is critical due to the loss of control many have reported feeling regarding their child's disability. Zimmerman

notes that individuals should be provided opportunities to develop and practice skills they have learned, learn about resources, work together with others to reach a common goal, expand one's social support system, and develop leadership skills. Zimmerman cautions researchers not to generalize one's ability to become empowered. Individual needs and differences such as age, sex, and socioeconomic status must be taken into consideration. Empowerment can also change over time. As quickly as one can be empowered, one can be disempowered or empowerment can improve (Zimmerman, 1995). Empowerment is an individual process in which individuals can be more or less empowered than others, even given the same circumstances. Supports for parents of children with ASD should be designed in such a way to incorporate these components to ensure parents are provided these empowerment opportunities.

Zimmerman's Components of Psychological Empowerment

Zimmerman (1995) provides a three-part framework of Psychological Empowerment (PE) that divides the empowerment components of performance and perception into three inter-related components: intrapersonal, interactional, and behavioral. Together, the components help define the empowerment traits of an individual.

The intrapersonal component of PE describes perceptions that influence the behaviors of people. This includes perceived control, perceived self-efficacy, motivation for control, and perceived competence. Perceived control is the perception that one is able to control an outcome. This component is categorized into personality, cognition, and motivation (Zimmerman, 1995).

The interactional component of PE is the knowledge and awareness of a system with which one is working, the resources and support available within that system, and how to obtain what one needs. This includes the acquisition of skills; these include problem-solving, decision-making, and leadership skills (Zimmerman, 1995).

The behavioral component of PE involves the actions and behaviors by an individual to influence, control and achieve desired outcomes. Intrapersonal and interactional components would also influence the behavioral component. In this study, behaviors could include participating in a support group, involvement in community organizations or using coping skills (Zimmerman, 1995).

Research Questions

The overall purpose of this study was to investigate the effect of demographic factors on empowerment attributions of parents of children with ASD. Specifically, this study was guided by five research questions. They included

- (1) Is there difference in parent formal and informal participatory behavior with respect to marital status;
- (2) Is there difference in parent formal and informal participatory behavior with respect to gender;
- (3) Is there difference between parent education level and skills and knowledge about ASD;
- (4) Is there any difference in parent attitude with respect to ASD and their perceived severity of the child's ASD; and
- (5) Is there a relationship between formal and informal participatory behavior and parental skills and knowledge with respect to ASD?

Definition of Terms

Autism Spectrum Disorder (ASD)-The DSM-IV-TR (American Psychiatric Association, 2000) describes the characteristics of ASD as deficits in 1) social interaction, developing peer relationships, seeking, or sharing interests with others, a lack of social reciprocity; 2) impairments in communication which includes delay or lack of spoken language, a marked impairment in the ability to initiate or sustain a conversation with others, repetitive use of

language, and lack of spontaneous social play appropriate to developmental level; and 3) repetitive and stereotyped patterns of behavior, interests, and activities which can include the preoccupation with one or more topic and restricted patterns of interest that is abnormal either in intensity or focus, inflexibility with routines or rituals, repetitive motor manners (hand or finger flapping, etc.) and a persistent preoccupation with parts of objects. Asperger syndrome includes the same characteristics as ASD but the individual must not demonstrate 1) clinically significant impairment in social, occupational, or other important areas of functioning; 2) no clinically significant general delay in language; and 3) no clinically significant delay in cognitive development or in the development of age-appropriate skills. PDD-NOS criteria include presentations that do not meet the criteria for Autistic Disorder because of late age at onset or demonstrating symptoms of ASD that are mild or not in all areas of criteria.

Empowerment- Empowerment is defined as a process where people are provided opportunities and support to help gain control over their own lives and take action to get what they need (Akey, Marquis, & Ross, 2000). For the purpose of this study, the focus was on empowerment as a family-centered behavior, an empowerment process that is applicable to understanding relationships between demographic factors and parents of children with ASD.

Parent- For the purpose of this study, the perspective of the parent was provided by the individual who is or serves the role as primary caretaker of a child. Parents may include mothers, fathers, foster mothers or foster fathers, grandmothers or grandfathers, or other adult guardians of the child with ASD. For the purpose of this study, the participants must be a parent of a child or children with ASD ages 3-21 years in the state of Alabama.

Summary

With the rapid increase in the number of children diagnosed with ASD, the impact on the family has increased dramatically during the past decade. Parent stress from the care of a child with ASD is significant. Studies have shown that parents of children with ASD experienced greater stress than parents of children with other disabilities. Helping parents cope with stress not only benefits the parents, but also enhances the overall outcomes for children with ASD. With the swift increase of children being diagnosed with ASD in the U.S., the well being of parents is an issue that professionals working with the child and the parents need to address. Formal and informal support systems can be effective in reducing parental stress by educating the parents about the disorder and treatment choices as well as providing social support.

Little research has been done on the impact of demographic factors in regard to parent empowerment for parents of children with ASD. With parents having an essential role in the development and well-being of children with ASD, a better understanding of the impact demographic factors have on the parents' overall empowerment in regard to caring for their child with ASD could not only help children with ASD and their parents, but also impact the way professionals in the field of ASD, family education, and support systems best serve the child and the parents. Chapter two focuses on three major topics: parental stress and coping, parent support systems, and parent empowerment in regard to parents of children with ASD.

CHAPTER II:

REVIEW OF THE RELATED LITERATURE

This chapter presents the review of related research on ASD. Specifically, this chapter describes ASD (Autism Spectrum Disorders); the impact ASD has on the family system and ways parents may cope; the importance of support for parents of children with ASD; types of formal and informal supports; and the effect of demographic factors on parenting a child with ASD. A review of empowerment in regard to parenting a child with ASD is also provided.

A thorough literature search was performed in order to compile and analyze the most relevant information describing the empowerment of parents of children with ASD and an attempt to identify all the available research in support and empowerment for this population. The primary database (Wilson Web and Academic Search Premiere) for this type of information were searched extensively by combining descriptors such as ASD, support, empowerment, stress, coping, and parent. Additionally, the most recent issues of a number of relevant journals were searched including *Journal of Autism and Developmental Disorders*; *Focus on Autism and Other Developmental Disabilities*; *Research in Autism Spectrum Disorders*; and *Autism*. Additional articles were identified through article reference lists.

Autism Spectrum Disorders (ASD)

The Impact of ASD on the Family

ASD not only impacts the individual with the disorder, but the family and society in general. Jarbrink, Fombonne, and Knapp (2003) reported the considerable financial impact raising a child with ASD has on the family. Ganz (2007) estimated that the lifetime cost to care

for an individual with an ASD is \$3.2 million. Ganz called attention to the notion of a significantly higher cost to care for a child during the first five years of life, which is an already stressful time for parents of a child recently diagnosed with ASD. Families of children with ASD, more specifically the parents, are often responsible for seeking out information about their child's disorder, finding treatments to address the different characteristics of the disorder, and implementing interventions to help address the child's deficits. Previous literature on parenting children with ASD has indicated that there is a higher likelihood for parental stress, depression and anxiety for parents of children with ASD. Baker-Ericzen, Brookman-Fraee, and Stahmer (2005) examined parent stress before and after participation in an inclusive toddler program for parents of children with ASD and typically developing children. Parents of children with ASD reported higher levels of stress related to raising a child with ASD. Results of a study by Bromley, Hare, Davison, and Emerson (2004) revealed that mothers of children with ASD disclosed high levels of psychological distress due to high levels of challenging behaviors from the child. The mothers also noted low levels of family support. Parents of children with ASD who participated in a study by Gray (2002) on the psychosocial adaptation of parents of children with ASD reported substantial amounts of stress, anxiety, and depression. The parents who reported the greatest levels of distress also reported having a child with significant behavioral problems. Other challenges indicated by the parents were social stigma and rejection by other parents or family members. Higgins, Bailey, and Pearce (2005) examined the stress experienced by parents of a child with ASD, more specifically the impact on family functioning and marital satisfaction. The outcome of the study reported parents of children with ASD indicated significantly less marital satisfaction, poor adaptability in the family, and a lack of family unity.

Improving parents' coping and stress management skills can help reduce stress on the entire family system.

Parental Stress

Parents of children with ASD are faced with complex responsibilities compared to parents of typically developing children do (Dunst & Dempsey, 2007). For parents with a child diagnosed with ASD, the diagnosis can be a considerable turning point in the life of a family (Banach, Iudice, Conway, & Couse, 2010). Parents are dealing with adjustments due to the characteristics of child's ASD, the life changes needed to accommodate the needs of the child, and the challenge of trying to access services to support the child and the family (Guralnick, Hammond, Neville, & Connor, 2008).

Researchers have taken the position that parents of children with ASD are at risk for high levels of stress and anxiety due to the strain of daily care, the challenges of parenting, the potential for social isolation, and other contributing factors. Benson (2006) reported that parents of children with ASD were at increased risk for poor mental health, not only because of the demands of caring for a child with ASD, but also because of other stressors engendered or exacerbated by their child's disability. In a longitudinal study of parental stress, Higgins et al. (2005) reported that mothers and fathers of a child with ASD had lower levels of marital happiness, family adaptability, and family cohesion than parents who do not have a child with ASD. Hare, Pratt, Burton, Bromley, and Emerson (2004) reported a strong association between emotional stress and unmet need for support in parents of adults with ASD. Sharpley, Bitsika, and Efremidis (1997) reported that the three most stressful factors for parents of children with ASD were (a) the permanency of the condition; (b) the lack of acceptance of behavior associated with ASD by family members and society; and (c) the low levels of support provided. Additional

sources of stress for parents of individuals with ASD that were identified by other researchers including (a) the economic burden of raising a child with ASD, including the negative impact on parents' career and/or income (Jarbrink, Fombonne, & Knapp, 2003; Sharpe & Baker, 2007); (b) parents' concerns about the future for their children, specifically problems that may arise when the children reach adulthood (Hare, Pratt, Burton, Bromley, & Emerson, 2004; Pisula, 2007); (c) challenging behavior of children with ASD (Bromley et al., 2004; Hastings, 2003b; Hastings et al., 2005; Lecavalier, Leone, & Wiltz, 2006); and (d) psychological characteristics of the parents such as perceived self-efficacy, locus of control, and coping style (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Sivberg, 2002).

Parents of children with ASD indicated that upon the ASD diagnosis of their child, they had feelings of relief, grief and loss, shock and surprise, and self-blaming. When asked what it had been like to parent a child with ASD, 66% of the participants indicated it was stressful. The parents noted that parenting a child with ASD made it difficult to have fun or plan vacations, required them to plan ahead, and placed a great deal of strain on their marriage (Hutton & Caron, 2005). Midence and O'Neill (1999) established that some parents felt relieved after their child was diagnosed but also reported the lack of support received after the diagnosis. The feelings revealed in these studies align with the grief process often experienced by parents that have had a child pass away (Barnett, Clements, Kaplan-Estrin, & Fialka, 2003). In a study assessing the relationship between parenting a child with ASD and stress, Schieve, Blumberg, Rice, Visser, and Boyle (2006) found that parents of children with ASD ages 4 to 17 years reported higher levels of stress and aggravation than parents of children with developmental challenges or special health care needs. Parents of children with ASD reported even greater levels of stress and aggravation when their child required special interventions than parents of children with

developmental challenges or special health care needs. Hastings et al. (2005) explored the psychological functioning in families of a child with ASD. Results of the study reached the conclusion that maternal stress and positive perceptions were predicted by maternal depression. The child's behavioral challenges and a partner's depression had a strong correlation to reported maternal depression. In addition, the mothers and fathers identified positive perceptions about their child and his or her impact on themselves and other family members

Coping Strategies for Parents

Glidden, Billings, and Jobe (2006) define coping as behavioral and emotional responses and regulation to something that has happened. Improving parents' coping and stress management skills can help reduce stress on the entire family system (Baker-Ericzen, Brookman-Frazer, & Stahmer, 2005). Research suggests the effectiveness of coping depends on the positive coping strategies used by the parents, the resources available within the family, and the availability of social support from the spouse, family and informal networks (Tarakeshwar & Pargament, 2001). Acquiring social support and reframing the experience to see some positives are most frequently used coping strategies (Luther, Canham, & Cureton, 2005). Hardiness and social support are predictors of successful adaptation (Weiss, 2002). There is no direct relationship between social support and isolation suggesting that some of the parents feel isolated despite receiving social support (Dunn, Burbine, Bowers, & Tantliff-Dunn, 2001). The internet allows stressed parents of children with ASD to forge ties among themselves and extricate themselves from their isolation (Fleischmann, 2005). Research indicates that it is important to discourage parents from using escape and avoidance as a coping style. Encouragement of more appropriate coping methods and receipt of social support is seen as beneficial in buffering the stress and reducing negative outcomes (Dunn, Burbine, Bowers, & Tantliff-Dunn, 2001).

Research involving parents of autistic children indicates that a positive evaluation of direct services to their child (e.g., “believing that my child’s program has my family’s best interest in mind”) was the most helpful resource in coping with the challenges of autism (Tarakeshwar & Pargament, 2001).

Dunn, Burbine, Bowers, and Tantliff-Dunn (2001) examined the relationship between parenting children with ASD and stress, support, coping, and negative outcomes. The study revealed that social support and coping strategies assisted parents in adapting to parenting a child with ASD. Parents who reported higher levels of social support indicated less spousal problems (Dunn et al., 2001). The study also highlighted when parents had a stronger control over things that happen to them and a reported lower level of depression and isolation. In regard to the role coping played in parental outcomes in this study, parents who reported using the coping style of escape-avoidance and distancing also reported increased depression, isolation and marital issues. Dunn et al. (2001) suggests a more beneficial coping strategy for parents may be to spend time with others to help facilitate interpersonal relationships.

Based on results from a study on how parents of children with ASD cope over time, Gray (2006) reported that parents prefer the use of treatment services and family support as the most popular coping skills regarding their child’s disorder. Over 50 parents of children with ASD participating in the study reported that other favored coping skills were respite care, social withdrawal, and religion or spirituality. The results revealed that reliance on such coping skills did change over time with the assumption that the needs of the child or family had changed or treatment service option availability had changed. In a study comparing the coping behaviors of parents of children with ASD and parents of typically developing children, Sivberg (2002) revealed that parents of children with ASD reported more negative coping skills than parents of

children that did not have a disability. Parents of children with ASD in the study reported using coping behaviors such as withdrawal and escape from difficult situations. The parents of children that did not have a disability reported more use of positive coping strategies such as self-control, social support, and problem solving skills.

Glidden, Billings, and Jobe (2006) explored the role of parental personality on the coping strategies of parents of adopted children with a developmental disability. The coping strategies analyzed in this study were as follows: 1) planful problem solving: approaches that are planned or deliberate to solve the problem; 2) seeking social support: seeking information, emotional or material support; 3) confrontive coping: aggressively trying to solve a problem; 4) self-controlling: regulating one's own emotions; 5) positive reappraisal: focusing on personal growth; 6) distancing: minimizing the importance of a problem; 7) accepting responsibility: trying to do the right thing to address an issue; 8) escape-avoidance: actions to escape from or avoid a problem; parents' self-reports reflected the use of planful problem solving most frequently and used the escape-avoidance coping strategy least. The researchers concluded that parents always reported using seeking social support as the second or third most used strategy. Mothers were more likely to seek information, emotional or material support than fathers.

Hastings et al. (2005) explored the coping strategies, stress, and mental health of parents of children with ASD. The study was specifically aimed to show that maternal stress is related to the behaviors of the child and the mental health of their partner. Mothers and fathers of children with ASD who were enrolled in a preschool designed to evaluate the effects of intensive behavioral intervention were participants in the study. Parents completed a variety of questionnaires to assess problem behavior exhibited by the child; the severity of the child's autism; parental mental health; parental stress; and the perceived positive impact the child has on

the parent. Overall, the results found no difference in the reported stress between mothers and fathers. The mothers of children with ASD correlated their stress to the child's behavioral problems and autistic symptoms. The study also indicated a strong correlation between depression of one partner on the reported stress of the other partner. The researchers noted that this effect might have a negative impact on the support each partner gives each other, especially when partners are used to having a strong system of support for his or her partner. This support may be less available if a partner is depressed (Hastings et al., 2005).

Hare, Pratt, Burton, Bromley, and Emerson (2004) acknowledged the lack of empirical research on families caring for adults aged 16 and older with an ASD spectrum disorder by investigating the support and service provision available to, and used by families of young adults with ASD and the relationship between the level of support and psychological wellbeing of the principal family care service provider. This study focused primarily on the mother of the adult with ASD. One of the most significant findings of this study in comparison of other studies on the stress and coping of parents of individuals with ASD was the lack of reported distress by the caretakers regarding the individual's ability and behavior. The researchers made the assumption that over time caretakers may have acquired ways of responding to or accommodating the needs of their adult child with ASD. Of notable interest in the study was the debate whether participants had reported more complacency with their situation because they had overcome the trials of raising a child with an ASD or had the parents resigned to a reduction in expectations or satisfaction with services. The families reported that they did attend more support group type programs when their child was younger but as they child got older they participated less. The families in this study revealed that they had little access to family and informal support but also reported a greater access to more formal support such as respite care. The main outcome from

the study was the need for more ASD-specific day services for adults with ASD. The parents reported they were supported when there was care for their adult child.

These outcomes support the need for parents of children with ASD to develop coping strategies that enable them to have more positive outcomes within the family system. Providing parents of children with ASD support and information regarding their child's disorder may improve their ability to cope and in return, decrease stress levels.

It is however important to note that raising a child with an ASD does not always have a negative impact on the family. Bayat (2007) explained that even though families of children with ASD do face extraordinary challenges, a number of families demonstrate resilience and report becoming stronger as a family system as a result of their child's disability. For better outcomes, Bayat suggested the importance of recognizing the difference in the needs of the family compared to the needs of the child with ASD when supporting parents of children with ASD.

Parental Differences in Stress

Among parents who care for children with and without disabilities, researchers have found significant differences in stress and coping. Little (2002) examined the gender differences in stress and coping of 103 marital couples who were parents of a child with ASD. The study revealed that mothers reported higher levels of stress than fathers in regard to parenting their child with ASD. The mothers reported seeking professional help and medication more often for stress than fathers. The mothers also utilized more coping strategies and reported more positive outcomes from the use of the strategies than the fathers. An important element of this study to consider is that only 34% of the mothers worked full time with 91% of the fathers working full-time. The question then arises if the mothers may have been more responsible for the care of and

interaction with the child with ASD and if this could have led to the differences in stress and coping concerning parenting a child with ASD.

The purpose of a study conducted by Weiss (2002) was concerned with differences in hardiness and social support as predictors of stress for mothers of children with disabilities (ASD and intellectual disabilities) and without disabilities. The study involved 40 mothers from each group respectively. In general, mothers who reported high levels of personal accomplishment in parenting; high self-esteem; high degrees of social support; had good perceived control over their lives; and reported low levels of anxiety also reported low degrees of depression. Mothers who reported higher levels of emotional exhaustion and depression also indicated higher levels of anxiety. Findings revealed that mothers of children with ASD had higher levels of depression, anxiety, somatic complaints, emotional exhaustion, depersonalization, and lack of personal accomplishment than mothers of children with intellectual disabilities and mothers of children without disabilities. Mothers of children with ASD reported slightly higher levels of depression than mothers of children with intellectual disability. Mothers of typically developing children demonstrated the hardest attitudes and perceived emotional support and friendship as most available. Mothers of children with ASD demonstrated the least hardy attitudes and perceived emotional support and friendship as significantly less available. Support from a spouse was found to result in fewer somatic complaints and a greater accomplishment in parenting. The results of this study are important because according to Weiss mothers who report higher levels of self-esteem and social support also report lower levels of depression.

Other researchers have supported the finding that mothers of children with ASD are more likely to take over the responsibilities of the childcare and related tasks and will in turn experience greater stress than fathers (Hastings et al., 2005; Heller, Hsieh, & Rowitz, 1997;

Little, 2002). Research has indicated that fathers of children with ASD typically assume fewer responsibilities than mothers in regard to the care of the child and often report being less depressed (Hastings et al., 2005; Trute & Hiebert-Murphy, 2005). Keller and Honig (2004) conducted a comparative study of parental stress in mothers and fathers of children with disabilities and found that maternal stress was related to the demands a child placed on the mother and the lack of social support and respite care for the mother. However when a child's physical, cognitive, and emotional needs did fall outside of "normal" standards, mothers had less difficulty establishing a relationship with the child and reported lower levels of stress than fathers. The fathers reported having a more difficult time forming a close relationship with the child. It is important to note that 37% of the mothers worked full time with 83% of the fathers working full time. As noted in a previously reported study (Little, 2002), an assumption can be made that if the mother is not working as often as the father, she may have had more responsibility caring for the child and more opportunity to form a relationship with the child than the father did. Throughout the research, fathers have reported lower incidences of depression and negative feelings towards parenting a child with ASD. Tehee, Honan, and Hevey (2008) further supported that mothers and fathers of children with ASD differ in their means of coping and therefore, may differ in need for coping resources. The mothers of children with ASD in this study reported higher levels of stress and more involvement regarding the care giving of their child than fathers. The study which investigated factors that contribute to stress for parents of children with ASD further revealed that parents' needs may change over time based on the developmental stages the child with ASD progresses through. The researchers emphasized the need for information and support services take into consideration the changes in the child's development and individualize services consequently. The outcomes highlighted the importance

of providing parents with support and information in order to help improve their access to services, which will in turn help parents of children with ASD cope and ultimately reduce the levels of stress they acquire. Hastings et al. (2005) substantiated this finding in a study with 89 mothers and fathers of preschool aged children with ASD. In an analysis of the stress and positive perceptions related to parenting a child with ASD, the fathers reported lower levels of depression than mothers. Both partners shared that their level of depression was dependent on the level of stress their partner exhibited. Hastings et al. (2005) noted the importance of considering that this outcome may be due to a disruption of support within the marital system when a partner is depressed, therefore, increasing the level of depression for both partners. Paternal stress was associated with maternal depression and maternal stress was more associated with the behavioral challenges of the child. This correlates with prior studies by Hoffman, Sweeney, Hodge, Lopez-Wagner, and Looney (2009); Osborne and Reed (2008); and Tobing and Glenwick (2002) that found mothers of children with ASD were more likely affected based on the severity of child's needs or behavior. Osborne and Reed (2008) evaluated the relationship between the behavior problems of children with ASD and parenting stress. The researchers were curious to know whether parenting stress was associated more with the child's behavior problems or with the severity of the child's ASD. Participants, parents of children with ASD ages two – four years, indicated that in most cases, there was a strong correlation between the child's behavior problems and parenting stress rather than the severity of the child's ASD. However, when the child was younger, the severity of the child's ASD was correlated with higher levels of parenting stress. Osborne and Reed (2008) measured the relationship between the behavior problems of children with ASD and parent stress. Two subsequent studies specifically targeted parents of young children (ages 2-4 years) with ASD to determine if parents

of younger children experience more stress. The majority (60% or higher) of the parents who participated in the study were married and had a college education. All of the fathers worked and about half of the mothers did not work. Parents completed a series of assessments and checklists to help understand the severity of the child's ASD, behaviors associated with the child's ASD, and parent stress. The findings of the first study were that parenting stress is strongly correlated to the severity of the young child's ASD rather than the severity of the young child's behavior. Parents stress was found to be a strong predictor of future behavior problems of the child with ASD. The second study did support the relationship between parenting stress and the severity of the child's behavior over the severity of the child's ASD. The results of both studies support the notion that parenting stress does relate to ASD severity whether it is the perceived perception of the parent regarding the child's severity or the severe behaviors the child demonstrates (Osborn & Reed, 2009).

Abbeduto et al. (2004) found mothers of individuals with ASD reported higher levels of depression and a more distance relationship with their child with ASD than mothers of children with Fragile X and Down syndrome. The behavior of the child played a significant role in the psychological well being of the mothers in the study. Higher scores on the Autism Behavior Checklist predicted more maternal pessimism, greater depressive symptoms, and a less closeness in the parent/child relationship. Abbeduto et al. (2004) indicated that maternal education, number of children in the family, and number of additional children with a disability also correlated to maternal well being. Bromley, Hare, Davison, and Emerson (2004) analyzed the impact raising a child with ASD had on mothers. Interviews with the mothers disclosed high levels of psychological distress and high levels of challenging behaviors from the child. The interviews also revealed low levels of family support for the mothers.

An examination of the way mothers made sense of their child's diagnosis of ASD exposed high levels of stress but low levels of depression in the mothers. The mothers did indicate high expectations for their child's future (Dale, Jahoda, & Knott, 2006). Having a child with ASD seemed to be the main cause of stress for mothers of children with ASD in a study by Duarte, Bordin, Yazigi, and Mooney (2005). The mothers also reported other factors such as lack of socialization with others, being an older mother, or having a younger child were also found to be contributing factors of stress. A comparison of stress in mothers of children with ASD and mothers of children with Down syndrome revealed that mothers of child with ASD reported higher stress levels compared to the mothers of children with Down syndrome. The mothers of children with ASD indicated concern about their child's dependence on others for care, their child's future, and the lifelong effects of the condition.

Tunali and Power (2002) found that mothers of children with ASD were more likely to place less emphasis on career success, spent more time with family for leisure activities, were less concerned what others felt about their child's behavior, and emphasized spousal support and parental roles than mothers of typically developing children. The only negative finding in the study was the mothers of children with ASD had more difficulty understanding their child's behavior than mothers of children without ASD. Gray (2003) looked at the differences in coping between mothers and fathers of children with ASD. The mothers took on almost full responsibility for the care of the child. This caused the mothers to reveal feelings of emotional distress and reported changes in lifestyle in order to take on responsibility for the medical and educational responsibilities in caring for the child. The fathers in the study reported an indirect effect of the child's disability on their lives. On the other hand, Hastings (2003c) explored the psychological well being of mothers and fathers of a child with ASD. The mothers and fathers

did not differ in their levels of stress or depression. The mothers did report more anxiety than fathers. In addition, the mothers stress strongly correlated with the behavioral challenges of the child and the mental health of the father. Herring et al. (2006) explored the effects of emotional and behavioral problems of toddlers with PDD-NOS and with developmental delay on the parents. As predicted, the behavioral and emotional problems of the child did have a significant impact on parent outcomes. However, the mothers consistently reported higher levels of stress than the fathers did. Fathers of children with PDD-NOS reported higher levels of stress than fathers of children with developmental delays. Mothers were more affected by the child's emotional and behavioral problems than the actual diagnosis of the child, delay, or gender. Similar findings by Lecavalier, Leone, and Wiltz (2006) and Tomanik, Harris, and Hawkings (2004) found that mothers of children with ASD indicate that the child's behavioral problems were strongly associated with maternal stress. Mothers in the study by Tomanik and colleagues specifically identified child irritability, social withdrawal, hyperactivity, noncompliance, child dependence and inability to communicate as the major sources of stress for them regarding their child's behavior.

There has been little research on stress and coping in fathers of children with ASD and the impact of support systems designed specifically with fathers in mind (Baker-Ericzen, Brookman-Frazer, & Stahmer, 2005). A weakness in previous research and in the support that is available to fathers of children with disabilities is the vast focus on mothers. Focusing on mothers in parent training and other child centered activities, may have harmful outcomes on the progress of children with disabilities (Elder, Valcante, Won, & Zylis, 2003). Fathers could feel left out, unimportant, or insignificant. The fathers were less likely to participate in education or support activities and therefore, are poorly equipped to meet the demands of their child with

disabilities. Weiner, Vasquez, and Battles (2001) validate that support for parents needs to be gender-specific in order to meet the needs of fathers of children with disabilities. A study that examined the psychosocial adjustment and stress of father's parenting a chronically ill child found that the fathers experienced significantly higher amounts of stress and psychological distress than fathers of children that did not have a disease. The fathers of children infected with a chronic disease indicated a strong desire for help and support regarding their child's condition. Noted key points were a need for help with planning for their child's future, insurance and medical services, disease management, support for their own personal relationships, discipline, support group services, and how to communicate the child's conditions to others. Many of the fathers indicated they would be more likely to utilize a face-to-face or online support group designed specifically for fathers. Weiner et al. stressed that fathers would make use of services designed to meet their psychological needs if available.

Lee (2009) gave attention to the coping and adjustment of parents of children with high-functioning ASD spectrum disorders (HFASDs) and parents of children without a disability. The study also focused on the differences in coping and adjustment between mothers and fathers. This study found a higher level of stress and poorer mental health reported by parents of children with HFASDs. Both the mothers and fathers reported high levels of depression and lower marital adjustment scores than parents of children without a disability. The parents of children with HFASDs indicated a lower level of self-esteem, had less informal support from family members, were less positive about their situation and were overall less psychologically stable. The parents of children with HFASDs relied on spirituality and sought professional help and help from peers. The mothers of children with HFASDs demonstrated a greater level of depression and anxiety over fathers of children with HFASDs. They also were more likely to seek

professional, spiritual and peer support than fathers. Lee (2009) suggests the importance of understanding the differences in coping and stress of mothers and fathers and to tailor supports to also educate fathers in helping care for their child with ASD.

Impact on Family Subsystems

When parents place a great deal of time and energy into caring for a child with ASD, other relationships in their lives can be overlooked. Parenting a child with ASD takes quality time away from other family members. There is often an impact on the marital and sibling relationship within the family.

Impact on Marital Subsystem

Parenting a child with ASD can be complex but with the support of a spouse or significant other, the responsibilities can be shared. If there are not supports in place to help parents work towards more positive relationships with each other, both the marital and sibling relationships can suffer. Raising a child with a disability places couples under a chronic state of stress. Parents can become emotionally overwhelmed when their child receives a diagnosis of a disability. Parents can experience feelings of denial, anger, blame, or fear when their child is identified as having a disability. Research indicates that parents raising a child with a disability report more stress than parents raising a child without a disability (Dunn, Burbine, Bowers, & Tantliff-Dunn, 2001; Dyson, 1997; Hastings & Johnson, 2001). Having a child with a disability can be destructive to any marital relationship. Dunn, Burbine, Bowers, and Tantliff-Dunn (2001) hypothesized that parental marital satisfaction is negatively impacted by a child's disability. Marriages are more likely to end in divorce when partners are unable to support each other. Support between the marital partners should be equally important.

Despite the evidence that a child with a disability is a source of stress on the family system, certain disabilities can be more distressing to the family than others. Research indicates parents who have a child with ASD are at a higher risk for marital problems than parents of children with other disabilities (Weiss, 2002). Although the strain of raising a child with ASD is not a sole determinate of marital satisfaction, the presence of a child with ASD appears to have an impact on the family. Parents can become overwhelmed by the constant need required to care for a child with ASD.

Having a child with ASD can make parents feel isolated from the peer groups and society in general. Children with ASD also demonstrate challenging and disruptive behaviors that can be frustrating to parents. The general public has little knowledge about ASD and is often insensitive to the behavior of children with ASD. Parents have reported feeling as if they are being judged by others when their child had disruptive behaviors (Weiss, 2002). More commonly, parents have had to miss opportunities that could better their own lives such as vacations or job opportunities in order to avoid disrupting the life of their child with ASD (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001).

Men and women respond differently to caring for a child with ASD. Mothers tend to take a more personal responsibility for their child's problem than fathers (Boyd, 2002; Gray, 2003). Mothers are more likely to question their own parenting abilities, often believe they are being judged by others, and are more affected by the distance created between them and their spouse.

Children with ASD are delayed in their developmental growth, which can impact the family and marital relationship. The National Research Council (2001) reported there are better outcomes when the family is involved in learning about the child's disorder and is able to provide a supportive environment. Tremendous demands of time, energy, and finances are

placed on parents when they seek out services to help support them in the care of their child with ASD. This stress may hinder the parents' ability to work together to support each other at a time when it is most crucial.

Impact on Sibling Subsystem

According to Rivers and Stoneman (2003), when parents had more marital stress, siblings reported to have a less satisfactory relationship with their sibling with ASD. The study explored the association between marital stress and the sibling relationship when a child has ASD found that the siblings reported an overall positive relationship with their sibling with ASD. However, when families experienced higher marital stress and sought greater support from professionals and formal resources the typical siblings reported more negative sibling behaviors. Rivers and Stoneman (2003) reported that this might be because families may be seeking help for other reasons that are not related to the sibling relationship that highlights the importance of families seeking out support to address needs other than that of the child with ASD. Hastings (2003a) explored the adjustment of siblings of child with ASD who was participating in an intensive ABA early intervention program. The siblings in families with children with ASD who exhibited less severe behavior had fewer adjustment problems when formal social support was available to the families than siblings in families with ASD who did not have formal social support available. Hastings (2003b) investigated variables that may affect the adjustment of siblings of children with ASD. The siblings were found to have more problems with peers, an increase in adjustment issues, and lower prosocial behavior.

Kaminsky and Dewey (2002) examined the adjustment of siblings of children with ASD compared to siblings of children with Down syndrome or those typically developing. Self-administered measures indicated that siblings of children ASD were not at an increased risk for

loneliness or difficulties with social adjustment. Siblings of children with ASD appeared to have a more positive self-concept than siblings of typically developing children in a study on the psychosocial and emotional adjustment of siblings of children with ASD and of typically developing siblings (Macks & Reeve, 2007). The presence of a child with ASD did have a negative impact on the typically developing sibling as the demographic risk factors increased.

Siblings of children with ASD in a study by Mascha and Boucher (2006) reported being negatively impacted by their sibling's behavior, being embarrassed at times, and the impact of their sibling's aggressive behavior. Although some positive aspects of being a sibling of a child with ASD were reported, there was an overall negative impact reported. Siblings of a child with ASD in a study by Ross and Cuskelly (2006) also reported being negatively affected by the anger and aggression of their sibling with ASD.

Siblings of children with other disabilities have reported more positive relationships and interactions. Orsmond and Seltzer (2007) found that siblings of children with Down syndrome had closer relationships and spent more time with their sibling than siblings of a child with ASD. Siblings of children with Down syndrome indicated more optimism about their sibling's future and an overall closer sibling relationship.

In order for an individual with ASD to have more positive outcomes, there must be a support system in place. This support often begins within the family. These studies indicate future research should look at ways both formal and informal support systems can help serve to help protect families from the impact of family stress when raising a child with ASD.

Family-Centered Support

Family-centered support for mothers and fathers of children with disabilities has become a foundational aspect of service-provision (National Resource Center for Family-Centered

Practice, 2009). Family-centered support is not only mandated by Individuals with Disabilities Education Improvement Act of 2004 but has also become an accepted practice among service providers (Sandall, Hemmeter, Smith, & McLean, 2005). National Resource Center for Family-Centered Practice (2009) define family-centered support as “both an approach and a set of services, supports and opportunities that enable and empower families to successfully nurture and care for their children. The family centered support approach affirms that all families have strengths as well as needs; it recognizes parents as the experts on their children and families and normalizes the need for support for all families. The family support approach is not limited to social services; it can be infused into social institutions such as schools and health care. Family support services are preventive, typically voluntary, and usually community based.”

Family-centered support not only positions the family as the focus of support but includes the family in the decision-making process and respects and supports the family’s decision. Support should aim to strengthen the function of the family.

Sofronoff and Farbotko (2002) designed a parent-training program to help improve parent self-efficacy for parents of children with Asperger syndrome with problem behaviors. Participants in the program received either individual training sessions or training in one-day workshops. The outcome of the study reported significant decreases in the problem behaviors reported by parents. Parents also reported an increase in self-efficacy in the management of their child’s behavior. The results of this study suggest that the skills and information gained through parent training can help parents manage their child and increase their own sense of parental competency.

Family-centered practices and principles go back to early studies by Dunst, Johnson, Trivette, and Hamby (1991). The family is seen as a constant in the child’s life based on the

theory of family-centered practices. Families are assisted by professionals in decision making about their children by being provided with information that is complete and impartial, receiving emotional support, and receiving individualized services based on family needs which includes sensitivity to their cultural, racial and ethnic diversity (Dunst et al., 1991). In family-centered practice, professionals focus on the family as a whole (McWilliams, Tocci, & Hardin, 1998).

Empowerment

Zimmerman (1995) defines empowerment as “processes where people create or are given opportunities to control their own destiny and influence the decisions that affect their lives” (p. 583). Empowerment helps people gain control over their own lives and take action to get what they need (Akey, Marquis, & Ross, 2000). Empowering parents will help them gain resources and information, have their voices heard, advocate for their children, and take action for better outcomes.

Important characteristics must be taken into consideration in order to better understand Zimmerman’s (1995) theory of psychological empowerment. First, psychological empowerment has different meaning for different people. Various personal factors, such as ethnicity, socioeconomic status, and education can attribute to different outcomes in Psychological empowerment. Empowering experiences may vary in different contexts. Empowerment may occur differently for someone in the home than at work or in a social setting.

Psychological empowerment is a unique process in that it changes over time. It may vary such that an individual can be empowered at times or in certain domains and disempowered at other times and in other domains. As life experiences occur, the factors that indicate empowerment for an individual may also change over time. There is no sound method to develop

a universal measure of empowerment because psychological empowerment may vary across individuals, communities, cultures, and time.

Although many definitions of empowerment exist, a number of common themes can be identified in the literature. Boehm and Staples (2004) refer to empowerment as both a process and outcome. As a process, individuals participate in the decision-making process of groups or community organizations and take action with others. Outcomes are products of the process such as gaining access to community resources and information. Second, empowerment functions at both the personal and community levels. Personal empowerment refers to increased personal power such as self-determination and competence. Community empowerment refers to connecting with others, developing a sense of belonging, and involvement in the community in order to take action and have influence (Hur, 2006).

Zimmerman et al. notes that individuals should be provided opportunities to develop and practice skills they have learned, learn about resources, work together with others to reach a common goal, expand one's social support system, and develop leadership skills. Support groups for parents of children with ASD should be designed in such a way to incorporate these components to ensure parents are provided these empowerment processes. Zimmerman and colleagues caution researchers not to generalize one's ability to become empowered. Individual needs and differences like age, sex, and socioeconomic status must be taken into consideration. Empowerment can also change over time. As quickly as one can be empowered, one can be disempowered or empowerment can improve. Empowerment is an individual process in which individuals can be more or less empowered than others, even given the same circumstances. For parents of children with ASD this is important due to the loss of control many have reported feeling throughout the life span of their child's disability. Thorough and varied investigations of

empowerment should be conducted in order to maintain a more informed perspective of how different groups of people are empowered differently in varying contexts.

Zimmerman's Components of Psychological Empowerment

Psychological Empowerment (PE) is the perception that one has the knowledge, capabilities, and authority to be an active agent in their own life and in the surrounding community (Zimmerman, 1995). Zimmerman describes empowerment in terms of the individual's perceived control, the application of this control to their social and political environments, and participation in collective action. The three components of Zimmerman's theory include intrapersonal, interactional, and behavioral empowerment.

The intrapersonal component of PE describes perceptions that influence the behaviors of people. This includes perceived control, perceived self-efficacy, motivation for control, and perceived competence. Perceived control is the perception that one is able to control an outcome. This component is categorized into personality, cognition, and motivation (Zimmerman, 1995).

The interactional component of PE is the knowledge and awareness of a system with which one is working, the resources and support available within that system, and how to obtain what one needs. This includes the acquirement of skills. Skills include problem-solving, decision-making, and leadership skills that help parents advocate for what they need (Zimmerman, 1995).

The behavioral component of PE involves the actions and behaviors by an individual to influence, control and achieve desired outcomes. Intrapersonal and interactional components would also influence the behavioral component. Behaviors could include participating in a support group, involvement in community organizations or using coping skills (Zimmerman, 1995).

Empowerment Outcomes

Empowerment enables parents to have an active role in their child's education and treatment (Dempsey & Dunst, 2004). A number of studies have shown the benefits of empowerment on the family system and individuals within the family subsystems, specifically more positive outcomes for the parent and child. Dempsey, Foreman, Sharma, Khanna, and Arora (2001) describe empowerment outcomes as the behaviors, attitudes and knowledge related to the parental perceptions of control and confidence in raising a child. Dunst and Dempsey (2007) note the relationship between parents and professionals are essential to parental perception of control. That sense of control may be positively related to their judgments parents make about their capabilities when they have access to desired supports and resources (Trivett & Dunst, 2004).

Dunst and Trivette (1987) hypothesized principles that help achieve parent empowerment through parent-professional relationships. The theory focused on strengths of the family, access to resources and the control the family had to those resources, and the collaboration between the family and professionals. A number of studies have developed based on Dunst's theory. Dempsey, Foreman, Sharma, Khanna, and Arora (2001) found when families were part of a positive family-professional relationship there was a significant increase in empowerment regardless of the personal or socio-economic background of the participants. Dempsey and Dunst (2004) examined the relationship between help-giving practices and parent empowerment of parents of children with disabilities. Help-giving practices can be described as treating parents with dignity and respect; sharing relevant information so parents can make informed decisions; offering families' choices in the provision of and their participation in

services; and forming partnerships with families and collaborating with them (Dunst, Trivette, & Snyder, 2000).

Parents of children with disabilities in North Carolina and Australia participated in the study by Dempsey and Dunst (2004) by completing a questionnaire regarding: 1) how comfortable parents are with their relationship with service staff; 2) the extent of collaboration that exists in the relationship between parents and staff, and parents and their informal support networks; and 3) the degree of autonomy parents perceive they have in their relationship with staff. The results of the study found that despite significant differences in the characteristics of the participants and the differences in the programs the children with disabilities participated in, the findings were similar for both groups. Help-giving practices were the only significant predictor of empowerment. The researchers noted that combined help-giving practices were found to contribute to differences of parent empowerment.

To further study the relationship between parents and professionals and parents' judgments of their feelings of empowerment, Dunst and Dempsey (2007) focused on the partnership between parents and professionals and the association between partnerships and empowerment and parents' competence. The study sought to find a way to measure valid and reliable parent-professional partnerships, determine what the relationship is between parent' perceptions of partnerships and empowerment outcomes, and parents' perceptions of their competence, confidence, and enjoyment. The study indicated that a partnership was related to the empowerment of the parents. A relationship was found between the personal control parents reported and the partnership with professionals.

Taub, Tighe, and Burchard (2001) examined the effects of parent empowerment on adjustment for children receiving mental health services. The overall goal of the study was to

determine if a child's participation in mental health services contributed to increases in three domains of parental empowerment (Family, Service System, and Community) and if these domains played a role in the child's adjustment and outcomes. The area of family empowerment showed the greatest improvement over time and had the strongest correlation to adjustment for the child. This outcome highlights the link between parent empowerment and child outcomes. As the child's emotional and behavioral challenges improved so did the parental sense of control and value which contributes to and improvement in parental empowerment.

An experimental research study with African American fathers and father figures of children in Head Start programs in a Northeastern urban community by Fagan and Stevenson (2002) examined the effects of an empowerment intervention on the fathers. A program based on the empowerment theory called *Men as Teachers* was utilized as the intervention for this study. *Men as Teachers* was designed as a self-help program for African American fathers to help improve fathers' parenting attitudes and to increase an overall sense of well being. *Men as Teachers* is a curriculum-based, face-to-face training program over a course of a four-month period. Findings of this study indicated an empowerment-based intervention might be more effective than using a videotape to help fathers' learn to teach their children. Improved satisfaction and attitude were more prevalent in resident African American fathers than nonresident African American fathers. This outcome is important to consider for future interventions designed to help empower parents.

Creating Opportunities for Parent Empowerment (COPE) program was the focus of a study on mental health and coping outcomes by Melnyk et al. (2004) with 174 mothers of critically ill young children. The COPE program was designed to help parents recognize and understand behaviors children may exhibit during and after being hospitalized and direct

emotional and physical care of their child. The intervention involved a multi-step process of audio and written material designed to educate the parent. The outcome of the study established a positive correlation between improving the coping skills of mothers and the improvements in the outcomes of critically ill children. The mothers participating in the COPE program reported decreases in anxiety and post-traumatic stress disorder symptoms and improvements in overall mood. The mothers were also more involved in the care of their child while hospitalized and demonstrated improvements in care during the child's transitions of care while in the hospital.

Nachshen (2005) states parent empowerment has been identified as an important focus for the research of families of children with developmental disabilities (DD). The research on parent empowerment currently remains more of a theoretical perspective than practical. Nachshen and Minnes (2005) examined factors that contribute to the empowerment of parents of school-aged children with and without disabilities. The study found that parents of children with DD reported more stress and less wellbeing than parents of children without DD. Even though the parents of children with DD reported more behavioral problems from their child, they also reported more social support than the parents of children without DD. Parents of children without DD reported more community support. Interestingly, both groups had positive reports regarding their ability to manage daily life with their family and dealing with their child's development. Even though parents of children with DD reported more negative effects of raising a child with a disability, they reported the ability to cope the same as parents of children without a disability. Both groups of parents viewed school-services as family-centered.

Support as a Coping Mechanism for Parents of Children with ASD

Parental response to the stress of having a child with ASD may depend greatly on the type of support the parent receives. Parents may seek out information in order to have a better

understand of the disorder and to provide support to their child (Gray, 2002). A ten-year longitudinal study on the psychosocial adaptation of parents of children with ASD by Gray et al. formulated two conclusions regarding the outcomes for the parents. The first outcome revealed that most of the parents in the study had positive outcomes. The parents reported their ability to cope over time was a contributing factor in the outcome of their situation. The second outcome was more negative. Some parents did not have an improvement in their situation over time. The severity of the child's condition appeared to play a role in this outcome. Effective parenting for individuals with ASD emphasizes the importance of having skilled, educated parents that have been equipped with the ability to meet the needs of their child and cope with the affects the disability may have on the family. When parents of children with ASD are supported in relation to their child's disability, they report being more satisfied with their needs being met and have a better understanding of their child's disability (Whitaker, 2002). Research indicates that parents of children with ASD benefit from both formal (agency resources; professionals) and informal (family members; friends) sources of support (Webber & Boromeo, 2005; Weiss, 2002; Whitaker, 2002). Families of children with disabilities often seek support from family members, friends, professionals or other parents (Most & Zaidman-Zait, 2001).

An analysis of responses of 55 parents of children with ASD who completed the Family Crisis Orientation Personal Evaluation Scale (F-COPES) found that 68% of participants sought support from friends, 80% sought information from professionals, and 93% sought information and support from families with a child with ASD (Toy, Connolly, & Novak, 2006). Mackintosh, Myers, and Goin-Kochel (2006) examined sources of information and support reported by parents of children with ASD. The study surmised the most frequent source of both support and

information was other parents of children with ASD. Lower-income parents used fewer supports and information sources.

Guralnick, Hammond, Neville, and Connor (2008) established the greatest benefit for parents of children with ASD was access to a support network and receiving support related to the child. The study analyzed responses of 55 mothers of children with ASD using the Parenting Stress Inventory and the Inventory of Parenting. The mothers completed an initial assessment and the same assessment two years later. The second assessment revealed four types of support had somehow reduced stress for the mothers and the child. This was most significant when the supports were combined.

The benefits of support can not only help parents learn new interventions to help deal with a child's behavior but also help parents gain advocacy skills to get the services their child needs (Banach, Iudice, Conway, & Couse, 2010). Parents can learn to navigate complex educational, social, and medical systems when effectively supported. Parents of children with ASD in a study by Whitaker (2002) indicated more information about ASD was needed and there is lack of general and local support opportunities for parents. Banach et al. recommends that parents have supports throughout the lifespan of the child to help them adapt to the impact of the diagnosis over time.

Social Support

Schaefer, Coyne, and Lazarus (2002) define social support as support that comes from the social network of an individual. The members of the social network provide information, aid, or emotional support. Dunst, Trivette, and Deal (1988) identified four types of social support: companionship, emotional support, material help, and information. Margalit and Raskind, (2009) define companionship and emotional support as spending time with others, feeling

mutually close, expressing appreciation and regarding people as valued. Material support is defined as the provision of resources and assistance, whereas informational support involves advice and counseling. According to Ruffolo, Kuhn, and Evans (2005) social support helps to decrease caregiver feelings of embarrassment and loneliness. O'Connor (2002) provided four ways that the provisions of social support in parent groups affect the caregiver experience: 1) assists the caregiver to construct a self-identity as a "caregiver," 2) promotes a sense of personal competence; 3) fosters the use of formal support groups; and 4) creates a community context within which to experience the care giving role. O'Connor further noted that these experiences can help contribute to a sense of empowerment for the caregiver.

A study on social support, parent education and empowerment by Ruffolo, Kuhn, and Evans (2005) reiterated findings by O'Connor (2002) in the role that support plays in the empowerment of parents of children with special needs. The study summarized the effectiveness of an intervention program for caregivers of children with serious emotional disturbance (SED) enrolled in a community-based child and youth intensive case management program. The parent group focused on social support, parent education and parental empowerment. The researchers indicated the purpose of such a group is to not only reduce family stress but to help increase the overall quality of life of the families. The results of the study indicated a reported significant decrease in the behavioral symptoms of the children of the parents participating in the group. The study did find that the children still presented a high level of challenging characteristics related to their disability and indicated the parents will continue to face challenges in raising a child with an emotional disturbance. The researchers suggest intervention continues throughout the lifespan of the child and intervention addresses the changes in the child's development and family issues that arise. Siklos and Kerns (2006) looked at the perceived needs for social support

by parents of children with ASD and Down syndrome. Many of the needs reported needs and the needs being met reported by both groups were similar. However, the mothers of children with ASD reported less satisfaction with services and social support after the diagnosis. Benson (2006) sought to understand the relationship between the severity of a child's ASD symptoms and parent stress and further examine the role social support plays in reducing parent stress and depression. The investigation reported severe psychological distress in parents. Parents of children with less severe behaviors had a decrease in reported depression symptoms after receiving informal support.

Parent-to-Parent Support

Parent-to-parent programs may help provide support to parents that have children with disabilities by pairing them with a parent that has a child with the same disability (Baker-Ericzen, Brookman-Fraze, & Stahmer, 2005; Kerr and McIntosh, 2000). Kerr and McIntosh (2000) aimed to explore the impact of parent-to-parent support for parents of children with disabilities. The study included interviews regarding parent-to-parent support with 63 parents of children with limb deficiencies. Parents revealed the emotional feelings they felt at the time of their child's birth, lack of support from the medical professionals involved in their child's care, feelings of isolation, and concern about their child's future. The parents reported that they realized they were not alone and felt like the other parents of children with the same disability were the only ones who could understand. By talking to the other parents, there was a more positive outlook regarding their child's future and the child would learn to cope well with their disability. The most positive outcome of the study was the parents eventually felt like they were able to help other parents and were not in need for as much support as they were initially. An interesting finding of the study to note is not all parents had reached a level of acceptance with

their child's condition to seek contact with other parents. Some parents benefit from talking to other parents but not seeing the parent face-to-face. This is an important finding for other professionals to consider when helping families of children with disabilities find an appropriate support system.

McCabe (2008) conducted a study on the importance of parent-to-parent support for families of children with ASD. The parents in the study disclosed two major themes in regard to the outcomes of participation in a parent-to-parent group, sharing and learning from each other and support and acceptance of each other. When parents were asked how their participation in the program affected them, the parents noted they were not only able to learn by watching how parents responded to the training and instruction but when they were able to discuss ASD related issues with other parents, they were able to learn more. Parents indicated they felt acceptance and were encouraged by other parents. They found it difficult to talk to other parents that didn't have a child with ASD, so when they interacted with the parents of children with ASD there was a sense of bonding. This helped uphold their spirits and confidence as parents. McCabe (2008) suggested parent-to-parent support is incorporated as part of an intervention program so parents can provide a direct source of support for other parents. Banach, Iudice, Conway and Couse (2010) measured the effects of a support group on the advocacy skills and self-efficacy of parents of newly diagnosed children with ASD. The parents who participated in the study reported an increase in knowledge and empowerment in regard to supporting their child. Parents were able to help each other during a time when learning of the diagnosis could be challenging and emotional. The parents indicated they benefitted from the group the most by being able to discuss how to get services for their child.

The ability for parents of children with ASD to have interactions with other parents of children with ASD is clearly beneficial. However, with the fast paced demands in society today, many parents do not have the time to attend face-to-face support groups. Other parents may report the desire to connect with other parents, but have yet reached a comfort level to take that step. Professionals assisting parents of children with ASD by connecting them to support systems must be prepared to share other options with the parents. Parents who need information and support but are unable to fully commit to attending meetings, group activities or other face-to-face opportunities may benefit more from online opportunities with the right guidance.

Support Groups

McCurdy, Gannon, and Daro (2003) describe support groups as groups of people who share a common condition or interest. Support programs for parents are designed to decrease the stress associated with raising a child with special needs and to provide parents with the skills needed for more positive parenting. Support groups have a variety of formats, including face-to-face or online. Face-to-face support groups are often run by parents or parent-focused organizations, hold meetings, focus on a specific topic or theme, and may have an expert or professional come teach a specific strategy or technique (Soloman, Pistring, & Barker, 2001). Online support groups follow the same premise with the information and support being available on the Internet in the form of a chat room, blog, social networking site, website, online journal, email or listserv. Whether in a face-to-face or online support group, participants are seeking information about a disorder or its treatment, giving or receiving emotional support and encouragement, and venting frustrations about their condition or the condition of a loved one and how it affects their life. Solomon, Pistring, and Barker (2001) provided an analysis of the benefits of mutual support groups for parents of children with disabilities and identified three

primary domains where the most benefit occur; sociopolitical, interpersonal, and intraindividual. In the area of sociopolitical benefit, mutual support group participation helped parents shift from a negative identity perception to a more positive identity. Parents gained a sense of control over their situation and had more positive relationships with those around them. A sense of empowerment was the ultimate benefit in this domain. The parents were no longer recipients of information regarding their child's condition but played an active role in the child's care. The interpersonal benefits of mutual support group participation gave parents a sense of community membership, a sense of being understood and accepted in that community and establishing relationships and networks as a source of support. The third domain, intraindividual, helped increase parental self-esteem, feel less guilt about their child and reach a higher level of acceptance regarding their child's condition. Some parents reported improvements in their parenting skills.

Woodgate, Ateah, and Stecco (2008) gave attention to the issue of social isolation for parents of children with ASD. In the study, parents reported extreme social isolation and lack of understanding from others. The study exposed the need for parents of children with ASD to find support from others. Parent support groups have long been utilized by parents of children with disabilities to obtain information, share personal experiences, and get emotional support (Bull, 2003; Huws, Jones, & Ingledeu, 2001; Soloman, Pistring, & Barker, 2001). Law, King, Stewart, and King (2001) found that parents of a child with a disability demonstrated considerable positive gains from participating in support groups. The parents reported a sense of belonging and an increase in empowerment in their ability to advocate for their child. The parents reported increased knowledge and skill in dealing with the challenges of their child's condition. A support group model proposed by Barnett, Clements, Kaplan-Estrin, and Fialka (2003) focused

on helping parents work through the grief process after their child's diagnosis of ASD. A reported benefit of parent-to-parent support, professional support, emotional support and an overall sense of belonging was reported. Participants in a study by Mansell and Morris (2004) indicated that the most useful post-diagnosis service was a support group provide by a local clinic.

Research has shown that by participating in support groups, parents of children with ASD can reduce stress, decrease social isolation, and gain other positive outcomes (Boyd, 2002; Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Row, 2005; Solomon et al., 2001; White & Hastings, 2004). Participation in a support group with others who share similar experiences can provide information regarding ways to cope when a child has been diagnosed with a disability like ASD. The exchange of information is one of the most valuable elements of participating in a support group. Moreover, support groups offer people the opportunity to release emotions they may otherwise keep to themselves. Haggman-Laitial and Pietila (2007) reported parents of children with disabilities who participated in support groups reported the most important benefit of their participation in the groups was the knowledge they gained. The parents indicated they felt like the information they received was relevant to their needs and were inspired to look for more information. The parents also reported that their participation in the group was satisfying because it gave them a sense of companionship with other parents and was overall refreshing. Knowing that others shared common struggles and issues regarding parenting helped them feel empowered. Parents were often able to take suggestions they received back into their own families to help address challenges. There was an overall sense of improvement in self-esteem and family health.

Professional Support

Research indicates positive partnerships between parents and professionals can help the nurture parental empowerment (Dunst & Trivette, 1996). IDEA 2004 (Individuals with Disabilities Act) and NCLB (No Child Left Behind Act) set forth policy regarding parent–professional partnerships. Parents were encouraged to become more involved in their child’s education. A partnership with educators and other stakeholders was emphasized (Christie, 2005). The role of identifying and evaluating their children with disabilities was to be shared with parents. Parents shared equal involvement in the development, implementation, and revision of their child’s educational programs.

A school sponsored support group may be a way for professionals and parents to collaborate for more positive child and family outcomes. However, there is little published research on parent support systems in schools today (Banach, Iudice, Conway, & Couse, 2010). Parent education and support appears to be a more often served in community-based parent support groups (Fish, 2006; Spann, Kohler, & Soenksen, 2003). Kratochwill, McDonald, Levin, Scalia, and Coover (2009) gave attention to one school-sponsored support group for parents of children with disabilities. The results introduced the idea that there is a benefit to school-sponsored support groups because there was a significant increase in reported adaptability of the parents that participated. The lack of research of school-sponsored support groups demonstrates a need for more supports, especially for parents that may also be limited in community resources regarding their child’s disability. Tonge et al. (2006) examined the impact of a parent education and behavior management intervention on the mental health and adjustment of parents of young children with ASD. Parents participated in a parent education and skills training program and a

parent education-counseling program. The study indicated positive benefits to the parental mental health and well being as a result of participation in the support and education groups.

Banach, Iudice, Conway, and Couse (2010) sought to determine if short-term parent ASD support group for parents of a child recently diagnosed with ASD that provided information about ASD, community resources and self-advocacy met the needs of families. The group was run by a social work graduate student and an early childhood special education graduate student. The parents who participated in this study reported a gain in knowledge about ASD and had a sense of empowerment in regard to raising their child. The parents indicated that being in a group with others parents of children with ASD afforded them the ability to discuss intervention and treatment options for their child. A reported gain in self-efficacy was also assumed to be correlated to participation in the school-supported group. Parents were able to help each other.

The purpose of the study conducted by Baker-Ericzen, Brookman-Fraze, and Stahmer (2005) was to examine parent stress before and after participation in an inclusive toddler program. The program included parents of children with ASD and typically developing children. The study indicated significant higher levels of stress related to raising a child with ASD. The mothers of children with ASD did report a decrease in child-related stress after participating in the program. Hastings and Johnson (2001) explored predictors of stress of parents participating in an intensive home-based intervention for young children with ASD. The parents reported more stress than parents of children with other disabilities. The more severe the child's condition, the higher stress was reported by the parents. The reported predictors that lowered parent stress were adaptive coping skills, informal social support, and a belief in the effectiveness of the intervention.

Online Support

The internet has become a popular tool in society today. The ability to communicate, shop, work, and learn from the comfort of home is a luxury that modern civilization has grasped tightly. Obtaining information and connecting with others across the world has become just a click away. As the prevalence of ASD continues to increase, the need for parents to utilize the Internet as a source of information and support about their child's disability has increased. Previous studies on parents' use of online communication suggest that they seek information on effective parenting strategies and problem solving skills (Blackburn & Read, 2005; Sarkadi & Bremberg, 2005). Eysenbach, Powel, Englesakis, Rizo, and Stern (2004) evaluated patients' online community experience and examine its impact on patients' attitude toward healthcare organizations and its services because there had been limited research focus on measuring or evaluating patients' experience in such online health communities. Margalit and Raskind (2009) note that few studies have examined the role that online sites for parents of children with disabilities play in their lives.

Traditionally, parent education and support has been delivered through workshops and training, parenting classes, community based programs, training videos, books, and handouts. Technology is now altering the traditional ways people seek out support in regard to a stressful situation like raising a child with a disability such as ASD. With the use of the Internet on the rise, online support groups have given parents of children with ASD another option for support for those individuals who cannot attend face-to-face support group meetings. Online support groups enable parents with similar interests to form a virtual support group online regardless of their location or schedule. An examination of Internet support groups for caregivers of children with special health needs by Baum (2004) established that parents join online support groups to

find people in similar situations, to receive social support for their situation, and to receive direction which are the same reasons parents join face-to-face support groups. Online support groups provide parents of children with disabilities anytime access, anonymity, and flexibility when seeking support regarding their child's disorder (Chang, Yeh, & Krumboltz, 2001; Colvin, Chenoweth, Bold, & Harding, 2004). Eastin and LaRose (2005) report that parents enjoy the anonymous nature of online interactions that allows them to freely express emotions and thoughts and gave them a sense of companionship which decreased the feeling of being lonely.

Online support groups have flourished in recent years to offer support for a variety of issues and challenges. Online support groups can provide members the same emotional and educational support and provide the same sense of belonging as a face-to-face support group when members are unable to participate in face-to-face meetings (Chang et al., 2001; Colvin et al., 2004). Margalit and Raskind (2009) examined the roles and functions of mothers of children with LD and ADHD who participated in an online community. The study revealed two major empowerment roles related to their participation in the online community that was the provision of support and the provision of information. In regard to the provision of support, the mothers expressed that their participation in the online community decreased their sense of loneliness and gave them a renewed sense of closeness with other mothers of children with LD and ADHD. The mothers noted they felt they were able to disclose personal feelings and opinions without being judged and felt a sense of compassion from others. In regard to the provision of information, the mothers indicated they liked that the information provided to them online was researched-based and they felt the online community was individualized to their specific needs. The mothers were able to make better decisions for their child and explore new options. The

study did not find any correlation between the time the mothers had spent online and overall benefit of their participation.

Participation in online support groups does have some challenges. Research indicates for parents of children with a complex disorder like ASD, the ability to gain support from the comfort of their home can be beneficial or more harmful depending on their experience with that support (Baum, 2004; Blackburn & Read, 2005; Bragadottir 2008; Finn, 1999).

Finn (1999) evaluated the use of online self-help and mutual aid groups and explored the extent to which advantages and disadvantages to online support groups for issues related to disabilities. The results indicated that the members of this group shared information about a wide-variety of health-related information. The community provided a caring environment in which participants were more likely to take on a “helper role” by providing support, empathy and care instead of asking for assistance. Because the group was not limited to one specific disability, a wide variety of disability topics were discussed. This study does provide some evidence that an online self-help group for issues regarding disabilities can be beneficial.

Wright (2000) conducted an in depth study regarding online support groups. One aspect of the study focused on the advantages and disadvantages of computer-mediated support groups versus face-to-face support groups. Participants in the study were members of substance abuse recovery, eating disorders, terminal illnesses, social anxiety, and mental illness support groups online. The advantages of online support group participation most frequently reported by study participants was ambiguity and not feeling ashamed when communicating with other participants in the online group. Participants noted they liked online support because it was easier to be open and express feelings, is more available, and communication with others with similar issues was beneficial. The most common disadvantages of participation in an online support group as

reported by participants in the study were the lack of physical communication with others and the lack of nonverbal cues that often help prevent misunderstanding in comments. Other underlying issues reported by participants were the use of negative comments by other members of the online support group, member deception and the slower response to feedback than face-to-face communication. Participants noted it was much harder to form a relationship with others when participating in an online support group. Parette, Meadan, Doubet, and Hess (2010) take the position that often technology-based supports have been created by professionals who, had good intent, but may not have collaborated with families in the design and implementation of such supports.

Baum (2004) reported similar findings in the majority of the participants of online support groups indicate satisfaction with their participation (93%). The participants reported that the ability to get ideas they can use, an overall improved relationship as a caregiver, and the ability to find someone they could trust were the primary factors that played a role in their satisfaction with the online group. In regard to coping, the participants indicated the ability to get ideas that applied to their situation and the ability to help others played a role in their ability to cope better with their child's condition. Overall, the participants said their participation in the online group made them feel better. They reported becoming more hopeful and relieved regarding their child's condition.

One issue in regard to online support for parents of children with ASD is whether one type of support can benefit fathers as much as mothers. Even though the needs of mothers and fathers of children with ASD may vary depending on the circumstances, online support groups may be vast enough to satisfy this need. A study on computer-mediated support group intervention for parents of children with cancer by Bragadottir (2008) indicated that participation

in an online support group resulted in an overwhelming decrease in depression for the mothers and a decrease in anxiety for the fathers. Mothers were more likely to participate on a regular basis than fathers. Both parents reported feeling a sense of helpfulness, hope, and unselfishness from their interactions with others in the group. The feeling that they were not alone in their feelings and struggles as they faced their child's condition was comforting. The parents did report a feeling of uneasiness in disclosing their own personal information online to the group. Overall, a sense of satisfaction with participation in the online support group was reported.

The use of the Internet as a source of information and support for parents of children with ASD is not always the best route for parents to pursue. Like face-to-face support groups, online groups often attract a specific demographic that is not always sensitive to the diverse and cultural differences of the parents that are raising a child with ASD. Using the Internet to find reliable sources of information and support takes time and skill in order to weed through the sea of information. Blackburn and Read (2005) examined the experiences of parents of children with disabilities that use the Internet for information about their child's condition. The study identified that the majority of the parents that used the Internet for information regarding their child's disability were female, ages 30-44, and Caucasian. When parents were asked about problems and barriers they face regarding the use of the Internet the parents ranked the most common problem as "it takes too much time to get information" (86%) as most problematic and "can't find the information needed" (85%) as the second most problematic. Other areas of concern reported were the difficulty of navigating websites, slow Internet connection, and difficulty understanding the use of the Internet. In regard to circumstantial barriers to use the parents ranked "lack of time due to demands of other commitments" (61%) and "lack of time due to demands of caring for the

child” (57%) the most critical to their use. Other areas of concern were cost, access, and overall education and training regarding the use of the Internet.

Pew Research Center (2010a) found that individuals reporting higher household incomes also report higher Internet usage. Only 60% of individuals reporting a household income of \$30,000 or less report Internet usage. Internet usage by individuals reporting a household income of \$50,000 to \$74,999 was at 84% and increased to 94% for individuals reporting an income of over \$75,000.

Participants in a study by Parette, Meadan, Doubet and Hess (2010) reported they preferred using the Internet to seek information about their child’s disability, other disability specific information such as treatment and intervention and email with professionals and other parents. A little more than half of the participants indicated that they depend on the Internet for social support.

In order to better understand the extent to which families of children with ASD and other developmental disabilities use available technology-based supports or what the features are of these technology tools are that are preferred by families, Parette, Meadan, Doubet, and Hess (2010) conducted study of families regarding their use of technology-based supports. It is important to note that the majority of study participants (74%) were in the 30-49 age group. Pew Research Center (2010) found that 81% of Internet users (age 18 and older) are in the 30-49 age group. The majority of study participants also reported a higher education. A reported average of 94% of Internet users have a college degree or higher according to Pew Research Center in Washington, DC (2010). With the majority of communication and education moving towards provision on the Internet, these demographic factors are important for professional to take note

of. If a parent of a child with ASD does not have access to or does not choose to use the Internet for support, professional must be prepared to provide other support options.

Demographic Factors Affecting Support

Professionals cannot rely on one form of support to meet the needs of every family of a child with ASD. For instance, attending support group meetings can be difficult for some due to time constraints, transportation issues, lack of child care, comfort level of interacting with others, or lack of understanding of the benefits (Biegel, Shafran, & Johnson, 2004; Goelitz, 2003; VanLear, Sheehan, Withers, & Walker, 2005). In a study of African-American and Caucasian caregivers of individuals with mental illness from lower socioeconomic status, Biegel et al. investigated factors that influence participation in support groups among low-income caregivers. Participants identified lack of time to be a key factor in the inability for parents to participate in support groups. Participants also indicated that the perceived drain of personal energy and having less optimistic expectations with regard to gaining knowledge or having increases in emotional coping skills as other barriers. Biegel et al. noted that support group participation could improve if there were more education about support groups and more outreach to participants. Support groups are also more often utilized by a specific gender, race and overall demographic population. Support groups rarely address the diverse needs and cultural differences of the families they are serving. A study concerned specifically with support group membership by Mandell and Salzer (2007) found that the majority of the participants in ASD support groups were mothers of children with ASD (86%) and Caucasian (83.5%). Most parents came from an upper middle class socioeconomic status and lived in suburban areas of their community. The parents who participated were primarily married or cohabitating and had a college education. The demographics of the participants in support groups for families of children with ASD plays

an important role in the way that professionals provide support to families. These factors should be taken into consideration for professionals to create a more diverse approach to the support they provide. A vast amount of studies have revealed support group participants are more often Caucasian, middle-class, educated, married females (Heller, Roccoforte, & Cook, 1997; Little, 2002). The topic of maternal education level was a reoccurring theme in the outcomes of a study by Little (2002). Mothers, in the study, who had lower education levels reported being more pessimistic regarding parenting a child with ASD, were more likely to take antidepressants and were less likely to find coping skills helpful related to maintaining family stability. The study indicated the reason(s) for higher negative outcomes for mothers is an area that needs further inquiry of research.

To date, little research has focused on the influence of ethnicity on parent support program participation (McCurdy, Gannon, & Daro, 2003). Akey, Marquis, and Ross (2000) note that empowerment can vary across demographic groups so it is important that these factors are taken into consideration in research studies. To further support this claim, Baxter and Kahn (1999) found that low income parents of children with disabilities reported different needs of support regarding the care of their child than other parents that are not considered low income. Approximately 37 families of a child with a developmental delay or at-risk for a developmental delay, reported factors such as food, shelter, transportation, information and personal time as areas of strain in their lives. Mothers who were less educated had a more negative attitude regarding their child's future and was found to be more likely to take medication to cope with depression than educated mothers in the study. Treating ASD can cause a family a large financial burden (Sharpe & Baker, 2007). This burden is more prevalent at the early intervention phase due to the need for intensive therapies in multiple domains. Thomas, Ellis, McLaurin, Daniels,

and Morissey (2007) identified family characteristics associated with the use of ASD services. Access to care was limited for low-income families, minorities, families living in rural communities, and those seeking more non-traditional treatments and care. An examination of the perceived negative impact of parenting a child with ASD by Bishop, Richlet, Cain, and Lord (2007) revealed some interesting differences in between different demographic groups. African American mothers reported less negative impact than Caucasian mothers. Mothers with fewer children in the home than mothers who had more children reported a higher perceived negative impact. Interestingly, this study did not find a correlation between the characteristics were not predictors of perceived negative impact on the parents.

In a study by Bailey et al. (1999) 200 Latino parents of children with developmental disabilities reported that they needed information about their child's condition, services, and coping skills the most. The parents reported receiving more support from family and formal sources than from friends or informal sources. Higher levels of support and fewer needs were reported by parents with greater English language proficiency than those with more language barriers. Language barriers had the most significant effect on the support and needs of the families. Bailey et al. noted the importance of understanding the individuality of each family situation is just as important as understanding the cultural characteristics that make up the family.

A study investigating the relationship between ethnicity and retention among parents participating in a child abuse prevention support program was conducted by McCurdy, Gannon, and Daro (2003). The participants were parents expecting a new baby or of a newborn baby that had been identified as at risk for poor parenting based on an interview prior to participating in the study. Mothers were the only gender utilized in this study. The ethnic groups who

participated in this study consisted of African Americans, European Americans and Latinos. The European American participants were more likely to choose to not participate in the home visitation program. The study was unable to determine the reason for this outcome. The African American and Latino participants were equally open to participation in the services. The African American was the only demographic group that showed a benefit of an ethnic match in services. African American parents who also had an African American service provider received eight more visits and three more months of services than the other ethnic groups participating in the study that also had the same ethnic service provider. McCurdy et al. recommend it may be beneficial to foster an alliance between ethnically similar service providers and participants in support programs, specifically in the African American demographic group due to higher prevalence of poverty, health issues and social disadvantages that are more often supported by non-African American service providers.

For single parents raising a child with ASD, the need for support may be even greater than parents who are married. Reyes-Blanes, Correa, and Bailey (1999) surveyed 96 mothers of children with disabilities in a study that assessed the needs and support for mothers of children with disabilities. Single mothers and mothers that saw their child's disability as more severe reported a greater need for support than mothers who were married or that saw their child's disability as less severe. Mothers that were married indicated the primary sources of support came from their spouse and other adult family members. Single mothers received more support from agencies. This study indicated single mothers may have higher stress as the sole caretakers of their child with a disability. Single mothers stressed a need for more support from outside agencies and support systems. A more in depth study look at the experiences of single parents and the support networks utilized. Webber and Boromeo (2005) reported that single parents rely

on both informal support and organizations to help them cope. The majority of the participants (90%) reported participation in support networks helped improve their overall well-being and ability to support their child. Support included a range of sources including friends and family, agencies, community support, church, and counselors.

Parents of children with ASD need supports in place to help them gain an understanding of their child's disability, skills to help their child and to acquire coping skills and strategies that help increase the probability of more positive child and family outcomes. The need for support to parents of children with ASD is central to their adaptability to the child's disorder and their survival as a family. Not only can professionals help parents of children with ASD access the resources and support systems that are available to them, but can also help empower the parents to be more proactive advocates for their child. Heller, Roccoforte, and Cook (1997) discovered in a study on support group participation of families of a person with mental illness that women who are older, Caucasian, educated and middle class are more likely to participate in support groups. Future research should explore the barriers to participation in family support groups by individuals from diverse backgrounds. To further support this idea, Mahoney et al. (1999) noted that "the population of children and families in early intervention is multicultural. Research is needed as a basis for understanding parenting within cultural contexts and to develop parent education strategies and content that fit the cultural values of families" (p. 137).

Sofronoff and Farbotko (2002) highlighted the gender differences in parental self-efficacy of parents of children with Asperger syndrome after a parent-training program. The results of the study disclosed a significant improvement in self-efficacy for mothers after the training. The fathers in the study did not report any change in their self-efficacy at any point in the study. After a three-month period, the mothers reported preservation of their improvement in

self-efficacy. The authors note that the mother may be better able to manage the child's behavior due to their role as more frequently the primary caregiver. This role gives the mother more opportunity to implement the strategies learned. Because fathers may not be able to have more practice implementing skills learned, the father may be less likely to self-report an increase in self-efficacy.

One area of support that is minimally documented in the literature is the use of religion or spirituality as a form of coping for parents of children with ASD. Tarakeshwar and Pargament (2001) assessed the use of religious coping among parents of children with ASD. Overall, better religious outcomes and stress-related growth were correlated with religious coping. When the parents experienced negative religious coping, an increase in depression and low religious outcome was reported. Regardless of the type of support, a post-diagnosis support system can help parents adapt to the diagnosis, reduce stress, and help parents' access resources (Banach, Iudice, Conway, & Couse, 2010).

Summary

In this section, the literature pertinent to support and parental empowerment among parents of children with ASD was reviewed. A profile of the differences in parents of children with ASD and empowerment was provided based on a series of descriptive studies. Empowerment theory was explored with discussions of empowerment, parental stress and coping related to raising a child with ASD, types of support for parents of child with ASD, and the importance of the relationship between support for families of children with ASD and empowerment. Empowerment should be the ultimate goal of support services for parents of children with disabilities because empowered parents are able to support their child and

empowerment encourages more positive outcomes (Turnbull & Turnbull, 2001). Chapter III discusses the methodology and procedures utilized in this study.

CHAPTER III:
METHODOLOGY AND PROCEDURES

Overview of the Study

This chapter addresses the methodology utilized in this research study. The chapter begins with a discussion of the research design, characteristics of the participants, instrumentation, data analysis, followed by the assumptions and limitations of the study. Quantitative research methodology was used in this study. The goal of this study was to explore the influence of demographic factors on empowerment attributions of parents of children with ASD. Quantitative analyses were performed to measure the effects of specified demographic factors on parents' self-reported responses on the three dimensions of the Psychological Empowerment Scale (PES), namely attitude, formal participation, informal participation and skills and knowledge. The sample was drawn from the population of parents of children with ASD from a southeastern state in the United States.

Research Questions

This study was guided by the following five research questions that measured how specific subscales of the Psychological Empowerment Scale (i.e., attitude, formal and informal participation and skills and knowledge) are affected by demographic factors.

1. Is there difference in parent formal and informal participatory behavior with respect to marital status;
2. Is there difference in parent formal and informal participatory behavior with respect to gender;
3. Is there difference between parent education level and skills and knowledge about ASD;

4. Is there any difference in parent attitude with respect to ASD and their perceived severity of the child's ASD; and
5. Is there a relationship between formal and informal participatory behavior and parental skills and knowledge with respect to ASD?

Research Design

The study utilized quantitative research methods to examine the effect of demographic factors on empowerment attributions of parents of children with ASD. Quantitative research focuses on numerical analysis and is reported in terms of scores. Fraenkel and Wallen (2009) define quantitative research as research that attempts to shed light on experiences through data collection and analysis that has been carefully designed. Quantitative methods are appropriate when identifying those factors that might influence a specific outcome or when testing a particular theory (Creswell, 2009). The theoretical frameworks guiding this study are Turnbull and Turnbull's family systems theory and the empowerment theory by Zimmerman (1995). Turnbull and Turnbull's (2001) framework for understanding the emotions, dynamics, and elements of family systems has allowed professionals to work more effectively with families. The family systems theory is built upon the premise that by understanding and identifying the basic characteristics, interactions and functions of families, professionals can build better partnerships and support systems for families and children with disabilities. Zimmerman's theory of empowerment specifies that individuals should be provided opportunities to develop and practice skills they have learned, learn about resources, work together with others to reach a common goal, expand one's social support system, and develop leadership skills (Zimmerman, 1995). Zimmerman's theory is analogous with the family system's theory because both theories share the same perspective which indicates individual needs and demographic differences must be taken into consideration when working with a family.

The Psychological Empowerment Scale and demographic questionnaire instrument was used in this study to examine the role of demographic factors in the empowerment of parents of children with ASD (see Appendix A). According to Creswell (2009), survey design is an “approach that provides a quantitative or numeric description of the attitudes, perceptions, and opinions of a population by studying a sample of the population” (p. 145). From the results, the researcher generalizes the findings to the population. Survey research asks questions with the answers serving as the data of the study. Some of the important attributes of using a survey instrument is as follows (Kelley, Clark, Brown, & Sitzia, 2003; Salant & Dillman, 1994):

1. a survey can identify attitudes and perceptions of a large population of respondents efficiently;
2. is cost effective, particularly when dealing with large populations;
3. easy to administer;
4. a familiar format to most people;
5. less biased;
6. easy to analyze; and
7. less intrusive.

For the purpose of this study, a survey allowed the researcher to collect information from a group of people (parents of children with ASD) across Alabama in order to portray some characteristics of the population of which the group is a part.

The survey research used for this study was chosen because it quantitatively described specific aspects of parents of children with ASD in regard to empowerment. The data required for survey research was collected from the parents and was, therefore subjective. Using a survey for this research study allowed a portion of the population to be selected from which the findings could later be generalized back to the population. The more that is known about human behavior

and experiences, the better society will be able to understand them. Consequently, the more that is known about parents of children with ASD, the better able professionals can be to help them.

Participants

A prerequisite to sample selection is to define the target population as narrowly as possible (Salant & Dillman, 1994). This study was conducted with parents of children with ASD in a largely populated state in the South East United States. Careful attention was given to the process of selecting the setting for this research and the method of data collection and analysis. The parents of children with ASD were recruited from different ASD resource service providers. These include but are not limited to the state Autism Society; statewide ASD face-to-face and online support groups; more well-known organizations such as Easter Seals; school systems; respite providers and medical or therapy service providers for individuals with ASD. In addition, I was able to gain access to potential participants in the research study during an ASD conference. The ASD conference included participants who were parents of children with ASD or professionals who serve individuals with ASD and their families. I provided the coordinators of the conference with copies of the research study as well as a consent form, hard copy of the survey and a stamped, self-addressed return envelope. These were then given to each participant the morning of the conference.

For the purpose of this study all ASD resources, providers, organizations and supports are referred to as “service provider.” This study also made all attempts to recruit participants drawn from diverse ethnic, cultural, economic, and educational backgrounds.

Parents of children with ASD who were ages 3-21 years throughout the target state were eligible to participate in this study. The age range for the child was for a number of reasons. First, the average age of diagnosis for ASD is between ages 3 and 4 (Easter Seals, 2013).

Selecting an age below three years would decrease the likelihood of parent certainty of a child's diagnosis. Second, the age was set up to 21 years in accord with school age children's age of eligibility for special education services under the Individuals with Disabilities Education Act (2004). Even though an individual is considered an adult at 18, special education services are often provided to individuals with ASD to age 21 (Easter Seals, 2013). Children who are still in an age range to attend school may also still receive services, therapies, interventions or support regarding their ASD. Parents of children in this age range may still seek information and support regarding parenting a child with ASD, even if the information is in regard to transition planning for an adult child with ASD.

Participants were recruited from statewide service providers who serve individuals with ASD and their families. I made personal contact using email, online advertisement pages or via phone contact with each ASD service provider. First, I utilized information provided on a service provider database on the state autism society webpage. The website of the autism society in the target state has a directory of the variety of information about ASD service providers in the state. The database included statewide support groups, intervention and therapy providers, medical providers, resource centers and treatment facilities. Utilizing this information, a document was compiled that listed each service provider in alphabetical order (see Appendix B). The following information was included for each listed service provider: 1) name of service provider; 2) primary contact person at the service provider; 3) the location and address of the service provider; 4) a short description of the type of ASD service provider; (5) the website for the service provider (if applicable); 6) an email address for the contact person of the service provider; 7) the phone number of the contact person of the service provider; 8) fax number of the service provider; and 9) any valuable miscellaneous information about the service provider .

Approximately 110 statewide ASD service providers were identified on the state Autism Society website. Note that this total might not have included the different divisions or branches of a service provider such as Easter Seals, which has a facility throughout multiple cities across the state. The primary facility was noted on the list and then individual facilities were contacted once the researcher began to reach out to each service provider. The provider list was created as a Microsoft Word document and printed. Any additional service providers that were discovered or identified were also included throughout the research process. In addition to this list of statewide ASD service providers, a list of all state Autism Society ASD parent support groups across the state was compiled (see Appendix C). This list comprised of 32 ASD parent support groups across the entire state. The researcher noted the location (city or county) of the support group, name of the support group leader, contact email address and website (if applicable) of each support group. The final list of ASD resource contacts included statewide special education directors or coordinators (see Appendix D). This list was provided by the State Department of Education per my request, which included 78 special education directors or coordinators from all county and city school systems across Alabama. I used this list to contact each director or coordinator about their willingness in sharing information about the research study with the parents of children with ASD in their respective school systems.

Once a list of state ASD service providers was established I contacted each service provider on the list. Initial contact with each service provider was made via email. For each contact made via email, I introduced myself, explained the study, explained my role as the primary researcher, explained the role of the participants in the study and explained the steps for participation in the study. The IRB approved informed consent (see Appendix E) and research study advertisement (see Appendix F) was attached to the email. Each service provider was

given the option of sharing the study advertisement with potential participants, sharing the consent form and link to the online survey or could request hard copy research packets to be mailed to them. I also offered to meet face-to-face with anyone or a group in order to provide potential participants with information regarding the research study.

In addition, social networking sites like Facebook as well as statewide online ASD parent support group pages (i.e. Yahoo) were also utilized to advertise the study. Information about the study was posted on statewide ASD related Facebook pages. Individuals who were interested in the study made contact with the researcher to request more information.

Potential participants who requested hard copy information about the study contacted the researcher by email or phone to make the request. Each individual making a request for an information packet provided a mailing address or email for where to send the information. The researcher provided a stamped addressed envelope with all hard copy survey requests in order for the participants to be able to easily return completed surveys to the researcher upon completion. I maintained a follow-up log in order to document information on service providers who made direct contact with me to request more information, request hard copies to be mailed or to express that they currently couldn't not assist with the distribution of information about the study because they currently did not serve any individuals with ASD or parents of children with ASD (see Appendix G).

Response

About 350 actual hard copy surveys were mailed to share with potential participants and over 300 actual contacts were initiated with ASD service providers and parents.

The majority of the hard copy surveys were requested by large ASD resource organizations or ASD support group leaders who offered to share with potential participants.

Four parents of a child with ASD directly contacted me to request a hard copy of the survey. These parents had heard about the research study through an advertisement that had been shared with them by their ASD support group leader.

Because of the confidentiality involved in the study, follow up was only conducted with individuals who requested research study packets. Follow-up occurred after one week to check on any further needs or queries. Further, once every week an advertisement was posted on statewide ASD social networking resource pages and statewide ASD parent online support group pages.

Overall there were 115 survey responses returned out of which 96 were completed online at Survey Monkey and 19 were hard copy. Frankel and Wallen (2009) recommend that a sample should be as large as the researcher can obtain within a reasonable expenditure of time and energy. The IRB required 100 surveys to be collected in order for the study to end. Given the limits set forth by the IRB, once 115 surveys had been collected all data collection efforts were completed.

The anonymity of potential participants in this study and the nature of the advertisement procedures of the study prevented an accurate calculation of the response rate. The initial information about the study was shared with organizations who serve individuals with ASD and their families. In turn, the organizations either requested research study packets to pass out to potential participants or shared the advertisement about the study with potential participants. There was no way to document the exact number of potential participants who were invited to participate through the advertisement or had access to research packets, therefore, a true calculation of percentage of return rates was not possible. Even if an organization requested a set number of research study packets, this was done so with the intention to share with potential

participants but not with specific participants in mind. There was no way to track if all packets requested or distributed to ASD resource providers were indeed given to potential participants or if a potential participant chose to participate in the study once they read information in an advertisement or the research study packet.

Institutional Review Board Process

In accordance with The University of Alabama requirements, The University of Alabama Institutional Review Board (IRB) approved this plan of research (see Appendix H). Informed consent and protecting the participants' confidentiality was a primary concern. Careful attention was given to the dissemination of information provided to potential participants regarding this research study. The researcher maintained storage of data and identifying information was carefully safeguarded. The researcher made contact with each ASD resource providers through email or study advertisement utilizing the scripts approved by the IRB (see Appendix F). Upon introduction, a script was read to explain the concept of research design, the details concerning individualized data security and protection and guidelines for participant participation. The informed consent provided a detailed description of the study, background information, procedures, risks and benefits, and the confidential nature of the study (see Appendix E). The participants were also provided with personal contact information.

Informed consent forms were returned with all completed hard copy instruments. The IRB gave permission to waive the need for a signed consent form from participants who chose to complete the instrument online. Online participants were given a copy of the informed consent form as part of the advertisement of the research study and were also notified in any advertisement that they could request a copy of the informed consent prior to completion of the online instruments.

Signed letters of consent were returned with completed instruments by participants who chose to complete a hard copy. There were no foreseeable risks to the participants beyond use of their time. The main benefit of participating in the study was the opportunity each participant had to reflect on his or her own empowerment as a parent of a child with ASD.

A variety of measures were taken to maintain data were kept confidential throughout the research process. There was no information on the questionnaires that contributed to the identification of a participant such as a name, address or phone number. Consent forms were separated from the hard copy questionnaires upon return and kept in a different file. All hard copies of completed instruments and consent forms were maintained in a locked file cabinet. Copies of questionnaires completed online were printed and kept in the locked file cabinet as well. Access to questionnaires completed on the online host Survey Monkey also required a login and password to access.

Instrumentation

The study utilized an instrument named the Psychological Empowerment Scale (PES) developed at The University of Kansas, Beach Center on Disability. Permission was granted by Dr. Jean Ann Summers who is the Beach Center research director (see Appendix I). Dr. Summers also granted permission for additional demographics to be added for this study. To facilitate answering the research questions for this study, I conducted a search for appropriate existing instruments whose validity and reliability was already pre-established. The PES instrument was considered appropriate in terms of the constructs that it measures. A demographic component was added targeting demographic factors that had been established in previous research or were hypothesized to make a difference in parents' empowerment attributions. The demographic components of the instrument included parent self-reports of the

following: 1) type of support group membership; 2) gender; 3) marital status; 4) level of education; 5) highest level of education; 6) household income; 7) type of child's ASD; and 8) perceived severity of child's ASD. Parents also indicated the types of general ASD supports they participate in as well as the specific online supports they participate in. The demographic aspect of the instrument included a list of different types of general supports such as the Internet, workshops and conferences, friends and family or books and literature and online supports such as websites, chat rooms, blogs or training modules; participants indicated by checking a box the supports specific to their own participation in regard to parenting a child with ASD.

The PES is based on Zimmerman's (1995) theory of psychological empowerment. Zimmerman's theory consists of three dimensions of psychological empowerment: 1) attitudes, 2) skills and knowledge; and 3) formal and informal participatory behaviors. Parents were given a copy of the PES to complete. Parents rated their own empowerment attributes in regard to the three dimensions of psychological empowerment. The instrument also included demographic items such as gender, marital status, education level, household income, type and severity of the child's ASD. Participants were also asked to indicate the types of general ASD supports they participate in as well as the specific online supports they participate in. Given a list of different types of general supports such as the Internet, workshops and conferences, friends and family or books and literature and online supports such as websites, chat rooms, blogs or training modules; participants indicated by checking a box the supports specific to their own participation in regarding to parenting a child with ASD. Although this information was not specifically correlated to the research questions in this study, this is important data for future research.

The objective of this study was to understand how demographic factors influence parent empowerment of children with ASD. The dependent variables were perceived empowerment and parental demographics comprised the independent variables.

The PES is a 32-item scale that was created to be used as an assessment tool in a research or program evaluation to measure psychological empowerment (see Appendix A). Four primary subscales were included in the survey: attitudes of control & competence (intrapersonal dimension), critical skills & knowledge (interactional dimension), and formal & informal participatory behavior (behavioral dimension). Zimmerman (1995) defines the intrapersonal component of psychological empowerment as perceptions that influence the behaviors of people. This includes perceived control, perceived self-efficacy, motivation for control, and perceived competence. The interactional component is defined as the knowledge and awareness of a system with which one is working, the resources and support available within that system, and how to obtain what one needs. This includes the acquisition of skills. Skills include problem-solving, decision-making, and leadership skills that help parents advocate for what they need; and the behavioral component as the actions and behaviors by an individual to influence, control and achieve desired outcomes. Behaviors could include participating in a support group, involvement in community organizations or using coping skills.

The response format of the PES is a five-point likert-type scale where 1 = strongly disagree, 2 = disagree, 3 = neutral, 4 = agree, and 5 = strongly agree. The demographic information collected about the study participants included, marital status, income level, gender, educational level, and perceived severity of the child's ASD (see Appendix A).

Akey et al. (2000) established construct validity of the PES. The study utilized information from 293 parents of children with disabilities that represented a diverse population

across multiple ethnicities, income levels and residential settings. Confirmatory Factor Analyses (CFA) were conducted to evaluate the internal structure of the PES and the reliability of its scores. The results of the CFA provided evidence that each item was more significantly related to its own factor than to other factors. The four subscales were separate but related dimensions. The results of the confirmatory factor analyses (CFA) provided evidence of validity for the scores from the four subscales underlying the PES: 1) attitudes of control and competence; 2) cognitive appraisals of critical skills and knowledge; 3) formal participation in organizations; and 4) informal participation in social systems and relationships. Reliability coefficients for the subscale scores and total scale score ranged from .90 to .97 and the subscales ranges from .30 - .43.

Pilot Study and Research Procedures

Before the current study was conducted, a pilot study was developed and PES was administered so that any problems could be determined. The pilot study was designed to determine whether there were significant divergences in viewpoints regarding perceived empowerment associated with such demographics as type of support group membership, gender, age of parent, ethnicity, marital status, level of education, income, age of child with ASD and severity of child's ASD.

Sample Characteristics of Pilot

Data were collected from parents of children with ASD. Criteria for eligibility to participate in the pilot study included (a) parent of a child with ASD and (b) participant (current or former) in an online or face-to-face ASD support group. Any member of an ASD support group in the community had access to this survey. However, the sample was limited to those parents who received the survey. Descriptive characteristics of the pilot test subsample are presented in Table 1. Age of participants ranged from 28 to 68 years. The majority of the

participants (95%, n=38) were female, married (86%) and white (90%). Most participants (85%) had completed some education beyond high school level while 15% had a high school or lower level of education. Eight participants (20%) had an annual household income of less than \$50,000 and over 78% reported a household income of more than \$50,000 per year. The average reported age of the child with ASD was age 12 or under (83%) and the majority of participants indicated their child had mild to moderate ASD (90%).

The language and comprehension aspects of the questionnaires were evaluated during and after the administration of the instrument. None of the participants had problems responding to the items on the instrument and they did not verbalize any comprehension difficulties during or after the administration of the instrument.

Reliability of the instrument for the pilot study was a Cronbach alpha coefficient of .939. Akey, Marquis and Ross (2000) reported initial reliability scores, which ranged from .84 to .94. These readings give solid evidence to the reliability of the instrument. George and Mallery (2003) note Cronbach alpha scores of $\alpha > .9$ indicate 'excellent' internal consistency.

Table 1

Characteristics of Pilot Study Participants (N=40)

<i>Characteristic</i>	<i>Number</i>
<i>Member of an Autism Support Group</i>	
Yes	25
No	15
<i>Types of Support Group</i>	
Face-to-Face	7
Online	9
Both	15
Neither	9
<i>Gender</i>	
Female	38
Male	2
<i>Age</i>	
24-34	9
35-45	20
46-56	10
57-68	1
<i>Ethnicity</i>	
White	36
African American	2
Asian	1
Other	1
<i>Household Income</i>	
Less than \$25,000	2
\$25,001 - \$50,000	6
\$50,001 - \$75,000	6
\$75,001 - \$100,000	12
Over \$100,000	14
<i>Marital Status</i>	
Married	35
Divorced	4
Other	1
<i>Highest Education</i>	
Less than High School Diploma	1
High School Diploma	5
College	22
Graduate	7
Post-Graduate	5
<i>Age of Child with ASD</i>	
4-7	17
8-12	16
13-16	5
20-23	2
<i>Severity of Child's Autism</i>	
Mild	23
Moderate	13
Severe	4

Quantitative Data Analysis Procedures for Current Study

Both descriptive and inferential statistics were used to analyze the survey data.

Descriptive statistics were used to find the means, standard deviations, and ranges for all variables. Inferential statistics were used to answer all the research questions. This study used inferential statistical analysis such as Kruskal Wallis Tests, Mann Whitney U test, Spearman Rank Correlation co-efficient and multivariate methods like exploratory and confirmatory factor analysis. Psychometric properties of the instrument were accessed using reliability and validity analyses. Cronbach alpha was conducted to ensure reliability of the instrument and confirmatory factor analysis was used to check validity of the instrument.

Factor analysis was used in providing validity evidence for the instrument. Factor analysis describes any possible covariance relationships between variables in terms of few essential random quantities also known as factors (Floyd & Widaman, 1995). In other words, factor analysis facilitates in creating group/groups for highly correlated variables measuring the construct. The two types of factor analysis conducted for this study were Exploratory Factor Analysis (EFA) and Confirmatory Factor Analysis (CFA). The EFA is a very useful tool in developing the scale and must be used when no prior hypothesis about factors are known (Finch & West, 1997). The CFA is used when the researcher already has a sense of factors or if the factors have already been established. CFA is used to determine the ability of a predetermined factor model to fit an observed set of data. Because the PES instrument has four subscales (attitudes of control and competence, critical skills and knowledge, formal participatory behavior and informal participatory behavior) that were already known, CFA was performed to test the hypothesis that there was no difference between the pre-established factors comprising the four subscales of PES. As stated previously, the pre-existing factors of the PES were based upon

studies of parents of children with different types of disabilities not specifically and exclusively parents of children with ASD as was the case in this study. Additionally, an EFA was performed in order to determine whether the variables that made up the subscales in the current study were indeed similar to those from the pre-established subscales. Thus establishing that the same variables comprised the factors that made up the subscales (attitudes of control and competence, critical skills and knowledge, formal participatory behavior and informal participatory behavior) was an important step in the validation of the PES as an instrument that is valid for use with parents with parents of children with disabilities in general and ASD in particular. SPSSTM software was used to conduct all analyses. The software takes data from different types of files and generates tabulated reports, charts, and plots (IBM Corp., 2005). Since data was submitted via the web or on hard copies, the survey responses were converted to a SPSS dataset. A visual review of a sampling of the surveys was made to ensure the conversion was accurate.

The alpha level for research questions 1,2,3 and 4 was set at .05. The alpha level for research question 5 was set at .01. The alpha level was the probability of a Type I error which means the probability of the null hypothesis being rejected when in fact it was true (Fraenkel & Wallen, 2009). Initially, the data was tested for normality and equal variance assumptions using Shapiro-Wilk test and Levene's test respectively. Classical statistical methods such as t-test and ANOVA are used if assumptions are valid else non-parametric tests such as Kruskal Wallis and Mann-Whitney U test are performed. Also, since the data was assumed to be completely independent, no separate test for verifying independence assumption was performed.

Kruskal-Wallis Test

The Kruskal-Wallis is a nonparametric method for testing equality of population medians among groups. The test is utilized when analyzing one independent variable with two or more

levels and an ordinal dependent variable, i.e. it is the non-parametric equivalent of ANOVA (Frankel & Wallen, 2009). In this study, the test was utilized to answer the following research questions (RQ): (a) RQ1- the independent variable ‘marital status’ contains 3 levels (married, single/divorced and in partnership) while the dependent variable ‘participatory behavior’ was calculated using items that had “ordinal ranking.” The dependent variable ‘participatory behavior’ was calculated from Formal Participation Subscale (Items 2, 5, 12, 15, 18, 21, 28, and 30) and Informal Participation subscale (Items 3, 6, 9, 16, 19, 22, 25, and 31). (b) RQ 3- the independent variable is parents’ education level defined as less than college and college, while the dependent variable was ‘skills and knowledge’ calculated using Skills and Knowledge ordinal Subscale. The dependent variable ‘skills and knowledge’ was calculated using Skills and Knowledge Subscale (Items 4, 7, 10, 13, 20, 23, 26, and 29). Parents’ education level (less than high school; high school; college; graduate school) served as the Independent variable. (c) RQ4- The independent variable is perceived severity of the child’s ASD defined (mild; moderate; severe), while the dependent variable was ‘parent attitude’ calculated using Attitudes Subscale (Items 1, 8, 11, 14, 17, 24, 27, and 32) which utilizes an ordinal scale.

Mann-Whitney U Test

The Mann-Whitney U test was used to analyze variables that contained an independent variable with two or more levels and dependent variables that were nominal with only two values (Frankel & Wallen, 2009) i.e., RQ 2- The dependent variable ‘participatory behavior’ was calculated using formal participation subscale (Items 2, 5, 12, 15, 18, 21, 28, and 30) and informal participation subscale (Items 3, 6, 9, 16, 19, 22, 25, and 31). ‘Gender’ (female; male) served as the Independent variable.

The Spearman Rank Correlation Co-efficient

The Spearman Rank Correlation coefficient was utilized to analyze the relationship between formal and informal participatory behavior and parental skills and knowledge in respect to ASD (Frankel & Wallen, 2009) (RQ5). The dependent variable was parental “Skills and Knowledge” was calculated using skills and knowledge subscale (Items 4, 7, 10, 13, 20, 23, 26, and 29), while the independent variables were: formal participatory behavior which was calculated using formal participation subscale (Items 2, 5, 12, 15, 18, 21, 28, and 30) and formal participatory behavior calculated using the informal participation subscale (Items 3, 6, 9, 16, 19, 22, 25, and 31).

Assumptions of the Study

Frankel and Wallen (2009) define an assumption in research as a statement presumed to be true but not actually confirmed by the researcher. The first assumption of this study was that the sample represents the entire population of parents of children with ASD. The outcomes of this study can be generalized to individuals from the same population. The researcher assumed participants answered the survey truthfully and with experience and knowledge related to the topic. The following assumption is rational due to the preservation of anonymity and confidentiality and that the participants were volunteers who could withdraw from the study at any time and with no ramifications. Participants were involved in the study by choice and otherwise had no reason to provide information that was inaccurate or dishonest. The data was assumed to be completely independent and random. Also any errors were assumed to be minor and will not have any significant outcome of the study.

Limitations of the Study

The limitations of this study included generalizability, survey approach, reliability and validity of the instrument, diversity of the participants, and data collected at a certain point in time.

The current study is limited by the small sample size. This study confined itself to studying aspects of one specific population; parents of children with ASD. The small sample size, lack of available resources in the geographical area and lack of a control group may decrease the generalizability of the findings related to the quantitative research. However, the findings are not intended to be considered in isolation. Those findings are intended to contribute to the body of research around the empowerment of parents of children with ASD. Like any other parent group, parents of children with ASD are a heterogeneous population within different demographic groups. However, these differences are likely to be relatively insignificant and secondary considering the traits that parents of children with ASD do share.

A limitation of this study lay in the use of a survey approach. Critics of survey research methodology believe it forces respondents to formulate opinions and critics note that some survey items poorly predict actual behavior (Garson, 2012).

Anytime an instrument is used for a study the results are subject to the known reliability and validity of that instrument. Although some information about the instrument in regard to reliability and validity (in the case of the PES) was known, the instrument may have had limitations in measuring what it claims to measure. Only future research with other audiences and with other instruments will help further the understanding of the concepts being measured in the study.

Another limitation of this study is the sample. Recruitment of participants from diverse subgroups can be challenging. Due to factors such as lack of trust, cultural differences, and inability to relate to the importance of the study; the recruitment of participants from ethnic, minority or elderly groups may require a different approach (Levkoff, Levy, & Weitzman, 2000; McNeilly et al., 2000). Patel, Doku, and Tennakoon (2003) identify issues such as time, travel, financial and inconvenience as deterrents for potential participants from diverse backgrounds. Even though participants for this study were targeted based on specific characteristic or traits (i.e. parents of children with ASD) the researcher was unable to verify the identity of the participants and the truthfulness of their responses due to the anonymity of the participant's identity.

Summary

This chapter provided a rationale for selecting quantitative inquiry as the main research methodology for this study. The participants were parents of children with ASD in a southeastern state in the United States. In order to measure the effect of demographic factors on empowerment attributions of parents of children with ASD, data collection methods included the collection of survey results from the completion of the Psychological Empowerment Survey (PES) and participant personal demographics and demographics in regard to their child with ASD. Finally, to explore the effect of demographic factors on empowerment attributions of parents of children with ASD a Kruskal Wallis test, Mann Whitney U test, and Spearman Rank Correlation coefficient were used. Chapter IV presents the findings of the study.

CHAPTER IV:

FINDINGS

The purpose of this study was to explore the effect of demographic factors on empowerment attributions of parents of children with ASD. This study utilized a quantitative research design to examine the impact of demographic factors on parent empowerment using an instrument called Psychological Empowerment Scale (PES). The participants' demographics and responses facilitated in examining attributions of their empowerment relative to rearing a child with ASD. The instrument provided quantitative data used to answer five research questions. This chapter presents the data analyses and results from the study.

Establishing Instrument's Fit

Psychological Empowerment Scale (PES), a 32-item scale was used to measure the empowerment attributions of parents of children with ASD. Parents responded to each of the 32 items by indicating their agreement on a Likert-type response scale (1 = *Strongly Disagree*, 2 = *Disagree*, 3 = *Undecided*, 4 = *Agree*, 5 = *Strongly Agree*). A demographic component comprising of the following was included in the instrument: (a) type of support group membership; (b) gender; (c) marital status; (d) highest level of education; (e) household income; (f) type of child's ASD and (g) perceived severity of child's ASD. Parents also indicated the types of general ASD supports they participate in as well as the specific online supports they participate in.

Reliability

Reliability of the instrument was established during the pilot study phase of this research study. The Cronbach alpha coefficient was .939 ($\alpha \geq 0.9$ is considered excellent) (George &

Mallory, 2003). Thus the high internal consistency indicated that the items on PES measured the same construct. For this study, the internal consistency for the PES for the entire sample was excellent ($\alpha = 0.902$) compared to the initial reliability of the instrument which ranged from .84 - .94.

Table 2

PES Subscales, Sample Questions, Number of Questions, and Alpha Reliabilities (N=32)

Subscale	Sample Question	Number of Questions	Cronbach's Alpha
Attitudes	I have control over decisions that are made concerning my child.	8	.800
Formal Participation	I hold a leadership role in a parent organization or service program.	8	.837
Informal Participation	I help other parents advocate for their child's needs.	8	.771
Skills and Knowledge	I think I feel competent to meet my child's needs.	8	.614

Factor Analysis

Factor analysis was used to establish the validity of the instrument. Both the Exploratory Factor Analysis (EFA) and Confirmatory Factor Analysis (CFA) were conducted. Costello and Osborne (2005) recommend using CFA to test hypothesis or theories and researchers about the validity of the constructs being tested by an instrument. In the case of this study, CFA was used to test the hypothesis "if this instrument as used with the population of parents of children with ASD have the same structure as when used with parents of children with disabilities in general?" Additionally, exploratory factor analysis (EFA) was used to explore whether a similar factor structure as the one previously established would emerge or not. EFA also established if the factors loading significantly into the model were the same as the pre-established or not.

Confirmatory Factor Analysis (CFA)

Table 3

Confirmatory Factor Analysis (CFA) for a 4 factor Model (PES)

Model	χ^2	<i>df</i>	RMSEA	NFI	NNFI
4-factor Model	732.6	458	0.07	0.56	0.74

The primary objective of the CFA was to determine the ability of a predefined factor model to fit an observed set of data. CFA allows researchers to test hypotheses about a particular factor structure (Albright, 2006). CFA produces many goodness-of-fit measures to evaluate the model but do not calculate factor scores. CFA is a special case of the structural equation model (SEM), also known as the linear structural relationship (LISREL) model (Jöreskog & Sörbom, 2004).

Another commonly reported statistic is the *Root Mean Square Error of Approximation* (RMSEA), a measure of fit introduced by Steiger (2007). RMSEA “incorporates a penalty function for poor model parsimony” and thus becomes sensitive to the number of parameters estimated and relatively insensitive to sample size (Brown 2006: 83-84). Absolute fit indices determine how well a priori model fits the sample data (McDonald & Ho, 2002) or how the variables are related (Floyd & Widaman, 1995). The most current research on good and excellent fit (i.e. RMSEA) is a value close to 0.06 and upper limit of 0.07, respectively (Hu & Bentler, 1999; Steiger, 2007). The discrepancy between the χ^2 value of the hypothesized model and the χ^2 value of the null model are analyzed using normed fit index (NFI) (Bentler & Bonnett, 1980). It is important to note NFI is subject to the sample size (Bearden, Sahrma, & Teel, 1982). When the sample size is small--below 200, fit indices overestimate the fit (Fan, Thompson, & Wang, 1999). The non-normed fit index (NNFI) may resolve some of the issues of sample size (Bentler,

1990). Values for both the NFI and NNFI should range between 0 and 1, with a cutoff of .95 or greater indicating a good model fit (Hu & Bentler, 1999). According to Schumacker and Lomax (2004) a model is regarded as acceptable if the Normed Fit Index (NFI) exceeds .90.

Exploratory Factor Analysis (EFA)

The primary objectives of EFA in this study were to determine whether a similar factor structure would emerge from the data with this sample compared to the Akey, Marquis and Ross (2000) PES validation sample. Additionally, EFA allowed for the assessment of the strength of the relationship between each factor and each observed measure. Table 4 reports EFA using output from the standard statistical package SPSS.

Table 4

Summary of Exploratory Factor Analysis Results for Psychological Empowerment Scale (PES) Using Varimax Rotation with Kaiser Normalization (N = 113)

Items	Informal	Attitude	Skills and Knowledge	Formal
I help lead a support group for other parents	.81			
I hold a leadership role in a parent organization or service program	.78			
I am actively involved in a formal parent organization.	.77			
I take an active role improving services to families through a formal parent organization.	.75			
I am on an advisory board for a parent organization or service program.	.69			
I offer my services as a supporting parent in a parent organization.	.48			
I often get together with other parents to discuss a common problem affecting our families.	.42			
Regardless of what other people do, I have control over how my family needs are met.		.72		
I have control over what happens in my family.		.72		
I think I made good decisions about what my family needs.		.67		
I have control over decisions that are made concerning my child.		.62		
I think my decision making skills are as good as other parents.		.61		
I can usually solve problems that confront my family.		.56		
I feel like I have choices for my family.		.53		
I advocate effectively for my child with professionals.		.41		
I am involved in decision making in a parent organization or service program.			.61	
I have many choices about how to meet my family's needs.			.55	
I spend time with other parents talking about my family.			.55	
I communicate my ideas to others clearly.			.52	
I have the power to get what my family needs.			.50	
I feel competent to meet my child's needs.			.50	
When I have to get something done, I get to work on it quickly.			.47	
I try to learn new skills even if they seem difficult.			.47	
I feel in control of my life.			.47	
I am able to explain myself until I make myself clear.			.46	
I try to act as an emotional support to other parents.				.79
I informally share information with other parents.				.62
There is at least one other parent I can go to for emotional support.				.53
I participate in a support group for parents of child with a disability.				.51
I feel a sense of community with other parents who have a child with a disability.				.51
I help other parents advocate for their child's needs.				.42

Participants

Participants consisted of 115 individuals who were parents of children with ASD across residing in a southern State in the United States. Individuals who chose to participate in the research study had to be a parent of a child(ren) with ASD (autism, Asperger’s syndrome or PDD-NOS) ages 3-21 years, live in the targeted research area and be willing to complete both questionnaires.

Table 5

Characteristics of Research Study Participants (N=113)

Characteristics	Number
<i>Gender</i>	
Female	95
Male	18
<i>Household Income</i>	
< \$25,000	14
\$25,001 - \$75,000	47
\$75,001 >	52
<i>Marital Status</i>	
Married	91
Divorced	18
Other/Partnership	4
<i>Highest Education</i>	
Less than College	32
College	81
<i>Type of ASD</i>	
Autism	68
Asperger Syndrome	30
PDD-NOS	15
<i>Perceived Severity of Child’s Autism</i>	
Mild	68
Moderate	30
Severe	15

The descriptive characteristics of the entire sample (N=115) are presented in Table 5. Of the 115 questionnaires returned, only 113 were usable for the purpose of this study. The age of the participants ranged from 24 to 68 years. The majority of the participants were female (N

=95) and married ($N = 91$). However, the remainder of results represented a diverse demographic group. Approximately 72% of the participants had attended college while almost 30% had a high school degree or less. A total of 12% of the participants indicated a household income of less than \$25,000 per year which would be considered living in poverty for an average family of four in the U.S. today (The United States Department of Health and Human Services, 2013). In regard to the type of ASD the child was diagnosed with, the participants reported the majority of the children (ages 3-21) had autism ($N = 59$), 27% had Asperger syndrome and the remaining 13% had PDD-NOS (Pervasive Developmental Disorder-Not Otherwise Specified). The severity of the children's ASD was reported as 32% of the children having a mild form of ASD, 50% of the parents perceived their child to have a moderate form of ASD and 17% reported their child having more severe ASD.

Quantitative Data Findings

RQ1: Is there difference in parent participatory behavior (both formal and informal) by marital status? The Kruskal-Wallis test indicates that there is no statistically significant difference in informal parental participatory behavior among the three marital status $\chi^2 (2, N = 113) = 3.32, p = .190$. Similarly, no statistically significant difference in formal parental participatory behavior among the three marital status $\chi^2 (2, N = 113) = 1.71, p = .425$

RQ2: Is there a difference in parent formal and informal participatory behavior by gender? Parent participatory behavior was measured using the Formal and Informal subscales, while parent gender was defined as female and male. The Mann-Whitney test showed that there was a statistically significant difference between gender and informal participatory behavior, with female informal participatory behavior ($Mdn = 60$) being higher than males ($Mdn = 43$), U

= 1,110, $p < .045$. There was no statistically significant difference in regard to gender and formal participatory behavior, $U = 802$, $p < .680$.

RQ3: Is there a difference in parent skills & knowledge about ASD by parent education level? Parent skills & knowledge was measured using the Skills and Knowledge Subscale, while parent education level was defined as less than college (less than high school and high school) and with college (college education or higher). Significance was set at .05. The Kruskal-Wallis test showed that there is statistically significant difference in parent skills & knowledge between the two parent education levels $\chi^2(2, N = 113) = 8.45$, $p = .015$.

RQ4: Is there a difference in parent attitude by their perceived severity of the child's ASD? The Kruskal-Wallis test indicates that there is no statistically significant relationship between the severity of the child's ASD and parent attitude, $\chi^2(2, N = 113) = 3.73$, $p = .155$. Because the overall test is not significant, pairwise comparisons among the groups was not completed.

RQ5: Is there a relationship between participatory behavior (formal and informal) and parental skills and knowledge in respect to ASD? The Spearman's rank correlation coefficient, which measures the strength of relationship between two variables, was utilized (see data analysis above). The results indicated that there was a statistically significant positive correlation between formal participatory behavior and skills and knowledge, ($r_s(113) = .330$, $p < 0.01$). Similarly, a statistically significant positive correlation was found between informal participatory behavior and skills and knowledge ($r_s(113) = .574$, $p < 0.01$).

Table 6

Analysis and Findings

RQ No.	Relationship	Test Conducted	<i>p</i> -value
1	Is there difference in parent participatory behavior (formal and informal) by marital status?	Kruskal-Wallis	
	a) R/ship between formal and marital status		0.425
	b) R/ship between informal and marital status		0.19
2	Is there a difference in parent participatory formal and informal participatory behavior by gender?	Mann-Whitney	
	a) R/ship between formal and gender		0.680
	b) R/ship between informal and gender		0.045
3	Is there a difference in parent skills & knowledge about ASD by parent education level?	Kruskal-Wallis	0.015
4	Is there a difference in parent attitude by their perceived severity of the child's ASD?	Kruskal-Wallis	0.155
5	Is there a relationship between parental participatory behavior and ASD skills and knowledge?	Spearman's Rank	
	a) R/ship between formal and parental ASD skills & knowledge		<0.01
	b) R/Ship between informal and parental ASD skills & knowledge		<0.01

Participatory Behaviors

One aspect of Turnbull and Turnbull's (2001) theory on family-centered practice is for professionals to respect families' choices regarding the level of their participation in support services. In order for professionals to understand how to better support the individual needs of parents of children with ASD, an understanding of the types of supports parents of children with ASD most participate in is needed. A set of questions included in the demographic questionnaire for this study asked participants to indicate the types of general ASD supports they participate in as well as the specific online supports they participate in. Given a list of different types of

general supports such as the Internet, workshops and conferences, friends and family or books and literature and the more specific supports online such as websites, chat rooms, blogs or training modules; participants indicated by checking a box the supports specific to their own participation with regard to parenting a child with ASD. Although this information was not specifically correlated to the research questions in this study, this is important data for future research. The figures below present the results of these questions.

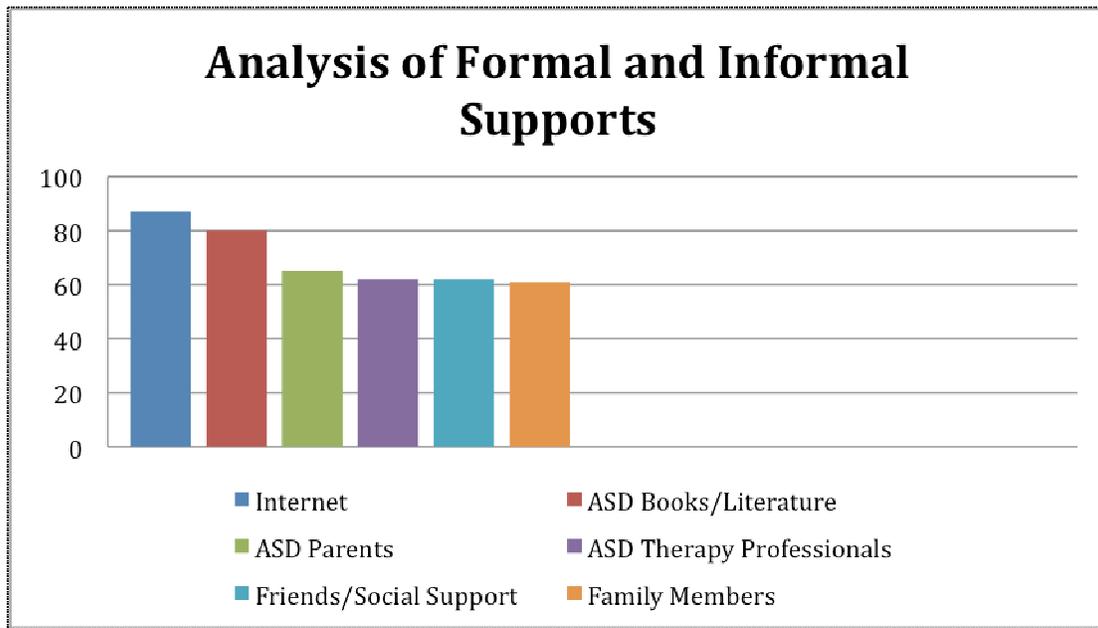


Figure 2. Analysis of Formal and Informal Support

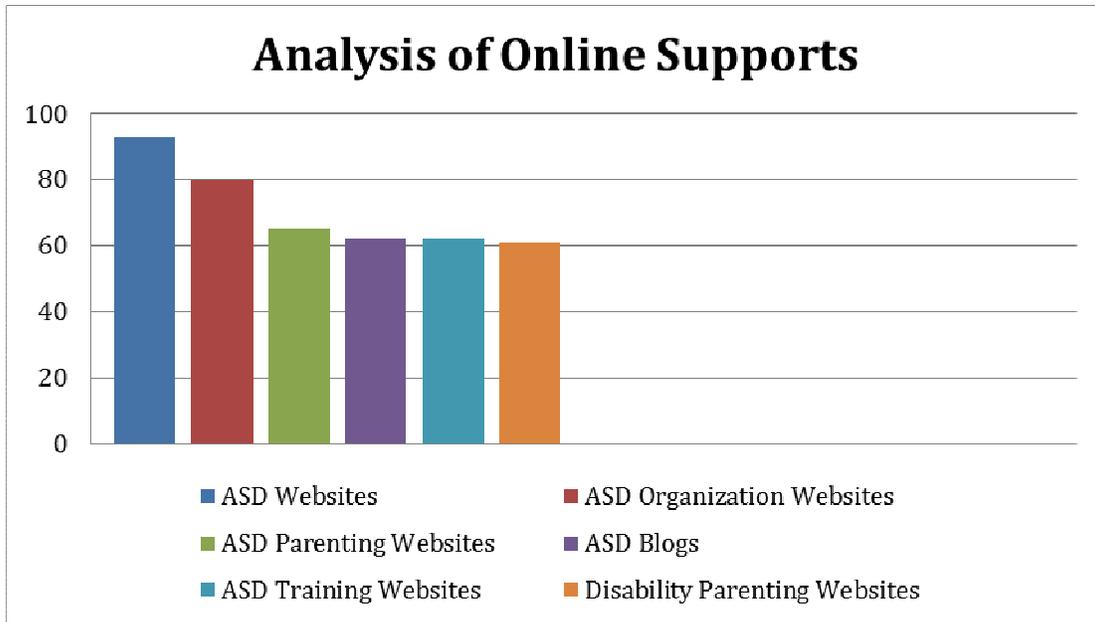


Figure 3. Analysis of Online Support

The participants in this study reported sources such as books and literature ($N=80$), ASD therapy professionals ($N=62$), friends and social support ($N=62$) and family support ($N=61$) as the most prevalent sources of education and support regarding ASD. Sources such as specific training on ASD ($N=27$), medical professionals ($N=42$) or religion or spirituality ($N=47$) were rated very low. However, the highest rated source of support was the Internet with 87 participants reporting the use of the Internet as the primary source of education and support regarding ASD.

The study also asked participants to rate the types of Internet sources utilized for their education and support regarding ASD. Participants in the current study reported the use of general ASD websites ($N=93$) as the most used source on the Internet for education and support. Other highly ranked Internet sources were ASD specific organization websites ($N=69$), ASD specific parenting websites ($N=48$) and ASD blogs ($N=45$). Surprisingly, parents reported a

very minimal use of parenting chat rooms ($N = 12$), ASD chat rooms ($N = 14$) and ASD listservs ($N = 14$).

Summary

In summary, this chapter presented data analyses and findings of all research questions. Instrumentation used to collect quantitative data from parents of children with ASD was presented. The results served to provide insight, confirmation, and elaboration regarding the analysis of demographic factors on empowerment attributions of parents of children with ASD.

Chapter V presents the summary of this study and provides conclusions drawn from the findings. The conclusions include a summary of the findings. A discussion of limitations, implications, and recommendations for future research is offered.

CHAPTER V: DISCUSSION AND RECOMMENDATIONS

The increase in prevalence of Autism Spectrum Disorders (ASD) has drawn attention to a greater need for education and support for parents of children being diagnosed with ASD. The CDC (2012) reported a prevalence of 1 in 88 children identified as having an ASD diagnosis. ASD continues to crossover ethnic, racial, or socioeconomic boundaries. Most significantly impacted by the diagnoses of a child with ASD are the parents. With more children being diagnosed with ASD, research specific to educating and supporting parents children with these conditions becomes critically important. One area of research on parents with children with ASD relates to issues of empowerment. However, understanding the contributing factors that may affect a parent's sense of empowerment in regard to parenting a child with ASD requires further examination.

Research has reported high levels of stress in regard to parenting a child with ASD (Baker-Ericzen, Brookman-Frazee, & Stahmer, 2005; Bromley, Hare, Davison & Emerson, 2004; Gray, 2002; Higgins, Bailey, & Pierce, 2005). Children with ASD can exhibit a range of challenges, behaviors, needs and deficits that correlate with increases in parental stress. Studies have documented the benefits of education and support for parents of children with ASD that can ultimately lead to the empowerment of a parent (Dempsey & Dunst, 2004; Dempsey, Foreman, Sharma, Khanna, & Arora, 2001; Trivett & Dunst, 2004). Theoretical speculations about empowerment have evolved throughout the years.

According to Akey, Marquis, and Ross (2000), empowerment helps people gain control over their own lives and take action to get what they need. Parent empowerment is a process in

which parents who lack power increase their power in order to gain access to resources and information, get their voices heard, become advocates for their children and take action to help provide opportunities for better outcomes for their children. Empowerment allows parents to be independent and in control of the processes where they create or are given opportunities to control their own destiny and influence the decisions that affect their lives (Zimmerman, 1995). A common theme that emerges from each of these perspectives is the fundamental importance of individuals gaining an understanding of and control over their own lives.

A number of studies have shown the benefits of empowerment on the family system and individuals within the family subsystems, specifically more positive outcomes for the parent and child. Dempsey, Foreman, Sharma, Khanna, and Arora (2001) found when families were part of a positive family-professional relationship there was a significant increase in empowerment regardless of the personal or socio-economic background of the participants. Dempsey and Dunst (2004) recognized help-giving practices as a significant predictor of empowerment. Treating parents with dignity and respect; sharing relevant information so parents can make informed decisions; offering families' choices in the provision of and their participation in services; and forming partnerships with families and collaborating with them defines the foundation of help-giving practices (Dunst, Trivette, & Snyder, 2000).

Although an influential body of literature has emerged in regard to the relationship between the education and support of parents of children with disabilities and empowerment, as well as the study of different demographic subgroups, a significant gap in the research remains. Nachshen (2005) states parent empowerment has been identified as an important focus for the research of families of children with developmental disabilities. The research on parent empowerment currently remains more of a theoretical perspective than a practical one. To date,

there has been little research on parents of children with ASD in regard to education, support, empowerment and demographics. More specifically, there is a paucity of research on the relationship between demographic factors and empowerment attributions. This issue is addressed in the current study.

Research Questions

1. Is there difference in parent formal and informal participatory behavior in respect to marital status;
2. Is there difference in parent formal and informal participatory behavior in respect to gender;
3. Is there difference between parent education level and skills and knowledge about ASD;
4. Is there any difference in parent attitude in respect to ASD and their perceived severity of the child's ASD; and
5. Is there a relationship between formal and informal participatory behavior and parental skills and knowledge in respect to ASD?

Discussion

This section provides detailed discussion and conclusions about the findings of this study. The discussion is organized around individual research questions addressed in this dissertation. The overarching purpose of this study was to measure the effect of demographic factors on empowerment attributions on the empowerment of parents of children with ASD.

Research Question 1

Question 1 sought to explore any differences in parent formal and informal participatory behavior in respect to marital status. Quantitative analyses of responses from the PES and demographic surveys were analyzed to answer Research Question 1. Results indicated that there was no significant difference between formal participatory behavior and marital status nor

informal participatory behavior and marital status. This means that parents who were married did not report a significant difference in perceived empowerment based on their own education or support participatory behaviors than parents who were not married or parents who reported being in a partnership. Even though there were no significant differences reported in this study, this does not diminish the fact that parents of children with ASD have needs that require education and support in order to help strength the empowerment attributes which ultimately contribute to positive outcomes for both parent and child.

As noted by Dunn, Burbine, Bowers, and Tantliff-Dunn (2001) parental marital satisfaction is often negatively impacted by a child's disability. The need for support is even greater for single parents raising a child with ASD than parents who are married raising a child with ASD. Reyes-Blanes, Correa, and Bailey (1999) looked at the needs of and support for mothers of children with disabilities. Mothers reported a greater need for support when they also indicated their child's disability as more severe than mothers who reported less severe behavioral challenges exhibited by their child. Mothers who were married indicated the primary sources of support came from their spouse and other adult family members. Single mothers stressed a need for more support from outside agencies and support systems and also indicated they received more support from agencies. Reyes-Blanes et al. reported that overall, single mothers may have higher stress as the sole caretakers of their child with a disability. In the case of the current study, the lack of significance in regard to differences in empowerment between parents of children with ASD who are married and those parents who are not married (or in a partnership) may indicate that even though previous research has found higher levels of stress for parents of children with ASD, single parents of children with ASD may have supports in place which help contribute to their empowerment. Webber and Boromeo (2005), in a study examining the

experiences of single parents and the support networks utilized, reported that single parents relied on both informal support and formal support to help them cope. The majority of the participants (90%) reported that participation in support networks helped improve their overall well-being and ability to support their child. Support included a range of resources including friends and family, agencies, community support, church, and counselors. Parents who participated in the current study reported utilizing similar types of formal and informal support systems.

The results of the current study indicate that parents of children with ASD did not differ in regard to marital status and participatory behaviors (formal and informal) attributions. These results may further support that single parents of children with ASD who do receive more support from ASD service providers do indeed benefit utilizing this resource insofar as their sense of empowerment is concerned. The challenge for ASD service providers will be their accessibility to single parents of children with ASD who need additional support but do not access the support due to other contributing factors such as poverty, lack of local ASD service providers, motivation, and /or lack of time. Educational and support service providers need to make an intentional and purposeful attempt to reach families from diverse populations who may have challenges which prevent them from getting the support needed for more positive empowerment outcomes. Single parents of children with ASD are one such population.

Effective services are those that assist families with care and lead to reduced levels of stress, thereby preventing possible family breakdown and the need for long-term, out-of-home care. Research has demonstrated that respite services can make a significant positive difference in the lives of parents of children with ASD, allowing them to take a break and increase their social and emotional well-being (Cowen & Reed, 2002). In recent years, respite care has

emerged as an important component in the array of services that have been developed to support families who have a child with a disability (Chan & Sigafos, 2000). Results of a study by Gray (2006) reported over 50 parents of children with ASD indicated respite care as a favored coping skill. The results of studies on formal and informal education and support services need to take into consideration the challenges single parents of a child with ASD may face and set into place services like respite care which support those needs to help single parents access education and support opportunities.

Research Question 2

Question 2 looked at the effect of gender on parent participatory behavior in education and support systems (formal and informal). The analysis showed that there was a highly statistical significant difference between gender and informal participatory behavior. There was a specific difference in formal participatory behaviors between mothers and fathers. More specifically, mothers' participatory behavior was higher than fathers' participatory behavior. Female participants, mainly comprising mothers, in this study reported higher levels of empowerment in regard to the attributes of participatory behaviors regarding parenting a child with ASD. This outcome demonstrates the need for professionals to consider gender when approaching the supports they provide to parents. These results have also been further supported in previous literature.

Weiner, Vasquez, and Battles (2001) examined the psychosocial adjustment and stress of father's parenting a chronically ill child found that the fathers experienced significantly more stress and psychological distress than fathers of children that did not have a disease. Many of the fathers indicated they would be more likely to utilize a face-to-face or online support group

designed specifically for fathers. This outcome validates the claim that support for parents of children with ASD needs to be more gender-specific in order to meet the needs of fathers.

The differences in the needs of mothers and fathers of children with ASD is further supported in a research study by Little (2002) which examined the gender differences in stress and coping of 103 marital couples who were parents of a child with ASD. The study revealed that mothers reported higher levels of stress than fathers in regard to parenting their child with ASD. The mothers reported seeking professional help and medication more often for stress than fathers. The mothers also utilized more coping strategies and reported more positive outcomes from the use of the strategies than the fathers. An important element of this study to consider is that only 34% of the mothers worked full time with 91% of the fathers working full-time. The question then arises if the mothers may have been more responsible for the care of and interaction with the child with ASD and if this could have led to the differences in stress and coping concerning parenting a child with ASD.

There has been little research that has focused specifically on stress and coping in fathers of children with ASD and the impact of support systems designed specifically with fathers in mind (Baker-Ericzen, Brookman-Fraze, & Stahmer, 2005). A weakness in previous research and in the support that is available to fathers of children with disabilities in general is the vast focus on mothers. Focusing on mothers in parent training and other child-centered activities may have harmful outcomes on the progress of children with disabilities (Elder, Valcante, Won, & Zylis, 2003). Fathers could feel left out, unimportant, and insignificant. The results of the current study as well as the literature which reports similar results indicates the need for more gender specific supports for parents of children with ASD.

Supports for fathers of children with ASD are limited as well as research on this population. Nonetheless, fathers of children with ASD need places to work through their grief, anger, sorrow and depression. Men traditionally have been taught to be providers, problem-solvers, protectors, competitors and controllers. They glory in being self-sufficient, in charge, and strong. Fathers of children with ASD perceive few support systems in their environment which address their needs specifically, in part because little research has been conducted that focuses exclusively on this population.

Professionals working with families should promote these differences by recognizing that every male in a child's life has strengths and these strengths play a major role in family functioning. For example, centering approaches to education and support for fathers of children with ASD could encourage the father to take a lead in advocating for the child and family, or encourage the father to build an adaptive device for his child. Getting fathers involved in adaptive sports programs like *The Miracle League*, a baseball league for children with special needs, allows a father and his child to participate together in a shared interest of sports and physical activity. This opportunity also encourages fathers to interact with other fathers of children with special needs who may share some of the same challenges and needs.

Father-to-father activities for fathers of children with ASD could also be a beneficial way to provide educational and support opportunities. Social opportunities that encourage male bonding through shared interests such as hobbies or career similarities can help fathers of children with ASD gain the education and support they need without the pressure or bias of a support group. Interactions such as these can also be a great opportunity for fathers of children with ASD to develop a consistent source of social support. Activities such as these also allow professionals who are involved in the same activities to observe the interactions of fathers of

children with ASD and ultimately gain a greater sense as to the needs of fathers of children with ASD. In turn, more specific education and supports can be developed that are gender and need specific for fathers of children with ASD.

Research Question 3

Research Question 3 assessed differences between the parent education level and skills and knowledge about ASD. Quantitative analyses of responses from the PES and demographic surveys were used to analyze Research Question 3. Results indicated that there was significant difference between parent education level and skills and knowledge. The most significant difference was between parents who had attended college (72%) and parents who had not attended college. Parents who had not attended college reported having a high school education or less. Parents who had attended college reported higher levels of empowerment in regard to the attributes of skills and knowledge regarding parenting a child with ASD. The correlation between parent education level and participation in formal and informal support systems has been well documented in the literature regarding parenting a child with a disability. Specific research on the participatory behaviors for parents of children with ASD and parent education level has yet to be documented in the literature. Because of the relationship between participatory behavior and skills and knowledge regarding parenting a child with a disability, this is an area of research that demands more attention; more specifically in regard to the understudied population of parents of children with ASD.

Many studies have discovered support group participants are more often college educated (Heller, Roccoforte, & Cook, 1997; Little, 2002). A study concerned specifically with support group membership by Mandell and Salzer (2007) found that the majority of the participants in ASD support groups had a college education. The topic of education level was a reoccurring

theme in the outcomes of a study by Little (2002). Mothers who had lower education levels reported being more pessimistic regarding parenting a child with ASD, were more likely to take antidepressants and were less likely to find coping skills helpful related to maintaining family stability. Previous literature on parenting a child with a disability has indicated a strong presence of parents with a college education participating in formal and informal support systems as well as different access to information and support regarding ASD (Heller, Roccoforte, & Cook, 1997; Little, 2002; Mandell & Salzer, 2007)

The Internet has become a popular tool for parents of children with ASD to access information and support about ASD. Former research studies have indicated that education level is one of the strongest predictors of whether someone has access to and utilization of the Internet. Pew Research Center in Washington, DC (2010) reported that 94% of internet users have a college degree or higher. Only 64% of individuals with a high school diploma report having Internet access where over 90% of college graduates report having Internet access. Pew Research Center (2011) reported differences among adults with various levels of education and health information gathering online. Almost 90% of the participants using the Internet to get health care information had a college degree compared with only 70% of users who had a high school degree. The numbers dropped even further when looking at adults who have less than a high school education with only 38% of users going online.

This data further indicates that there is a relationship between parent education level and the empowerment attribute of skills and knowledge. With more resources being accessible online for parents of children with ASD in order to get information, education or support about their child's disability, the access to such information and participatory behaviors of parents from different demographic groups should be reliable and valid. Further research on the development

of specific online supports for parents of children with ASD would help ensure better outcomes regarding the education and support for this population.

Education and support for parents of children with ASD should be family-centered regardless of the education level of a parent. With the high prevalence of parents of children with ASD who have a college degree having more access to and participating in formal and informal supports, there are a population of parents who have needs not being met. The result can be poor family outcomes and ultimately poor child outcomes for a child with ASD.

Purposeful planning of education and support opportunities for all parents of children with ASD should be designed to attract a more diverse population of participants. Programs should seek out parents of children with ASD within diverse communities and target less traditional parent education settings such as churches, community centers, and medical facilities. Access to a more diverse group of parents of children with ASD will be a step towards the removal of demographic barriers. The importance of breaking down demographic barriers which limit ASD education and support participation is critical to more positive empowerment outcomes for parents of children with ASD. Once more access to parents of children with ASD who have lower education levels have been acquired, needs-based education and support can be developed based on the demographic factors of the population served. Sensitivity to the cognitive needs of the population served and not necessarily the education level of the individual should drive the development of the education and support practices. Education level should not simply be a determining factor in the needs of the parent.

Research Question 4

Research question 4 explored differences between parent attitude and the perceived severity of the child's ASD. Results indicated that there was not a significant relationship

between the severity of the child's ASD and parent attitude. Parents of children with ASD who participated in this study did not indicate that the severity of their child's ASD had an effect on their empowerment attribute of attitude. The results of this analysis were some of the most interesting findings of the study because of a strong representation in previous research that indicated a correlation between the severity of a child's disability and negative parent outcomes.

Studies by Hoffman, Sweeney, Hodge, Lopez-Wagner, and Looney (2009), Osborne and Reed (2008), and Tobing and Glenwick (2002) reported that mothers of children with ASD were more likely affected based on the severity of child's needs or behavior. A two-part study by Osborne and Reed (2008) evaluated the relationship between the behavior problems of children with ASD and parenting stress. A strong association between parenting stress and child behavior problems were noted when the researchers controlled for other factors, such as ASD severity and intellectual functioning. However, Study 1 indicated that when the children were very young (2-4 years), ASD severity related most strongly to parenting stress. Hoffman et al. reported that even though mothers of children with ASD reported higher levels of stress than parents of typically developing children, mothers of children with ASD did report close relationships with their children just as parents of typically developing children. Baker-Ericzen, Brookman-Frazer, and Stahmer (2005) examined parent stress before and after participation in an inclusive toddler program for parents of children with ASD and typically developing children. Parents of children with ASD reported higher levels of stress related to raising a child with ASD. Results of a study by Bromley, Hare, Davison, and Emerson (2004) revealed that mothers of children with ASD disclosed high levels of psychological distress due to high levels of challenging behaviors from the child. Parents of children with ASD who participated in a study by Gray (2002) on the psychosocial adaptation of parents of children with ASD reported substantial

amounts of stress, anxiety and depression. The parents who reported having a child with significant behavioral problems also reported the greatest levels of stress.

The results of previous research studies (Baker-Ericzen, Brookman-Frazee, & Stahmer, 2005; Bromley, Hare, Davison, & Emerson, 2004; Gray, 2002; Hoffman, Sweeney, Hodge, Lopez-Wagner, & Looney, 2009; Osborne & Reed, 2009; Tobing & Glenwick, 2002) do indicate that the actual behavior of the child and not necessarily the perceived severity of the child may have the greatest impact on the overall well-being and attitude of the parent. The results of the current study indicated that perceived severity of the child's ASD did not significantly impact the attitude factor of the parental empowerment. This outcome may begin to define parents of children with ASD as a unique subgroup of parents of children with disabilities who have different strengths and needs in regard to empowerment. In the current study, perceived severity was reported by the participants as mild, moderate or severe. This study did not assess the actual behavioral challenges of the child although severity of a disability has often tended to be more of a perception than an objective measure. Because of the relationship between ASD and behavioral characteristics, further research in this area may contribute more to the knowledge base about the impact the severity of the child's behavior may have on parent empowerment for parents of children with ASD.

Research Question 5

Research Question 5 examined the relationship between formal and informal participatory behavior and parental skills and knowledge in respect to ASD. Quantitative analyses of responses from the PES and demographic surveys were used to analyze Research Question 5. Results indicated that there was a strong, positive correlation between formal participatory behavior and skills and knowledge and informal participatory behavior and skills

and knowledge. A relationship between the empowerment attribute of participation in informal and formal supports and the empowerment attribute of skills and knowledge was validated. These results further sustain the role that education and support contribute to the outcomes for parents of children with ASD in regard to their child's disability.

Previous research studies explain factors that may have contributed to this finding. Parents often seek out information in order to have a better understand of the disorder and to provide support to their child. When parents of children with ASD are supported in relation to their child's disability, they report being more satisfied with their needs being met and have a better understanding of their child's disability (Whitaker, 2002). Research indicates that parents of children with ASD benefit from both formal (agency resources; professionals) and informal (family members; friends) sources of support (Webber & Boromeo, 2005; Weiss, 2002; Whitaker, 2002). Families of children with disabilities often seek support from family members, friends, professionals or other parents (Most & Zaidman-Zait, 2001). Gray (2002) reported that parental response to the stress of having a child with ASD may depend greatly on the type of support the parent receives. The benefits of support can not only help parents learn new interventions to help deal with a child's behavior but also help parents gain advocacy skills to get the services their child needs (Banach, Iudice, Conway, & Couse, 2010).

The results of the current study demonstrated a positive relationship between participation in formal and informal supports and skills and knowledge. Further, the results of the study also indicated unique strengths and needs of parents of children with ASD. These findings support the value of offering diverse and culturally sensitive parent education and support programs to parents of children with ASD. A more in depth understanding of how parenting a child with ASD affects parent's efforts to seek education and support services would

be valuable, including opportunities for parent education, and whether the impact of parenting a child with ASD is arrived at individually or through cultural norms.

Characteristics of Research Study Participants

Results showed that participants in this study were primarily Caucasian females, married, college educated with household incomes over \$75,000 a year. These results are consistent with research literature that has indicated a strong presence of married, female, college educated participants who are Caucasian in disability support systems (Heller, Roccoforte, & Cook, 1997; Little, 2002). Blackburn and Reed (2005) reported similar findings that identified the majority of the parents that used the Internet for information regarding their child's disability were female, ages 30-44, and Caucasian. Over 60% of participants in a study Osborne and Reed (2008) who measured the relationship between the behavior problems of children with ASD and parent stress were married and had a college education.

Another important finding of this study is the low participation rate of fathers of children with ASD. Based on previous literature (Elder, Valcante, Won, & Zylis, 2003), a weakness in previous research and in the support that is available to fathers of children with disabilities is the vast focus on mothers. Glidden, Billings, and Jobe (2006) indicated mothers of children with disabilities were more likely to seek information, emotional or material support than fathers. However, in a study by Little (2002) mothers reported higher levels of stress than fathers in regard to parenting their child with ASD and ultimately reported seeking more professional help than fathers do. The mothers reported seeking professional help and medication more often for stress than fathers. The mothers also utilized more coping strategies and reported more positive outcomes from the use of the strategies than the fathers. These outcomes may carry over to father participation in research studies in regard to their child with a disability as well. The

higher rates of fathers working outside of the home may also contribute to the lower participation rates in research studies as well. In the previously mentioned study by Little (2002) only 34% of the mothers worked full time with 91% of the fathers working full-time outside of the home. A study on parental stress in mothers and fathers of children with disabilities by Keller and Honig (2004) had similar findings where only 37% of the mothers worked full time with 83% of the fathers working full time outside of the home. All the fathers who participated in a study on behavior problems of children with ASD and parent stress by Osborne and Reed (2008) worked full time. Tunali and Power (2002) report that mothers of children with ASD are often more likely than mothers of typically developing children to place less emphasis on career success, spent more time with family for leisure activities, were less concerned what others felt about their child's behavior, and emphasized spousal support and parental roles. Gray (2003) indicates that mothers of children with ASD take on almost full responsibility for the care of the child which in turn can cause emotional distress and reported changes in lifestyle in order to take on responsibility for the medical and educational responsibilities in caring for the child. These responsibilities can lead to higher levels of stress and a need for support and coping which may be why Glidden, Billings, and Jobe (2006) report that mothers were more likely to seek information, emotional or material support than fathers.

More than half of the participants in this research study reported an income higher than \$75,000. The participation rate in research studies for parents of a child with ASD may be consistent with former research literature which reports that lower-income parents use fewer supports and information sources (Mackintosh, Myers, & Goin-Kochel, 2006) than parents with reported higher levels of income. Pew Research Center (2010) found that individuals reporting higher household incomes also report higher Internet usage. Even though attempts to share the

current study in a hard copy format was pursued in order to reach a more diverse population, many ASD organizations and other research participants shared information about this study via the Internet. In another perspective, Baxter and Kahn (1999) found that low-income parents of children with disabilities reported different needs of support regarding the care of their child than other parents that are not considered low income. Approximately 37 low-income families of a child with a developmental delay or at-risk for a developmental delay, reported factors such as food, shelter, transportation, information and personal time as areas of strain in their lives. Thomas, Ellis, McLaurin, Daniels, and Morissey (2007) identified that access to care was limited for low-income families, minorities, families living in rural communities, and those seeking more non-traditional treatments and care. These are often underserved population in research regarding parents of children with disabilities as well. Because of the reoccurring themes in the literature regarding the lower rates of participation in supports for a low-income parent of a child with a disability, it can be assumed participation in research studies would be affected as well.

The majority (81%) of the participants in the current research study were married. Outcomes from previous literature indicate the need for support is even greater for single parents raising a child with ASD than parents who are married. Reyes-Blanes, Correa, and Bailey (1999) found that mothers who were married indicated the primary sources of support came from their spouse and other adult family members and single mothers received more support from agencies. Even though this research study was shared with many parents of children with ASD throughout the state of Alabama by organizations, the study by Blanes, Correa, and Bailey (1999) indicated single mothers may have higher stress as the sole caretakers of their child with a disability. Because there is a strong correlation between single parenting and poverty, this factor must also be taken into consideration. Families with children with developmental disabilities experience

increased financial burden due to the elevated costs of disability-related care such as specialized therapy and equipment, home adaptations, and medical care (Newacheck & Kim, 2005; Parish & Cloud, 2006). Parish, Rose, Swaine, Dababnah, and Mayra (2002) compared single mothers of children with developmental disabilities, married mothers of children with developmental disabilities and single mothers without children with developmental disabilities. The results of the study found single mothers of children with developmental disabilities had markedly worse financial well-being. Single mothers caring for children with developmental disabilities faced adverse financial well-being as compared with other mothers. Given the high rates of poverty among single mothers and the increased financial burden of raising a child with developmental disabilities, single mothers of children with developmental disabilities are likely at an even greater risk for reduced financial well-being than mothers who are married. The reported higher rates of stress for single parents of a child with a disability who may also be living in a low income situation may mean less time or interest in the participation of research studies regarding their child's disability. Therefore, this may suggest the reason for the low participation rate of single parents in this research study.

Many studies have noted higher rates of participation in disability research studies from parents who have a college education or higher (Mandell & Salzer, 2007; Osborne & Reed, 2009; Pew Research Center, 2010). The higher rates of participation by college-educated parents in this research study were no exception. More than 80 of the participants in the current research study had attended college. Nogurea (2002) indicates that many low-income parents are less likely to have a college degree, which is related to high rates of unemployment and lack of access to economic, education, social, medical, and mental health resources. Little (2002) found that mothers who had lower education levels reported being more pessimistic regarding parenting a child with ASD. Since the majority of the participants in the current study were mothers of children with

ASD, this factor may correlate with the low participation rate of mothers of children with ASD who had less than a college education.

Self-reports of types of autism and the severity of the child's ASD indicated a diverse representation of children with ASD in this study. An interesting finding from this study is the relatively equal numbers of type of ASD to the severity of the ASD. The same amount of parents who reported their child had a general autism diagnosis also reported a child to have a mild form of ASD. The same number of parents who reported the child had Asperger syndrome or PDD-NOS also reported the same numbers of reported levels of moderate or severe severity. While the analysis did not indicate if the same parents who reported autism as the diagnosis also reported a mild level of severity, this correlation may be interesting to consider for future research.

Parent Participation in Formal and Informal Supports

Analyzing the responses from parents in the current study regarding their use of formal and informal supports provided insight into the types of supports parents of children with ASD access most frequently and most commonly. The findings revealed that parents use the Internet (77%) more than any other support available. Parental use of ASD related books or literature was almost as common at 70% with over 50% of participants reporting social support such as friends or other parents of children with ASD serving as a strong source regarding parenting a child with ASD. Over 50% parents also reported relying on ASD therapy professionals to educate and support them regarding their child with ASD. These results align with the results of a study by Braithwaite et al. (1999) which found informational, emotional, and network supports to be the most common types of supports used by individuals seeking support, specifically those seeking support online.

With the Internet serving as a more popular source for support, further examination regarding types of online support was analyzed. Over 80% of participants in the study reported the use of general ASD websites as the most common online source for information. Other common ASD websites utilized by parents were ASD organization websites (60%), ASD parenting websites (42%), and ASD blogs (39%). These are all types of informational support; support in which the individual gets information but does not give out information. None of these types of support require the parent to interact, share information, or express feelings or thoughts. This information regarding parent use of the Internet is important to note for a variety of reasons.

First, the use of the internet has become a popular method for parents to seek education and support regarding parenting a child with a disability. Today the possibilities to find information on children, health, and parenthood on the internet are vast. The use of the Internet as a source for information or to establish contact with others in similar situations is of particular importance for parents whose children are suffering from different varieties of illnesses or whose children have a disability (Plantin & Daneback, 2009).

One of the greatest challenges facing parents of children with ASD and the use of the Internet as a primary source of education and support is the quality of the information or support received. Several studies have reported that health-related information available to parents on the Internet can be misleading and erroneous (Eysenbach, Powell, Kuss, & Sa, 2002; Pandolfini, Impicciatore, & Bonati, 2000). The results from a study by Hardwick and MacKenzie (2002) analyzed 19 web sites containing pregnancy health and medical information and found that the majority of web sites were maintained by either individuals or self-help groups. The quality of the information was generally poor when compared to the guidelines stipulated by medical

practitioners. Several parents indicated the issue of receiving information that did not apply to their situation or may not work for their child even though it may have worked for someone else.

The Social Systems Model of Family Functioning (Dunst et al., 1986) states that members of the family and individuals from ecosystems that surround the family influence each other. The parents who participated in this study reported the use of ASD therapists or other parents of a child with ASD as a more common source of education and support regarding parenting a child with ASD. This is most likely in the form of social informational support. According to research on parenting a child with ASD, parents may feel a strong sense of stress and isolation following the diagnosis of a child with ASD (Gray, 2002). Many parents will turn to a friend or other family member for support. Eventually, parents begin to turn towards other parents of a child with ASD or professionals in the field as a source of support more related to the child's ASD but also receive a sense of emotional support in return. Data analysis showed that parents in this study utilized such supports in regard to parenting a child with ASD.

Factor Analysis

The results of these analyses indicate that the PES instrument may not be the best fit as an indicator of empowerment attributes for parents of children with ASD. It is important to note that CFA typically requires a larger sample size (over 200) than an EFA in order to produce inferential statistics (DeCoster, 1998). Bartlett, Kotrlik, and Higgins (2001) report that less than 100 samples is considered "small" and maybe appropriate for very simple models; 100-200 is "medium" and maybe acceptable minimum sample size if the model is not too complex. Small sample sizes can cause problems running the analysis. Research indicates that a large sample size will allow conclusions made based on the results of a study to be more generalized to the population of interest (Costello & Osborne, 2005). Although the sample used in this study was

considered appropriate (113) for a medium size for CFA, EFA was conducted in order to more adequately draw conclusions about the results much more confidently. The study could be improved by using a larger sample across states.

Exploratory Factor Analysis

Principal factors extraction with varimax rotation was performed through SPSS on the 32 psychological empowerment items. Four factors were extracted. Community values were well-defined by this factor solution, with all variables exceeding .41.

The variables that loaded highly on the first factor all related to formal participatory behaviors. These results are consistent with the questions that related to formal participatory behaviors from the study used to validate the PES. The majority of the variables that loaded highly on factor 2 all seem to relate to attitude but there were a few differences. Question 7, “I advocate effectively for my child with professionals,” loaded on the subscale of skills and knowledge in the study used to validate the PES however, this variable loaded with the attitude subscale in the current study. The 10 questions that loaded highly on factor 3 demonstrated the most significant differences for the factor of skills and knowledge than the former validation study for the PES. Questions 4, 7, 10, 13, 20, 23, 26, and 29 were the questions that loaded for the factor of skills and knowledge in the validation study. In the current study, questions 4, 10, 13, 20, and 26 loaded which are consistent with the findings from the previous study; however questions 5, 8, 9, 17, and 27 also loaded for the factor of skills and knowledge. Because of the significant differences in the outcomes for this factor compared to the previous study, further examination is needed to determine how parents self-reported perceptions of their own empowerment attributes differ than that of parents of children with disabilities in general. Finally, the questions that loaded highly on factor 4 all contain some component of informal participatory behavior; therefore, this is consistent with the previous study results. This analysis

seems to reveal that this questionnaire, in reality, is composed of four subscales but the factors that make up these subscales may differ for parents of children with ASD in regard to empowerment. Question 3, “I often get together with other parents to discuss a common problem affecting our families,” and question 18, “I participate in a support group for parents of children with a disability,” both loaded on the factors of informal and formal participatory behaviors. This outcome may provide insight into the perception parents of children with ASD have regarding their interaction with other parents of children with ASD. Some may see that interaction as a social type of support and others may see the interaction as a more formal type of support. Regardless, since the parents in the current study reported high rates of participation with other parents of children with ASD as a source of support, then there is a possibility that the parents contribute this to their own empowerment. Professionals should take note of this outcome in that there were high reports of such interaction within the sample of this study as well as a correlation of such interaction as both a source of informal and formal support. Professionals should implement practices to help determine the individual support needs or preferences of a parent in how to best support them with the interaction of other parents of a child with ASD.

There are two possibilities regarding this analysis here. The first is that the PES does measure some related constructs. The second is that these four constructs are sub-components of psychological empowerment; however, the factor analysis does not indicate which of these possibilities is true.

Confirmatory Factor Analysis

Confirmatory factor analysis yielded a Root Mean Square Error of Approximation (RMSEA) index of 0.072532. The most current research on good and excellent and good fit is a value close to 0.06 and upper limit of 0.07, respectively (Hu & Bentler, 1999; Steiger, 2007).

The RMSEA index for this study was .07. The discrepancy between the chi-squared value of the hypothesized model and the chi-squared value of the null model was analyzed using normed fit index (NFI) (Bentler & Bonnett, 1980). It is important to note NFI is subject to the sample size (Bearden, Sahrma, & Teel, 1982). When the sample size is small--below 200, fit indices overestimate the fit (Fan, Thompson, & Wang, 1999). The non-normed fit index (NNFI) may resolve some of the issues of sample size (Bentler, 1990). Values for both the NFI and NNFI should range between 0 and 1, with a cutoff of .95 or greater indicating a good model fit (Hu & Bentler, 1999). According to Schumacker and Lomax (2004) a model is regarded as acceptable if the Normed Fit Index (NFI) exceeds .90. In the case of the results of the CFA for this study, the NFI was .56 and NNFI was .74.

Implications of the Study

This study examined the effect of demographic factors on empowerment attributions of parents of children with ASD. This section offers implications for ASD parents, service providers, policy makers, and researchers.

Implications for Practice

There is currently a lack of the representation of studies on the impact of demographic factors in regard to raising a child with ASD. Parents from more underserved demographic populations such as ethnic, low-income, single-parent homes, lower-education parents and men are often also often underrepresented in research studies (Byrd et al., 2011; Sheikh, 2006; Watkins, 2011). In order for service providers to better educate and support families of children with ASD, a clearer understanding of the needs of such diverse groups are necessary. This study sought to explore a better understanding of the empowerment attributes of parents of children with ASD in regard to different demographic factors.

The outcomes from this study begin to define parents of children with ASD as a unique, diverse subgroup of parents of children with disabilities who require an individualized approach to education and support. Regardless, the ultimate goal for service providers who serve families of children with ASD should be the contribution of factors which ultimately lead to the overall empowerment of the parents.

Given these results, parent support strategies should focus on creating or strengthening these aspects of demographic factors and parent empowerment. Moreover, these findings seem to suggest that professionals should play a major role in removing demographic barriers and inequities in supports for empowering parents. Intervention or programs must be intentional and powerful to facilitate empowering parents in terms of the attributes that Zimmerman (1995) indicated ultimately lead to empowerment. To achieve those, professionals will need to create parent empowerment programs that are specific to the diverse needs of the demographic population served. Furthermore, professionals must utilize creative and innovative nontraditional approaches to help parents develop empowerment attributes.

American Academy of Pediatrics (2013) supports that parents and children have more positive outcomes when the family is included in the treatment of the child. Others studies report that parents who receive individualized care and one to one support do significantly better in handling and coping with stress during adjustment periods (Neff, 2003). Emphasis on family-centered practice is rooted in the desire to improve outcomes for families and children. In family-centered practice, the strengths of the child's family are valued, emphasized, and acted upon (Turnbull, Turnbull, Erwin, & Soodak, 2006). Professionals engaging in family-centered practice should encourage and respect families' choices and their decision-making. Effective family-centered practice is characterized by sensitivity, diversity, and flexibility. A recent

movement towards implementing the family-centered care approach leads to the further study of its benefits.

Implications for Future Research

The findings of the current study suggest that there are some relationships between demographic factors and parent empowerment attributes for parents of children with ASD. Specifically, gender and parent education level appear to contribute to the outcomes for parent empowerment. Further, interactions of participatory behaviors and skills & knowledge related to components of parent empowerment. Interestingly, relationships between demographic factors and empowerment attributes which had been previously been established in the research literature as being significant did not demonstrate a relationship in this study. For example, previous literature reported a relationship between empowerment and marital status (Reyes-Blanes, Correa, & Bailey, 1999). In the current study, there was no relationship found between the two factors. Furthermore, the relationship between the perceived severity of a child's behavior and lower reported attributes of empowerment have been repeatedly reported in the research (Hoffman, Sweeney, Hodge, Lopez-Wagner, & Looney, 2009; Osborne & Reed, 2009; Tobing & Glenwick, 2002). In the current study, parents of children with ASD did not demonstrate a correlation of perceived severity of the child's behavior and attributes of empowerment. The fact that there was not a relationship between these factors further supports the importance of service providers for parents of children with ASD to determine what may be contributing to these reported higher levels of empowerment.

At the time of this study, limited research was available on the empowerment of parents of children with ASD. In particular, because this research is being conducted with parents of children with ASD from different demographic groups, more studies are needed to replicate and

extend the findings. Very limited research was found that investigated the role of demographics in the empowerment of parents of children with ASD. Future research might be conducted with more diverse samples. Studies conducted on disability and parenting primarily examine Caucasian mothers from college educated, middle-class socio-economic backgrounds. This might be due to the consistent reports in the research literature that indicates mothers in this demographic subgroup are more likely to seek out education and support regarding their child's disability (Baker-Ericzen, Brookman-Fraze, & Stahmer, 2005; Glidden, Billings, & Jobe, 2006; Little, 2002). The parents in this study did not exhibit a great deal of demographic diversity. However, the participants do reflect the documented demographic make-up of the local parent population seeking services for children with ASD. Future studies should seek ways to include parents from diverse demographic backgrounds. Additionally, including more than one group in the sample or groups that focus on different types of disabilities could help us better understand the effectiveness of supports that specifically target the empowerment attributes of parents of children with disabilities in general. Future research should seek ways to include parents from low participation levels.

Considering the dynamic and complex nature of empowerment, Cattaneo and Chapman (2010) suggest that longitudinal data methodology may be effective to examine empowerment. Longitudinal studies are needed to explore two issues: The first issue is the factors that contribute to the longevity of empowerment attributes of parents of children with ASD. Although this study attempted to explain some of these factors, future research is needed to verify the current study findings. The second issue is the way that supports can be individualized to better meet the needs of underserved populations.

Summary

The findings of the current study demonstrated the relationship between demographic factors and parent empowerment for parents of children with ASD. The results of this study have implications for parents, service providers, policy makers, and researchers. Furthermore, these data may begin to provide insight into the theoretical framework of the parent empowerment to guide research and practice. Using a national as well as longitudinal study with large data may make a significant contribution to the literature on parenting, empowerment or ASD studies. As the diagnosis of ASD continues to impact parents, it is expected that there will be an increasing demand for parent support and education in order to help contribute to more positive outcomes in parent empowerment. This study has begun to provide important information on the interaction effects of demographics on parent empowerment; however, further research is needed. Therefore, it is possible to see more studies conducted on this topic in the near future.

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APPENDIX A

PSYCHOLOGICAL EMPOWERMENT SCALE AND
DEMOGRAPHIC QUESTIONNAIRE

Directions: The following survey is designed to measure your perspective of your own empowerment attributions in regard to your role as a parent of a child with ASD. For the purpose of this study, please base your responses on empowerment to your role as a parent of a child with ASD. To complete the survey respond to the questions using the following scales: Strongly Disagree; Disagree; Neutral; Agree; Strongly Agree.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
1. I have control over decisions that are made concerning my child.					
2. I offer my services as a supporting parent in a parent organization.					
3. I often get together with other parents to discuss a common problem affecting our families.					
4. I communicate my ideas to others clearly.					
5. I am involved in decision-making in a parent organization or service program.					
6. I informally share information with other parents.					
7. I advocate effectively for my child with professionals.					
8. I feel in control of my life.					
9. I spend time with other parents talking about my family.					
10. I am able to explain myself until I make myself clear.					
11. I feel like I have choices for my family.					
12. I help lead a support group for other parents.					
13. When I have to get something done, I get to work on it quickly.					
14. Regardless of what other people do, I have control over how my family's needs are met.					

15. I hold a leadership role in a parent organization or service program.					
16. I help other parents advocate for their child's needs.					
17. I have many choices about how to meet my family's needs.					
18. I participate in a support group for parents of children with a disability.					
19. There is at least one other parent I can go to for emotional support.					
20. I try to learn new skills even if they seem difficult.					
21. I take an active role in improving services to families through a formal parent organization.					
22. I try to act as an emotional support to other parents.					
23. I think I made good decisions about what my family needs.					
24. I have control over what happens in my family.					
25. I have worked informally with other parents to address a need common to all of us.					
26. I feel competent to meet my child's needs.					
27. I have the power to get what my family needs.					
28. I am actively involved in a formal parent organization.					
29. I think my decision-making skills are as good as other parents.					
30. I am on an advisory board for a parent organization or service program.					
31. I feel a sense of community with other parents who have a child with a disability.					
32. I can usually solve problems that confront my family.					

FAMILY BACKGROUND QUESTIONNAIRE

I want to learn more about how demographics may contribute to the empowerment of parents of children with an autism spectrum disorder (ASD). Please answer all questions and remember your responses will not be shared with anyone.

1. **Do you participate in any support group related to autism spectrum disorders?**

yes no

2. **What type of ASD support group have you participated in:**

online (chat room, blog, listserv)

face-to-face (support meeting, parent group)

3. **What other types of supports do you have in regard to parenting a child with ASD:**

(check all that apply)

ASD related books or literature

ASD specific training

ASD educational professionals

other ASD parents

religious/spiritual support

Internet resources

Other: _____

ASD workshops/conferences

ASD therapy professionals

ASD medical professionals

family support

friends/social support

medical

4. **What types of online resources have you used:**

General ASD websites

ASD organization websites

Websites on parenting (general)

ASD chat rooms

Parenting chat rooms

Listservs

Websites on parenting (disability)

Websites on parenting (ASD)

ASD training/education websites

ASD related blogs

Parenting blogs

ASD email groups

5. **Your gender:** M F

6. **Marital Status:** married single/divorced partnership/other

7. **Highest level of education completed:** Less than high school diploma

High school diploma College Graduate School

8. **Household income:** <\$25,000 \$25,001-\$50,000 \$50,001-\$75,000

\$75,001-\$100,000 \$100,001>

9. **Child's autism diagnosis:** ____ Autism ____ Asperger syndrome ____ PDD-NOS

10. **Severity of child's autism:** ____ Mild ____ Moderate ____ Severe

APPENDIX B

LIST OF STATEWIDE ASD SERVICE PROVIDERS

Alabama Autism Resources

Resource	Contact	Location	Description	Website	Email	Phone	Fax
ABC Services, LLC	Jane Barnes	Statewide	provide in home, clinical and school ABA programming and training in addition to group therapy services throughout the state of Tennessee and are expanding to Alabama	www.abc-services-llc.com	jane@abc-services-llc.com	615-331-1141	615-331-1141
Advanced Autism Consulting	Tina Halbert	202 Meadow Lane, Deatsville, AL	Elmore, Autauga, Montgomery counties		autism@more.rr.com	334-399-1520	
Alabama Council for Developmental Disabilities		RSA Union Building, 100 North Union Street, Montgomery, AL 36130	To serve as an advocate for Alabama's citizens with developmental disabilities and their families	www.acdd.org	exec.director@myra.jones@mh.alabama.gov	205-242-9373	
Alabama Disabilities Advocacy Program (ADAP)		PO Box 870395, Tuscaloosa, AL 35487			adap@adap.ua.edu	205-348-4928	
Alabama Interagency Autism Coordinating Council (AIACC)		Montgomery, AL	created to meet the urgent and substantial need to develop and implement a statewide comprehensive, coordinated, multidisciplinary, interagency system of care for individuals with autism spectrum disorder and their families	www.autism.alabama.gov	Anna McConnell 205-478-3402		
Alabama Network for Children with Disabilities	Jean Winter	Alabama Parent Education Center ANCD Project PO BOX 118 Wetumpka, AL 36092	provide parents with training and information to help them become meaningful participants in their children's education	www.alabamaparentcenter.com	jean@alabamaparentcenter.com		
Alabama Parent	Michelle Harris						

Education Center Alabama Special Education Consultation and Advocacy Services	Claudia V. Rice									
ACT: All-Inclusive Child Therapies	Holly Foster, M.S., CCC/SP #411 Karen Sewell, M.Ed. Amber K. Aull, M.S., B.C.B.A		Speech and Language Therapy Early Intervention Therapy	www.hollyfostertimetotalk.com www.karensewell.com	hollyfoster.timetotalk@gmail.com sptcher@bellsouth.net	205-587-6847 205-410-6263				
Amber K. Aull, M.S., B.C.B.A	Amber K. Aull, M.S., B.C.B.A	485 Lee Road 453, Waverly, AL 36879	Offers behavioral intervention and verbal behavior training to all ages		?	334-502-5333				
Applied Behavioral Concepts, Inc.	Carol Vancil	PO Box 6773, Huntsville, AL 35813		www.appliedbehavioralconcepts.net	info@appliedbehavioralconcepts.net	256-783-5151				
ARC of Alabama		300 South Hull Street, Montgomery, AL 36104		www.thearcofalabama.com	info@thearcofalabama.com	334-262-7688	334-834-			
Aaron's Staff - Asbury United Methodist Church	Tim Trimble, President Julie Parks	2698 Highway 58 Helena, AL 35080 980 Hughes Road, Madison, AL	Respite Care for Children with Disabilities Respite Care: Fourth Friday of each month, except May, Nov., and Dec Behavioral therapy	www.aaronstaffrespite.org	info@aaronstaffrespite.org	205.261.9915 256-837-0365				
Ashley Paige Simmons, MS, ECE	Ashley Paige Simmons, MS, ECE	2314 4th Ave North, Pell City, AL 35125			ashleypsimmons@hotmail.com	205-884-7621 205- 706-9449				
Auburn University Psychological Services Center (AUPSC)	Polly Dunn, Ph.D., Clinic Director	101 Cary Hall Auburn University, AL 36849			aupsc@auburn.edu dunnpol@auburn.edu	(334) 844-4889 (334) 844				
Autism Asperger Syndrome Consulting Group, LLC	Kerry Mataya, M.S.Ed., Jason Elmer	3985 Parkwood Road, Suite 109-144, Bessemer, AL 35022		www.aascg.com	jasonaelmer@gmail.com	205-572-1143	866-477-			
Autism Diagnostics, Consultation and	Caroline R. Gomez, PhD	228 Chadwick Lane, Suite 205, Auburn, AL 36830				334-444-3910	866-309-			

Training Autism Resource and Knowledge Center	<i>Sally Davis</i>	701 Andrew Jackson Way, Suite 201, Huntsville, AL 35802	Provides counseling, referrals, & support			256-534-5164
The Autism Spectrum Counseling Center		821 S Perry Street Montgomery, AL 36104-0519	Provides services like Mitchell's Place or Glenwood	www.autismspectrumcenter.org		
Behavior Analysts of Central Alabama	Dr. David Bicard, Ph.D., BCBA-D, LBA	108 Twelve Oaks Court Prattville, AL 36066	Specializes in early, intensive behavioral interventions for children birth to age seven	www.bacallc.com		334.595.3673
Behavioral - Educational Consultants of Alabama, Inc. (BECA)	Amanda Bellmyer	9096 Merritt Land, Suite D, Daphne, AL 36526		amanda@beca-consultants.com	<i>not working</i>	251-605-8444
Behavior Unraveled	Jane Veverka, M.Ed., BCBA		Autism & Behavior Therapist/Consultant	www.bahaviorunraveled.com	<i>behaviorunraveled @ gmail.com</i>	256.714.4363
The Bell Center				www.thebellcenter.org		
Camp ASCCA Easter Seals		5278 Camp ASCCA Drive Jackson's Gap, AL 36861			<i>John @ compassa</i>	256.825.9226
The Center for Child and Adolescent Development (CCAD)		4154 Lomac Street, Montgomery, AL 36106 <i>Greenville, AL</i>			<i>?</i>	334-262-5744
Cheaha Regional Head Start/Early Head Start	Bernadine Herring Parrish, Special Needs Coordinator	925 North Street East Talladega, AL 35160- 2501			<i>admin@a cheahahead start.org</i>	256.362.3852
Child's Play Therapy Center- Birmingham	Kerri Bailey, OTR/L	3057 Lorna Road, Suite 220, Birmingham, AL 35216	Occupational Therapy	www.childisplaytherapycenter.com	<i>info</i>	205-978-9939
Child's Play Therapy Center- Huntsville	Kerri Bailey, OTR/L	4801 University Square, Suite 19, Huntsville, AL 35816	Occupational Therapy	www.childisplaytherapycenter.com	<i> </i>	256-837-2470
Children's Advocate for	Dr. Deborah Horton Jordan	PO Box 547, Huntsville, AL 35804			<i>dhortonjordan@bellsouth.net</i>	256-651-8100

Special Education (CASE)										
Children's Rehabilitation Services (CRS)	Kimber Zellner, OTR/L	3000 Johnson Road SW, Huntsville, AL 35805							256-650-1701	
Children's Therapy Services	Andrea Batt, PT, PCS; K. Bridget Jedlovec, MS, PT; Janet Taylor, OTR/L; Leslie Moore, OTR/L; Julie Yokel, CCC-SLP	2075 Max Luther Drive, Huntsville, AL 35810							256-852-2600 852-5600	
Community Advocates for the Developmentally Disabled		4412 Linpark Drive, Birmingham, AL 35222							205-592-9075	
Community Options Autism Service Team, Inc. (COAST)	Pam Black	1401 Old Russellville Road, Jasper, AL 35503							(205) 221-6110	
Chrysalis Academy		Mobile, AL						atrehem@msn.com	251-423-4102	
Cumberland Hospital for children and adolescents	John W. Dent							john.dent@psysolutions.com ↑?? (not working)	334-462-3426	
Dossett Clinic for People with Autism	Rebecca Dossett, PhD	2305 Arlington Avenue, Birmingham, AL 35205						address@hweasy.net ?	205-933-5476	
Dragonfly Pediatric Therapy, Inc.	Sharon Y. Mandeville, OTR/L, IMC	2522 Woodhurst Drive SE, Huntsville, AL 35803						dragonflyped@att.net	256-797-6001	256-883-

Dr. Matthew Remick (Pitts and Associates, Inc.) Eagles Wings, Inc.	2700 Rogers Drive, Suite 101, Birmingham, AL 35209 2205 9th Avenue Northport, AL 35476	Serving Adults with Special Needs			205-870-3520 205-345-5484	205-870-3520 205-345-
	Terrance Anderson, Executive Director or Connie Stokes, Director of Community Relations					
Easter Seals- Achievement Center	510 West Thomason Circle Opelika, AL 36801-5499				334.745.3501	334.749.1
Easter Seals Alabama, Inc. - Corporate Office	5960 East Shirley Lane Montgomery, AL 36117				334.395.4489	800.388.1
Easter Seals of the Birmingham Area	200 Beacon Parkway West Birmingham, AL 35209				205.942.6277	205.945.2
Easter Seals of Central Alabama ASD Diagnostic Clinic	2125 East South Boulevard, Montgomery, AL 36116		www.eastersealsca.org		334-288-0240	
Easter Seals of the Gulf Coast (Alabama)	2448 Gordon Smith Drive Mobile, AL 36617				251.471.1581	251.476.2
Easter Seals Northwest Alabama	1450 East Avalon Avenue Muscle Shoals, AL 35661				256.381.1110	256.314.1
Easter Seals- Opportunity Center	217 West 13th St Anniston, AL 36202				256.820.9960	256.820.1
Easter Seals West Alabama	1110 Sixth Avenue East Tuscaloosa, AL 35401				205.759.1211	205.349.1
Easter Seals West Central Alabama	2906 Citizen's Parkway Selma, AL 36701-3915				334.872.8421	334.872.1
Effective	PO Box 62,		www.effectivesip.com		866-849-4608	

remick@a
bellsofth.net
eagleswingsin
634@
bellsoftho
net

info@al.easter
seals.com

traci@effectivesip.com
effectivesip.com

Homewood Church of Christ School	Mueller	Street, Elberta, Alabama 36530 Mailing Address: P.O. Box 46, Elberta, AL 36530 Homewood, AL	Respite Care: 4th Friday of month 6:30-9:30pm	www.horizonsschool.org		205-942-6232	
The Horizons School		2018 15th Ave South, Birmingham, AL 35205		www.independenceplaceofalabam a.org		800-822-6242 205-322-6606	
Independence Place of Alabama Center of Mobile		5304 B Overlook Road, Mobile, AL 36612				251-460-2872	251-341-
Independence Living Resources of Walker	Trecin C. Benefield		To empower people with disabilities to fully participate in the community	www.ilrgb.org		205-387-0159	205-387-
Indian Springs First Baptist Church		3375 Cahaba Valley Road, Pelham, AL 35124	Respite Care: Third Friday of each month. 6-10pm			205-988-3662	
JLT Therapeutic Services, Inc.	Yvonne Madison OTR/L	Birmingham, AL				205-669-7455	
Lane S. Schmitt, MA, CCC-SLP	Lane S. Schmitt, MA, CCC-SLP	4 Office Park Circle Suite 314A Birmingham, AL 35223	Licensed Speech-Language Pathologist / Academic Coach; Developing communication and independence with children and adults in the optimum setting: office, home, school			205-259-8698	205-262-
			Offering speech and language evaluation/therapy including social skill development; also organizational, time management, and study				

The Learning Tree, Inc.	Leigh Ann Adams, MS, BCBA	PO Box 1306, Semmes, AL 36575	techniques for students who are on the autism spectrum and for those with AD/HD.		informobile@learning-tree.org <i>contacted director of all</i>	251-649-4420	251-649-
The Learning Tree, Inc.	Patricia Murphy, MED	PO Box 908, Jacksonville, AL 36285			pmurphy@learning-tree.org	256-447-9349	256-447-
The Learning Tree, Inc.	Dr. Marc Williams	PO Box 780639, Tallassee, AL 36078			mwilliams@learning-tree.org	334-257-0025	334-252-
Life Church of Birmingham		Birmingham, AL	Respite Care: 4th Friday of the month 6-10pm.			205-986-5433	
Lifelong Coordination Clinic		1530 3rd Avenue South, Room 160, Birmingham, AL 35294		www.circ.uab.edu/Life/lcc.htm	<i>web site clinic (special)</i>	205-934-2965	205-975-
Medical Autism Clinic, Children's Hospital		The Children's Hospital of Alabama, 1600 7th Avenue South, Clinic 7, Birmingham, AL 35233	Serves children diagnosed with Autism Spectrum Disorders	www.chsys.org		(205) 939-5275 (205) 939-5277	(205) 975
Milestones Behavior Consulting, LLC	Ashlie Grill, MS, BCBA			www.milestonesaba.com	ashlie.grill@yahoo.com	(850) 221-0924	
Mission to North America	Joel Wallace		Special Needs Ministry (working with churches to develop disability ministries)		joelwallace@bellsouth.net <i>verify</i>		
Mitchell's Place		4778 Overton Road, Birmingham, AL 35210		www.mitchells-place.com		205-957-0294	
Oak Mountain Presbyterian Church	Gwen McLeod	Birmingham, AL 35242	Respite Care: 2nd Friday of the month, 6-10pm			205-995-9694	
Partners In Policymaking of Alabama (PIPA)			Involves and empowers individuals with developmental disabilities and their families in the policymaking arena	www.acdd.org/about/pipa.html	<i>Debra A. Dora</i> <i>M.H. Alabama.gov</i>	334-353-9328	
Pediatric Therapy Link of North Alabama, LLC	Mary Mayhan, OTR/L	97 Hughes Road, Suite H, Madison, AL 35758		http://www.pediatrictherapylink.com <i>info@pediatrictherapylink.com</i>	pediatrictherapylink@bellsouth.net <i>n.a.</i>	256-883-7338	

Premier Therapy - Ft. Payne	213 38th Street North East, Fort Payne, AL 35967	Pediatric Speech, Occupational, Physical and Interactive Metronome Therapy.	http://www.premiertherapyllc.net	(256) 844-2992	(256) 844
Progress Listening Center	215 Midland Street, Ashford, AL 36312	Our center offers Enlister, a Tomatis based program for Auditory Processing.	www.progresscenter.us	334-899-4333 334-596-0476	
Puzzle Piece	Mountain Brook, AL 35223			205-969-8080	205-969-
Rainbow Omega	P.O. Box 740 Eastaboga, AL 36260		www.rainbowomega.org	(256) 831-0919	
Riley Behavioral and Educational Center	1900 Gulf Road, Suite E, Huntsville, AL 35802		www.TheRileyCenter.org	256-882-2457	256-882-
Spectrum Center for Autism and Related Disorders	217 Graceland Drive, Suite 1, Dothan, AL 36035		www.spectrumdothan.org	334-671-1650	334-671-
St. Mark United Methodist Church	2901 Columbiana Road, Birmingham, AL 35216	Respite Care one Friday nite per month	www.saintmarkumc.org	205-620-9497	
The Sundance Center, LLC	660 Main Street Montevallo, AL 35115	Office and in home services		205-585-0730	
Sunny Speaker Davenport, MT-BC	Sunny Speaker Davenport, MT-BC	Board Certified Music Therapist		MusicTherapyofAlabama@gmail.com	(205) 587-7166
Susan Heatter	210 South Mobile St. # 19, Fairhope, AL	Behavioral therapy		sheatter@sprynet.com	251-990-9736
TriCounty Agency for Intellectual Disabilities	85 North Walston Bridge Road, Jasper, AL 35504	Provides service coordination for individuals diagnosed with an intellectual disability		tricomadd1h@intermail.com	(205) 384-4953
UAB Civitan - Sparks Clinics	930 20th St. South, Birmingham, AL 35205	provides an extensive range of interdisciplinary clinics offering comprehensive diagnosis, evaluation, and treatment of the needs of children and adolescents, age 2-18 with diverse medical and	www.circ.uab.edu/sparks	205-934-5471	

ucp
huntsville

		neurodevelopmental disorders, such as ASD and PDD				
UCP of Alabama c/o UCP of East Central Alabama	301 E.A. Darden Drive, Box 694 Anniston, AL 36202		www.ecaucp.org	executivedirector@ecaucp.org	256-237-8203	256-235-
UCP of Greater Birmingham	120 Oslo Circle Birmingham, AL 35211		http://www.ucpbham.com	jellison@ucpbham.com	(205) 944-3900	(205) 944
UCP of Huntsville & Tennessee Valley	2075 Max Luther Drive Huntsville, AL 35810		http://www.ucphuntsville.org	tracyc@ucphuntsville.org	256-852-5600 (256) 852-5673	(256) 852
UCP of Mobile	3058 Dauphin Square Connector Mobile, AL 36607		http://www.ucpmobile.org	info@ucpmobile.org	(251) 479-4900	(251) 479
UCP of Northwest Alabama	4212 Jackson Highway Sheffield, AL 35660		http://www.ucpshoals.org	elisan@ucpshoals.org <i>sent several from website</i>	(256) 381-4310	(256) 381
UCP of West Alabama	1100 UCP Parkway Northport, AL 35476		http://www.ucpwa.org	lisaucp@comcast.net	(205) 345-3031	(205) 345
Uniquely Different, LLC	Samantha Sterling, M.S., B.C.B.A		www.uniquelydifferentbehavioralconsulting.com	samantha_sterling@hotmail.com	205-492-9671	
University of Alabama ASD Clinic	Melanie DeRamus, Ph.D.		www.autism-clinic.ua.edu	autismclinic@ua.edu	205-348-3130	205-348-
University of Montevallo Speech and Hearing Clinic	Dr. Linda Murdoch	Speech and hearing evaluations and therapy.			205-665-6720	
University of South Alabama, Developmental Pediatrics	Hanes Swingle, MD and Stephanie Anderson, MD				251-415-8624 251- 415-8577	
Valleydale Church	Birmingham, AL 35242	"Outside the Box" Support Group for parents of special needs children.			205-437-1117	

~~Facebook/cherokee;~~
karenlaineadams@hotmail.com
• bettobi.gwilliams150@yahoo.com

ucp: admin: dl11kpage@ucpbham.com
handbook: lharison@ucpbham.com
" " : lindsey@ucpbham.com

Wellness Health + Pharmacy	3401 Independence Dr., Suite 231, Birmingham, AL 35209		3rd Sunday of the month at 5:30 p.m		(800) 227-2627	(800) 369
Weatherly Heights Baptist Church	Vicki Timmerman 1306 Canstatt Drive, Huntsville, AL 35803		Respite program: First Friday of each month, 6:00 - 10:00 p.m.		256-881-6882	
Whiteburg Baptist Church	Kathy McCown 6806 Whitesburg Drive, Huntsville, AL 35802	www.wbccares.org	Offers special needs ministry and hosts the Making Connection Conference with the ASA held in October		256-881-0952	
Woody's Song: For Kids on the Autism Spectrum	5459 Able Court, Mobile, AL, 36693		day program for elementary age children on the autism spectrum	jstarr@learning-tree.org	251-331-8021	

STOP: start with private/non-public schools!!

APPENDIX C

LIST OF STATEWIDE ASD PARENT SUPPORT GROUPS

Autism Society of Alabama Parent Support Groups

	Name of Support Group	Contact Name	Contact Email	Contact Number	Website
1	Alabama Autism & Asperger's Statewide Info & Support Network	Mike Turmin Susan Ogle	AlexanderCityNetworkingGroup@autism-alabama.org		www.AlabamaAutism.org
2	Alexander City Networking Group	Julie Brown	AuburnNetworkingGroup@autism-alabama.org	(334) 887-3909	
3	Auburn/Lee County Networking Group	Gerrit Taylor			http://www.regionalaautismnetwork.org
4	Autauga, Elmore, Montgomery Region AL Autism Network	Anajnette Burkett Robinson	arobinson@glenwood.org	205-212-6722	http://health.groups.yahoo.com/group/BirminghamAlabamaAutismSupportGroup/
5	Birmingham (Adults with Aspergers) Support Group: Glenwood, Inc.	Tracy Cron			
6	Birmingham Online Support Group	Jennifer Proctor Amanda Simpson	BlountCountyNetworkingGroup@autism-alabama.org		
7	Blount County Networking Group	Tracy Robinson	CalhounCountyNetworkingGroup@autism-alabama.org	(205) 221-6110	www.calhouncountyautisminfo.com
8	C.O.A.S.T. (Jasper)	Felicia Agnew	feliciaagnew@yahoo.com	(205) 396-7973	
9	Calhoun County Online Networking Group	Donna Jennings	info@chiltonautism.org		www.chiltonautism.org
10	Centerpoint Networking Group	Charity Fields	ClarkeWashingtonCounties@autism-alabama.org		
11	Chilton County Autism Networking (CAN) Networking Group	Rhonda Davis and Jessica Dyson	pdrc@hotmail.com jessdysonfam@earthlink.net	256-982-2208 256-339-1151 (334) 875-6001	
12	Clarke & Washington Counties Networking Group	Carolyn C. Bate	ccbates_sdap@gmail.com		
13	Cullman County Networking Group	Jan Applin Cindy Morgan	jeppling2626@aol.com cinmorgan34@aol.com	256-303-6609	
14	Dallas County Networking Group	Bobbi Wallen	DekalbCounty@autism-alabama.org	256-612-0290	
15	Decatur/Hartselle Networking Group	Fran Helsner	janiewalton@yahoo.com	334-793-8714	
16	Dekalb County Networking Group	Janie Waiton	GadsdenNetworkingGroup@autism-alabama.org	256-764-1331	
17	Dothan-FASE Networking Group	Sonia Maini	GreaterBirminghamNetworkingGroup@autism-alabama.org		
18	Florence Networking Group	Dr. Karen Dahle			
19	Gadsden/Etowah Networking Group				
20	Greater Birmingham Networking Group				

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21	Gulf Shores - Special Parents, Exceptional Kids	Andrea Frogue Plante	SpecialParentsExceptionalKids@autism-alabama.org		
22	Hamilton Networking Group	Tanya Sanderson	MakingConnectionsHSI@autism-alabama.org	(205) 412-4745	www.makingconnectionsasd.com
23	Huntsville Networking Group (Making Connections)	Debbie Burbicka			
24	Limestone County Networking Group	Todd J. Zomerlin	LimestoneCounty@autism-alabama.org		
25	Lineville Networking Group ("Incredible Families")	Cindy Langston	Lineville@autism-alabama.org	256.405.8380	
26	Mobile Networking Group	Angel Loewen	angel@autism-alabama.org MobileNetworkingGroup@autism-alabama.org		
27	North AL Chapter Autism Society of AL	Teresa White	trtrwhite@msn.com	256-773-0549	
28	St. Clair County Networking Group	Tina Brasher	stclaircounty@autism-alabama.org		
29	Sumter County Networking Group		Sumtercountynetworkinggroup@autism-alabama.org		
30	Talk About Curing Autism (TACA) Now! Support Group	Margaret Stewart and Carmen Atkins			http://www.tacanow.org/
31	Tuscaloosa Networking Group	Tracy Camp & Lisa Riley	tracy4autism@aol.com lisa4autism@aol.com	205-330-8995	
32	Winfield Networking Group	James Gory	205-495-8951		

APPENDIX D

LIST OF STATEWIDE SPECIAL EDUCATION COORDINATORS AND DIRECTORS

REVISED: September 11, 2012

ALABAMA STATE DEPARTMENT OF EDUCATION
SPECIAL EDUCATION SERVICES

ALABAMA SPECIAL EDUCATION COORDINATORS

LEA	Special Ed Coordinator	Phone	Address	Email	FAX
Albertville City	Mrs. Tara Wilson	(256) 891-1183	107 West Main Street, Albertville, AL 35950	twilson@albertk12.org	(256) 891-6303
Alexander City	Ms. Kristi Boone	(256) 234-5074	375 Lee Street, Alexander City, AL 35010	kboone@alex.k12.al.us	(256) 234-8649
Andalusia City	Mrs. Sonja Hines	(334) 222-3186 x5	122 Sixth Avenue, Andalusia, AL 36420	hines10@gmail.com	(334) 222-863
Anniston City	Mrs. Gwendolyn A. Baker	(256) 231-5100 X113	Post Office Box 1500, Anniston, AL 36202	bakerg@annistonschools.org	(256) 231-5106
Arab City	Mr. Patrick Crowder	(256) 586-6011	750 Arabian Drive Northeast, Arab, AL 35016-1161	perowder@arabcityschools.org	(256) 586-6013
Athens City	Dr. Gwen Hardnett	(256) 233-6600	455 U.S. Highway 31 North, Athens, AL 35611	gwen.hardnett@acs-k12.org	(256) 233-6640
Attalla City	Ms. Pamela Burgess	(256) 538-3700	101 Case Avenue, Attalla, AL 35954	pburgess@attalla.k12.al.us	(256) 538-3720
Auburn City	Dr. Tim Havard	(334) 887-2100 cell 334-707-0863	Post Office Box 3270, Auburn, AL 36831-3270	tshavard@auburnschools.org	(334) 887-2107
Autauga County	Ms. Lillie Bowling	(334) 361-3843	127 West 4th Street, Prattville, AL 36067-3011	lillie.bowling@aacboe.net	(334) 365-1672
Baldwin County	Ms. Carol Palumbo	(251) 972-6860	1091 B Avenue, Loxley, AL 36551	cpalumbo@bcboe.org	(251) 972-6861
Barbour County	Ms. Tara Johnson	(334) 775-3533	Post Office Box 429, Clayton, AL 36016-0429	johnson@barbourschools.org	(334) 775-7301
Bessemer City	Ms. Brenda Hunter-Jones	(205) 432-3002	Post Office Box 1230, Bessemer, AL 35021	bhunterjones@bessk12.org	(205) 432-3087
Bibb County	Dr. James Gray, Jr.	(205) 926-9880	721 Walnut Street, Centerville, AL 35042-2277	gray@bibbed.org	(205) 926-4138
Birmingham City	Dr. David Patterson	(205) 231-4780	Post Office Box 10007, Birmingham, AL 35202	dpatterson@bhsm.k12.al.us	(205) 231-4825
Blount County	Ms. Becky Brothers	(205) 625-4102 X3218	Post Office Box 578, Oneonta, AL 35121	bbrothers@blountboe.net	(205) 695-4100
Boaz City	Ms. Connie Riggsby	(256) 593-7311	126 Newt Parker Drive, Boaz, AL 35957	eriggsby@boazk12.org	(256) 593-8780
Brewton City	Dr. Baxter Baker	(251) 867-8400	811 Belleville Avenue, Brewton, AL 36426	bbaker@brevtoncityschools.org	(251) 867-8403
Bulloch County	Mrs. Sylvia F. Phillips	(334) 738-4187 X6001	Post Office Box 231, Union Springs, AL 36089-0231	sphilips@bullock.k12.al.us	(334) 738-2802
Butler County	Mr. Willie Thornton	(334) 382-2665	211 School Highlands Road, Greenville, AL 36037	willie.thornton@butlerco.k12.al.us	(334) 382-8607
Calhoun County	Ms. Charlene Hill	(256) 741-7427	Post Office Box 2084, Anniston, AL 36202	chill@calhoun.k12.al.us	(256) 237-5332
Chambers County	Mrs. Diane G. Sherriff	(334) 864-9466 X203	Box 408 D, Larayette, AL 36862	sherridg@chambersk12.org	(334) 864-9619
Cherokee County	Dr. Trina Wood	(256) 927-5893	130 East Main Street, Centre, AL 35960-1599	twood@cherokeek12.org	(256) 927-4204
Chickasaw City	Mrs. Mary B. Kercher	(251) 452-3452	Post Office Box 11493, Chickasaw, AL 36671-0493	mikercher@chickasaw.k12.al.us	(256) 463-5709
Chilton County	Dr. Benita H. Cahalane	(205) 280-2917	1705 Lay Diam Road, Clanton, AL 35045	bcahalane@chilton.k12.al.us	(205) 755-6549
Choctaw County	Mr. Douglas Marsh	(205) 459-3031 X235	107 Tom Orr Drive, Butler, AL 36904	dmarsh@choctawk12.org	(205) 459-3037
Clarke County	Ms. Velma Rowden	(251) 275-3255 X28	Post Office Box 936, Grove Hill, AL 36451	vrowden@clarkecountyschools.org	(251) 275-8061
Clay County	Dr. JoAnne Blair	(256) 354-5414	Post Office Box 278, Ashland, AL 36251	blairj@clay.k12.org	(256) 354-5415
Clayborne County	Ms. Tammy Burkhardt	(256) 463-5624 X107	93 Education Street, Heflin, AL 36264	tburkhardt@clayburnschools.net	(256) 463-5709
Coffee County	Mrs. Becky Hardiman	(334) 897-5016	400 Reddoch Hill Road, Elba, AL 36323	becky@coffeecounty.k12.al.us	(334) 897-6207
Colbert County	Mr. Wade Turberville	(256) 386-8565	1101 Hwy 72 East, Tuscumbia, AL 35674	wturberville@colbert.k12.al.us	(256) 381-9375
Conecuh County	Ms. Rita Young	(251) 578-7073	100 Jackson Street, Evergreen, AL 36401-2843	rita.young@conecuhk12.com	(251) 578-7082
Coosa County	Mr. William Walker	(256) 377-4430 X24	Post Office Drawer 37, Rockford, AL 35136	wwalker@coosascchools.k12.al.us	(256) 377-2385
Covington County	Ms. Kelly McCollough	(334) 222-7571	807 C.C. Baker Avenue, Andalusia, AL 36420	Kelly.mccollough@cov.k12.al.us	(334) 222-7573
Crenshaw County	Ms. Sherry Sport	(334) 335-6519 X 3	183 Votee Drive, Luverne, AL 36049	ssport@crenshawschools.org	(334) 335-6510
Cullman City	Mrs. Debbie Wright	(256) 734-2233 X22	301 1st Street Northeast, Suite 102, Cullman, AL 35055	dwright@cullmancats.net	256-734-8524
Cullman County	Mr. Charles Clemmons	(256) 739-0486	17600 Highway 31, Cullman, AL 35058	Clemmons@ccboe.org	(256) 739-0458
Dale County	Mrs. Beverly Jones Lampkin	(334) 774-2355	113 West Reynolds Street, Ozark, AL 36360	blampkin@dalecountyboe.org	(334) 774-3503
Daleville City	Dr. Katherine Horace	(334) 598-4463	626 N. Daleville Avenue, Daleville, AL 36322	horacek@daleville.k12.al.us	(334) 598-9006

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ALABAMA STATE DEPARTMENT OF EDUCATION
SPECIAL EDUCATION SERVICES

ALABAMA SPECIAL EDUCATION COORDINATORS

LEA	Special Ed Coordinator	Phone	Address	Email	FAX
Dallas County	Ms. Sharon Streeter	(334) 872-7075	Post Office Box 1056, Selma, AL 36702-1056	sstreeter@dallask12.org	(334) 872-2706
Decatur City	Ms. Stefanie Underwood	(256) 552-4637	110 Johnston Street Southeast, Decatur, AL 35601	stefanie_underwood@dcs.edu	(256) 355-8270
DeKalb County	Ms. Pam Gann	(256) 638-4131	Post Office Box 1668, Rainsville, AL 35986	pfann@dekalbk12.org	(256) 638-4073
Demopolis City	Ms. Kim Logan	(334) 289-1671 X4	Post Office Drawer 759, Demopolis, AL 36732	klogan@demopoliscityschools.org	(334) 289-1689
Dothan City	Ms. Carol Cunningham	(334) 793-1397 X243	500 Dusy Street, Dothan, AL 36301-2506	cacunningham@dothan.k12.al.us	(334) 792-7213
Elba City	Mr. Leroy Carnley	(334) 897-2801 X222	131 Tiger Drive, Elba, AL 36323	lcarnley@elbaed.com	(334) 897-5601
Elmore County	Ms. Temeyra McElrath	(334) 567-1224	Post Office Box 817, Wetumpka, AL 36092-0014	temeyra.mcelrath@elmore.k12.al.us	(334) 567-1242
Enterprise City	Ms. Gloria Stewart	(334) 347-4287	Post Office Box 311790, Enterprise, AL 36331-1790	gstewart@enterpriseschools.net	(334) 393-7105
Escambia County	Mrs. Suzanne Barnett	(251) 296-0633	1607 Poplar Street, Flomaton, AL 36441	sbarnett@escambia.k12.net	(251) 296-2199
Etowah County	Mrs. Sharon Brown	(256) 442-1051	209A Grand Avenue West, Rainbow City, AL 35906	sharon_brown@ecboe.org	(256) 442-1077
Eufaula City	Ms. Linda Creel	(334) 695-2496	333 State Docks Road, Eufaula, AL 36027	creel@ecs.k12.al.us	(334) 687-1121
Fairfield City	Mrs. Ardrene Bishop	(205) 783-6807	6405 Avenue D, Fairfield, AL 35064	abishop@fairfield.k12.al.us	(205) 783-6805
Fayette County	Mrs. Mary Gravlee	(205) 932-4611	Post Office Box 686, Fayette, AL 35555	mgravlee@fayette.k12.al.us	(205) 932-7246
Florence City	Mrs. Lynn P. Sharp	(256) 768-3072	541 Riverview Drive, Florence, AL 35630	lsharp@fcs.k12.al.us	(256) 768-3008
Fort Payne City	Mrs. Paula Muskett	(256) 845-0915	Post Office Box 681029, Fort Payne, AL 35968-1029	pmuskett@ftpayk12.org	(256) 845-5845
Franklin County	Mrs. Robin Pharr	(256) 332-8814	3435 Broad Street, Phil Campbell, AL 35581	robpharr@franklin.k12.al.us	(256) 993-4174
Gadsden City	Ms. Rhonda Perry	(256) 549-2917	Post Office Box 184, Gadsden, AL 35902	rperry@gcs.k12.al.us	(256) 549-2996
Geneva City	Mr. Stephen Swann	(334) 684-1090	511 Panther Drive, Geneva, AL 36340	swanns@genevacityschools.com	(334) 684-3128
Geneva County	Mr. Max Whittaker	(334) 684-5694	Post Office Box 250, Geneva, AL 36340	whittaker@GenevaCoboe.org	(334) 684-5601
Greene County	Ms. Angelina Hood	(205) 372-3161 X16	220 Main Street, Eutaw, AL 35462-1002	ahood@greene.k12.al.us	(205) 372-3247
Guntersville City	Mr. Keith Swisher	(256) 582-4180	Post Office Box 129, Guntersville, AL 35976-0129	k.swisher@gcboe.net	(256) 582-1475
Hale County	Ms. Christine Day	(334) 624-2293	1115 Powers Street, Greensboro, AL 36744-1219	cpday@halek12.org	(334) 624-2286
Haleyville City	Mrs. Mitzi Petty	(205) 486-5824	2011 20th Street, Haleyville, AL 35565	mpetty@havc.k12.al.us	(205) 486-8833
Hartselle City	Mr. Jamie Roden	(256) 773-0717	305 College Street Northeast, Hartselle, AL 35640	jamie.roden@hcs.k12.al.us	(256) 773-5433
Henry County	Mrs. Lesa Knowles	(334) 585-2206 X230	Post Office Box 635, Abbeville, AL 36310	lknowles@henryschools.org	(334) 585-2551
Homewood City	Ms. Charlotte Kerr	(205) 870-4203	7 Hollywood Boulevard, Homewood, AL 35209	ckerr@homewood.k12.al.us	(205) 879-5970
Hoover City	Dr. Barbara Mayer	(205) 439-1050	2810 Metropolitan Way, Hoover, AL 35243	bmayer@hoover.k12.al.us	(205) 439-1001
Houston County	Ms. Denise Whitfield	(334) 794-5363	404 West Washington Street, Dothan, AL 36301	denise.whitfield@hchoe.us	(334) 673-8991
Huntsville City	Mrs. Aмосene Sledge	(256) 428-6872	Post Office Box 1256, Huntsville, AL 35807-4801	asledge@hsv.k12.al.us	(256) 428-6871
Jackson County	Mr. Robert Downey	(256) 259-9500	Post Office Box 490, Scottsboro, AL 35768-0490	downeyr@jackson.k12.al.us	(256) 259-0076
Jacksonville City	Ms. Donna Lloyd	(256) 782-5682	123 College Street Southwest, Jacksonville, AL 36265-2154	dloyd@jacksonville.k12.al.us	(256) 782-5685
Jasper City	Ms. Betty Odom	(205) 387-1468	907 12th Avenue Southwest, Jasper, AL 35502	bodom@jasper.k12.al.us	(205) 387-5214
Jefferson County	Mrs. Susan Wirt	(205) 379-2032	2100 18th Street South, Birmingham, AL 35209-1891	swirt@jetcoed.com	(205) 379-2305
Lamar County	Mr. Thomas Howell	(205) 695-6195	Post Office Box 1379, Vernon, AL 35592-1379	Howell@lamar.k12.al.us	(205) 695-7678
Lanett City	Ms. Christy Carpenter	(334) 644-5907	105 North Lanier Avenue, Lanett, AL 36863	ccarpenter@lanettcityschools.org	(334) 644-5910
Lauderdale County	Mrs. Kimberly Bates Gray	(256) 760-1300	Post Office Box 278, Florence, AL 35631-0278	Kimberly.gray@lcschools.org	(256) 766-5814
Lawrence County	Mrs. Donna Flannagan	(256) 905-2400 X28	14131 Market Street, Moulton, AL 35650	dflannagan@lawrenceal.org	(256) 905-2469
Lee County	Mr. Eddie Clark	(334) 745-0258	2410 Society Hill Road, Opelika, AL 36804-4830	clark.eddie@lee.k12.al.us	(334) 745-5014
Leeds City	Mrs. Amy Terry	(205) 699-5437	Post Office Box 1083, Leeds, AL 35094	aterry@leeds.k12.org	(205) 699-6629
Limestone County	Ms. Tara Bachus	(256) 232-5353	300 South Jefferson Street, Athens, AL 35611-2549	Tara.Bachus@lcsk12.org	(256) 233-6699

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ALABAMA STATE DEPARTMENT OF EDUCATION
SPECIAL EDUCATION SERVICES

ALABAMA SPECIAL EDUCATION COORDINATORS

LEA	Special Ed Coordinator	Phone	Address	Email	FAX
Linden City	Mrs. Iris Lartey Richardson	(334) 295-8802	Post Office Box 480579, Linden, AL 36748-0609	irichardson@lindencity.org	(334) 295-8801
Lowndes County	Dr. Deann Stone	(334) 548-2131	Post Office Box 755, Hayneville, AL 36040-0755	dstone@lowndesboe.org	(334) 548-5513
Macon County	Dr. Kenneth P. Oliver	(334) 727-1600	501 South School Street, Tuskegee, AL 36083	oliverk@maco.k12.al.us	(334) 724-9990
Madison City	Dr. Maria Kilgore	(256) 464-8370 X 233	211 Celtic Drive, Madison, AL 35758	kgilgore@madisoncity.k12.al.us	(256) 464-8291
Madison County	Ms. Mary Stump	(256) 852-2557 X 2257	146-A Shields Road, Huntsville, AL 35811	mstump@madison.k12.al.us	(256) 852-9799
Marengo County	Ms. Kathy Pritchett	(334) 295-2229	Post Office Box 480339, Linden, AL 36748-0339	kpritchett@marengo.k12.al.us	(334) 295-2259
Marion County	Mr. Kevin Dulaney	(205) 921-3191	188 Winchester Drive, Hamilton, AL 35570	kdulaney@mcbe.net	(205) 921-7336
Marshall County	Ms. Annie Spike	(256) 582-3994	12380 United States Hwy 431 South, Guntersville, AL 35976	spikeaj@marshalk12.org	(256) 582-8799
Midfield City	Ms. Debra Walker	(205) 923-2262	417 Parkwood Street, Midfield, AL 35228	dwalker@midfield.k12.al.us	(205) 929-0585
Mobile County	Dr. Sheila Martin	(251) 221-4220	Post Office Box 180069, Mobile, AL 36618-0069	smartin@mcps.com	(251) 221-4232
Monroe County	Ms. Phyllis Cook	(251) 743-3194	Post Office Box 967, Monroeville, AL 36461-0967	pcook@monroe.k12.al.us	(251) 575-9353
Montgomery County	Mrs. Katrina Johnson, Interim	(334) 269-3808	1153 South Lawrence Street, Montgomery, AL 36104	katrina.johnson@mps.k12.al.us	(334) 269-3799
Morgan County	Ms. Lana Tew	(256) 309-2117	1325 Point Mallard Parkway Southeast, Decatur, AL 35601	ltew@morgank12.org	(256) 309-2179
Mountain Brook City	Ms. Shannon Hess Mundy	(205) 414-3836	32 Vine Street, Mountain Brook, AL 35213	mundy@mtmnbk.k12.al.us	(205) 414-3829
Muscle Shoals City	Mrs. Lisa Highfield	(256) 389-2676 X1080	Post Office Box 2610, Muscle Shoals, AL 35662-2610	lhighfield@mscs.k12.al.us	(256) 389-2675
Oneonta City	Mrs. Phyllis Shirley	(205) 625-5812	27605 State Hwy 75, Oneonta, AL 35121	pshirley@oneonta.k12.al.us	(205) 274-2910
Opelika City	Mr. Otis V. Stephenson	(334) 741-5601	Post Office Box 2469, Opelika, AL 36803-2469	Ottis.Stephenson@opelikaschools.org	(334) 741-5602
Opp City	Ms. Sharon Spurlin	(334) 493-3173	Post Office Box 840, Opp, AL 36467	sspurlin6@oppboe.com	(334) 493-3060
Oxford City	Mrs. Khrisite Goodwin	(256) 241-3153	310 East Second Street, Oxford, AL 36203-1799	kgoodwin@oxford.k12.al.us	(256) 831-8620
Ozark City	Ms. Ian Bowen	(334) 774-5197	1044 Andrews Avenue, Ozark, AL 36360	ibowen@ocbe.k12.al.us	(334) 774-2685
Pell City	Mrs. Christa Bryant	(205) 884-4440	1000 Bruce Etheredge Parkway, Suite 201, Pell City, AL 35128	cbryant@pellcityschools.net	(205) 814-1010
Perry County	Ms. Cynthia Hogue	(334) 683-4974	Post Office Box 900, Marion, AL 36756	Cynleia95@yahoo.com	(334) 683-8427
Phenix City	Mrs. Mary Jane Riley	(334) 298-0534	Post Office Box 460, Phenix City, AL 36868-0460	mjriley@pcboe.net	(334) 298-2674
Pickens County	Ms. Alesia Williams	(205) 367-2064	Post Office Box 32, Carrolton, AL 35447	williams@pickens.k12.al.us	(205) 367-8404
Piedmont City	Mrs. Rovonda Pruitt	(256) 447-9481	502 Hood Street West, Piedmont, AL 36272	rpruit@piedmont.k12.al.us	(256) 447-6486
Pike County	Dr. Mark Head	(334) 566-1850 X2	101 West Love Street, Troy, AL 36081-2613	mhead@pikecountyschools.com	(334) 566-2580
Randolph County	Dr. Lemoyen Hunter Apostle	(256) 357-2176	182 Circle Drive, Wetwee, AL 36278	lapostle@randolph.k12.al.us	(256) 357-4844
Roanoke City	Mrs. Donna Hodges	(334) 863-6819	Post Office Box 1367, Roanoke, AL 36274	dhodges@roanokecityschools.org	(334) 863-2849
Russell County	Mrs. Vivian Reff	(334) 855-0516	91 Poorhouse Road, Seale, AL 36875	reffv@russellcsd.net	(334) 855-4830
Russellville City	Ms. Claudia Askew	(256) 331-2000 X8	1945 Waterloo Road, Russellville, AL 35653-5432	claudia.askew@rcs.k12.al.us	(256) 332-7323
Saratoga City	Ms., Barbara English	(251) 375-5429	943 Highway 43, South, Saraland, AL 36571	benglish@saralandboe.org	(251) 375-5430
Satusma City	Ms. Sheila Smith	(251) 380-8200	305 South Scott Street, Scottsboro, AL 35768-1952	ssmith@satusmaschools.com	(256) 218-2190
Scottsboro City	Dr. Melinda Adkins	(256) 218-2108	2194 Broad Street, Selma, AL 36701	madrkins@scottsboschools.net	(334) 874-1604
Selma City	Ms. Angemette Carter	(334) 874-1658	300 West Sixth Street, Sheffield, AL 35660-209	angemette.carter@selmacityschools.org	(256) 386-5704
Sheffield City	Mr. James David Jones	(256) 683-0400 X4	2284 Highway 35, Pelham, AL 35124	jdjones@scs.k12.al.us	(205) 682-5855
Shelby County	Dr. Marla Aldrich	(205) 582-5850	410 Roy Drive, Ashville, AL 35953	maldrich@shelbyed.k12.al.us	(205) 594-4441
St. Clair County	Ms. Teresa Arnold	(205) 594-7131 X2267		teresa.arnold@sccboe.org	

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ALABAMA STATE DEPARTMENT OF EDUCATION
SPECIAL EDUCATION SERVICES

REVISED: September 11, 2012

ALABAMA SPECIAL EDUCATION COORDINATORS

LEA	Special Ed Coordinator	Phone	Address	Email	FAX
Sumter County	Mrs. Aslean Jones	(205) 652-9605 X101	Post Office Box 10, Livingston, AL 35470	amjones@sumter.k12.al.us	(205) 652-9641
Sylacauga City	Ms. Jennifer Rosato	(256) 249-7012	605 West Fourth Street, Sylacauga, AL 35150	rosatoj@mail.sylacauga.k12.al.us	(256) 249-7033
Talladega City	Mrs. Ophelia Nash	(256) 315-5630	501 South Street East, Talladega, AL 35160-2532	onash@mail.talladega-cs.net	(256) 315-5606
Talladega County	Mrs. Gayle Jones	(256) 315-5134	Post Office Box 887, Talladega, AL 35161-0887	gjones@tcboe.org	(256) 315-5125
Tallapoosa County	Ms. Nancy Hatcher	(256) 825-1023	125 North Broadnax St., Rm 113, Dadeville, AL 36853	nhatcher@tallapoosak12.org	(256) 825-1003
Tallassee City	Ms. Lynell Carr	(334) 283-5675	308 Kings Street, Tallassee, AL 36078	lynell.carr@tcschools.com	(334) 283-4338
Tarrant City	Mrs. Linda Guetschoff	(205) 849-3700	1318 Alabama Street, Tarrant, AL 35217	Guetschoffl@tarrant.k12.al.us	(205) 849-3728
Thomasville City	Ms. Tracy White	(334) 636-9955 X8606	750 Gates Drive, Thomasville, AL 36784	twhite@thomasvilleschools.org	(334) 636-4096
Troy City	Ms. Christie Armstrong	(334) 566-4351	Post Office Box 529, Troy, AL 36081	armstrongc@troyschools.net	(334) 566-9761
Trussville City	Mrs. Mandi Logan	(205) 228-3025	113 North Chaikville Road, Trussville, AL 35173	mandi.logan@trussvillicityschool.s.com	(205) 228-3001
Tuscaloosa City	Mrs. Deborah Anderson	(205) 759-3531 X223	1210 21st Avenue, Tuscaloosa, AL 35401	danderson@tusc.k12.al.us	(205) 759-3551
Tuscaloosa County	Mrs. Ruth Graves	(205) 342-2789	Post Office Box 2568, Tuscaloosa, AL 35403	rgraves@tcss.net	(205) 342-2729
Tuscumbia City	Ms. Marsha Rieks	(256) 389-2900 x212	303 North Commons Street, East, Tuscumbia, AL 35674	mmrieks@tuscumbia.k12.al.us	(256) 389-2903
Vestavia Hills City	Mrs. Linda L. Brady	(205) 402-5316	Post Office Box 660826, Birmingham, AL 35266-0826	bradyll@vestavia.k12.al.us	(205) 402-5134
Walker County	Ms. Sandy Crump	(205) 387-0555	Post Office Box 311, Jasper, AL 35502-0311	crumps@wclsive.com	(205) 387-7245
Washington County	Mrs. Betty Moorer	(251) 847-2401	Post Office Box 1359, Chatom, AL 36518	betty.moorer@wcbek12.org	(251) 847-6348
Wilcox County	Ms. Makeitha Shamburger	(334) 682-5917	Post Office Box 160, Camden, AL 36726-0160	boemsham@wilcox.k12.al.us	(334) 682-5809
Winfield City	Ms. Deborah Box	(205) 487-4255	Post Office Box 70, Winfield, AL 35594-0070	dbox@winfield.k12.al.us	(205) 487-4603
Winston County	Mrs. Georganna Comeens	(205) 489-3439	Post Office Box 9, Double Springs, AL 35553	gcomeens@winstonk12.org	(205) 489-3203

* Interim ** Acting

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WCB

APPENDIX E

INSTITUTIONAL REVIEW BOARD APPROVED INFORMED CONSENT

Effect of Demographic Factors on Empowerment Attributions of Parents of Children with ASD

Researcher: Ashley H. Perry, PhD candidate

Consent Form for Research Participants

You are invited to take part in a study for parents of children with Autism Spectrum Disorder (ASD). The study will assess the effect demographics have on the empowerment of parents of children with ASD.

If you are a mother or father of at least one child diagnosed with ASD (autism, Asperger syndrome, or PDD-NOS) ages 3-21, please read this consent form and ask any questions you may have before completing the surveys. You will be asked to sign and return this consent form with your surveys.

This study is being led by Ashley Perry, a graduate student from The University of Alabama in Tuscaloosa, Alabama. Ms. Perry is being supervised by Dr. Kagendo Mutua, an assistant professor of education at The University of Alabama.

Background Information

This study will help determine if demographic factors impact the empowerment of parents of children with ASD. These factors include income, level of education, marital status, and the severity of the child's ASD.

Empowerment, defined as a process that helps people gain control over their own lives and take action to get what they need (Akey, Marquis, & Ross, 2000), is important for parents of children with ASD because of the impact the child's condition can have on the family. This study seeks to recruit a minimum of 100 participants.

Procedure

If you agree to participate in this study, you will complete two surveys; a short survey with your personal demographic information and a survey regarding empowerment. It should take 15-20 minutes total to complete both surveys.

Demographic questions will request basic personal information. You will not be asked to provide your name. The empowerment survey will ask questions such as, "I offer my services as a supporting parent in a parent organization" or "I feel a sense of community with other parents who have a child with a disability". You will mark each statement with one of the following: "strongly agree", "agree", "neutral", "disagree" or "strongly disagree".

You can choose to complete a paper copy of the surveys or complete the surveys online on (*Survey Monkey*). Paper copies of the surveys and a stamped addressed envelope have been provided in this packet. Please complete the paper surveys and return in the stamped envelope

UNIVERSITY OF ALABAMA IRB
CONSENT FORM APPROVED: 8/27/2012
EXPIRATION DATE: 8/26/2013

provided. No other tasks are required. If you would like to complete the surveys online, please type this link (*link*) into your computer and follow the directions. Once you have completed and returned your surveys, your participation in this research study is complete.

Risks and Benefits of Participating in the Study

The only risk associated with this study may be the sensitive nature of some questions. You may choose to withdraw your participation in this study or skip any questions you find to be too sensitive to answer.

While the study itself offers no direct benefits to you, you will provide data that is of benefit to ASD research. The results of this study may help professionals in the field of ASD understand the individual needs of parents in regard to empowerment. Professionals may be better able to provide more individualized support to parents based on those needs.

There is no monetary reimbursement for participating in this study.

Confidentiality

Your name will not be on the surveys and your responses will be kept private. The researcher will keep all records from this study in a secure location.

If the researcher publishes any part of the report, the published material will not include any data that would make it possible to identify a participant.

Voluntary Nature of the Study

Your decision to participate in the study is voluntary. Should you decide to participate, you are free to withdraw at any time.

Contacts and Questions

If you have any questions or concerns regarding this study, please contact Ashley Perry, the researcher for this study, at ahperry@crimson.ua.edu, 205-213-7647. You may also contact the dissertation chair, Dr. Kagendo Mutua, The University of Alabama, kmutua@bamaed.ua.edu.

If you have any questions, concerns or complaints about your rights as a participant in this research study, you may contact Ms. Tanta Myles, the Research Compliance Officer at The University of Alabama, at 205-348-8461 or 1-877-820-3066.

You may also ask questions, make suggestions, or file complaints and concerns through the IRB Outreach website at http://osp.ua.edu/site/PRCO_Welcome.html or email us at participantoutreach@bama.ua.edu. After you participate, you are encouraged to complete the survey for research participants that is online at the outreach website or you may ask the

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EXPIRATION DATE: 8/26/2013

investigator for a copy of it and mail it to the UA Office for Research Compliance, Box 870127, 358 Rose Administration Building, Tuscaloosa, AL 35487-0127.

Statement of Consent

I have read the above information. I have asked all questions that were necessary and have received satisfactory answers. I am prepared to participate in this study.

Participant Signature: _____

Date: _____

Participant Name: _____

Researcher Signature: _____

*For participants completing the surveys online, your submission of the completed surveys indicates your consent to participate in this research study.

UNIVERSITY OF ALABAMA IRB
CONSENT FORM APPROVED: 8/27/2012
EXPIRATION DATE: 8/26/2013

APPENDIX F

INSTITUTIONAL REVIEW BOARD RESEARCH STUDY ADVERTISEMENT APPROVAL

Effect of Demographic Factors on Empowerment Attributions of Parents of Children with ASD

VOLUNTEERS NEEDED

For a research study on effect of demographic factors on empowerment attributions of parents of children with autism spectrum disorder

Participants must be

- A parent/guardian living in the state of Alabama who has a child diagnosed with an autism spectrum disorder (ASD)
- Minimum age of parent is 21 years
- Child with ASD should be between the ages of 3-21 years

Participants will

- Complete a short demographic profile questionnaire
- Complete a questionnaire on empowerment in regard to parenting a child with ASD
- Total time to complete both questionnaires is **15-20** minutes
- Questionnaire can be completed online or in writing. This will be provided to you by the researcher

Additional information

- There is no monetary reimbursement for participating in this study
- All personal information is kept confidential and at no time will the identity of a participant be shared
- Your decision to participate or not participate in the study is voluntary. You are free to withdraw at any time.

Contact Information:

Ashley H. Perry, PhD Candidate
The University of Alabama
Department of Special Education and Multiple Abilities
Tuscaloosa, AL
ahperry@crimson.ua.edu
205-213-7647

UA IRB Approved Document
Approval date: 8/27/2012
Expiration date: 8/26/2013

APPENDIX G

RESEARCH STUDY PARTICIPANT
FOLLOW-UP LOG

Alabama Autism Resources
Follow-up List

Name	Type of Response	Indicated Info. Shared	Request Surveys Mailed	# of Surveys Mailed	Misc.
1. Campascca John Stephenson	email	-	✓	50	
2. Easter seals Achievement ctr. Star Wray	email	-	✓	25	
3. UCP B'ham Amy Lindsey	email	-	-	-	Indicated their clients are too young (under age 3)
4. The Progress Ctr. Angie Marshall	email	✓	-	-	
5. UCP - West AL. Dr. La Monica Herron-McCoy	email				Indicated her facility currently does not have any clients with ASD
6. Trish Croley (parent)	email	-	✓	2	

Alabama Autism Resources
Follow-up List

Name	Type of Response	Indicated Info. Shared	Request Surveys Mailed	# of Surveys Mailed	Misc.
7. Calhoun County Networking leader (ASA) Tracy Robinson	email	✓	-	-	copied me on email sent to parent group
8. Cullman ASA conference	-	-	-	200+	1 presented at the conf. A research packet was given to each attendee. ^{extras taken by ASA}
9. Jerre Brimer (exec. director of all Little Trees)	email	✓	-	-	Forwarded study info. to all Little Tree prex's + Woody's sang (Mobile)
10. Rajesh K. Kana PhD - Sparks Clinic	email	✓	-	-	Info. shared with ASD family user - groups.
11. Todd Tomerlin ASA Networking (Athens)	email	-	✓	25	(He + his)
12. Brandi Pitts (band leader in semper - Alex City, AL)	Facebook	-	✓	2	both returned

Alabama Autism Resources
Follow-up List

	Name	Type of Response	Indicated Info. Shared	Request Surveys Mailed	# of Surveys Mailed	Misc.
13.	Tina Brasher Pell City ASA Networking group	email	-	✓	50	1/2 - for parent group 1/2 - she will take to schools
14.	Caroline Banez - Ad professor - autism specialist in au. - group leader	Facebook	✓	-	-	requested advertisement to share
15.	Debbie Bumbicka - support group leader	11	✓	-	-	11
16.	TACA-AL Margaret Stewart	Tagged me in their post	✓	-	-	
17.	Diane sheriff special. coord. Chambers Co.	email	✓			Sent info + advertisement about study to all sped. teachers in her system.
18.	all AL sped coordinators					

APPENDIX H

INSTITUTIONAL REVIEW BOARD RESEARCH STUDY APPROVAL

Office for Research
Institutional Review Board for the
Protection of Human Subjects

THE UNIVERSITY OF
ALABAMA
R E S E A R C H

August 27, 2012

Ashley Hayden Perry
Department of SPEMA
College of Education
Box 870232

Re: IRB # 12-OR-292: "Effect of Demographic Factors on Empowerment
Attributions of Parents of Children with ASD"

Dear Ms. Perry,

The University of Alabama Institutional Review Board has granted approval for your proposed research.

Your application has been given expedited approval according to 45 CFR part 46. You have also been granted a waiver of written documentation of informed consent for the online participants. Approval has been given under expedited review category 7 as outlined below:

(7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

Your application will expire on August 26, 2013. If the study continues beyond that date, you must complete the IRB Renewal Application. If you modify the application, please complete the Modification of an Approved Protocol form. Changes in this study cannot be initiated without IRB approval, except when necessary to eliminate apparent immediate hazards to participants. When the study closes, please complete the Request for Study Closure (Investigator) form.

Please use reproductions of the IRB-stamped consent document.

Should you need to submit any further correspondence regarding this application, please include the assigned IRB application number.

Good luck with your research.

Sincerely,



358 Rose Administration Building
Box 870127
Tuscaloosa, Alabama 35487-0127
(205) 348-8461
FAX (205) 348-7189
TOLL FREE (877) 820-3066

Stuart Usdan, Ph.D.
Chair, Non-Medical Institutional Review Board
The University of Alabama

APPENDIX I

PERMISSION TO USE THE *PSYCHOLOGICAL EMPOWERMENT SCALE*

March 19, 2010

Ashley H. Perry, PhD Candidate
The University of Alabama, Tuscaloosa
Department of Special Education

Dear Ms. Perry,

I am writing to inform you of our permission to use our Beach Center Psychological Empowerment Scale as part of your dissertation research. You have our permission to use the scale free of charge, with the proviso that you reference the scale appropriately to its authors.

If you need further information from me concerning the application or use of the scale, please feel free to contact me.

Good luck in your study. I will be interested to see your results.

Sincerely,

s/Jean Ann Summers
Jean Ann Summers, Ph.D.
Research Professor
Beach Center on Disability
University of Kansas