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SUPPORTS PROVIDED BY FAITH COMMUNITIES FOR CHILDREN DIAGNOSED WITH

AUTISM AND THEIR FAMILIES

By

SUSAN LEE MOERSCHBACHER

A doctoral dissertation submitted to the
College of Education
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AN EXPLORATION OF PARENTAL PERCEPTIONS OF INCLUSIVE SERVICES AND

SUPPORTS PROVIDED BY FAITH COMMUNITIES FOR CHILDREN DIAGNOSED WITH

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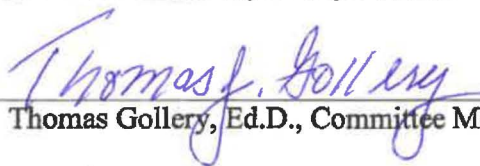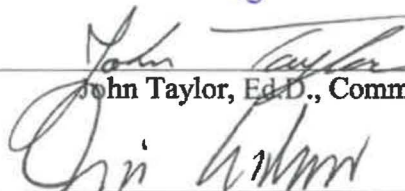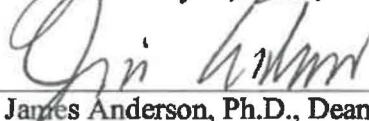SUSAN LEE MOERSCHBACHER

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DEDICATION

I dedicate this dissertation to all parents of children with ASD who face the daily challenges of raising a child with special needs. I hope the dissertation sheds light on the uniqueness of ASD children and provides a path for faith communities to follow as they create inclusive environments for all families.

Words fail to fully express the gratitude I have for my parents and siblings who provide unwavering love and support in all my undertakings. Although at times, they may question my sanity, they continually cheer me on as I face new obstacles and challenges. Special thanks go to my mom who taught me how to persevere, the power of faith, and the value of family. I appreciate that you were willing to sacrifice your time and energy so I could succeed. To my sister Deb, you have been one of my biggest cheerleaders since the day I began attending SEU. You praised each step I took towards attaining my degree and never doubted that I would complete the program (even when I did).

To my children, Alex and Katie, thank you for your love, understanding, and patience during my academic journey. On several occasions, you told me how proud you were of me for pursuing my Ed.D. These words often echoed in my ears whenever I felt discouraged or overwhelmed. Thank you for inspiring me to reach for my goals.

To my wonderful husband, Jason, thank you for the numerous meals you prepared, the trips you made to the grocery store, and parenting responsibilities you handled so I could focus on my coursework and dissertation. Never once during this endeavor did you complain or

dissuade my efforts. Conversely, you provided unconditional support and empowered me to pursue my dreams. I can never express the depth of my gratitude and love for you. I could not have succeeded without you.

Finally, this work is also dedicated to the memory of Bill Boehnen. May his life be an example of how to serve and love one another.

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Lastly, to my fellow doctoral colleagues in Cohort D, thank you for sharing the journey with me. The camaraderie forged from this unique experience will never be forgotten or taken

ABSTRACT

The purpose of the study was to explore the perspectives of parents of children diagnosed with ASD regarding the inclusive supports and services provided by their congregations. Identifying supports and services that are deemed helpful by the parents of ASD children may assist faith communities in developing programs and ministries that address the unique needs of these families. The quantitative study utilized a survey research method to address eight research questions. At two sites in Florida, parents of children diagnosed with ASD were invited to complete a survey assessing the helpfulness of nine inclusive supports. Additionally, the availability of these services, as well as the influence on the parent's commitment level to the place of worship providing the supports, was evaluated. The nine inclusive supports identified in the survey were found to be helpful to parents of ASD children at a significant level. More specifically, the study's participants perceived the helpfulness of a family resource center as the most important support. Additionally, parents who perceived the church as implementing helpful inclusive support services reported a higher level of an overall commitment to that church. Implications of the study include strategies for including ASD families in congregations and providing opportunities for spiritual growth.

Keywords: autism spectrum disorder; faith communities; congregations; parental commitment; inclusive supports; special needs ministries; family resource center

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I. INTRODUCTION

Parents of children with autism spectrum disorder (ASD) face challenges and stressors related to the cognitive, social, and physical limitations their child may present that are associated with the diagnosis. Moreover, in addition to focusing on the unique needs of their child, parents must cope with their own psychological state concerning the emotional strain and pressure of caring for a child with a disability. One approach for parents who rely on organized religion in their daily lives to address the challenges presented by ASD is to turn to their faith as a means of support and assistance. Past research has found that strength of religious faith was among the most prominent predictors of family quality of life as reported by parents of youth and young adults with special needs (Boehm, Carter, & Taylor, 2015). A reliance on faith provides parents and families of disabled children with a continual, stable coping mechanism for addressing the ever-changing obstacles presented by the disability as well as a source of support, purpose, and guidance for their stressful lives (Bennett, Deluca, & Allen, 1995; Boehm et al., 2015).

One way to strengthen religious faith and spirituality is to participate in a faith community. Vogel, Holloway, and Smith (2006) provided insight into the matter of how participation in inclusive faith communities could lead to an improved self-concept, increased spirituality, and a sense of belonging and friendship for individuals diagnosed with a disability. Likewise, similar benefits to the family members of persons with disabilities

have been reported. These benefits include receiving strategies for coping, a sense of empowerment, increased optimism, feelings of connectedness, and renewed feelings of strength and hope (Bennett et al., 1995; Cheung, 2016; Tarakeshwar & Pargament, 2001; Webb, 2012). Churches that provide support to families with a child on the autism spectrum strengthen the family's social network and create an essence of community and care (Webb, 2012). These associations are particularly important to many parents of ASD children who may have experienced feelings of isolation and separation in other social settings due to their child's behaviors. Thus, the advantages gained by participation in faith communities for disabled children and their families are numerous and substantial.

However, despite the positive benefits, some parents find they are unable to participate in religious activities due to the lack of inclusionary services and supports available to their ASD child (Ault, Collins, & Carter, 2013a; Howell & Pierson, 2010). In the limited research conducted regarding perspectives of religious activities, parents stated that church attendance could be an exhausting and frustrating experience due to the needs of their children (Poston & Turnbull, 2004; Speraw, 2006). Parents may feel their child's actions are misunderstood and misjudged by others in the worship service. Congregants may view the child as a disturbance and not fully understand the characteristic behaviors associated with ASD. In turn, the family feels unwelcomed and unaccepted in the place of worship and is unwilling to return (Ault et al., 2013a; Webb 2012). Some parents report they would rather not attend religious services than contend with the unpleasant situations that can arise when their child exhibits inappropriate behavior (Ault et al., 2013b); however, Carter, Boehm, Annandale, and Taylor (2016) emphasized that a place of worship should be where people with disabilities and their families feel acknowledged, welcomed, and accepted.

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As a result, researchers are beginning to examine the presence and impact of inclusionary supports in faith communities not only for the child with the diagnosis but also for the parents of these children. However, limited research has been conducted in this area. Additionally, no information was found within the professional literature regarding how the implementation of these services influences parents of ASD children concerning their commitment level to a place of worship. The study examined the perceptions of parents of children with ASD regarding inclusive supports and services provided by their place of worship. Also, the level of parental commitment to the church resulting from these services was explored.

Although the extent of research in this area is sparse, the results from one recent study will be utilized in the current research. Carter, Boehm, et al. (2016) examined the needs and experiences of families with disabled children regarding involvement in religious activities. Parents of the children were administered a survey regarding the helpfulness and availability of 14 congregation-provided supports. One of the findings of the research was that nine congregation-provided supports were rated as somewhat to very helpful by the parents responding. These nine identified supports were utilized in the current survey as indicators of inclusive support services provided by places of worship. These supports include support groups for parents, congregation-wide disability awareness efforts, a resource center for families, an advocate to work with families, respite care, spiritual counseling from a congregational leader, modifications to religious education programs, a religious education plan for the child, and someone to support the child during religious education. The theoretical basis guiding the current research is the social exchange theory. The theory was developed by George Homans (1961) who defined social exchange as "the exchange of activity, tangible or intangible, and more or less rewarding or costly, between at least two persons" (p. 13). According to the theory,

people weigh the potential gains and risks of social relationships. When a relationship is viewed as a means of maximizing benefits, an individual is likely to value and continue the affiliation. Conversely, when the risks outweigh the rewards, people are likely to abandon or terminate the relationship. Extensive research has been conducted since the inception of the theory concerning social exchange and a variety of factors such as responsibility, fairness, trust, dedication, and obligation, to name a few.

Eisenberger, Huntington, Hutchison, and Sowa (1986) extended the social exchange theory from a personal to an organizational level. The perceived organizational support (POS) theory refers to employees' perceptions concerning the extent to which the organization values their contributions and cares about their well-being. Employees who perceive a level of appreciation and concern from their workplace are likely to reciprocate by exhibiting positive behaviors that are advantageous for the organization. Additionally, the POS theory seeks to explain an individual's affective commitment to their organization. Organizations exhibiting high regard for their employees may receive in return an increase in loyalty and dedication from the staff (Eisenberger et al., 1986). Thus, in the current study, faith communities serving ASD families represent the organization, and the parents of ASD children represent the employee/individual. Therefore, identifying which inclusive services parents of ASD children perceive as helpful and what factors contribute to their perception can provide pertinent information for church leaders as they seek to serve these families.

Purpose Statement

The purpose of the study was to explore the perceptions of parents of children with ASD regarding the inclusive supports and services provided by their congregations. Additionally, the

availability of these services, as well as their influence on the parent's commitment level to the place of worship providing the supports, were evaluated.

Research Questions

In order to address the stated research problem of the proposed study, the following research questions were formally posed:

1. Regarding Carter's nine support services, to what degree do parents of ASD children perceive the supports as helpful or important?

2. Regarding Carter's nine support services, to what degree do parents of ASD children perceive their place of worship as providing those support services?

3. Does a place of worship's implementation of inclusive supports services for children diagnosed with ASD represent a statistically significant predictor of the parent's attendance at a church?

4. Which individual inclusive support indicator of *helpfulness* was perceived as the most helpful of inclusive supports?

5. Which individual inclusive support was perceived by the parents as being provided to the greatest degree by the participant's church?

6. Does a church's implementation of inclusive support services for children diagnosed with ASD represent a statistically significant predictor of the parent's commitment to volunteerism?

7. Does a place of worship's provision of inclusive support services predict the likelihood of monetary giving by the parent of a child with ASD?

8. Does a church's implementation of inclusive support services for children diagnosed

    with ASD represent a statistically significant predictor of the parent's overall level of

    commitment to that church?

Methodology Overview

The research design and methodology for the research study was broadly quantitative,

non-experimental, and more specifically survey research. A convenient and purposive sample

was drawn for study purposes from two sites in central Florida. One site was comprised of

parents of participants in a special needs ministries program designed for children with

disabilities. The second site was identified as a middle school and high school program for

students with intellectual disabilities or other mild learning disabilities. The participants of the

study were limited to parents of children diagnosed with ASD who reported as attending a place

of worship on a regular basis. Demographic variables included age, gender, marital status,

ethnicity, and religious affiliation. At the two identified research sites, parents of children

diagnosed with ASD were invited to complete a survey regarding their perspectives of the

helpfulness and availability of inclusive support services provided by their place of worship as

well as their level of commitment to the institution.

The research instrument represented an adaptation of a survey created by Carter, Boehm,

et al. (2016) addressing the demographics, strengths, skills, support needs, spirituality, well-

being, and community involvement of people with disabilities. Two congregation-related

measures, (congregational provided supports and congregational inclusion) were the focus of the

survey as well as several related variables. One of the results of the survey by Carter et al.

(2016) was that nine of the 14 congregation-provided supports were rated as somewhat to very

helpful by the parents responding. These nine identified supports were utilized in the current

survey as indicators of inclusive support services provided by places of worship. These supports include support groups for parents, congregation-wide disability awareness efforts, a resource center for families, advocate to work with families, respite care, spiritual counseling from a congregational leader, modifications to religious education programs, religious education plan for the child, and someone to support the child during religious education.

Analysis Overview

Data Analyses

Prior to addressing the research questions in the study, preliminary analyses were conducted. Specifically, missing data, internal consistency (reliability) of participant response to survey items, and essential demographic data were assessed.

Preliminary Analyses

Missing data were analyzed using descriptive statistical techniques. Frequencies and percentages comprised the primary statistical methods of analysis and interpretation. Little's MCAR test statistic was utilized to evaluate the randomness of subsequent missing data. An MCAR value of $p > .05$ was considered indicative of missing data that are sufficiently random in nature.

The internal consistency or reliability of participant to the survey items was addressed through the application of Cronbach's alpha (a) test statistic. The statistical significance of a was assessed through the F test. The value of $p < .05$ was considered statistically significant.

The study's essential demographic information was assessed using descriptive statistical techniques. The mean, standard deviation, frequency counts (n), and percentages (%) represented the primary methods of descriptive analysis.

Delimitations

The intent of the study was to provide insight into how parents of ASD children perceive inclusive support services within their places of worship and the influence of these services on parent commitment levels; however, the study had some delimitations. The sample for the study was purposive in nature and primarily identified and accessed from two specific sources, both located in central Florida. The first source consisted of parents of children attending a special needs ministry program designed for children with disabilities. The second source was the parents of children attending a middle and high school program for children with disabilities. The second delimitation of the study was the sample size of 31 parents. Therefore, the perception of the parents participating in the study may not be representative of all parents of ASD children. Additionally, care must be exercised in the generalization of eventual findings in light of the sample issue.

Definition of Key Terms

Autism Spectrum Disorder

According to the National Institute of Mental Health (NIMH, 2016), autism spectrum disorder (ASD) is the name for a group of neurological developmental disorders. ASD manifests impairments in the domains of social skills, communication, rigid and repetitive behaviors, and symptoms that inhibit the individual's ability to function socially, at school or work, or in other areas of life. Typically, the initial symptoms appear in the first two years of life. Some people are mildly impaired by their symptoms, while others are severely disabled, thus reflecting the wide range or spectrum of the disorder.

Inclusive Support Services

For the purposes of the study, the nine support services identified by Carter, Boehm, et al. (2016) as somewhat or very helpful by at least half of the participants in their study were utilized as indicators for inclusive support services.

Summary

The intention of the chapter was to outline the premise and professional implications of the study. Identifying inclusive services parents of children diagnosed with ASD perceive as helpful is important for faith communities serving these families. Eight research questions were posed to examine the topic of interest. The basis of the research methodology was outlined as well as limitations and delimitations of the research study. The definition of key terms concluded the chapter. In Chapter 2, the benefits of religion for ASD families and the barriers preventing participation will be reviewed. Additionally, the theoretical framework guiding the research conducted in the study will be addressed.

II. REVIEW OF LITERATURE

The prevalence of autism spectrum disorder (ASD) in the United States has consistently risen since the tracking of the disorder began in 2000. As discussed by Rice (2007), according to the *Morbidity and Mortality Weekly Report Surveillance Summaries* issued by the Centers for Disease Control and Prevention, the estimated prevalence of ASD in 2000 was 6.7 per 1,000 (one in 150) children. For 2014, the prevalence estimate from the same report was 16.8 per 1,000 (one in 59) children (Baio et al., 2018). The numbers reflect a 150% increase in reported cases of ASD during the time period. The noted increase may be a result of a combination of factors including a heightened occurrence of accurate diagnoses as well as an improvement in the tracking and documentation of the prevalence of the disorder. However, most authors agree the dramatic escalation of reported cases signifies that ASD is one of the fastest-growing developmental disorders in the United States, and more families are facing the challenges of raising a child with the disability. Not only does the diagnosis impact the child but the development and well-being of the entire family as well.

Autism Spectrum Disorder

Recognition of the symptoms and characteristics that accompany a diagnosis of ASD is essential to understanding the challenges presented to families and caregivers of children with the disorder. ASD is a neurodevelopmental disorder that is characterized by persistent deficits in reciprocal social communication and social interaction as well as engagement in restricted, repetitive behaviors, interests, or activities (American Psychiatric Association, 2013). For a child to be diagnosed with ASD, presentation of the symptoms must occur in the early development period and impair the child's ability to function in day-to-day-life. The expressions

of ASD differ according to a child's developmental level and chronological age; however, impairment in stated areas is present in all diagnosed cases (APA, 2013).

The clinical picture of ASD may vary widely amongst children. At the time of diagnosis, the clinician assesses the current symptomology of the disorder and identifies the severity by a level system. The least severe is Level 1, "requiring support." The individuals on this level have deficits that cause evident impairments when supports are not in place. Level 2, "requiring substantial support," indicates the individual has marked deficits even with supports in place, and Level 3, "requiring very substantial support," signifies severe impairments and difficulties (APA, 2013). The levels are based on the deficits and impairments exhibited by the child, thus reflecting a spectrum of disorders that fall within a range from mild to profound (APA, 2013). A child functioning on the high level of the spectrum may differ significantly in terms of abilities and intellectual functioning compared to a child who falls at the opposite end of the spectrum.

Characteristics of ASD

To better understand the needs of the child, the family, and the potential impact on the typical church/religious community, a review of the characteristics of ASD may be helpful. One of the two fundamental characteristics of ASD is persistent impairment in reciprocal social communication and social interaction. The impairment may be both verbal and nonverbal in nature. According to the NIMH (2016), behaviors reflecting these deficiencies may include: limited speech, difficulty engaging and maintaining a conversation, the inability to maintain consistent eye contact, utilizing facial expressions, movements and gestures that do not match what is being said, exhibiting an unusual tone of voice that may be flat or robot-like, and/or lacking the ability to understand another person's point of view or perspective. Additionally, the

child may be deficient in the ability to share enjoyment, interests, or achievements with others and may not reciprocate social or emotional actions (APA, 2013).

The second fundamental characteristic is the presence of restricted, repetitive behaviors, interests, or activities. Individuals with ASD may fixate on particular interests in intense ways that restrict them from attending to other areas of life or enjoying other activities (APA, 2013). Expression of overly focused interests, such as with moving objects or parts of objects, or a keen interest in particular topics, such as numbers, details, or facts, is common (NIMH, 2016). Repetitive behaviors are often displayed and may extend to the repeating of words or phrases, referred to as echolalia. Another form of repetition may be present in daily routines where individuals adhere to strict routines and become upset by slight changes in schedules (NIMH, 2016). Additionally, children with ASD may engage in unusual behaviors such as hand flapping, body rocking, toe walking, and finger flipping. Hypersensitivity to sensory input such as bright light, loud noises, clothing, or temperature may also be displayed (NIMH, 2016).

Comorbidity with other disorders is a common feature of ASD. Approximately 70% of individuals with ASD have at least one other mental diagnosis, and 40% may have two or more (APA, 2013). Disorders related to intellectual impairment, learning difficulties, and structural language difficulties are frequently associated with the diagnosis. Additionally, behavioral issues such as impulsivity, aggressive behaviors, self-injurious behaviors, temper tantrums, and noncompliance may be evident. Medical conditions often present alongside the psychiatric features. Ailments such as epilepsy, sleep disturbances, gastrointestinal problems, and feeding issues are commonly reported (APA, 2013).

Impact of Diagnosis on Parents and Family

Due to the impairments aligned with the diagnosis, the obstacles parents experience when taking care of a child with ASD may be extensive. As a result of the complexity of the disorder and the hardships presented by the presence of behavioral issues, communication challenges, and the inability to express emotions, autism has been described as one of the most demanding childhood developmental disabilities that a family can face (Gray, 2006). Unquestionably, caregivers of children with ASD may experience increased burdens and stress resulting from the demands associated with caring for children with special needs. Not only do the parents of these children face challenges presented by the symptomatic characteristics of the disorder, but they also must learn to cope with the effects of the disorder on their own functioning.

Past researchers have found that the effects of a child's autism spectrum diagnosis on parents include, but are not limited to, higher levels of stress, poorer mental health, and greater levels of marital discord and family instability (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Ekas, Whitman, & Shivers, 2009). Stress can result from features of the disorder such as obtaining a diagnosis, finding appropriate treatment and educational programs, and coping with the financial burden of paying for services (Ekas et al., 2009). Furthermore, parents may question their ability to effectively parent a child with ASD, resulting in feelings of incompetence. To avoid these negative emotions, parents may choose to isolate themselves and their child instead of taking their child out in public where they may feel judged by others (Dunn et al., 2001).

A profound impact on a parent's mental health may occur when a child is diagnosed with ASD. Fernańdez-Alcántara et al. (2016) conducted a qualitative study investigating the emotional aspects of raising a child with ASD. Twenty parents participated in semi-structured

interviews addressing experiences related to the diagnostic process, the support provided by professionals and family members, and daily reaction to the disability. The research indicated that parents may experience feelings of "unexpected child loss" (Fernańdez-Alcántara et al., 2016, p. 315), as a diagnosis of ASD is often perceived with the same force as a death. The disorder signifies the loss of the dream of a healthy child and introduces uncertainty about the prognosis and development of their child. The loss may result in feelings of shock, denial, sadness, and anger. The parents may believe their genetics, behaviors, and actions caused the disorder, resulting in guilt and shame (Fernańdez-Alcántara et al., 2016). In addition, ASD currently has no cure, and the disorder impacts an individual throughout the lifespan. Depending on the severity of the diagnosis, parents may be faced with the possibility of lifelong challenges associated with caring for a child on the spectrum. Emotionally, the strain of the diagnosis and future implications may be so great that parents seek professional psychological assistance for problems, including depression and anxiety (Higgins, Bailey, & Pearce, 2005).

The identification of a child as special needs can adversely affect marital relations. Studies have found primary caregivers of a child with ASD report lower levels of marital happiness, satisfaction, and intimacy and higher levels of marital discord compared to couples without children on the spectrum (Dunn et al., 2001; Higgins et al., 2005). A parent's feelings of fear about the future, differing responses to the stress of the disability, incompatible discipline techniques, and lack of positive affirmations have been linked to increased strain within a marriage (Phelps, McCammon, Wuensch, & Golden, 2009).

The feelings of adversity can extend outside the marital dyad and influence the nuclear family system as a whole. Higgins et al. (2005) surveyed 53 primary caregivers of children diagnosed with ASD focusing on family functioning, marital satisfaction, self-esteem, and

coping techniques. Families with ASD children report lower family adaptability and family cohesion when compared to families with typically developing children (Higgins et al., 2005). Often these families demonstrate less flexibility and lack of warmth and connection compared with normative data. The caregiver's time availability may play a significant role in the adjustment of other family members. Siblings may feel jealous of the time and attention given by the parents to the child with autism. They may resent that normal, spontaneous family outings are restructured by the behavior of the ASD child or avoided altogether to minimize the stress they may cause for all parties involved (Higgins et al., 2005; Phelps, Hodgson, McCammon, & Lamson, 2009).

Autism Spectrum Disorder and Religion

The challenging behaviors exhibited by children with ASD can present unique stressors to the family system as a whole, making the support derived from their faith, the opportunities for church involvement, and encouragement from a supportive church community important factors for these families (Gajeton, 2016; Howell & Pierson, 2010; Speraw, 2006). The positive impact of beliefs and active engagement in church life can be profound and significant. Boehm et al. (2015) found that strength of religious faith was among the foremost predictors of family quality of life as reported by parents of youth and young adults with IDD. Furthermore, researchers have recorded strong linkages among congregational involvement and family well-being (Ault, 2010; Collins & Ault, 2010; Tarakeshwar & Pargament, 2001).

Benefits of Religion

Consistent evidence exists that participation in faith communities and the utilization of spiritual beliefs are beneficial to ASD children and their families. In the literature, the most frequently cited advantages include providing inspiration, the development of coping

mechanisms that give meaning to the disability, a positive framework to assess problems, and the establishment of a social network. Recognizing the importance of inspiration, Bennett et al. (1995) investigated how parents of children with disabilities use religion as a means of support. The exploratory study involved in-depth interviews with 12 parents with a child with a disability. The study addressed three research questions, including the manner in which parents of children with disabilities use religion as support, the types of support employed during differing life cycle stages, and if religion contributed to a parent's sense of empowerment. A variety of methods of analysis were utilized to assure the rigor of the data. These methods included triangulation, group debriefings, and member checks. The results indicated that prayer, church attendance, and specific religious beliefs were identified as sources of support that helped some of the parents feel a growing sense of hope and strength. Further, the findings highlighted that religious support could be a continuous coping strategy utilized throughout the life cycle of a family, whereas some other approaches were limited in their scope of usefulness across time periods.

Bennet et al. (1995) recommended that professionals and individuals affiliated with faith communities be cognizant of the needs of these families and seek approaches where they can serve as a means of support. The results were generally consistent with more recent findings that when times are difficult, parents who have children with disabilities reported that their faith helped them meet the challenges they faced on a daily basis and provided a source of encouragement (Poston & Turnbull, 2004; Tarakeshwar & Pargament, 2001).

In a qualitative study consisting of focus groups and individual interviews, Poston and Turnbull (2004) interviewed 187 individuals regarding the concept of family quality of life. The participants included parents and siblings of children diagnosed with a disability, eight individuals with a disability, service providers who deliver services to disabled children, and

administrators of the agencies that employ the service providers. The questions of interest for

the research included how spiritual beliefs and practices contribute to family quality of life and

the role community organizations play in the enrichment of a families' spiritual well-being. The

data obtained from the interviews were analyzed using the constant-comparative method to

identify categories and subcategories, as well as interpret themes and patterns present in the

transcriptions. The results indicated the importance of spirituality and participation in religious

communities for families of disabled children (Poston & Turnball, 2004). The participants stated

that their spiritual beliefs contributed to their emotional well-being and overall family quality of

life. Additionally, the parents reported that their faith gave them strength and attributed meaning

to the disability. Implications from the research included recommendations for religious

communities to heighten awareness towards congregants with disabled children and provide

support and assistance that fill the practical, emotional, and spiritual gaps for these families.

In a mixed-methods study designed to research the use of spirituality as a coping

mechanism, Coulthard and Fitzgerald (1999) surveyed 60 families of children with ASD. The

two objectives outlined by the researchers were to explore if personal beliefs and organized

religion serve as sources of support for parents of children diagnosed with ASD and to

investigate the relationship between organized religion, personal beliefs, and health status. A

variety of instruments were used for gathering data, including the Diagnostic and Statistical

Manual of Mental Disorders, Childhood Autism Rating Scale, the General Health Questionnaire,

Support from Religious Organizations and Personal Beliefs Scale, and a semi-structured

interview schedule. Simple linear regression, correlational analysis, paired and two-sample *t*

tests were used to analyze the relationships between support from organized religion, support

from personal beliefs, and health status. The findings indicated that 66% of the parents used

prayer and personal spiritual beliefs as a source of comfort in coping with issues. Parents

reported that prayer provided an avenue to not only physically engage in an activity to assist their

child but also as a means of letting go of the problem. This type of strategy may lessen a

parent's feelings of guilt and personal responsibility regarding the disorder by deferring to a

higher authority and establishing a sense of peace. Furthermore, higher scores on support from

personal beliefs, particularly the use of prayer, were correlated with better health (Coulthard &

Fitzgerald, 1999).

The role of religion as a means of coping for families with autistic children was also

studied by Tarakeshwar and Pargament (2001) in a mixed methods approach. Forty-five parents

responded to a survey that assessed stressors, religious coping, psychological adjustment, stress-

related growth, and religious outcome related to raising a child with ASD. A subsample of

parents ($n = 21$) participated in semi-structured interviews, focusing on types of strategies

employed to cope with difficulties associated with raising a special needs child. The researchers

examined the association between positive and negative religious coping strategies and self-

reported psychological distress. Descriptive statistics, correlational analyses, hierarchical

regression, and qualitative analyses were employed to interpret the data. The analyses confirmed

that the use of positive religious coping methods, defined as seeking a positive relationship with

God and experiencing peace and harmony with Him, were associated with effective strategies for

addressing stress and better spiritual outcomes. Additionally, religion appeared to be especially

helpful in offering the participants a sense of meaning to the seemingly unexplainable aspects of

autism (Tarakeshwar & Pargament, 2001). The results of the study bear notable implications for

professionals who engage with ASD children and their families. For many parents of children

diagnosed with ASD, religion is a means of coping that endures. The importance of religion

appears to continue throughout the lifespan, while other sources of support may wane in significance. Therefore, faith communities should focus attention on creating supportive environments to assist ASD parents in using their religious practices and beliefs as a resource for addressing the complex issues associated with a diagnosis of ASD.

Gray (2006) conducted an ethnographic longitudinal study lasting approximately a decade to assess the coping strategies of 28 parents of children with autism. The methods used in the study included in-depth interviews and participant observation. The interviews consisted of questions regarding the child's symptomatology and medical history, the impact of the child's diagnosis on the parent's well-being, the effects of ASD on the family's social activities, coping strategies used by the parents, and expectations for the child's future. The purpose of the research was to investigate how parental coping mechanisms changed during the lifespan of the child. An interactive process of data analysis was used in the study. In the first stage of analysis, the parental interviews were transcribed, indexed, and categorized. In the second stage, identifiable themes in the parent comments were noted. Lastly, a comparison of the parent comments from each stage of research was conducted to explore the variations in coping responses over time. The results indicated that over time parents shifted from a problem-focused approach, such as reliance on service providers, to an emotion-focused approach, such as relying on their faith, as a means of coping with issues associated with raising an autistic child (Gray, 2006). Based on interviews with the parents who reported religion as their primary means of coping, the researcher derived that religion provided parents a positive perspective to view the disorder and acknowledge the permanence of the disability. Lastly, the results underscored the important role religion plays for parents of ASD children not only when their children are young, but as they grow into adulthood (Gray, 2006).

The benefits of utilizing religion as a positive framework to assess problems have been reported by Ekas et al. (2009), who examined the influence of religious beliefs, religious activities, and spirituality on maternal socioemotional functioning for 119 mothers of children with ASD. The participants completed questionnaires assessing spirituality, religiosity, and a wide range of outcome variables including life satisfaction, stress, positive affect, depression, sense of control, and self-esteem. The researchers hypothesized that higher religiosity and spirituality in mothers of children with ASD would be associated with less negative outcomes and more positive outcomes. Data analyses were conducted in a series of steps. These steps included descriptive statistics, correlations, and hierarchical regressions. The findings indicated higher scores on the religious beliefs, and spirituality measures were associated with higher life enjoyment, self-esteem, life satisfaction, positive affect, psychological well-being, optimism, and locus of control. Besides the positive outcomes, mothers who related higher levels of religious beliefs and spirituality also reported lower levels of negative feelings and depression (Ekas et al., 2009). The findings suggest that religious beliefs and spirituality not only serve as protection from adverse outcomes but also promote a sense of positive appraisal. Belief in God and religious principles mediates the family's hardships and provides context to address challenges more constructively and effectively (Ekas et al., 2009; Greeff & van der Walt, 2010; Poston & Turnbull, 2004; Tarakeshwar & Pargament, 2001; White, 2009).

Beyond the benefits such as those described above, integration into a religious community may give persons coping with stressful events a sense of belonging and a strong network of social support (White, 2009). In a mixed-method approach, the researcher conducted a study where 177 parents of children diagnosed with ASD completed an internet-based questionnaire that assessed religiosity beliefs, religious practices, parental stress, parental well-

being, and acceptance of the disorder. An open-ended section was included at the end of the questionnaire for additional comments regarding parenting a child with ASD. The researchers examined how religiosity in parents of ASD children and the stress related to raising their offspring are associated with the well-being of the parent and acceptance of the diagnosis. The data were analyzed using Pearson's correlation coefficients to identify significant relationships between the variables.

The analyses indicated a positive correlation between religiosity and both well-being and acceptance of the child's disorder (White, 2009). Additionally, several themes were denoted in the qualitative data. The themes centered on the role of religious faith in the lives of the parents surveyed. Religious faith was described as a source of strength needed to raise children, a provision for finding meaning in the child's disorder and to accept their role as the primary caretaker of the child with ASD. Based on these findings, the researchers suggested that for parents with an ASD child, a faith community can serve as a source of support, strengthen one's well-being and acceptance, and weaken the influence of stress (White, 2009).

The presence of a faith-based, social support group has been associated with overall positive family and child outcomes as well as an increase in the ability of parents to adapt to chronic stressors in the home related to a diagnosis of ASD (Cheung, 2016). In a literature review, the researcher sought to identify the stressors parents of ASD children experience, the factors that contribute to the parent's ability to cope with these stressors, the impact of Christian beliefs in addressing challenges related to raising an ASD child, and recommendations for church pastors and leaders in supporting these families. Cheung's (2016) review of relevant research suggests that parents of children with ASD have significantly higher levels of stress compared to parents of normally developing children. The process of obtaining the diagnosis,

securing supportive services, and managing the child's symptomology can cause great strain for the primary caretaker and other family members.

The results of Cheung's (2016) study indicated that to cope with the demands of raising an ASD child, the parents may seek assistance from a variety of sources, including medical professionals, school administrators, social agencies, family, and friends. One source that has a significant positive impact for parents to find meaning in life and endure the challenges of raising a child with ASD is the parent's Christian faith. Parents report that through biblical teachings, they receive guidance, comfort, and hope as they encounter the obstacles presented by the diagnosis. Additionally, a church family can provide parents with social support, a sense of belonging, and encouragement that lessens their daily burdens and reduces their overall psychological distress. For parents who often feel isolated as a result of symptomology related to the diagnosis, the social support derived from a congregation is an important factor related to emotional well-being (Cheung, 2016). These findings support prior research (Greeff & van der Walt, 2010; Poston & Turnbull, 2004; Speraw, 2006), that due to the complexity of symptomology related to a diagnosis of ASD, a social support system within a faith community may serve a variety of roles for a parent. For example, the church can provide a hub for social activities, connections with friends, and a place for spiritual expression. Along with these personal benefits, the clergy and church leaders can provide professional guidance and direction for spiritual growth as parents face the struggles associated with ASD (Poston & Turnbull, 2004).

Barriers to Participation

Families of children with autism find it difficult to participate in community activities that are common to families without children with autism (Higgins et al., 2005). One of the

activities where participation is limited is in faith communities. In a report commissioned by the National Organization on Disability (NOD, 2010), the researchers related a 13% gap existed when comparing the participation rate of individuals with and without disabilities within faith-based ministries. Specifically, 57% of individuals without disabilities attended a religious ministry at least once a month, whereas 44% of individuals with disabilities reported the same level of attendance (NOD, 2010).

Similarly, as part of a larger ongoing longitudinal study, Orsmond, Krauss, and Seltzer (2004) investigated peer relationships and participation in social and recreational activities among ASD children and young adults. A survey was administered to 235 parents of children diagnosed with autism. The questionnaire addressed the key areas of friendships, social activities, individual characteristics, and environmental factors. Both descriptive analyses and regression analysis were used for data interpretation. The results indicated that more than two-thirds of the participants stated that their children did not participate in any weekly faith-based events, and only approximately 10% participated more than once or twice a month. Additionally, attending social activities at religious events was a rare occurrence (Orsmond, Krauss, & Seltzer, 2004). The implications of the study suggest that many children diagnosed with ASD are not actively involved in their places of worship; however, the reason for their absence is not apparent. Further research in this area was recommended to determine possible barriers for the population.

Terry (2015) conducted a literature review to examine faith community inclusion for ASD children and their families and to identify the barriers that prevent these individuals from attending places of worship. Despite the literature review revealing a plethora of positive outcomes resulting from inclusionary practices, the findings suggest a gap exists between policy

and actual practices within congregations. Many churches and denominations have doctrines stating all are welcomed in their place of worship; however, many ASD families encounter hostility, judgment, and isolation when they attend religious service (Terry, 2015). Based on the review of literature, several solutions for minimizing barriers were recommended including implementation of services to educate congregational members, staff, and administrators about ASD, establishing a welcoming attitude to all attendees regardless of abilities, and identification of community agencies that can assist churches with the integration process. The researcher concluded that faith communities have the ability to foster feelings of great happiness or deep pain to families caring for ASD children and only by eliminating the barriers will they achieve the former.

Despite the findings that religious faith provides numerous advantages and the potential to enhance the quality of life for ASD children and their families, prominent barriers still exist that affect their level of attendance in worship services. According to Carter (2007), several types of barriers may be present that impede the participation of people with disabilities and subsequently their caregivers in religious activities. The impediments include architectural, programmatic, liturgical, and attitudinal barriers. First, architectural barriers may result when physical accessibility is compromised, resulting in a special needs child having difficulty navigating in an environment. Commonly when addressing structural barriers, faith communities consider the need for ramps or wider hallways to accommodate disabled children. However, for an ASD child, the focus is different. In all physical settings, including churches, ASD children often must make an effort to assimilate in their surroundings (Vasquez & Torres, 2013). A lack of appropriate design criteria can lead to hardships for these children due to their impairments in sensory information processing. Children diagnosed with ASD need settings that

provide clear structure, transitional environments, visual support for communicating, wide areas for play, as well as spaces to retreat if they feel overwhelmed by stimulation (Vasquez & Torres, 2013). However, often these logistical considerations are not addressed, resulting in obstacles that prevent attendance.

Second, programmatic barriers may present challenges for both the child and parents who desire to participate in religious activities. Many ASD children require additional assistance to participate fully in activities within the church community. The lack of appropriate supports not only affects the child but the entire family. Parents may be unable to benefit from attendance in worship because they spend their time providing direct support to their child. If appropriate religious educational programs and lessons are not available for their children, parents may be hesitant to attend (Jacober, 2010; Poston & Turnbull, 2004). Often faith communities will express a desire for all people regardless of abilities to attend their establishment; however, the leaders of the church may not have implemented best practices for serving special needs populations (Carter, 2007). As a result, they do not offer modifications or adaptations in the curriculum, do not have an infrastructure in place to support persons with disabilities in the ongoing activities of the community, or mistakenly place persons in disability-segregated or age-inappropriate programs (Carter, 2007; Howell & Pierson, 2010; Terry, 2015).

Third, for some faith communities, liturgical barriers exist. Some organized religions may refuse to make accommodations for persons with developmental or intellectual disabilities to participate in certain sacramental rituals or practices due to beliefs that the individual cannot adequately understand or appreciate the meaning of the ritual (Carter, 2007). For many families, the rituals (e.g., Holy Communion, church membership, confirmation, baptism, Bar Mitzvah) mark life milestones and act as rites of passage in their faith journeys. Some of the rituals

involve the family and the members of the congregation. During the sacrament or ceremony, the

congregation may commit to supporting a child as he walks and grows in his faith. From the

parent's perspective, denying a child the right to participate in these traditions results in the child

being unjustly ostracized from the faith community and not receiving an equally meaningful

religious experience as other typically developing children (Coulthard & Fitzgerald, 1999;

Jacober, 2010).

Lastly, among the barriers mentioned in the literature, a lack of a welcoming attitude

from church members is a prominent theme (Carter, 2007; Howell & Pierson, 2010; Jacober,

2010; Poston & Turnbull, 2004; Terry, 2015). Children with disabilities and their families

sometimes encounter "words and actions—most likely well-intentioned—that they perceive to be

demeaning, condescending, or paternalistic" (Carter, 2007, p. 11). The attitudinal behaviors and

actions of the congregational members can result in some families not feeling accepted and

wanted (Ault et al., 2013a; Webb, 2012). Parents may feel their child's actions are

misunderstood and misjudged by others in the worship service. Congregants may view the child

as a disturbance and not fully understand the characteristic behaviors (rocking, humming,

shouting out, and being disruptive) associated with ASD. As a result of this type of reception,

some ASD parents report that they find it difficult to attend or would rather not attend religious

services than contend with the unpleasant situations that can arise when their child exhibits

inappropriate behavior (Ault et al., 2013b; Gajeton, 2016).

Congregants are not the only individuals in the church who may make the families feel

unwelcomed. Discontent with church leaders and their response, or lack thereof, in addressing

the unique needs of disabled children is a reoccurring topic expressed by parents throughout the

literature (Speraw, 2006; Tarakeshwar & Pargament, 2001). The feelings of dissatisfaction can

stem from a variety of actions. Often church leaders who lack the education and training required to effectively integrate ASD children in their congregations may suggest inappropriate approaches in attempts to resolve issues. The approaches include suggestions to leave the child at home, advising the parents to educate their child in their faith on their own, requesting the parent assist in the Sunday School class to manage the child's behavior, or implying the family may be better served elsewhere (Gajeton, 2016; Speraw, 2006). In some cases, researchers found church leaders even suggested that the disability is the result of a parent's sinful past or demonic possessions (Buglione, 2016; Yih, 2013).

Although the innuendos that parental abominations are responsible for the disability are not readily found in scholarly literature, respected lay publications, such as the *Autism Support Network*, report documented cases of this type of behavior. For example, in some faith communities, fellow congregants may suggest to the parents of ASD children to seek exorcism for their child to extract the abnormal behaviors (Buglione, 2016; Yih, 2013). These insensitive comments may leave the parents and children feeling isolated and rejected. In turn, parents are unwilling to seek assistance from their church when faced with difficulties associated with their child's disability, possibly because they do not perceive the church as being more supportive of them than other agencies (Coulthard & Fitzgerald, 1999; Pitchlyn, Smith-Myles, & Cook, 2007). Thus, parents who are seeking comfort and support from their place of worship may instead experience feelings of being ostracized. However, Jesus instructed:

> When you give a luncheon or dinner, do not invite your friends, your brothers or sisters, your relatives, or your rich neighbors; if you do, they may invite you back and so you will be repaid. But when you give a banquet, invite the poor, the crippled, the lame, the

blind, and you will be blessed. Although they cannot repay you, you will be repaid at the

resurrection of the righteous. (Luke 14:12-14, NIV)

Clearly, Christians are commanded to care for those with disabilities and not turn a blind eye to

their needs.

The existence of an inclusive and welcoming environment is a predictor of the presence

of ASD children and their families in faith communities. Ault (2010) conducted a mixed-

methods study of parents of children with disabilities who regularly attended a place of worship.

The participants ($n = 416$) completed a survey assessing the supports available in faith

communities that promote inclusion and the helpfulness of available programs. Additionally, a

sample ($n = 45$) of the respondents participated in interviews to contextualize the findings and

provide first-hand experiences. Descriptive statistics were calculated on each quantitative

measure, and open coding, categorization, and development of themes were used for qualitative

measures. Ault reported that 91.5% of the participants reported that a welcoming attitude

towards people with disabilities was the strongest factor predicting their participation in church

activities. The results include accounts of families feeling discriminated against, uncomfortable,

rejected, and overly excluded as they confronted negative and unyielding attitudes toward their

son or daughter. Conversely, inclusion was facilitated by displays of approval, adoration,

support, and welcome (Ault, 2010).

Similarly, in a phenomenological study that explored the experiences of 26 parents and

caregivers representing 44 children with special needs and 15 different faith traditions who

sought formal religious education for their children with disabilities, Speraw (2006) found a

correlation between the religious involvement of parents and caregivers and the manner in which

their children were received and included in a faith community. The study participants were

interviewed in their homes and responded to open-ended questions concerning the process of seeking an organized religious program for their disabled child. Subsequently, the transcriptions of the interviews were analyzed through the identification of contextual themes and integration of central elements. Four figural themes emerged: (a) parents believed that a spiritual connection existed between God and their child, (b) typically, the connections were degraded or unrecognized by others, (c) parents were expected to assume sole responsibility of educating their child on faith-based matters, and (d) the participant's own faith was significantly impacted by the manner in which a religious community regarded their child. Parents in the study expressed it was not enough for their children to be simply acknowledged and respected by a select few members of the church; instead, "it was necessary for congregants as well as clergy to take an interest and create a place within the community for their child—a place that was equally welcoming to that created for typically developing children" (Speraw, 2006, p. 226). Although parents desire this type of inclusion, finding an inviting church home is not easy. Many parents of special needs children spend years searching for a place of worship that meets the needs of all family members. Frequently, parents will change churches, even crossing denominational lines, to find a place where their family is accepted and welcomed (Ault, 2010; Barnes, 2012; Gajeton, 2016; Speraw, 2006).

Research on ASD and Inclusion

Based on these findings, inclusionary supports and services appear to be important factors for families of children with ASD. However, when considering inclusion for children, the academic environment has received considerable attention while other social situations have not gained as much focus. The integration of children with special needs into regular education classrooms is a common practice in schools nationwide and has been the source of a plethora of

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research touting the benefits (Chandler-Olcott & Kluth, 2009; Kirby, 2017; Shogren et al., 2015). In turn, as the numbers of documented cases of children diagnosed with ASD has dramatically risen, church ministry teams are experiencing more families wanting similar services and supports within their faith-based organizations (Barnes, 2012). Although past research has identified the benefits of the integration of special needs children and their families into religious communities and the barriers preventing participation, limited empirical research exists addressing how faith-based organizations can effectively serve these children and their families.

Slocum (2016) conducted a literature review examining inclusion in faith communities and recommendations to increase the presence of people with special needs in the life of the church. Slocum's extensive search resulted in the identification of 22 articles that contained suggestions for implementing strategies for including people with disabilities in religious activities. Most of the articles (56%) were descriptive, theoretical, or surveys, and the remaining were literature reviews or case studies. Thirteen of the articles in the review described a lack of meaningful inclusion for individuals with disabilities; three articles described cases in which faith communities were making efforts with mixed results, and four articles indicated the successful integration of people with disabilities in faith communities (Slocum, 2016). Based on the review of the literature, several strategies were recommended including utilizing special educators, implementing explicit teaching strategies, and providing training for church leaders and congregants. The author highlighted the lack of literature addressing the participation of people with disabilities in faith communities and the need for more research concerning the topic.

Despite the limited research in this area, a few noteworthy studies provide a window into the efforts of some faith communities in establishing inclusive services and supports for ASD

children and their families. To gain a better perspective of issues impacting religious involvement for children with autism, Howell and Pierson (2010) interviewed four mothers of seven children with the diagnosis. The families in the descriptive study attended church on a regular basis, and their church homes were located throughout southern California. The interview questions were developed to gain information in five main areas: the congregation's awareness and interactions with the children with disabilities, sibling perspectives of the child with autism, the child's feeling about attending church (as perceived by their mothers), suggestions to the church to encourage inclusion practices, and the mother's desire for the child's religious journey (Howell & Pierson, 2010). The interviews were transcribed and reviewed. Although the mothers had different individual experiences within their places of worship, commonalities were found among their responses that were categorized as themes All four of the mothers related that the church had a responsibility to include children with autism, and they each wanted their children to be able to express their faith in their own way (Howell & Pierson, 2010). When asked about suggestions concerning inclusion and the role the church could take in facilitating engagement, the mothers related several themes including the need for a supportive leadership team, peer buddies, trained aides and staff, developmentally appropriate religious education materials, special education task forces, and respite services provided by church volunteers (Howell & Pierson, 2010). As evidenced by these statements, the need for inclusive supports and services are not only for the child diagnosed with autism but for the entire familial unit. A diagnosis of ASD can cause considerable stress for all household members, and support can be beneficial for everyone residing in the home. Due to the limited number of participants in their study, generalization to the larger population of children with ASD and their families was

not possible. However, the findings can be a useful guide now for churches as they develop inclusionary programs.

O'Hanlon (2013) examined the importance and satisfaction of religious community support services provided to families of children with disabilities. Fifty-eight parents of children with disabilities representing a cross-section of religious affiliations completed an online survey concerning their experiences, as well as their child's, in their faith community. Families were asked to indicate what activities and types of supports were important regarding their child's participation in their spiritual community. More than 90% of the respondents rated all religious activities (worship gatherings, religious education, formal religious rites, and youth activities) and the support from both religious leaders and members of the congregations as important or very important. Additionally, most parents (75%) indicated that their overall experiences with faith communities were positive. However, not all of the findings were encouraging. Almost 70% of participants reported that their child had a negative experience within their faith community, and 37% of parents had considered switching their place of worship as a result of the unfavorable occurrences. Participants reported that receiving support from religious leaders was most important for their overall family participation, although 33% never received this type of service (O'Hanlon, 2013).

In a mixed-methods study designed to explore parents' perceptions of inclusive supports and services within congregations, Ault et al. (2013a) surveyed 416 parents of children with intellectual and developmental disabilities, mainly ASD. The respondents resided in 35 states across the United States, and the majority (88%) were mothers of the children. The study examined ways in which parents and their children with special needs participated in their congregations. The parents completed a four-section survey responding to questions concerning

their child's disability, the frequency and involvement of their child in religious programs and activities, the parent's perception of congregational support provided to their child, and an open-ended section requesting parents identify what has assisted or hindered their participation within faith communities. Descriptive and correlational statistics were utilized to summarize the close-ended responses of the survey. The open-ended responses were coded using a constant-comparative method.

Ault et al. (2013a) found that over 97% of the parents expressed that their faith was important or somewhat important to them. Nearly all the parents (88.1%) stated they attended worship services on a consistent basis (at least once or twice a month), although the children attended religious services slightly less frequently than their parents. Parents reported the activities their child most commonly participated in were religious services (85.3%) and religious education (60.8%). The majority of parents indicated that their child participated in regular activities alongside peers with or without support. Conversely, over 20% of the parents related that their children were not involved in any activities at all (Ault et al., 2013a).

In general, parents were not satisfied with the level of supports provided by their congregations. Parents rated nine factors in terms of helpfulness and availability in their faith communities. The most important factors included a welcoming attitude, additional support services to participate in regular activities, and accessible facilities. Parents reported a discrepancy between the level of helpfulness of services and availability within congregations. As a result, 56% of parents of children with disabilities had restricted their children from partaking in a religious event because support services were not in place, and over 30% of the parents stated they changed their place of worship because their child was not welcomed (Ault et al., 2013b). Parents related that the lack of acceptance and support was not only frustrating but

also mentally taxing. Fatigue was an issue limiting participation. Some parents stated they did

not possess the strength and stamina required to overcome the barriers presented by their

religious communities, resulting in their family's lack of attendance at their place of worship

(Ault et al., 2013b). Lastly, the role of church leaders was also addressed. Families underscored

that knowledgeable and caring church leaders who modeled welcoming attitudes and advocated

for the rights of special needs children contributed to parental satisfaction, and the lack of such

leadership led to disappointment (Ault et al., 2013b).

The results of Ault et al.'s study (2013b) support previous research findings suggesting

the importance of faith and support services in the lives of families of children with disabilities

(Bennett et al., 1995; O'Hanlon, 2013; Poston & Turnbull, 2004). The overall conclusion was

that faith communities that provide effective supports, welcoming attitudes, and church leaders

who are educated regarding inclusive practices can contribute to enhanced quality of life for

families and their children with disabilities, and provide a valuable resource for all (Ault et al.,

2013a).

Recognizing the challenges families of disabled children encounter when seeking

inclusion within faith communities, Carter and his fellow researchers (Biggs & Carter, 2016;

Boehm et al., 2015; Carter, Biggs, & Boehm, 2016; Carter, Boehm, et al, 2016; Liu, Carter,

Boehm, Annandale, & Taylor, 2014) initiated a mixed-methods project entitled The Faith and

Flourishing Project, which examined the impact of faith in the lives of special needs children and

their families. The research addressed spiritual observances, support needs, communal activities,

and quality of life of nearly 500 youth and young adults with intellectual disabilities or autism.

In one of the studies, Carter, Biggs, et al. (2016) explored the experiences of belonging

among 25 parents who were involved in a local church and had a child with a disability. In a

qualitative study, participants responded to a semi-structured interview designed to stimulate responses regarding the concept of belonging and other themes related to the larger project. The researchers sought to understand how youngsters and their families perceive full integration in their worship environment and ways congregations can adopt effective inclusion strategies. Using a constant-comparative analysis of the data, researchers identified ten dimensions of belonging. The domains included to be present, invited, welcomed, known, accepted, supported, cared for, befriended, needed, and loved (Carter, Biggs, et al., 2016), and all were identified as qualities of what it means to be fully included in a congregation. When viewed together, the dimensions serve as indicators of the importance of relationships within a church. The parents' responses signified a need for deeper connections rather than superficial acknowledgments. The families desired that their children be recognized for "their strengths, gifts, passions, personalities, and needs" (p. 137) and not simply by a label or deficit. Carter, Biggs, et al. pointed out that although support services and individualized accommodations are essential for children with disabilities and their families, so are the basic needs of feeling valued and welcomed.

In consideration of the pivotal role parents provide in caring and supporting their children with intellectual disabilities or autism, Boehm et al. (2015) explored family quality of life (FQOL) among families with transition-age youth and young adults. The study was a component of the Faith and Flourishing project. The participants in the study were 425 parents or caregivers of an adolescent or young adult with a disability. Over 40% of the parents identified their child had autism, 38% indicated their child had an intellectual disability, and 12% indicated their child had been diagnosed with both disorders. The purpose of the study was to examine how parents describe their FQOL and what factors predict FQOL for transitional age

children. Parents were asked to complete 15-page packets comprised of multiple measures addressed in the Faith and Flourishing project. However, for the study, the analyses were related specifically to the FQOL variables. Participants in the study completed a modified version of the Beach Center Family Quality of Life Scale, which assesses family satisfaction within five domains (family interaction, emotional well-being, physical/material well-being, parenting, and disability-related supports). Response options ranged from 1 (very dissatisfied) to 5 (very satisfied) on a 5-point Likert-type scale. Additionally, parents were asked to complete a Strength of Religious Faith Questionnaire to explore other factors related to FQOL and to provide demographic information about their child and family. The researchers found the participants indicated overall parental satisfaction with their FQOL ($M = 3.99$, $SD = 0.63$); however, the ratings across individual items were uneven. Three of the items within the Emotional Well-Being domain concerning the accessibility to supports and relationships were amongst the lowest. Approximately 40% of parents reported dissatisfaction with the availability of outside assistance to care for the unique needs of the family, over 30% indicated dissatisfaction with support to relieve stress, and 20% expressed dissatisfaction with support received from friends and others (Boehm et al., 2015). Therefore, even though parents reported a surprisingly high level of FQOL, several areas of support were lacking or nonexistent for these families. Additionally, correlations amongst variables were analyzed to identify factors predicting FQOL. The strongest positive association with FQOL satisfaction ratings was strength of religious faith, and the strongest negative associations were the presence of challenging behaviors and greater support needs. The strongest correlations were between the FQOL and items regarding active participation in one's faith or congregation and interactions with others who share the same faith beliefs (Boehm et al., 2015). Thus, parents who engaged on a regular basis in worship services

and interacted with fellow congregants reported higher levels of FQOL than those who did not. The results of the study provide insight into a previous gap in the literature regarding transitional age youngsters and reinforce the importance of careful consideration in developing and delivering spiritual services for these individuals.

In further research for the Faith and Flourishing Project, Carter, Boehm, et al. (2016) explored parental perspectives of inclusionary supports provided by faith communities. The researchers surveyed 433 parents and caregivers of youth with intellectual disabilities or ASD regarding the helpfulness and availability of 14 congregation-provided supports. The supports listed included support groups, disability awareness efforts, resource centers, family advocates, respite care, spiritual counseling from church leaders, modified religious programs, spiritual education plans, aides for religious education and worship services, special worship services, financial support, transportation, and physically accessible congregations. The researchers also examined indicators of congregational inclusion and the parent's responsiveness to various child, family, and congregation factors. Most of the participants (85%) were mothers, and over half reported attending worship services at least once a week. Most parents identified as Protestant Christian or Roman Catholic, although 35 different religious traditions were reported.

The analysis of the data included the use of descriptive and correlational approaches (Carter, Boehm, et al., 2016). For nine of the 14 surveyed supports, more than half of the families indicated each would be somewhat to very helpful if offered by their faith community. Approximately 70% of parents reported that support groups, disability awareness efforts, resource centers, and family advocates to be helpful or very helpful. Most parents indicated that the majority of the desired supports were not available in their place of worship, and 44% of the parents reported none of the 14 supports were available in their congregation (Carter, Boehm, et

al., 2016). The most frequently available supports were spiritual counseling from a faith leader (32.8%) and a physically accessible congregation (22.8%). In places of worship where inclusive services were present, a significant positive correlation was found to exist between frequency and length of attendance at religious services and the number of inclusive supports provided. Additionally, the size of the congregation was positively correlated with the number of supports offered (Carter, Boehm, et al., 2016).

Carter, Boehm, et al. (2016) also measured the parents' perception of inclusiveness and welcoming behaviors within their congregation. Overall, 70% of parents agreed or strongly agreed that they were very satisfied with how welcoming members of their congregation were of people with disabilities (Carter, Boehm, et al., 2016). Church leadership emerged as a prominent factor, receiving both the highest and lowest level of agreement. Most parents (89%) strongly agreed or agreed that the church leaders accepted their child with a disability, but fewer (69.2%) strongly agreed or agreed that the leadership of the church exhibited a commitment to including people with intellectual disability or ASD. The authors stated the discrepancy may be due to the interpretation of acceptance as a passive response, whereas commitment requires a more active response. Thus, the increase in the presence of children with disabilities in worship services reflects acceptance but the lack of appropriate services to meet the needs of these children signals a lesser degree of commitment (Carter, Boehm, et al., 2016).

Carter, Boehm, et al. (2016) concluded an array of inclusive supports have the potential to be helpful for families if provided by their faith communities. However, a substantial gap exists between supports parents identified as helpful and the availability of these services. Although it was not presumed that a single congregation would provide all or a majority of supports, the reports that almost half of the faith communities did not offer any of the supports

was unexpected. The findings indicate the considerable disconnect between the needs of the families and the faith communities they attend.

Theoretical Framework

The researcher for the current study seeks to expand the findings reported by Carter, Boehm, et al. (2016) and explore if the presence of inclusive services is associated with frequency, length of attendance, and the level of commitment a parent has to a congregation. An exhaustive search of the literature found no research regarding parental perception of inclusive services for ASD children and commitment level to a place of worship. However, parallels can be drawn to organizational designs such as in the business world. In the competitive and ever-changing realm of organizational effectiveness, "there has been an increasing concern with factors that influence the stability and intensity of employee dedication to organizations" (Eisenberger, Huntington, Hutchison, & Sowa, 1986, p. 500). As a result, recent research has focused on factors associated with employee commitment. Throughout the literature, a reoccurring finding reported was a positive correlation between perceived organizational support (POS) and employee commitment (Eisenberger et al., 1986; Kim, Eisenberger, & Baik, 2016; Meyer & Allen, 1991). The framework underlying much of the research in this area is the social exchange theory.

Social Exchange Theory

Eisenberger et al. (1986) contended the resulting relationship between the employee and organization is rooted in social exchange theory. The theory was developed by George Homans (1961) who defined social exchange as "the exchange of activity, tangible or intangible, and more or less rewarding or costly, between at least two persons" (p. 13). Homan's objective was to explain the central components of social behavior (status, power, leadership, compliance, and

fairness) as a result of the social processes of mutual reinforcement (Cook & Rice, 2006). For example, in exchanges where one person performs a favorable act for another person, an expectation forms that the goodwill will be repaid. However, the time and form of repayment are often unclear (Wayne, Shore, & Linden, 1997). In social relationships, the perceived balance of reciprocity between the two parties guides decisions determining the worth of the affiliation. Relations may strengthen if both entities encounter benefits as a result of the exchanges. Conversely, the relationship may terminate due to failure of reinforcements (Cook & Rice, 2006).

According to social exchange theory, employees act on the basis of the norm of reciprocity to seek a balance between the favorableness of their actions toward the organization and the organization's actions toward them (Eisenberger et al., 1986). Thus, the high regard and caring conveyed by perceived organizational supports should help fulfill socio-emotional needs and be repaid, in part, by supportive organizational behaviors such as reduced absenteeism, heightened performance, and an increased level of commitment. Social exchange theorists claim that resources received from others are more highly valued if they are based on personal choice rather than circumstances dictated to the donor. Voluntary support is perceived as an indicator that the donor has genuine care and concern for the recipient (Eisenberger et al., 1986).

Perceived Organizational Support

Perceived organizational support refers to employees' perceptions concerning the extent to which the organization values their contributions and cares about their well-being (Eisenberger et al., 1986). The emotional bonds employees have with their work organizations have been deemed critical factors associated with dedication and loyalty (Meyer & Allen, 1991). Employees who are affectively committed to their place of work are seen as having a sense of

belonging and identification that increases their involvement in the organization's endeavors, their willingness to pursue the goals of the organization, and their retention with the organization (Meyer & Allen, 1991). POS seeks to explain employees' affective commitment to their organization. The approach assumes that in order to meet socioemotional needs, such as esteem, approval, and affiliation, employees form general beliefs concerning how much the organization values their efforts and is concerned about their welfare. The perception of being appreciated and respected by the organization fosters the integration of organizational membership into the employee's self-identity and thereby strengthens the emotional relationship with the organization (Eisenberger et al., 1986).

Conclusion

The chapter has presented past research concerning the participation of children diagnosed with ASD and their families in faith communities. The benefits of participation, as well as the barriers that prevent involvement, were addressed. In the next chapter, the focus turns to the methodology utilized in the current study.

III. METHODOLOGY

Introduction

Chapter III contains an explanation and presentation of the methodology utilized in the broadly quantitative, nonexperimental, and more specifically, survey research study. The focus of the study was to explore the perspectives of parents of children with ASD regarding the inclusive supports and services provided by their faith communities. Additionally, the availability of these services, as well as their influence on the parent's commitment level to the place of worship providing the supports, was addressed. The chapter discusses the participants, research instrumentation, procedures, and data analysis.

Participants

The sample selected for the study was convenient and purposive in nature. The participants were identified for the study purposes from two sites in central Florida. One site was comprised of parents of participants in a special needs ministries program designed for children with disabilities. The program offers a variety of services including Sunday School classes, monthly Saturday morning respite programs, summer camps, and other periodical special events. The program is open to all children with special needs and religious affiliations. The program coordinator reports the majority of children attending the program have received a diagnosis of ASD. The second site was identified as a private, Christian, middle school and high school program for students with intellectual disabilities or other mild learning

disabilities. The school offers a student-centered, core curriculum of life skills, spiritual growth, and academic standards. Fifty-seven students are enrolled in the school, and 37 of the students identify ASD as their primary disability. Recruitment of the participants occurred in a single two-week phase that included one initial distribution of the survey and one follow-up reminder of the survey distribution the following week. All survey packets included a statement of informed consent (see Appendix A) as well as the survey itself (see Appendix B). Due to the scope of the study, participants were limited to parents of children diagnosed with ASD who identify as attending a place of worship on a regular basis. Respondents to the survey that did not meet the outlined requirements were excluded from the study. Demographic variables included age, gender, marital status, ethnicity, and religious affiliation.

Research Instrumentation

The research instrument used in the study represents an adaptation of a survey created by Carter, Boehm, et al. (2016) addressing the demographics, strengths, skills, support needs, spirituality, well-being, and community involvement of people with disabilities. Two congregation-related measures—congregational-provided supports and congregational inclusion—were the focus of the survey as well as several related variables. Due to the absence of an existing measure for specific study purposes, Carter, Boehm, et al. incorporated 14 supports addressed in prior studies and lay publications focused on including people with disabilities and their families in faith communities in the research instrument. Moreover, input from their interdisciplinary research team that included doctoral students and staff in both Special Education and Divinity School programs was solicited in the initial crafting of the instrument. All measures were piloted with a sample of 12 parents of children with IDD from

diverse faith traditions. The researchers sought feedback from the pilot participants concerning the content, clarity, and length of measures.

One of the results of the survey creation and piloting by Carter, Boehm, et al. (2016) was that nine of the 14 congregation-provided supports were rated as somewhat to very helpful by the parents responding to the survey. These nine identified supports were subsequently utilized in the current survey as indicators of inclusive support services provided by places of worship.

The research instrument developed for the study was used to specifically assess the helpfulness and availability of nine potential congregation-provided supports for parents raising children with ASD. First, the parents were asked to indicate how helpful each support would be in raising their child with ASD, assuming the support was available in their congregation. The supports include: support groups for parents, congregation-wide disability awareness efforts, a resource center for families, an advocate to work with families, respite care, spiritual counseling from a congregational leader, modifications to religious education programs, a religious education plan for children with ASD, and someone to support child during religious education. Next, parents identified the degree to which the same nine supports are currently available in their congregation. Responses were provided on a 5-point Likert type scale (1 = Strongly disagree, 2 = Disagree, 3 = Uncertain, 4 = Agree, and 5 = Strongly agree).

In the second portion of the survey, participants were asked to respond to questions regarding congregational commitment. Participants were asked to rate variables concerning attendance, length of tenure, volunteerism, financial contribution, and overall commitment level at their place of worship.

Procedures

 At the two identified research sites, parents of children diagnosed with ASD were invited to complete a printed survey regarding their perspective of the helpfulness and availability of inclusive support services provided by their place of worship as well as their level of commitment to the institution. The printed survey consisted of 28 total questions: nine questions that measured the helpfulness of an identified support service, nine questions that measured the availability of the identified support service in their congregation, five questions evaluating congregational commitment, and five demographic questions. A total of 31 survey responses (50% return rate) were used for study purposes after two requests for survey returns. Participant data were extracted from the surveys and stored on the researcher's password-protected laptop, and hard copies were secured in a locked file cabinet. The data were imported into IBM Statistical Package for the Social Sciences (SPSS) Version 25 for data analysis.

Data Analysis

Preliminary Analyses

 Prior to addressing the study's research questions, preliminary analyses were conducted. Specifically, missing data, internal consistency (reliability) of participant response to survey items, and essential demographic data were assessed for study purposes.

 Missing data were analyzed using descriptive statistical techniques. Frequencies and percentages comprised the primary statistical methods of analysis and interpretation. Little's MCAR test statistic was utilized to evaluate the randomness of subsequent missing data. An MCAR value of $p > .05$ was considered indicative of missing data that are sufficiently random in nature.

The internal consistency or reliability of participants to the survey items was addressed through the application of Cronbach's alpha *(a)* test statistic. The statistical significance of alpha was assessed through the *F* test. The value of $p < .05$ was considered statistically significant.

The study's essential demographic information was assessed using descriptive statistical techniques. The mean, standard deviation, frequency counts (*n*), and percentages (%) represented the primary methods of descriptive analysis.

Analyses by Research Question

Research Questions 1, 2, and 4 were addressed using both descriptive and inferential statistical techniques. Measures of central tendency (mean scores), variability (standard deviations), and percentages represented the primary descriptive statistical techniques applied. The single sample *t* test represented the inferential statistical technique by which respective mean score comparison with the Likert-Scale null value were evaluated for statistical significance. The threshold value for statistical significance was $p < .05$. The magnitude of effect (effect size) was assessed using Cohen's *d*. Cohen's conventions represented the guideline for the interpretation of all effect size values.

Research Questions 3 and numbers 5 through 8 were associative and predictive in nature, using one independent predictor variable. As such, the Pearson Product-Moment Correlation Coefficient was used to assess the mathematical relationships of respective variables inherent in the research questions. Mathematical relationships manifesting *p*-values $<.05$ were considered statistically significant.

Simple linear regression was utilized to assess the predictive aspect of the research question. Predictive model fitness was assessed through ANOVA table *F*-values. ANOVA values of $p < .05$ were indicative of predictive model fitness. R^2 values represented the basis for

the evaluation of predictive effect. The formula $R^2 / 1 - R^2$ was used to calculate the effect size of the predictive model. Values of .35 or greater were considered large predictive effect sizes. The statistical significance of predictive effect was interpreted through the respective slope (t) values of independent predictor variables. Test assumptions associated with predictive modeling were addressed and satisfied through visual and statistical methods.

Summary

Chapter III outlined the methodology used in the quantitative study regarding the influence of inclusive services and supports provided by faith communities for parents of children diagnosed with ASD. In Chapter IV, the findings of the research will be reported. Preliminary analysis including missing data within the study's data set, internal reliability of participant response to survey items, and essential demographic information are presented. Additionally, the findings for each research question will be presented along with the data collected via the methodology described in Chapter III.

IV. RESULTS

Chapter IV features a presentation of the results of the quantitative, non-experimental study of parents of children diagnosed with ASD. The focus of the research was upon an assessment of the perspectives of the participants regarding the inclusive supports and services provided by their place of worship. The availability of these supports and their influence on the parents' commitment level to their faith community were also evaluated. Data were collected at two sites through the use of a survey administered to parents of children diagnosed with ASD. The response rate of the participants was 50%, with 31 out of the 62 surveys completed. The results of the data are presented in the chapter.

Preliminary Analyses

In advance of the analysis of the study's eight questions, preliminary analyses were conducted. Evaluations of missing data within the study's data set, internal reliability of participant response to survey items, and essential demographic identifiers represented the primary preliminary analysis conducted for study purposes.

Missing Data

Participant response to the survey items reflected a minimal level of 1.34% ($n = 8$) of missing data. Moreover, the missing data are considered sufficiently random in nature (Little's MCAR x 2 (46) = 49.51; $p = .34$). The internal reliability of participant response to the study instrument's survey is considered very high ($a = .84$; $p < .001$).

Primary Demographics

A total of 31 parents of children diagnosed with ASD participated in the study. The majority of the study participants identified as being married (87.1%), and approximately three in four participants (71.0%) identified as Caucasian in terms of ethnic status. Regarding participation in faith communities, slightly over six in 10 (61%) participants noted that they attend church on a weekly basis or more. Nearly half of study participants (42%) stated that they have been members of their respective churches for 10 years or more, while almost two in 10 participants (19.4%) identify their membership at one year or less.

Regarding giving, either monetarily or in terms of time, nearly three in four study participants (71.0%) related that they tithe to their church on a regular basis. Nearly one-third of study participants (32.3%) provided volunteer service at their church on a regular basis, whereas slightly over one-third of study participants (35.5%) stated that they never volunteer at their respective churches.

Findings by Research Question

Research Question 1: Regarding Carter's nine support services, to what degree do parents of ASD children perceive the supports as helpful or important?

Using the one-sample t test to assess the statistical significance of finding in Research Question 1, study participants perceived the inclusive supports to be *helpful* overall ($M = 3.93$; $SD = 0.49$) and the findings were at a statistically significant level ($t_{(28)} = 10.29$; $p < .001$). Moreover, the magnitude of effect for helpfulness of inclusive supports is considered very large ($d = 1.90$).

Research Question 2: Regarding Carter's nine support services, to what degree do parents of ASD children perceive their place of worship as providing those support services?

Using the one-sample t test to assess the statistical significance of finding in Research Question 2, study participants did not perceive the inclusive supports as being provided by their church overall ($M = 2.78$; $SD = 0.93$). The finding for Research Question 2 was not found to be statistically significant ($t_{(29)} = -1.31$; $p = .20$). In addition, the magnitude of effect for perceived evidence of inclusive supports in the churches of study participants is considered small ($d = -.24$).

Research Question 3: Does a place of worship's implementation of inclusive supports services for children diagnosed with ASD represent a statistically significant predictor of the parent's attendance at a church?

Using the simple linear regression test statistic to assess the predictive ability of a church's provision of inclusive supports for children and youth with ASD and parent tendency to attend church, a non-statistically significant effect was manifested in the predictive model ($p = .24$). The independent predictor variable of church provision of inclusive support services accounted for only 4.9% ($R^2 = .049$) of the explained variance in the model's dependent variable (church attendance), with a concomitant trivial predictive effect of $d = .10$. Table 1 contains a summary of findings for the predictive model used in Research Question 3:

Table 1

Predicting Church Attendance from Church Provision of Inclusive Support Services

Model	β	SE	Standardized β
Intercept	4.12	0.83	
Supports Provided	0.34	0.29	.22

Research Question 4: Which individual inclusive support indicator of *helpfulness* was

perceived as the most helpful of inclusive supports?

Using the one-sample *t* test to assess the statistical significance of the finding in Research

Question 4, study participants perceived the *helpfulness* of the inclusive support of a *Family*

Resource Center ($M = 4.70$; $SD = 0.54$) as most important. The finding for Research Question 4

was found to be statistically significant ($t_{(29)} = 17.41$; $p < .001$). Moreover, the magnitude of

predictive effect for perceived evidence of inclusive supports in the churches of study

participants is considered very large ($d = 3.15$).

Research Question 5: Which individual inclusive support was perceived by the parents as being

provided to the greatest degree by the participant's church?

Using the one-sample *t* test to assess the statistical significance of the finding in Research

Question 5, study participants perceived the provision of the inclusive support of *Spiritual*

Counseling ($M = 3.30$; $SD = 1.21$) as most often. The finding for Research Question 5 was not

found to be statistically significant ($t_{(29)} = 136$; $p = .18$). The magnitude of effect for perceived

evidence of inclusive supports in the churches of study participants is considered small ($d = .25$).

Research Question 6: Does a church's implementation of inclusive support services for children

diagnosed with ASD represent a statistically significant predictor of the parent's commitment to

volunteerism?

A simple linear regression test statistic was utilized to assess the predictive ability of a

church's provision of inclusive supports for children and youth with ASD and parent tendency to

volunteer at church. A liberally-interpreted, statistically significant predictive effect was

manifested in the predictive model ($p = .10$). The independent predictor variable of church

provision of inclusive support services accounted for 9% ($R^2 = .09$) of the explained variance in

the model's dependent variable (church volunteering), with a concomitant small predictive effect

of $d = .20$. Table 2 contains a summary of findings for the predictive model used in Research

Question 6:

Table 2

Predicting Church Volunteering from Church Provision of Inclusive Support Services

Model	β	SE	Standardized β
Intercept	1.33	1.25	
Supports Provided	0.71	0.43	.30[a]

[a] $p = .10$

Research Question 7: Does a place of worship's provision of inclusive support services predict

the likelihood of monetary giving by the parent of a child with ASD?

Using the simple linear regression test statistic to assess the predictive ability of a

church's provision of inclusive supports for children and youth with ASD and parent tendency to

provide monetary support for the church (tithe) at church, a non-statistically significant

predictive effect was manifested in the predictive model ($p = .17$). The independent predictor

variable of church provision of inclusive support services accounted for 6.7% ($R^2 = .067$) of the

explained variance in the model's dependent variable (monetary support), with a concomitant

small predictive effect of $d = .15$. Table 3 contains a summary of findings for the predictive

model used in Research Question 7:

Table 3

Predicting Church Monetary Support from Church Provision of Inclusive Support Services

Model	β	SE	Standardized β
Intercept	2.20	0.35	
Supports Provided	0.17	0.12	.26

Research Question 8: Does a church's implementation of inclusive support services for children diagnosed with ASD represent a statistically significant predictor of the parent's overall level of commitment to that church?

Using the simple linear regression test statistic to assess the predictive ability of a church's provision of inclusive supports for children and youth with ASD and parent overall commitment to the church, a statistically significant predictive effect was manifested in the predictive model ($p = .03$). The independent predictor variable of *helpfulness* of inclusive support services accounted for 15.9% ($R^2 = .159$) of the explained variance in the model's dependent variable (provision of inclusive support services), with a concomitant predictive effect approaching medium ($d = .38$). Table 5 contains a summary of findings for the predictive model used in Research Question 8:

Table 4

Predicting Parent Overall Commitment to the Church by Church Provision of Inclusive Supports

Model	β	SE	Standardized β
Intercept	2.06	0.49	
Supports Provided	0.39	0.17	.40*

*$p = .03$

V. DISCUSSION

The focus of the study was to examine the perspectives of parents of children with ASD regarding the inclusive supports and services provided by their congregations. Also explored were the availability and helpfulness of these services as well as the influence on the parents' commitment level to the place of worship providing the supports. Specifically, commitment in terms of attendance, tenure, tithing, volunteerism, and overall level of commitment was evaluated. Designing and implementing inclusive provisions within places of worship can lead to positive benefits for both the child diagnosed with ASD and the family. The benefits include improved self-concept, increased spirituality, strategies for coping, a sense of empowerment, and feelings of connectedness (Bennett et al., 1995; Cheung, 2016; Tarakeshwar & Parament, 2001; Vogel et al., 2006; Webb, 2012). The study provides insight into the factors that may increase feelings of inclusivity and encourage the presence of ASD children and their families in faith communities.

Statement of the Problem

The prevalence of ASD in the United States has steadily increased during the last decade. According to the *Morbidity and Mortality Weekly Report Surveillance Summaries* issued by the Centers for Disease Control and Prevention, the estimated prevalence of ASD has increased 150% since the tracking of the disorder began in 2000 (Baio et al., 2018). Due to the marked difficulties in behavior, social interaction, and communication associated with the diagnosis,

the challenges parents experience when taking care of a child with ASD may be vast. The symptomology exhibited by children with ASD can present unique stressors to the family system as a whole, making the support derived from their faith, the opportunities for church involvement, and encouragement from a supportive church community important factors for these families (Gajeton, 2016; Howell & Pierson, 2010; Speraw, 2006). However, families of children with autism often find it difficult to participate in worship services. In a report commissioned by the National Organization on Disability (2010), the researchers related a 13% gap existed when comparing the participation rate of individuals with and without disabilities within faith-based ministries.

Similarly, in a survey administered to over 200 parents of children diagnosed with ASD concerning their attendance at religious community events, more than two-thirds of the participants stated that their children did not participate in any weekly faith-based activities, and only 10% participated more than once or twice a month (Orsmond, Krauss, & Seltzer, 2004). The purpose of the study was to evaluate the perspectives of parents with ASD regarding the inclusive supports and services provided by their congregations and the influence of these services on the parents' commitment level to their place of worship. Understanding the supports that increase the participation and commitment level of these families to their faith communities should equip church leaders with the knowledge and information needed to create congregations that are receptive communities for children diagnosed with ASD and their families.

Review of Methodology

The study was quantitative and non-experimental in nature. A convenient and purposive participant sample was selected from two sites in central Florida. One site was comprised of parents of participants in a special needs ministries program designed for children with

disabilities. The second site was a middle school and high school program for students with intellectual disabilities or other mild learning disabilities. Due to the scope of the study, participants were limited to parents of children diagnosed with ASD who identified as attending a place of worship on a regular basis. The total sample size of respondents to the survey was 31. A response rate of 50% was achieved from the distributed surveys.

The research instrument used in the study represents an adaptation of a survey created by Carter, Boehm, et al. (2016) that addressed the demographics, strengths, skills, support needs, spirituality, well-being, and community involvement of people with disabilities. Additionally, the survey focused on congregation-provided supports and congregational inclusion, as well as several other related variables. One of the results of the survey created and piloted by Carter et al. was that nine of the 14 congregation-provided supports were rated as somewhat to very helpful by the parents responding to the survey (Carter, Boehm, et al., 2016). These nine identified supports were subsequently utilized in the current survey as indicators of inclusive support services provided by places of worship.

Prior to addressing the formally stated research questions of the study, preliminary analysis was conducted. Specifically, missing data, internal consistency of participant response to the research instrument, and essential demographic data were assessed for study purposes. The study's data set reflected a minimal level of missing data that was sufficiently random in nature. The internal reliability of participant response to the study was considered very high (a = .84; $p < .001$).

Discussion by Research Question

The research questions were addressed through a combination of both descriptive and inferential statistics. The following information represented how each research question was addressed analytically.

Research Question 1: Regarding Carter's nine support services, to what degree do parents of ASD children perceive the supports as helpful or important?

The results indicated that the parents surveyed perceived the supports to be helpful at a statistically significant level (t_{28}= 10.29; $p < .001$). Moreover, the effect size ($d = 1.90$) for helpfulness of inclusive supports approximated a very large effect.

The findings are consistent with the results obtained by Carter, Boehm, et al. (2016) in identifying the congregation-provided supports parents found to be helpful in raising their children. Due to the absence of an existing survey instrument designed to evaluate the perception of parents regarding congregational supports, Carter, Boehm, et al. developed an original survey tool to utilize for their research. ASD is a complex disorder with a spectrum of symptoms related to the diagnosis. As a result, the expectation would be that parents would vary in their perception of services or supports depending on the individual needs of their child. Carter, Boehm, et al. sought to encapsulate supports and services that the majority of parents with ASD children would describe as helpful. The results rendered from Research Question 1 provide support for the validity of the survey instrument created by Carter, Boehm, et al. and the adapted version of the tool utilized for the current study.

Research Question 2: Regarding Carter's nine support services, to what degree do parents of ASD children perceive their place of worship as providing those support services?

The results indicated that the parents surveyed did not perceive the inclusive supports as being provided by their church overall ($M = 2.78$; $SD = 0.93$). The finding for Research Question 2 was not found to be statistically significant ($t_{(29)} = -1.31$; $p = .20$). In addition, the magnitude of effect for perceived evidence of inclusive supports in the churches of study participants is considered small ($d = -.24$).

Statistical significance aside, the inverse findings suggest the results are not random in nature and that the response set is moving more to disagreement. In Research Question 1 for each support listed, 96.6 % of the parents surveyed indicated they "strongly agree" or "agree" that the supports would be helpful in raising their child. In Research Question 2, when rating the same supports in terms of provision within their faith community, the parents indicated they "strongly agreed" or "agreed" at a rate of only 46.7%. Therefore, a clear discrepancy exists between parents' perception of helpful services and what is provided by their faith communities.

The findings of Research Question 2 complement previous literature indicating parents of children diagnosed with ASD do not perceive their faith communities as providing the inclusive supports deemed helpful (Carter, 2007; Slocum, 2016; Speraw, 2006). The existence of helpful services can positively influence a parent's perception of a church, while the absence of inclusive supports can lead to negative experiences. The presence of services designed to promote the inclusion of ASD children are important factors parents consider regarding their place of worship. Although it is beyond the scope of the current study, other authors have found when parents are not consistently satisfied with the level of supports provided by their faith communities, they may react by changing their place of worship, restricting their children from participating in religious activities, or, in the worst-case scenario, turning their back on organized religion (Ault et al., 2013b; Speraw, 2006).

Research Question 3: Does a place of worship's implementation of inclusive supports services for children diagnosed with ASD represent a statistically significant predictor of the parent's attendance at a church?

Research Question 3 assessed the predictive ability of a church's provision of inclusive supports for children and youth with ASD and parental tendency to attend church. The results indicated a non-statistically significant predictive effect was manifested in the predictive model ($p = .24$).

While previous research (Griffin et al., 2012; O' Hanlon, 2013; Poston & Turnbull, 2004) has indicated a positive correlation between church attendance and congregations that offer accommodations to include the special needs child in religious activities, the finding does not point to the same results. The difference may lie in the population participating in the study. According to Pew Center Research (2014), 36% of U.S. adults surveyed reported attending church on at least a weekly basis. In the current study, slightly over six in 10 participants (62%) noted that they attend church on a weekly basis or more. Furthermore, nearly half of the study participants (42%) stated that they were members of their respective churches for 10 years or more. The reported average frequency of church attendance by the participants in the study is largely greater than the national average.

One of the defining features for inclusion in the study was that participants attend church on a regular basis. The finding for Research Question 3 suggests that participants in the study are more inclined than the general population to attend church despite the obstacles they may face. One parent wrote on the margin of the survey, "It is hard to attend church with my child"; however, she reported regular attendance. To address the challenges of attendance, caretakers of ASD children may feel compelled to seek unconventional alternatives in order to be present.

Instead of participating as a family unit, parents may alternate dates of attendance whereas one parent can supervise the child at home, or they may obtain a babysitter or family member to care for their child during their absence (Ault et al., 2013b). In both instances, one could assume that the family is excluded from the opportunity to worship together as a unit and may feel further isolated and segregated from their congregation.

Research Question 4: Which individual inclusive support indicator of *helpfulness* was perceived as the most helpful of inclusive supports?

The inclusive support "Resource center for families with a child diagnosed with a disability" reflected the greatest degree of helpfulness among participants. The finding for Research Question 4 was found to be statistically significant ($M = 4.70$; $SD = 0.54$). Using the Cohen's d test statistic, the magnitude of effect for the item is considered very large ($d = 3.15$).

The results of Research Question 4 imply that parents most desire a centralized location to find services and programs designed to assist in the navigation of the often-difficult challenges and obstacles presented by a child diagnosed with ASD. Family resource centers typically provide information regarding support groups, community activities, resources, and local professionals specializing in ASD. The assistance provided is not limited to the church but extends to the home and community. The finding firmly and strongly supports the results of the Carter, Boehm, et al. (2016) study in which over 69% of the parents described family resource centers as either somewhat or very helpful.

It is not surprising that the supports parents value the most are designed to assist the entire familial unit and not specifically the ASD child. Some churches create classes and opportunities for children with disabilities, but the parents and siblings are often left out of the equation (Howell & Pierson, 2010). A diagnosis of ASD can cause considerable stress for all

household members, and support can be beneficial for everyone residing in the home. Thus, a family resource center can be a welcome refuge for an exhausted family and ease the burden of responsibility they may carry.

The least degree of helpfulness noted by the study's research instrument was manifested in the support service "A spiritual or religious education plan for my child." While the study focused on helpfulness rather than non-helpfulness, the result aligns well with research conducted by Carter, Biggs, et al. (2016), signifying parents of ASD children value being welcomed, connected, and included more than other programmatic supports. Families desire that their children be recognized for their unique strengths and abilities and not by a label or deficit. Regarding the parent's perception of belonging, structured religious education plans may not be viewed as positively as compared to other inclusionary supports.

Research Question 5: Which individual inclusive support was perceived by the parents as being provided to the greatest degree by the participant's church?

To identify the individual inclusive support perceived as being provided to the greatest degree, a single sample *t* test was employed. Although no single support exhibited a statistically significant mean, the indicator "Spiritual Counseling" was reported as most provided. The magnitude of effect is considered small ($d = .25$).

While the overall results were not statistically significant, these results are consistent with the Carter, Boehm, et al. (2016) findings of the most frequently available support within congregations. Previous research has indicated that church administrators are aware of the significant increase in recent years of children diagnosed with ASD and the subsequent distress the diagnosis creates for families. Many parents seek to draw strength from their faith to understand why this happened to their child and to deal with the feelings of guilt, sadness, and

pain. As a result, many spiritual leaders are reaching out to these families to provide spiritual healing and guidance (Ault et al., 2013b; Griffin et al., 2012; O'Hanlon, 2013).

The second highest scoring indicator was "Someone to support my child during religious education." The presence of an individual assigned to walk alongside a child with ASD as he or she participates in activities within the church can provide respite for the parents of the child, so they can attend their worship services. It is interesting to note that both services parents perceive as being provided to the greatest degree involve an individual reaching out to provide assistance to the family in need. Neither support represents a congregational effort to address the issue at hand. A solitary approach, such as the services described above, can be of concern to a family. When a single entity is responsible for maintaining a program for children with special needs, a problem can arise if the individual leaves the church or is no longer able to fulfill the position. Often when the individual departs the church, the service terminates, and the support diminishes as well (Terry, 2015).

The indicator "A resource center for families with disabilities" was perceived as provided the least by participants in the study. Again, the finding is harmonious with the findings of Carter, Boehm, et al. (2016) as the least often reported available support. Therefore, the service deemed most helpful in Research Question 4 was also reported as the least provided by faith communities.

Research Question 6: Does a church's implementation of inclusive support services for children diagnosed with ASD represent a statistically significant predictor of the parent's commitment to volunteerism?

Research Question 6 was associative and predictive in nature. A liberally interpreted statistically predictive effect ($p = .10$) was manifested in the predictive model. A larger sample size may have increased the predictive power of the indicator.

The results indicate a tendency for parents of ASD children who feel supported by their church to be more inclined to donate their time and energy via volunteering efforts. Despite the fatigue and stress resulting from caring for a special needs child, many ASD parents demonstrate a willingness to contribute resources and alter their schedules to support churches that include their children. Often parents volunteer by sharing their knowledge and experiences. Parents may develop outreach programs, create disability ministries, and teach religious education classes to increase the participation of their sons and daughters in faith communities (Ault et al., 2013a).

However, many parents may feel limited in their ability to volunteer due to the challenging and atypical symptomology exhibited by their children. One parent wrote on the margin of the survey, "I can't volunteer due to nobody to watch child." The comment reiterates the isolation ASD parents may feel when they are unable to participate in similar activities as other congregants. Parents may be willing to contribute their God-given talents and abilities to their church but find they are unable to do so as a result of their child's unique behavioral oddities (Terry, 2015).

Research Question 7: Does a place of worship's provision of inclusive support services predict the likelihood of monetary giving by the parent of a child with ASD?

Research Question 7 was also associative and predictive in nature. A non-statistically significant predictive effect was manifested in the predictive model ($p = .17$).

The results indicate an inverse effect indicating the more provisions by a faith community, the less financial contributions donated by a parishioner.

Although surprising, the results may be more reflective of a societal shift regarding tithing in general. During the last three decades, charitable donations to religious institutions have decreased by approximately 50%, although charitable giving in the USA has increased (Giving USA Foundation, 2015). The current trend indicates Americans are providing monetary gifts to philanthropic causes but are directing their offerings to establishments other than the church. When explicitly addressing donating on a regular basis, approximately 3-5% of the U.S. population tithe, and the majority of tithers (80%) give 2.5% of their income to their local church (Nonprofits Source, 2018).

Another factor to consider is that parents of children with autism have significant out-of-pocket expenditures related to their child's care, including but not limited to expenses for medical assistance, medications, therapeutic programs, special dietary supplements, private schools, and speech therapy (Zuleyha, Marcus, & Mandell, 2012). On average, ASD costs an estimated $60,000 a year through childhood, with the bulk of the costs in special services and lost wages related to increased demands on one or both parents (Center for Disease Control and Prevention, 2018). Additionally, many of the autism specific therapeutic services needed are not covered or only partially covered by private health care, resulting in financial implications for the family (Zuleyha, Marcus, & Mandell, 2012). Although speculative, it seems the extenuating financial burdens related to an ASD diagnosis may impact a family's monetary contribution to the church.

Research Question 8: Does a church's implementation of inclusive support services for children diagnosed with ASD represent a statistically significant predictor of the parent's overall level of commitment to that church?

Research Question 8 is associative and predictive in nature. A statistically significant predictive effect ($p = .03$) as manifested in the predictive model, with a concomitant predictive effect approaching medium ($d = .38$). For every full unit of increase of inclusive supports provided, there is a .4 unit of increase in overall commitment to the church.

The findings of Research Question 8 are congruent with previous research in the domains of commitment and organizational support. The theory of perceived organizational support focuses on an individual's perceptions concerning the extent to which an organization values their contributions and cares about their well-being (Eisenberger et al., 1986). Further, Eisenberger et al. contended the resulting relationship between the individual and organization is rooted in social exchange theory. According to social exchange theory, individuals act on the basis of the norm of reciprocity to seek a balance between the favorableness of their actions toward the organization and the organization's actions toward them (Eisenberger et al., 1986). Thus, the high regard and caring conveyed by perceived organizational supports should help fulfill socio-emotional needs and be repaid, in part, by supportive organizational behaviors such as an increased level of commitment.

In the current study, the result of Research Question 8 highlights the relationship between perceived organizational support from a faith community and a parent's commitment to a church. Parents who perceived the church as implementing helpful inclusive support services reported a higher level of an overall commitment to that church. In relation to social exchange theory, the perception implies parents feel a sense of loyalty to a church that regards their family as worthy

as witnessed by an effort to accommodate their unique needs. Parents may reciprocate these feelings through a variety of actions that can be beneficial to a faith community such as active participation and volunteering their time and gifts. The factors affecting a parent's overall commitment level to a place of worship are complex and multilayered, but the perceived level of inclusive services appears to be an essential factor for parents of ASD children.

Study Limitations

As in all studies, the research was not without limitations that need to be considered when interpreting the findings. First, a few characteristics of the study sample hindered the generalizability of the results. The two sites selected for participation in the study were purposive in nature and located in central Florida. Amongst the respondents, several homogeneous factors were present. Eighty-seven percent of the parents surveyed were married, 71% identified as Caucasian, and the only two denominations parents reported affiliation with were Catholic and Protestant. Therefore, the sample may not be representative of the larger population of parents with children diagnosed as ASD. Additionally, even though the sample size (n = 31) allowed for data to be reliably analyzed, the strength of the study could have been enhanced with a larger number of participants.

Second, the data were drawn exclusively from quantitative methods allowing only numeric responses. The format of the survey was limited to close-ended responses and did not allow the researcher to establish follow-up questions to confirm the accuracy of data or to expand upon responses. The addition of open-ended questions would have potentially created avenues for integrating personal reflections to more richly describe the experiences and encounters of parents of children with ASD.

Implications for Professional Practice

The study provides new insights into the influence of inclusive services and supports provided by faith communities for parents of children diagnosed with ASD, adding to the sparse body of literature concerning the issue. The number of children diagnosed with ASD has increased dramatically in the past decade (Baio et al., 2018). As a result, an abundance of research has focused on a variety of social and community supports that can be provided to assist children and families affected by the diagnosis. However, one milieu that has not received significant attention is faith communities. Understanding parental perspectives regarding congregational efforts to embrace ASD children, as well as how the presence or lack of these services can influence the commitment level of parents to their places of worship, is vital in creating an environment that provides not only effective assistance but also fosters spiritual development for all family members. While additional research is warranted, some implications can be drawn from the study.

Implications for Faith Communities

Parents raising children with a diagnosis of ASD face unique challenges associated with the diagnosis. Participation in a faith community and the utilization of spiritual beliefs can assist parents in many ways, including developing coping mechanisms for dealing with the daily stressors that accompany the disorder and give meaning to the disability (Poston & Turnbull, 2004). In the study, results showed that faith communities can provide specific supports and services that are deemed helpful by parents of children with ASD. Due to the multifaceted strengths and needs of children with ASD, parents may perceive a variety of services as being advantageous depending on their unique circumstances. However, from the research, nine supports emerged as being universally beneficial, including support groups for parents,

congregation-wide disability awareness efforts, resource center for families, an advocate to work with the family, respite care, spiritual counseling from a congregational leader, modifications to religious education programs, a spiritual plan for the child, and someone to support the child during religious education.

Further, the research participants indicated at a significant level that the helpfulness of the inclusive support "Family Resource Center" was most important. The finding is consistent with research by Carter, Boehm, et al. (2016) in which over 69% of the parents described family resource centers as being somewhat or very helpful. Past research has highlighted that ASD parents are seeking more than just Sunday school classes for their families (O'Hanlon, 2013). ASD families desire truly holistic programs such as resource centers that extend outside the walls of the church and assist not only the child with the diagnosis but the entire family. A need exists for spiritual communities to recognize that parents and siblings also require support and care to better cope with the stressors of raising a child with a disability. Also, families wish for these provisions to continue throughout the week and not cease to exist once they walk out the doors of the church on Sunday.

Additionally, recognizing and understanding a parent's perception of helpful inclusive services and creating provisions of these supports is a critical first step in creating spiritual communities that integrate ASD families. The overall results of the current study indicated a striking discrepancy in this area. The participants in the study reported the provision of inclusive services were minimal and for the most part not available. More importantly, when supports were provided, they were not the services families found to be most helpful. The finding is supported by other research in which parents have reported dissatisfaction with the level and types of support provided by their places of worship (Ault et al., 2013a; Poston & Turnbull,

2004; Speraw, 2006). It is clear from the study that before creating and implementing programs

for ASD children and their families, faith communities would be behooved to engage parents in

conversation concerning their specific needs and the manner in which to address the request.

Programs and tools that church leaders and members may consider advantageous may not be

held in the same regard by the intended recipients.

Implications for Pastors and Church Leaders

Poston and Turnbull (2004) stated, "Families who choose to incorporate spirituality and

religion into their individual and family life want to turn to religious institutions for information

and support" (p. 103). Likewise, in the study, parents reported the provision of spiritual

counseling from a congregational leader as the inclusive service offered to the greatest degree.

Consequently, expectations are present that church leaders will possess the expertise and skills to

provide guidance to these families, although in truth, they may have no formal training in this

area. Therefore, to bridge the gap in knowledge, the utilization of educational resources and

collaboration with experts in the field may be needed.

However, not only should church leaders be personally educated, but they should

champion efforts to engage the entire congregation in these efforts. Past research indicates the

support derived from faith, the opportunities for church involvement, and the encouragement

from a supportive church community are important factors for families of special needs children

(Gajeton, 2016; Howell & Pierson, 2010; Speraw, 2006). However, the results of the study

indicate the services most provided are solitary in nature. Most congregations are not including

ASD families. A family cannot feel a part of a place of worship if the pastor and church staff

only acknowledge them. Leaders in the church need to guide their congregations concerning

how to involve ASD families in their churches.

Implications for Positive Collaborations

In a society where church participation is declining nationwide (Pew Research Center, 2015), the population of ASD families appears to be overlooked as a captive audience that seeks to be involved and connected in faith communities. However, these families often experience difficulty identifying a place of worship that is accepting of the child and his disability (Speraw, 2006). The results of the current study indicate that when families identify a supportive environment, they are likely to express their appreciation by reciprocating with helpful behaviors. Specifically, the findings indicated at a significant level a tendency for parents of ASD children who feel supported by their church to be more inclined to donate their time and energy via volunteering efforts. The willingness to give back to the spiritual community can create a fruitful collaboration where both entities are benefitting from the experience. Through the partnership, the families would reap support and spiritual nourishment and the church would gain the unique skills, talents, and expertise that the individuals in the familial units can bring to the congregation.

Another encouraging finding from the study is at a significant level: Parents of ASD children who perceive the church as implementing helpful inclusive services report a higher level of overall commitment to that church. It appears not only do parents appreciate the provision of services but at a deeper level form an allegiance and devotion to the religious organization offering these services. Meyer and Allen (1991) pointed out that individuals who are committed to an organization have a sense of belonging and identification that increases their involvement in the group's endeavors, their willingness to pursue the goals of the organization, and their retention with the institution. As a result, church leaders who recognize the magnitude of

promise that can be found in creating inclusive programs for ASD families stand to receive innumerable positive outcomes in return.

Recommendations for Future Research

Reflections on the procedures and outcomes of the current study have generated recommendations for possible future research that may be beneficial to all members of faith communities.

Sample Size and Demographics

The study focused on the views of families from one city located in central Florida. The experiences and opinions of parents in the sample may differ from those of parents living in other states and regions. To overcome the homogeneity of the characteristics of participants and small sample size, future researchers should replicate the study in other locations and seek out a broader array of families from different cultural, economic, and denominational backgrounds.

Increase Perspectives

Although the study provided an opportunity for parents of ASD children to impart their perspectives on factors associated with their participation and the inclusion of their sons and daughters in congregational life, far less is known about the ways in which congregational members and church leaders understand these same issues. Future researchers should explore the perspectives of these critical stakeholders to inform the development of useful models for supporting congregational inclusion.

Families that Departed

The study interviewed parents who were actively involved in a church and who reported attending on a regular basis. Families who have left congregations or left the faith altogether would also bring a unique and valuable perspective on how the attitudes and actions of faith

communities left them feeling unwelcomed or excluded. Future studies could be focused on the viewpoints of these families in order to identify barriers to their participation and possible actions the church may have taken to prevent their departure.

Qualitative Method Studies

Future studies might include a qualitative or mixed-method approach to add to the depth and thickness of existing quantitative results. Giving a voice to parents of ASD children would allow the researcher to understand the challenges and hardships experienced by these families more fully. Hearing about ministries, programs, and individualized services that parents value and covet can help church leaders shape the trajectory of programs designed to reach and serve this population.

Conclusion

Understanding how to fully support and integrate children with ASD and their families in faith communities is an integral step in providing all members, regardless of their limitations, spiritual guidance, connections, and involvement. The current study adds to the limited research available concerning the topic, and the findings fill a gap in the literature regarding parental perspectives of inclusive services for a child with a diagnosis of ASD and the influence of the supports on the parental commitment level to a faith community. Associations among inclusive services and the parent's level of commitment to a place of worship highlight the importance of providing helpful and meaningful programs, ministries, and practices and suggest new directions for research on the integration of ASD families in faith communities.

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APPENDICES

Appendix A

Dear Potential Participant,

My name is Susan Moerschbacher and I am a doctoral student at Southeastern University. I am writing to invite you to participate in a research study regarding inclusive services and supports provided by faith communities to children diagnosed with Autism Spectrum Disorder. I obtained your contact information from Dr. Taylor who suggested you may be willing to participate. The survey will take approximately 5 -10 minutes to complete, and all responses will be confidential.

Thank you again for considering this research opportunity.

Sincerely,

Susan Moerschbacher, M.A.

PARTICIPANT INFORMATION SOUTHEASTERN UNIVERSITY

Title: An Exploration of Parental Perceptions of Inclusive Services and Supports Provided by Faith Communities for Children Diagnosed with Autism and their Families

Investigator(s): Steven J. Henderson, Ed.D.
Associate Professor
Southeastern University

Susan Moerschbacher, M.A.
Student, Ed.D. in Organizational Leadership
Southeastern University

Purpose: The purpose of the research study is to explore the perspectives of parents of children diagnosed with Autism Spectrum Disorder (ASD) regarding the inclusive supports and services provided by their congregations. Additionally, the availability of these services, as well as the parent's commitment level to the place of worship providing the supports, will be evaluated. You must be 18 years or older to participate.

What to Expect: Participation in the research will involve completion of one questionnaire. In the first portion of the questionnaire, you will be asked to indicate the helpfulness and availability of congregational provided supports designed to assist children with ASD. In the second portion of the questionnaire, you will be asked to respond to questions regarding congregational commitment. You may skip any questions that you do not wish to answer. It should take you about 5-10 minutes to complete.

Risks: There are no risks associated with the project which are expected to be greater than those ordinarily encountered in daily life.

Benefits: There are no direct benefits to you. However, you may gain an appreciation and understanding of how research is conducted.

Your Rights and Confidentiality: Your participation in the research is voluntary. There is no penalty for refusal to participate, and you are free to withdraw your consent and participation in the project at any time.

Confidentiality: The records of the study will be kept private. Any written results will discuss group findings and will not include information that will identify you. Research records will be stored on a password protected computer in a locked office and only researchers and individuals responsible for research oversight will have access to the records. Data will be destroyed five years after the study has been completed.

Contacts: You may contact any of the researchers at the following addresses and phone numbers, should you desire to discuss your participation in the study and/or request information about the results of the study:

Susan Moerschbacher, M.A.
smoerschbacher@seu.edu
(863) 255-3290

Steven Henderson, Ed.D.
sjhenderson@seu.edu
(863) 667-5369

If you have questions about your rights as a research volunteer, you may contact the IRB Office
IRB@seu.edu

If you choose to participate: Please complete the enclosed questionnaire. By completing the survey, you are indicating that you freely and voluntarily agree to participate in the study and you also acknowledge that you are at least 18 years of age. Once you answer the provided questions, please place the survey in the provided packaging and seal the envelope. No one other than the researchers will have access to your responses.

Follow up letter

Thank you to the parents who completed the survey last week. If you did not have an opportunity to complete the survey, the invitation to participate has been extended. Your input is valuable and will assist in identifying congregational support services that are important to families of children diagnosed with ASD. The survey will only take 5 – 10 minutes to complete. If you have any questions, please do not hesitate to contact me.

Thank you for your time and consideration,

Susan Moerschbacher

smoerschbacher@seu.edu

(863) 255-3290

Please return the completed survey by Wednesday, September 19th.

Please indicate how helpful each support would be in raising your child:

	S.A.	Agree	Uncertain	Disagree	S.D.
Support group for parents	5	4	3	2	1
Congregation-wide disability awareness efforts	5	4	3	2	1
Resource center for families with disabilities	5	4	3	2	1
An advocate to work specifically with families	5	4	3	2	1
Respite care	5	4	3	2	1
Spiritual counseling from a congregational leader	5	4	3	2	1
Modifications to religious education programs	5	4	3	2	1
A spiritual or religious education plan for my child	5	4	3	2	1
Someone to support my child during religious education	5	4	3	2	1

My current place of worship provides this support

	S.A.	Agree	Uncertain	Disagree	S.D.
Support group for parents	5	4	3	2	1
Congregation-wide disability awareness efforts	5	4	3	2	1
Resource center for families with disabilities	5	4	3	2	1
An advocate to work specifically with families	5	4	3	2	1
Respite care	5	4	3	2	1
Spiritual counseling from a congregational leader	5	4	3	2	1
Modifications to religious education programs	5	4	3	2	1
A spiritual or religious education plan for my child	5	4	3	2	1
Someone to support my child during religious education	5	4	3	2	1

Composite Score

Congregational commitment variables - (Please circle the answer that reflects your response)

1. How often do you attend a place of worship?

 At least weekly   2-3 times a month   Once a month   Several times a year

 Once or twice a year   Never

2. How long have you attended your current place of worship?

Do not attend   One year or less   2-4 years   5-9 years   10-19 years   20+ years

3. How often do you volunteer at your place of worship?

At least weekly   2-3 times a month   Once a month   Several times a year   Once or twice a year

Never

4. a. How often do you tithe or provide financial contributions to your place of worship?

On a regular basis   Only during special events/occasions   Never

  b. If you tithe on a regular basis, what percentage of your income do you contribute annually to your place of worship?

0 – 5%   6- 10%   More than 10%

5. Overall, how would you rate your perception of commitment to your place of worship?

High   Moderate   Low   None

Demographic information

Age:

Current marital status:

Ethnicity:

Religious affiliation/ denomination:

Do you have a child diagnosed with ASD?