SANCTUARIES, “SPECIAL NEEDS,” AND SERVICE: FAITH COMMUNITY LEADER PERCEPTIONS ON INCLUDING CHILDREN WITH DISABILITIES

by

Jared Stewart-Ginsburg

A thesis submitted to the faculty of
The University of North Carolina at Charlotte
in partial fulfillment of the requirements
for the degree of Master of Education in
the Child and Family Studies Program

Charlotte

2018

Approved by:

____
Dr. Cynthia Baughan

____
Dr. JaneDiane Smith

____
Dr. Belva Collins

ABSTRACT

JARED STEWART-GINSBURG. Sanctuaries, “Special Needs,” and Service: Faith Community Leader Perceptions on Including Children with Disabilities. (Under the direction of DR. CYNTHIA BAUGHAN)

Religion plays an important role in providing support, purpose, and positive emotional health in the life of a family with a child with a disability. Yet studies on parent and child perceptions indicate that many families struggle to feel accepted and supported by faith communities. Faith communities are defined as a group of people who share a particular set of religious beliefs and rituals and are often principally led by a member of the clergy, who is ordained or licensed by a religious denomination or association. Religion and the communities that teach and espouse such values have a proclivity to influence the greater community, which necessitates that even unaffiliated community members should take interest in what occurs inside. This study investigates the experience, knowledge, and attitudes of faith community leaders on including children with disabilities and their families in faith communities. Participants include clergy and non-ordained laity who serve in a leadership capacity in churches, synagogues, and mosques. The study utilized a mixed-methods approach to include quantitative data through an online survey and qualitative data through semi-structured focus groups. The Faith Community Leader Inclusion Perceptions survey was administered to assess leader perceptions. Three hundred six participants completed the anonymous survey and four focus groups with a total of 13 participants were conducted. Demographic data were analyzed to determine relationships between demographic variables and survey responses. Thematic analysis was conducted on transcribed data from the qualitative focus groups designed to make meaning of participant responses. Observations of trends found in these responses were explored. Data from both measures were corroborated to explore relationships between both data sets and the relationship to the body of literature.

DEDICATION

Thank you to my parents, Keith and Gina, for showing me what it looks like to persevere, encouraging me to take chances, and kvelling over everything. Thank you to my sister, Hannah, for telling me jokes when I needed a laugh. Thanks to Mr. and Mrs. Stewart, Janie, Matt, Amanda, Dustin, and Ridge for the love shown through calls, texts, and Bitmojis. Thanks to Matt and Sallie Anna for your encouragement and friendship.

Words fail to fully express the gratitude I have for Amy Stewart-Ginsburg, whose thoughtfulness and selflessness serves as a daily inspiration. Your good sense and sagacity is what led me to begin this degree and thesis in the first place and what grounds me every day. You love dangerously, recklessly. I am thankful for every single hug, curry dinner, nudge, listening ear, round of dishes, and minute you gave as I worked on this. Thank you for your unending patience and insight to see this as important, meaningful work and listen to my ideas. Thank you for the encouraging sticky notes I kept in my pockets and read frequently. I am privileged to know you and live in your sunshine.

This work is dedicated to the memory of Phillip Klippel. May his memory be a blessing, and may we honor his memory in the way we love others. Go Eagles.

ACKNOWLEDGEMENTS

My sincerest appreciation to Dr. Cynthia Baughan, my faculty research chair, for scholarly wisdom, direction, endless rounds of revisions, and seeing this project as much more than just a thesis. Thanks to Dr. JaneDiane Smith, who challenged me to pursue this topic and continued to ask tough questions, and to Dr. Belva Collins, in whose scholarly footsteps I am privileged to walk in and whose legacy I look forward to continuing.

TABLE OF CONTENTS

LIST OF TABLES

CHAPTER 1: INTRODUCTION

Religion plays an important role in providing support, purpose, and positive emotional health in the life of a family with a child with a disability (Ahlert & Greeff, 2012; Ault et al., 2013b; Balsundaram, 2007; Marshall et. al., 2003; Michie & Skinner, 2010; Poston & Turnbull, 2004; Shogren & Rye 2005; Skinner et al., 2001; White, 2009). Yet studies on parent and child perceptions indicate that many families struggle to feel accepted and supported within faith communities (Howell & Pierson, 2010; Jacober, 2010; O'Hanlon, 2013; Pitchlyn, Smith-Miles, & Cook, 2007; Trealor, 2000; White, 2009). Faith communities are defined as a group of people who share a particular set of religious beliefs and regularly participate in religious rituals together. Faith communities are often principally led by a member or members of the clergy, who is ordained and/or licensed by a religious denomination, association, or network.

1.1 Statement of the Problem

For families that recount positive experiences within faith-based communities, one of the major contributing factors is the attitude and encouragement of leaders in faith communities (Griffin et al., 2012). Leaders of faith communities have the ability to shape and impact programs, policy, and attitudes, all of which can make a child with a disability and their family feel welcomed and appreciated. Yet despite the influence leaders hold to promote inclusion in a faith community, little empirical research has been conducted to demonstrate the perceptions of a wide body of faith community leaders towards children with disabilities and inclusion in their respective faith community. Perceptions can best be described as the conglomeration of experience (past encounters and situations), knowledge (current skills and conceptualizations), and attitudes (outlook and operational stances).

Several studies (e.g., Howell & Pierson, 2010; Jacober, 2010; Skinner et al., 2004) found that parents felt community leaders lacked proper training and experience in serving in ministry with persons with disabilities. However, these studies stopped short of identifying where potential gaps in this training and/or experience lie and how they can be filled.

1.2 Research Questions

The purpose of this study was to examine a nuance of the relationship between faith communities and families of children with disabilities by investigating the perceptions of faith community leaders. This study aimed to answer the following questions: a) What experiences, knowledge, and attitudes do faith community leaders possess in including children with disabilities in the faith community? b) What is the influence of participant demographics on these experiences, knowledge, and attitudes? c) What training do faith community leaders desire to receive on including children with disabilities in the faith community?

CHAPTER 2: REVIEW OF THE LITERATURE

In order to examine relevant literature, keyword searches were conducted using various combinations of the terms *child, clergy, disabilities, faith community, inclusion, perceptions, perspectives, special needs, spirituality, religion,* using the PsychINFO and ERIC databases, respectively.

2.1 Theoretical Background

In examining the relationship between religion and families of children with disabilities and special needs, it is helpful to understand the theoretical framework that underpins this discipline. For the purpose of this study, religion is defined in two distinct, but similar, manners. The first is a set of personal understandings, beliefs, and practices related to understanding and connection with a divine, spiritual God, Presence or Being. This definition can also be understood as "faith" or "spirituality." The second part to the definition of religion is formal participation in community rituals, practices, and gatherings designed to express and build these personal understandings. It is important to note both the personal aspect of religion as well as the social-communal aspect.

Faith communities are understood to be formal, structured organizations that exist to offer opportunities for ritualistic worship, personal faith formation, religious education, and socialization amongst those who engage in these activities. The term 'faith community' is purposefully nonspecific in terms of religious identification so as to include many distinct religious traditions.

Religion and faith communities are often falsely seen as isolated forces that do not affect those who do not participate in them. Yet faith communities are often instrumental in influencing the ideologies, viewpoints, and priorities of those who faithfully participate in them. This triggered activism and interest can influence society on both local and national levels, leading prominent media experts to call for an increased scholastic and journalistic study of religion and its leaders (French, 2016; Gross, 2016; Wecker, 2015).

Religion can be a pervasive influence on a family. Bowen's Family Systems Theory asserts that families function as a systemic unit (Bowen, 1966). Each member has a role to play and rules to respect. Inside of this system, certain patterns emerge as the behavior of individual family members influences and is influenced by the behavior of other family members. Kerr (2000) builds on this notion to incorporate religion, maintaining that participation in a religion (both as a family unit and larger community) is seen as a factor in the way a nuclear family responds to stress and conflict. Bronfenbrenner's (1994) Human Ecology Model also informs this intersection: participation in religious institutions (included in the Mesosystem) impacts the values and beliefs of an individual.

In considering the applied purpose of religion, Frank's (1995) concept of "wounded storytellers" is helpful in understanding how spirituality can play a role in constructing meaning of a disability. The Wounded Storyteller model focuses on first-person stories of individuals affected by illness or disability and their search for meaning in the challenges that the disability brings. Storytellers create or reclaim their own voice and story within or against the backdrop of a medical narrative consisting of charts, test results, diagnosis, and prognosis, with the understanding that they speak for others who have not yet found their voice.

A scholastic focus on religion and spirituality in children with a disability is a crucial field. Harris (2015) attests that children with disabilities may conceptualize and organize spirituality and religion in different ways that align with the disposition of their disability, and that attention to the spiritual domain can help children with disabilities foster a sense of personal worth, respect, dignity, and belonging. The author adds that spiritual well-being is best fostered in an inclusive environment, which exists when “children with and without disabilities are physically engaged and interact with one another as a community in a variety of activities” (Harris, 2015, p. 162). Harris adds that children with disabilities are often categorized in religious contexts as ‘the least of these’ (Matthew 25:40, Common English Bible), but instead possess much wisdom to share with others.

Jacober (2010) identified openness to inclusion as a “spiritual journey,” and asserted that it is crucial to take into account the journey that leaders of faith communities experience. Catholic theologian and priest Henri Nouwen served as a priest-in-residence with *L’Arche*, a community for adults with intellectual disabilities. In writing about the way the community helped develop his spirituality, he identified the move from exclusion to inclusion as one of the key seven movements of spiritual maturity (Nouwen, Christensen, & Laird, 2010), citing the need for faith communities to “create space for a wide range of human experience” (p. 91).

While clergy members typically lead rituals, rites, sacraments, and faith formation opportunities, the scope of influence in a faith community is not limited to these individuals. Many congregations operatively function under what Harris (2004) referred to as the Distributed Model of Leadership. Harris suggested this as a “way of thinking about leadership,” asserting, “distributed leadership concentrates on engaging expertise wherever it exists within the organization rather than seeking this only through formal position or role” (p. 13). While only one or two individuals may have the title of rabbi, imam, or pastor, dozens of individuals within a faith community hold leadership positions as lay staff, teachers, group leaders, and committee members.

The goal of fully including children with disabilities and special needs applies to all environments in which individuals immerse themselves; thus, inclusion is an ongoing practice. TASH (2000), an international advocacy association of persons with disabilities, maintains that "children and adults with disabilities should have opportunities to develop relationships with neighbors, classmates, co-workers and community members" (para. 5), and that community organizations should be oriented toward viewing and presenting persons before their disability.

The American Association on Intellectual and Developmental Disabilities (AAIDD) and the Arc (2010) published a joint position statement on spirituality and inclusion, maintaining that spirituality and religious expression are important aspects of human experience, and persons with disabilities should be able to choose to express or not express this aspect in a manner they see fit. They add that faith communities should welcome and support individuals with intellectual and/or developmental disabilities, nurture their families, provide inclusive age-appropriate supports and programs, and work with other organizations to develop inclusive practices and resources. Full inclusion in faith communities is a multi-disciplinary recognized objective. Anderson (2015) summarizes these theoretical understandings:

> But rather than being something we 'do,' inclusion must reflect who we 'are.' Being inclusive starts with understanding a theology of interdependence, which promotes hospitable classrooms and draws on principles of biblical justice.
>
> (p. 183)

2.2 The Role of Religion

The role of religion has been increasingly studied as an influence on physical, emotional, and mental health for both individuals and families (Ahlert & Greeff, 2012; Gallagher et al., 2015; Harris, 2015). The conception of 'religion' operatively conglomerates theological belief, faith, personal spiritual disciplines/practices, and participation in a faith community (Skinner et al., 2001).

The study of religion naturally forms an intersection with the study of early intervention and special education when considering the influence of religious practice and participation in families of children with disabilities and developmental delays. Michie and Skinner (2010) found that religion can assist in parents' ability to make meaning of parenting a child with a disability. They investigated this transition in mothers of children with Fragile X syndrome (FXS), specifically in terms of the construction of a disability narrative. 'Narrative,' an anthropological term, is a mechanism used to positively reframe perspective (Frank, 1995). The authors applied Frank's model and used the framework of an existing study to analyze semi-structured interviews with 60 mothers of children under the age of 12 who had FXS, an inherited genetic disorder. The study participants comprised a diverse spread of religious affiliation (including five mothers who claimed no religious affiliation).

The researchers did not explicitly mention religion in the study; instead, they pinpointed religious and spiritual themes in hopes of assessing the scope of the role that religion plays. They found that 62% of the participants indicated that religion was a daily source of meaning, support, or encouragement (Michie & Skinner, 2010). All mothers who indicated this support were either Catholic or Protestant. Mothers from lower income households were slightly more likely to include a religious narrative. Sixty-eight percent of mothers reported that religious faith was either important or extremely important, and 55% of participants indicated that their religious faith had assisted in understanding FXS in their family.

Interestingly, two mothers responded ambivalently in explicitly attributing the role religion plays in their family, yet their narratives included heavy religious themes. Michie and Skinner (2010) hypothesized that this is due to the mothers' perception of what constitutes a religious lifestyle. Parents may not frequently attend a house of worship or subscribe to an established creed or theological profile but may still rely on faith or personal religiosity as a way of making meaning of a complex situation in their lives. The theology that the mothers expressed points to one of reconciliation: themes of "getting well," "heroic returns from illness," and their child's diagnosis as being a burden or curse gave way to perceiving disability as a meaningful blessing and making peace with their child's disability (Michie & Skinner, 2010).

The role of religion in families of a child with a disability is not limited to children with Fragile X Syndrome. Ahlert and Greeff (2012) conducted semi-structured interviews with parents to identify resilience qualities that support families. Each parent had a child under the age of 10 years who was deaf or hard-of-hearing. Fifty-four families participated in semi-structured interviews; the sample participants mostly (87%) identified as non-white and were mostly (93%) mothers. Religion was not a central focus in the study, but it emerged as an important component. Parents were asked to list the most important factors or strengths that have helped their family cope with their child's disability. Thirty-three percent of respondents listed 'faith in God' (the second most-frequent response after support from school and professionals) and 13% of participants responded ‘viewing the child as a gift from God’ (Ahlert & Greeff, 2012). Faith gives both purpose and meaning to caring for a child who is deaf or hard of hearing, which enhances family functioning (Ahlert & Greeff, 2012).

Skinner, Correa, Skinner, and Bailey (2001) examined the role of religion in the lives of Latino families of children with a developmental delay. The researchers conducted interviews in Spanish with 250 parents of Mexican or Puerto Rican heritage who had a child younger than six years of age with a developmental delay. Ninety-two percent of families reported being somewhat or very religious, and the same percentage reported membership in a faith community (Skinner et al., 2001). On average, parents reported attending religious activities slightly less than once a month, but responses regarding frequency varied (e.g. *never* to *more than once a week*). Personal theology and faith were significant methods of support for parents. Mothers reported a higher level of personal faith than did fathers, but there was no significant difference between married and unmarried parents. Parents stated that their personal faith provided a much higher level of support than their faith community/congregation (Skinner et al., 2001).

The influence of disability on religion (and vice versa) was interesting to note; an overwhelming majority of both mothers and fathers reported that their faith increased after receiving a diagnosis on their child’s condition. Concurrently, half of the participants stated that their participation in religious activities remained the same or decreased after this diagnosis; a third of fathers reported an increase in participation. Those who attended said the church rituals provided experiences that gave them strength, socioemotional support, and practical aid, though many parents did not feel that the church provided direct support to their child and family (Skinner et al., 2001).

Poston and Turnbull (2004) studied the effects of religion on quality of life outcomes of parents and siblings of a child with a disability, conducting focus groups and individual interviews. Many parents spoke of a personal reliance upon God for coping with the daily rhythms of the disability; half of the parents spoke of using their faith as a way to make some sense of their child having a disability or the disability being a gift from God.

Marshall et al. (2003) conducted a qualitative descriptive study using semi-structured interviews with 32 parents who were members of the Church of Jesus Christ of Latter Day Saints. All families had at least one child with a developmental delay under the age of 18 years. Families reported positive adaptation over time and the important role their personal faith played in making peace with their child's disability and providing strength both for them and their families. Families relayed that this journey of adaptation was often hampered by well-meaning church members who offered theological advice and interpretation, such as telling them that if they had more faith or prayed enough, their child would not have a disability. Despite this, parents generally felt their faith community was supportive.

Balasundaram (2007) conducted semi-structured focus groups with an undisclosed number of mothers of children with an intellectual disability in a colony in South Delhi, India. The mothers lived in communities of extreme material poverty that lacked substantial health and sanitation facilities and identified with either Islamic or Hindu faith traditions. As part of a weekly support group, the author investigated the role that faith played in the mothers' feelings toward and acceptance of their child's disability. The mothers expressed that as their child's disability worsened, they continued to lose faith and trust in their God. One mother believed her situation was *karma* (the belief that previous actions in this and previous states of existence determined fate in this and future existences) at work and was discouraged when the *pujari* (priest in the Hindu temple) told her that her two children born with an intellectual disability would improve. She saw her plight as a punishment, yet expressed that over time she came to believe that God gave her strength. This seeming paradox was a theme that consistently emerged with mothers' responses.

In a qualitative interpretive study, Chang and Hsu (2007) explored the perceptions of 117 Taiwanese parents of children with a disability by conducting semi-structured interviews. Religion was not a central focus of the study, but respondents indicated that spirituality and religious beliefs held distinct meanings for them. All of the parents interviewed identified as practicing Buddhists. Many parents relayed that their religious beliefs had assisted in accepting and understanding their child's disability and relieving stress. Other parents described participating in religious rituals as an attempt to bring healing to their child. The authors concluded that religion forms the foundation of parents' support system and that religious groups can offer a supportive environment for these families (Chang & Hsu, 2007).

Luong, Yoder, & Canham (2009) conducted interviews with nine parents of children between the age of three and 10 years with mild to severe Autism Spectrum Disorder (ASD) diagnoses. The study was designed to determine and understand their coping mechanisms. The eight mothers and one father who participated were first-generation Southeast Asian immigrants to the United States and identified as either Buddhist or Catholic. All nine participants expressed that they used religious practices to cope with their child's diagnosis, which they found beneficial. "Religious practices, such as simple praying at home, recharged their hope" (p. 227), and spirituality helped them to feel a sense of purpose.

Jegatheesan, Miller, and Fowler (2010) extended this inquiry by exploring explicitly religious themes in Muslim families raising children with ASD against a backdrop of a more prevalent xenophobic climate. The parents from the three families who participated emigrated from South Asia to the United States and had a five or six-year-old son with an Autism Spectrum Disorder diagnosis. Ethnographic measures were employed for this longitudinal study; the researchers conducted interviews with caregivers and utilized audio and video recordings of the family designed to elicit religious themes and practices. The families reported a high level of religiosity. The families' religious practices and beliefs were direct influencers of the deep understanding they had of their children with ASD: they expressed the belief that this is God's child, and they were chosen to love and protect this child. Each caregiver expressed the desire for their child to be included in everyday life and religious rituals. Fathers shared experiences of bringing their sons with them to the mosque to pray and attested that their faith community was not bothered by their son's wandering or atypical behavior during prayers because they understood he had a disability.

White (2009) conducted a study of parents of children diagnosed with ASD. Most of the 177 participants were mothers (87%); their children ranged from two to 31 years of age, with a mean of nine years. White found that parents who reported higher levels of religiosity were more accepting of their child's diagnosis and possessed a greater well-being. However, they found both positive and negative aspects of religious involvement, most of which involved barriers to involvement in religious organizations for children with

Autism and their parents. White identified several important supports that a faith community could provide to help families of children with Autism participate, including leaders who carried a “perspective of openness and acceptance” (p. 112).

Shaked (2005) investigated ultra-Orthodox Jewish mothers raising children with ASD in Israel. The tight-knit ultra-Orthodox community discourages assimilation into normative society. Thirty mothers participated in the study, along with three fathers. Most of the children did not participate in religious rituals, even those who were required to by religious law, as the strict religious regulations deem them “unclean” or “deviant” due to characteristics involving the way their diagnosis presents. Twenty-five mothers communicated the belief that their children had a mystical connection with the divine due to their disability. Several parents reported negative experiences with *rabbis* and spiritual leaders in the community. For example, one mother went to a well-respected rabbi with her family in hopes of obtaining a blessing. The rabbi spoke a blessing on each member of the family, except for the child with Autism. She engaged in norm-defying advocacy and insisted that she would not leave until he blessed her son. Another mother shared an experience of a spiritual leader scolding her for relying upon medical advice, instead of his, to support her child.

> In a study exploring stress and well-being in families of children with ASD, Ekas, Whitman, and Shivers (2009) highlighted the relationship between religiosity and stress. One hundred nineteen mothers completed a survey as part of a larger study on stress. Each mother had at least one child who had an ASD diagnosis and was younger than 18 years old. They found that religious beliefs and spirituality were associated with greater positive and fewer negative maternal socioemotional

> outcomes; however, greater involvement in religious activities were associated with fewer positive and more negative outcomes and uniquely predicted parenting stress, parenting affect, and depression. “Strong religious and spiritual beliefs appear to assist an individual in appraising life and its challenges in a different more positive light” (p.716), but the authors theorized that involvement in religious activities with their children with ASD produced stress and/or “religious institutions do not offer the supports mothers are seeking” (p. 717).

Gallagher, Phillips, and Lee (2015) examined the relationship between spirituality and depression in caregivers (primarily parents) of children with developmental disabilities. The 32 parents who participated in the study cared for a child between the ages of three and 19 years; two-thirds of those children had an ASD diagnosis. The results confirmed a negative association between depression and social support, which the authors found unsurprising. What the authors did find surprising was that spirituality was positively related to depression: “parents who held stronger spiritual beliefs reported more depressive symptoms” (Gallagher et al., 2015, p. 362).

To further examine this finding, the researchers designed a second qualitative study. Five parents from the previous sample were invited to participate. Each showed high scores on the spirituality scale and scored quantitatively for potential depression. The five women reported diverse religious affiliations: one identified as Muslim, one as Protestant Christian, three as Roman Catholic, and one identified a mixed religious heritage (Christian and Muslim) but had no official faith community affiliation. Three participants cared for a child with Autism, one participant cared for a child with Down syndrome, and one participant cared for a child with Trisomy 18 (Gallagher et al., 2015).

The authors conducted and analyzed one-hour interviews with each parent. They found that personal spirituality was mainly used as a crucial source of support, but religion was viewed as both a source of comfort and frustration. Frustration occurred when parents perceived that their prayers were left unanswered and their situation unchanged. A need for respite away from the caregiving role strongly emerged; the authors theorized that this is why faith communities are often found to play a critical role in helping parents cope. The positive influence of religion, it seems, is most potent when personal spirituality is teamed with the support of a faith community who can provide respite (Gallagher et al., 2015).

The influence of religion and faith is not limited to parents of children with disabilities. Liu, Carter, Boehm, Annandale, and Taylor (2014) investigated the role of religion in the lives of teenagers and young adults. The authors conducted interviews with 20 participants with an intellectual disability diagnosis or Autism Spectrum Disorder diagnosis, ages 13 to 21 years old. Six participants were female, 14 were male. Nineteen participants affirmed a “personal” relationship and/or connection with the Divine, which was expressed through daily communication and prayer. Thirteen participants addressed participation in religious activities. When they did participate, these activities almost always took place at segregated disability-focused ministries and groups unaffiliated with the participant’s home faith community. All participants had little to no involvement in the youth activities sponsored by their home faith community, and only two respondents mentioned participating in religious education in inclusive settings.

Advocacy work in faith communities hinges on the capacity of parents to build self-efficacy in advocating for their children, which leads to a higher level of perceived effectiveness (Wright & Taylor, 2014). Yet parental advocacy in faith communities is a nuanced concept because parents and family members spend most of their week advocating in other settings for their child, and desire that their faith community be a place of respite for their family, their child, and them (Michie & Skinner, 2010). In studying parental self-efficacy, for example, Wright and Taylor (2014) found that only 22% of families advocated for their child in a faith community setting. Of those who did, only 31% found it effective or highly effective.

2.3 Parent Perceptions of Inclusion in Faith Communities

Because of the important role that personal and corporate religion plays for families of children with disabilities, it is important to consider how families perceive faith communities in regards to including their child with a disability or developmental delay. Trealor (2000) attempted to provide insight through a qualitative study on perceptions of inclusion in faith communities. Thirty participants were interviewed, including 13 parents of children with developmental disabilities, nine adults with physical disabilities, and eight other family members. The participants were primarily Caucasian and all identified with a Christian faith. Three parents did not attend a church, citing the stress of caregiving and the lack of provided accommodation as reasons. A young adult chose not to attend church because the people at the church made him feel detached and different from the group . Each parent stated that their present faith community or the faith community they had most recently held membership at had, to some degree, fallen short of their expectations and failed to fully support their family. Many parents described the constant fight they engage in to ensure that their child's needs are being met in their faith community, advocating and pressuring leaders to make sure their child(ren) is/are included. Parents described the difference between physical accessibility and what the author called 'attitudinal accessibility.' Only two participants had ever heard a pastoral lesson that addressed disabilities. The lack of teaching and perceived irrelevance of the Bible and sacred texts in regards to disability caused several parents to distance themselves from faith communities and/or religion in general. Parents also expressed the desire for faith community leaders to ask about ways to support their family (Trealor, 2000).

Howell and Pierson (2010) continued this inquiry in focusing on parents of children with Autism Spectrum Disorder. They conducted semi-structured ethnographic interviews with four mothers of 12 children. Seven of the mothers' children had an Autism Spectrum Disorder diagnosis, and the interviews focused on the child's participation in their church's Sunday School program. Each family attended a different church (each of a different size) in a southern California suburban community. The mothers each indicated that their faith community was aware of their child(ren)'s diagnosis. Overall, mothers felt that their faith community and leaders did not understand Autism. One mother cited being told that her child's behavior was a choice, leading to her belief that leaders and members of the faith community were not aware of the child's strengths and abilities. Another participant expressed her belief that those who work directly with her sons understand their strengths, though her sons do not have friends at church or interactions with their peers outside of the Sunday School environment (Howell & Pierson, 2010).

The mothers each had compelling suggestions for what the role of the church should be with respect to inclusion. Two key themes emerged: programming and leadership. Mothers indicated the need for churches to create multisensory, inclusive religious programs where all children could engage in meaningful participation, as well as family support programs, such as respite nights. Most of the suggestions, however, centered on leadership. All parents expressed the desire for faith community leaders to vocally support inclusion from the pulpit, learn about Autism, put knowledgeable persons in positions to train and work alongside volunteers, and pursue opportunities to educate the congregation as a whole in theological understandings of and responses to disability (Howell & Pierson, 2010).

O'Hanlon (2013) investigated the importance, availability, and satisfaction of faith community activities and supports to families and children with special needs. Fifty-eight parents of children with disabilities completed an online survey to measure these perceptions; the disabilities represented were cross-categorical. Parents' religious affiliations included Protestant, Muslim, Jewish, and Catholic, with Protestant being the largest group represented; the majority of parents (62.7%) attended faith community activities every week. Over 90% of the respondents rated all religious activities (religious education, form religious rites, worship gatherings, and youth activities, respectively) and the support from both religious leaders and members as *important* or *very important*. Parents reported that their children participated in religious education and social activities more often than worship services. Over 75% of respondents indicated that their overall experience was positive, but 66% of participants reported that their child had a negative experience in their community. Thirty-three percent of parents reported never receiving support from spiritual leaders. Families relayed that receiving support from faith community leaders was most important for their overall family participation. "Thus," the authors concluded, "religious communities need to self-examine to determine what they are contributing to this environment" (O'Hanlon, 2013, p. 55).

Jacober (2010) studied the experiences of families of adolescents with disabilities and their relationship with churches and youth ministries. Prior to the study, the author unsuccessfully attempted to recruit participants by asking more than two dozen religious education leaders and seminary professors if they had any students with disabilities in their youth group or knew of any teenagers with disabilities who attended their church. The answer was typically no. Several youth workers answered that the family had decided that the youth group was not a good fit. Parents and guardians from 17 families participated in semi-structured interviews. Of the parents who participated, a minority described positive encounters with ministries, but these were outnumbered by negative encounters. Families described hurtful experiences, such as being told a Sunday School teacher would not teach if their child was in her class, or that the church was unwilling to offer accommodations, or realizing that the experience of church had nothing to offer their child. Parents relayed the gifts that their children could offer their faith community, such as a deep connection with God, benevolent hospitality, and contagious joy. The author concluded with an implication for further research: understand the perspectives and spiritual journey of religious education leaders regarding including adolescents with disabilities (Jacober, 2010).

Poston and Turnbull (2004) examined how faith communities can enhance families' spiritual well-being. Several of the parents they surveyed described their religious community as a place of unconditional love and full acceptance, citing stories of their child finding joy in the music or singing in the choir. Other respondents, however, were less eager to praise, citing stories where their child encountered difficulty being accepted or not having perceived support. “There’s a lot of people [in the church] that don’t know how to deal with your autistic child,” one mother stated (Poston & Turnbull, 2004, p. 103). Parents explained that challenges from other aspects of life can be lessened through the strength offered in religious beliefs and faith community support. Several parents asserted they were seeking supports for their child in the faith community, but instead spent time providing those supports themselves instead of meaningfully participating in worship and community rituals.

In a descriptive study, Pitchlyn, Smith-Miles, and Cook (2007) investigated the extent that parents of children with cognitive disabilities perceive religion as a coping strategy. The authors surveyed 16 parents (half African-American, half Caucasian) in an urban, low-SES, high-poverty setting. The majority of parents self-identified as Catholic and all participants attended religious activities on a weekly basis. Sixty-nine percent of parents agreed that the clergy at their faith community was/were helpful to them when their child was diagnosed with a disability. When their child with cognitive disabilities was born, fifty percent of parents did not become more active in their church, seek out assistance from the church, or perceive the church as being more supportive to their family when compared to other agencies. Fifty percent of respondents also perceived that their personal religious beliefs helped them to make peace with their child's disability, provided strength, and brought them closer to God. The authors suggested the urgency for faith communities to be more assertive in embracing persons with disabilities and their families, and develop resources to provide information to congregants regarding disabilities.

2.4 Practices of Inclusion in Faith Communities

With many parents and children sharing the perception that they often feel unwelcome and misunderstood in faith communities, it is beneficial to understand which practices faith communities engage in to intentionally include children with disabilities and their families. Carter, Boehm, Annandale, and Taylor (2016) explored which congregation-provided supports were most helpful to parents. They also examined the availability of the supports, the faith community's responsiveness to persons with intellectual disabilities or Autism Spectrum disorder diagnoses, and with which factors (e.g., parent support groups, respite care, family advocates) this responsiveness is associated. The authors surveyed 433 parents or caregivers of adolescents and young adults with developmental disabilities. Most (85%) parent participants identified as the mother (biological, step-, or adoptive); parents identified with 35 different religious traditions, mostly Protestant Christian or Roman Catholic. Over half of the respondents indicated that they attended worship services at least once a week. The survey listed 14 potential supports, such as respite care, support groups, physical accessibility, special worship services, and family advocates. Parental perceptions of overall support was significantly positively correlated with the availability of individual supports. Almost half (44.9%) of the respondents said none of the supports were available in their faith community. The most frequently available supports were spiritual counseling from a faith community leader (found in 32.8% of participants' faith communities) and a physically accessible faith community (22.8%). A family advocate and resource center for families with disabilities were the least available supports (6.3% and 4.4% of respondents, respectively). The size of the congregation was positively correlated with the supports offered (Carter et al., 2016).

The authors also measured parent perceptions of inclusiveness. Interestingly, both the "highest and lowest levels of agreement [to a faith community being perceived as inclusive] related to congregational leadership" (Carter et al., 2016, p. 382). Most (89%) parents agreed or strongly agreed that the leaders of their faith community accepted their child with a disability, but fewer participants (69.2%) agreed or strongly agreed that the leaders of the faith community demonstrated a commitment to including people with an intellectual disability or Autism Spectrum disorder diagnosis. In the discussion, the authors noted a subtle nuance between "*acceptance* as a more passive response and *commitment* as a more active response" (Carter et al., 2016, p. 386). Acceptance, they theorized, was indicated by support for the presence of people with intellectual disabilities in worship and programs, whereas commitment was indicated by the availability of supports and the allocation of time, effort, and monetary resources to persons with intellectual disabilities and their families.

The authors also highlighted the fact that the study did not include perspectives of clergy and other faith community leaders. "Understanding their [clergy] perspectives on the support needs of families, the capacity of their congregation to address such needs, and the theological reasons for doing (or not doing so) is also a critical pursuit" (Carter et al., 2016, p. 386).

Vogel and Reiter (2003) employed a qualitative design to explore the significance of a *b'nai mitzvah* (child of the commandments/covenant) ritual ceremony for Jewish children with developmental disabilities. They observed and conducted interviews at two Masorti/Conservative Jewish programs in Israel that worked with 21 children with developmental disabilities. The authors found that the *bar mitzvah* and *bat mitzvah* ceremonies of each child contributed to the renewal of the entire community and that children with and without disabilities could benefit from and appreciate religious education and rituals shared by others. While the environment was self-contained, the program models could be generalized for inclusive environments as well.

Ault, Collins, and Carter (2013a) investigated the congregational participation of parents and caregivers of people with disabilities and their families. The authors surveyed 416 parents and caregivers who attended or had previously attended a faith community. The respondents came from 35 different states and the District of Columbia. Most were mothers who identified as Protestant or Catholic (89.5%), and cared for a child under the age of 18 (88%). Fewer than 5% of respondents identified as Buddhist, Mormon, or Jewish. Parents cared for children with Autism Spectrum Disorder and intellectual disabilities.

Almost all (97.6%) of the participating parents attested that their faith was important or somewhat important, though the children attended religious services slightly less frequently than their parents. The majority of parents (60.7%) stated that their children participated in faith formation activities (e.g., Sunday school and Vacation Bible School) with their peers and with or without support; 12.1% of respondents indicated that their children participated with younger peers with or without support (Ault, Collins, & Carter, 2013a). Parents responded that out of a list of nine factors, the most important in participation in faith communities are physical accessibility, welcoming attitudes, and additional support. Parents further admitted that the helpfulness of each support was higher than its availability. A minority (42.5%) of parents perceived their congregations as supportive; almost one third of parents said that they chose to attend a different faith community because they did not feel their child was welcomed. More than half of the respondents had never been asked the best way to include and support their children in religious activities by a faith community leader (Ault et al., 2013a). Parents of a child with intellectual disabilities were more likely to say that their faith communities were supportive than parents of a child with Autism. The authors concluded that faith community leaders and members may be uncomfortable with or untrained in working with individuals with disabilities and determined that it is necessary to study inclusion from the vantage point of faith community leaders and capture the nuance of the complex relationship (Ault et al., 2013a).

Ault, Collins, and Carter (2013b) found that 64.7% of parents provided comments about the absence of needed accommodations and the refusal of the church to provide such. Others shared experiences of encountering unwelcoming attitudes, such as a minister who refused to visit a family's home because their child with ASD made him feel uncomfortable, a priest who was aware of the child's disability but was still critical of the child's handwriting, or a pastor who had refused to allow a child with an intellectual disability to attend a camp because he said he did not have time to babysit. Parents relayed their children expressing that they felt ignored or made fun of by their peers. The authors listed a leader who advocates for inclusion as an important factor in the perceived level of support and inclusion. Parents stressed the value of training leaders and congregation members with knowledge and strategies to foster inclusion.

Slocum (2016) conducted a review of 22 articles focused on inclusion in faith communities. Most articles (66%) were theoretical, descriptive, or survey-based; the rest were literature reviews or case studies. Thirteen articles described a lack of meaningful inclusion in faith communities, three described cases where faith communities were engaged in intentional efforts to include children with disabilities and reported mixed results, and four described successful inclusion efforts.

Five articles recommended that special educators provide training in creating inclusive environments to faith communities; four suggested that seminaries include coursework on disabilities and special needs. Other articles recommended creating a task force to address inclusion in the faith community, making accommodations and modifications of religions education programs, and concentrating on strengths of individuals with disabilities (Slocum, 2016). Notably, each recommendation was related to the training, education, participation, and influence of leaders within the faith community.

2.5 Leadership in Faith Communities

Goldstein and Ault (2015) addressed these recommendations in a theoretical article listing a framework for including individuals with disabilities in a faith community. They relayed that faith communities described as inclusive featured supportive leadership who took initiative to listen and offer support, welcomed community expertise, provided training, modeled inclusive attitudes, provided support to families of individuals with disabilities, and followed up on progress. The authors noted that partnership between faith community leaders, families, and community resources is the most successful approach. As the previous strands of literature indicate, this is often not the case in praxis, resulting in what appears to be a vast disconnect between the needs of families and the perceived abilities of faith community leaders.

For many faith community leaders, the journey of faith community leadership formally begins at a graduate-level theological training school or seminary. In a theoretical article, Anderson (2003) summarized the lack of experience that many seminaries attest to, quoting an oft-heard phrase: “our institution has no expertise with this area of study” (p.133), concluding that in theological education, pastoral theology professors may briefly mention disability, but there is typically no overall plan for building theological responses to disability or inclusive practices into the curricula.

Kleinert, Sharrard, Vallance, Ricketts, and Farley (2010) extended the inquiry into experiences of seminarians. They created a Family Mentorship program that paired 25 seminary students with a family of a child with a disability as part of a required externship for a pastoral care class. The student was required to complete three visits with the family in a variety of settings and reflect on the experience. The disability diagnoses included Autism, Down Syndrome, and Cerebral Palsy. Participants were trained in expectations, disability etiquette, and person-first language before beginning their visits. All of the students that participated were upper-level students, ranging in age from 24 to 60 years old. On a retrospective pretest, more than three quarters of the students reported that their knowledge about services available to persons with disabilities, potential treatment by the public, impact on a family, and the unique needs and challenge a person with a disability faces was *not at all, minimal,* or *somewhat.* The largest change from pretest to posttest following the externship experience was an increase in awareness of the unique needs and challenges faced by persons with a disability and their families in relation to a faith community.

Francis and Jones' (2015) study adds to the picture, indicating that clergy seem reluctant to discuss disability in a theological context, let alone actively advocate for inclusion. The authors explored the relationship between psychological type and Hermeneutical Theory, where the interpretation and dialogue between the text and reader is shaped by characteristics of both the text and reader. Twenty-three Anglican clergy in a residential training program (12 women and 11 men) were grouped according to their Myers-Briggs Type Indicator profile in two series of groupings. They were given two passages of Christian scripture and asked to ruminate upon what elements of the text they would reflect upon in a sermon or homily. The two passages utilized were suggested for use on Disability Awareness Sunday, a pan-denominational day of observance. Observances differ by faith community and denomination, but most faith communities participate in this day by discussing issues related to the needs of persons with disabilities and utilizing persons with disabilities to lead worship. In both scripture passages that participants studied (Mark 2:1-3 and Mark 10:46-52, respectively), Jesus 'heals' a man with a disability (a man born blind and a man who was paralyzed) by removing their disability and tells each that their sins are forgiven.

After reading the passages, participants expressed confusion over the notion of pairing physical healing of a disability with forgiveness of sin. They also admitted concern that this may bewilder members of their congregation who have disabilities. Theological discussions ensued as clergy members attempted to reconcile their theological understanding of disability and the nature and characteristic of God in an applied theodicy. Many clergy members also expressed the desire to find another passage of scripture to use for the observance or find someone else to preach on the passage. The overall study conveys the uncertainty and discomfort that clergy experience when preaching and teaching about disability and illness (Francis & Jones, 2015).

McNair and Sanchez (2007) further explored the theological understandings of faith community leaders toward disability. The authors chose a sample frame of pastors and church leaders enrolled in the National Organization on Disability Accessible Congregations Campaign and used random sampling to select every seventh church on the list. The sample of 41 pastors included churches from 11 denominations (mostly Lutheran). The majority of respondents disagreed that parents were selected by God to have a child with a disability, that the disability is a result of sin, that possessing enough faith could bring healing, that God gives someone a disability because God has a special mission for them to accomplish, and that people with disabilities have disabilities in order to teach others about life. While these are the majority conclusions, they are far from a monolithic opinion: each question had at least 20% percent of participants responding unsure or in agreement with the above statements (McNair & Sanchez, 2007).

Respondents agreed overwhelmingly that people with or without a disability are equal in the eyes of God (97.6%) and created in the image of God (100%). Most clergy (64.1%) believed that persons with cognitive disabilities are unaware of the fact that they have a disability; some expressed they were unsure (28.2%). Answers to whether or not persons with intellectual disabilities suffer from their disability were widely varied (McNair & Sanchez, 2007). One of the open ended questions asked why persons with intellectual disabilities and other disabilities are present in the world. The answers were incredibly diverse: some answered with specific reasons, such as genetics, accidents, the completion of God's work, reflecting and spreading God's love, and "confounding each of us." Other respondents felt it was a direct effect of sin and living in a 'fallen world' (a world in which evil is present due to human imperfection). Seven participants answered they simply did not know (McNair & Sanchez, 2007). The overarching conclusion was the presence of confusion about several of the theological issues surrounding disability.

The distributed model (Harris, 2004) is reflected in LaRocque and Eigenbrood's (2005) survey of 91 faith communities (Jewish, Protestant, Catholic, and Muslim communities, respectively, in order of highest percentage included). Respondents used a 4-point Likert scale to self-report where their faith community stood (*not started, getting* *started, well on our way,* and *we're there*) in relation to 14 statements measuring congregational commitment to inclusion from the National Organization on Disability. A majority of respondents indicated that their faith community was *well on our way* or *we're there* for statements measuring physical and attitudinal accessibility and inclusive environments. However, the majority of respondents indicated that their faith community had *not started* or were *getting started* on items that reflected a systemic change toward inclusion, such as recruiting persons with disabilities for leadership roles. Interestingly, the five components that reflect a systemic change toward inclusion each derive from knowledgeable and supportive leadership (LaRocque & Eigenbrood, 2005).

The scholastic inquiry into the perceptions of leaders of faith communities is even supported by marketplace research. Leaders in the workplace (at all levels) who have experience in, knowledge of, and a favorable attitude toward including individuals with disabilities naturally create workplace environments where persons with and without disabilities and special needs thrive and work together (Gilbride et. al., 2003).

McGee (2010) explored ways in which pastoral leaders can include families with children with Autism Spectrum Disorder in Catholic congregations. McGee theorizes:

> ...it is the combination of juggling priorities, lack of knowledge or expertise, assumptions about the role and guidelines of pastoral leadership, the lack of support, lack of mentors, the lack of skills...that can cause leaders to shy away from developing inclusive catechetical programs for children with disabilities (p. 290).

To remedy this, McGee recommends that pastoral leaders view their role as minister first, embrace a view of sacraments as sacred action rather than performance, and give more attention to the 'why we do this' (understanding) behind sacraments than the ‘what to do and where to go’ (action and logistics). McGee attests “without a pastoral advocate who is willing to invite families into our liturgical celebrations, religious formation, and sacramental preparation programs, it is virtually impossible for families to feel affirmed in their faith and welcomed” (p. 291).

2.6 Summary

Religion and personal faith play a pervasive role in families of children with disabilities, providing parents, siblings, and caregivers with the ability to accept and make meaning of their child’s disability (Ahlert & Greeff, 2012; Marshall, et al., 2003; Michie & Skinner, 2010; Skinner et al., 2001). Religion offers children with disabilities the opportunity to foster a sense of personal worth and belonging (Harris, 2015; Liu et al., 2014). Religion is most beneficial to families when practiced in the context of a supportive faith community that fully includes children with disabilities (Gallagher, 2015). Faith communities often fall short of providing this environment because of active barriers and attitudes, passive apathy, or lack of understanding (Howell & Pierson, 2010; Jacober, 2010; O’Hanlon, 2013). When families feel excluded by faith communities, they begin to lose faith and are denied the opportunity to foster meaningful, supportive connections (Gallagher, 2015; Poston & Turnbull, 2004; Trealor, 2000).

Findings in the literature indicate that the most common and essential factor in a faith community moving toward inclusion is clergy and lay leadership throughout the faith community (Harris, 2004) that is empathetic and supportive of families with disabilities and knowledgeable of ways to include persons with disabilities in the faith community (Ault et al., 2013a; Larocque & Eigenbrood, 2005; McNair & Sanchez, 2008; Vogel & Reiter, 2003). Most seminaries and training programs for clergy do not strategically address issues concerning disabilities (Anderson, 2003; Kleinert et al., 2010); thus, many members of the clergy personally wrestle with theological issues concerning disability and feel uncomfortable discussing these issues (Francis & Jones, 2015; Kleinert et al., 2010). Several studies suggest studying the perceptions of faith community leaders regarding including children with disabilities and special needs (Ault et al., 2013a; Carter, et al., 2016; Jacober, 2010; O'Hanlon, 2013; Trealor, 2000; Slocum, 2016), yet the body of literature stops short of addressing these important issues. Since leadership is the most influential factor in a faith community including families with children with disabilities, it is necessary to understand what experience, knowledge, and attitudes faith community leaders possess so that the field can further understand how to equip leaders with the knowledge and strategies to include children with disabilities within their faith community.

CHAPTER 3: METHODOLOGY

This study utilized a mixed-methods design, involving both quantitative and qualitative components, to investigate the perceptions of faith community leaders on including children with disabilities in faith communities. Research findings may be useful to understand where gaps exist in equipping faith community leaders to fully include children with disabilities and special needs. For the quantitative component, an online survey was used to collect the perceptions of current faith community leaders and faith community leaders in training. For the qualitative component, focus groups of current faith community leaders and faith community leaders in training were conducted to collect in-depth perceptions.

3.1 Rationale

In many studies within the body of literature regarding perceptions of inclusiveness in faith communities, the most potent and frequently-mentioned factor in meaningfully including children with disabilities in faith communities is the practices exhibited by faith community leaders (Ault et al., 2013a; Larocque & Eigenbrood, 2005; McNair & Sanchez, 2008; Vogel & Reiter, 2003). Several studies (e.g., Ault, Collins, & Carter, 2013a; Carter, et al., 2016; Jacober, 2010; O'Hanlon, 2013; Slocum, 2016; Trealor, 2000) specifically highlight the need to study the prior experiences, current knowledge, and attitudes of faith community leaders regarding this topic; yet few studies have explored these perceptions. This study attempted to focus specifically on this strand of research. Because of the limited body of research regarding these perceptions, it was important to collect many perspectives to illustrate a broad picture and explore why these perceptions exist. This study employed the Distributed Model (Harris, 2004) as a framework to understand the perspectives of individuals in different roles who serve faith communities. Harris advocated that the Distributed Model allows for leaders to develop a reciprocal learning process where all professionals have gifts to offer to the organization. Rather than only limiting the study to a specified role, the inclusion criteria included leaders at various levels who hold influence in faith communities.

3.2 Participants

The term "faith community leaders" is intentionally broad and encompasses many faith traditions and positions within the faith community organization (Harris, 2004). This study focused on two populations: (1) practicing, ordained or licensed clergy serving a local faith community or denomination and (2) lay (non-ordained) staff members who serve a local faith community. Following Institutional Review Board approval, potential participants were found through denominational organizations in three states in the southeastern United States. The researcher shared participant inclusion criteria with denominational and network contacts. These contacts then provided a contact list of potential participants who met the inclusion criteria. The contact list included only e-mails and no names. These e-mail listservs were compiled into a database of all potential survey participants. Concurrently, social media posts were made in two electronic community groups that were likely to include a population that met the inclusion criteria. Out of the 1,636 e-mail contacts that denominational contacts provided, 306 faith community leaders completed the survey for an 18.7% response rate.

Survey respondents varied widely in their age range, with no major plurality (See Table 1 for participant demographics). Most participants served as either a senior/lead minister capacity (37.6%), a religious education director (29.1%), or an associate/assistant minister (24.5%). Others served in various support roles (See Table 1 for participant roles). Respondents reported a wide range of experience (see Table 3 for participant experience), with most serving in this capacity for ten years or less (57.2%). The nature of training for the role in which they currently serve varied, with most participants indicating they completed training at a seminary or graduate theological preparation program. Participants also differed on the faith community denomination they represented (see Table 5). The largest religious tradition represented was Christianity, with a cumulative 199 respondents (65%) identifying with this faith tradition. Ninety participants (29.4%) represented a Jewish faith community and 17 respondents (5.5%) served an Islamic faith community.

Faith community demographics. Faith communities were also diverse in terms of size and membership (see Table 2 for demographics of participants' faith communities): the three most frequent sizes were between 100 and 249 members (22.5%), 250 to 499 members (24.5%), and 500 to 749 members (14.4%). Settings of faith communities also varied, with most participants (81%) serving a faith community in an urban or suburban setting.

Participants were asked to indicate words using a multi-select option that described the worship style of their faith community. 'Contemporary' was most often selected, followed by 'traditional.' 'Contemporary' often references a style of worship that is written with the present context in mind in terms of presentation, delivery, and music. A contemporary service will often feature music performed on a variety of instruments and a band-based approach. The worship leaders or presiders may wear more casual clothing, and lyrics to songs may be projected for congregants to use during the service (Burke & Selz, 2012). Traditional worship, conversely, typically references a style of worship that emerges out of a current local tradition and incorporates period-inspired music, often with a choir, piano/organ, and orchestral instruments (Burke & Selz, 2012).

Focus group participants. Thirteen faith community leaders participated in four focus groups. Faith community leaders represented a variety of roles, age ranges, experience levels, and contexts (see Table 8 for focus group participant demographics). Three participants were in what they referenced as ‘dual roles,’ meaning they served as a faith community leader, but also as a parent of a child with a disability or diagnosis. These included two associate ministers and one lead minister.

3.3 Setting

The online survey was hosted on Qualtrics, a secure survey site. Potential participants were found through denominational organizations in three states in the southeastern United States. In-person focus groups were held in private, secure locations.

3.4 Instruments

Faith Community Inclusion Perceptions (F-CLIP). The F-Clip is a researcher-adapted instrument based on three peer-reviewed constructs: (a) Attitudes to Inclusive Education and Specific Disabilities Scale (Haq & Mundia, 2012), (b) the Teacher Attitudes to Mainstream Inclusion of Children with Speech and Language Difficulties Measure (Sadler, 2005), and (c) the Intellectual Disability Literacy Scale (Scior & Furnham, 2011). The questions were reworded to make them contextualized and applicable for faith community leaders instead of the measure’s intended population of classroom educators. The F-CLIP measure collected eight pieces of demographic data on the respondent and their respective faith community and included 18 questions designed to measure experiences, knowledge, and attitudes. Twelve questions measured perceptions on a yes/no rating scale, four questions ask respondents to measure perceptions with a multi-select response, and one question measures perceptions with a Likert scale. A case study was then presented, which contains follow-up questions on a yes/no rating scale. No personally identifying information was collected.

Focus Groups Discussion Guide. The focus group discussion guide is a researcher- adapted instrument based on two published instruments that measure attitudes on inclusion (Hsieh & Hsieh, 2012; Scior & Furnham, 2011). Question stems from the original measures remain intact, but the questions were reworded to utilize language relevant to faith community leaders. Focus group sessions included the questions on the attached interview protocol; however, additional questions were added as indicated by the continuous analysis of quantitative data from the online survey results. The researcher employed follow-up questions based on participant answers to these questions in order to elicit details and further information.

3.5 Piloting of the Instruments

Prior to the current study, the researcher piloted both the survey instrument and the focus group prompts to determine feasibility. Because the instruments used were adapted by the researcher, it was imperative to ensure they were valid and reliable. The researcher conducted a pilot focus group with five participants matching the population after consent was given. The online survey was piloted by 10 personal contacts of the researcher. Feedback was collected for both pilots and slight revisions in word choice and phrasing were made based on feedback in order to ensure clarity and context.

3.6 Procedure

Quantitative component. Participants completed an electronic version of the Faith

Community Leader Inclusion Perceptions (F-CLIPS) measure, hosted on Qualtrics, a secure survey site. The online survey was used to collect data between September 2017 and January 2018. Data received were in no way connected to email addresses used for recruitment. The Qualtrics survey was also set up so that no private identifiable information was collected. Online survey data were directly inputted into SPSS for analysis. Participants in the survey did not participate in the focus groups.

Qualitative component. In-person focus groups were organized and conducted through contacts at denominational offices. These contacts were given participant inclusion criteria and provided an e-mail list of potential focus group participants to the researcher who met the inclusion criteria organized by region in one southeastern state; these participants were separate from those included on the survey contact list. The PI contacted individuals on the e-mail list and requested their participation in the focus group. Four focus groups were conducted in February and March 2018. Focus group sessions were recorded, transcribed, and double-coded for meaning and thematic analysis. Focus groups were conducted in a semi-structured format and included the questions on the interview protocol.

Before entering the secure room, the researcher met with all of the potential focus group participants to offer and explain the notice of informed consent that outlines potential risks/rewards, the research process, the inclusion criteria for participation, and voluntary nature of participation. They were asked to review the consent form on their own. The PI invited them to enter the secure room, explaining that by entering the room, they are indicating consent and acknowledging they meet the inclusion criteria. The PI invited them to dismiss themselves from the study, if they choose to for any reason, by not entering the secure room. They were not asked to sign the consent form as to not collect any personally identifying information. Focus groups lasted between one and two hours. All focus groups participants provided consent; groups were conducted and recorded in a quiet, neutral location where the participants were not in danger and there was no intimidation or coercion.

Focus group sessions were audio recorded, transcribed, and double-coded. Participant full names were not used during focus group discussions. Any unintentionally gathered identifying information shared during focus group discussions was removed from transcriptions. Further, no data can be connected to email addresses used for recruitment.

3.7 Data Collection

This study began in August 2017 and continued through March 2018. The online survey was used to collect data between August and December 2017. Focus groups were conducted in February and March 2018. Online survey data were directly entered into SPSS (IBM Corp., 2013) for analysis. Focus group sessions were recorded, transcribed and coded for meaning.

3.8 Data Analysis

Quantitative data analysis. Data analysis for the proposed study included an in-depth analysis for trends and patterns in the collected descriptive survey data and relationships between survey items. The PI also analyzed demographic data to find relationships between demographic data and survey responses.

Qualitative data analysis. Thematic analysis was conducted on transcribed data from the qualitative focus groups designed to make meaning of participant responses. Transcribed data were double-coded by the principal investigator and the faculty committee chair and compared to ensure validity. Observations of trends found within these responses was explored. Data from both measures were corroborated to explore relationships between both data sets.

CHAPTER 4: RESULTS

4.1 Quantitative Findings

The responses that participants provided in the online survey are presented as they pertain to the research questions, beginning with demographics of both participants and the faith communities they serve. Participants experiences, knowledge, attitudes, desired future training, and response to a case study are then presented.

Table 1

Survey Participant Demographics

Factor	Frequency N = 306
Age Range	
18-24 years old	10 (3.3%)
25-30 years old	33 (10.8%)
31-35 years old	52 (17.0%)
36-40 years old	42 (13.7%)
41-45 years old	24 (7.8%)
46-50 years old	36 (11.8%)
51-55 years old	34 (11.1%)
56-60 years old	28 (9.2%)
61-65 years old	31 (10.1%)
65+ years old	16 (5.2%)
Participant Role	
Senior/Lead Minister	115 (37.6%)
Associate/Assistant Minister	75 (24.5%)
Religious Educator/Education Minister	89 (29.1%)
Seminary/Graduate Student	6 (2.0%)
Music Director/Minister	5 (1.6%)
Special Care/Special Needs Staff	3 (1.0%)
Outreach/Community Coordinator	4 (1.3%)
Executive Director/Executive Board Member	3 (1.0%)
Preschool/Day School Director	3 (1.0%)
Other/Non-specified	3 (1.0%)
Participant Experience	
Fewer than two years	42 (13.7%)
Between two and five years	66 (21.6%)
Between five and 10 years	67 (21.9%)
Between 11 and 20 years	77 (25.2%)

Between 21 to 30 years	34 (11.1%)
30 years or more	20 (6.5%)
Training*	
Seminary/Graduate-level theological preparation program	199 (65%)
Graduate degree, not related to religious preparation	63 (20.6%)
I have had no formal training	55 (18%)
Undergraduate religious degree	53 (17.3%)
Graduate religious certificate/coursework	42 (13.7%)

Note. *Percentages may not add up to 100 as participants were asked to check all that apply.

Table 2

Participant Faith Community Demographics

Factor	Frequency N = 306
Religious Denomination/Affiliation	
Christian – Protestant Evangelical	102 (33.3%)
Christian – Protestant Mainline	93 (30.4%)
Christian – Catholic	2 (.7%)ers
Christian – Orthodox/Coptic	1 (.3%)
Christian – Unitarian	1 (.3%)
Jewish – Reform	37 (12.1%)
Jewish – Conservative	30 (9.8%)
Jewish – Reconstructionist	15 (4.9%)
Jewish – Orthodox	7 (2.3%)
Jewish – Renewal	1 (.3%)
Islamic – Sunni Tradition	16 (5.2%)
Islamic – Shiia Tradition	1 (.3%)
Size of membership (count individuals)	
Fewer than 100	21 (6.9%)
100 to 249	69 (22.5%)
250 to 499	75 (24.5%)
500 to 749	44 (14.4%)
750 to 999	27 (8.8%)
1000 to 1999	37 (12.1%)
2000 to 2499	19 (6.2%)
2500 to 4999	10 (3.3%)
5000+	4 (1.3%)
Context of faith community	
Suburban	146 (47.7%)
Urban	102 (33.3%)
Town/Village	36 (11.8%)
Rural	22 (7.2%)
Style of worship*	
Contemporary	155 (50.7%)
Traditional	151 (49.3%)
Informal	102 (33.3%)
Blended (more than one style)	101 (33.0%)
Formal	54 (17.6%)
Contemplative	34 (11.1%)

Note. *Percentages may not add up to 100 as participants were asked to check all that apply.

Experiences of faith community leaders. Most survey respondents indicated that they had served at least one child with a disability or developmental delay, though 12 faith community leaders (3.9%) responded that they had not. Most respondents (283 or 92.4%) had served at least two children with two distinct diagnoses, and 141 respondents (46.1%) noted that they had served a child with multiple disabilities/diagnoses. See Table 3 for experiences of faith community leaders.

The majority of participants (86.9%) responded they knew a child with a disability or developmental delay outside their work in their current faith community. Those who answered yes then indicated or listed where or how they made this connection, with options for more than one response. The most common points of connection were through a friend, colleague, or neighbor (n = 67), through a family member (n = 49), or through previous work. Responses indicating that the point of connection was through previous work, their spouse's/partner's work, or through coursework were all in the field of education, social work, and/or health.

Table 3

Experiences of Faith Community Leaders

Factor	Frequency N = 306
Previous experience by diagnosis	
Learning disability	262 (85.6%)
Autism Spectrum disorder	247 (80.7%)
Behavioral disorder	215 (70.3%)
Intellectual disability	189 (61.8%)
Physical disability	178 (58.2%)
Multiple disabilities/diagnoses	141 (46.1%)
Health impairment	130 (42.5%)
Communication disorder	128 (41.8%)
Hearing impairment	102 (33.3%)
Vision impairment	83 (27.1%)
I have never served a child with a disability	12 (3.9%)
Source of connection*	
Through a friend, colleague, or neighbor	67 (21.9%)
They are a member of my family	49 (16.0%)
Through previous work	39 (12.7%
Through volunteer and/or community involvement	29 (9.5%)
I am the parent of a child with a disability	27 (8.8%)
Through work in a previous faith community or camp setting	22 (7.2%
Through involvement in a school	19 (6.2%)
Through my spouse's/partner's work	3 (1.0%)
Coursework in the field of education, health, and/or social work	3 (1.0%)

Note. *Percentages may not add up to 100 as participants were asked to check all that apply.

Participant knowledge. Two hundred ninety-two participants (95.4%) completed this section, where respondents provided answers regarding their knowledge on including children with disabilities. Eighty-eight respondents (30.1%) said they had received training on ways to include children with disabilities in faith communities as part of their preparation, while 199 respondents (68.2%) said they had not. Five participants (1.7%) indicated they did not know whether they had received training. This question intentionally did not define ‘training’ so as to serve as a catch-all for all methods that faith community leaders considered training. See Table 4 for participants’ knowledge.

Table 4

Survey Participant Knowledge

Factor	Frequency N = 298
Source of training*	
Workshop, seminar, or conference	40 (13.7%)
Elective seminary course/topics covered in seminary class	14 (4.8%)
Undergraduate courses	8 (2.7%)
Previous work experience	6 (2.1%)
Informal or on-the-job training	6 (2.1%)
Through a graduate degree, unrelated to faith communities	3 (1.0%)
Through an internship or volunteer experience	3 (1.0%)
Through a congregational member	3 (1.0%)
Clinical Pastoral Education coursework	2 (.7%)
Self-study or self-directed research	2 (.7%)
Self-perception of understanding of laws	
Yes	87 (29.8%)
Somewhat	147 (50.3%)
Not at all	58 (19.9%)
Self-perception of adequate preparation	
Yes	40 (13.7%)
Somewhat	126 (43.2%)
Not at all	126 (43.2%)
Self-perception of skills/abilities by diagnosis	
Learning disability	205 (70.2%)
Physical disability	186 (63.7%)
Autism Spectrum disorder	173 (59.2%)
Intellectual disability	159 (54.5%)
Health impairment	147 (50.3%)
Behavioral disorder	146 (50.0%)
Hearing impairment	122 (41.8%)
Multiple disabilities/diagnoses	118 (40.4%)
Communication disorder	111 (38.0%)
Vision impairment	107 (36.6%)
None of these	59 (20.2%)

Note. *Percentages may not add up to 100% because participants were able to check as many as apply.

Participants who indicated they had received training listed the methods and settings for which this training had occurred, with options for multiple responses. The most common method was through a workshop, seminar, or conference (n = 40), but courses in seminary, graduate degrees, undergraduate degrees, previous work, internship training, and informal training were also listed as methods of training. Three respondents indicated that a member of their congregation had provided training for them.

Participants then ranked their agreement with statements on perceptions and attitudes toward inclusion. The first statement assessed their familiarity with laws that concern making faith communities accessible to children with disabilities. As with ‘training,’ ‘laws’ were not defined so as to allow a variety of conceptualizations. Eighty-seven respondents (29.8%) indicated *yes*, 147 leaders (50.3%) indicated *somewhat*, and 58 respondents (19.9%) chose *not at all*. Most respondents (86.4%) indicated *somewhat* or *not at all* in agreement with the statement “I believe my theological training adequately prepared me to include children with disabilities in the faith community.”

Participants indicated whether they had received support and/or resources from their denomination, organization, or association to make appropriate accommodations or provide support for children with disabilities; 187 participants (64.0%) said they had, while 105 participants (36.0%) said they had not. This question was followed up by asking leaders if they knew where they can find additional support for serving children with disabilities and their families. Most leaders (78.1%) said they did, with 64 participants (21.9%) indicating they did not.

Participants then indicated whether they feel they have the skills and knowledge to include children with specific diagnoses, with options for multiple responses. Learning disability (n = 205) and physical disability (n = 186) diagnoses were the most often selected. Except for these two categories, fewer than 60% of respondents indicated they felt they had the adequate skills to include children with each diagnosis. Fifty-nine participants (20.2%) answered that they felt they did not have adequate skills and knowledge to include a child with any of these diagnoses in their faith community.

Participant attitudes. Two hundred eighty-seven participants (93.7%) completed this section of the survey. Nineteen participants elected not to complete this part. Respondents were presented with several statements and asked to rank their agreement on each item. These items measured their agreement with theoretical underpinnings in the introduction to the Individuals with Disabilities Education Act of 2004 (IDEA), contextualized for faith communities instead of the classroom. The reference to IDEA was not provided.

Participants overwhelmingly (99.3%) responded that children with disabilities should be given the opportunity to worship in the same environment as children without disabilities (See Table 5 for participant attitudes). Most respondents (76.0%) disagreed that children with disabilities are best served worshipping with other children with disabilities.

Participants indicated whether or not they believed that children with disabilities learned better when grouped together with other children like them. This language, while condescending in the view of the researcher, is patterned after several observations of faith community leaders using the same verbiage. Seven participants said *always* (2.4%) and 14 said *never* (4.9%), with 266 participants (70.7%) answering *sometimes.* Most participants said they felt comfortable communicating with children with disabilities and their parents (70.7%, 75.3%, respectively).

Table 5

Survey Participant Attitudes

Factor	Frequency N = 287
"Children with disabilities should be given the opportunity to worship in the same environment as children without disabilities."	
Yes	285 (99.3%)
No	2 (.7%)
"I feel uncomfortable communicating with children with disabilities."	
Yes	19 (6.6%)
No	203 (70.7%)
Sometimes	65 (22.6%)
"I feel uncomfortable communicating with parents of children with disabilities."	
Yes	18 (6.3%)
No	216 (75.3%)
Sometimes	53 (18.5%)
"I ask families of children with disabilities about their needs and goals before making a plan of faith formation."	
Yes	227 (79.1%)
No	60 (20.9%)
"I feel comfortable articulating my personal theology of disability."	
Multiple disabilities/diagnoses	118 (40.4%)
Communication disorder	111 (38.0%)
Vision impairment	107 (36.6%)
None of these	59 (20.2%)

Two hundred twenty-seven participants (78.1%) indicated that they ask families of children with disabilities about their needs and goals before making a plan of faith formation, while 60 respondents (20.9%) did not. A faith formation plan typically refers to a structured method in which individuals are taught the principles and beliefs about their tradition in hopes that the individual would develop and practice this faith as an adult (Goldstein & Ault, 2015; Vogel & Reiter, 2003). Most participants (78%) felt comfortable communicating their personal theology of disability, while 63 respondents (22%) said they did not. The survey defined this term as a theological understanding of why disabilities and illnesses exist.

Future training. Two hundred eighty-six participants (93.5%) completed this part of the survey in which faith community leaders indicated their desire for the modes to receive further training on including children with disabilities. The most popular selections were a go-to website of resources (69.9%), a workshop (60.8%), and training for their staff, volunteer team, and/or congregation (59.4%). The least popular option was a regular peer-to-peer small group method (18.2%) See Table 6 for participants' desired future training.

Table 6

Survey Participant Desired Future Training

Desired training	Frequency N = 286
Method of training*	
Go-to website of resources	200 (69.9%)
Workshop	174 (60.8%)
Training for my staff/volunteer team/congregation	170 (59.4%)
Webinar	107 (36.6%)
Mailing list of resources	72 (25.2%)
Coaching program	66 (23.1%)
Regular peer-to-peer small group	52 (18.2%)
Other method (unlisted)	6 (2.1%)
None of these	26 (9.1%)
Area of training*	
Serving parents of children with disabilities	189 (66.1%)
Worshipping with children with disabilities	169 (59.1%)
Inclusive religious education/faith formation	163 (56.9%)
Theology of disability	75 (26.2%)
Preaching/teaching on disability	69 (24.1%)
Serving children with an Autism Spectrum diagnosis	12 (4.2%)
Serving children with a behavioral disorder diagnosis	6 (2.1%)
Serving children with an ADD/ADHD diagnosis	2 (.7%)
Serving children with an intellectual disability diagnosis	2 (.7%)
Serving children with a learning disability diagnosis	1 (.3%)
Serving children with a Down's Syndrome diagnosis	1 (.3%)
Serving children with a mental illness diagnosis	1 (.3%)
Serving children with a medical illness/diagnosis	1 (.3%)
Programming accommodations	1 (.3%)
None of these	42 (14.7%)

Note. *Percentages may not add up to 100% because participants were able to check as many as apply.

In answering which, if any, specific areas they would like to receive training in including children with disabilities, respondents most commonly selected training in serving parents of children with disabilities (66.1%), worshipping with children with disabilities (59.1%), and inclusive religious education and faith formation (56.9%); the least selected options were training in specific diagnoses (9.2%).

Participant response to a case study. Participants read a case study presented as the story of a child with a disability named Nia who had just begun attending their faith community. The case study included a description of the presentation of her diagnosis in non-technical language and the stress dynamics imposed on her family system. The measure then asked participants to rate their responses to this situation in terms of how they would feel, their level of comfort, and their knowledge of how to serve Nia and her family.

Two hundred eighty-five participants completed this section (see Table 7 for participants' response to the case study). Most participants indicated they would feel compassion for Nia (95.8%) and feel the need to help her (78.6%). Most respondents indicated they would not be scared by her (87.7%), feel angry (90.2%), feel irritated (72.6%), or feel annoyed by her (76.8%). Most participants answered 'maybe' in knowing how to help her (59.6%) and serve her family (59.6%).

Table 7

Reactions to Nia's story

Prompt	Frequency of Response		
	Yes	Maybe	No
I feel compassion for her.	273 (95.8%)	8 (2.8%)	4 (1.4%)
I feel the need to help her.	224 (78.6%)	61 (21.4%)	0 (0%)
I would know what to say to her parents.	116 (40.8%)	136 (47.7%)	33 (11.6%)
I would feel sorry for her.	94 (33.0%)	93 (32.6%)	98 (34.4%)
I would know how to serve her family.	80 (28.1%)	165 (57.9%)	50 (14.0%)
I would know how to help her.	52 (18.2%)	170 (59.6%)	63 (22.1%)
I feel uncomfortable.	21 (7.4%	118 (41.4%)	146 (51.2%)
I would feel annoyed by her.	7 (2.5%)	59 (20.7%)	219 (76.8%)
I feel angry.	6 (2.1%)	22 (7.7%)	257 (90.2%)
I would feel irritated.	6 (2.1%)	72 (25.3%)	207 (72.6%)
Nia scares me.	2 (.7%)	33 (11.6%)	250 (87.7%)

4.2 Qualitative Findings

The perceptions of faith community leaders that emerged during focus group discussions are described below. Findings are presented as they relate to the themes of experiences with, knowledge about, and attitudes toward including children with disabilities in faith-based settings.

Table 8

Focus Group Participant Demographics

Factor	Frequency N = 13
Age Range	
25-30 years old	2 (15.4%)
31-35 years old	4 (30.8%)
36-40 years old	3 (23.1%)
41-45 years old	0 (0%)
46-50 years old	1 (7.7%)
51-55 years old	0 (0%)
56-60 years old	1 (7.7%)
61-65 years old	2 (15.4%)
Participant Role	
Senior/Lead Minister	3 (23.1%)
Associate/Assistant Minister	3 (23.1%)
Religious Educator	4 (30.8%)
Special Care/Special Needs Staff	1 (7.7%)
Preschool/Day School Director	1 (7.7%)
Denominational Executive/Staff	1 (7.7%)
Faith Community Setting	
Urban	3 (23.1%)
Suburban	6 (46.2%)
Town/Village	2 (15.4%)
Rural	2 (15.4%)
Religious Denomination/Affiliation	
Christian – Protestant Evangelical	2 (15.4%)
Christian – Protestant Mainline	10 (76.9%)
Jewish – Reform	1 (7.6%)

Experiences of faith community leaders. All faith community leaders reported serving at least one child with a disability in their current or most recent congregation, as well as in different contexts. Faith community leaders' descriptions of their experiences generally fell within two general themes: experiences that represented successful inclusion and experiences that represented unsuccessful inclusion. Within each of these broader themes, subthemes related to contributors to unsuccessful (i.e., barriers) or successful inclusion experiences (i.e., supports) emerged.

Contexts of faith communities. Focus group participants conveyed experiences of serving children with disabilities and their families in four primary contexts: (a) in worship services, which involved engagement in spiritual practices in a group setting such as singing, praying, and reading and reflecting on holy scriptures; (b) in faith formation activities and groups, which involved learning, discussing, and/or exploring aspects and beliefs of their religion in a group setting, (c) in faith-based weekday preschools that functioned as academic early childhood settings operated by the faith community; and (d) in faith-based camp settings.

Successful or unsuccessful inclusion? Some experiences were perceived to be successful when (a) the child and/or child's family communicated an impression of being included and (b) the child and family continued to participate in the faith community as indicated by attendance in gatherings and events. Other experiences were regarded as unsuccessful when (a) the faith community was unable to provide adequate support to the child and/or family and/or (b) the family chose to not be an active member in the faith community. Focus group participants described a total of 32 successful experiences and 32 unsuccessful experiences.

Barriers to inclusion. Several patterns and subthemes emerged from focus group descriptions about what faith community leaders conceived as barriers to inclusion that seemed to result in more unsuccessful experiences, and what faith community leaders perceived as supports to inclusion that seemed to result in more successful experiences.

Parental perceptions of faith communities. Participants indicated they believe parents enter faith community settings with preconceived perceptions or apprehension about participation in the setting that can negatively affect the experience. All participants communicated their belief that many parents do not feel that there will be a space for their child and family or they will not be welcomed and included once they visit. This perception was especially communicated when discussing worship and camp contexts. One senior minister reflected on parents' desires for their child with a disability to participate in the faith community:

> Most of my experience is [parents of children with disabilities saying] "don't carve us out…we don't want to be a niche." You know, "I want my child to be a part of the youth program." If the youth are crucifers or carrying the processional cross, "I want my child to do that." If the youth are meeting at 5:00, "I want my child to show up at 5:00." And they want to feel a part of the life of church as a whole.

Ten faith community leaders said they believe parents feel exhausted after serving as a child's advocate all week. This, they stated, can make attendance and participation in a faith community difficult and an added stress. A participant, who serves as an associate minister and is a parent of a child with a disability, affirmed:

> I kind of serve a dual role in this, but many, many, many of the parents I have talked to…it is so hard for them during the week. They feel like it's a constant battle for them during the week. They don't want to go to a new environment, a new situation and start all over again with the battles just trying to get equality for their children.

"You've got to work with us." Participants expressed the necessity of productive communication and partnership between faith community leaders and family members of children with disability. Some (n = 5) faith community leaders reported that parents were

helpful in answering questions about their child’s diagnosis and providing necessary information such as best practices and medical routines. However, other faith community leaders (n = 6) expressed that families had not been forthcoming with information and did not acknowledge their child’s disability. Other faith community leaders (n = 3) reported that they knew at least one child in their congregation who regularly exhibits symptoms of particular diagnoses, but their parents had not communicated the presence of any diagnosis. One faith community leader with the latter experience expressed it in these terms:

> We had a family come and they had one older child that definitely had a variety of needs, but um, disabilities. They were pretty upfront about her situation, but they didn’t say anything about her younger brother. And it became really clear that he had a lot of the same issues. And I said, “I wish you would have just talked to me about it.”

Another leader shared this experience about a lack of parental communication:

> But you know, when I was at [faith community], we had a child with a lot of issues and he was just three and broke one of my fingers. We tried and tried to get the mom [to share with us], [asking], you know, “Can you give us some direction?” without saying, “What’s wrong with him?” And she never shared anything and of course, they left after he broke my finger, which was their decision.

A participant weighed in on the challenge of supporting parents when they do not share helpful strategies or information:

> The expectations of the parents were hard to deal with also. They just wanted to drop him off and him be taken care and then not have to deal with

> it at all...they wanted a day off, which I get, but you’ve got to give us more information. You’ve got to work with us.

A faith formation director, who was a school social worker prior to working for a faith a community, attested that she asks for IEP goals, coping skills, and supports in order to provide consistency between home, school, and church:

> More information about the family is always more beneficial. Because it helps to speed up the relationship aspect of it. If I then have to navigate and walk through the dark by myself then what could take two months takes eight months, to build trust with the parents, to build trust with that youth or kid, and to create an atmosphere where I’m not making mistakes on how to respond.

She acknowledged that parental response to that has been “50-50,” meaning there is a 50% chance that parents will not communicate information.

Congregational response. Participants described responses of members of the faith community towards children with disabilities and how it can serve as a barrier to inclusion. All faith community leaders articulated that their congregation’s response to children with disabilities could be categorized as uneasy, uncomfortable, fearful, and overwhelmed, coupled with a desire to learn and be helpful. Some participants said they believed that faith community leaders and/or the congregation placed behavioral expectations upon children. These rules, norms, and traditions, are often unspoken:

> Any kind of established faith community is often very rigid. The thing about special needs kids, especially kids who are on the Autism Spectrum including my child, [name], is, by default, they challenge that [rigidity].

> And there’s two ways you handle that: either you shame them or shun them and communicate that they’re not welcome. [Child] is laying in the floor. And you can see the old ladies [some of the members] going, ‘Ohhh, there he goes’.

Three participants conceptualized these norms as a “box” that children must fit in, which looks like sitting quietly in worship gatherings and linked congregational response to whether or not that child stays “inside the box:”

> In the stereotypical traditional church, this is the box in which the child acts. And if my child doesn’t act within that box, am I going to get judged and glared at? Even in public settings, right in public settings, there’s that, “This is how kids act.”

Lack of resources. Participants described ways in which insufficiency impeded their ability to fully include children with disabilities. Several participants expressed frustrating experiences where they were unable to make accommodations for a child with a disability because they did not have the human capital, material resources, or administrative approval to do so. The lack of volunteer capacity was often discussed as a barrier when faith community leaders did not have enough volunteers to provide the supports and accommodations that a child needed. For example, the director of a faith-based preschool discussed an experience providing supports for a student who had a behavioral disorder diagnosis:

> We’re out here on our own. We do have some trained employees on things like that [inclusion], but again, the district usually helps with that [supporting children with disabilities] in a state-sanctioned preschool or

> afterschool program. So, we ended up letting him go due to us not having what was needed for him. We do not know what happened to them after that.

A minister and mother of a child with a developmental delay expressed her frustration with a lack of material resources and faith-focused supports:

> And I wouldn't have any knowledge of it [including children with disabilities] other than being a mother of it, and even as a mother, there's nothing out there for us! We're just figuring it out as we go along. Where, for example, for drug and addiction, there's at least some kind of program, or some kind of way, some resource for it. Poverty's the same thing – there's at least some resource out there. There isn't anything out there (for us).

One participant attests that she shifts this expectation with the words she uses before worship gatherings:

> I've even started off saying in that service at the beginning, "This is the service where kids do wiggle and giggle and you have children and they can be children." You just have to make it [atypical behavior] normal, or a new normal.

Rituals in faith communities. Several faith community leaders shared experiences that pertained to a child's interaction with formal religious rituals such as contemplative prayer and listening to sermons/homilies. In these interactions, children with disabilities were either unable to participate in the ritual or discouraged from participating in the ritual in a way that was meaningful for them. When describing a young member of their faith community with an Autism Spectrum diagnosis, a lead minister described the ongoing challenge of helping him participate in aspects of the gathering:

> There are times we know just by his nature of [not liking] noises and crowds, it's impossible for him to sit down. Just think about a worship service: it's impossible for him to sit in place or be silent during a prayer. You can't go up to the front… or can you go up to the front? What does [child] want to do every worship service? Run up to the front and lay on the floor. And most of the time we were like, 'Get off the floor! Come on!' And finally, it occurred to us: with our praise band, they're rocking some loud bass. And what's he doing though? He loves to hear it so he's laying on the floor, so he can feel the reverberation and sensory [input] is one of his big things. So, who would think that the praise band is serving a helpful function for him, as well as theological. [Child] is just playing on the floor and you're thinking, 'He must be miserable,' and if you're watching him, you're feeling, 'He's exhausted and miserable.' But for the lack of vocabulary he has, he starts moaning, 'Daddy's car. Go in daddy's car. Go to church? Gotta go to church? Go in daddy's car.' And he says it over and over again. And why is he saying that? Because he's ready to go, and he wants to go, and we've learned that he's telling us that that is something he cares about, and he expects to be at and wants to be that. Watching from the outside, [people may think] it's like, 'Is your son ok?' And I get that, I don't judge them for thinking that. But, I've learned that he's connected to the body of Christ in his own way and it's been our education for learning what that looks like and so we do. And so now it matters. And so, with a special needs

> kid when you find something that he really loves and wants to be a part of, you'll move heaven and earth to make it work.

Supports to inclusion. Faith community leaders attributed positive experiences in welcoming children with disabilities and their families to several factors that supported inclusion.

The presence of persons with disabilities in leadership and service in faith communities. Participants communicated the importance of having persons with disabilities in visible roles in the faith community. One participant serves as the director of a faith community preschool and also has a physical disability. This participant communicated that parents occasionally report choosing the program in part or in whole because of their presence in leadership and that they are able to understand and support children with disabilities in the program and their families, such as a deaf child with a cochlear implant or a child with dwarfism. Other leaders reported the impact of seeing persons with disabilities in leadership roles, such as speaking to the congregation and leading or serving sacraments and religious rituals:

> I had an incredible kid with Down syndrome [in my church], and the highlight of his week was helping me serve communion. And it was just a matter of me asking him [to serve] on a Sunday. Instead of the two-minute talk before church that I would have with other youth, I would have to wait until after church and give a longer talk and practice for an hour so he could grasp it [the actions and the meaning]. He did everything the same, it just changed how I had to do it.

This faith community leader shared how empowering him to serve in this role allowed the congregation to demystify Down syndrome, which the leader attested is an often-misunderstood diagnosis. Another participant discussed the impact of showing an empowering video:

> We showed a video this time last year during Lent. It was a prayer written by [Catholic theologian] Father Richard Rohr that had been put to video and music. And it was young and middle-aged adults who had some disabilities who were living in a group home together and washing the dishes. And that was the whole background to this beautiful, beautiful Lenten prayer. It was so simple, but it sticks out in your mind so that [you say], "Oh I've seen this person before, when they walk in the door. It may not be the same person, but I've seen this before. And I know that this too is a part of the body of Christ."

Advocates and buddies for children with disabilities and their families. Along with helping members of the congregation more fully include children with disabilities, participants reported that the presence of advocates were another factor that led to successful inclusion. One participant who served as a faith formation director unknowingly described his advocacy efforts with a child with Cerebral Palsy in these terms:

> When we did praise and worship music, he would make noise. And, initially speaking, people would make comments. I knew his parents, and there was a lot of fear, like "we shouldn't bring him in [to church]," and I said, "You should totally bring him in." And he was not part of the youth group, but was like, "He does good in youth." And it was "weird" with other youth for a while. But two sessions in, they loved the kid and he's awesome and he's

> one of them. And so he should be part of this larger congregation too, and they [the congregation] can just get over it. And they [his family] would sit in the back and I would be like, "bring him up front." Who cares? Sit where you wanna sit. It doesn't matter. If you're part of our family, then you should sit where you want to sit.

The participant's humorous attitude towards the negative comments of congregation members acted to reassure the child's parents that their child would be able to participate. In fact, participants reported that in terms of congregational response to children with disabilities, feelings of being uncomfortable, fearful, and overwhelmed were said to be mitigated when one critical factor was present: the presence of a buddy who worked directly with the child and family and/or advocates who actively considered the needs of children with disabilities and their families and gave vocal support to acts of inclusion.

Another participant, who serves as a faith formation director, assumes the role of advocate by sharing helpful information that she has gathered about a diagnosis or behavior with her leaders, both high school students and adults:

> I've pulled student leaders aside and just said, "Hey this is what this [atypical] behavior means, this is what's actually going on." And then because they're student leaders, the way they respond that becomes the new normal and that's how you make change. People don't understand what Down Syndrome is. Well, let's talk about what it is. Let's have that conversation. That demystifies it, that makes it no longer something 'special,' it's just a part of the D.N.A. in the body…I've said, "This is what

> stimming means, and so when you're sitting next to a person and they're rocking like crazy or flipping their hands, these are a few of the thoughts that could be going on in their head. And just be sensitive about it and be aware of what it is instead of making fun of it. And then beyond that, [I share] 'these are some ways to respond when that behavior is happening.'

This participant discussed the effect of these conversations in an example of a student in the faith community with an anxiety disorder:

> She sits in youth group and just bounces her foot the entire time because it makes her feel calm. And so, I've talked about that with students, and her friend will just put her hand on her leg, and you can immediately see her entire body relax because we've brought it out and talked about what that means, and it makes her feel comfortable.

Two participants, who serve as ordained ministers and parents to children with a developmental delay and a moderate Autism Spectrum diagnosis, respectively, communicated that their role as advocate often occurs through their non-response to their child's vocalizations or behavior in the service:

> My child has preached with me. Just two weeks ago she preached with me. During that service she came up [to the stage] and I just kept on preaching and I didn't make any big deal of it. And in some congregations that would have been *unacceptable*. But luckily this congregation has learned that that's going to happen from time to time. And she was fine. I mean, she just stood there and she actually several times copied what I was doing as if she was preaching.

The father shared:

> Because he [my son] is a pastor's kid and I'm preaching, they [the congregation] have learned to [think], 'Maybe it's not such a big deal.' And the congregation sees this is not just a child of God, this is the body of Christ who was being left out. And now we're having conversations about that, which is really cool.

The second participant also reported a very helpful experience that occurred when, after he began working at the church, a Sunday school teacher approached and communicated his willingness to learn the best practices so that the minister's child could participate in the Sunday school class with neurotypical peers:

> We were thinking 'You have no idea what you're asking for!' But he just felt called and he said, 'Teach me how I can do this.' So, we did, and he expects [name] to be there, and it's a little chaotic: I hear [child] running down the hall to escape and [teacher]'s running right after him. And we go back in and hear nothing but laughter. And that has freed our family so that we can all do Sunday school and we can be a part of the body of Christ, which we were not before. It's different because I'm teaching, but to see my wife involved, to see my other children involved...but they couldn't [be involved], because they had to go home…that was a specific decision that he did, and we were prepared to equip him.

The buddy-advocate support was reported as helpful in a faith-based camp as well, when a participant worked with the camp to ensure that their child would have one-on-one support and be able to attend camp. This occurred after the camp experienced two unsuccessful years of running a camp exclusively for children with disabilities, where they were “overwhelmed.”

Another faith community leader related engaging in advocacy through her vocal acceptance of disruptions in the service, which brought relief to parents:

> We had a family visiting and they had an infant, who started crying during the service. I guess it was during my sermon or the pastoral prayer, I can’t even remember. But I was talking, and she started to leave with the kid. And I just said, “[name]” and she paused and turned around, and I said, “No. Sit right back down. There’s no better sound to this congregation than a crying baby,” And I got applause. They [the congregation] applauded me for that because they haven’t had a baby there for a long time, long before I was there. So they were excited. I’m going to tell mama it’s “okay. It’s perfectly fine to be here, you don’t have to leave.”

Another faith community leader shared that buddies she had recruited provided feedback that they learned and felt that they “got a blessing” (a feeling of spiritual connection and joy) through serving in this manner. One participant, who serves as a lead minister, shared that her advocacy efforts include asking about supports that can be offered children during worship gatherings:

> [I ask] “What are their triggers? What can I do for him or her to make her feel comfortable?” And I would change things in worship to make it a different experience. If it [a trigger] is lights, if that comes up with the parents and I know that’s a concern, and if I know I can’t change it, I would

> make sure they were aware and be like, "what can we do about that? Can we find some sunglasses? Fun sunglasses? Kooky sunglasses? Earplugs?"

Opportunities for engaging in conversation. Three faith community leaders reported their perceived positive effect of experiences where they facilitated opportunities for children and adults with disabilities to share a meal with able-bodied members of the congregation. The relationships and rapport built during these experiences helped faith community members develop empathetic understanding and notice their similarities instead of differences.

Participant Knowledge. Some (n = 7) reported receiving training on including children with disabilities in faith communities. However, the method through which this training was obtained, and their perceived level of knowledge varied widely. Eight participants reported that they had received no formal training on including children with disabilities.

Sources of training. Faith community leaders who reported receiving training on including children with disabilities articulated that this training occurred in both formal and informal contexts. Formal training occurred through conferences and workshops. Two participants reported that including children with disabilities was a topic covered briefly in their graduate-level theological training: one in terms of learning styles and another in terms of congregational safety. Aside from this, all other forms of training (both formal and informal) were voluntary. Several (n = 4) expressed frustration over the fact that many prominent conferences for faith community leaders have limited, if any, sessions or workshops on serving children with disabilities. Some (n = 4) leaders expressed discouragement about the unavailability of resources in theology of disability and contextualized accommodations and supports in faith communities, leading one participant to attest, “we make it up as we go, because there’s just nothing to use.” Another expressed, “We [faith community leaders] have to take what’s out there for educators and from the field of psychology and create out of that our own theological understanding of how to deal [with providing supports].

Training occurred informally for faith community leaders through the advice and education of parents of children with disabilities (e.g., when parents shared helpful strategies and tips for serving with their child or children with similar diagnoses), special education teachers who were members of the congregation, and on-the-job training. The latter method, according to one participant, occurs when a child with a disability ‘shows up’ to the faith community: “You reach into your bag of tricks and hope they work.”

Perceived level of knowledge. Faith community leaders reported their perception of their own level of knowledge in including children with disabilities. When asked, all faith community leaders responded that they did not feel their training had prepared them adequately to include and serve children with disabilities and their families. According to the consensus of participants, accommodations made for children in faith communities depended on the severity of the disability and most often resulted in self-contained environments. Four participants said self-contained environments are the easiest mode of faith formation and education and the best utilization of their volunteer and material resources. Several faith community leaders reported the difficulty of determining and making accommodations, especially when it relates to sensory overstimulation and ensuring the safety of all children and volunteers.

All faith community leaders communicated that their knowledge and training (whether acquired through formal or informal settings) is only as effective as that of their lay volunteers. Lay volunteers serve as teachers, small group leaders, hosts, greeters, and other roles that interact with children with disabilities and their families. Faith community leaders reported that offering information and training to volunteers is difficult due to constraints of time, participation, and available resources and that when training or information is offered to volunteers, topics that relate to including children with disabilities are often not the most important issues to cover. Faith community leaders agreed that training for both faith community leaders and the volunteers they serve with is often sought or given on an as-needed basis.

Participant Attitudes. Faith community leaders expressed many opinions and convictions that were informed by their experience and knowledge. Several categorical sentiments emerged:

The 'what now?' factor. Perhaps the most prevalent theme was the uncertainty about the preparedness of faith community leaders and the readiness of their faith community if/when children with disabilities showed up. Almost all faith community leaders vocalized feeling this uncertainty at present or at some point in their service to a faith community.

Fear for safety. Another common sentiment in including children with disabilities was fear, which was expressed through several different ways. Several faith community leaders ($n = 4$) expressed fear for the safety of all children (children with and without diagnoses) and reported feeling conflicted in balancing fully including one child with keeping others safe when a child exhibits behavior that could potentially cause harm. One faith community leader expressed this fear in relation to an experience they had in allowing a child with a diagnosis to attend the faith formation class at their developmental age rather than chronological age:

> We had a child who was coming here who was fine for a long time, and then he got super aggressive and honestly, I...we did not have the skill or the ability or the volunteer base to deal with it...at some point, when the child gets a certain size, the other parents are not comfortable leaving a small child, toddler with someone who's so much bigger than their child. It becomes a safety issue.

Fear of offense or misunderstanding. Participants admitted feeling afraid that their words and/or actions would in some way upset or affront children with disabilities and and/or their parents and family members. Faith community leaders communicated a fear of offending children by "saying the wrong thing" or "doing the wrong thing." Five participants expressed this as one of the biggest barriers to including children with disabilities. One participant, who serves as a faith formation director, reflected:

> Yeah, that's the probably the biggest barrier to all of this is that some people have great intentions but don't want to offend you. They don't want to say the wrong thing, and in a world where everything is the wrong thing, in some way or the other, am I right? That's the thing that holds people back I would say. It's not the not knowing, it's not knowing what to ask or who to ask and not being judged on this end for it. What to say, what not to say. Because they [might have] said something one time and the reaction of the parent was, 'Whoa, whoa, whoa, whoa.' And that's not their intent to begin

> with. But a small group setting like this, with this number of participants, I could ask. 'Well where do you put this?' and I would feel comfortable with that.

Another participant opined:

> It's very scary for people that have not been in contact with children or adults with disabilities because they're afraid of what they would say or do; there's that fear. And they don't want to come across fearful either…

A lead minister described how while she does not hold this fear, she is aware that her congregation does. Her experience informs her belief that the fear of offense is a sentiment that both the congregation and the family of a child with a disability experience:

> The greatest challenge [in including children with disabilities] is in getting adults to understand and accept [atypical behavior], and lessening their anxiety levels over such things, including the parents of the children with disabilities. "Oh, I can't have so-and-so participate because he'll flip out if he's on the [Autism] Spectrum." So, even parents saying no [to participating] out of fear that their kids will embarrass them. There is anxiety around it on both ends: church members on knowing how and what to do and parents having fears of, 'is my child going to have a meltdown? What if they interrupt?' Or, 'is he going to run around, and will that be accepted?' Or, 'will I get those glares that all parents fear?'

Theology of Disability. Participants communicated their perspectives on theological matters concerning why disabilities and illnesses exist and what they mean in relation to God and humanity. All participants expressed some level of comfort with communicating and discussing their personal theology of disability. Throughout the focus group meetings, the conversations were peppered with statements that encapsulated and communicated participants' personal theology of disability. While not all participants expressed these ideas using the same words, all participants discussed children with disabilities in terms that underscore these beliefs. These tenants included, "every child has value, dignity, worth. God has a plan for each child," "God made me this way," "God made us perfectly," "we have to notice the person before the disability and use language that reflects that," "we have to teach children these ideas about disability," and "we all have needs, weaknesses, and things we struggle with, regardless of if we have a disability or not."

Theology and children with disabilities. Faith community leaders stated their desire for children with disabilities to understand and communicate faith but belong and feel valued within their faith community first. This ideal came with the acknowledgement by faith community leaders that they often impose a mandate on children to communicate their understanding of faith in verbal, creedal, dogmatic methods that they said can be harmful and counterproductive to faith formation. Several faith community leaders (n = 4) communicated the belief that serving in ministry with children does not always equate to ministry with children that have disabilities and several other faith community leaders (n = 5) believe serving in ministry with children with disabilities takes a "calling" or Divine prompting.

Teaching on disability. Most participants reported that they did not frequently preach, teach, or lead conversations on theology of disability or illness. Some did when the passage of scripture that they were scheduled to reflect on contained a theme related to disability, such as someone being healed. None expressed taking this task on by their own volition, communicating that they felt hesitance with what they perceived as "making it the agenda," in which a leader continuously engages in preaching, teaching, and advocating towards an objective past a point of saturation. Participants felt that this would make individuals with disabilities uncomfortable since "no one wants to be the token demo [demographic]." The exceptions to this were the two ministers who were also parents of a child with an Autism Spectrum diagnosis and a child with a developmental delay. One shared:

> I did get up and preach about it [my child's diagnosis journey]. I knew it was coming, so I warned the congregation that we're going to talk about this. Not so much about him, but me and the grief process we went through...the theological formation that I used was I didn't want to make [child] a prop. It was really about me seeing him as a child of God. So, you think the sermon sounds like it was going to be about him, but it was about me as I went through this process… it was about healing my grief and my loss. And [the child] is not a broken person that hasn't fit, he's a child of God that has worth. And that's the sermon, and that became an invitation for everyone. ….and I could tell the congregation kind of wanted to hear this and needed to hear this. Now. I probably wouldn't have [preached on disability] before our son was born. But we don't have a choice; we deal with it or not.

The other minister reported incorporating stories about her daughter into several sermons that both illustrated points and helped the congregation become more comfortable talking and hearing about disability. She delivered one of these within a few weeks of beginning to serve the faith community so that they could understand more about her family.

One senior minister discussed the importance of context in preaching and teaching, which they defined as knowing the places in a spiritual journey that faith community members are. In their faith community, they attested, preaching and teaching on disability did not make sense because there are usually no children in the faith community, and most of their congregation does not know any children with disabilities. Thus, while important, they believe it would be seen as irrelevant when their community is experiencing other challenges, such as substance abuse. However, they added that while regularly preaching and teaching on including children with disabilities sometimes does not make sense, "if you're in the pulpit every Sunday, you can choose different illustrations from real-life context to highlight whatever my theological emphasis is on my sermon and I can easily go through different litanies and pastoral prayers that you can say to include everybody, and I often do, and special needs folks are in there and people with disabilities," and some of these illustrations can include empowering stories of persons with disabilities. This participant shared that peppering these examples and stories can lead to systemic shifts in congregational responses.

"Nobody puts baby in a corner…" In one focus group, the oft-quoted line from the 1987 movie *Dirty Dancing* was referenced several times. Faith community leaders humorously utilized this phrase to vocalize an important conceptualization they shared: 'including' children with disabilities moves beyond simply creating a welcoming space, but also finds ways to utilize gifts and interests so that children of all abilities can serve as

active members of the faith community. A senior minister highlighted the necessity that all faith community leaders "have the lens that everyone has something to offer." A participant who is the parent of a child with a developmental delay shared the experience of her daughter serving in the faith community:

> One of the things my child loves to do is pass out the bulletins. And so, I always have this prayer that we have the right greeters at the door who will just hand over the bulletins without fighting her. Because once she has that task she *loves* it and focuses and feels like she's contributing to worship.

A colleague who had seen the child serving before added what the child's unique gifts and presence added:

> And every person is *seen.* Because I've been one of those people walking in the door who gets a bulletin from [child]. And every single person is *seen* as they walk in and that isn't always what happens when adults do it. She is right in front of you; she is looking at you when she is handing you a bulletin. *Every* person is seen.

A faith formation director summarized the notion in reference to both of these experiences:

> It's different than [just] belonging. When you get to that point what she just said, that's true inclusion. Belonging means, 'Ok, there's other people here who look like me, so I belong here, so I can be a part of this,' but inclusion means what she just said: empowering and including differences.

"They're an invisible population." In communicating their experiences, a theme emerged that several faith community leaders (n = 11) perceive children with disabilities

and their family as an “invisible population.” A senior minister encapsulated this sentiment, which was met with total agreement from five participants of this particular focus group:

> Most churches are operating from a position of ignorance, like I did when I was at my last [church] appointment and a family said, ‘Do you realize how many families with special needs kids are around this area?’ [I said] ‘No.’ [They said] ‘Well, we have a lot!’ Most churches don’t even realize...what’s the survey you do around demographics? If you were able to do something around that for special needs, there are some churches -- I’m not saying all -- that would be very surprised by the population because they are invisible.

A religious faith formation director chimed in:

> I’m in that ignorant category. I only know what I know because parents have told me. If parents have not told me, then I only know what I know. I wouldn’t know if you don’t tell me [about your child’s diagnosis]. And that I’m willing. But it’s almost like we need them [parents] to start the conversation. Which is backwards, but in some ways, it’s true. Because we don’t want to assume. Because everyone’s not as open about it and might not be at the spot, like you [participant] said, it’s a journey. And sometimes parents I can see their child is functioning on the spectrum maybe at a different level so they’re trying to not have to mention it for whatever reason. Is that true? I don’t know.

A leader and parent of a child with an Autism Spectrum Disorder diagnosis added their experience to support the above statements:

> That’s absolutely true...you don’t want your child labeled as ‘a special one’ because then they get all the crosses they bear with that along with their families. There is a little bit of false comfort in like, staying under that radar because [people think] ‘Oh your kid’s *that.*’ And then you get all the ignorant baggage that comes with that. It took a long time for my wife and me to come to terms with and become public about [child]’s diagnosis. We kept it quiet for a very long time and I was the first one to say, ‘We gotta tell people!’ I think it was a lot of grief, we were worried about what will people say. Especially our peers who know us and know [child].

Hope for the future. Participants acknowledged their belief that their faith community does not fully welcome and include all children with disabilities. However, each focus group ended with participants expressing hopeful statements on the future of faith communities and inclusion and the ability of their faith community to grow in this area and become more inclusive and welcoming. One leader summarized: “I think that we really do want to serve them [children with disabilities] …. (group agreement)..I’ve not met a church that says, ‘aw, no’ [when a child with a disability visits]. And we want to know you’re there, you know. Tell us.”

A participant shared ambitions in creating systemic change in faith communities through helping children with disabilities discover and use their gifts. She drew a comparison to recent events in which students across the country have noticeably called for systemic change and noted, “if we empower our students and children I firmly believe they will lead the way for our adults…that’s exactly what happened with [students in] Parkland [Florida].”

Another leader expressed trust in the volunteer nature of faith communities as an asset to inclusion:

> It’s cool because they [faith communities] are the only organizations who do things because they want to. Like, schools and government programs include children with disabilities in classrooms because they legally have to, or they’ll get sued. But faith communities can be radical in making sure children with disabilities can fully participate just because of what we believe, without anyone else telling us to.

CHAPTER 5: DISCUSSION

5.1 Quantitative Findings

Participant and faith community demographics. Respondents served faith communities in the monotheistic Abrahamic faith traditions of Islam, Judaism, and Christianity. While Christian leaders represented a majority of respondents (65%), the perspective of three religions enhanced the study with a wide array of perceptions. While half of respondents (50.7%) selected “contemporary” to describe their faith community worship style, virtually the same number of respondents (49.3%) selected “traditional.” These two descriptors are often seen as stylistic poles, though many faith communities embrace both in order to meet preferences of a larger range of community members (Burke & Selz, 2012).

Participant experiences. Most survey respondents (96.1%) had served at least one child with a disability and many (93.4%) had served more than one child with a disability. This appears consistent with literature indicating the prominence of religion and faith communities in the lives of children with disabilities and their families (Ahlert & Greeff, 2012; Ault et al., 2013; Balsundaram, 2007; Marshall et. al., 2003; Michie & Skinner, 2010; Poston & Turnbull, 2004; Shogren & Rye 2005; Skinner et al., 2001).

The diagnoses that faith community leaders more commonly reported interacting with were learning disabilities, Autism Spectrum Disorder, behavioral disorder, and intellectual disabilities, respectively. In considering the accommodation tiers that Campbell, Milbourne, and Kennedy (2012) recommends for these diagnoses, it is interesting to note that fewer accommodations need to be made for a child with one of these diagnoses to fully participate in common rituals and rites when compared to the common forms and method of worship rituals as described by Burke and Selz (2012).

This appears to indicate that children with diagnoses that typically call for more adjustment and support may be less likely to be present in congregations. Further research may be necessary to determine how congregations can support children with diagnoses such as health impairments, communication disorders, hearing impairments, and vision impairments, whom faith community leaders in this study reported having less prior experience serving.

Surprisingly, the most common source of connection to a child with a disability outside their work with a faith community was made through a non-familial relationship, including colleagues, neighbors, friends, or community members. Kleinert et al. (2010) reported on the positive impact that these informal relationships can have in a leader's theology, empathy, attitudes, and perceptions.

Participant knowledge. While the vast majority of participants had served at least one child with a disability, just over 30% of participants reported receiving training on including children with disabilities. Informal relationships aside, this disparity between training and praxis is notable. The variety of roles included in the conception of 'faith community leader' coupled with the religious diversity represented in survey participants ensures a wide variety in methods of preparation.

For those who answered 'yes' (n = 88), 87 respondents listed where they received training. Most sources of training (52%) were through elective measures, meaning that leaders were not required to specifically undergo this specific topic of training, but chose to do so. These methods included workshops, seminars, a volunteer experience, or self-study/self-directed research. An additional 19.5% of respondents reported being trained through programs that were unrelated to their current role in faith communities, including undergraduate courses, graduate courses unrelated to faith communities, and previous work experience.

Still, another 10% of participants reported receiving training informally through on-the-job training or a member of the congregation. In two instances, this training was provided by a parent of a child with a disability, and in one instance, this training was provided by a professional who worked in the medical field. This echoes Poston and Turnbull (2004), who found that parents often spent time providing support or training others to provide support to their child instead of meaningfully participating in gatherings of the faith community. This finding also embodies the recommendation of Goldstein and Ault (2015) that the most successful approaches to inclusion are through partnerships between faith community leaders, families, and community resources.

Fourteen respondents (16%) reported that this training came through seminary/theological preparation, though all mentioned the training was a topic covered as part of a broader course or an elective course. This appears consistent with findings by Anderson (2003) and Kleinert et al. (2010) that many graduate-level theological training schools and seminaries do not have a plan for building theological responses to disability or inclusive practices into the curricula.

Just over 20% of participants have never served a child with a disability. The lack of training and less-than-ideal experience perhaps may contribute to the overwhelming feeling of ill-preparedness to include children with disabilities, since most respondents said their training did not equip them to do so. Apart from learning disability and physical disability diagnoses, at least 40% of respondents felt they did not have the skills and knowledge to include children with other diagnoses. This is perhaps why Howell and Pierson (2010) found that mothers of children with Autism Spectrum diagnoses saw an unmet need for multisensory, inclusive services and faith formation environments.

Fortunately, a strong majority of leaders (64.0%, 78.1%, respectively) reported that they had received support from their denomination, organization, or association to make appropriate accommodations or provide support for children with disabilities, and/or knew where to find additional support. This indicates that if they have not had thorough training, faith community leaders often seek training or support as a necessity on a case-by-case basis.

Participant attitudes. Faith community leaders in this sample believed in the principle of inclusion, especially in the context of worship, as they overwhelmingly agreed that children with disabilities should be able to worship with their peers. Twenty-four percent of respondents, however, believe that children with disabilities are best served worshipping with other children with disabilities, and 95.1% of participants believe children with disabilities sometimes or always learn better when grouped together with other children like them.

It is reassuring that most respondents feel comfortable communicating with children with disabilities (70.7%), communicating with their parents (75.3%), communicating their personal theology of disability (78%), and discussing faith formation goals and needs with families before making a plan (78.1%). This strand of agreement seemed to indicate a pattern: faith community leaders seem more confident in providing personal pastoral care to children with disabilities and their families, and less confident in ensuring meaningful participation for children with disabilities and their families in communal environments such as worship services.

This is encouraging, especially in view of the fact that pastoral care, counseling, and/or support of the family are often considered the most important factors in familial participation (Carter et al., 2016; O’Hanlon, 2013). This distinction between pastoral care and programmatic support may explain why in studies on faith community leaders making accommodations for children with disabilities to participate in religious rites, rituals (such as *b'nai mitzvot* or first communion ceremonies) often take place in more private, self-contained contexts belying full inclusion, such as the environments in case studies by Vogel and Reiter (2003) and McGee (2010).

The overall comfort of faith community leaders in communicating their personal theology of disability signaled a discrepancy between this result and the literature. In several studies (Carter et al., 2016; Howell & Pierson, 2010; Trealor, 2000), participants did not recall ever hearing a faith community leader preach, teach, or share on the topic of disability, and several parents perceived the Bible to be irrelevant in terms of disabilities. This begs the question of why there is a gap between confident faith community leaders and a perception of institutional silence on theology of disability, especially when parents of children with disabilities desire vocal support of inclusion from faith community leadership (Howell & Pierson, 2010).

Francis and Jones (2015) attempted to explain one aspect of this: clergy may be knowledgeable and comfortable in their personal theology, but reluctant to make the professional commitment to broach the topic. Further research may be needed to understand how, when, and why faith community leaders respond in this manner. As McNair and Sanchez found (2007), comfort in discussing their personal theology of disability by no means ensures that their theology is free from harmful or outdated understandings of disability, such as the thought that the source of disability being a punishment from God.

Most participants attest that they discuss faith formation goals with families before making a plan, but this appears to be at odds with Ault, Collins and Carter (2013a), who found that in a study of 416 parents of children with Autism or intellectual disabilities, more than half had never been asked the best way to include and support their child(ren) in religious activities. Perhaps faith community leaders conceptualize goals in terms of religious content knowledge and creedal acquisition and not in terms of accommodations and best practices.

Future training. In terms of potential methods of training on including children with disabilities, most faith community leaders said they would utilize a go-to website of resources (69.9%), a workshop to attend (60.8%), and training for their team and/or congregation (59.4%). The latter two options were consistent with the methods that many leaders (46.0%, of those who responded) considered their primary source of training on including children with disabilities. Other modes were far less popular.

Out of a lengthy list of topics, faith community leaders indicated an interest in further training in serving parents of children with disabilities (66.1%), worshipping with children with disabilities (66.1%), and inclusive religious education and faith formation (56.9%). These responses indicate a sense of self-awareness: as evidenced in the literature, parents of children with disabilities typically feel underserved (Carter et al., 2016; Howell & Pierson, 2010; Jacober, 2010; O'Hanlon, 2013; Poston & Turnbull, 2004; Trealor, 2000) and these responses are consistent with others that faith community leaders are unsure of methods to include children with disabilities in worship and faith formation.

Further training on specific diagnoses was less important to participants, with fewer than 5% indicating a desire for this training. This is telling of a 'generalized' view of including children with disabilities that faith community leaders appear to hold, as well as the overarching idea that ensuring meaningful participation for children with disabilities in the faith community is not an active consideration until the opportunity presents itself. Perhaps this is why families felt that while religion is important and valuable, parents did not feel that their faith community provided direct support (Skinner et al., 2001) or why some parents chose not to attend a faith community due to the absence of provided accommodations (Trealor, 2000).

Participant response to a case study. The majority of participants (at least 76% for each item) projected feeling compassion, feeling the need to help, and not feeling angry, annoyed, or scared. Yet only 28.1% of participants said they would know how to serve Nia and her family, and 18.2% of leaders said they would know how to help Nia. These answers were consistent with answers on similar themes in the survey and demonstrates that faith community leaders appear more empathetic and less prepared.

The 10% increase between knowing how to help Nia and knowing how to serve her family is encouraging because it displays a family-centered approach to pastoral care, which is a recommended best practice in inclusion (Division of Early Childhood, 2014). It is discouraging, however, because it indicates that faith community leaders lack understanding in the processes and strategies for including children with disabilities in the faith community who exhibit moderate-to-severe diagnoses.

All sections of the survey responses appear to point to an overarching theme for further research: an understanding of how, when, and why faith community leaders can move from passive theologians to active advocates for children with disabilities and their families within the broader faith community, which McGee (2010) attests is absolutely necessary for meaningful participation, and which Carter et al. (2016) found was one of the least-available supports for parents and caregivers.

5.2 Qualitative Findings

Experiences of faith community leaders. The reported experiences of serving at least one child with a disability in their current or most recent congregation appeared consistent with results reported in the survey, where 96.1% of respondents indicated this answer. The delineation and patterns of 'unsuccessful' versus 'successful' inclusion experiences throughout focus group conversations indicates that faith community leaders and parents in this sample share the same understanding of what constitutes successful inclusion, as indicated in studies on parent perceptions of faith communities (Howell & Pierson, 2010; Trealor, 2000).

Barriers to inclusion. Faith community leaders reported several elements that, in their experience, lead to more unsuccessful experiences of inclusion. These results appear consistent with those that have been described in previous research and create a context for future implications that can assist in eliminating some of the barriers.

Participants admitted they believe parents may feel there will not be a space for their child and family in the faith community. Participants also expressed the belief that parents are exhausted after advocating for their child all week. Both of these self-aware statements may be viewed as refreshing to parents as they echo studies which have found this to be a predominant perception from parents of children with disabilities (Jacober, 2010; O'Hanlon, 2013; Poston & Turnbull, 2004; Trealor, 2000).

Faith community leaders also believe communication between leaders and family members can become a barrier to inclusion. Around 25% of focus groups participants reported an experience where a child's parent(s) had not communicated helpful information about the child’s diagnosis or behavior. This was a juxtaposition to Ault, Collins, and Carter’s finding (2013a) that more than half of parents who participated in their study had never been asked the best way to include and support their children in religious activities. In the survey, 79.1% of faith community leaders attested they ask families of children with disabilities about their goals and objectives when making a faith formation plan (a written or verbal strategy and intent to help a child become an adherent to their religion and understand/accept the beliefs in such). This survey question, however, did not address the manner in which they ask or the extent to which parents responded to the faith community leaders’ inquiry.

The reported responses of the congregations that the faith community leaders serve emerged as the “other side” of the story in why parents may often perceive faith communities as less than supportive and is consistent with findings from previous studies of parents’ perceptions (O’Hanlon, 2013; Pitchlyn, Smith-Miles, & Cook, 2007). It may be inferred from this study that the non-welcome could perhaps be attributed to uneasiness, fear, and misgivings rather than hostility or ill will. This distinction is nuanced and requires families of children with disabilities to see beyond the initial ‘implicit or explicit’ communication that families of children with disabilities are not welcome, which could be an unrealistic expectation. White (2009) notes the necessity of a faith community to possess “a perspective of openness and acceptance” (p. 112), noting the lack of this as a significant barrier to religious parents of children with disabilities participating in faith communities.

Lack of resources. The participant-reported attribution that inclusive environments are often not present because of a deficiency in resources seemed to confirm McGee’s (2010) speculation that leaders shy away from creating and leading inclusive programs due to lack of knowledge, support, buddies/mentors, skills, and communication about roles. The stated perception that some participants held that working with children with disabilities is a distinct calling separate from working with neurotypical/typically developing children could be a source of the volunteer scarcity as faith community leaders only encourage members who feel called specifically to this “population” to serve in ministry with children with disabilities. Yet the reliance upon self-contained models of ministry with children with disabilities appears to be fueled by the barriers of volunteer capacity, creating what was perceived as a cyclical challenge. This particular barrier was addressed using less hopeful tones as it is often perceived as an insurmountable barrier (i.e., there are no ways to secure more material resources in the foreseeable future).

The experience of the faith-based preschool director (discussed in contexts that experiences took place) communicated both frustration and pervasive isolation in supporting children with disabilities. Most (64.0%) of survey respondents said they had received support and/or resources from their denomination, organization, or association to make appropriate accommodations or provide support for children with disabilities, and most survey respondents (78.1%) knew where they can find additional support for serving children with disabilities and their families. The contrast of these data could indicate that, while faith community leaders may know of a place for resources and supports, these resources and supports are not relevant and/or adequate enough to be used in their faith community. The utilization of these resources could also vary by faith community and context of where the children need accommodations and supports (i.e., weekday preschool, worship gatherings, faith formation environments).

Rituals in faith communities. The experience of a lead minister included a description of how a child with an Autism Spectrum Disorder diagnosis enjoyed lying next to the subwoofer during worship gatherings. This personified Harris' (2015) assertion that children may understand spirituality and a connection with the Divine in nontraditional methods that are in line with the nature of their disability. Swinton and Trevett (2009) attest that the religious and spiritual conceptualization is a vastly overlooked dimension in the experience of individuals with Autism. The experience that the lead minister reported in changing their approach towards this child, from fighting the connection to celebrating the connection, models the journey that Carter et al. (2016) describes, conceptualizing inclusion as an active commitment to celebrate atypical behaviors if they serve a functional purpose.

The nature of these reported interactions suggests a delineation between a child with a disability simply being physically present and a child engaging in meaningful participation. Transforming rituals to ensure that children with disabilities can participate in them points to what Carter et al. (2016, p. 386) asserted: inclusion is a nuanced concept that requires an active "commitment."

Supports to inclusion. The experiences that faith community leaders shared pointed to several factors that, in their experience, foster inclusion in faith communities. The perceived factors that appeared to lead to more successful experiences relate well to literature and serve as a starting point for continuing the conversation.

The presence of persons with disabilities in leadership and service in faith communities. Many studies that examined the response of faith communities to children with disabilities found that actively-supportive leadership was one of the most important factors for parents of children with disabilities feeling welcomed and supported (e.g., Carter et al., 2016; Howell & Pierson, 2010). Thus, one could extend that line of argument to include the notion that seeing persons with disabilities actively serving in leadership roles in faith communities also fosters a more welcome, inclusive environment. The experiences that the preschool director shared provide anecdotal examples of this, where parents chose to enroll their child in the program based (at least in part) on her leadership and two children with a disability thrived in the as a result of her experience and presence.

Advocates and buddies for children with disabilities and their families. According to faith community leaders, the presence of a buddy and/or advocate acted as a buffer to congregational uneasiness, which was consistent with findings from the literature (Ault, Collins, & Carter, 2013a). While Carter et al.'s (2016) study on faith community inclusion supports found that parents perceived a buddy to be among the most helpful, it was also the least available: only 6.3% of respondents said this support was available in their congregation.

The stated impact of advocates and buddies who work with family members to ensure that children with disabilities are fully included in the congregation echoes the findings of Carter et al. (2016), Ault et al. (2013a), and White (2009) who report that family advocates and buddies/mentors are a helpful factor in faith communities being perceived as inclusive by parents of children with disabilities. From experiences that faith community leaders reported in the focus groups, advocates assisted in several key ways. First, advocates helped leaders, and/or the congregation reframe their understanding and theology surrounding the child's disability. Examples of this include the lead minister who helped the congregation become accepting of a child's behavior by their example and the faith formation director who ensured the child with Cerebral Palsy sat where they wanted and participated in youth group meetings. This verbal, cognitive reframing often occurs through modeling behavior or explicitly stating affirming beliefs. Benson (2014) found that cognitive reframing is a powerful tool that fosters positive emotional connections of family members of children with disabilities.

Second, advocates found ways to make accommodations, which enabled children to actively participate in what their parents described as meaningful ways. As evidenced in the example of the lead minister whose son has an Autism Spectrum diagnosis, inclusion of the child created opportunities for the entire family to participate and receive benefits from a faith community. The family played an active role in communicating and partnering with faith community leaders, which, as the father reported, contributed to a successful experience. Goldstein and Ault (2015) attest that partnership between families, community resources, and faith community leaders is the most conducive approach to families feeling supported.

Facilitating opportunities for engaging in conversation can be a type of active advocacy and resembles the discussions that seminarians engaged in with families of children of disabilities in the program that Kleinert et al. (2010) studied. Participants in the program reported that these conversations and shared time provided them with a greater sense of empathy and understanding, which seem to confirm what focus group participants noticed.

Participant Knowledge. Fifty-three percent of focus group participants said they had received at least some training on including children with disabilities in faith communities. This is a higher percentage of participants than results from the quantitative survey, in which 30.1% of participants reported receiving training.

Sources of training: formal and informal. In-service workshops, seminars, and conferences were the most frequently-mentioned sources of training in both quantitative and qualitative results. Seminaries and graduate theological training programs were the second-most frequently mentioned source of training in both measures, though in focus groups, participants admitted that (a) the curriculum did not specifically address methods of inclusion and accommodation, and (b) the training was a topic briefly covered as part of a class. These reports are consistent with Anderson's (2003) observation that seminaries do not have an overall plan for thorough curricula regarding including persons with disabilities in the faith community.

Faith community leaders in this sample also received training through parents and members of the faith community who work professionally with children with disabilities. This is consistent with both the survey responses and the literature, the latter of which indicates that faith community leaders who are supportive of children with disabilities and their families welcome community expertise (Goldstein & Ault, 2015). The lack of preparedness and training that each of the focus group participants expressed appears consistent with Kleinert et al. (2010), who found that current seminarians self-report of their knowledge about services available to persons with disabilities, potential treatment by the public, impact on a family, and the unique needs and challenge a person with a disability faces was *not at all, minimal,* or *somewhat.*

Perceived level of knowledge. All focus group participants attested they did not feel their training had adequately prepared them to include children with disabilities. This is consistent with survey results, where 86.4% of respondents said they feel their training had prepared them *somewhat* or *not at all.* Faith community leaders reported inadequate training indicates they may not know what behaviors/presentation to look for in developmental delays and disabilities. This could be one of the reasons that faith community leaders rely on strategies provided by family members or tactics found in their 'bag of tricks.'

It is interesting to note that participants communicated the necessity of knowledge not just for themselves but also for volunteers that they serve with. This finding indicates that it is not sufficient for only the faith community leader to receive training but must include *all* who serve in leadership capacities.

Participant Attitudes. It appears that faith community leaders derive the attitudes and perspectives they possess about including children with disabilities in their faith communities almost directly from their experience and knowledge. Participants described their approach to including children with disabilities in concert with stories and examples where they had served children with disabilities and their families.

The communicated uncertainty and ill preparedness that participants expressed feeling in including children with disabilities seems to embody one mother's perception in Poston and Turnbull (2004): "There's a lot of people [in the church] that don't know how to deal with your autistic child" (p.103). This fear, along with fears of safety of other children and fears of offense seemed to be a realization of the lack of adequate preparation, training, and knowledge that faith community leaders reported receiving. These perspectives provided the picture that faith community leaders do not have the proverbial tools in their tool belt to welcome and include children with disabilities.

Factors that participants had experienced were categorized as supports or barriers to inclusion depending on if participants believed they lead to successful or unsuccessful inclusion experiences. However, it became clear that attitudes that faith community leaders possess could be categorized in a “successful” and “unsuccessful” manner as well, based on whether the attitudes were communicated within the context of successful or unsuccessful experiences. The discussions echoed Ault et al.’s (2013a) hypothesis that faith community leaders and members may be uncomfortable with or untrained in working with individuals with disabilities.

Theology of Disability. Participants expressed a nuanced, complex understanding of disability in a theological sense. The statements that describe how they view the nature of disability points to welcome and wholeness instead of healing and perfection.

Theology and children with disabilities. The necessity for children to feel valued and a sense of belonging is supported by literature on nurturing spirituality in children with disabilities, which emphasize (regardless of specific religious affiliation, or lack thereof) that leaders emphasize and foster belonging and connectedness. The stated belief that serving in ministry with children with disabilities is a calling for a select few is a complicated statement as it gives credence to divine prompting to serve and ensures that leaders share a true desire to work with children with disabilities. However, this language also creates an implied sense of segregation in that it takes a ‘special calling’ to serve children with disabilities and insinuates the need for separate environments for children with disabilities.

Teaching on disability. All participants expressed some theoretical level of comfort with communicating and discussing their personal theology of disability, but this did not seem to translate into praxis. None of the participants engaged in regular discussion, teaching, or preaching on the topic of disability, except for ministers who were also parents of a child with a disability who utilized this spiritual journey as a catalyst for understanding faith. Faith community leaders listed several reasons for this: a desire to not make others uncomfortable (both faith community members with and without disabilities), a determination to avoid redundancy and saturation, a philosophy of the role of worship gatherings in avoiding charged topics, an awareness of faith community members' discomfort with the topic, and the perceived irrelevance of the topic.

These statements echoed those that seminarians provided in Francis and Jones' (2015) study when discussing how they would handle preaching on texts that involved the healing of a person with a disability or illness. Participants in the focus groups echoed the overall hesitancy when it comes to discussing disability in worship using scripture.

Francis and Jones' (2015) study only examined discussing disability in the context of a worship gathering and not in smaller group settings. All participants in the focus groups relayed their willingness to discuss theology of disability in these contexts, which they felt provided room for discussion and interaction over the topic instead of simply passive listening. This demonstrates a willingness to engage in meaningful discussion over theological understanding of disability instead of simply 'presenting' a model attitude.

Two exceptions emerged as parents of children with disabilities who also served as ministers utilized their family's story and the spiritual journey that resulted from a diagnosis. Other participants agreed that these stories needed to be shared and discussed, but felt the parents were much more equipped to do so. The only motivation in preaching on disability and the only cause for intentionally devoting consistent time in worship gatherings to this topic was the experience of being impacted by disability.

"An invisible population." This emergent theme appeared to be a point of

frustration for participants as they began to process the complexity of engaging what they conceptualize as an invisible population. Faith community leaders communicated the need for communication between leaders and family members of children with disabilities in order to “break the silence.” This curious sentiment encapsulates what appears to be a misunderstanding and mischaracterization of children with disabilities and their families. The phrase “children with disabilities” is a broad term, encompassing several categories such as behavioral disorders, learning disabilities, speech and language delays, and physical disabilities, with scores of distinct diagnoses. Diagnoses and presentation of disability are as unique as a child is, and, therefore, necessary accommodations that would allow for meaningful participation also are divergent (Campbell, Milbourne, & Kennedy, 2012). Conceptualizing all of these diagnoses and supports as one large group of children with ‘disabilities’ or ‘special needs’ is helpful in classification but may not be helpful in understanding the more specific supports needed for a child with a specific diagnosis. Faith community leaders discussed the need to “see the person before the disability,” and applying this argument to all children with disabilities may serve faith community leaders in providing meaningful supports to children and families.

Summary. From the themes that emerged in focus groups, it became clear that the hostility that many parents perceive from faith communities could be misunderstood compassionate unpreparedness that is the result of a three-part systemic failure: training institutions do not adequately prepare leaders and program leaders sometimes attest they “have no expertise with this area of study” (Anderson, 2003, p.133); faith community leaders do not have adequate resources to discuss, teach, and implement theological understandings of disability and inclusive religious practices; and partnerships between faith community leaders, ministry volunteers, family members, community resources, and professionals who work with children with disabilities are underdeveloped and underutilized. Participant responses in the focus groups imply that faith community leaders are more compassionate, empathetic, and willing to include children with disabilities and their families than literature indicates but are less prepared and knowledgeable than they would like to be.

5.3 Limitations and Implications for Further Research

Limitations of the study. When compared to existing literature, results of both the survey and focus groups establish several implications for further research. The religious makeup of both survey and focus group participants did not incorporate all major world religions. Survey responses consist of participants mostly from Christian and Jewish faith traditions, with some Islamic respondents. No respondents from outside the Abrahamic faith traditions completed the survey, such as faith community leaders from Buddhist or Hindu traditions. Focus group participants were mostly from mainline Christian traditions. Future research should be conducted to incorporate other faith traditions to determine if the findings of the study are generalizable beyond Abrahamic faith traditions. The survey measure used to study perceptions was a researcher-adapted measure that had not been used in prior research, which is also a limitation of a survey.

Another limitation to the study is the reliance on self-reported data in the survey and focus groups, which cannot be independently verified. Respondents were geographically bound within three southeastern states, so further research may be needed to determine if results are generalizable to other locations. Ethnicity and culture-related data of both faith community leaders and the faith communities they serve were intentionally not collected as they were not a central focus of the study. However, further research may seek to understand what (if any) relationship cultural practice has in the experience, knowledge, and attitudes of faith communities and those who lead them.

Implications for further research. The emergence of experiences surrounding independent faith-based school environments and faith-based camps contributes to the importance of this scholastic discipline through expanding the conversation on including children with disabilities in faith-based community organizations to encompass these settings as well. With the stated difficulty that faith community leaders reported in successfully supporting children with disabilities in faith-based camps and preschools, more research is needed to understand the unique supports and barriers to inclusion in these environments, both from families' and leaders' perspectives, and determine best practices and leadership models.

The study revealed a juxtaposition in perceived communication: the literature highlights that parents often perceived that faith community leaders do not ask how to serve their child (Ault et al., 2013a) and the study found that faith community leaders attest that they usually consult with parents and sometimes feel that parents do not communicate with them. This sets an important implication for research and practice: finding ways to ensure, catalyze, and streamline communication between families of children with disabilities and faith community leaders. As one focus group participant summarized, the faith community must show an interest in the child and family. These communication methods may be employed for individual families as well as for the community, in order to effectively communicate a message of welcome for what leaders conceptualize as "the invisible population."

Given the reported perception in both the survey and focus groups of inadequate preparation, it seems that further research is needed to address methodologies of training faith community leaders on the nature and presentation of disabilities and diagnoses, as well as evidence-based practices and accommodation methods for including children with disabilities in the faith community. This implication echoes the value of training leaders and congregation members with knowledge and strategies to foster inclusion that parents expressed (Ault, Collins, & Carter, 2013b).

One of these areas for research and training is understanding and communicating ways that individuals with diagnoses can and do conceptualize religion and faith that is consistent with the nature of their disability. It is imperative that faith community leaders understand this notion and seek to allow children with disabilities to connect and express their understanding of God in the way that they are able.

Results from the study also suggest that research is needed to develop resources and determine best practices in implementing a buddy and/or advocate system in the faith community. Further research is needed to examine methods and practices of ensuring the presence of advocates for children with disabilities and their families. Since many faith community leaders received training on including children with disabilities from special education, social work, and healthcare professionals who were members of their congregation, this appears a likely place to begin.

Lastly, most faith community leaders who completed their preparation at a seminary or graduate theological training program did encounter adequate training in this area. Therefore, further research is needed to study the perspective of seminary administrators and seminary students in hopes of understanding the unique experiences, knowledge, and attitudes they possess. This topic could be further studied to understand if and how training programs incorporate theology of disability, faith responses to disability, potential accommodations/supports, and other inclusion-related practices into their curricula and/or student life, such as the program created by Kleinert et al. (2010), and the efficacy of these programs.

Implications for practice. Establishing a process for welcoming persons with disabilities and understanding proper language and terms are categories in the National Organization on Disability survey distributed to congregations in the study by Laroque and Eigenbrood (2005). Focus group participants' admission of these fears indicates their congregation would most likely fall in the *getting started* phases of this survey. Conversations regarding appropriate universal accommodations in worship and ways for the congregation to advocate for persons with disabilities in the community are unable to take place if hesitancies exist towards how to talk about children with disabilities and what to do if one shows up.

Faith community leaders should actively consider and plan ways that accommodations can be made to rituals so that children with disability can meaningfully participate. This implication echoes a suggestion of Carter et al. (2016) on accommodations. Faith community leaders should also apply Harris' Distributed Model of Leadership (2004) in order to ensure that individuals with disabilities have many opportunities to serve in leadership and influence the community in their roles. It also creates an imperative for faith community leaders to share voices and stories of individuals with disabilities in an authentic way that does not make them a "prop."

Faith community leaders opined that a small group setting is more conducive to facilitating discussion, so results of the study suggest that faith community leaders should find and facilitate ways to discuss theology of disability, stereotypes of disability, and theological responses to individuals with disabilities in small group settings with their faith community.

Further research is needed to examine methods and practices of ensuring the presence of advocates for children with disabilities and their families. Since many faith community leaders received training on including children with disabilities from special education and healthcare professionals who were members of their congregation, this appears as a likely place to begin.

Implications for research and practice for denominations and networks. Faith community leaders responded that a major barrier to inclusion was a lack of resources in materials, strategies, and support. It seems incumbent upon denominations and faith networks to ensure that faith community leaders have access to relevant, helpful materials on theology of disability and accommodations, as well as accessible opportunities to learn more about these, as most faith community leaders had not had formal training in this area. Most faith community leader reported greater comfort in discussing challenges as part of a small group. Thus, denominations may be well-served to facilitate cohorts or groups to discuss challenges of including children with disabilities in the faith community and share accommodations and strategies together. Faith community leaders reported that oftentimes, their knowledge and experience is only as good as that of their volunteers'. Therefore, as faith community leaders receive training, it is serving to ensure that their lay volunteers are prepared. Denominations and networks that organize training should consider how the training can extend beyond clergy to incorporate all who serve in ministry with children. Further research may be conducted to implement and evaluate programs that facilitate discussion between able-bodied individuals and children with disabilities to determine their efficacy, as well as establishing methods for facilitating these opportunities.

CHAPTER 6: REFERENCES

Ahlert, I. A., & Greeff, A. P. (2012). Resilience factors associated with adaptation in families with deaf or hard of hearing children. *American Annals of the Deaf*, *157*(4), 391–404.

American Association on Intellectual and Developmental Disabilities and the Arc. (2010). *Spirituality: Joint position statement of AAIDD and the Arc*. Retrieved from http://aaidd.org/news-policy/policy/position-statements/spirituality

Anderson, D. W. (2015). Beauty and Disability. *International Journal of Christianity & Education*, *19*(3), 182–196.

Anderson, R. C. (2003). Infusing the graduate theological curriculum with education about disability: addressing the human experience of disability in the theological context. *Theological Education*, *39*(1), 131–153.

Ault, M. J., Collins, B. C., & Carter, E. W. (2013a). Congregational participation and supports for children and adults with disabilities: Parent perceptions. *Intellectual and Developmental Disabilities*, *51*(1), 48–61.

Ault, M. J., Collins, B. C., & Carter, E. W. (2013b). Factors associated with participation in faith communities for individuals with developmental disabilities and their families. *Journal of Religion, Disability & Health*, *17*(2), 184–211. Retrieved from https://doi.org/10.1080/15228967.2013.781777

Balasundaram P. (2007). Love is not a feeling: faith and disability in the context of poverty. *Journal of Religion, Disability & Health*, *11*(2), 15–22.

Bowen, M. (1966). The use of family theory in clinical practice. *Comprehensive psychiatry, (7)*5, 345-374.

Bronfenbrenner, U. (1994). Ecological models of human development. In *International Encyclopedia of Education, Vol 3, 2nd Ed.* Oxford: Elsevier.

Burke, S., & Seltz, M. (Eds.). (2012). *Worship Matters: An Introduction to Worship*. Augsburg Fortress.

Campbell, P. H., Milbourne, S. A., & Kennedy, A. A. (2012). *CARA's Kit for Toddlers: Creating adaptations for routines and activities*. Baltimore, MD: Brookes Publishing.

Carter, E. W., Boehm, T. L., Annandale, N. H., & Taylor, C. E. (2016). Supporting congregational inclusion for children and youth with disabilities and their families. *Exceptional Children*, *82*(3), 372–389.

Chang M, & Hsu L. (2007). The perceptions of Taiwanese families who have children with learning disability. *Journal of Clinical Nursing*, *16*(12), 2349–2356. Retrieved from https://doi.org/10.1111/j.1365-2702.2007.02013.x

Division for Early Childhood. (2014). DEC recommended practices in early intervention/early childhood special education. Retrieved from http://www.dec-sped.org/recommendedpractices.

Ekas, N., Whitman, T., & Shivers, C. (2009). Religiosity, spirituality, and socioemotional functioning in mothers of children with autism spectrum disorder. J*ournal Of Autism & Developmental Disorders, 39*(5), 706-719. doi:10.1007/s10803-008-0673-4

Francis, L. J., & Jones, S. H. (2015). Preparing for Disability Awareness Sunday: an educational exercise drawing on psychological perspective for biblical hermeneutics. *International Journal of Christianity & Education*, *19*(3), 197–214. Retrieved from https://doi.org/10.1177/2056997115602485

Frank, A.W. (1995). *The wounded storyteller: Body, illness, and ethics*. Chicago: University of Chicago Press.

French, D. (2016, December 14). If you don't 'get' religion, you can't 'get' America or the world. *National Review.*

Gallagher, S., Phillips, A. C., & Lee, H. (2015). The association between spirituality and depression in parents caring for children with developmental disabilities: social support and/or last resort. *Journal of Religion and Health*, *54*(1), 358–370. Retrieved from https://doi.org/10.1007/s10943-014-9839-x

Gilbride, D., Stensrud, R., Vandergoot, D., & Golden, K. (2003). Identification of the characteristics of work environments and employers open to hiring and accommodating people with disabilities. *Rehabilitation Counseling Bulletin*, *46*(3), 130–37.

Goldstein, P., & Ault, M. J. (2015). Including individuals with disabilities in a faith community: A framework and example. *Journal of Disability & Religion*, *19*(1), 1–14. Retrieved from https://doi.org/10.1080/23312521.2015.992601

Griffin, M. M., Kane, L. W., Taylor, C., Francis, S. H., & Hodapp, R. M. (2012). Characteristics of inclusive faith communities: A preliminary survey of inclusive practices in the United States. *Journal of Applied Research in Intellectual Disabilities*, *25*(4), 383–391.

Gross, T. 2016. Dean Baquet on the new terrain of covering Trump [Radio]. In Gross, T. & Miller, D., *Fresh Air.* Philadelphia: WHYY-FM and National Public Radio.

Harris, K. I. (2015). Children's spirituality and inclusion: strengthening a child's spirit with community, resilience and joy. *International Journal of Children's Spirituality*, *20*(3/4), 161–177.

Harris, A. (2004). Distributed leadership and school improvement: Leading or misleading? *Educational Management Administration & Leadership*, *32*(1), 11–24.

Haq, F. S., & Mundia, L. (2012). Attitudes to inclusive education and specific disabilities scale. *PsycTESTS*. Retrieved from https://doi.org/10.1037/t39746-000

Howell E. J., & Pierson M. R. (2010). Parents' perspectives on the participation of their children with autism in Sunday school. *Journal of Religion, Disability & Health*, *14*(2), 153–166. Retrieved from https://doi.org/10.1080/152289610036223023

Hsieh, W.-Y., & Hsieh, C.-M. (2012). Urban preschool teachers' perceptions of inclusion questionnaire. *PsycTESTS*. Retrieved from https://doi.org/10.1037/t39436-000

IBM Corp. Released 2013. IBM SPSS Statistics for Macintosh, Version 22.0. Armonk, NY: IBM Corp.

Jacober AE. (2010). Youth ministry, religious education, and adolescents with disabilities: Insights from parents and guardians. *Journal of Religion, Disability & Health*, *14*(2), 167–181. Retrieved from https://doi.org/10.1080/15228961003622310

Jegatheesan, B., Miller, P. J., & Fowler, S. A. (2010). Autism from a religious perspective: A study of parental beliefs in South Asian Muslim immigrant families. *Focus On Autism & Other Developmental Disabilities, 25*(2), 98-109. doi:10.1177/1088357610361344

Kerr, M. E. (2000). *One family's story: A primer on Bowen theory.* Washington, D.C.: The Bowen Center for the Study of the Family. Retrieved from http://www.thebowencenter.org.

Kleinert, H. L., Sharrard, D., Vallance, M., Ricketts, E., & Farley, J. (2010). Teaching seminary students about faith inclusion for individuals with developmental disabilities: The role of family mentorships. *Journal of Religion, Disability & Health*, *14*(1), 6–27. Retrieved from https://doi.org/10.1080/15228960903517299

Larocque, M., & Eigenbrood, R. (2005). Community access. *Journal of Religion, Disability & Health*, *9*(1), 55–66. Retrieved from https://doi.org/10.1300/J095v09n01_04

Liu, E. X., Carter, E. W., Boehm, T. L., Annandale, N. H., & Taylor, C. E. (2014). In their own words: The place of faith in the lives of young people with Autism and intellectual disability. *Intellectual & Developmental Disabilities*, *52*(5), 388–404.

Luong, J., Yoder, M. K., & Canham, D. (2009). Southeast Asian parents raising a child with Autism: A qualitative investigation of coping styles. *Journal of School Nursing, 25*(3), 222-229. doi:10.1177/1059840509334365

Marshall, E. S., Olsen, S. F., Mandleco, B. L., Dyches, T. T., Allred, K. W., & Sansom, N. (2003). “This is a spiritual experience”: Perspectives of Latter-Day Saint families living with a child with disabilities. *Qualitative Health Research*, *13*(1), 57–76. Retrieved from https://doi.org/10.1177/1049732302239411

McGee D. (2010). Widening the door of inclusion for children with autism through faith communities. *Journal of Religion, Disability & Health*, *14*(3), 279–292. Retrieved from https://doi.org/10.1080/15228961003622351

McNair, J., & Sanchez, M. (2008). Christian social constructions of disability. *Journal of Religion, Disability & Health*, *11*(4), 35–50. Retrieved from https://doi.org/10.1300/J095v11n04_04

Michie, M., & Skinner, D. (2010). Narrating disability, narrating religious practice:

Reconciliation and Fragile X Syndrome. *Intellectual and Developmental Disabilities*, *48*(2), 99–111.

Nouwen, H. J., Christensen, M. J., & Laird, R. J. (2010). *Spiritual formation: Following the movements of the spirit* (p. 91). San Francisco, CA: HarperOne.

O'Hanlon, E. E. (2013). Religion and disability: The experiences of families of children with special needs. *Journal of Religion, Disability & Health*, *17*(1), 42–61. Retrieved from https://doi.org/10.1080/15228967.2012.731874

Pitchlyn, C. L., Smith-Myles, B., & Cook, V. H. (2007). Urban parents' perceptions about the role of organized religion and spiritual beliefs in their family life. *Multiple Voices for Ethnically Diverse Exceptional Learners*, *10*(1/2), 8–16.

Poston, D. J., & Turnbull, A. P. (2004). Role of spirituality and religion in family quality of life for families of children with disabilities. *Education and Training in Developmental Disabilities*, *39*(2), 95–108.

Sadler. (2005). Teacher attitudes to mainstream inclusion of children with speech and language difficulties measure. *PsycTESTS*. Retrieved from https://doi.org/10.1037/t43027-000

Scior, K., & Furnham, A. (2011). Intellectual disability literacy scale. *PsycTESTS*. Retrieved from https://doi.org/10.1037/t06971-000

Shaked, M. (2005). The social trajectory of illness: autism in the ultraorthodox community in Israel. *Social Science & Medicine, 61*(10), 2190-2200.

Shogren, K. A., & Rye, M. S. (2005). Religion and individuals with intellectual disabilities. *Journal of Religion, Disability & Health*, *9*(1), 29–53. Retrieved from https://doi.org/10.1300/J095v09n01_03

Skinner, D. G., Correa, V., Skinner, M., & Bailey, D. B., Jr. (2001). Role of religion in the lives of latino families of young children with developmental delays. *American Journal on Mental Retardation*, *106*(4), 297–313.

Slocum, V. (2016). Recommendations for including people with intellectual disabilities in faith communities. *Christian Education Journal*, *13*(1), 109–126.

Swinton, J., & Trevett, C. (2009). Religion and Autism: Initiating an interdisciplinary conversation. *Journal Of Religion, Disability & Health, 13*(1), 2-6.

TASH resolution on life in the community. (2000). Retrieved from http://tash.org/about/resolutions/tash-resolution-life-community/

Treloar, L. L. (2000). Spiritual beliefs, response to disability, and the church: Part 2. *Journal of Religion, Disability & Health*, *4*(1), 5–31. Retrieved from https://doi.org/10.1300/J095v04n01_02

Vogel, G., & Reiter, S. (2003). Spiritual dimensions of Bar/Bat Mitzvah ceremonies for Jewish children with developmental disabilities. *Education and Training in Developmental Disabilities*, *38*(3), 314–322.

Wecker, M.. (2015, October 2). Why the religion beat poses unique challenges for some reporters. *Columbia Journalism Review.*

White, S. E. (2009). The influence of religiosity on well-being and acceptance in parents of children with Autism Spectrum Disorder. *Journal Of Religion, Disability & Health, 13*(2), 104. doi:10.1080/15228960802581503

Wright, A. C., & Taylor, S. (2014). Advocacy by parents of young children with special needs: Activities, processes, and perceived effectiveness. *Journal of Social Service Research, 40*(5), 591-605.

APPENDIX A: Focus Group Consent Form

UNC CHARLOTTE
Cato College of Education
Department of Special Education and Child Development
9201 University City Blvd, Charlotte, NC 28223-0001
t/ 704.687.8828 f/ 704.687.1625 www.uncc.edu

You are being asked to participate in a study examining the perceptions of faith community leaders on including children with disabilities and special needs. Participation in this study takes place through a focus group meeting, the group duration will be between 1.5 and two hours.

The focus group conversation will be audio recorded and transcribed. Your decision to take part in this research is completely voluntary. You may refuse, and if you agree to take part you can stop at any time. If you decide not to participate or choose to stop, you will not be penalized in any way. Information gathered during this study will be kept confidential. At no time will your identity be revealed. There are no foreseeable risks associated with participation in this study. Results of the study may be used to allow professionals to understand faith community leader perceptions. The content of focus group discussion and answers given are confidential; please do not discuss them with parties outside the focus group.

If you have any questions about this project, please contact Jared Stewart-Ginsburg at 980.349.8525 or Dr. Cynthia Baughan at 704.687.8179. UNC Charlotte is eager to ensure that all research participants are treated in a fair and respectful manner. If you feel you have been mistreated in any way or have questions about research-related injuries during participation in this project, you should contact the Office of Research Services, Institutional Review Board for Research with Human Subjects (704.687.1871).

I have read the information above (or have had it read to me), I am at least 18 years of age (or legally emancipated), and I agree to participate in this research project. My choice to participate indicates that I have had the opportunity to ask questions about this study and my participation, and that my questions have been answered to my satisfaction; that I have decided to participate; and, that I have received a copy of this form for my records.