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DISABILITY AND BELONGING IN AN INCLUSIVE CHRISTIAN FAITH

COMMUNITY

By

Deborah W. Huggins

B.A., Liberal Arts, St. John's College, 1997
M.A., Special Education, University of New Mexico, 2004
MDIV, Divinity, University of Dubuque, 2014

DISSERTATION

Submitted in Partial Fulfillment of the
Requirements for the Degree of

Doctor of Philosophy
Special Education

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Dedication

I would like to dedicate this dissertation to people with intellectual or developmental

disabilities who participate in the life of faith communities. Thank you for the millions of

gifts that you bring to the faith, for your bravery in making a way where it has been difficult,

and for your patience and persistence as our teachers.

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ABSTRACT

The voices of people with Intellectual and Developmental Disabilities (IDD) are underrepresented in research examining their participation in faith communities. This qualitative case study examined the participation of people with IDD in one intentionally inclusive Christian faith community with a primary focus on the perceptions of faith community members with IDD. This community was unique in its theological stance toward inclusion, and in the steps the community had already taken to be inclusive. I conducted two types of interviews (in-depth individual and Photo-Voice) with people with disabilities who were active in the community and their family members to explore their perceptions of participation and belonging in the faith community. I also conducted in-depth interviews with three of the faith community leaders. I supported interview data with field observations and a document review. I prioritized the voices of people with IDD by using in-vivo coding strategies based on their words and used thematic analysis across data sources. Five primary themes emerged from this analysis including: Leadership, relationships, traditions and

routines, hospitality and beliefs with the first three themes focusing on the experiences

of people with IDD, and the last two on the community. The implications of this study

include suggestions to support authentic participation of people with IDD in faith

community settings, implications for research with people with IDD in these settings,

and the need for systemic changes in faith community structures or policies to support

inclusive practice beyond the tenure of one faith community leader.

Keywords: disability, intellectual and developmental disability, faith

community, inclusion, participation, descriptive, case study

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Chapter One: Theoretical Framework

As articulated in the Individuals with Disabilities Education Act (IDEA), disability is a natural part of the human experience and in no way diminishes the right of individuals to participate in or contribute to society (2004, § 1400.C.10). This statement frames our understanding of disability not only in the IDEA, but also in state education law and laws providing services and protections for people with disabilities (e.g., Developmental Disabilities Assistance and Bill of Rights Act of 1970 and 2000). Freedom of religion is also a fundamental right guaranteed to all Americans in our Bill of Rights. (U.S. Const. amend. I § 2). Clearly, disability in no way diminishes a person's right to religious freedom as a protected freedom in this country and it should not limit people's ability to participate in or contribute to religious life.

Disability status does not change how people value religious expression. Shogren and Rye (2005) conducted a study with people with intellectual or developmental disability (IDD) and found that they value faith in a way that is similar to members of the general population. This included the same tendency toward belief or non-belief and similar findings of importance or value of religion in their lives, with people with IDD expressing faith as very important, somewhat important, or not important at the same rates as members of the population at large. Based on this finding and our nation's legal codes, one would expect religious participation among people with disabilities to be on par with the general population, but this is not the case. According to Carter et al. (2015b), fewer people with disabilities participate in faith communities than the general population.

This finding is counterintuitive when considering that faith communities may be a source of natural supports for people with disabilities. Shogren and Rye (2005) noted that

interactive opportunities presented in faith communities are among the highest of any community-based activity in which people with disabilities commonly engage. *Putting Faith to Work*, a program of the Collaborative on Faith and Disability, conveys the potential resource that faith communities can be for people with disabilities as a support for job creation (Gaventa et al., 2014). Liu et al. (2014) echoed this sentiment by accenting the value of faith communities as a natural source of social support for adolescents, and young adults with IDD.

The value of inclusion in faith communities does not solely benefit individuals with disabilities. There is a theological argument that faith communities as a whole also benefit from inclusion. Swinton (2012) argued that the inclusion of people with disabilities offers increased faith community health and wholeness, as the absence of people with disabilities keep faith communities from being complete. Reynolds (2008) asserted that faith communities that express hospitality by being inclusive of people with disabilities offer greater hospitality to those within the faith community with and without disabilities and are more welcoming to outsiders in general. Both of these scholars argue that the inclusion of people with IDD is a source of renewal for faith communities.

Disability inclusion is a growing area of interest among faith community leaders. This is demonstrated with more disability inclusion specialists on staff in large congregations and in denominational support roles; the commissioning of missionaries to families affected by disability; and conferences and continuing education events for clergy and other practitioners that include theological and practical offerings on disability. Publishers are increasingly including support materials in religious education curriculum for children, youth, and adults with Matan, Friendship, and Congregational Ministries Publishing being three examples of

publishers who provide materials to address the inclusion of people with disabilities in religious education. Most national and local youth events, conferences, and camps now offer support on including youth with disabilities. Despite this growing interest, there are few studies in peer-reviewed empirical academic journals that study the inclusion of people with disabilities in faith communities.

Statement of the Problem

In spite of the value of religious freedom in our country, the parity of interest in religion among people with and without disabilities, and a growing interest in disability inclusion in faith communities, a participation gap between people with and without disabilities in faith communities persists. A participation gap is a difference between the expected rate of participation based on statistics, and the observed rate of participation. Carter et al. (2015b) analyzed the data from the National Core Indicators from the 2012-2013 data cycle and noted a 9% participation gap between participation of people with disabilities overall, with a widening gap for people with moderate and severe disabilities (12–22%). This gap indicates that people with disabilities are not present in faith communities at the same rate as people without disabilities. This gap may be even wider if we measure other indicators of belonging in faith communities beyond presence such as membership in small groups, service, or leadership.

Faith communities have the ability to extend or to deny membership to people with disabilities (Healy, 2009), the ability to extend or withhold invitations (Wilson, 2011) and the ability to provide or deny natural and formal supports (Carter, 2007). Additionally, faith communities have a role in how disability is constructed or enacted in our society (Eiesland, 1994) that may have influence in the larger society beyond the community of faith. Because

of the critical role that faith communities play in disability inclusion, this study seeks to explore the experiences of people with IDD within a faith community.

Theoretical Framework Undergirding Theology of Disability Inclusion

For this study, I used the theoretical framework that Eiesland (1994) outlined in *Disabled God*. Eiesland, who developed the first systematic theology of disability, voiced both the role that the church has played in creating a disabling understanding of the natural diversity of human experience, and the need of the church to understand God's image as fully affirming of the disabled person. Eiesland's work was influenced by the earlier work on liberation theology and Freirian philosophy. I will describe each of these in more depth below.

Liberatory Theology of Disability

Nancy Eiesland was a student of feminist liberation theology and had a physical disability. Liberation theology as expressed by Gustavo Gutiérrez (1973/1988) was foundational to her work. Out of her own experience as someone with a physical disability, she developed a liberatory reading of scripture that made sense of disability as a blessing that carried God's preference. In her 1994 book *Disabled God*, Eiesland challenged her readers to develop an *imago Dei,* or image of God, that affirms and includes people with disabilities.

The concept of *imago Dei* is a theological idea that encompasses both a sense of appearance- what might God look like- and a sense of how human beings, who are created in God's image, show God's image in the world (Aquinas, ST I Q. 93 A.1-6, trans. 1947). For theologians working in liberation theology, the conception of the physical manifestation of God is tied to group and individual identity. Valuing images for God that embrace marginalized people groups is widely understood in Black Liberation Theology as a promoter

of positive black identity and self-determination for Black believers (Calhoun-Brown, 1999;

West, 1993). In her 1994 book Eiesland gives evidence for the persistent physical disability

of Christ into the eschaton and presents an image of God as having a physical disability and

using a sip-puff wheelchair for mobility. Eiesland's *imago Dei* with a disabled body

challenged the church to confront ablest stereotypes and to embrace a framework that leads

to the full welcome and embrace of people with disabilities.

      In addition to her work in *imago Dei*, Eiesland addressed many ways that the church

as a framer of culture has framed disability in a negative light. She discussed the way that the

church has embraced the medical model and challenged people with disabilities and the

church to embrace a self-empowered identity instead of considering disability as punishment

for sin or the result of disease.

Liberation Theology

      To better understand Eiesland, a basic understanding of liberation theology is helpful.

After completing his theological studies in Europe, Gutiérrez, a Latin American priest, saw

the juxtaposition of the Latin American church that was Eurocentric and wealthy while the

people that it served lived in poverty. Gutiérrez saw the lack of a Latin American Theology

that would speak to their experience of faith. Gustavo Gutiérrez's (1973/1988) wrote his

systematic liberation theology based on this experience as a Peruvian priest and scholar and

was also informed by the work of Paulo Freire, a Latin American philosopher of the same

era. According to Gutiérrez, scriptures show a preference for the poor. He claimed that the

poor embodied the ideal of closeness to the divine more easily than those of means

(Gutiérrez, 1973/1988). Gutiérrez called for theologians and clergy to join in the life of the

poor and advocated for the development of small group learning in faith communities that

prioritized the voices of the laity over clergy. Gutiérrez allowed people to engage in dialogue about the beliefs fundamental to their lives, thus moving away from the model of the church where people were passive consumers of religious teaching. He taught faith communities to value their experiences and understanding, and to enter conversations that would be transformative for clergy and laity alike (Gutiérrez, 1973/1988). In its essential teachings, this theology was about changing the dynamics of power in faith communities, giving preference to those who have been silenced by structures of ability, race, gender, sexual identity, class, and education. Gutiérrez relied on the value of co-constructing meaning from sacred texts with members of the community (Freire, 1970/2003). Liberation theology persists as a study with writers in Black liberation, womanist liberation, Palestinian liberation, Queer, Jewish liberation, and Mujerista liberation theology among others.

Freirian Philosophy

As a foundation for Gutiérrez's liberation theology, Freire's educational philosophy is a part of the framework of my proposed study. Freire worked with adult literacy learners in Brazil. He reported that his own experiences of hunger and poverty as a child, helped him to understand the silencing of the poor that happens in traditional education. These experiences led him to develop a system of education where people learn through reflection on their own experiences (Shaull, 1970/2003). In *Pedagogy of the Oppressed*, Freire claimed that the traditional form of education, in which expert teachers deposit knowledge into the mind of novice learners, builds the power of the teacher and the dominant culture at the expense of the learner. Instead, Freire argued for education built on dialogue and on the experiences of the learning community. Freire maintained that dialogue teaches students to become critical

thinkers and to use experiences to solve relevant problems using the community's strengths (Freire, 1970/2003).

Disability Theology

Eiesland's theology, founded on the work of Gutiérrez and Freire and informed by the work of the disability rights movement, provided a strong framework for my study. She articulated the role of faith communities as framers or constructors of disability in our society and emphasized the crucial role that these institutions play in constructing disability. Further, she articulated the value of individuals with disabilities to God, their valued role in reflecting the *imago Dei* and by extension, their status as full members and leaders in faith communities. In the theology of many Christian churches, church members are called the body of Christ, they believe that they are not only created in God's image, but that they are called to act and move in the world as God's body to carry out God's mission. Eiesland's work is poignant when looking at belonging of people with disabilities in communities of faith. She pointed to the high stakes that are at play when communities offer full membership to people with disabilities. Communities who offered full membership, according to Eiesland, accept that the body of Christ includes, and values disabled bodies. With a history of embracing the charity model of disability, and exclusion through the support of the medical model, this move represents a significant paradigm shift for faith communities.

It is important to note that although Eiesland's theology was from a Christian perspective, her theology provided a rationale for disability inclusion in other traditions. Although Eiesland built her argument on the persistent disability of Christ, she moved in the final section of her book to the first person of the Christian trinity- the creator God. Her *imago Dei* is a theological concept across the Abrahamic traditions, with a strong basis in the

Talmud. Eiesland's interpretation and her envisioning of God is valuable to traditions outside

of her own and may be useful in other theological framework with an envisioned deity.

Purpose of the Study

In the emerging field of faith and disability there has been significant research on

clergy attitudes (Patka & McDonald, 2015), promoters of inclusive practices (Griffin et al.,

2012), and the value of religious practice for people with IDD (Carter et al., 2015a; Healy,

2009; Liu et al., 2014; Shogren & Rye, 2005). However, with only 14 empirical research

studies that include people with disabilities as participants, more research needed. Much of

the published scholarship in faith and disability articulate the position of scholars and

practitioners toward inclusion of people with disabilities in faith communities. These position

papers contribute valuable resources to the field, but they fail to give empirical evidence in

support of the position. Of the empirical research on faith and disability, much has focused

on therapeutic issues around providing appropriate care to patients in in-patient settings or on

the experiences of clergy, parents, or service providers. Although these perspectives may

help researchers and practitioners, they fail to voice the experience of belonging or

participation from the point of view of the primary reporters in faith and disability, namely

people with disabilities. Because belonging of people with IDD is the focus of faith

inclusion, the value of research with participants with IDD cannot be overstated. The limited

number of studies reporting the primary experiences of people with disabilities represents an

important gap in this literature. The purpose of this study was to address this gap in the

research in faith and disability by investigating and reporting the experiences of people with

IDD within communities of faith. Keeping in mind both the location of the problem of

inclusion in the faith community and the primacy of the experience of people with IDD in

those communities, I developed this research question to guide my study: What does the participation of people with intellectual or developmental disability look like in one intentionally inclusive Christian faith community?

Definition of Terms

Intellectual Disability (ID)

According to the 2010 definition of intellectual disability from the American Association on Intellectual and Developmental Disability, ID was "characterized by significant limitations in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 18" (Schalock et al., 2010 p. 5).

Developmental Disabilities (DD)

The Developmental Disabilities Assistance and Bill of Rights Act of 1970 defined the term developmental disabilities. Revised in 2000, this definition states "people with physical or mental impairment manifested before 22 with significant needs for coordinated, individualized support to function in one of the major life activity areas" (2000, §102. 8).

Intellectual or Developmental Disability (IDD)

Disability rights organizations and service providers have developed the term IDD as an umbrella term for intellectual disability and developmental disabilities to include people in both of these categories who have functional need for supports. According to Brown et al. (2017) although people with ID also have a developmental disability (DD), there are people with DD who do not have ID. This may occur for people with developmental disabilities such as cerebral palsy, or spina bifida who may have a physical but not a cognitive disability (DD) or with some manifestations of autism spectrum disorder (ASD). Although these

individuals do not have ID, their functioning in one or more life activity areas is improved

significantly by the application of supports. IDD is the umbrella term for both ID and DD

because of the similarity in functional support needs for both groups.

Inclusion

TASH defined inclusion as belonging in the community as an equal member.

Inclusion includes physical presence, social interaction, and access to supports to promote

equity, diversity, and quality of life for children and adults with disabilities. This definition

was applied in community and institutional settings and includes the application of

individualized supports to increase functioning, belonging, and access for people with

disabilities (Almazan, 2009).

Faith Communities

Faith communities are groups organized for and focused on the practice or

observance of rites, festivals, study of sacred texts, or other acts of worship, education,

service, or fellowship related to faith expression. Faith communities may be large recognized

communities with denominational affiliation, or small, independent communities without

hierarchy or formal doctrine. Faith communities may or may not be associated with a

national, traditional, or historic identity. Faith communities in this study included the major

world religions of Islam, Judaism, Buddhism, Hinduism, and Christianity.

Intentionally Inclusive Community

Carter (2007) indicated steps that congregations could take to be more inclusive.

These steps included ways that congregations could respond to people with disabilities and

how they could support people with disabilities and their families while working with service

providers and partnering for community wide inclusion networks. Faith communities taking active steps like these are intentionally inclusive.

Position Statement

I am a white, Anglo-Saxon woman, and an ordained minister of word and sacrament in the Presbyterian Church (USA), a mainline Christian denomination. I am employed as an associate pastor for youth and children in an established, historic church in an affluent suburban community. I have been identified in the local press, in religious education curricula, and at national conferences for religious leaders as an advocate for disability inclusion in faith communities. I hold a master's degree in special education and a master's degree in divinity. I have experience as: a special educator, a clinical supervisor for student teachers, a pastor for youth and children, and as a Director of Christian Education.

I hold several positions that are valued as authority within the community with which I partnered for research. In formulating questions and in gathering data, I needed to be very careful that participants did not give me the answer that they thought I wanted to hear. In addition, I needed to establish a commitment to confidentiality to encourage participants to feel comfortable sharing experiences that they may not want repeated to their pastor, caregiver, or other members of the community.

In addition to issues of power and acquiescence, I needed to be aware of my bias toward inclusive practices in faith communities and to be cautious in developing tools and in analysis so that my bias does not cloud data collection or analysis. Finally, as a novice researcher, I was grateful to be working with an advisor and committee who have helped me use good practices for research design, data collection, and analysis so that in this study I can

report the experiences of people with IDD who participate in intentionally inclusive faith communities.

Organization of the Dissertation

To this point, I have framed the problem of a lack of research exploring the experience of people with IDD in inclusive faith communities. In Chapter Two, I will review the current research in the field of faith and disability. In Chapter Three I will lay out the methods I used in this study to best understand the experiences of people with IDD in an intentionally inclusive faith community. In Chapter Four I will outline my research findings, and in Chapter 5, I will discuss my findings in light of the larger research.

Chapter Two: Review of the Research

In this chapter, I am reviewing the relevant research in faith and disability to situate my research question in a larger research literature. In posing the problem, I claimed that there is a significant gap in the participation of people with IDD in faith communities. In this section, I will explore that statement further using the research literature that describes the experiences of individuals with IDD in faith communities. Specifically, I will review the research in faith and disability that includes participants with IDD to examine their experiences in faith communities. Using a thematic analysis of the findings of the current literature, I will be laying ground work to discuss the current experience of inclusion for people with IDD in faith communities, how people experience belonging from the point of view of physical presence in faith communities, how they engage in communities when they are there, and how faith communities are meeting the needs of people with disabilities in their religious institutions.

Research Question

Because this study focuses on the experience of people with IDD as they participate in, and contribute to faith communities and because faith communities bear responsibility for invitation, access, and hospitality, I have developed the following question to guide my research: What does the participation of people with intellectual or developmental disability look like in one intentionally inclusive Christian faith community?

Overview of the Field

The inclusion of people with IDD into communities of faith is a field of growing interest within the literature in several disciplines, such as practical theology, disability studies, special education, nursing, and the fields of sociology and psychology. The research

in this area includes studies exploring the effects of religious belief on mental health and coping, the expanding theological understanding of disability, and ways to meet the spiritual needs of people with disabilities while they are in health care and community-based settings. The broadness of the field makes doing a systematic review of research challenging. Standard search terms have not emerged, and research appears in publications across many disciplines. Even though the library search I conducted for this review returned a large group of studies, it did not return all of the relevant research. To include all of the relevant research studies, I did both library and cited reference searching. The small number of original empirical research articles I found suggested the limited research that has been done in this field and the significant gaps in research addressing people with IDD in faith communities. By narrowing the literature for this review to include only empirical research in which people with IDD are participants, I found 14 empirical studies that focused on the experience of inclusion in faith communities for people with IDD.

Method

Search Protocol

In this review of research, I included original empirical research studies that addressed the participation of people with IDD in faith communities and included people with IDD as participants. I did the search in two phases: searching electronic databases and searching article references.

I conducted a review of the peer-reviewed literature around faith communities and disability by completing several library searches using broad terms. I used the key words Disability + Faith + Community using a library search engine to look at 27 databases including: World cat, ArticleFirst, PsycARTICLES, Project Muse, Education Abstracts,

Academic Search Complete, ERIC, JSTOR Arts & Sciences Collections, and MLA International Bibliography. This returned 3,999 articles. I next removed duplicate articles and read abstracts to identify peer-reviewed original empirical research investigating disability and faith written in English. Because I did not limit the search by date, I examined articles from as early as the 1960s. Next, I read abstracts and applied exclusion and inclusion criteria to identify studies for this review. Studies were included if the study was: (a) original empirical research; (b) focused on the participation of people with IDD in faith communities; and (c) if participants in the research were people with IDD. Articles were excluded if the article was: (a) not original empirical research (e.g., theological research, position papers, research reviews); (b) focused on religion or spirituality but not on faith community participation (e.g. mental health and religion or parochial school education); (c) examined disabilities other than intellectual or developmental (e.g., age-related disability, chronic health related disability such as cancer or diabetes; mental health disability); or (d) did not include people with IDD as participants in the study. By applying the inclusion and exclusion criteria to the 3,999 originally identified articles, I found 25 articles that then required further detailed study for this review.

Cited Reference Searching

Because of the variation in key words and search terms in this body of research, cited reference searching was a valuable tool for identifying additional relevant research. I examined the reference sections of the 25 included papers located through the abstract review and identified 24 additional studies for further investigation. I applied the same inclusion and exclusion criteria to their abstracts as explained above. I examined references from these 24 research studies and identified an additional six papers for abstract and reference review. I

reviewed the references from these six additional studies and found that their references did not return any unique, relevant references in the return of references (i.e., reached saturation).

I next read the full studies for this group of 55 (25 from the initial search and 30 from searching references) and applied the same inclusion and exclusion criteria carefully, eliminating articles which at first appeared to fit the inclusion and exclusion criteria but which, after more careful reading, did not. This process yielded a final total of 14 articles representing empirical research on faith and disability, including people with IDD as participants, and focusing on faith community participation.

Coding

I conducted coding in two phases. My initial coding was based on characteristics of the research studies and my secondary coding examined studies' findings about participation of people with IDD in faith communities. My initial coding for the articles meeting inclusion and exclusion criteria was based on characteristics of the research: methods used and participant demographics. When I looked at research methods, I was especially interested in seeing if studies employed qualitative, quantitative, or mixed methods, and identifying the type of study design. Because only articles that included participants with IDD were included in this study, participant characteristics were especially important and were examined to compare articles by: relationship of the respondent to disability (e.g., person with a disability, family member, direct support personnel, non-disabled), age, and major ethnic group identity (e.g., Caucasian, African American, Hispanic, Asian, American Indian or Alaska Native, Pacific Islander) with the sub-group of faith community affiliation (e.g., Muslim, Jewish, Christian).

After I finished primary coding by demographic information, I coded the articles again by key findings about how people with IDD participate in faith communities. Using a grounded theory approach (Glaser & Strauss, 1967), I read the first article looking at the research question and asking how the key findings of that article described the participation of people with IDD in faith communities. I noted findings that addressed the experience of faith community participation for people with IDD. I read the next article asking the same question, and I identified answers in the findings. I read the next article with additional findings identified until I had read all of the studies several times and identified no new findings. After creating a list of findings, I grouped findings into categories of similar meanings. For instance, findings for prayer, communion, and festivals were categorized under religious participation; findings around physical access, the use of a disability action group, and the kinds of natural supports found in a faith community were all categorized under accommodation and hospitality. I continued this process until I had re-read all of the articles and categorized the listed key findings for participation in faith communities. I added categories as needed (i.e., if something new emerged from a study). After the findings were categorized, I re-examined the list of categories and grouped similar, more specific categories into more general categories. For example, accessibility, supports, and flexible requirements for membership were all categorized into accommodations.

I next analyzed the categories and saw that findings encompassed experiences of belonging, not belonging, and partial belonging and included three main categories: belonging as presence, belonging as religious participation, and belonging as accommodation/ hospitality. These three categories, as they were expressed in this body of

research, are defined below. (For further discussion of the coding themes, including

examples, please see the table below.

Table 1.

Coding Definitions Table

What does the inclusion of people with intellectual or developmental disability look like in

an intentionally inclusive faith community?

Definitions

1. Belonging includes presence

2. Belonging includes religious participation

3. Belonging includes hospitality/ accommodation

Coding Definitions

Presence: Being present or attending a faith community is the first step to belonging.

Examples: Participation data including demographic factors and how those affect participation (Carter et al., 2015b; McNair & Smith, 2000; Shogren & Rye, 2005)	Non-examples: Natural or formal supports used (Carter et al., 2015b; McNair & Smith, 2000; Shogren & Rye, 2005)

Hospitality/ Accommodation: Accommodations are those supports given by the community to include people with disabilities. When this term includes a theological grounding of welcome, it may be called hospitality. This includes attitudinal, physical, and programmatic supports. Supports may be formal or natural.

Examples: Community offers kindness, assistance, friendship, healing, or protection (Bunning & Steele, 2006; Griffin et al., 2012; Liu et al., 2014; Minton & Dodder, 2003; Poston & Turnbull, 2004; Wilson 2011). Faith communities modify conditions for belonging to accommodate people with disabilities (Healy, 2009)	Non-Examples: Faith communities do not modify conditions for belonging to accommodate people with disabilities (Healy, 2009), people not allowed to participate in rites of the faith community (Healy, 2009) and lack of access (King, 1998; Möller, 2012).

Coding Definitions

Religious Participation: Religious participation includes those things that people do as an expression of their faith. This definition is inclusive of individual and corporate practices and includes both large and small group activities.	
Examples: Participation in worship, prayer, Bible study, festivals, fellowship or service, personal or family devotion. Full-religious participation would also include the expression of non-belief. (Bunning & Steele, 2006; Healy, 2009; Liu et al., 2014; Minton & Dodder, 2003; Möller, 2012; Poston & Turnbull, 2004; Shogren & Rye, 2005; Turner et al., 2004;)	Non-Examples: Exclusion from religious participation including worship, religious education, fellowship, or devotion. (Healy, 2009; King, 1998; Möller, 2012)

Belonging as Presence

Being present or attending a faith community is the first step to belonging (Carter, 2016). Although it is not a measure of full participation, without physical presence, full participation is impossible. Moreover, the participation gap between people with and without disabilities, or between people with differing support needs is often used as a rationale for conducting research on disability in faith communities (Carter & Annandale, 2014; Carter et al., 2015a; Griffin et al., 2012; McNair & Smith, 2000).

Belonging as Religious Participation

Faith community participation was discussed in the findings of almost all of the reviewed studies (n = 12). Religious participation included individual and corporate action such as attending worship, prayer, social activities within the community, service, and financial giving. Participants in the reviewed studies valued access to all of these areas of faith community life.

Leadership. Leadership is defined as a sub-category of religious participation. Worthington (2016) wrote that leadership in faith communities was developed out of a sense

that people are called by Allah to lead the community and that the community acknowledges that call. This idea of call and fulfillment was echoed in the research literature around faith and disability. Examples of leadership included worship leadership (e.g., singing in the choir, reading scripture or public prayer) and leadership within the structure of the community (e.g., serving on boards or leading small groups).

Belonging as Accommodation or Hospitality

Faith community accommodation includes those supports provided to an individual by the community to enhance or facilitate that individual's participation in the faith community. When this term includes a theological grounding of welcome, it may be called hospitality (Reynolds, 2008). Accommodations may include attitudinal, physical, liturgical, and programmatic supports. Supports may be formal, such as the use of a paid support person or trained volunteer, or natural, such as a member of the faith community offering support with transportation.

As a final step, I read all articles again using the coding categories as defined above; no additional categories emerged. Table 2 provides a summary of each study's findings for each category and the next section discusses these findings in detail.

Findings

Primary coding looked at characteristics of the research, including research designs and methods, and participant characteristics. In the second phase of coding, I examined the findings of the returned articles and used a grounded theory approach to uncover themes (Glaser & Strauss, 1967). Findings from both stages of analysis are described below.

Characteristics of the Research

Primary coding examined participant characteristics and research designs and methods for the 14 relevant studies. These characteristics offered notable insights into the state of research in the field and the common methods or approaches used in conducting research in faith and disability.

Table 2.

References for Review: Primary Coding

Reference	Type	No.	Disability Category	Faith Tradition	Ethnic Identity	Age
Bunning & Steel (2006)	Qualitative Intervention strategy with interview	4	ID, ASD	Jewish		Young adults 18-21
Carmeli & Carmeli (2001)	Quantitative Experiment	8	ID	Jewish		Adolescents 12-23
Dennis & Murdoch (2001)	Qualitative Interviews and PAR		General	Christian		Adults
Griffin et al. (2012)	Quantitative Survey	416	ASD, LD, ADHD, PSI, DS, ID, DD	Christian 88.8% Jewish 4.4% Buddhist .6% Other 5.7%	Caucasian 91% African American 5% Asian 2% Other 1%	Mean age 43.72 (SD 13.68)
Healy (2009)	Qualitative Document review	30	General	Christian		Adults
King (1998)	Qualitative Interview	5	DD, VI	Christian	African American	Adults

Reference	Type	No.	Disability Category	Faith Tradition	Ethnic Identity	Age
Liu et al. (2014)	Qualitative Interview	20	IDD, ASD,	Christian	Caucasian 75% African American 15% Asian 5% Other 5%	Young People13-21
McNair & Smith (2000)	Quantitative Questionnaire	92	DD	Christian	Caucasian 73% Hispanic 17% African American 10%	Adults
Minton & Dodder (2003)	Qualitative	35	DD	Christian		Adults
Möller (2012)	Qualitative PAR	65	OI, ID, VI, OHI	Christian		Adults
Poston & Turnbull (2004)	Qualitative Focus group and interview	187	IDD	Christian	African American 42% Hispanic 3% Caucasian 26% Other 4% More than one Ethnicity 3%	Adults and Children
Shogren & Rye (2005)	Mixed Methods Norm referenced testing and interview	41	ID	Christian, Jewish	Caucasian 71% African American 29%	Adults

Reference	Type	No.	Disability Category	Faith Tradition	Ethnic Identity	Age
Turner et al. (2004)	Qualitative Interview	29	IDD	Christian, Muslim, Hindu		Adults
Wilson (2011)	Qualitative Interview	18	ID	Christian, Spiritual		Adults

Note. ASD = Autism Spectrum Disorder, ADHD = Attention Deficit Hyperactivity Disorder, DD = Developmental Disability, DS = Down Syndrome, FC = Faith Community, ID = Intellectual Disability, IDD = Intellectual Developmental Disability, LD = Learning Disability, OHI = Otherwise Health Impaired, OI = Orthopedic Impairment, PAR = Participatory Action Research, PSI = Psychiatric Impairment, VI = Visual Impairment

Participant Characteristics

These characteristics included ethnic group identity (including faith tradition), age, and disability category. Researchers in thirteen out of fourteen of the studies identified the religious affiliation of participants. Participants in seven studies were exclusively Christian; participants in two were exclusively Jewish. Of the five remaining studies, Poston and Turnbull (2004) did not identify the religious tradition of their participants but discerned that most of their respondents were Christian based on their findings. The other four studies included participants who identified as Spiritual, Muslim, Hindu, and Buddhist in addition to those who identified as Jewish or Christian.

Only six studies accounted for major ethnic group identity data other than religious affiliation. Eight of the studies did not collect or report major ethnic group identity information (e.g., Caucasian, African American, Hispanic, Asian, American Indian or Alaska Native, Pacific Islander). They only included religious identity in ethnic identity reporting. Of the six studies that collected major ethnic group identity, four had 70% or more Caucasian participants, and two had a majority of African American participants. Only two included data for any Hispanic or Asian participants (see Table 2). Eleven studies included only adult participants. Of the remaining three studies, only one included children (ages 2–60; Poston & Turnbull, 2004); and two included adolescents (ages 12–23, Carmeli & Carmeli, 2001; ages 13-21, Liu et al., 2014).

All of the studies included at least one participant with IDD. Researchers in two of the studies did not report that participants had additional disability labels other than IDD. Three studies included people with autism spectrum disorder (ASD). Two studies included a participant with visual impairment (VI), and one study each included participants who

identified as having additional disability eligibility as Other Health Impaired (OHI),

Orthopedic Impairment (OI), Learning Disability (LD), Attention Deficit Hyperactivity

Disorder (ADHD), Psychological Impairment (PSI), and Down syndrome (DS). Please see

Table 2 for more detail.

Research Design

Of the 14 studies included in this review, 10 used qualitative methods, three used

quantitative methods, and one was a mixed methods study. Of the three quantitative studies,

Griffin et al. (2012) conducted a survey; McNair and Smith (2000) used a questionnaire; and

Carmeli and Carmeli's (2001) study was an experiment testing the efficacy of a teaching

strategy to increase religious symbol recognition. Shogren and Rye (2005) conducted a

mixed methods study including results from norm referenced assessment and interview data.

Of the ten studies using only a qualitative design, Healy (2009) conducted an analysis of

written first-hand experiences of the sacraments, Möller (2012) and Dennis and Murdoch

(2001) conducted Participatory Action Research (PAR), and the rest of the research teams

conducted studies using interviews. Please see Table 2 for more detail.

Conclusion

The primary coding of these articles uncovered the limited research in this emerging

field and underlined the need for further research with greater attention to major ethnic group

identity (e.g., Caucasian, African American, Hispanic, Asian, American Indian or Alaska

Native, Pacific Islander). Researchers in this field may have conflated ethnicity and religious

identity. It is important that both ethnicity and religious identity are considered separately as

one cannot assume ethnic identity based on religious identity, or the reverse. The practice of

reporting religious identity without reporting other ethnic identities made results difficult to

interpret and compare. A second finding of the primary coding was that the literature supported using qualitative methods for research in this field. Qualitative methods were chosen in eleven out of fourteen studies with a variety of methods employed successfully. Interview data was common with eight studies relying on interviews for at least part of their results.

Thematic Coding: Analysis of Study Findings

After completing the primary coding, I used the approach described in the method section to identify themes across coding categories. Three categories emerged from this analysis: belonging as presence, belonging as religious participation, and belonging as accommodation or hospitality.

Table 3.

Literature Review Findings

Reference	Presence	Religious Participation	Accommodation/ Hospitality
Bunning & Steel (2006)		FC practices included: Traditional dress, participation in festivals and celebrations, worship, prayer, participation in Youth Movement.	Jewish identity and youthful identity reported at same rate. Participants reflected a strong sense of inclusion and belonging in their community life.
Carmeli & Carmeli (2001)		Strategy used to increase religious participation.	This study provided an accommodated learning strategy to give people increased access to the religious expression.
Dennis & Murdoch (2001)		Families found ways to express their faith outside FC when they did not have supports to attend the FC.	Disability focus groups provided: greater awareness of disability; more people with disabilities participating; leadership for inclusion; direct support to people with disabilities inside and outside of FC; members of the group consulted as experts; effective inclusive sacramental education.
Griffin et al. (2012)		Roles available to people with disabilities in faith communities were limited. Communities with a disability resource person were more welcoming and inclusive	More inclusive FCs: rated inclusion of people with disabilities as important or very important; rated as fairly accessible; rated fairly welcoming and inclusive; had

Reference	Presence	Religious Participation	Accommodation/ Hospitality
		and had more opportunities for people with disabilities to lead. *Leadership:* Factors of inclusion also predicted leadership.	relationships with disability organizations; utilized educational resources addressing disability; had informal worship, made decisions by consensus, kept in closer contact with inactive members and were involved in social justice. Family members of people with IDD rated their faith communities lower than parishioners and leaders on these measures. Larger faith communities were more physically accessible.
Healy (2009)		Full religious participation included: Community experience of faith (Kenosis); experience with the Holy (Synergy); evangelism; sacraments; reconciliation; preaching, ordination of the spirit; prayer for others. *Leadership:* Member of disability inclusion team and evangelism	Identified requirements for belonging (confirmation, communion, baptism) and asserted that how communities chose to interpret those requirements led to either belonging or exclusion and that adherence to rules can be worse than breaking them. Provided examples of accommodation and welcome and non-accommodation and exclusion.
King (1998)		People with IDD were expected to be dependent on others. *Leadership:* Leadership in choir was discouraged because of disability.	Described unsolicited faith healings and comments on the faithfulness of the person related to their disability (sign of lack of faith). Described feeling discrimination from members of their FC based on disability status including avoidance and lack of

Reference	Presence	Religious Participation	Accommodation/ Hospitality
			accessible seating. Described feeling "spotlighted" instead of like a typical member of the congregation: Asked to pray and called out as an example in sermons.
Liu et al. (2014)		Personal prayer; experience of the power of God; beliefs and behaviors (e.g. accepting a core belief, and studying scripture, and preaching); FC activities (e.g., worship, Sunday School, youth fellowship, retreats, camp); rites of passage (e.g., baptism, confirmation, and communion); social connection; service to others (e.g. financial giving, and serving outside of the community); faith seen as a journey; connections with family core to faith; people felt known and understood by God with disability part of God's design. *Leadership:* ushering, greeting, serving communion, singing.	Community offered: Belonging, kindness, help (financial, academic, physical, emotional, relational), friendship/ love, healing, and protection.
McNair & Smith (2000)	54% of adults attended church in the last 7 days	Most people with ID who attend FCs attended with a family member (48% or attenders)- even though most respondents lived in a group home (52%).	

Reference	Presence	Religious Participation	Accommodation/ Hospitality
Minton & Dodder (2003)		People enjoyed FC participation, participated in Sunday School, enjoyed singing and playing music, and FC sponsored summer camp. In worship people sang, prayed with natural supports offered by congregation- sometimes more appropriate than others. Sunday School for individuals with IDD involved lots of interruptions in both classes. Leadership: person with disabilities not allowed to lead because their disability would make others uncomfortable.	People reported being treated well at FCs but noted that they do not receive visits or calls. 4/25 people reported having negative experiences with FCs. The four house managers felt the different FCs only minimally accepted the men and women from group homes. Pentecostal clergy expressed that his church was more accepting of a variety of behaviors and that it was more inclusive and welcoming. FCs provided separate class with separate curriculum because membership felt uncomfortable with adults with ID.
Möller (2012)		Sacraments and rituals. People with disabilities viewed as competent and able to contribute gifts to others in the church. Leadership: Giving testimony, serving as a Deacon, running a mother's group, doing maintenance.	Lack of physical access was a barrier to participation: inaccessible transportation; inaccessible toilets; seating; inadequate lighting; inaccessible times. Disabling Biblical interpretation was common: People must be healed from disability; and disability is a result of sin. Disabling attitudes: Offensive language and labeling; overprotective and patronizing; unwillingness to learn about disability; and stereotyping. Accommodations offered: invitations

Reference	Presence	Religious Participation	Accommodation/ Hospitality
			for meals; waiting to hear testimony; making adaptations especially around seating.
Poston & Turnbull (2004)		Spiritual beliefs contributed to emotional and family quality of life allowing family members to: make sense of disability; find a source of blessing, patience, and strength. Prayer seen as a means of communicating with God. People reported participating in: Meetings, activities, and choir.	½ felt Religious community was a place of acceptance with children accepted into all facets of religious community. The same number described difficulty because they did not have support to participate fully and they were not accepted.
Shogren & Rye (2005)	76% attended worship regularly- their participation in FC was as frequent as other activities such as watching television, eating out, or using public transportation. 83% viewed themselves as religious.	People thought about God and understood theological concepts. Religious participation included: Prayer, reconciliation, fellowship, financial support, attending worship, and Religious Education. Sunday School / Bible Study participation was less frequent. They most often attended with a paid support person. Participation was not tied to severity of IDD.	

Reference	Presence	Religious Participation	Accommodation/ Hospitality
Turner et al. (2004)		Participation in sacraments denied. People with IDD participated in programs, worship, fellowship, and received visits. Leadership: FCs denied leadership. People with IDD helped the less fortunate, caring for the blind, putting an arm around someone upset.	Experiences with FCs were diverse. There was a sense that FCs had done little to make worship accessible. People need someone to accompany them for support (often family) with lack of transportation an issue. People also reported faith communities as a source of support, friendship, and relationships.
Wilson (2011)			Volunteer leaders had a sustained commitment, stressed welcome and blessing, and used curriculum to balance learning objectives and socialization. Denominations were willing to accommodate people with ID, but did little outreach.

Note. ID = Intellectual Disability, DD = Developmental Disability, IDD = Intellectual Developmental Disability, FC = Faith

Community.

Belonging as Presence

The experience of participation in a faith community begins with being present in the community. Belonging is impossible without first being a part of the physical community. In the research literature I reviewed, two studies directly examined the presence of people with IDD in faith communities. McNair and Smith (2000) and Shogren and Rye (2005) examined participation rates of individuals with IDD in faith communities. These two studies provided a somewhat inconclusive look at participation with contradictory findings on the rate of participation, with whom people with disabilities attended faith communities (e.g., paid support, faith community leader or friend, on their own, or with family), and how frequently they participated compared to participation in other activities.

Rates of Participation. When examining rates of participation, the two authors did not find similar rates of attendance in faith communities. Shogren and Rye's (2005) participants were 42 people with IDD living is six different care communities, three of which identified as affiliated with a religious tradition. Eighty-three percent of these participants viewed themselves as religious and 76% of them reported attending religious services regularly. McNair and Smith (2000) examined participation of 92 people with IDD from one geographic area who lived in a variety of settings and found that 54% of these adults attended religious services at least weekly.

The two studies also had conflicting findings regarding rates of participation in faith communities as compared to other types of community engagement. McNair and Smith (2000) found that participation in faith communities was lower than rates of participation in other facets of life, such as exercising or shopping. Shogren and Rye (2005) found that

people attended faith communities at the same rates as they participated in other activities such as watching television or going out to eat.

Support for Participation. When looking at who attended activities in faith communities with individuals with IDD, the two studies again showed conflicting results. McNair and Smith (2000) found that 48% of faith community attenders in their study went with a family member to their faith community, even if they lived in a group home. Conversely, Shogren and Rye (2005) found that most participants in their study attended with paid support staff (e.g., from their group home).

Belonging as Religious Participation

Researchers in 12 out of 14 studies in this review included findings about participation in large group, individual, and small group religious practices. Types of practices and participants' roles in these practices varied. These studies' findings underline the role of religious participation as an aspect of belonging to a faith community.

Participation Roles. Of the twelve studies examining how individuals with IDD participate in faith community life, worship was the most commonly reported form of participation with ten of the studies reporting participation in corporate worship as one of the ways that people with disabilities participate in faith communities (see Table 3). Prayer, social activities, and financial giving to the faith community were mentioned in six studies (Healy, 2009; Liu et al., 2014; Minton & Dodder, 2003; Möller, 2012; Poston & Turnbull, 2004; Shogren & Rye, 2005). Participation in religious education was mentioned three studies (Liu et al., 2014; Minton & Dodder, 2003; Shogren & Rye, 2005), and participation in religious festivals was mentioned in two (Bunning & Steele, 2006; Carmelli & Carmelli, 2001).

Restricted Roles. Besides reporting ways that they experienced belonging, participants in five studies described how their religious participation was denied or limited in some way. Dennis and Murdoch (2001) noted that after humiliating experiences of exclusion, people with IDD and their families often chose to express their religion outside of any faith community. King (1998) found that people with IDD were expected to be dependent during worship (e.g., ushers pushed them to their place without being asked and without eliciting preference). Participants in the Griffin et al. (2012) study described the roles available to people with IDD in worship was limited, especially in the area of worship leadership. Turner et al. (2004) also found that roles in worship services were denied to people with IDD in their study, including receiving the sacraments. Healy (2009), who focused on the sacraments in his research, identified seven sacraments and described painful feelings associated with denying people religious rites and reported that inclusion or exclusion from sacraments was described as creating a feeling of closeness or distance from God, not just the faith community.

Leadership Roles. As a particular expression of religious participation, leadership was mentioned in seven of the studies. Healy (2009) reported that service to others was an external example of people's internal religious life. Leadership was reported to include roles during worship in a responsibility such as singing in the choir and serving as a greeter; or as an organizational leader like an officer, teacher, or small group facilitator. This need was not diminished by person's support needs or the severity of their disability. Turner et al. (2004) examined religious expression in adults with IDD and reported that people with IDD in their study expressed their capacity for leadership by helping the less fortunate, caring for the blind, or putting an arm around someone who was upset. Möller's (2012) participants

expressed a desire to lead in their faith communities, stating that access to leadership was an important part of participating in the life of a faith community. Healy (2009) found that people with extensive support needs participated in committees and served as evangelists in their congregations. Liu et al. (2014) found that part of how young people with disabilities reported the place of faith in their lives included financial giving, ushering, greeting, singing in worship, and service outside of the community. These were identified as central to the faith expression of religious youth with disabilities.

In contrast, Minton and Dodder (2003) reported that people being denied access to participation by faith community leadership could be a barrier to inclusion in the community. They found that being denied the role of greeter was a source of disappointment and confusion for a participant who had held that role in a previous congregation. King (1998) also reported that participants in the study expressed feeling discouragement when their faith communities kept them from singing in the choir.

Belonging as Accommodation or Hospitality

Twelve of the fourteen articles included findings related to accommodation or supports. In these articles, faith communities provided, or were asked to provide, supports to enhance the individual's participation in the religious and social life of the community. The findings around accommodation were very mixed. Participants in four studies commented that faith communities were a source of support for them (Bunning & Steele, 2006; Carmeli & Carmeli, 2001; Dennis & Murdoch, 2001; Liu et al., 2014). Participants in five studies (Healy, 2009; Minton & Dodder, 2003; Poston & Turnbull, 2004; Turner et al., 2004; Wilson, 2011) reported the simultaneous presence of and lack of needed supports. Other

studies (King, 1998; Möller, 2012) reported a lack of supports as a barrier to belonging in the faith community.

      Accommodation for Belonging. In the reviewed research, researchers reported situations in which faith communities provided accommodations for people with disabilities and situations in which they did not. One group of articles represented the use of intentional supports for people with disabilities offered by faith communities. These supports included the use of trained volunteer advocates within the faith community and programs for mastering religious content. Direct support was discussed in three strategy-based studies (Bunning & Steele, 2006; Carmeli & Carmeli, 2001; Dennis & Murdoch, 2001). The findings of these three studies focused on the supports being offered through these interventions and the efficacy of the interventions. Dennis and Murdoch (2001) examined the efficacy of developing a disability focus group to increase the participation of people with disabilities in faith communities. Carmeli and Carmeli (2001) used a teaching intervention to increase familiarity with symbols related to religious festivals, and Bunning and Steele (2006) examined the efficacy of using talking mats as a way to explore Jewish identity with adolescents with IDD. All three-strategy research studies reported positive results in increasing participation of people with IDD in faith communities.

      The research further shows the results of faith communities providing direct and indirect supports. Liu et al. (2014) described the ways that youth with IDD felt supported by their congregations. With this focus on the individual, there is less focus on how the community provided supports, and more of a focus on the results for individuals. The researchers identified six ways that youth with IDD have felt supported by their faith communities: belonging, kindness, help, friendship, healing, and protection.

Mixed Accommodation. Like the findings regarding religious participation, the findings around accommodation included mixed results. Minton and Dodder (2003) found a mixed experience of accommodation. People experienced both support by the faith community in worship and religious education while simultaneously experiencing the barrier of being forbidden from a church picnic unless individuals with disabilities could provide their own professional support people. Turner et al. (2004) described people being supported in programming and social events and finding barriers to participating in important rites of the faith community. Poston and Turnbull (2004) found that about half of their parent participants described faith communities as a place that supported their children, and half reported a lack of accommodation. Wilson (2011) noted that although experienced and caring teachers were prepared with solid curriculum to serve people already in the church, they fell short of offering hospitality to outsiders by extending an invitation. In his 2009 study of first-hand accounts of people around Christian rites of membership (e.g., communion, baptism, and confirmation), Healy (2009) reported similar mixed findings (please see Table 3 for more detail).

Lack of Accommodation as a Barrier for Belonging. Two articles highlighted a lack of accommodation as a barrier to belonging in the faith community (King, 1998; Möller, 2012). These missing supports were related to physical, liturgical, and attitudinal barriers within the community. King (1998) noted both overprotection and spotlighting as attitudinal barriers in her study. Participants explained that faith community members tried to do things for them without invitation (overprotection), and the communities made participants feel as if they were being made into an example during public prayer or exhortation (spotlighting). Both of these behaviors kept people with IDD from feeling like typical members of the

community. Möller's (2012) participants added the use of offensive language and an unwillingness to learn about disability as two additional attitudinal barriers for belonging. She also identified barriers to worship in faith communities. One type of barrier was liturgical. These liturgical barriers included a theological stance toward disability as people in need of healing, or the belief that disability is the result of sin. Participants noted that these statements from clergy during sermons were especially hurtful and made them feel unwelcomed. Lack of physical access was also a significant and persistent concern for participants in both studies.

Conclusion

Findings from the initial and secondary coding established the current research in the field and highlighted additional significant questions arising from the existing body of research in relation to the experiences of people with IDD in faith communities. In the next section, I will discuss these findings focusing on the significant questions raised in the research.

Discussion

The findings of the reviewed studies resulted in the emergence of three themes addressing participation of people with IDD in faith communities. These themes addressed physical presence of people with IDD in faith communities, the experience of participation within faith communities, and accommodations that were offered or needed in faith communities. There are several implications of these findings for future research. Two characteristics of them are: the reporting of participant characteristics in the research literature, and the methods for research.

The majority of the studies in this review (n = 8) identified participant religious identity without including their major ethnic group identity information (e.g., Caucasian, African American, Hispanic, Asian, American Indian or Alaska Native, Pacific Islander). The lack of reporting of major ethnic groups is not typical in empirical research. In addition to representing a need in the field for further research; it suggests an underlying assumption in the field of faith and disability about religious identity and other ethnic identities and suggests that there may be a conflation of the two. According to the National Core Indicator Data interpreted by Carter et al. (2015b), religious affiliation may not be as predictive of participation rate as ethnic group identity. They found that African Americans with IDD attending at higher rates (60.1%) than white (43.9%) or Hispanic (46.4%) respondents. In light of this finding, the non-reporting of major ethnic group identity in the reviewed studies leaves readers to wonder how major ethnic group identity might change the interpretation of data in these findings.

Another informative finding related to characteristics of the reviewed research was the research design and methods used. Eleven of the fourteen studies used at least some qualitative methods. Qualitative studies are helpful in looking at complex communities, smaller populations, and in answering how and why questions instead of what questions (Denzin & Lincoln, 2003). Denzin and Lincoln explained that qualitative methods allow researchers to consider multiple points of view with multiple methods. Faith communities represent different points of view with different and sometimes conflicting experiences. Allowing for the complexity of the community experience is an important part in telling the full story of how faith communities accommodate people with IDD so these types of qualitative methods may be most appropriate.

Findings from the thematic analysis of the reviewed studies also provided several important conclusions about the current research in faith and disability and provided directions for future research in this area. One important implication arising from this review is considering the physical presence of people with IDD in faith communities as a first step toward inclusion (Carter, 2016). The empirical research in this review does not provide enough information to determine the reasons for a participation gap definitively, but it does raise the complexity of such an examination and the need for careful analysis of differences in faith community participation. This review suggests that the participation gap is not simply attending or not attending faith community activities, but also the ways in which people participate within the available activities.

Once physically present, it is also important to consider how individuals with IDD participate in the life of the faith community. Restricted roles for people with IDD were discussed directly in four of the reviewed studies indicating that not all individuals with IDD have the same types of experiences within faith communities as do people without disabilities. Seven of the studies looked at leadership as a particular way that people express their faith, with all seven articles calling for increased role access for faith community members with IDD. These findings document that the participation rates of people with IDD for worship are much higher than their participation in other faith community activities. It is not clear from the research if faith communities offer participation to individuals with IDD in small group programs such as religious education, at the same rate as congregate activities such as corporate worship. There is need for future research that examines if there are barriers to participation in small group activities for people with IDD; and what supports might be effective in helping people engage in these programs.

IDEA (2004) states that disability should in no way lessen an individual's ability to contribute to or participate in society. These findings raise the question do people with disabilities participate fully in faith communities and are they able to contribute to them completely? It is likely that congregate worship experiences are less personal and offer fewer opportunities to connect more deeply with other faith community members than small group activities. If people with IDD participate in large group worship but not in small group settings, such as religious education, fellowship, or leadership, then they may not have access to the same experience of belonging as their typically developing peers. This suggests that even when people with IDD are present in faith communities, they may not belong.

Leadership in faith communities also holds implications for disability related fields because faith communities have historically provided a leadership training and development for marginalized groups. When people with disabilities are denied leadership opportunities in faith communities, they are not developing the skills that they need as field leaders (Eiesland, 1994; Healy, 2009; Patka & McDonald, 2015). Leadership development is essential to the disabilities' rights movement and to the civil rights movement in general. Griffin et al. (2012) looked at factors to increase leadership opportunities and the urgency of pre-service clergy training and continuing education for clergy around disability inclusion (Kleinert et al., 2010). Faith communities could hold a valuable place in the development of leaders with IDD who could serve not only their faith community but also the society as a whole.

Finally, research on accommodation gives a practical guide to practitioners about what is working in faith communities, what is valuable to people with disabilities and their families, and where the greatest needs continue to persist. Although physical access still ranks high as a need in much of the research, attitudinal barriers and programmatic access

issues may be even more urgent in faith communities. Research such as Dennis and Murdoch (2001) provided a model of a working group made up of people with disabilities, their caregivers, and members of the congregation who could elicit and address concerns of people with IDD in the congregation. In addition to advocacy, these groups provided expertise to address issues of access and theological or educational needs. In addition, Griffin et al. (2012) pointed to the use of published resources and partnering with disability advocacy groups as two effective strategies that congregations who were more inclusive utilized. These resource publications are readily available from a variety of religious presses, seminaries, and from Centers for Developmental Disability.

Conclusion

The paucity of research examining disability and faith community participation is clear from the limited number of empirical studies with people with IDD as participants. This established fact on its own indicates a need for more research. The finding that eight of those studies did not account for the ethnic identity of participants outside of their religious affiliation or consider how this might affect belonging is an even stronger indicator for more research in this field.

Qualitative research using in-depth interviews and field observations was effective at eliciting the deep meaning of an individual or group experience (Rossman & Rallis, 2012). Using a qualitative approach to study faith and disability was supported in the research, and the research provided several models for conducting research including interview, focus group, literature review, and participatory action research. Having these models for my study supported my use of qualitative methods and was helpful in developing questions and protocols. My research question was "What does the inclusion of people with intellectual or

developmental disability look like in one intentionally inclusive Christian faith community?" Because of the descriptive phenomenological nature of the study, descriptive qualitative methods were especially appropriate. I used in-depth interviews and field observations to capture a widely experienced pattern of life to guide understanding of participants' experiences in the study.

By reporting the experiences of people with IDD in an intentionally inclusive faith community from the point of view of people with IDD, their families, and members of their faith community I explored the experiences of participation including access to leadership roles, the routines and patterns of participation, the value of relationships, and how the faith communities' actions and beliefs influenced these experiences.

Looking at belonging and religious participation was crucial to answering my research question, especially in exploring the complexity of that experience. In Chapter Five, I discuss my data in relationship to the findings of other researchers around worship, prayer, fellowship, religious education, and the like. Because of the research review, I was especially attentive to leadership and membership and the ways that the faith community bestows and marks them.

The current empirical research in faith and disability shows a complexity of experiences that raises many questions. By providing an in-depth view of the experiences of people with IDD in one community I hope I have engaged with these questions and provided insight into the experiences of people with IDD in communities of faith. In the next chapter, I will describe the methods used in this study including participant recruitment and characteristics, data collection methods, and analysis.

Chapter Three: Research Method

In spite of the value of religious freedom in our country, the parity of interest in religion among people with and without disabilities (Shogren & Rye, 2005), and a growing interest in disability inclusion in faith communities, a participation gap between people with disabilities and without disabilities in faith communities persists. This means that there are fewer people with disabilities in faith communities than population statistics predict. Carter et al. (2015b) estimated that this gap is between 9 and 22% depending on the severity of the disability, with those with more severe disabilities participating at a lower rate. Furthermore, as discussed in Chapter Two, there is some evidence that even when people with disabilities are present in faith communities, they may not fully participate or belong in the community (Carter, 2016). Further, a review of the research shows that people with IDD are rarely participants in research on faith and disability. Parents, clergy, and caregivers are asked to describe their experiences more frequently than individuals with disabilities. With these issues in mind, I developed the research question: "What does the participation of people with intellectual or developmental disability look like in one intentionally inclusive Christian faith community?"

Based on the theoretical framework discussed in the first chapter and in conversation with the analysis of related research in the second chapter, in this chapter, I outlined the research design and methods for my study. Specifically, I described the qualitative case study design that I used; these included the setting or context for the study, recruitment, participant selection and demographics, data sources, instruments, ethical considerations and data analysis procedures.

Theoretical Framework

In Chapter One of this proposal I presented the theoretical framework for this study. This proposal is grounded in the work of Eiesland (1994), Gutiérrez (1973/1988) and Freire (1970/2003). In this section I will describe how this grounding guides the design of research.

As I stated in Chapter One, Gutiérrez wrote a theology of liberation based on the works of educational theorist Paulo Freire, and a liberatory reading of Christian scripture. Gutiérrez's reading of the scripture said that God is never on the side of the powerful but always on the side of the oppressed. Gutiérrez provided a clear commission for his readers: If believers want to be on the side of God, they need to be on the side of the poor and the oppressed. Based on this theology, Eiesland (1994) argued that God is on the side of people with disabilities. This liberatory theology of disability challenged people of faith to several actions. According to Eiesland, people of faith need to recognize the divine call to explore their own predispositions and biases toward people with disabilities. They need to join with people with disabilities in the struggle for self-determination. Finally, she asserted that their faith called them to recognize people with IDD and other disabilities as gifted and valued members of the community.

Taking into account Eiesland's framework, my study examined the experience of people with IDD in an inclusive faith community. I used methods and analysis that kept a connection between the words of participants with disabilities and the findings by using in vivo coding strategies (Saldaña, 2015). I also used Dedoose Version 8.3.19 analysis tools that kept coding linked to the verbatim transcript. Finally, the words and experiences of participants with IDD was privileged in the analysis, and given greater weight as they represented the experiences of true experts in the field of faith inclusion. I accomplished this

by using the words of the two participants with IDD, James and Sydney, to develop codes first, and always returned to these primary sources whenever I re-coded the interviews and other data sources and re-defined the codes. Whenever available, I used exemplar quotes from these two participants in the theme and code books.

Research Design

Yin (2018) taught that case study is especially appropriate when looking to answer in-depth descriptive questions that address a contemporary social phenomenon. He stated that case study was especially helpful when a question was deeply tied or connected to its context, and when it relied on multiple perspectives. His description applied closely to this faith community. For this reason, I used a descriptive, single case study design looking at a single faith community to answer the research question: "What does the participation of people with intellectual or developmental disability look like in one intentionally inclusive Christian faith community?"

In case studies, it is important to describe the case and the boundaries of the case (Yin, 2018). The case for this study is St. Thomas. It is one intentionally inclusive faith community in an affluent suburb of a major US city. The case is bound within the time frame of the community's current head pastor, Karen. Single case study design is appropriate when there is a special case that describes a situation that is somewhat unusual or special (Yin, 2018). Single case study design is appropriate for St. Thomas because the faith community has taken special steps to be intentionally inclusive of people with disabilities, making it a model community for other faith communities seeking greater inclusion for members with disabilities.

In this case study, I explored the points of view of people with IDD in the faith community, their family members, and faith community leaders (laity and clergy). I used semi-structured in-depth interviews, field observations, local archival analysis, and a technique often used in participatory research called PhotoVoice. These data sources will be described in more detail in the sections on Data Sources and Data Collection Methods found below.

Method

Setting/Context

This study was conducted within a mid-sized Christian Protestant church in a suburban mid-Atlantic city. The city is pre-dominantly Caucasian (82%), with Asian (9%), and Hispanic (8%) populations, and a small population of people who identify as multiracial (1.3%), and Black or African American (0.5%). The median household income is $163,000 and the median property value is $731,000 (DataUsa, 2020).

St. Thomas, the church for my study, was a mainline protestant Christian church. Its membership is approximated at 321 members with about 125 people in worship each week. Records provided from the senior pastor showed the membership in 2018 was 6% American Indian, 1% Black or African American, 7.5% Asian, and 92% White. Approximately 5% of the population identified as having an IDD.

I chose this site because the community met my definition of an intentionally inclusive faith community. For the past seven years, the church has had a senior minister (Rev. Karen Evans) who had specialized training in disability through her clinical pastoral education. During her training, she studied with Bill Gaventa, a former president of the American Association on Intellectual and Developmental Disabilities (AAIDD) and a field

leader in faith and disability. Karen was well-read in the theology of disability with two sons with ASD.

Under Karen's leadership, the church has actively sought members with disabilities, and offered education for all members in support of the inclusion of individuals with disabilities within their congregation. In the past two years, the church piloted a summer camp for children on the autism spectrum. Their recently completed capital campaign (financial campaign for the built environment) was to increase accessibility in their building and support the inclusion of an adult with an IDD who also had physical disabilities. The faith community also has a reputation for inclusion in the region.

Recruitment

Research with human subjects needs to be conducted ethically, with risk to participants carefully weighed with potential gains. Research done with vulnerable populations, such as students, people in prison, children, people of color, and people with disabilities requires additional consideration. I conducted research with adults and children, some of whom had disabilities; I attended to potential risks for these populations. In this study coercion of participants and privacy were two primary risks as discussed below. For a detailed timeline of the data collection, please see Table 5.

Coercion

Informed consent is central to ethical research. Coercion, or the appearance of coercion is unacceptable in ethical research. Participants in research need to feel comfortable participating in the study, declining to participate, and comfortable withdrawing from the study at any time. Because this study involved an important community of membership for participants in the study, and because the clergy and governing board were in support of the

project, it was essential that every safeguard was considered and that coercion or the appearance of coercion was avoided. This is especially true because of my position as a member of the clergy as addressed in the position statement below.

To mitigate the potential for coercion, I used careful recruitment strategies. I invited participants to be a part of this study through the use of flyers, posting in the faith community's internal publications, and information sessions. After initial recruitment efforts, I also used purposeful sampling asking participants to invite others to participate in the research. Flyers included my contact information so that potential participants could contact me directly. At the informational meetings I provided informed consent/assent forms, a cover letter and an envelope so that people who wanted to participate could return the forms via mail or drop them off in the church office. (Please see Appendix A for a copy of the flyer and the section on recruitment below for more details.) I provided a copy of the demographic questionnaire to all participants before interviews via email or U.S. mail and copies of the consent and assent forms (please see Appendix B). I reminded participants that they were free to withdraw from the project without any penalty at any point in the process, before, during or after interviews, or PhotoVoice. All data were collected using informed consent protocols under the supervision of my advisor, dissertation committee, and the UNM Internal Review Board.

Privacy and Confidentiality

Privacy is another important risk in this study. Because I asked members of a community about their experiences, I took measures to secure documents, photographs, field notes, and recorded and transcribed interviews. Participant names were not shared with the church leaders, and interviews were conducted away from the church. Whenever possible,

identifying information was not gathered, and when collected, it was reported only as

aggregate data. When individual data were reported, individuals were assigned a pseudonym.

Interview transcripts were de-identified as part of the review process before they were

uploaded to Dedoose Version 8.3.19 for analysis. In addition, confidentiality was maintained

between the researcher and participants.

Position Statement

In Chapter One, I provided an analysis of power as a researcher in this community. I

noted there that I am a faith leader, inclusion advocate, curriculum writer, and researcher. I

hold several powerful roles within the community. To mitigate the influence of these power

positions, I carefully attended to the consent and assent procedures, recruitment guidelines

set out by the UNM IRB, maintained privacy and confidentiality, and used language and

customs that were welcoming and inclusive. I provided explanations in simple terms and

avoided jargon. I avoided clothing that signifies my position as a member of the clergy, and I

referred to myself only by first or last name (not using Reverend, or Pastor). I offered basic

hospitality to all participants like offering breaks, explaining how equipment works, and

answering questions and maintaining a conversational tone with people and comfortable

social eye contact.

Individuals with IDD and Family Members

I recruited active members at St. Thomas with an IDD and their family members by

posting flyers on the church's bulletin boards, and by sending out the flyer through the

community's newsletter (weekly email) (please see Appendix A). The flyer contained a brief

overview of the study and my contact information so that anyone could email or call me to

get more information. I conducted one informational meeting (approximately 30 min in

length) for individuals with IDD and their family members at the faith community. I held the

session after the main worship service on a Sunday morning. During the meeting I explained

the context of the study, the purpose of the study, the research activities involved, and

answered questions posed by individuals with disabilities, family member, and community

leaders in attendance.

At the information session I provided packets for potential participants containing a

demographic questionnaire, a contact information card, copies of consent, assent, and

parental permission forms as appropriate for each group of participants, and preaddressed

envelopes (please see Appendix B). I asked people interested in participating to complete and

sign the forms and return them to me within two weeks. I invited potential participants to

email or call me if they had additional questions.

Once I received the completed demographic questionnaires, I contacted participants

to schedule interviews at times convenient to them. After recruiting two individuals with IDD

as participants, I amended my protocol with the IRB to allow for purposeful sampling, and

reached out to participants in the study to help identify other individuals with IDD who might

be interested in participating in the study. This did not yield further participants with IDD.

Clergy/Lay Leader Recruitment

To recruit participants from this group I used purposeful sampling. I contacted the

church's head pastor directly and ask her to participate in the study. I asked her to identify

key leaders who had positions that affect inclusion of individuals with disabilities (e.g., the

leader of the Christian education program). Once these leaders were identified, I reached out

to invite them to participate in the study. During this meeting (phone or in person) I

explained the study and the research activities and answered questions.

Once individuals agreed to participate in the study, I contacted them to schedule a semi-structured interview at a time convenient to them. I asked if they would provide their email addresses or physical mail addresses and if they did, I sent a brief demographic questionnaire and a copy of the informed consent to them at least one week before the scheduled interview. I asked them to bring the form with them to the interview or email it back to me (please see Appendix B for a copy of the questionnaire).

Participant Selection

The study included three groups of individuals as participants: (a) individuals with IDD, (b) the parents of the individuals with IDD, and (c) the faith community's clergy and professional lay leaders. The selection of participants in this study prioritized the voices of people with IDD while providing multiple sources of data from faith community leaders and family members. A total of six individuals were recruited and chose to participate.

Individuals with IDD

I recruited two individuals with IDD who were members or regular attenders of the faith community. I sampled from two age groups: 13-17, and adult (18+). Because this study used methods that required individuals to communicate about their experiences of belonging, participants needed an established means of communication, either verbal or with alternative or augmentative communication (AAC) systems, that allowed the me to gather data through interviews. The inclusion criteria for selection of participants with IDD were that they: (a) were nine years or age or older; (b) had IDD (i.e., people with intellectual disability or developmental disabilities who have functional need for supports; Brown et al., 2017); (c) were members of the faith community (i.e., were formal members or attend regularly), and (d) were verbal or used AAC at a level that allowed them to participate in interviews.

Exclusion criteria were that they: (a) were younger than nine years; (b) did not have IDD; (c) were not members of the faith community as I defined membership, or (d) did not have verbal communication or an AAC system that allows them to communicate at a level for participation in an interview.

Parents/Family Members

For participants with IDD who attended services with a family member, I recruited one parent or other adult family member for each participant with IDD, for a total of two family member participants. Inclusion criteria for this group of participants were that they: (a) were the parent or other family member of an individual with IDD who is a participant in this study, (b) attended faith community activities with the individual with IDD regularly enough to be knowledgeable of the individual's experience of belonging there, and (c) were over the age of 18. Exclusion criteria were that they (a) were not parents or other family members of an individual with IDD who is a participant in this study; (b) that they did not attend faith community activities with the individual with IDD regularly enough to be knowledgeable of the individual's experience with belonging; or (c) under the age of 18.

Clergy and Lay Leaders

I recruited three faith community leaders: professional clergy in the congregation (two), and a professional lay leader (one) with direct decision-making regarding disability inclusion. One of these participants, Jennifer, also served as the family member participant for Sydney. Inclusion criteria for this group were that they were: (a) professional clergy working at the faith community or (b) lay leaders of the community with direct decision-making responsibility regarding disability inclusion in the faith community. Exclusion criteria for this group were that they were not (a) professional clergy, (b) lay leaders, or (c)

that they did not have direct decision-making responsibility regarding disability inclusion at the faith community.

Participant Demographics

Each of the participants completed a demographic survey. They identified their race and ethnicity by choosing from one of the US census categories, their age, their gender, their membership status at St. Thomas's and their disability label and status. Participants had three options to describe their disability status: "I have a disability, my family member has a disability, none of these categories describe me." Please see Table 4 for more details.

Table 4.

Participant Demographics

Participant	Disability	Age, Ethnicity, Race, Gender	Role in FC
Sydney/ person with IDD	ASD*, ADHD*	15-24, White, non-Hispanic, female	member
James/ person with IDD	ASD*, ADHD*	25-34, White, non-Hispanic, male	member
Jennifer/ parent of Sydney		45-54, White, non-Hispanic, female	staff
Hugh/ parent of James		55-64, White, non-Hispanic, male	member
Kim		45-54, White, non-Hispanic, female	clergy
Karen/ parent of James		45-54, White, non-Hispanic, female	clergy

Note. ASD = Autism Spectrum Disorder, ADHD = Attention Deficit Hyperactivity Disorder.

Data Sources and Data Collection Methods

In this case study I used an initial in-depth, semi-structured interview and a follow-up interview with each participant in the study. In addition to the initial interviews, I conducted PhotoVoice interviews with participants with IDD and their family members. I also completed a review of internal church documents and did field observations of the physical structure that the community uses and several events that the community held. Using multiple data sources allowed me to examine multiple points of view to answer the same question, providing sources for triangulation, one of the ways to establish validity in a case study (Yin, 2014). Please see Table 5 for the data collection timeline.

Table 5.

Data Collection Timeline March 11, 2019 – July 7, 2019

Week	Data Collection Activities
Week One	Obtained annual reports from the church administrator.
	Completed initial field observation- building tour.
	Began recruitment with flyers and announcements.
Week Two	Conducted initial interview with Karen.
	Attended 2 worship services and offered information session.
	Conducted initial interview with Kim.
	Attended adult forum.
Week Three	Conducted initial interview with Jennifer.
Week Four	Conducted initial interview with Sydney.
Week Six	Attended worship service.
	Attended worship service.

Week	Data Collection Activities
Week Eight	Conducted initial interview with James.
	Conducted follow-up and PhotoVoice interviews with Sydney.
	Conducted follow-up family member interview and PhotoVoice interview with Jennifer.
Week Nine	Conducted follow-up interview with Kim.
	Conducted follow-up field observations.
Week 15	Conducted initial interview with Hugh.
Week 17	Conducted follow-up leader interview with Jennifer.
Week 18	Conducted follow-up field observations.
	Conducted follow-up interview with Karen.
Week 20	Conducted follow-up and PhotoVoice interviews with James.
	Conducted follow-up and PhotoVoice interviews with Hugh.

Data Collection Tools

I used a Tascam DR-05 portable handheld digital audio recorders to audio record interviews. This recorder used standard AA batteries, and I used two recorders, two microphones and back up batteries for each interview. I tested the digital recorder during the interview and keep the indicator light visible during the interview to be sure that power did not go off during the interview process. I showed the recorder to the participants at the beginning of the interview and asked if they had any questions about the recorder. I tested the recorder with the participant at the beginning of each interview. I backed up the audio files into secure files on my laptop.

I used Rev Transcription Service (rev.com) to transcribe all audio files verbatim. When transferring files to the transcription services I uploaded files to the transcription service using encryption through Transport Layer Security 1.2 on their secure server and receive transcriptions via email (https://www.rev.com/security). I used the specific transcription protocols (to review all transcribed data and compare it to audio files, enhancing and correcting transcription and redacting identifying information as needed (please see Appendix D).

I assigned pseudonyms to protect the identity of participants while preserving a sense of humanity and connection to the person participating in the study. To do this, I used a baby name generator to identify a name from the same time period with same level of popularity as the participants' own names. I assigned pseudonyms and removed other identifying names before downloading them. I kept a key of the pseudonyms and real names in a locked file on my laptop. Physical artifacts, and completed paper forms were kept in a locked filing cabinet in a secure office inside of a secure building. I used Dedoose Version 8.3.19 qualitative analysis software to assist with data analysis. The Dedoose platform used secure cloud-based storage for all data. I kept backups of data on my external hard drive in password-protected files.

Participants used a variety of devices, such as their personal smart phones or tablets, to take digital photographs for the PhotoVoice activity. When participants selected three images that they felt typify belonging in the community, I asked them to print them and bring them to the interview or text or email the digital copy of the photograph to me. All of the participants chose to email me picture files.

I used my personal Samsung 7 cell phone to take photographs of the physical space during my field observations. I transferred all photographs to my password protected laptop via email. I erased photos from my phone and email after the transfer was completed.

I used my password protected personal laptop as my primary computer. This computer is password protected with automatic cloud storage for files that is also protected with a password. Audio files were downloaded to password-protected files to ensure security as an added layer of security, I partitioned a password protected drive on my computer to store all materials related to the study.

Document Review

LeCompte and Schensul (2013) stated that local archival data can "further the comprehensiveness of data collection, understanding of results, and the cross-cultural and cross-national generalizability of a specific study" (p. 50). Faith communities typically have extensive local archival data in the form of annual reports, newsletters, meeting minutes, budgets attendance records, and curriculum. I analyzed the faith community's archives by looking at how the congregation supports inclusion of individuals with IDD through written policies, budget, and programing. To understand how the congregation used their resources to support inclusion, I looked at the annual budget and annual reports of the congregation to track expenditure and changes in expenditure, and to track how the congregation spends its time in education and other events that promote inclusion (e.g., advocacy or outreach).

The annual reports represented the most complete and organized source of written data from the church. The annual reports included budgets, summaries of each program area of the church (e.g. music, religious education, outreach), and the occasional reflection or editorial written by a church member or one of the staff. Year-to-year the reports had similar

content, format and length. The reports were written by lay and professional leaders in charge

of programs (e.g., clergy, staff, members of the vestry, or board of directors for the church,

youth group volunteers). I read the reports in whole, making notes on the budget, programs,

and any mention of disability or disability related terms (e.g., ASD, special needs). I

uploaded the reports into Dedoose Version 8.3.19 for analysis. I used the same coding

strategy outlined in the data analysis section below. (For the annual report timeline, please

see Table 7 in Chapter Four.)

In addition to the annual reports, I included the transcript of the capital campaign

video. This video was created by the church to encourage giving to the church's fundraising

efforts to increase the physical accessibility of their building. The video included interviews

with the senior pastor, lay leaders, and church members, including Daniel, a man with

disabilities who had been excluded from his family's church because of his sexuality. This is

the same man that Karen mentioned in her interviews. He reached out to the church to find a

place to be included, and found a connection with the church. I downloaded the video from

the church website, and using the same protocol as the other documents, I uploaded the video

to Rev.com for verbatim transcription as described in the interview section, and then revised

the transcription to fit the transcription protocol found in Appendix D. I uploaded the video

transcript into Dedoose Version 8.3.19 and used line-by-line coding using the codes

established by participant interviews.

My document review was limited to the annual reports and the capital campaign

transcript. The church did not keep minutes for their board meetings, monthly newsletters, or

written policies or training materials around disability. The church did have weekly email

updates, but I chose not to review these because after a careful examination of the emails, I

found that the information repeated from week to week, and was largely limited to announcement flyers, many of which were posted in the church building and mentioned in the annual reports.

Field Observations

Often considered the backbone of a case study, field notes allowed me to triangulate information from other data sources, providing more data to support or interpret interviews or PhotoVoice. Field notes were useful in studying a faith community because the community has a strong identity with a built space (Long, 2001). Field notes allowed me to include artifacts, architecture, and the geography of worship and meeting spaces. I took field notes as raw notes taken in the field using the form in Appendix C.

St. Thomas is a two-story building built in the 1960s with Christian education rooms, a preschool, and offices in the basement. Upstairs there is a large hall, kitchen, sanctuary and library. I did a general tour of the building to familiarize myself with the layout, then did follow-up mini tours based on the interviews. For instance, when Sydney discussed organizing the acolyte's closet, I re-visited the closet to see the work that she did. I spent extra time (and noted) the sanctuary (worship space) and the church's bulletin boards.

I attended two regular Sunday morning worship services, and two special services for children. After the services I took notes using the field notes form in Appendix C. I kept the bulletins for all four services, but did not take photographs during the services. I uploaded the notes into Dedoose Version 8.3.19 and used them to write analytic memos based on the visits. I used the same process to record the one adult education event that I attended. All of these services and events were open to the public and I did not collect consent from any of

the participants there. All data on both the field notes form, and as it is reported in this

dissertation, were recorded in aggregate without identification of individual participants.

In addition to the field notes, I took pictures of important artifacts, printed material, or

places in the building. I then wrote memos from the notes as the primary source of analysis,

and uploaded these notes into Dedoose Version 8.3.19. I did not code the memos because my

writing is already my analysis, but I was able to easily reference codes and citations when

writing the memos. For a more in-depth description of the analysis of these memos, please

see the analysis section below.

Participant Interviews

I used semi-structured interviews with three different populations: people with IDD;

family members of participants with IDD; and a third set with faith community clergy and

lay leaders. I audio recorded interviews using a digital voice recorder. Interviews were

professionally transcribed verbatim using rev.com, and then I re-checked them using the

transcription protocol attached in Appendix D. I analyzed the transcripts as I explain in the

analysis section below.

Individuals with IDD. Two semi-structured interviews with participants with IDD

were developed to answer the question: What does the participation of people with

intellectual or developmental disability look like in one intentionally inclusive Christian faith

community? I used in-depth interviews to capture descriptions of the experience of belonging

in an intentionally inclusive faith community. In developing the interview questions, I looked

at ethnographic interview methods because they allowed participants to describe their

experiences in a systematic way focusing on routines and typical interactions (Spradley,

1979). Interview questions asked participants what activities they engage in as part of the

faith community and what that engagement involves. Questions focused on participation and leadership in worship, in small groups, service, or mission activities (e.g., helping in a food bank, community trash pick-up or work trip), and in social community events (e.g., community meals, or movie nights). In the semi-structured interviews, I asked participants to describe what they did within these activities by using grand tour questions and followed up with mini tour questions to ascertain descriptions of the domains, or areas of participation for participants (see the semi-structured interview questions in the Appendix E).

Interviews were semi-structured, meaning that I used the interview questions in the appendices as a guide (please see Appendix E, F and G) but had flexibility during the interview to use prompts for further discussion, to repeat or skip questions to promote the flow of the interview and to accommodate participant's needs. I also allowed time to divide the interview into more than one session or to provide breaks to support the participant.

Interviews took place in a neutral location comfortable for the participant such as the participant's home or office. Interviews with children (anyone under 18) were conducted in the participants' home with a parent at home but not in the same area. It is important to avoid any duress, or the appearance of duress during interviews. For this reason, I included allowances for breaks and multi-session interviews in my protocols.

After the initial in-depth interviews, I conducted follow-up interviews with each participant to clarify questions from the first interview and to check for my understanding. For the faith community leaders, I conducted these interviews after initial coding as a separate session. For James, Sydney, and Hugh, participants with IDD and their family members, I conducted follow-up interviews and PhotoVoice interviews during the same appointment. To accommodate Jennifer's dual role as a faith community leader and a parent

of a participant in the study, I conducted the initial interview, follow-up interview, and PhotoVoice interviews in three separate sessions. This allowed me to ask clarifying questions about Sydney's interview and Sydney's participation on a separate day than asking follow-up questions about church programs.

Modifying Interviews. I modified interview questions for people with IDD to support meaningful responses. I addressed the need for privacy, the difficulty with abstract content, avoidance of complicated grammar, and the use of concrete description. I describe these modifications in the sections below.

Abstract Concepts. Belonging is an abstract concept and it offers a challenge for any participant to understand, or describe. Finley and Lyons (2001) suggested that questions within a specific context and which focus on events from a person's life can be helpful when interviewing people with IDD. To help respondents with IDD answer questions about belonging I asked about concrete events and concrete actions (e.g., when you come into the sanctuary, did someone meet you there? What did they say? Did they give you any things or directions?). I also found that PhotoVoice was especially helpful in discussing abstract concepts. By identifying, titling, and describing photographs, participants with IDD addressed abstract concepts with greater depth and clarity than the initial in-depth interviews.

Specific Questions before General. Finlay and Lyons (2001) also suggested using specific questions before general questions as one strategy to increase participation in interviews. They found that when the interview uses a specific question first, that a more in-depth response to general questions follows. Although in-depth interviews generally begin with Grand Tour questions followed by mini tour questions, I used warm-up questions about

specific actions in each section to help respondents activate their prior knowledge and before providing descriptions.

Simplifying Timelines and Multi-Step Answers. Multiple step directions can be difficult to follow. I broke the Grand Tour questions into prompts for smaller segments. Another modification for the interviews for people with IDD was to allow more time for probing, follow-up questions, and clarification. In each of the semi-structured interview sets I used prompts to guide the interview and to ask about missing information. Interviews with people with IDD can be difficult when people are asked for timelines or frequency. I supported respondents in the interviews by using context specific time markers within the interview such as asking what happened right before an event or right after. In family member interviews I verified frequency data by checking local documents, in follow-up interviews or in interviews with leaders and family members.

Sentence Structure and Vocabulary. In addition to using simple vocabulary that is familiar to the participants in the study, Finlay and Lyons (2001) reported that certain grammatical constructions were particularly difficult for people with IDD. They suggested that the use of passive voice, modifiers at the end of the sentence and subjects and objects that can be swapped for one another could all be confusing. To avoid confusing participants, I eliminated these grammatical issues and worded questions with simple grammatical constructions. Even taking these steps, I found that the use of follow-up questions and probes was important to record the experiences of people with IDD in communities of faith.

Interviews with Family Members. Semi-structured interviews with family members of people with IDD provided a second source of data that describes the experiences of people with IDD. When conducting interviews with people with IDD, researchers often interview

people who can reinforce or clarify the interviews (Smyly & Elsworth, 1997). Hugh was interviewed for James. The semi-structured interview protocol for this interview mirrored the interview done with people with IDD (see Appendix E). Interviews with family members were conducted at a location comfortable for the participant and recorded using a digital recording device. I used verbatim transcription and read through them while listening to the audio file before doing follow-up interviews to address further questions. Hugh was asked to focus on James's experience of belonging. I met with Hugh for the initial interview and then for a second interview which combined the Photovoice and follow-up interviews in one session. This was not as straight forward for Sydney's mother. Sydney attends church with her mother, Jennifer, who is also the staff member at St. Thomas for community engagement. Because Jennifer was already being interviewed as a church leader, I did not do a second in-depth interview with her focusing on Sydney's participation at the church. I did complete a follow-up interview for her church leader interview and then a separate follow-up interview as Sydney's parent. At this parent follow-up session, I also completed the PhotoVoice interview with her to ask clarifying questions about Sydney's photographs and responses. This meant that Jennifer completed a total of four interviews in three sessions, one more follow-up interview than the other participants.

PhotoVoice. Another source of data for this case study was PhotoVoice. PhotoVoice is a research method associated with Participatory Action Research (PAR) or Community Based Participatory Research (CBPR). PhotoVoice combines photographs taken by participants with descriptions provided by the participants (Catalani & Minkler, 2012). Catalani and Minkler explained that this technique is valuable as a tool for expression and dialogue. They see PhotoVoice as a tool to elicit an experience for Freirian critical

consciousness. This technique has been shown to be valuable with marginalized populations and has been used with participants with IDD with success (e.g., Cardell, 2015).

I used PhotoVoice with individuals with IDD and their family members as follows. At the end of the first interview with a person with IDD or their family member, I explained what PhotoVoice is and how it is part of this study. I asked each participant with IDD to use their own digital device (e.g., smart phone, iPad) to take three pictures, or to choose existing pictures, that typify belonging for the participant with IDD. I asked Sydney and James to take or select photographs during the week following the initial interview. I offered to provide a device if they did not have one available. I asked each of them to share the three photographs they selected with me via email.

After participants with IDD took and shared the photographs, I set up a second interview with the participants with IDD where they described the three photographs that they selected. I asked the participants to provide a description of the photograph, including why the photograph was an example of belonging in the faith community, and a title for the photograph. Photovoice interviews with Jennifer and Hugh were conducted separately from their children, using the same photos Sydney and James had selected (please see Appendix G for PhotoVoice interview questions). I asked for a release form for each picture for both the people being photographed and the photographer (Appendix I).

Interviews with Clergy and Lay Leaders. Semi-structured interviews with clergy and lay leaders of the community asked clergy to identify a time when people with IDD were included in the faith community and to reflect on the actions that leaders took to promote belonging of people with IDD in the faith community. Leaders identified lessons learned and need for further support to promote inclusion. (Please see the Appendix F for these semi-

structured interview questions.) I conducted in-depth interviews with follow-up interviews to clarify any questions and to check for understanding with participants. For a timeline detailing data collection, please see Table 5.

Data Analysis

I gathered data from multiple sources for this case study looking at people with IDD's experience of participation in an inclusive faith community. I conducted interviews, read documents, and conducted field observations. For all of these data sources I used qualitative data analysis as described below.

Document Analysis

In this case study, documents provided additional data that corroborated interviews and field notes, provided a consistent report of programs, and recorded how the community allocates its time and money resources. As described in the "Data Sources and Data Collection Methods" section above, I collected the capital campaign transcript and 2012-2018 annual reports from the church's secretary. She emailed them to me as PDF files and I downloaded them to secure files on my laptop. After erasing them from my email, I uploaded the files into Dedoose Version 8.3.19. I read them as a full body to identify relevant sections, and wrote in-process memos for each report.

After developing codes from the interview data (described below), I applied the codes to the annual reports and capital campaign video transcript using the same coding protocol described in more detail in the next section. Even though the interviews with people with IDD were prioritized in the development of codes and code definitions, I still used these archival documents to refine definitions and used several example excerpts from them in the codebook. After initial coding, I re-read the in-process memos and used the visual functions

in Dedoose Version 8.3.19 to help pinpoint relevant evidence. Based on this work, I developed analytic memos which contributed to the development of the themes as described in a later section, Analysis of the Case. (Please see Chapter Four, Table 7 for the Annual Report Timeline and Table 9 for a further discussion of the themes.)

Field Observations

Bernard and Ryan (2010) explained that because field notes represent the researcher's thoughts and language, they should not be coded with the other data. The authors of *Writing Ethnographic Field Notes* (Emerson et al., 2011) explained that analysis of raw field notes begins by creating in-process memos. I recorded field notes of key events as noted in the Data Sources and Data Collection Methods section above (i.e., worship, fellowship, building). For my observations, I collected raw field notes on the attached form (please see form in Appendix C) based on my building tour, and artifacts and places described in the in-depth and PhotoVoice interviews. Next I used in-process memos to reflect on the observations. These memos were helpful in shaping follow-up interview questions, and follow-up observations (e.g., if the annual report mentioned ADA compliant bathrooms, field notes confirmed that the bathrooms indeed met ADA guidelines). After I collected other data, I analyzed my field notes and memos as a whole by reading them as a complete body. Field observations were an important set of data in developing and clarifying the themes. Analysis of the different parts of the study is described below in "Developing Themes." Please see Table 9 for a further discussion of the themes.

Interviews

As described in the Data Collection Tools section above, I hired Rev Transcription Services to transcribe audio-recorded interviews using their standard transcription protocol

for verbatim transcription with time stamping. I then downloaded the transcribed interview

files as Word documents onto my computer in secure files. I listened to the audio interviews

and edited the transcriptions to assign pseudonyms, to de-identify them, to ensure they

matched the transcription protocol (please see Appendix D) and to check for accuracy. Once

this was completed, I uploaded them into Dedoose Version 8.3.19 and began coding the

interviews for meaning while preserving the words of participants.

To facilitate primary and secondary coding, I uploaded transcripts into Dedoose

Version 8.3.19 via their secure server (https://www.dedoose.com/about/security). I assigned

descriptors and used the visual tools in Dedoose to identify codes by participant, and

participant type. These visual tools were especially helpful in developing the codebook,

refining the definitions, identifying key citations, assigning parent codes and developing

categories. For instance, codes assigned to only one participant, especially if the participant

was not an individual with IDD, were treated with greater scrutiny.

In light of Eiesland's mandate that the voices of people with disabilities be primary,

and the paucity of research focused around the voices of people with IDD, I emphasized the

voices and experiences of people with IDD in the analysis of the data. I treated the voices and

experiences of people with IDD as the most expert and authoritative with family members

and leaders serving to strengthen their evidence.

One way that I did this was by using the words of participants with IDD to develop,

define and refine the codes and code definitions. Initial codes came out of the words of

participants with IDD using an in-vivo descriptive initial coding strategy in which I

examined and tagged transcripts (Saldaña, 2015). Using the technique outlined by Bernard

and Ryan (2010), I coded for meaning and used a constant comparison technique. I isolated

excerpts based on meaning, (i.e., words or phrases that represented a distinct moment in the conversation), and assigned codes. I did initial coding for each transcript before conducting follow-up interviews. By using Dedoose Version 8.3.19 software tools, the verbatim transcriptions of the words and phrases of participants were linked to codes and categories, preserving those words through every level of analysis.

After the initial coding, I refined the code definitions and developed a codebook with exemplar codes, prioritizing the excerpts of people with IDD for each code. After refining the definitions and developing parent and child codes, I completed line-by-line coding of all of the interviews. For the second round of coding, I prioritized the words of people with IDD by coding their interviews first.

PhotoVoice

As described in the "Data Sources and Data Collection Methods" section above, PhotoVoice offers a visual data source with a primary analysis done by the participants through an interview. People with IDD and their family members took photographs of belonging in the life of the faith community. Then, they chose three photographs that they described in the PhotoVoice interview (please see Appendix G). I recorded these interviews and had them transcribed as described above. After editing and checking transcripts, I entered transcripts from these interviews into Dedoose Version 8.3.19, assigned descriptors, and did first and second cycle coding in the same manner described above. Prioritizing the voices of participants with IDD I used the same code book and updated codes until no new codes emerged. In addition to transcripts, I used field notes to provide a description of the photographs using the form found in Appendix C. I used memos to provide analysis of this data as described in the field notes section above.

Codes/Categories

As described above, I completed 13 interviews with participants in this study. Analysis of those interviews began with coding. I used the coding and category structure that I developed with in-vivo, descriptive coding prioritizing the words of participants with IDD. The use of parent and child codes in Dedoose Version 8.3.19 was especially helpful and these parent codes emerged as categories after the initial coding of all of the documents and annual reports was completed and the codebook was developed. For more detail, please see codes in Table 6 below.

Table 6.

Code Table

Parent Codes	Beliefs	Hospitality	Leadership	Programs	Rhythm	Relationships
Child Codes	Divine Image	Accom-modation	Formal Roles	Baptism	Like Best	Church Relationships
	Inclusive	Education and Training	No Require-ment Form	Christian Education	Like Least	Really Polite
	Suffering and Divinity	Generosity		Communion	Routes	Family Relationships
	Trans-formation	Invitational		Community Service		
		Lessons Learned		Confirmation		
		Parental Supports		Mission Trip		
				Day Camp		
				We are Friends		
				Worship Services		
				Youth group		

Development of Themes

The strength of case study design is to look at a complex phenomenon in context (Yin, 2018). By looking at multiple points of view to answer one research question, case study allows for a rich description of the experience of people with IDD in an intentionally inclusive community. Findings based on data can be used to guide best practices, compare findings of other studies and used to support further research.

In this study, I used multiple data sources to build evidence for my findings; semi-structured interviews, PhotoVoice, document analysis, and field notes. After coding all of the interview and document data, I re-read the initial field notes, codebook, and in-process and analytic memos. After taking in the information as a whole, I created a graphic organizer using the parent and child codes, and categories, with the purpose of developing the themes. First, I wrote the names of parent/child codes and categories on different colored post-it notes. Then, I developed the organizers in several stages to look at the relationships between parent and child codes, and the relationships between the categories. I used frequency and descriptor data in Dedoose Version 8.3.19 at this stage. I also used the color-coded post-it notes and a large window to organize and re-organize the codes, categories, and key findings from the memos and developed several models to show the dynamic relationship between them.

Using these tools, I looked at the interplay between the categories. I added lines of connection to the organizer. After introducing these lines, I changed them to arrows, or vectors, showing not only connection, but influence, reciprocity, and flow between one category and another. It was at this stage that I created a new organizer with the five themes and 14 subthemes described in Chapter Four.

Member Checking

After developing themes, I created a theme definition book with the theme and exemplar citations. I sent this theme book to participants in the study through email to do member checking. I edited each entry in the theme book to include relevant citations for each participant (i.e., they only saw their own words). Then I sent these theme definitions and exemplar citations to each participant requesting that they read the excerpts to ensure that they "reasonably belong" with the theme as I defined it. Participants were also invited to make comments. They all responded and confirmed that the developed themes described their interviews.

Trustworthiness

According to Yin (2018), data triangulation is one type of triangulation that may be used to verify the trustworthiness of data by using multiple sources of data to corroborate the same finding. In this study I used semi-structured interviews with people with IDD, parents or family members of people with IDD, and clergy and lay leaders in the faith community to triangulate findings. PhotoVoice interviews and photographs provided another source of data to support findings in the study. Field observations and document analysis also provided additional sources of data triangulation.

Conclusion

By conducting this descriptive single case study based on the question "What does participation of people with intellectual or developmental disability look like in one intentionally inclusive Christian faith community?" I was able to collect data describing the participation of people with intellectual or developmental disability in one intentionally inclusive faith community . In the next chapter, I will present the findings from this study.

Findings from this study came from the six data sources outlined above: documents; field observations; individual interviews with people with IDD; family members of people with IDD interviews; church leader interviews; and PhotoVoice Interviews of people with IDD and their family members. These six sources of data provided a reliable description of the participants'' experiences in this faith community. Findings included five themes and 14 subthemes that I will describe in detail in Chapter Four.

Chapter Four: Findings

The purpose of this study was to examine the experience of people with intellectual or developmental disability as they participated in one intentionally inclusive Christian faith community, especially with an eye toward how people with IDD experience belonging. In this chapter, I will present my research findings by describing the results of analysis of church documents; data from field observations that provide the context for the study; and interviews with people with IDD, their family members, and faith community leaders. The associated themes and subthemes that emerged from the analysis of the data collected are defined and described in detail.

Description of the Research

I conducted this research in one Christian community in a suburban community in a mid-Atlantic state. This community describes itself as inclusive of people with disabilities and has made intentional steps to welcome people with IDD in the community. As described in Chapter Three, I collected data from March 2019-July 2019. I collected annual reports from the organization, conducted informal observations during church activities, took photographs of the building, and conducted interviews. I also conducted two interviews with two individuals with IDD who attended the church regularly. I asked them to talk about their experiences at St. Thomas, and then I did a second interview where I asked them to describe and explain three photographs of their experiences at St. Thomas (i.e., PhotoVoice) that expressed their feeling of belonging within the community. I also interviewed a family member for each of these participants with IDD who regularly attended the faith community with them, and three church leaders, (i.e., both of the professional clergy and the professional church educator).

Findings

Documents

One source of data for this study was the review of documents related to the life of

the congregation (i.e., annual reports, capital campaign video transcript). The analysis of the

annual reports showed multiple ways in which the faith community used its financial and

other resources to create opportunities for inclusion and belonging for individuals with IDD

and their families. For example, the faith community had recurring donations to an autism

activism organization for 2012 and 2013. They also initiated a capital improvements

campaign to increase physical accessibility within the church building in 2016 (for

approximately $200,000), and they spent significant staff and volunteer resources to develop

a church-based day camp for children with IDD (2017-2018). A summary of the findings

(i.e., key events or items included in the reports related to intentionally including individuals

with IDD) is included below.

Table 7.

Annual Report Timeline

Annual Report Year	Key Events
2012	Described the inception of a *Faith and Disability* series in the church aimed at adults and youth to increase disability awareness and explore theology of disability.
	Included an essay from the parent of a child with a disability that references a feeling of social isolation and then a sense of belonging after joining St. Thomas.
	Mentions that 40 members participated in an autism awareness walk, where they raised $2,000.

Annual Report Year	Key Events
2013	Discussed in the finance and buildings and grounds reports current challenges and opportunities to increase physical access in the church building.
	Discussed the *Faith and Disability* series including disability awareness education for adults, youth and children.
	Budget showed an increase in funds for the autism awareness walk.
2014	Outlined the capital campaign to increase physical access in the building.
	The autism walk was removed from the outreach budget.
2015	Reported capital campaign giving and pledging.
	Outlined the plan for projects including improvement to physical access of the building.
2016	Reported the completion of the construction of the elevator and updates to the bathroom making them ADA compliant.
2017	Described the development of a disability specific weeklong summer day camp (Vacation Bible School or day camp).
	Described the development of special church services during Lent aimed at children with IDD.
2018	Celebrated the second year of the day camp
	Reported the conclusion of the capital campaign.

Note. ADA = Americans with Disabilities Act, IDD = Intellectual or Developmental

Disabilities.

Field Observations

A second source of data in this case study was field observations. Field observations

provided insight to the context around the documents and individual and PhotoVoice

interviews, and added evidence to findings from the annual reports and interviews. Based on

my observations, I took field notes as described in Chapter Three. During the study, I toured

the building, attended worship and an educational event for adults. Table 8 describes key

findings from these observations.

Table 8.

Key Field Observations

Location	Key Observations
Building	Elevator is in a back corner. It gives access to the basement, sanctuary and fellowship floors. It does not access the choir loft of entrance landing.
	Signage makes the elevator easy to find. Signage uses symbols and language.
	Bathrooms have been retrofitted with wide doors, and substantial grab bars. Gender neutral bathrooms on the upper level.
	Parking is available near an accessible door.
	Postings on the bulletin boards refer to disability 14% of the time including activity flyers, announcements, and photographs.
	Sanctuary was not renovated as part of the capital campaign.
	It was designed with pew cuts. There are four cut pews near the baptismal font. These are cuts on the central aisle in the middle of the sanctuary seating area.
	The Chancel area is not physically accessible, there are several steps to reach it.
	There is designated furniture for lay leaders on the chancel including: special seats and podiums for lay leaders including benches on the chancel for acolytes, a stand for the acolyte's torch and cross, and a special podium for lay readers.
Worship Services	All participants were welcomed at the door and given a program for the service.
	Program did not include all directions (e.g., when to kneel, stand or genuflect).

Location	Key Observations
	Participants in the service were friendly, with a time to greet one another built in.
	Worship led by lay and professional leaders, adults and children.
	Worship was interactive, with participants invited to draw on a special cloth, to serve each other communion and in call and response.
Adult Education	All participants were met and welcomed three times: At the door of the building, near the entrance to the stairs or elevator, and at the entrance to the room where the event took place.
	Participants were welcoming. They initiated conversations, offered to help.
	Participants used call and response liturgy from the service.
	Participants listened well and all participated in the conversation and discussion.

Interviews

As I described in the previous chapter, I interviewed six participants using individual in-depth and follow-up interviews with all of the participants for a total of 12 initial and follow up interviews. Next, I did PhotoVoice interviews with participants with IDD and their parent for a total of four interviews. I audio recorded the interviews with permission of the participants, transcribed the data, and analyzed them as described in the previous chapter. In the following sections I will describe the themes arising from analysis of the 16 interviews, field observations, and document analysis (see Chapter 3 for details of this analysis). See Table 9 for an overview of themes and subthemes.

Themes

After coding the interview data, church documents, and field notes from observations, I examined the relationships between the codes and how they related to participants'

experience of belonging in the faith community. This process created primary categories related to leadership, relationships, traditions and routines, hospitality and beliefs. Further examination of these and consideration of the reciprocal relationships between them resulted in the emergence of five primary themes and 14 subthemes. Please see the table below for more detail.

Table 9.

Themes and Subthemes

Theme or Subtheme	Definition	Key Excerpt
1. "A Role that I Uphold:" Leadership	Individuals with and without disabilities holding formal and informal roles in the faith community that generate a reciprocal sense of responsibility to the community and being valued by the community.	*"I like I feel like I'm included in a way because I have like have a role that I uphold."* -Sydney
1a. Lay Readers	Non-ordained individuals read from the Bible or other worship texts during weekly worship services.	*"Well, it shows me participating in the, what are they called? Is it called the…"?* I helped James find the word "worship." –James
1b. Mentorship	The use of experienced peers to guide novice leaders in learning to fill formal roles at the church.	*"Yeah. I've had I did show two kids how to do it and so I felt like accomplished. And I turned to Aaron and I'm like, 'wow, I'm old.'"* -Sydney
1c. Making Mistakes	Not requiring credentials for leadership participation or expecting that individuals in leadership roles would never make mistakes.	*"No there's no like requirement form or anything."* -Sydney
2. "We are Friends:" Relationships	Connections with people in the faith community including family, intergenerational, pastoral, or mentoring relationships as well as formal relationships and peer relationships. These relationships could be reciprocal or more one-sided.	*"…we basically uh, had pizza. And then, we played the games like, Connect Four."* -James

Theme or Subtheme	Definition	Key Excerpt
2a. Church Relationships	Individuals with whom participants engaged in an activity at the church or someone with whom they shared an interest. Not always people with whom they had close personal relationships.	*Well I'm definitely friend with a lot of, um, kids but there's people that like, I wouldn't like, hang out with just like if I see them at church then I'm just like really polite and like talk to them.* -Sydney
2b. Family Relationships	Participants described attending faith community events and activities with their family members, or at the request of family members, and described an identity as members of the church that was negotiated through their family.	*"Um, shows me hanging, uh, belonging to my family, so, and they belong to St. Thomas's, so."* -James
3. "Every Time She Goes Back There, It Won't Have Changed:" Traditions and Routines	Traditions are regular patterns of church participation for the congregation as a whole. Routines are the regular patterns of church participation for individuals and families.	*"Um, they do a specific routine, every time. And just like I, I do at work."* -James
4. "Why Don't You Come Stand by Me?:" Hospitality	Actions taken by the congregation or its leaders to welcome people or increase their sense of belonging in the faith community.	*And, you know, the thing about St. Thomas's is everyone is, is welcomed and accepted for, um, who they are and as they are…You know, whether you're gay, whether you're special needs. It's just, it doesn't matter.* -Hugh
4a. Accommodation	Formal or informal changes made to the curriculum, liturgy, environment, expectations; or the addition of support people to increase, alter, or allow participation of a person or group of people who	*This new-found ability to welcome all to our parish, regardless of ability, is a refreshing call to ministry through inclusiveness and welcoming to all. Our ability to invite everyone*

Theme or Subtheme	Definition	Key Excerpt
	would not otherwise be able to participate in church activities.	*to join us in worship – not just those who are able to navigate stairs... -Annual Report, 2016*
4b. Education and Training	Formal and less formal programs to educate the congregation, its children, and its leaders on disability awareness, the theology of the inclusion of marginalized people, and specific volunteer training to support children with behavioral needs in relationship to camp, Sunday school, or other programs at the church.	*"We spent time in adult education, looking at our deep-seated theological constructions that further isolate and stigmatize people as 'disabled.'"- Annual Report, 2012*
4c. Generosity	These are acts of care where people share time and resources to facilitate the participation of all people, especially those with disabilities. These acts are more corporate than personal.	*"...the contractors donated their time and their expertise to try and make it work um, and and um, but we paid just for the the the wood and supplies..." -Karen*
4d. Invitational	Reaching out directly to individuals with IDD or their families through personal contacts, group affiliation, or social media to invite them to be a part of programs at the church.	*"And nobody knew this boy except for we knew him, and he was coming. And he laughed so much doing this. And, and everybody was in- , you know, involving, you know, it was like, you know, we were just ... everyone was wrapping and laughing and photographing. And, um, he has come and sat in our church for service three times since." - Jennifer*
4e. Learning from Mistakes	Recognizing and deliberately communicating that leaders and members will not always know what to do, or do the right thing around disability, but that a continued relationship and effort is established.	*"I have learned um, from experience from stumbling over myself things like um, you know there are certain children who do not want to shake hands at the peace don't want to be touched." -Karen*

Theme or Subtheme	Definition	Key Excerpt
5. "Not Being Accessible, It's a Theological Problem:" Beliefs	Tenets or assumptions that faith community leader participants expressed related to disability and their religious convictions or the common beliefs of their faith community. Faith tenets guided programs, education, and training and participant's commitment to providing accommodations and support for people with IDD.	*This year, looking both inside and outside the windows of our church, we noticed there was a need. We noticed that a significant number of people deal with disability – whether it's genetic, developmental, or the result of age or an accident - and the questions we began asking ourselves are "Where is God in the midst of disability?" and "What is our definition of 'wholeness?'"- Annual Report, 2012*
5a. Divine Image	Theological concept expressing that humans are created in the image of God with divine intention and value of all people, including people with disabilities.	*"…when people come to our congregation, everybody who comes in, changes us changes who we are, because we're seeing a different part of God in them." -Karen*
5b. Inclusion	A commitment to intentionally worshiping, socializing, and educating people together without separation based on age, sexual identity, or disability status, membership status or other membership related criteria (e.g., baptism, confirmation).	*"Karen is very like inclusive. She wants to make sure everyone can do what they want. Or like no one's left out." -Sydney*
5c. Divinity and Suffering	A belief that God is present and supportive in the midst of painful or difficult circumstances, that contributes to a sense of belonging in and support by the community.	*"In an instant I felt completely isolated. Alone. Afraid. Angry. Angry at God. Where was God in all of this? How could God do this to us?... Our final piece in feeling less isolated and completely supported in our journey of disability and faith, was joining St. Thomas's Church." - Annual Report, 2012*

Theme or Subtheme	Definition	Key Excerpt
5d. Transformation	Encounters or experiences that elicit a change in perspective about disability or other experiences and which encourage behaviors of hospitality in the congregation or a subset of the congregation (e.g., youth).	*"It was a moment of inclusion and fulfillment for Daniel something that he had wanted for many years, after being excluded from the church. And here he was welcomed with the the saints and the angels of this congregation."* – Capital Campaign Video

"A Role that I Uphold:" Leadership

One of the strongest themes that emerged from analysis of the data was around leadership. "A Role that I Uphold" is defined as the formal and informal roles and responsibilities that participants had in the faith community. These roles generated a reciprocal sense of responsibility to the community and being valued by the community. Contribution to the life of the church through these roles came up in multiple data sources in relationship to perceptions of belonging within the faith community. The importance of fulfilling necessary roles in the faith community came up with both participants with IDD in their PhotoVoice interviews and their individual interviews and in interviews of the church leaders. The annual reports spent significant time addressing roles in the church and specifically mentioned roles for children, youth, and adults. There were also photographs displayed around the building of people with and without disabilities participating in leadership roles, and physical space within the church dedicated to supporting youth acolytes. I also observed youth leaders with and without disabilities leading the worship services that I attended.

At St. Thomas there are tasks or jobs crucial to the functioning of the community held by people with and without IDD. I have included a table with a brief description of the formal leadership roles at St. Thomas that participants mentioned as being roles held by people with IDD during the interviews and in the document review.

Table 10.

Formal Leadership Roles at St. Thomas Held by People with IDD

Role	Definition
Lay Reader	Formal role in weekly worship where lay members read one or more passages from scripture.
Acolyte	Formal role in the weekly worship service where young people carried the crucifer into worship, held the Bible, and helped with communion. This role was further divided into the levels: torchbearer, acolyte and crucifer. The torchbearer being the simplest of the three levels, often held by younger people, and the crucifer having responsibility for leading the processional, holding the Gospel and supporting the other acolytes.
Intern	Formal, planned volunteer work in the church supervised by clergy and staff. Work takes place over an extended period of several weeks or months.
Program/ Event Volunteer (Other)	Formal and informal roles within annual or occasional programs or events such as a soup fundraiser, movie nights with the preschool, or the Halloween party.
Day camp Counselor	Formal role in the church during day camp where adults and youth supervised children and facilitated programs during day camp.
Sunday School Leader	Formal role where lay people supervised children on Sunday morning and led lessons and activities based on faith traditions.

In her individual interview, Sydney noted that helping out was at the heart of belonging at St. Thomas. She explained, "I like I feel like I'm included in a way because I have like have a role that I uphold and… It's like something that will keep me doing something so I'm not just like sitting and doing nothing…" Leadership was essential to Sydney's sense of belonging at St. Thomas: "like if we don't have I don't have any jobs to fulfill like we won't really even go." Two out of three of the PhotoVoice pictures that she selected to represent belonging showed her engaged in leadership during worship: one as a

lay reader while she was also dressed as an acolyte; and one where she was holding a basin of water for hand washing during a special service at the church.

In their interviews, the leaders of the church also mentioned their intention to cultivate leadership of individuals with disabilities. Karen described the power of leadership in connecting people with IDD to the community, "I have found that um, giving a kid on the spectrum a torch with a flame is one of the best things ever. Um, it makes them feel important… because they are, in leadership." She explained the high value that the church placed on serving in these roles, pointing out that it made people with IDD, "…part of the proclamation of the gospel."

Kim, the associate priest, talked about the ways that leaders with IDD helped younger children with IDD see themselves as potential leaders. She described how two campers at the day camp experienced the leadership of a teenager with IDD by saying, "it would have given them, the understanding that that might be something that they could do when they got a little older." She explained that the teenager enjoyed reading to the kids each day, and that the campers enjoyed hearing him read. "Yes, they, that he was able to take that leadership role and, and be there, um, and wanted to be there in that moment… whether they consciously understood it or not, I'm sure it was an influence."

Under the theme of leadership, I found three subthemes, lay leaders, mentorship, and making mistakes (see also Table 8 that lists and defines the variety of roles mentioned across the data). In the following sections I will describe these beginning with two types of leadership roles mentioned by participants with and without disabilities that they saw as indicative of belonging.

Lay Readers. The first subtheme for "A Role that I Uphold" was lay reading. Worship services at St. Thomas always include opportunities for non-ordained individuals to read from the Bible or other worship texts. I included this role as a subtheme because there was so much data related to individuals with disabilities as lay readers. Both participants with IDD mentioned reading in the church worship service in the initial interview, and included it in the PhotoVoice photos.

Being a lay reader was something that James specifically mentioned in his initial interview. He shared a photograph of himself reading the text on a Sunday morning from the lectern for his PhotoVoice interview. When I asked James why he chose this photograph to show belonging he stated, "Well, it shows me participating in the, what are they called? Is it called the-…"? (I helped him find the word, worship.). I followed up by asking him how he prepared for the role. James stated that he read through the passages, highlighting and underlining words, checking on pronunciation, and bringing notes with him to the service. This gave evidence to the level of care and importance that James placed on the role of lay reader.

Sydney also selected a photograph of herself reading the Bible from the same place in the sanctuary. She stated that being the lay reader showed belonging, "Because I do a lot of things at church and this was one of the things that wasn't really, like, the latest one, but I definitely do this a lot and I always try to read." Like James, she highlighted her preparation to do a reading, "So I always go through it beforehand and I'll I used to underline words in pen, like, right underneath, how to say it." For Sydney, being a lay reader was related to being an acolyte. "So, it's kind of in junction [conjunction] with the whole crucifying [crucifering] because that's how I show that I help out." Later in the interview, she noted that

she prefers to be a lay reader on weeks when she is not acolyting, because she did not like the appearance of the acolyte's robe during the reading. She indicated that she looked better when she could wear her own clothes. This highlighted the visibility of the role of lay reader.

In addition to the interviews, lay reading's special role in the church is evidenced by the physical space and worship artifacts. Within the physical worship space, there was a prominent piece of furniture called a lectern dedicated to lay reading. It was a solid, wooden podium permanently affixed to the front of the chancel (raised, stage-like area of the worship space). The lectern was the closest piece of furniture to the people in the sanctuary. In addition to the physical space, the names of lay readers were also listed in the worship program, and the role was mentioned as part of the annual reports each year.

Related to lay reading was holding the Bible for the priest during the reading of the Gospel. During the initial interview, Sydney spent four minutes and twenty-nine seconds describing holding and carrying the Bible as part of her role as an acolyte. She described the weight of the book, the golden covers, and the difficulty she has holding it still for the Gospel reading (read by the priest). "Because like it definitely needs to be read. But so, it is definitely like an important role to have and I have, I definitely have the responsibility to do that." The repetition of the word definitely and the emphasis in the audio highlight the importance that Sydney places on the sacred text. Further, she spotlighted that she has "the *responsibility* to do that." For both participants with IDD in this study, reading the sacred text during the worship service illustrated an important aspect of belonging for them. Another aspect of belonging for Sydney related to leadership was mentorship.

Mentorship. I defined the second subtheme, mentorship, as the use of experienced peers to guide novice leaders in learning to fill formal roles at the church. Sydney, in

particular, described mentoring other young people in leadership roles as part of her experience of belonging. She described how she learned to fill leadership roles at the church with the help of experienced peer leaders and how she later showed less experienced children how to fill these leadership roles at the church. In reference to learning to be an acolyte, she described being mentored, saying, "the Reverend's son, older son um taught me kind of like the tricks and it was almost funny because it was these two junior/seniors and then this little me. So, I was the cute one." She also recounted being a mentor to other younger children. Sydney highlighted the link between mentoring and maturation, "I've had I did show two kids how [serve as an acolyte] and so I felt like accomplished. And I turned to Aaron and I'm like 'wow I'm old.'" Throughout her interview she referenced cuteness and youthfulness in the children around her, and she referenced her own mastery as a mentor several times. Sydney also pointed out the inclusivity of leadership at St. Thomas, as I describe below.

Making Mistakes. Another important subtheme related to participants' perception of leadership as key to belonging within the St. Thomas church was related to not requiring credentials for participation or expecting that individuals would never make mistakes. Throughout the interviews, participants referred to the faith community's openness to accept mistakes by those acting in leadership roles (e.g., mispronunciations in readings) and the community's wish to invite people to be leaders in the community even if they lacked traditional credentials (e.g., having been baptized, or gone through confirmation), skills, or prior experience. For example, when asked if individuals who are crucifers (head acolytes) need any special training, Sydney said, "There's nothing really needed. No, there's no like requirement form or anything." She indicated that Karen regularly invited people to be leaders when she said, "Karen is very like inclusive. She wants to make sure everyone can do

what they want. Or like no one's left out. So, if you wanted to be a torchbearer everyone would be super excited."

This same sense of inclusion was echoed by James's father who pointed out that the community's willingness to include young people with IDD as lay leaders set it apart as an inclusive community. The wide range of roles available and the inclusion of photographs throughout the church building depicting lay leadership also gave evidence of the community's readiness to extend the invitation to lead.

Sydney reflected the same sentiments expressed by church leaders around normalizing mistakes. She remarked that she was comfortable making mistakes at St. Thomas. When describing a reading that she did, she mentioned having difficulty reading one of the words. "So, I was like, I'm just gonna skip over this because I couldn't pronounce it, or I would've just butchered it." Skipping was the strategy that she used to keep from mispronouncing the words in the text, "but I think it was just that moment that's it was, it was a mix of awkward and just kinda like a, Ha-ha! I don't really know how to pronounce this. Hope no one minds." This same sense of comfort making mistakes was echoed in the findings related to hospitality under the subtheme "Learning from Mistakes" described below.

"We Are Friends:" Relationships

The second primary theme in this case study that arose from the data analysis was "We are Friends:" Relationships. I defined this theme as connections between people in the faith community that included family, intergenerational, pastoral, or mentoring relationships as well as formal relationships (e.g., Sunday School Teacher, chaperone) and peer relationships. These relationships could be reciprocal (e.g., between peers) or more one-sided

(e.g., chaperone-student), but each relationship contributed to and was an outcome of belonging.

Evidence of the importance of relationships as a marker of belonging came from multiple data sources. James and Sydney both discussed the importance of and different types of relationships they experienced at St. Thomas in their initial interviews. James also focused on relationships in two out of three of his photographs for the PhotoVoice study. He chose one picture of his family in worship. His mom was wearing a robe, and all three boys and dad are smiling with her as they posed together at the church. He chose a second photo of himself during the "We've Are Friends" program (i.e., a program hosted at the church aimed at building social connections between youth and young adults with IDD through structured, facilitated activities). In the photo he played a super-sized Connect Four game with a friend. He was smiling and seemed to be engaged in a conversation.

Additionally, church documents and my field observation supported the central importance of relationships within this faith community. Some examples of this included being greeted at the door of the sanctuary or church. During the educational event (evening forum), people were aware of each other and were sure to include every person at the table in discussion questions. The bulletin boards around the church building included photos and flyers related to many people with and without disabilities participating in activities together (e.g., event flyers for programs encouraging young people to come and spend time at the church together). The annual reports and capital campaign documents also mentioned relationships. Karen discussed the growing relationship between the congregation and Daniel, a man whose sexuality and disability had made him feel marginalized and unwelcome in the faith community of his birth, who reached out to St. Thomas and found a

place to belong. During the capital campaign video. Karen stated, "Two volunteers from our church offered to go and be with him [Daniel]… to just spend time with him, to bring him the Eucharist. And so, the community started to build from there. The relationship started to build." The annual report from 2013 described this same growing relationship.

The leaders and parents also mentioned the importance of relationships in their interviews. Karen talked about the value of an intergenerational relationship to one of her sons with IDD, and both Jennifer and Kim discussed the willingness of young people in the church to reach out to people with disabilities and to connect with them in a variety of settings.

In the sections below, I describe two categories of relationships that James and Sydney mentioned as particularly salient for them as they considered what it meant to belong to the St. Thomas community.

Church Relationships. Participants with IDD discussed one type of social relationship at church as part of their experience, participation, and their feeling of belonging that I have defined as church relationships. This type of friendship included individuals with whom they participated in an activity at church or someone at church with whom they shared an interest, but were not always people with whom they had close personal relationships. Analysis of their interviews showed that church relationships may or may not also be friends at school, work, or other community settings.

James, for example, described what he did with friends during "We are Friends," a social program at the church for youth and young adults with IDD that he attended. "…After that, we basically uh, had pizza. And then, we played the games like, Connect Four. Um, and then, we went home, after that." He explained that the program gave him the chance to

connect with friends that he went to school with and did not see very often, to spend time with his girlfriend, and to catch up with friends from work.

Hugh, James's father, reported that the "We are Friends" program was an example of "St. Thomas's going out of its way to open up, you know, it's the church hall to host an event where sp- special needs kids from multiple towns were invited in, and given an opportunity to have social interaction." He went on to explain, "especially the older they get—they get out of school, they don't really have the chance to get together on a regular basis." For James, "We are Friends" gave him the chance to talk, play games, and eat together with peers. His father explained, "And this kind of fills that void and gives them a, a social outlet and, you know, allows them to make new friends and connect with their older friends." Hugh explained that social relationships can be difficult, especially because James relies on public and peer transportation and his friends have different work schedules which made it challenging to get together with friends. "We are Friends" helped James deepen and sustain ties to his peers.

Participants with IDD were not afraid to explore the limitations of church relationships, however. Sydney wished that she had more in common with friends at the church. She stated, "Well I'm definitely friends with a lot of kids but there's people that like, I wouldn't like, hang out with just like if I see them at church then I'm just like really polite and like talk to them." Relationships overlapped with leadership at the church, and showed the value of volunteering with peers for people with IDD in fostering social relationships. Sydney spoke about how shared leadership roles helped her build social relationships with peers at the church. She pointed out, "I yeah I've done VBS [day] camp about two summers and a couple kids from the high school do come to that." Sydney went on to say, "…it's a

little bit easier for me to talk because there's like an event and we have stuff to talk about."

During her interviews, Sydney often lamented the fact that other kids do not share the same

interests that she has, and that it can be lonely without shared interests to connect them.

Volunteering at the day camp gave Sydney that point of connection, "it's easier for me like

we can talk about some of the kids or it's just easier for me to insert myself into the

conversation."

Family Relationships. A second subtheme under "We are Friends:" Relationships

was family relationships. For participants in this study, family relationships were biological

families and included members of their household. Participants described attending faith

community events and activities with their family members or at the request of family

members, and described an identity as members of the church that was negotiated through

their family.

In his PhotoVoice interview, James expressed his connection to church as negotiated

through his family. He selected a photograph showing himself with his whole family at the

church. He said that a good title for the photograph would be, "Evans Team," because it

"shows me… belonging to my family, so, and they belong to St. Thomas." James's dad

indicated that James is very family oriented, and that he identified strongly with the actions

and traditions of his family.

Sydney also explained how her family relationships encouraged engagement in the

faith community. For Sydney, a connection to her mom was at the heart of her participation

at church. She talked about how her mom encouraged her participation in the church.

According to Sydney, "there's a lot of events that… I really don't really have a lot of interest

in, but I go because it's nice or… because my mom wants me to." Sydney also mentioned

that she felt connected to her mom when she served communion. She explained that her

mother has gluten allergies and that one of her jobs is to get the gluten-free wafers out during

communion. Doing this act made her feel a special connection to the church and to her mom

when she was able to care for her mother in this way.

"Every Time She Goes Back there, It Won't have Changed:" Traditions and Routines

Another theme that emerged across the interviews, documents, and field notes was

the importance of traditions and routines to belonging. I defined traditions as the regular

patterns of church participation for church members. This included how the community

celebrated holidays, how they began and ended their gatherings, and how they worshiped.

Routines are similar, but they are patterns that individuals and families engaged in at the faith

community that were not necessarily followed by other community members. These included

things such as where people preferred to sit in the sanctuary, routes they typically took

through the building, and the people they interacted with. Routines and traditions provided an

important view of how participation in the church related to a sense of belonging for the

participants with IDD in this study. Routines came up in James's initial interview and in

Sydney's initial and PhotoVoice interviews. Routines were also mentioned in the church

leader interviews and recurring routines were evident in both my observations of the building

and in the activities that I observed.

One of the clear examples of the way in which traditions and routines represented

participation and belonging was found in the worship service. An expression of this was the

use of colored hangings to decorate the church. In her interview, Kim explained the

importance of these hangings, "we change the altar linens for all the different seasons and

feast days and everything, of the, in line with the liturgical calendar." As part of the service

there were also a number of actions that the congregation knew how to do without referring to written text in the bulletin or program. These repeated, predictable actions seemed to serve as cues for deeper participation. In contrast, as an outsider, I found myself relying on the people around me to know when to sit, stand or kneel, or to make the sign of the cross. Another example was that people used call and response during worship (e.g., "peace be with you," "and also with you,"), or repeated phrases during communion (e.g., "the body of Christ, the bread of heaven"). They even used some of these same responses to signal transitions to the gathered people at the adult education event. At the beginning of the evening, for example, everyone was gathering, getting food, and chatting. To gain the attention of the room and begin the program, the facilitator said, "peace be with you," and the people gathered spoke in unison and said, "and also with you."

In addition to worship, during my building tour, I saw that the church had a closet with traditional clothing and objects used in worship by the acolytes (e.g., robes, chasubles, cross necklaces, a large cross used during the processional, and torches). These costumes and artifacts were traditional to the roles that people held in the service. These traditional costumes supported participation and belonging by providing visual cues for worshipers and a clear delineation of roles for the leader. In addition, when I attended different services, I noticed that the sanctuary was decorated in purple for two of the services and in black for two of the services, and in green on other visits. These colored cloths were used to mark seasons and festivals in the church year. (e.g., purple and black were used to mark the time leading up to Easter). These traditions are consistent in other churches in the same denomination and tend not to change over time.

Participants mentioned specific traditions as some of their favorite parts of life in the faith community. Communion, one of the traditions at St. Thomas, was central to Sydney's experience in the faith community. She mentioned it several times as a focal point to her experience at the church. She described both serving and receiving it, and, as mentioned in the relationships section, it helped her feel connected to her mother. Sydney described receiving communion as her favorite part of church and spoke in detail, highlighting the value of this tradition to her experience of participating in the faith community.

> Um I always liked getting wafers: so, when I went up, I always liked dipping it. And something I do almost all the time I dip it in the wine and then I see how long the wafer will last with the wine. So, like it will melt like kind of like on my tongue and then I'll like flip it around or like try to see how long I can it can last.

In addition to traditional liturgy, worship, prayer practices, seasons, and holidays representing the ordered world of the life of the church, participants reported personal routines they associated with belonging, such as how participants entered the building, where a family sat, certain objects that they noticed. These particulars of participating in worship seemed to have a supportive role, contributing to a sense of belonging and increasing Sydney and James's participation. James articulated the value he placed on traditions in the church when he compared worship to his own work. When James made the connection between his work and his church, he made a connection to the support and belonging that he feels in both places. "Um, they follow the leader and they—they do a specific routine, every time. And just like I, I do at work." Engaging in a specific routine every time was supportive of successfully navigating his day, using public transportation, peer transportation, engaging in

competitive supported employment, and in his social life. Routines at church seemed to also support his participation there.

James also described his after-church routine. "We normally go straight from work, or straight from church to uh, the Coopersville Deli." This is important because while most people in the community engage in coffee fellowship after worship, James and his family prefer to go out to lunch. James and his dad both mentioned going to the deli, and both described it as a routine that they look forward to, something that they have done for years, part of their Sunday morning, and supportive of James's experience at St. Thomas.

James's dad, Hugh, also described that he liked to sit in a certain seat in the sanctuary each Sunday. Hugh stated, "Have my own pew. Very territorial. Don't like people sitting in my pew. People know it's my pew." Having a consistent place where he can sit seemed to be very comforting for him and highlighted his appreciation of having the same routine each time he attended worship. He described the people sitting around him on a typical Sunday— he pantomimed the action of shaking hands with them as he described the families sitting nearby and the relationships that he had with each of them.

Routines were also important for Sydney. One of the photos that she chose to represent belonging highlighted a routine at the church. She chose a statue of a hooded figure with his arms outstretched that sits near the entrance to the sanctuary. Sydney put a copy of the bulletin in the statue's hand and explained that she has done this since she was a little girl. She commented that this statue helped her feel like she belonged at St. Thomas. Sydney described the statue this way, "maybe just sense of like welcoming everyone. Like, not letting… I know it's a statue so it's not, like, a real human being. But, like, maybe just, um, the, the welcoming factor that's, like, everyone can be, like, be involved."

For the same photograph, Sydney's mom chose the title, "arms opened, for receiving." She thought that Sydney might have chosen the photograph of the statue as an example of belonging at St. Thomas because "the familiarity of walking by it all the time. And knowing that it's something that is consistent and available and every time she goes back it'll be there; it won't have changed." For Sydney, having something fixed and unchanging helped her feel like she belonged at St. Thomas. Her mom explained, "it's a, a regular, fixture versus the people can come and go."

Both the traditions and routines at St. Thomas seemed to be supportive for Sydney and James's participation in the church. The same rhythm that indicated the beginning of a meeting and inspired a sense of belonging among the adults in the evening forum, for example, was available each Sunday at St. Thomas and served as an important support to the participants in this study. Karen also expressed the value of traditions as a source of support to people with IDD and their families, and a source of invitation into religious life. She explained, "the church is a very ordered world. Um, our liturgical calendar is ordered by seasons by colors by sounds, and um, and for a child on the autism spectrum, it's the perfect world for them to enter into." This "ordered world" of the church was clear to me when observing worship, education events, and in the physical space and its decorations.

"Why Don't You Come Stand by Me?:" Hospitality

Hospitality was a strong theme that emerged from data analysis. I defined it as actions taken by the congregation or its leaders to welcome people or increase a sense of belonging in the faith community. The faith community extended hospitality to members, guests, and visitors. They extended welcome to people with diverse ages, races, sexual identities and to individuals with disabilities. Actions of hospitality shaped the context for the experiences of

people with IDD in an intentionally inclusive Christian faith community, and are essential to the experience of people with IDD in that faith community.

Hospitality had significant overlap with the themes of beliefs and leadership. In fact, the leaders in this study often pointed to their beliefs as reasons for actions and hoped that their actions would bring the community closer to the ideals expressed in their beliefs. For instance, Karen explained that her commitment to inclusion led to her intention to enact only inclusive programming at the church. She explained that while some faith communities have created separated spaces and programming for people with IDD, she is resistant to do that. Jennifer described the move toward inclusion of the youth in the community as she described a self-organized indoor snowball fight where kids worked to include everyone in the activity, young kids, older kids, and kids with disabilities. She told about an activity that she set-up for the annual meeting like this: "It was, um, they, um, we had a snowball fight. An indoor snowball fight...." She went on to describe the diversity of the participants, "they had created a game, by themselves and were doing this game. And they just created it as a group. And that was all different, um, like, like every age. We had 16, 18-year-olds. We had four-year-olds." She clarified how in the context of the game children worked to be inclusive of their peers with IDD. She described, "So now in a, in an autism-based situation you're gonna have the one kid who doesn't like that there's rules… they're gonna stand out and…not gonna go along with the, the group." But, she expounded, "because the children had been socialized around disability, because they had extensive experience and success helping people with disabilities be a part of the community, they were able to be inclusive." She explained, "There seemed to always be somebody that said, 'Okay.' You know and took that kid aside." This kind of peer leadership and inclusivity was also described by the assistant priest, Kim,

who mentioned a moment on a mission trip where a young person from the church made a

generous offer to help another child having a difficult time around a missing towel.

Five subthemes emerged from the data that described the congregation's intentional

actions of hospitality and inclusion of people with disabilities provided by participants, field

observations, and documents. These were accommodation, education and training,

generosity, invitation, and learning from mistakes. Each of these is discussed below as an

aspect of the intentional hospitality offered by the faith community.

Accommodation. The first subtheme, accommodation, was formal or informal

changes made to the curriculum, liturgy, environment, expectations, or the addition of

support people to increase, alter, or allow participation of a person or group of people who

would not otherwise be able to participate in church activities. Karen described a young man

with autism in the confirmation class who needed an accommodation to an assignment, "The

organ was just too sensory. It was too much for him." During confirmation, the young people

are required to attend a certain number of church services, "so we were trying to find a way

to accommodate him, um, so again he could come he could wear his headphones he could sit

outside, the actual um, sanctuary." The area used to accommodate the young man was the

glassed area to the left of the main entrance at the rear of the sanctuary. This was arranged as

a sitting area with comfortable seating, church photo albums, and with toys, fidget tools, and

sensory supports available. Karen described it as, "an area where we have a microphone

[speaker] set up so they can hear it without being, um, so you know, present to the vibrations

and kind of a little outside but still a part of it." The use of the glassed seating area was an

example of an accommodation that allowed the young man to participate in the program and

to meet the requirements of it, while also meeting his needs for comfort and freedom from a source of irritation.

Physical accessibility, a main focus in the annual reports and in the capital campaign video, was another type of accommodation that the faith community made. The annual report described the increased physical access allowed as a result of the capital improvements in the church. The report mentioned the use of the elevator during a memorial service, "…we are thrilled to be able to bless today for our community's use and for the accessibility of all, the new elevator and accessible restroom facilities." The author of the building report highlighted that, "this new-found ability to welcome all to our parish, regardless of ability, is a refreshing call to ministry through inclusiveness and welcoming to all." They noted that the church worked for years to accomplish the goal of physical accessibility and focused on how the new accessibility supports allowed them "to invite everyone to join us in worship–not just those who are able to navigate stairs." Annual reports from 2014-2018 discussed the building campaign that raised over $200,000 for the church and funded the installation of an elevator that made most of the building physically accessible, as well as updates to all of the bathrooms. In my tour I found that the bathrooms were spacious and well-appointed with grab bars. I found that the elevator was easy to use, and that signs made it clear where the elevator was from all of the entrances.

In addition to physical access and accommodation of needs that people have based on their sensory experiences (i.e., fidget toys, weighted blankets, and bounce chairs to accommodate sensory processing disorder), the church made an intentional effort to change attitudinal accessibility. One way that they did this was through education and training. In

addition to religious education, preaching, films, and book group, they partnered with outside

agencies for training, camp leadership, guest speakers and preachers.

Education and Training. A second subtheme within hospitality was education and

training. Education and training included formal and less formal programs to educate the

congregation's adults, children, and leaders on disability awareness and the theology of the

inclusion of marginalized people. It also included specific volunteer training on supporting

children with behavioral needs in relationship to the day camp. Their education and training

strategy also included partnerships with community agencies to lead religious education,

guest preaching, guest speaking, panel discussions and leadership for the day camp.

One formal way that the church strove to educate its membership was a *Faith and

Disability* series. The 2012 Annual Report stated, "we opened our three-week series on

'Disability and Faith.'" The report explained that the three-week series involved preaching,

activities, and classes. Attendees examined the theology of disability, "looking at our deep-

seated theological constructions that further isolate and stigmatize people as 'disabled.'"

They also addressed disability with "Sunday School children and Youth Group teens focused

on inclusivity in their lessons and activities." The series was reinforced with preaching on the

themes of disability inclusion in faith communities. The annual reports showed that this

series became a regular part of the life of the congregation. They repeated the series in 2012,

2013, and 2014. The series is not mentioned in the annual reports for 2015-2018.

Generosity. The third subtheme for hospitality was generosity. These are acts of care

where people share time and resources (e.g., bringing yoga balls, bean bags chairs, or

building ramps) to facilitate the participation of all people, especially those with disabilities.

These acts were more corporate than personal. They ranged from the simple, such as

providing exercise balls for summer camp, to the more complex, such as members of the church building a temporary ramp to provide access to the church building. Karen described the building of a temporary ramp that gave Daniel, a parishioner who used a wheelchair, access to the building. "Um, I think we only paid for the wood…the the contractors donated their time and their expertise to try and make it work um, and and um, but we paid just for the the the wood and supplies." This kind of generosity was echoed in smaller projects such as providing yoga balls for the day camp and supporting charities through-out the year.

Invitational. The fourth subtheme included in hospitality was around invitation which I defined as reaching out directly to individuals with IDD or their families through personal contacts, group affiliation, or social media to invite them to be a part of programs at the church. In addition to supports, programming and training, inviting people with disabilities into the church was a step toward inclusion. Jennifer described one family affected by disability who attended the Halloween party after receiving a personal invitation from the church, "Um, and we had, um, a young boy and his mom come. And nobody knew this boy except for we knew him, and he was coming." She recalled how he watched a game where the children were wrapping each other up in toilet paper, "he laughed so much doing this. And, and everybody was in-, you know, involving, you know, it was like, you know, we were just ... everyone was wrapping and laughing and photographing." Jennifer highlighted the importance of invitation when she reported that this child and his mother have become a regular part of special events through-out the year as a result of the invitation to join the Halloween celebration.

"Learning from Mistakes." The final subtheme associated with creating hospitality was recognizing and deliberately communicating that leaders and members did not always

know what to do, or do the right thing around disability. Leaders in the church communicated and modeled that they learned from challenges as well as successes. Participants described a willingness to accept mistakes and treat them as a time to grow; this included accepting mistakes made by young people (e.g., mispronouncing a word), and adults (e.g., sprinkling a child with water who had sensory issues). Leaders expressed that this openness encouraged everyone to participate and accept each other's success and mistakes without judgement. This subtheme is closely related to the subtheme under leadership called "Making Mistakes." The difference is that this theme is part of the actions intentionally taken by leadership to make it acceptable for others to lead even when they are not experts.

Karen expressed the importance of letting people know that she, a minister with special training in disability and the mother of two sons with IDD, still made mistakes around disability. For example, she said, "I have learned um, from experience from stumbling over myself things like um, you know there are certain children who do not want to shake hands at the peace, don't want to be touched." She said that being open about making mistakes increased the faith community members' capacity and willingness to extend welcome to people with IDD.

Karen described one instance where she made a mistake related to an event that occurred at the beginning of the school year when the children collect school supplies for the needy and bring their own backpacks in for a special blessing. "In September the first Sunday back with, after school starts, we do a blessing of the backpacks. The best way I have found to do a blessing of that many children was to use holy water and to sprinkle them…" Although the water is fun for most of the kids, one child hated the experience, "it upset him horribly." She went on to explain, "Next year came. He came up with the kids again I forgot.

I forgot that he didn't want to be sprinkled. Sprinkled again. Minor, minor tantrum…" She

described that after three years, she finally got the blessing right. This time she said, "okay

why don't you come stand by me and, you can help me sprinkle all of the children?" She

pointed out that it was important not only that she learned the lesson but also that, "the

congregation got to witness me, making a mistake."

Karen pointed out that as the mother of two sons with IDD and a professional

community leader that many people see her as an expert. She highlighted that it was

important that the congregation saw her making a mistake, and saw her remaining connected

to the child and the family. "Uh, it didn't mean I should back away from this child or be

afraid of interacting with him," instead, she found it important to model inclusion. "But we

were just going to, we were gonna find a way to include him and make it right for him. So

that he could still participate in the blessing of the backpacks." Making mistakes is

inevitable, according to Rev. Evans, but learning from them requires an intentional

commitment to communication and transparency. The commitment to listen and learn from

the actual experts, people with IDD, is at the center of understanding disability at St.

Thomas.

"Not Being Accessible, it's a Theological Problem:" Beliefs

I defined the theme "Not being accessible, it's a theological problem" as the tenets or

assumptions that clergy participants expressed related to disability and their religious

convictions or the common beliefs of their faith community. Leaders in the church stated that

these beliefs were important in guiding programs, education, and training, and their

commitment to providing accommodations and support for people with IDD. (These beliefs

were not expressed by the participants with IDD as part of their experience in the faith

community.) There were four subthemes that these leaders referred to as guiding their actions: Divine image, inclusion, divinity and suffering, and transformation. I will define and discuss each of these subthemes below.

Divine Image. The first subtheme described by the lay and professional leaders was the theological concept expressing that humans are created in the image of God. I defined this belief as the assumption that God created each person with divine intention and value. It asserts that all people, including people with disabilities, are created with divine gifts and purpose. Kim stated, "the message of Christ is that we are all worthy, we are all valued by God, we are all loved by God, cherished by God." This appeared to be a core value that shaped the actions of the faith leaders to include individuals with IDD in the faith community. For example, Karen stated, "The problem of not being accessible, it's a theological problem. It's a problem that when people come to our congregation, everybody who comes in, changes us changes who we are, because we're seeing a different part of God in them."

In her initial interview, Karen explained that the first thing she did in her ministry at St. Thomas was to address the theological assumptions of the congregation through education, preaching, and activism. Karen posited this as the essential question for her congregation, "can somebody who has a a disability is that person still made in the image of God?" She pointed at this belief as foundational for her church, "…we wrestled with that. Um, and, and, to me that was the the absolute grounding that we couldn't, we couldn't, we could not move forward as a community without that first." Kim also shared this point of view in her interviews and divine image was given as the primary reason to develop an educational series on *Faith and Disability and the capital campaign.* In the 2012 annual

report one of the parishioners wrote, "conversations have been opened, isolation has been broken, and God's image is being reflected."

Inclusion. The second subtheme was inclusion which I defined as a commitment to intentionally worshiping, socializing, and educating people together without separation. The church leaders that I interviewed talked about inclusion built on age, sexual identity, disability status, membership status, and other membership related criteria (e.g., baptism, confirmation). Throughout interviews and annual reports, the clergy and lay leaders referred to inclusion as a core and commonly held assumption. Kim stated, "one of the things that I, I really love about Karen is, she actually looks for ways and looks for areas in the life of this church where there are gaps in inclusivity." She referred to the capital campaign and also noted, "she looks for ways of including kids with special needs who often don't get experiences that quote unquote normal kids would have." Kim explained that this was the driving force for new programing at the church, "like the camp experience or after school sport experience…" Going beyond programing, Kim explained that this focus on creating inclusive activities is an outlook that comes, "from Karen's leadership and Karen's passion for wanting these kids to have these experiences because they deserve them, it will enrich their lives, it will give them self-esteem, it will give them a feeling of being wanted."

Divinity and Suffering. Another belief that the leaders raised in their interviews was the third subtheme, that God was fully present and connected whenever believers were in the midst of painful or difficult circumstances. Karen related this belief to her own experience. She recalled that during her pastoral training that she was struggling with a new diagnosis of a family member. She explained that she was struggling with many of the same issues as the patients at the rehabilitation center where she interned. She noted that she asked herself,

"…how can God let this happen? And um, is this the kind of God that I wanna believe in?" As part of this training, she was helping her patients understand "…that God had not abandoned them, uh, nor had God done this to them." The belief held by leaders at St. Thomas was that God is suffering with people, not causing the difficulty or pain. This belief helped leaders create structures in the faith community that contributed to a sense of belonging in and support by the community for individuals with IDD and their families. Karen described that this experience was foundational to her ministry with parents of children with IDD and foundational to her work in supporting them through life with a child with severe disabilities.

This belief was also reflected by the congregation. In the annual report, one of the authors (a member of the church) wrote, "No parent can really prepare themselves for hearing that your son is on the autistic spectrum. In an instant I felt completely isolated. Alone. Afraid. Angry. Angry at God. Where was God in all of this? How could God do this to us?" In the article, the author described how St. Thomas had supported her through the diagnosis of her children with autism. "Our final piece in feeling less isolated and completely supported in our journey of disability and faith, was joining St. Thomas's Church." She went on to explain that "Rev. Karen Evans has made it clear that we are all God's children no matter what diagnosis or disability…. At St Thomas's, we do not need to feel alone or isolated. We are in this together with the support of the parish and of God." A sense of being supported by God and the parish through a difficult time highlights the value of the church's understanding of suffering and divinity and the comfort of a place to belong and be supported.

Transformation. The fourth subtheme I found around belief was the theological concept of transformation. I defined transformation as encounters or experiences that elicited a change in perspective about disability or other experiences and which encouraged behaviors of hospitality in the congregation or a subset of the congregation (e.g., youth). Kim described the church's young people as especially generous and mature compared to other youth in her ministry. She attributed these characteristics to the church's work to be inclusive of people with IDD. Jennifer referenced the inclusivity and patience of young people in the church when she described children working together to create a game that everyone could play.

These leaders expressed a belief that including people with disabilities made church members without disabilities more likely to be welcoming and inclusive in new situations. When asked about resources needed in the congregation to promote inclusion, Karen cited the need for more encounters with people like Daniel, who would move (transform) the hearts of the congregation to create change. In the capital campaign video, for example, Karen said:

> They got [Daniel] up the two ramps, and as they were entering into the church all of the children from our pageant the Christmas Angels were gathering in the narthex, and just as they started to walk down the aisle Daniel and his mother wheeled in right behind them. It was a moment of inclusion and fulfillment for Daniel something that he had wanted for many years, after being excluded from the church. And here he was welcomed with the the saints and the angels of this congregation.

According to Karen, Daniel's inclusion at St. Thomas brought out the best in the congregation. She felt that his presence encouraged generosity, innovation, and a desire to connect to people on the margins.

In the next chapter I will provide a discussion of these findings. I will include how the findings relate to the relevant literature, and explore the implications of the research. This will include suggestions for churches, families, and service providers for practical application, and suggestions on directions for further research.

Chapter Five: Discussion, Implications, Recommendations

The question guiding this study was: What does participation of people with intellectual or developmental disability look like in one intentionally inclusive Christian faith community? By interviewing people with IDD who are active in an intentionally inclusive Christian faith community, I was able to uncover and describe their experiences. In this particular community, I found that participation went beyond being merely physically present to a reciprocal relationship between the individual with IDD and the faith community. Participation included the fulfillment of valued and essential roles and engagement in the traditions and routines of the community within an environment of supports that were flexible, provided by multiple people across a variety of settings, and which were largely seamless. In the previous chapter I outlined the themes that emerged in the data analysis; in this chapter I will describe the connections and interplay between these themes and the implications for practice and research.

Consideration of the five themes described in Chapter 4 resulted in identifying three particular factors (threads) that seemed critical to authentic participation of people with intellectual or developmental disability in this particular faith community: the seamless delivery of supports, the value of the rhythms of faith community life, and the importance of people with IDD not only participating in the faith community but holding valued roles. These are the threads that were woven throughout the study, connecting the themes and highlighting the interplay between them. In the following sections I will explore the ways in which these factors enhanced participation and a sense of belonging for the participants with IDD.

Seamless Delivery of Supports

One thread across the five themes that emerged from the data analysis was the way in which supports and accommodations for individuals with IDD are provided at St. Thomas. Supports are integral components of the daily life of this community and come from the community's intention that people of all abilities are authentic members of their community. Creating opportunities for leadership, fostering relationships, participating in the rhythms and traditions of the church were all enabled through supports that arose from a deep sense of hospitality and belief that all people are valued by God.

At St. Thomas, however, these supports were not always obvious to people with IDD. As an illustration, one answer that Sydney and James did not give to the question "What does participation look like at St. Thomas?" was describing the application of appropriate supports. Although previous research on participation of individuals with IDD in faith communities has frequently highlighted the visible role of supports in making such participation possible (e.g., Minton & Dodder, 2003; Poston & Turnbull, 2004), in this case study Sydney and James and their parents, Jennifer and Hugh, rarely discussed supports for Sydney and James's participation directly. Instead, James and Sydney both briefly mentioned some generic supports (i.e., supports available to anyone taking on roles within the faith community) that helped them prepare to be lay leaders (e.g., sometimes asking for help with certain words; mentoring to learn skills as the head acolyte), but they did not appear to be aware of the application of many other targeted supports that helped them participate in activities at the faith community (e.g., an accommodated confirmation curriculum, physical supports for sensory processing, preferential seating). Neither of their parents mentioned either a need for supports or the application of supports to facilitate their children's

participation in faith community activities. For example, they did not mention an inclusion committee whose role was to develop and implement supports or a point person who assisted them or their child with needed accommodations. Conversely, neither parents nor the participants with IDD mentioned any lack of supports that kept them from joining in an activity or program. This is in contrast to some previous research studies in which participants with IDD noted that a lack of appropriate support acted as a barrier to participation (e.g., King, 1998; Möller, 2012).

Both Sydney and James utilized formal supports in other parts of their lives, so it stands to reason that they did need at least some supports to fully participate in the faith community. The reason that participants did not identify supports was not because these were not needed. Instead, the supports that were provided to them were unobtrusive and seamless, woven into each activity in a way that did not make them obvious add-ons. Even though participants did not mention specific or individualized supports they needed for full participation in the community, there was clear evidence that they received the supports that they needed to fully engage in activities. Indeed, examination of field observations, annual reports, and interviews with all of the participants revealed that multiple types of supports were a vital part of every aspect of this faith community, from the physical structure of the building to social, educational, and worship activities. For example, in field observations, I saw people with disabilities being offered a menu of support options including: peer buddies; fidget toys, weighted blankets, and other supports for sensory regulation; dietary accommodations; and preferential seating. Supports were everywhere but were largely invisible to the participants in this study.

One component in how supports were seamlessly woven into all aspects of church life at this faith community was the experience and training of the professional leaders. All three professional leaders were themselves parents of children with disabilities. Jennifer also worked outside of the church with young adults with IDD to support their employment. Kim had years of experience in adaptive sports and volunteered at a therapeutic riding center, and Karen had completed formal education in faith and disability. All three of them identified specific supports and accommodations they used to support participation of people with IDD at St. Thomas such as letting confirmation students attend worship in the lobby or allowing children to decide how and when to participate during activities. All three participant leaders made references to the importance of communicating with individuals and their families to discern what supports were needed and how they leveraged community resources to provide those supports.

The way in which supports were seamlessly woven into the life of the St. Thomas faith community is similar in some ways to what is found in inclusive school settings where the staff are highly skilled in supporting students with disabilities within education contexts. Novice teachers in inclusive settings often struggle to create effective supports and the ones they do provide are often clearly retrofitted to the setting or activity. However, as teachers become more adept at including children with disabilities, the supports become less effortful and less obvious. Expert teachers describe the application of appropriate supports as something that they do without thinking about it. Supports become a part of their classroom culture. It seems that this same level of mastery has been achieved at St. Thomas where educating the congregation through the faith and disability series and other efforts has appeared to successfully increase their capacity to incorporate seamless supports.

A second component of providing seamless supports was volunteer training. Because faith communities are largely volunteer run, volunteer capacity for effectively administering supports is crucial. In a volunteer run organization like a faith community, the lay leaders organize and facilitate the programs of the church including parts of worship, fellowship, education, mission, and service. For supports in a faith community to feel seamless, it is critical that the members provide supports in the programs and activities that they administer. These volunteers played a crucial role in every aspect of community life at St. Thomas, and their abilities limited or supported the community's capacity for inclusive practices. The use of education and training of the whole St. Thomas community in disability awareness and an inclusive theology of inclusion was evidenced in the data (e.g., annual reports and interviews). It may be that the educational efforts of the community not only resulted removing attitudinal barriers for the laity of the church but that they worked to increase their receptivity for learning about disability.

The Rhythms of Faith Community Life

The answer that Sydney and James did share over and again to the question "What does the participation of people with intellectual or developmental disability look like in one intentionally inclusive Christian faith community?" was description of the small, repeated patterns of behavior that made up their participation at St. Thomas. James and Sydney engaged in routines and traditions individually, with their families, and with the whole community. These are the rhythms that made up the "ordered life of the church" that Karen described; they pervaded worship, community events, and were reflected in the built environment of the faith community. These patterns of participation supported Sydney's and James's experiences in worship, leadership, and relationships in the church.

Healy (2009) touched on routines in his discussion of the experience of worshiping God with a community and argued for the religious value of this experience for people with IDD. Routines were supportive of worship for James and Sydney. James mentioned sitting in the same location in the worship space as part of his worship experience, and Sydney focused on liturgical objects and costumes that held meaning for her.

Routines were also part of Sydney and James's leadership. Sydney's role as crucifer, or head acolyte, was visible, honored, and also intricate. In the services that I observed, the crucifer led the church procession with a slow and steady gait, holding a large metal and wooden cross perfectly upright. During this service, the crucifer not only directed the two other acolytes, he or she also held the Bible for the reading of the gospel, played a part in the preparation and service of communion, and led the recessional. Being head acolyte involved using at least five different artifacts and at least four multi-step tasks. It was complex, difficult to master, and Sydney described doing it in great detail. Sydney also described the way that she learned to fulfill the role, first as the torchbearer, then as the acolyte, finally becoming the lead acolyte or crucifer. Sydney learned each aspect of the role, piece by piece, adding layer after layer to the role until she had mastered it. In addition to repetition, modeling, peer supports, and direct instruction, a major factor in Sydney's successful leadership was that the roles themselves were unchanging. Steeped in tradition, this job remained the same year after year. This is one of the strengths of faith community traditions. Sydney could practice this role over and over, progressing over time to learn each aspect of the role, until she was comfortable enough to lead, and to teach others.

Although James only mentioned his service as a lay reader, James's connection between worship and his job was a powerful commentary on the value he places on leaders in

his church and shows his close identity with them. James explained that worship leaders

followed a routine, just like he did at work. This was a powerful statement because in his

work life, routines helped James use peer and public transportation, helped him succeed at

work in a competitive employment site, they helped him develop and maintain important

personal relationships, and allowed him to explore his passions outside of work. Routines

have been supportive in James's full and active life. When James connected these routines to

his church experience, he indicated their value to him and the importance for his participation

at St. Thomas.

Finally, social relationships at St. Thomas were supported by these routines. One

place where this was especially clear is a ritual called the passing of the peace. During

worship, the leader asks people to stand and great one another. During this time in the

service, people get out of their seats, shake hands, embrace and engage in brief

conversations. James and Hugh described the place where they sat and the people that they

sat near, and how they shake hands at this designated time in the service, appreciating both

the familiarity of being around the same people each week, and the routine way that they

greet one another. Not only was this time a part of the service, it was also short and

predictable, with the end signaled by the playing of music. This predictable pattern of actions

and cues enhanced James's social engagement at St. Thomas.

Patterns of behavior also supported Sydney's social experience at the church. Sydney

described many of her social relationships with peers at the church as "really polite,"

stressing the routines of conversation that were also a part of church life. Although Sydney

wished that people at church shared more of her interests, these "church friends"

acknowledged her at church, in the community, and at school. They also helped her negotiate

difficult social changes like her transition to high school and shared advice about challenging

teachers. Being really polite and encouraging in supportive relationships with peers was

something that Sydney identified as a valuable resource for her transition to high school. As

her friends at church grow older, they are also a likely source of support as Sydney looks

forward to high school graduation and further education and employment. There is research

suggesting that faith communities are a source of natural supports for people with IDD. The

church may also be a source of friendships, of leadership development, and even in acquiring

employment (Gaventa, 2017). It may be that Sydney's "church friends" will continue to be a

support to her through many of life's transitions.

Another pattern of behavior for James and Sydney were the routines that were a part

of their family participation at the church. Liu et al. (2014) also found that family

relationships were a part of the faith expression for young people with IDD, representing an

important connection to the church and an essential factor in what young people value and

participate in. Hugh mentioned Karen's sermons in his initial interview as something his

family enjoys and takes pride in. James identified his favorite part of church as these same

sermons but only when his mom was preaching. From James's perspective, listening to

Karen's sermons was a part of his family life. James described a second part of their life

together as a family at the church that was an important aspect of belonging for James. After

worship, James loved going to the Coopersville Deli with his father and brothers. Connection

and participation at the church seemed to deepen his family connection and family identity.

One of the photographs that he chose to show as belonging at St. Thomas was a photograph

of himself and his family. The five of them are in the church, and his mother is dressed in her

robe for worship. James explained that this photograph showed that his family were members of the church and that because he was a part of his family, he was a part of the church, too.

Family routines were also important to Sydney. She talked about how much she liked serving her mom special gluten free wafers during communion and about how they both enjoyed volunteering at the community wide soup fundraiser held at the church. Sydney explained that she and her mom both like to help out, that contributing to the church and to the community is important to her and it is a part of who she is and who her mother is. Sydney explained that some of the volunteer work that she does at the church is done because her mom wants her to do it and that church is a thing that they do together. Bunning and Steel (2006) spoke about the value of participation to build a stronger religious identity for participants in their study. For Sydney and James, church participation seemed to support and strengthen their relationships and identity with their families.

For both of these participants, the routines surrounding church participation were valued and supportive. The value of functional routines has been long established in the fields of special education and disabilities studies. Techniques such as task analysis and chaining have been used for years to teach people with IDD complex behaviors (e.g., Ford et al., 1989). The supportive nature of routines in the faith community is not surprising in this context, and as Karen points out, it may be an untapped resource for churches looking to invite people with IDD into the communities.

When I asked Karen what resources for faith inclusion were missing, she said that she wished there were more explicit materials about the routines in church. She explained, "… the church is a very ordered world. Um, our liturgical calendar is ordered by seasons by colors by sounds, and um, and for a child on the autism spectrum, it's the perfect world for

them to enter into." She saw this as not only a resource for supporting people with IDD, but also as a way to invite people to participate in the community, "I think we're missing out um, on a way to to invite them into, um, into worship… Um, into the rhythm of being uh, part of the Christian calendar. It's huge."

Participating and Holding Valued Roles

The third factor that stands out in this study related to participation and belonging is leadership. Rather than focusing on adding formal supports to children and youth programming, hiring a disability specialist or consultant, or forming an inclusion committee, the leaders at St. Thomas identified leadership in worship as the focus for inclusion of people with IDD into the life of the community. They created, modified, and supported visible roles for people with IDD in worship, and the participants in my study felt invited and welcomed in these roles, and they felt comfortable filling these roles.

This somewhat novel approach to disability inclusion breaks with the more education driven models of inclusion of people with IDD in separated or modified religious education classes, activities, or respite programs. Although leadership was identified as important in several of the studies that I reviewed for this dissertation, it was not seen as a *strategy* for inclusion or described as a *source* of connection. Liu et al. (2012) described leadership as a one of many sources of faith expression. Their finding, especially focusing on the need for available leadership roles, was echoed in the faith and disability literature (e.g., Minton & Dodder, 2003; Healy, 2009). Worthington's (2016) work on faith community leadership spoke about the value of leadership in cultivating a sense of purpose and belonging in the faith community. Möller (2012) echoed this sentiment in her research, finding that access to a variety of leadership roles was an essential part of faith community engagement. In this case

study there was significant evidence that leadership fosters a sense of belonging for people with IDD in the faith community.

Contributing to the faith community created a feeling of belonging for participants in this study. Filling essential roles in the community was central to how participants in this study knew that they were a part of the church. Both of them brought in photographs of themselves leading in worship for the PhotoVoice interviews. Sydney brought in two of these, one as a reader and one helping in a special service. James brought in a photo of himself reading the Bible on a Sunday morning. When asked why he chose a photograph of himself reading the Bible as part of a worship service, James explained that it showed him leading worship. Both participants with IDD also described serving as lay readers in their initial in-depth interviews. When I was in worship, I saw the lay reader reading from the highly visible position of the lectern, their name was written in the bulletin, and there was a special time designated in the service to fulfill this role. Holding this role at St. Thomas gave Sydney and James the space to be seen, to be heard, and to be admired. Kim mentioned that when children with IDD in the church see older people with IDD holding leadership roles, they identify with them and see themselves as potential leaders, and Karen said that she always has at least one person with IDD as a member of the worship leadership.

Leadership engagement at St. Thomas went beyond getting necessary roles filled for the functioning of the organization. The church used leadership roles to engage people with IDD. These valued roles contributed to their relationships, their sense of mastery and to their feeling of belonging in the faith community.

Leadership at St. Thomas also gave Sydney a place to explore and develop her passions while giving her the developmentally appropriate independence that she needed,

with appropriate supports, to be successful. Sydney stated that her professional goal was to work with children, and the volunteer work that she did in Sunday school gave her practical experience in her field. In addition to workforce development, leadership also gave Sydney a chance to develop relationships with her peers. She described volunteering at the day camp and the way that it not only gave her a chance to spend time with peers, but also gave them a common experience to talk about and connect over. Finally, leadership at St. Thomas was an expression of Sydney's faith. When Sydney took on the informal role of tidying up the acolyte's closet, I saw that the rhythm of leadership was not only as a support, but also a part of her expression, part of what she valued, enacted and contributed to her community.

Limitations

This descriptive case study described the experiences of two people with IDD within one faith community. Because of this design, it is important to acknowledge that there are limitations, and that although the findings may be very helpful to other faith communities, there are also particular characteristics of this community that may make these findings less transferable. I chose to do this study at St. Thomas because of the work that they did to be inclusive and the success of their efforts as evidenced by their demographics. Although I think that this case needed to be bound within one community (Yin, 2014), having only two participants with IDD in this study was a limitation. In future research, I would design this project with options for a lower commitment for participation to encourage a larger number of participants. When I spoke to potential participants, parents had concerns about the potential stress it might cause their children. I wish that I had used a tool, like a survey, to be distributed to more people with IDD in the community as a less time-intensive way to

capture information. In future research, I might develop protocols so that participants could opt into a survey, PhotoVoice, or in-depth interviews as a cascade of options.

In addition to designing the study with more options for participation, I see my own lack of experience as a significant limitation in this study. When speaking with prospective participants, I struggled to describe research activities in detail, to explain the enactment of protocols or the availability of modifications because although I had piloted my questions, reviewed them and read other research, I had not yet done these activities. In future research, I will have a greater depth of understanding and perhaps less anxiety when describing these activities which may be reassuring to potential participants.

The limited sample of people with IDD means that the voices of younger children with IDD and their families were not included in the study. I was not able to sample at least two participants in each age range or to over-sample with teenagers as originally planned. This means I was not able to really compare experiences and that the view of the experiences that I was able to include was limited.

Another limitation of this study was the over-representation of the voice of leadership in the study. Not only did I interview three church leaders, but both of the participants with IDD were children of participant leaders. It would have been more helpful to interview Jennifer in her role as a parent in the in-depth interview, instead of interviewing her as a faith community leader. Additionally, the voice of Karen, the senior priest at St. Thomas, was dominant in this community. Clearly Karen's work for inclusion should be applauded, but in the design of this study, I wish that I had thought through better how to have her voice be a smaller part of the study. As I noted in the literature review, there are few studies in faith and disability research that include the voices of people with IDD as participants. Through

conducting this research, I saw how precious, and even fragile these words are. As I outlined

in the analysis section, although I worked hard to keep the voices of participants with IDD

primary in the analysis, in the research question, and in the data collection process, it was

challenging to balance the voice of Karen with the other participant voices. She is someone

whose profession and training made her an effective speaker, so it was at times difficult to

include her voice without allowing it to overpower the voices of the two participants with

IDD. As I completed the analysis and wrote up this project, I often had to shorten or divide

quotes from Karen to keep them under the APA guideline of 40 words, but I never had to

shorten quotes from James. In conducting research with faith communities, researchers

should carefully consider how to highlight the voices of people with disabilities in their

research and how to keep them from being overpowered by the voices of professional clergy.

Further, there were limitations with the site of this case study. The first limitation was

the nearly exclusive focus on ASD in the church. This community has a large number of

members on the autism spectrum and very few with other intellectual or other developmental

disabilities. The church identified that of the 18 people in their community with IDD, 15 of

them had ASD and three had other intellectual or developmental disabilities.

Other demographics of this congregation also make it very difficult to compare to

other faith communities. It was both very white and very wealthy. Although the state where

this research was completed is considered a diverse state with a diversity index 5% higher

than the national average (Patenko, 2018) and a high percentage of the population of the state

identifying as Black or African American (17%), the community where this church is located

identified as 79% White, 9% Hispanic, 9% Asian, and 3% mixed race. St. Thomas matched

the community fairly closely, except it had no identified Hispanic members, so the White

population of the church was closer to 88%. One hundred percent of my sample identified as white. In addition to its lack of diversity, the wealth of the community sets St. Thomas apart from other communities. In this suburban community outside of a major metropolitan area, the median housing value in the community was close to $750,000; St. Thomas thus represents a very wealthy congregation compared to the rest of the country.

Implications of the Study

The implications arising from this study focus around roles that people with IDD in faith communities hold, relationships for people with IDD in faith communities, rhythms that support belonging, actions that faith communities can take to promote inclusion, and beliefs of clergy and other leaders in the faith community. In this section, I will look implications for practice and for research.

Looking Beyond the Inclusion Team: The Value of Congregational Education

A common recommendation in the literature for churches seeking to be more inclusive is to develop a disability inclusion team or point person to address support needs in the congregation (e.g., Dennis & Murdoch, 2001). This study highlighted the need for congregational education in support of disability inclusion, theology of disability, and finally preaching that includes the positive portrayal of disability in both practical and theological applications. St. Thomas's initial work was to help the congregation envision God as having a disabled body. According to their senior pastor, until they were able to do that, they were unable to be inclusive. Once this occurred, St. Thomas was able to deliver supports to people with IDD in such a way that they were not visible to them or to their family members. The initial education on disability and inclusion created a common or shared understanding that people with IDD would be accommodated and successful at St. Thomas. Other churches

seeking to be more inclusive should consider this model and consider implementing a similar

educational series on faith and disability delivered through preaching and religious education

for members of all ages as a first step in actively including people of diverse abilities.

Supports in Religious Education Settings

In this study, the needs of volunteer educators supporting children with disabilities in

faith community settings were not brought up directly. Perhaps this was because the

participants with IDD had aged out of Sunday School where many volunteer educators work,

or because Jennifer, the staff religious educator was able to deliver supports to young

children with IDD without effort, but this should not take away from the real challenges

faced by volunteer educators whose work is critical to create inclusion and belonging for

individuals with IDD. There is a need for easy-to-use support materials and specialized

training in inclusive strategies for volunteer educators in faith community settings. In order to

be inclusive, faith communities must address the need for parent respite (Griffin et al., 2012),

for example. Training for volunteers who assist in that type of activity is crucial for it to be

successful (e.g., for families to feel comfortable leaving their children with volunteers).

Many religious education publishers are including some curricular supports for inclusion

with their curriculum. Matan, Friendship, and Congregational Ministries Publishing are three

examples that I mentioned in the first chapter of this dissertation, but more widely available

curricular supports are needed. Limited volunteer time is a critical issue that affects

volunteer's capacity for sustained participation. Fatih communities need to adopt strategies to

maximize the quality of any training that is provided, as well as recruiting sufficient numbers

of volunteers so that no one person or group is asked to do more than they are able.

This study's findings did include supports and modification for the confirmation process that focused on flexibility in the process, environment and product for learners. This study would suggest the value and strength of focusing on rhythms and routines for children in religious education and other aspects of faith community life, and the importance of creating and supporting valued roles that people with IDD hold in these settings, and the need for broad education around disability in the religious education setting which could include the development of supportive peer relationships.

Leadership as Belonging: Supporting Leadership

Holding respected, public roles in the church was essential to belonging for Sydney and for James. People advocating for belonging in faith community life should look to St. Thomas's model of providing a wide range of formal and informal roles for people with IDD to serve the church. It is important to note that people with IDD were supported in these roles with direct instruction, peer mentors, routines, and repeated practice. People with IDD felt invited and encouraged to participate. In addition to supporting these roles and opportunities, it is notable that the participants in this study were comfortable with the roles, both in their levels of preparation, and for Sydney especially, the acceptance of the congregation in making mistakes. In addition to the six formal roles outlined in this case study (please see Table 10), many communities of faith also include people with IDD as choirs members, musicians, teachers and teaching assistants, group facilitators, greeters, in the kitchen, and helping with the physical plant of the church (i.e., landscape, room set-up, maintenance).

Explicit Routines

Support providers, families, and teachers are already familiar with the value of routines in supporting individuals with IDD. Using these same strategies in faith

communities is a clear implication from this research for practice. For faith communities and

disability professionals leveraging the routines and traditions of the faith community to

support the participation of individuals with IDD in faith community settings should be a

point of conversation. Looking at the routines in the faith community as a strength, this

investigation warrants the development of broadly applicable and site-specific supports such

as visual aids and schedules, explicit social skills supports and curricula, and communication

support. Supports like visual guides to the metastructures of worship would assist worshipers

with and without disabilities and enhance their inclusion. Not only would this encourage

participation, but it would allow for explicit instruction and skills development in areas of

communication, social skills, and leadership, to name a few skill areas. Guides to the

routines and traditions in worship would play to the strength of the existing rhythms in faith

communities, and allow greater access to participation in the community to facilitate a

feeling of belonging for people with IDD. These supports should be included in curriculum

guides, they should be widely available by publishing houses for communities to purchase

and make available in worship settings. They could also be developed by volunteers or

program staff on site as a support for individuals in the congregation.

Continuity

Research and experience show that in educational settings, inclusive classrooms often

stop functioning after a teacher leaves because of a lack of systemic supports for including

students with disabilities. In the archival research in this faith community I found weekly

emails and annual reports that described expenditures, programs and activities that the church

enacted to promote inclusion. I did not find memos, policies, program guides, stated

modifications or routines, or other explicit statements to support disability inclusion in this

faith community in the long term (i.e., should one or more of the highly expert staff leave the community). One important implication in this study is the development of systemic supports for the participation of individuals with IDD at a church or denomination level that will sustain inclusion at beyond the passion of one faith leader, such as Karen at St. Thomas. At St. Thomas, Karen's vision for disability inclusion seemed to be the driving force in much of their work for inclusion. It is imperative for disability inclusion work to be sustainable in faith communities beyond the tenure of a single pastor or other key community leader. The development of routines and structure to promote disability inclusion is an important next step in research, advocacy, and practice.

Value of Family

Although much of the literature focused on people in congregate care settings (e.g., McNair & Smith, 2000; Minton & Dodder, 2003), participants in this study identified strongly with the routines of their family and the value of family participation in their faith community. For individuals with IDD, faith community participation may be a valuable support in strengthening bonds with their families, may be a source of identity with a tradition or group, and may be a place to participate in routines and traditions that strengthen bond beyond the family. The role of faith community participation and family connection warrants further study.

Relationships are Hard

One of the surprising things about the findings around church relationships in this study was the level of engagement described by participants and their families. People described what Hugh called, "Facebook friends" and what Sydney called "church friends." These were valued social relationships that centered around activities at the church but did

not extend outside of the church to include a meal or an outing together. Church and community practitioners seeking to strengthen relationships in their church should learn from this study that even in an intentionally inclusive faith community, with seven years of work and an articulated commitment to disability inclusion, that social relationships with people with IDD that extend outside of the faith community and into the larger community were rare. St. Thomas's recent work to improve social relationships through its "We are Friends" program may be a promising answer to this issue, but more work needs to be done to uncover ways to foster and support both these formulaic social relationships within the faith community and relationships based on shared interests and experiences that may extend beyond the faith community.

Recommendations for Further Research

My recommendations for further research center around the ways that empirical researchers in the field of faith and disability can work to consistently include the voices of people with disabilities. Tools in this study like PhotoVoice and family interviews can be used as a support in research with people with IDD and also may be helpful to researchers. In addition to these expanded methods, I recommend that as empirical researchers in the field of faith and disability that we begin to look at research questions that serve to increase access and remove barriers to participation and move away from research questions that narrowly focus on the value or importance of religious participation for this population.

Much of the empirical research in faith and disability has been done with parents, educators and clergy, with only 14 articles including participants with IDD. With a clearly articulated mandate from Nancy Eiesland (1994), Gutiérrez (1973/1988), and Freire (1970/2003), research about people with developmental disabilities should be done with

people with developmental disabilities. This study shows a way to focus on the voices of people with IDD while also understanding the context of the community and the work of leadership. By prioritizing their voices, I believe that this study has provided a disability-centered perspective on the questions of faith and disability. Focusing on people with disabilities as experts in faith and disability is an important step in this emerging field.

A second implication of this study was the value of using PhotoVoice as a tool for interviewing people with IDD. I found that the PhotoVoice data not only triangulated data from the in-depth individual and parent interviews but also allowed me to gain a concrete description of abstract concepts. In the PhotoVoice interviews, participants were able to show, explain and label photographs as a way to articulate the abstract concept of belonging. In addition to its effectiveness in expressing difficult concepts, participants with IDD in my study seemed to enjoy the PhotoVoice interview even more than the in-depth interviews. For one, and they were much shorter. For people with IDD who may be reluctant to participate in research projects that feel like other evaluations that they need to do, PhotoVoice may offer an alternative, effective way of obtaining qualitative data. In addition, PhotoVoice engages participants in the initial analysis of their own data (Catalani & Minkler, 2012), making participants even more invested and central to the research as co-constructors.

Another promising implication was the use of family interviews as a means of supporting interviews with people with IDD. It is essential that more research on the experiences of people with IDD is done with people with IDD. This simple technique of including parent interviews allowed for the full participation of people with IDD in the study and served both to clarify and support their responses. As evidenced in this study, it is possible to develop interview protocols that allow family members to provide missing

information or to add to the data from participants with IDD without making the focus of the study the experiences of people without IDD.

Much of the empirical research on faith and disability has been in White Christian churches. This represents a very limited view of the experience of inclusion in our country's faith communities. It is imperative that more research be done in faith communities of color and faith communities that represent a tradition other than Christianity. In future research, some of the techniques in this study may be helpful, but it is essential to recruit endemic researchers and research partners for future research in faith and disability.

Finally, most of the literature in faith and disability focused on the experience or value of faith for people with disabilities. Shogren and Rye (2005) found that people with IDD have the same range of experiences of faith as the general population; these range from strong belief to no belief. This finding supports what we know about disability, namely that people with disabilities have the same wants and needs, the same desire for learning, relationships, meaning and growth. As a field, I hope that faith and disability research can move beyond questions of *if* people with IDD have faith or faith experiences that are valuable or important. In 2005, Shogren and Rye found that people with IDD have the same measures of intrinsic religiosity as the general population, meaning that people with IDD are just as likely as the general population to have a strong disbelief, strong belief, or be somewhere in between. Although the answer to these questions needs to continue to drive advocacy, policy change, curriculum development, program development, clergy training, and more because access is still limited, it is my sincere hope that we can move away from asking *if* people have faith, or *if* their beliefs are to be valued, and move toward questions of

how to support the important and valuable faith experiences of people with IDD who would like to have them.

Conclusion

Faith communities are a source of community engagement with strong natural supports for healthy outcomes for members of all abilities including greater civic involvement and increased interpersonal trust (Cox & Thompson-DeVeaux, 2019). For people with IDD, the value of faith community participation is no less important (Shogren & Rye, 2005) and may have positive impact on competitive employment (Gaventa et al., 2014), important connections to identity (Bunning & Steel, 2006), social opportunities, and benefits for the faith community including a deeper experience of hospitality (Reynolds, 2008), self-acceptance, fulfillment, and growth. However, faith communities currently provide uneven supports, and have an uneven success welcoming people with IDD (King, 1998; Möller, 2012). I developed this case study to look at the experiences of people with IDD in one congregation working to provide these supports across the lifespan, across activities, working to be an inclusive congregation.

I am deeply grateful to Sydney and James for sharing their experiences with me, and I believe that their stories may be a model for people with IDD seeking to have their faith valued and their voices heard in a faith community. I hope that this study acknowledges and celebrates their strengths and the authenticity of their faith and that it gives voice to their strengths and gifts for leadership. At the beginning of this paper, I recounted the participation gap that persists for people with IDD participating in communities of faith. I hope that Sydney and James's experiences have provided an example of what belonging in a faith community looks like.

For individuals and faith communities seeking to be more inclusive, this study provides a model for inclusive practice. In this qualitative study, I have looked in depth at one intentionally inclusive Christian faith community from the point of view of people with intellectual and developmental disabilities. This case study has found that participation and belonging hinge around the application of seamless supports to provide access to meaningful and respected roles in the community. At the center of this reciprocal engagement are relationships built on a congregation-wide approach to education and training in disability inclusion and a belief in the value and intentionality of people with disabilities being created in God's image. The focus of this community on broad theological and practical education as the first step in faith inclusion needs to be emphasized, as well as the powerful result of lay people providing natural supports to people with IDD in their community such that these people are no longer aware of them. Finally, congregations seeking to be more inclusive of people with IDD should look to St. Thomas's commitment to developing and supporting formal and informal roles for people with IDD. Sydney made it clear that she didn't come to church to just sit in the pew. Service to the community was central to her participation and her sense of belonging. Faith communities seeking to be inclusive need to develop and support opportunities for people with IDD to participate in and contribute to their community.

For faith community leaders and theologians, I hope that this study encourages scholars to reconsider the work of Nancy Eiesland and the call from God to include the full diversity of humanity in our understanding of scripture. Eiesland's work called for a reading of scripture in conversation with people with disabilities. I would encourage these scholars to consider the value of engaging conversation partners with disabilities in theological

scholarship and application. Consider the value of techniques like in-depth interview and PhotoVoice in understanding difficult and abstract concepts, and consider the fullness that we all may experience when the voices of people with disabilities are included as leaders in our faith communities. Disability studies provides many ways for scholars to engage with people with IDD as co-creators of research and theological application (i.e., sermons). I urge both the practical theologians in every house of worship and those in academia to consider employing similar techniques so that disability theology can avoid the pitfalls of marginalization. For pastors and other leaders looking to write inclusive theology or sermons, enlisting critical friends and partners with disabilities is an essential step in addressing faith and disability.

For empirical researchers, I hope that this study provides both practical support in methods for conducting research in faith communities with people with IDD as participants. For this field to move forward, it is essential that these voices are heard and regarded as the most expert in the field. Recommendations for further research focus on the primary need to include the voices of people with IDD as participants. For too long, others have been asked to speak on behalf of people with disabilities. Whether these others are doctors, clergy, or parents, these voices crowd out the essential, powerful, and authentic voices of the most expert people in the field of faith and disability, namely those with disabilities. We have seen too many instances to count of people in power using people with less power to push agendas, both theological and personal. It is necessary to instead privilege the voices of people with disabilities in this conversation. The field of faith and disability has spent too much time and energy celebrating the vulnerability of people with disabilities and too long discounting their strengths, leadership, and voice. If we are to guide and impact practice, it is

important that as this field develops, that we develop it with people with disabilities at the center. For too many years researchers have acted to reinforce the status quo in our society, further marginalizing people of color and the poor. In this emerging field, we have the chance to acknowledge people with disabilities as the center of their own experiences. Let us work together to develop and refine research practices that do that. My strong recommendation for further research is that the field would embrace the call to a disability-centered approach and take seriously the need to collaborate with self-advocates with disabilities. Faith and disability research should be focused on the perspective with people with disabilities. These voices need to be included as participants, presenters and partners in this field. Tools in this study like PhotoVoice and family interviews can be used as a support in research with people with IDD and may be helpful to researchers. Finally, in this emergent field, we need to both acknowledge the work that has been done and to see the need to move beyond looking at the value of religious expression to people with IDD and into the ways that we can support that experience.

The IDEA (2004) states that disability is a natural part of the human experience and in no way diminishes the right of individuals to participate in or contribute to society (2004, §1400.C.10). Faith communities represent one sector of society. Participation in these communities is important to many people, including people with disabilities, but a participation gap between people with and without disabilities persists (Carter, 2015b), people with disabilities are experiencing a diminished experience to participate in and contribute to this sector of society.

This diminished experience of participation does not need to persist. According to my research, faith communities can be a place for people with IDD to connect, to engage, and to

explore their passions. Faith communities are well positioned to support people with disabilities. At St. Thomas, the congregation as a whole received training and education to build their capacity for inclusion and the delivery of supports to people with IDD. People with IDD described their connection to the church, the ways that they contributed to it, and the relationships that they had with family and friends through the church. To become an inclusive congregation, St. Thomas relied on their strengths: the rhythms and routines of community life that make them predictable and safe for people with IDD, many volunteers who are ready to provide natural supports, and theological beliefs in common that support inclusion of people with disabilities. For communities seeking substantive change to a more inclusive culture, the value of a congregational approach, with congregational education in disability awareness and theology along with practical education and modeling in supports may produces a firm basis for increased capacity for the seamless delivery of supports to encourage authentic participation and belonging of people with IDD in the community. As communities develop increased capacity, they may be more capable of supporting a variety of roles for people with IDD in the faith community that allow them to explore and use their talents and passions while contributing to the function and joy of the faith community.

Our constitution guarantees the rights of all citizens to practice their faith. It is long overdue that people with disabilities also have this right. As our country looks forward to its 250th anniversary, and acknowledges and examines its history of religious freedom, it is time to seriously examine the systemic causes for the participation gap in faith communities for people with IDD. It is time for faith community leaders, disability rights advocates, educators, theologians, families and people with IDD to create a communities and systems of

support people of faith from all abilities are welcome to participate, where they can

contribute and where they belong.

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Appendices

Appendix A

Recruitment Flyer

Volunteer for a Research Study

Disability and Belonging in an Inclusive Church

We are looking for volunteers to help us find out what it's like for people with disabilities to be a part of a church that is working to be inclusive.

You may be eligible to participate if you…

- Are a member or regular attender here.
- Over the age of 9.
- Have an intellectual or developmental disability or
- Are the family member of a person with an intellectual or developmental disability

Your participation in this study will help researchers and church leaders learn how to be more inclusive of people with disabilities.

For more information, contact Deborah Huggins at:
(505) 873-3202
huggins1013@gmail.com

Participation includes two interviews that will take approximately 1.5 hours all together.

Deborah (1505)873-3202 Huggins1013@gmail.com

Appendix B

Demographic Questionnaire

Demographic information helps to compare findings between different studies, to apply research in different settings, and to guide future research. Information from this questionnaire will only be reported as a group (aggregate data), and precautions will be made to ensure the privacy of this information. Your name or other identifying information will not be collected with this questionnaire. This paper copy will be kept in a locked cabinet. If you provided an electronic copy it will be kept in a password-protected file.

Please answer the following questions as they pertain to you.

1) Gender: (Please circle one)

Female   Male   Other

2) Age: _____

3) Are you a member of a regular attender at St. Paul's? (Please circle one)

Yes   No

4) Please circle one or more of the following to indicate your primary ethnic identity:

American Indian or Alaska Native   Asian

Black or African American   Native Hawaiian or Pacific Islander

White

5) Describe your disability status: (Please circle one)

I have a disability. Please indicate disability label: _____

My family member has a disability. Disability label: _____

None of these categories describe me.

Appendix C

Field Note Template

Field Notes Template	
Codes	
Observer	
People	
Place	
Time	
Duration	
Event	
Planned Agenda	
Overview	Field Note Illustrates: Key Concepts: Sequence of Events:
Setting	
Atmosphere	
Raw Notes	
Pictures Y/N	
Video Y/N	
Audio Y/N	
Extras Y/N	
Memo	

Appendix D

Julia Scherba de Valenzuela's UNM Special Education Transcription Protocol

Transcription Key

- Type in the real names of the participants for the first draft. We will change them to pseudonyms after you transcribe the whole tape.

- Type EXACTLY what you hear. For example, if someone says "gonna" (not going to), type gonna. Same with *talkin'*, *doin'*, *y'know*, etc. Don't clean up the grammar or pronunciation. Spell and type everything exactly as you hear it.

- If you don't understand what someone says, listen to it a couple of times, the back up a bit and play it through (sometimes that helps) and then, if you still can't understand it, put XX, to indicate an unintelligible utterance.

- When one person talks, keep typing in the same paragraph. Don't hit the paragraph return until a new person starts talking.

- Don't use punctuation like you would when you write. When transcribing, punctuation has very specific meanings. For example:

  - Put a period at the end of a phrase that <u>sounds like</u> someone is ending a sentence, when their voice goes down at the end of a sentence.

  - Put a question mark at the end of a sentence which <u>sounds like</u> a question, when their voice goes up at the end of the sentence. It doesn't matter whether it is a question, grammatically. And, if a question doesn't sound like one, where someone's voice doesn't go up at the end of the sentence, don't put a question mark.

  - Use a comma to indicate a pause. Don't use it just because it is grammatically a phrase. There has to be a real pause there.

  - Use a dash to indicate when a word is broken off. For example, "w- what" would indicate that someone started to say what but only started it, but then said it again.

  - Don't use dots (...) to indicate that someone trailed off. I will need to use that later to indicate that I deleted part of a quote. Instead, if there is a pause, use a comma.

  - If two people talked on top of each other, put a square bracket ([) at the beginning of when the overlap occurs for the person who is talking and then, put the end bracket (]) at where the overlap starts. You will then do a paragraph return and type in what the second person said who was talking over the first person. That will also be in square brackets. Look at the example below to see how that works.

  - If someone is talking along and doesn't stop their flow of conversation but someone else interjects, then you use the = sign to link two parts of the transcript. This tells us that the first person didn't have a break in the conversation, but lets

you also indicate where the second person was talking interjecting without overlapping.

- Use double parentheses to indicate a description that you are including. For example, is someone laughs or pounds the table, or snaps their fingers, you would include it as ((laughing))   ((pounds table)) ((snaps fingers)) ((claps hands))

- Use a colon to indicate where a sound is prolonged more than usual.

- Use all caps when someone uses a HUGE emphasis on a word.

- If there's a break in the recording, like when the tape is turned over, use double slashes to indicate that. (see below)

Example One

Barb: ((laughing)) XX

Julia: Yeah people used to say that they a::, thought I was a::, talkative, 'till they met my family

Barb: Oh really. XX

Julia: Okay well hopefully this will re- yeah I think its recording, yeah

Barb: We can play it back in a second and see if it's

Julia: Yeah, well, it's pickin' up. The little monitor's going

Barb: Okay [XX]

Julia: [Okay, thanks] this: makes it a lot easier for me to transcribe if I'm not taping questions, uhm do you want to see a copy of the questions I'm gonna ask?

Barb: Yeah yeah

Julia: It makes it easier to follow along.

Barb: [okay]

Julia: [This is] very open ended and we'll just, go though 'em, and, ((chuckles)) and, if it's okay with you I'd like to interview you:, two more times and then come back to you at the end. for some. member check.

Barb: M'kay

Julia: So, to see if any of your, ideas about this change, through the whole process like the thirs time-, the third time I'll interview you would be a:fter, the external reviewers co:me

Barb: Oh okay

Julia: So.

Barb: And- the purpose to interview us? Why are you interviewing us?

Example Two

Julia: ((microphone noise)) I'm gonna move this closer to you so XX don't get a lot of uhm, fan ((noise in background))

Beth: Okay. That's not gonna hurt the, computer. Bill dropped something on it yesterday. ((laughing))

Julia: Okay, and you said were, both enlightened and confused. Can you tell me a little more about that?

Beth: Uhm, it seemed to me that THIS particular OGS review

Example Three

Julia: Okay. Today is, September 19th I believe? Is that right?

Chris: Uh huh.

Julia: September 19th and I'm interviewing Christine Mitchell for the second round of questions,=

Chris: M'kay.

Julia: =uhm, prior to the OGS visit. Which will happen next week. WELL, [Dr. Mitchell=]

Chris: [((laugh))]

Julia: =what do you see as the purpose of this OGS review.

Example Four

Julia: Yeah. So you know a part of me- you know today ((inaudible sentences for about 45 seconds)

//

         ((end of side 1 of tape))

//

Julia: So- so it's just kind of uhm, to bring out uhm, what kind of data do we want to

Appendix E

Semi- Structured Interview Questions for Children with IDD, Semi- Structured Interview Questions for Adults and Adolescents with IDD, Semi- Structured Interview Questions for Family Members of People with IDD

Semi-Structured Interview Questions for Children with IDD

Introduction

Introduce the research and establish rapport

- Welcome and attend to issues of comfort.

- Explain the research (briefly and give an overview of the interview expectations

    o Time required

    o Kinds of questions: I'm going to ask you to describe the different things that you do at (faith community name). Starting with worship, and then talking about different things that you do. When we talk about the different programs and activities that you do, I am hoping that you will describe them as if I have never seen them or done them- with lots of details.

- Preliminaries

    o Ethical Considerations- Just to remind you, you do not have to answer any question if you do not want to and we can take a break or stop at any time.

    o Go over interviewing equipment and procedures

    o Do you have any questions before we get started?

- Probing

    o Before we get started talking about (faith community name) please tell me about what you do when someone comes to your home to visit.

Main Questions for People with more Intensive Needs for Support and Children

These are examples of the kinds of questions that I will use in the interview- since this is a semi-structured interview, I may omit some of these questions, or use probes to explore a question further.

Introductory questions (Specific questions to activate prior knowledge):

- How old were you when you started coming to (faith community name)?

- Who brings you to (faith community name)? Who comes with you?

    o Mode of transportation

    o Companions

- What route do you take through the building?

    o Which door do you go in?

    o Stairs and passageways

Grand Tour Question: Worship

- We are going to talk about sitting in the sanctuary at (faith community name)- being in church. We will concentrate on three different parts of Sunday worship: Coming in, worshiping, and leaving. Please pretend that I've never been in your church, or seen your church, and give me as much detail as you can. Please tell me what you do at (faith community name) on Sunday morning when you come into worship.

    o Follow up Questions: Arriving

        ▪ Does anyone meet you when you come into church (the sanctuary)? What do they say or do?

        ▪ Please describe what people say or do to make you feel welcome.

        ▪ Where do you sit?

- Who do you sit with or near?

- Next, please describe what happens in church (worship)? Go through each part of worship step by step, giving me as much detail as you can remember. I have a copy of the bulletin from last week if you would like to look at it.

    o Follow up Questions: Worship

        ▪ Who are the leaders in church (worship) (who is in charge during worship)?

        ▪ Who else is there?

        ▪ How does church (worship) make you feel?

        ▪ What is your favorite part of worship?

        ▪ What is your least favorite part of worship?

        ▪ What do people say or do that let you know that you are welcome or that you belong?

- Next please describe how worship finishes and what you do afterward. Please describe it in lots of detail.

    o Follow up Questions: Leaving

        ▪ When church is over, how do you leave? Which door do you use?

        ▪ Which door?

        ▪ Who do you leave with?

        ▪ Where do you go?

        ▪ What do people say or do that makes you feel welcome at (name of faith community)?

Thank you, that was great. Now I am going to ask you about two other parts of worship: leadership and friendship.

Mini Tour Question One: Leadership in Worship

    Introductory questions (Specific questions to activate prior knowledge):

- Now I'm going to ask you some questions about leaders in the worship service. You mentioned that ____, ____, and _____ are leaders in worship. What are other jobs in the worship service- including small jobs in church (worship)?

    o Music

    o Helpers

    o Speakers

    o Sound/lighting

- Do people like you have roles in worship?

    o What do they do?

    o How do you think they got to do that job (role)?

        ▪ Age

        ▪ Gender

        ▪ Rite of the church

        ▪ Express interest

        ▪ Personal connection

        ▪ Be noticed

        ▪ Religious education

        ▪ Practice or contest

    o Have you ever had a leadership role in worship?

- What did you do?

- How long have you done it? Or how many times have you done it?

Mini-Tour Question: Please you describe (your experience of leadership in worship) for me as if I've never seen or done anything like this before?

- o Follow up Questions: Leadership in Worship

    - Where does this happen?

    - Why is it important?

    - Are there any important object or things associated with this?

        - What are they?

        - Please describe them to me in detail.

    - How do you know your part?

    - Does it ever change?

    - Who else is doing this with you?

    - How did you learn to do it?

    - What are the feelings that you have associated with this part?

- o Have you had other leadership roles in worship? (I will repeat this mini tour question up to three times).

Thank you so much. Now I'm going to ask you some questions about your friends in church. These could be people that you know really well, or people that you only know a little bit.

Mini Tour Question One: Friends in Worship

Introductory questions (Specific questions to activate prior knowledge):

- You mentioned that ____, ____, and _____ as people who sit near you, or people that you know. Does anyone else sit near you?

- Do you have any other friends in worship?

Mini-Tour Question: Please describe your friends from worship. Please be as specific as possible about who they are and what you do together.

      o Follow up questions: Do they talk to you? Do you do things together?

          ▪ What do you talk about? What do you do?

          ▪ How long?

          ▪ How often?

          ▪ Do you talk/do things outside of worship?

Thank you so much for answering my questions about worship. Now I am going to ask you some questions about other things that you do at (faith community name).

Other Activities or Programs in the Church

I will repeat the Grand Tour and Mini-tour format for activities or programs up to three addressing large group activities other than worship, religious education focused small group activity, fellowship or social small group activity, or service activity (small or large group).

Questions to identify Programs or Activities:

- Earlier, you mentioned ___, ____, and ____ as things that you do at ____. Are there other activities that you do here? Either every week or just around holidays? Or certain times of the year?

      o Movie nights

      o Confirmation

      o Vacation Bible School (VBS)

      o Choir

      o Prayer Shawls

- o Family Promise

- o Interfaith Food Pantry

- o North Porch

- o Autism Speaks

- o Jinny's Rainbow Comfort Quilts

- o Coffee Hour

- o First Sunday Brunches

- o Homework Club

- Of all of those activities that you have done- what are the three that you are most a part of?

- Repeat Grand Tour and Mini Tour questions for up to three programs.

Conclusion

Thank you for telling me about (faith community name) and the things that you do there. Before we finish I wanted to know if you have any questions for me?

Thank you very much. Would you like a copy of my dissertation when it's finished?

In the meantime, I would like to schedule a time to go over the pictures that you are going to be taking for my research. When we meet again, I will have a few questions about our interview today and then we will talk about the pictures that you are going to take. Will one of these times work for you? _____, _____, _____?

PhotoVoice Training Protocol.

Semi- Structured Interview Questions People with IDD (Adults and Adolescents)

Introduction

Introduce the research and establish rapport

- Welcome and attend to issues of comfort.

- Explain the research (briefly and give an overview of the interview expectations

    o Time requirement

    o Kinds of questions

        ▪ I'm going to ask you to describe the different things that you do here at

        (Faith Community). Starting with worship, and then talking about

        different things that you do here. When we talk about the different

        programs and activities that you do, I am hoping that you will describe

        them as if I have never seen them or done them- with lots of details.

- Preliminaries

    o Ethical Considerations- Just to remind you, you do not have to answer any

    question if you do not want to and we can take a break or stop at any time.

    o Go over interviewing equipment and procedures

    o Do you have any questions before we get started?

- Probing

    o Before we get started talking about (faith community name) please describe

    how you welcome someone to your home.

Main Questions for People with IDD (Adolescents and Adults)

These are examples of the kinds of questions that I will use in the interview- since this is a semi-structured interview, I may omit some of these questions, or use probes to explore a question further.

Introductory questions (Specific questions to activate prior knowledge):

- How many years have you been coming to (faith community name)?

- How do you get to (faith community name)?

    o Mode of transportation

    o Companions

- What route do you take through the building?

    o Which door do you go in?

    o Stairs and passageways

Grand Tour Question: Worship

- Please describe what you do on a typical Sunday morning when you come to church? Pretend that I've never been in your church, or any church before and describe it in detail.

    o Follow up questions:

    o Follow up Questions: Arriving

        ▪ Does anyone meet you? What do they say or do?

        ▪ Please describe what people say or do to welcome you.

        ▪ Where do you sit?

            • Who do you sit near?

    o Follow up Questions: Worship

        ▪ Who are the leaders in worship?

        ▪ Who else is there?

        ▪ How does worship make you feel?

        ▪ What is your favorite part of worship?

        ▪ What is your least favorite part of worship?

- What do people say or do that let you know that you are welcome or that you belong?

  o Follow up Questions: Leaving

  - How do you leave the worship space?

  - Which door?

  - Who do you leave with?

  - Where do you go?

  - What do people say or do that lets you know that you were part of worship with them?

Thank you, that was great. Now I am going to ask you about two other parts of worship: leadership and friendship.

Mini Tour Question One: Leadership in Worship

   Introductory questions (Specific questions to activate prior knowledge):

- Now I'm going to ask you some questions about leaders in the worship service. You mentioned that ____, ____, and _____ are leaders in worship. What are other jobs in the worship service- including small jobs in worship?

- Do people like you have roles in worship?

  o How are they like you?

  o What do they do?

  o Was there something that needed to happen before they could do that role?

  - Age

  - Gender

  - Rite of the church

- Express interest

- Personal connection

- Be noticed

- Religious education

- Practice or contest

- o Have you ever had a leadership role in worship?

    - What did you do?

    - How long have you done it? Or how many times have you done it?

Mini-Tour Question: Please you describe (your experience of leadership in worship) for me as if I've never seen or done anything like this before?

- o Follow up Questions: Leadership in Worship

    - Where does this happen?

    - Why is it important?

    - Are there any important object or things associated with this?

        - What are they?

        - Please describe them to me in detail.

    - How do you know your part?

    - Does it ever change?

    - Who else is doing this with you?

    - How did you learn to do it?

    - What are the feelings that you have associated with this part?

- o Have you had other leadership roles in worship? (I will repeat this mini tour question up to three times).

Thank you so much. Now I'm going to ask you some questions about your friends in church. These could be people that you know really well, or people that you only know a little bit.

Mini Tour Question One: Friends in Worship

    Introductory questions (Specific questions to activate prior knowledge):

-   You mentioned that ____, ____, and _____ as people who sit near you, or people that you know. Does anyone else sit near you?

-   Do you have any other friends in worship?

    Mini-Tour Question: Please describe your friends from worship. Please be as specific as possible about who they are and what you do together.

        o Follow up questions: Do they talk to you or do you do things together?

            ▪ What do you talk about? Or what do you do?

            ▪ How long?

            ▪ How often?

            ▪ Do you talk/ do things outside of worship?

Thank you so much for answering my questions about worship. Now I am going to ask you some questions about other things that you do at (faith community name).

Other Activities or Programs in the Church

I will repeat the Grand Tour and Mini-tour format for activities or programs up to three addressing large group activities other than worship, religious education focused small group activity, fellowship or social small group activity, or service activity (small or large group).

Questions to identify Programs or Activities:

- Earlier, you mentioned ___, ____, and ____ as things that you do at ____. Are there other activities that you do here? Either every week or just around holidays? Or certain times of the year?

  o Movie nights

  o Confirmation

  o Vacation Bible School (VBS)

  o Choir

  o Prayer Shawls

  o Family Promise

  o Interfaith Food Pantry

  o North Porch

  o Autism Speaks

  o Jinny's Rainbow Comfort Quilts

  o Coffee Hour

  o First Sunday Brunches

  o Homework Club

  o Wine and Cheese Parties

- Of all of those activities that you have done- what are the three that you are most a part of?

- Repeat Grand Tour and Mini Tour questions for up to three programs.

Conclusion

Thank you for telling me about (faith community name) and the things that you do there. Before we finish I wanted to know if you have any questions for me?

Thank you very much. Would you like a copy of my dissertation when it's finished?

In the meantime, I would like to schedule a time to go over the pictures that you are going to be taking for my research. When we meet again, I will have a few questions about our interview today and then we will talk about the pictures that you are going to take. Will one of these times work for you? _____, _____, _____?

PhotoVoice Training Protocol.

Semi- Structured Interview Questions for Parents or Family Members of people with IDD

Introduction

Introduce the research and establish rapport

- Welcome and attend to issues of comfort.

- Explain the research (briefly) and give an overview of the interview expectations:

  o Time requirement

  o Kinds of questions

    ▪ I'm going to ask you to describe the different things that you do with your family member with a disability at (faith community name). We will start with worship, and then talk about different things that (family member name) does. When we talk about the different programs and activities, I am hoping that you will describe them as if I have never seen them or done them- with lots of details.

- Preliminaries

  o Ethical Considerations- Just to remind you, you do not have to answer any question if you do not want to and we can take a break or stop at any time.

o Go over interviewing equipment and procedures

o Do you have any questions before we get started?

Main Questions for family members

Introductory questions:

- How long has your family member been a part of this Faith Community?

Grand Tour Question: Worship

- Please describe what you do on a typical Sunday morning when you come to church? Pretend that I've never been in your church, or any church before and describe it in detail.

    o Follow up questions:

        ▪ Entering the Space

            • Which door do you come in?

            • What do you see when you come in?

            • What do people say or do that let you know that you are welcome or that you belong?

        ▪ Where do you sit?

            • Who do you sit near?

        ▪ What happens in worship?

            • What is your family member's role or part in the service?

                o Is that an important role?

            • Who else is a part of worship?

            • Who are the leaders in worship?

- o What do people say or do that let you know that your family member is welcome or that he/she belongs?
  - ▪ What is (family member's name) favorite part of worship?
    - • How do you know?
  - ▪ What is (family member's name) least favorite part of worship?
    - • How do you know?
- o How does worship end?
  - ▪ How do you leave the worship space?
  - ▪ Which door?
  - ▪ Who do you leave with?
  - ▪ Where do you go?

Mini Tour Question One: Leadership in Worship

- Now I'm going to ask you some questions about leaders in the worship service. You mentioned that ____, ____, and _____ are leaders in worship. Can you describe what worship leadership is like in your church? Who leads and what they do?
- What are other roles in the worship service- including smaller roles in worship?
  - o Do people like your family member have roles in worship?
    - ▪ How are they like your family member?
    - ▪ What do they do?
    - ▪ Was there something that needed to happen before he/she could do this role?
      - • Age
      - • Gender

- Rite of the church

- Express interest

- Personal connection

- Be noticed

- Religious education

- Practice or contest

o Has your family member ever held a leadership role in worship?

- What did s/he do?

- How long has she/he done it? Or how many times has she/he done it?

- Please you describe it for me as if I've never seen or done anything

  like this before?

  - Where does this happen?

  - Are there any important object or things associated with this?

    o What are they?

    o Please describe them to me in detail.

  - How did your family member prepare?

  - Who supported her/him?

- Has your family member had other leadership roles in worship? (I will

  repeat this mini tour question up to three times).

Mini-Tour Question: Please describe (family member's name)'s friends from

worship. Please be as specific as possible about who they are and what you they do

together.

- o Follow up questions: Do they talk to (family member's name)? Or do things with (family member's name)?

  - ▪ What do they talk about/ do?

  - ▪ How long?

  - ▪ How often?

  - ▪ Do they talk/ do things outside of worship?

Thank you so much for answering my questions about worship. Now I am going to ask you some questions about other things that (family member's name) does at (faith community name).

Other Activities or Programs in the Church

I will repeat the Grand Tour and Mini-tour format for activities or programs up to three addressing large group activities other than worship, religious education focused small group activity, fellowship or social small group activity, or service activity (small or large group).

Questions to identify Programs or Activities:

- Earlier, you mentioned ___, ____, and ____ as things that (family member's name) does at the church. Are there other activities that she/he does here? Either every week or just around holidays?

  - o Movie nights

  - o Confirmation

  - o Vacation Bible School (VBS)

  - o Choir

  - o Prayer Shawls

  - o Family Promise

- o Interfaith Food Pantry

- o North Porch

- o Autism Speaks

- o Jinny's Rainbow Comfort Quilts

- o Coffee Hour

- o First Sunday Brunches

- o Wine and Cheese Parties

- Of all of those activities that (family member's name) has done- what are the three that she/he is most a part of?

- Repeat Grand Tour and Mini Tour questions for up to three programs.

Conclusion

Thank you for telling me about (faith community name) and the things that your family member does here. Before we wrap up I wanted to know if you have any questions for me?

Thank you very much. I look forward to sharing my dissertation with you when it's finished. In the meantime, I would like to schedule a time to go over the pictures that you are going to be taking for my research. When we meet again, I will have a few questions about our interview today and then we will talk about the pictures that you are going to take. Will one of these times work for you? _____, _____, _____?

PhotoVoice Training Protocol.

Appendix F

Semi- Structured Interview Questions for Clergy and Lay Leaders

- Explain the research (briefly and give an overview of the interview expectations

    o Time requirement

    o Kinds of questions

        ▪ I'm going to ask you to describe different times or programs where you felt like people with disabilities were included in the life of the church. If we have time, we will discuss a couple of these times.

- Preliminaries

    o Ethical Considerations- Just to remind you, you do not have to answer any question if you do not want to and we can take a break or stop at any time.

    o Go over interviewing equipment and procedures

    o Do you have any questions before we get started?

Introduction

- What is your position in the faith community?

    o How long have you held this position?

- What program areas of the community are you responsible for?

Main Questions

This is an example of the kinds of questions that I will use in the interview- since this is a semi-structured interview, I may omit some of these questions, or use probes to explore a question further.

Grand Tour: Please share an experience where a program or service that you were responsible for that was inclusive of a person with IDD? Please describe it in detail.

- o Where?

- o Who was there?

- o When?

- o What did you do?

- o What made it inclusive?

  - ▪ How did you know?

- What are concrete steps that you took to ensure that this event would be inclusive of people with disabilities?

  - o Did you do any special training? Or research?

  - o Is there a written policy or guideline for disability inclusion in this program area?

- What lessons did you learn from this event?

  - o How do you address needs as they come up?

- Can you identify any resources that have been helpful to you in promoting inclusion in this program?

- Can you identify any specific needs that you have for resources as you promote inclusion in this program?

- Mini Tour Question: How did people with disabilities share their gifts or strengths as part of this event? How were they leaders? Please describe it in detail.

- Mini Tour Question: Did it seem like people with disabilities were a part of the community during this event? How did you know? Please describe it in detail.

  - o Friendships

  - o Social engagement

If time allows I will repeat this line of questioning up to three times.

Appendix G

PhotoVoice Instructions and Interview Questions

PhotoVoice Instructions

During our interview you have told me about what you do (or your family member does) in worship and in ____, _____ and____. I would like you and (family member/ person with IDD name) to do a project together. Please take pictures to answer the question "What does belonging look at (faith community name)?" You can take pictures of places, objects, or activities that illustrate this for you.

Please look at the photographs together with (family member/ person with IDD name) and select two pictures that you think are good examples of what your family member is a part of here at (faith community name). Please send those to me via email (or leave paper copies at the church office for pick up), and please fill out a release for each picture for the photographer and anyone in the picture. Please don't take pictures of people other than you and (name of person with IDD/family member).

PhotoVoice Interview Questions

- Explain the research (briefly and give an overview of the interview expectations)
    o Time requirement
    o Kinds of questions
        ▪ We are going to look at the photographs that you took of your family member with a disability participating in the life of the community at (name of faith community), and I am going to ask you a couple of questions about them.

- Preliminaries

  - Ethical Considerations- Just to remind you, you do not have to answer any question if you do not want to and we can take a break or stop at any time.

  - Go over interviewing equipment and procedures

  - Do you have any questions before we get started?

  - Collect photo release for photographer and people pictured in photos.

- Please tell me about this photo.

  - Who?

  - What?

  - Where?

  - When?

- What name or title would you like to give your photograph?

  Tell me why you chose this photograph to illustrate (Family member's name)'s belonging to (Faith community name).

- What is your favorite part of this photograph?

  - Why?

- Is there anything else you want to tell me about this photo?

I hope to have my dissertation finished on _____. I would be happy to send you a copy of it.

Would you like a copy?

Appendix H

Interview Guidelines for Parents

Hearing your child's voice, what your child thinks or feels, is essential to this research. Although, as parents it's typical to assist, instruct, correct or focus our children, for the purpose of the research, please refrain. If your child is comfortable, please sit away from your child during the interview.

- Please allow your child to answer the question on their own. You will have a chance to comment on the interview transcripts and to add your reflections and thoughts.

- Wait time (letting your child take time before she or he answers) is ok- you don't need to prompt your child.

- As an interviewer, I won't correct your child, or challenge what your child says, even if they say something negative or inaccurate. This is good interviewing technique, but it may sound a little surprising. Please do not correct, instruct, or interrupt your child. You will have a chance to comment on the transcripts.

Thank you very much for allowing your child to participate in this research.

Appendix I

Photo Publication Release Form

Photo Publication Release Form
IRB No.:
Title of Research: Disability and Belonging in an Inclusive Faith Community
Date of IRB Approval:

PARTICIPANT CONSENT
I am 18 years of age or older and hereby grant the researcher designated below from the University of New Mexico to use my photograph or likeness in photograph(s) for publication for the above titled IRB approved research only. My name will not be used in any publication. I will make no monetary or other claim against UNM for the use of the photograph(s).

Printed Name: Date:
Signature:

If Participant is under 18 years old, consent must be provided by the parent or legal guardian:
Printed Name: Date:
Signature:

UNM RESEARCHER
Name: Date:
Address and Contact Information:
Signature:

Appendix J

Detailed Timeline

Date	Benchmark
12/14/18	Dissertation Proposal Defense
1/15/19	IRB submission
3/1/19	Data collection and primary analysis begin
8/30/19	Data Collection ends and secondary analysis begins
03/11/20	Completed Dissertation submitted
03/25/20	Dissertation Defense to the dissertation committee