Inclusion

Disability and Belonging in an Inclusive Christian Faith Community
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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 ASD (Autism Spectrum Disorder, a type of IDD) in one intentionally inclusive Christian faith community with a primary focus on the perceptions of faith community members with disabilities. This community was unique in its theological stance toward inclusion and in the steps the community had already taken to be inclusive. We conducted two types of interviews (in-depth individual and PhotoVoice) with people with severe and moderate disabilities who were active in the community to explore their perceptions of participation and belonging in the community. We supported interview data with field observations and a document review. We prioritized the voices of people with disabilities by using in-vivo coding strategies based on their words and used thematic analysis across data sources. Three primary themes emerged from this analysis including: Leadership, relationships, and traditions and routines. 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.

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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. We conducted two types of interviews (in-depth individual and Photo-Voice) with people with severe and moderate disabilities who were active in the community to explore their perceptions of participation and belonging in the community. We supported interview data with field observations and a document review. We prioritized the voices of people with IDD by using in-vivo coding strategies based on their words and used thematic analysis across data sources. Three primary themes emerged from this analysis including: Leadership, relationships, and traditions and routines. 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.

Keywords: disability, intellectual and developmental disability, faith community, inclusion, participation, descriptive, case study

DISABILITY AND BELONGING

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Participation in faith communities is valued by many individuals and is, indeed, guaranteed by the Bill of Rights (U.S. Const. amend. I § 2). Shogren and Rye (2005) and Lifshitz et al. (2009) established that disability does not change religious proclivity. They found that people with intellectual and developmental disabilities (IDD) value faith as very important, somewhat important, or not important at the same rates as members of the population at large. Participation in faith communities also offers benefits for members of these communities. Cox and Thompson-DeVeaux (2019) reported several natural supports offered by faith communities for the general population (e.g., increased interpersonal trust and civic engagement) that may also benefit individuals with IDD who participate in faith communities. For example, people with IDD in faith communities report high rates of social interaction opportunities (Shogren & Rye (2005), support in workforce development (Gaventa et al., 2014), and support in social skills development (Liu et al., 2014). These benefits are documented across the lifespan for people with IDD from youth (Liu et al., 2014), to adulthood (Healy, 2009), and can lead to a full sense of belonging (Carter & Boehm, 2019).

Given the importance of religious expression in the lives of many individuals with IDD and the legal protections associated with religions freedom, one would expect religious participation (e.g., attending worship, engaging in religious education activities) among people with disabilities to be on par with the general population, but this is not the case. Carter et al. (2015) found that fewer people with disabilities, as compared to the general population, participate in faith communities. They reported a participation gap of 9% between these two groups with a larger gap in participation for people with extensive support needs (12-22%; i.e., individuals with IDD who require supports across multiple life domains). This finding is

especially unfortunate given the benefits associated with participating in a faith community. Faith communities are also denied the benefits of diversity inclusion when people with disabilities are not present. The presence of marginalized groups has long been seen as a source of faith community renewal and growth, and this is no less true regarding the participation of people with disabilities (Reynolds, 2008).

Carter et al. (2016) posited that not only is there a participation gap in attendance, but there is also a gap in full engagement of individuals with IDD within faith communities. There is evidence that this engagement gap may be less significant for children and youth (e.g., Liu et al., 2014) than for adults with IDD, yet it still represents a barrier to what Carter et al. (2016) described as having presence in the faith community. These authors explored the distinction between being physically present in worship and having a presence in a faith community by interviewing 25 parents about the involvement and sense of belonging of their children with IDD within their churches. They found that physical presence is just the first aspect of experiencing a sense of belonging within the community and other dimensions of belonging are also critical. Based on the analysis of parent interviews, the authors identified and described 10 dimensions of belonging in faith communities for people with IDD. One of these, being needed, relates directly to findings from prior research that many people with disabilities who do attend faith communities are only given restricted roles within the faith community (Healy, 2009; King, 1998; Turner et al. (2004). People with IDD participate most often in worship services but less often in leadership roles (i.e., holding respected, public roles in the church in small group or corporate settings such as reading scripture, singing in a choir or playing in a band, leading prayers, preaching or giving testimony, writing curricula, teaching). Making a contribution to the community (being needed) represents a central role in perceptions of belonging, and more

research is needed to understand how the roles provided to individuals with IDD influence their active engagement in the life of the faith community.

Despite an increased interest by scholars in the role of faith in the lives of people with disabilities, research has largely relied on perspectives of clergy, parents, or service providers as participants. Fewer studies have explored the voices of people with IDD, particularly those with extensive needs for support, about their participation (e.g., Healy, 2009; Liu et al., 2014; Shogren & Rye, 2005). Findings based on perspectives of clergy, parents, and service providers help researchers and practitioners understand some aspects of faith and disability, but they fail to voice the experience of belonging or participation from the point of view of the primary reporters, namely people with disabilities. Persons with disabilities are the experts on their personal experiences of participation in faith communities. Further research that amplifies these voices is needed to guide practitioners, researchers, and support providers.

The purpose of this study was to provide a rich description of faith community participation from the perspective of people with IDD. In this descriptive case study, we focused on the voices of people with IDD who participated in an intentionally inclusive faith community by examining their descriptions of experiences, difficulties, and successes within their faith community and around their essential experience of belonging. We defined "intentionally inclusive" as a faith community that had a purposeful, articulated focus on including people with disabilities. We deliberately chose to situate the study in such a community to deeply examine the perceptions of the individuals with IDD who were the recipients of this concentrated focus on inclusion. Keeping in mind both the location of the problem of limited inclusion in faith communities and the primacy of the experience of people with IDD in those communities, we

developed the following research question to guide our study: What does the full participation of

people with IDD look like in one intentionally inclusive Christian faith community?

Method

Guided by the call to focus on the voices of people with disabilities as primary in this

field (Eiesland, 1994), we focused on the voices, photographic data, and experiences of people

with IDD as the primary reporters in this study in both in-depth semi-structured interviews and

Photovoice interviews. In addition to the interviews and photographic data, we used field

observation, document reviews, and ancillary interviews with family members and clergy to

create a descriptive case study focused on one case (Yin, 2018).

Setting

We selected St. Thomas as the site for the case study because of their work to be an

intentionally inclusive faith community. (Note that the name of the faith community and the

names of the participants are pseudonyms to protect privacy of participants). Neither author had

any connection with St. Thomas prior to the study. When searching for a faith community

partner for this study, we sought a community with an intentional, articulated focus on including

people with disabilities. The first author reached out to professional organizations promoting

disability and faith looking for recommendations (e.g., AAIDD Faith and Spirituality Interest

Network, Faith Inclusion Network, Institute on Theology and Disability). Members of these

organizations recommended several communities as possible sites. The first author reached out

to faith leaders at all recommended institutions. St. Thomas, a church that was deliberately

making changes to actively include individuals with IDD and their families in worship and

church education and other activities, was the first to respond. The first author then contacted the

head pastor of the church to learn more details about their efforts to include individuals with IDD

and to discuss the possibility of St. Thomas serving as the case study. After this meeting the governing board of the church reviewed the purpose of the project and agreed that the study could be conducted there.

St. Thomas was a mainline protestant Christian church of 321 members with average worship attendance of 125. Church records showed the membership in 2018 was 6% American Indian, 1% Black or African American, 7.5% Asian, and 92% White (Because members could select more than one race, the total percentage will exceed 100%.). Approximately 5% of the population identified as having an IDD. It had been led for the previous seven years by Rev. Karen Evans who had specialized training in disability through her clinical pastoral education and her experience as a parent of children identified with autism spectrum disorder (ASD). Under Karen's leadership, the church actively sought to be more inclusive of people with disabilities. Among other efforts, the church governing board made changes to the physical environment through a capital improvement campaign to enhance physical accessibility, clergy and lay leaders created educational opportunities for the entire membership about inclusion of individuals with disabilities and created opportunities for individuals with IDD to serve in volunteer leadership positions (e.g., serving roles in worship services), and clergy and lay leaders partnered with community organizations to provide special camps for children with ASD.

Participants

The study included three groups of participants: (a) individuals with IDD, (b) parents of the participants with IDD, and (c) the faith community's clergy. (See Table 1 for participant demographic information.) We purposefully selected participants in a manner that prioritized the voices of people with IDD while providing multiple sources of data from faith community leaders and family members.

Recruitment

Because this study used in-depth interviews that required individuals to communicate about their experiences of belonging to St. Thomas, we recruited church members who were adolescents or adults with IDD who had an established means of communication (e.g., used verbal speech). After securing approval from the university's institutional review board and the church's board of directors, we recruited members at St. Thomas with IDD and their family members by posting flyers with study information and the first author's contact information on the church's bulletin boards, and in the community's weekly email newsletter. The first author also hosted an informational meeting about the study after the main worship service on a Sunday morning for anyone interested in possible participation. Interested individuals could take a packet with them that contained a demographic questionnaire, and copies of consent and assent forms and were asked to complete and return the questionnaire if they wished to participate.

To gain the perspectives of the faith community leaders, we targeted recruitment of individuals who were clergy or leaders with direct decision-making responsibility regarding disability inclusion in the faith community. We began recruitment by contacting the church's head pastor directly and invited her to participate in the study. We also asked her to identify key leaders who had positions that affected inclusion of individuals with IDD (e.g., the leader of the Christian education program) and then contacted these individuals by telephone or in person to explain the study and answer any questions they night have about the study. If they wished to participate, we sent a demographic questionnaire and copy of the consent form to them.

Individuals with IDD and Family Members

Two individuals with ASD, a type of IDD, James and Sydney, agreed to participate in the study (See Table 1). We also recruited one family member of each individual with ASD. We

were not able nor thought it appropriate to request access to assessment data for participants with

ASD. Faith communities do not collect information from formal assessments while still

effectively administering supports to individuals with IDD. This is both a limitation and a benefit

to the community that we reflect in this study. Information on James' and Sydney's diagnoses

and support needs was gathered through a demographic form and through the interview process

described below. (See Table 1.) Both participants communicated verbally. Neither individual

required mobility supports or physical adaptations to participate in home, school, community, or

employment activities. James, a young adult with ASD, was the son of the senior minster of St.

Thomas; his father, Hugh participated with him. James lived with his parents and engaged in

supported work during the day; he required extensive supports across multiple life domains. For

example, James required significant support from caregivers or support staff with daily living

tasks, transportation, managing social opportunities, and engaging in employment tasks. Sydney

was a high school student with ASD who required moderate supports across multiple domains.

She needed assistance from her parents with organization and time management, transportation,

and she received modified instruction for all academic tasks in her school. She regularly attended

worship and participated in varied church activities. Her mother, Jennifer, a staff member at the

church, also agreed to participate.

Clergy/Staff

Two faith community leaders participated in this study: Karen and Kim. Karen, the head

pastor, was responsible for adult education, preaching, pastoral care, church staff supervision,

and leadership development (professional and volunteer). She was also the mother of James, one

of the participants with ASD. Kim, the associate minister, was responsible for programming with

youth and children and mission in the church.

Research Design

We used a descriptive case study design looking at a single faith community, St. Thomas, and focused on the experience of participation of members with IDD in the faith community. A case study of a single phenomenon is appropriate when there is a special case that describes a situation that is somewhat unusual or special (Yin, 2018). With its current leadership and clergy, St. Thomas presented a unique case because the church was led by clergy and staff with specific training in working with individuals with disabilities, actively sought members with disabilities, and offered education for all members in support of inclusion of individuals with IDD in the faith community. These characteristics made it an ideal case in which to examine the participation of individuals with IDD in a faith community (Yin, 2018).

Data Collection

We used multiple sources of data to develop a deeper understanding of the participation of individuals with IDD in a faith community. The first author conducted participant interviews, examined archival church documents, and conducted observations while taking detailed field notes. Each of the six participants was interviewed twice. The first author conducted an initial 20 − 66 min (average 41 min) semi-structured in-depth interview with each participant. She conducted a separate 6 − 9 min follow-up (Photovoice) interview (average 7 min) with Sydney and James and their participating parent. Clergy participants also participated in follow-up interviews of 20-45 minutes in length (average 32 min). All interviews were audio recorded and transcribed verbatim using a transcription protocol before being uploaded into an online qualitative data analysis program (Dedoose) for analysis. Initial interview questions with Sydney and James (our primary participants) began by asking them to describe their normal routine at church (e.g., Please describe what you do on a typical Sunday morning when you come to

church?) Follow up questions asked them to describe details of participation in different

activities (e.g., Does anyone meet you when you come into the church?). We used this general

question structure to ask about their participation in worship, relationships, and other activities

(e.g., Sunday School). (Please contact the first author for a copy of the interview protocols.) We

modified interview questions for people with IDD to support meaningful responses (e.g.,

providing concrete examples of types of activities within the church; asking specific questions

before general ones, rephrasing or simplifying wording; Finlay & Lyons, 2001).

   In addition to the in-depth interviews, the first author conducted follow-up Photovoice

interviews with individuals with disabilities and their family members. Photovoice combines

photographs taken by participants related to the phenomena under study with descriptions of the

photos provided by the participants. It is a popular methodology with marginalized populations,

and it prioritizes non-verbal communication (Catalani & Minkler, 2012). At the end of the first

interview with James and Sydney or their family members, the first author explained Photovoice

and asked participants to use their own digital device (e.g., smart phone, iPad) to take three

pictures, or to choose existing pictures, that typified belonging at St. Thomas for the participant

with disabilities. She did not provide a definition of belonging to avoid inadvertently steering the

participant toward a specific activity. Instead, she asked them to take or select photographs that

were good examples of what they were a part of at St. Thomas. Participants showed the

interviewer the photos they selected during the second follow-up interview, provided a

description of how the photos represented belonging in the faith community, and created a title

for each photo. Photovoice interviews with Jennifer and Hugh were done using the photographs

selected by James and Sydney and were conducted separately from their children.

The first author also examined documents archived by the faith community including the annual reports of the congregation, and the transcript of their capital campaign video describing how the congregation supported inclusion of individuals with IDD. She also conducted field observations of the faith community building, worship services, and other meetings. Finally, she used field notes to triangulate information from these multiple data sources (e.g., interviews, document analysis, field observations).

Data Analysis

Interviews were transcribed verbatim and these transcripts, faith community documents, and researcher fieldnotes were uploaded to Dedoose for analysis. The first author began by coding interview transcripts using a two-step process of in-vivo coding (Saldaña, 2015). She coded transcripts of the initial interviews before conducting the second interviews with participants. We used an inductive coding process (Bernard & Ryan, 2010). Initial coding focused on coding for units of meaning (i.e., words or phrases). Both authors discussed these initial codes, refined the code definitions, and developed a codebook with exemplar codes, prioritizing the excerpts from interviews with participants with disabilities for each code to ensure that the words of these participants were central to the analysis. Next, the first author completed line-by-line coding of all of the interviews, prioritizing the words of the participants with disabilities by coding their interviews first. She continued weekly discussions with the second author using the process described above and continuing to refine codes.

In the second phase of coding, the authors examined excerpts from interview transcripts that had been "lumped" under the major parent codes emerging in the initial phase and the refined definitions of parent and child codes. This process involved discussing agreements and disagreements thoroughly and refining our common understanding of each code definition. It

allowed for codes to next be placed into broader categories. The first author then examined the

ways that categories connected, influenced, or flowed between each other, resulting in

development of five themes and associated subthemes. Three of these themes, those that

highlight the perceptions and experiences of the participants with ASD, will serve as the focus of

this paper. These are described in detail below (See Table 2 for a list of themes, definitions, and

exemplar participant quotes.). Two additional themes that emerged from the analysis are

ancillary to the experiences of people with disabilities so, they will not be included in this paper

(See Table 2 for their definitions).

After developing codes from the interview data as described above, the first author

applied the codes to the annual reports and capital campaign video transcript using the same

coding protocol described above. Information from these archival documents helped to refine

definitions and to corroborate findings in the interviews with participants with ASD.

Trustworthiness

According to Yin (2018), data triangulation may be used to verify the trustworthiness of

data by using multiple sources of data to corroborate the same finding. In this study interviews

with participants, the photographs provided during the Photovoice interviews, field observations,

and document analysis all provided sources of data that helped to deepen understanding of the

participation of individuals with disabilities in the faith community. The convergence of findings

across these sources helped to establish the trustworthiness of the findings.

Member Checking

The first author conducted member checking by creating and emailing a document to

each participant with the name and definition of each theme and exemplar quotes from that

participant's own interview (they only saw their own words). She asked participants to read

theme descriptions and the quotes to ensure that the selected quotes reasonably belonged with each theme as it was defined. Participants with ASD were supported in the reading and analysis of this report by their parent. Participants were also invited to make comments on the themes. All participants responded and confirmed that the themes reasonably described their interviews.

Findings

We identified three primary themes and five associated subthemes based on the data analysis process described above. The themes focused on opportunities to engage in leadership, importance of relationships within the faith community, and the role of routines in fostering belonging and participation. We discuss these in detail below.

"A Role that I Uphold:" Leadership

One of the strongest themes that emerged from analysis of the data related to leadership roles. We defined these as the formal (e.g., liturgist, acolyte) and informal (e.g., setting out chairs, organizing a closet) roles and responsibilities that participants fulfilled in the faith community that generated a reciprocal sense of responsibility *to* the community and being valued *by* the community. Participating in leadership roles seemed essential to participants' sense of belonging to the faith community. Sydney stated, "like if we don't have I don't have any jobs to fulfill like we won't really even go." She went on to note that helping out was at the heart of belonging at St. Thomas, explaining that, "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…" Sydney's inclusion of a photograph of the acolyte's closet that she was responsible for tidying typified her sense of purpose in a job that she felt proud of. Three subthemes emerged within the larger theme of leadership (i.e., lay readers, mentorship, and making mistakes).

Lay Readers

Participants mentioned lay reading (i.e., non-ordained individuals reading from the Bible or other worship texts as a regular part of worship services at St. Thomas) as a significant formal role that denoted participation and belonging. James described his careful preparation for this role and shared a photograph of himself reading the text on a Sunday morning from the lectern for his Photovoice interview. When asked why he chose this photograph to show participation and belonging, he stated, "Well, it shows me participating in the, what are they called? Is it called the-…"? (The first author helped him find the word, worship.). This gave evidence of the level of care and importance that he placed on the role of lay reader. Sydney also included in her Photovoice interview a photograph of herself reading a text from the lectern in the church and shared several stories focused on reading in services in her interviews.

Mentorship

Mentorship, the use of experienced peers to guide novice leaders in learning to fill formal roles at the church, was another valued leadership role. Sydney, in particular, described mentoring younger youth and children in leadership roles as part of her experience of belonging. She highlighted the link between mentoring and maturation, "I did show two kids how [to serve as an acolyte] and so I felt like accomplished." During her Photovoice interview, Sydney also included a photograph of herself helping during a Lenten service for children, further highlighting her leadership with younger children.

Making Mistakes

Participants mentioned the importance to them of the faith community's willingness to accept mistakes when they acted 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 skills,

prior experience, or traditional credentials (e.g., being baptized, ordained, or confirmed). Faith

community leaders echoed this willingness to take risks and to model successful failure as part of

developing an inclusive culture.

"We Are Friends:" Relationships

The second primary theme that emerged was the importance of relationships. We defined

relationships 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-teenager), but each

relationship contributed to and was an outcome of participation and belonging. James and

Sydney mentioned two categories of relationships as particularly salient for them as they

considered what it meant to belong to the St. Thomas community.

Church Relationships

Both participants described church relationships as individuals at church with whom they

participated in an activity or someone with whom they shared an interest but who were not

always people with whom they had close personal relationships. Holding leadership roles, such

as volunteering with peers in church activities, helped foster these types of social relationships

for participants. In his Photovoice interview, James described the interactions he engaged in as

part of "We Are Friends" (a social group for young adults with IDD) as this type of relationship.

Sydney spoke about how shared leadership roles helped her build social relationships with peers

at the church. Sydney explained, "…it's a little bit easier for me to talk because there's like an

event and we have stuff to talk about."

Family Relationships

A second important relationship mentioned was with biological family members in and outside of their households. Participants described attending faith community events and activities with these family members and described an identity as members of the church that was negotiated through their family. In his Photovoice interview, James explained 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." In her Photovoice interview, Sydney described helping during the children's foot washing service and explained that her mother was one of the organizers of the service and that she enjoyed serving with her mom.

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

The importance of traditions to participation and belonging, which we defined as the regular patterns of active involvement in church events, also emerged as a main theme. Traditions included how the community celebrated holidays, how they began and ended their gatherings, and worship practices. Routines were included in this theme and defined as patterns that individuals and families engaged in at the faith community site that were not necessarily followed by other community members (e.g., where families preferred to sit in the sanctuary or routes they typically took through the building).

Routines and traditions provided a scaffold for active participation and nurtured a sense of belonging for participants with ASD. For example, as part of the worship service, there were a number of actions that the congregation knew how to do without referring to written text in the order of service (e.g., when to sit or to kneel). These repeated, predictable actions seemed to serve as cues for deeper participation by the study's participants. Participants also mentioned specific traditions as some of their favorite parts of life in the faith community. James focused on the reading of scripture and the sermon. Sydney described in detail receiving communion as her

favorite part of church, highlighting the value of this tradition for her experience of participating in the faith community and emphasizing how it helped her feel connected to her mother. Personal routines also supported participation and belonging for James and Sydney. James articulated the value he placed on routines in the church when he made the connection between his work and his church, "Um, they [congregation] follow the leader and they—they do a specific routine, every time. And just like I, I do at work." Routines at church supported his participation in his faith community just as the specific routines he used to navigate his day did at work (e.g., using public or peer transportation). Sydney included a photograph in her Photovoice interview of a statue in the church holding a bulletin. She focused on the statue's hand, stating that the way that he holds the bulletin is not only a personal tradition (she likes to slide a bulletin in between his fingers) but also a personal symbol of welcome.

Discussion

This study focused on the experiences and voices of people with disabilities in a faith community by interviewing people with ASD who were active in an intentionally inclusive Christian faith community. In this particular community, participation went beyond being merely physically present to a reciprocal relationship between the individual with disabilities and the other faith community members. Participants' perception of belonging to St. Thomas was manifested through engaging in the traditions and routines of the community, fulfilling valued and essential roles in the community, and establishing social relationships with community members. Our findings support those of prior research (e.g., Carter et al. 2016) and expand understanding of some of the factors that influence participation and belonging. Our findings enhance understanding of the value and importance of routine in strengthening participation and belonging, the value of assuming leadership roles as a tool for inclusion, and the special role of

family connection and identity as part of faith expression. Faith expression includes worship, personal devotion, service to others, fellowship or any other action to show or share faith. In the following sections, we describe ways in which these factors may enhance participation and a sense of belonging for the persons with disabilities and consider implications of these for leaders who wish to facilitate inclusion of individuals with disabilities in their communities.

The Rhythms of Faith Community Life

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, for example, have a strong research base for teaching people with IDD complex behaviors (e.g., Ford et al., 1989). The role of traditions in many faith communities makes explicit routines a natural part of the culture and may be a valuable natural resource for fostering inclusion in faith communities. These routines and traditions, the rhythms that make up the "ordered life of the church," pervade worship and community events. Leveraging these routines and traditions to support the participation of individuals with IDD in faith community settings could be an important first step for those communities wishing to become more inclusive of individuals with disabilities.

One area in which routines and rituals can increase participation of individuals with IDD is in the fulfillment of leadership roles, as they did for the participants in this study. These long-standing religious traditions and roles remain the same year after year. This predictability supports mastery of the multiple skills involved in various roles. James, for example, understood and explained that worship leaders followed a routine when leading services, similar to the routines he followed at work. The predictable expectation, pattern, and routines in worship thus facilitated his success in being a lay reader. Sydney, too, benefited from the consistent cues and action steps associated with the role of an alter server.

Social relationships that are essential for a sense of belonging can also be supported by the routines and rituals of a faith community. Familiar patterns of cues and actions such as greeting fellow members in a worship service (i.e., what is called passing of the peace in some communities), provided the support James' required to initiate and respond to social interactions from other members. He specifically mentioned this routine as meaningful and important to his experience of worship and sense of belonging within the church. This example provides not only an illustration of befriending that is mentioned in previous work as one of the aspects of belonging (e.g., Carter et al., 2016; Carter & Boehm, 2019; Liu et al., 2014), it also provides a roadmap of one way to make progress toward befriending, and the special role that faith communities may have in supporting and developing crucial relationships between people with and without disabilities. Relationships formed with peers in faith communities may also extend support beyond the community setting. Sydney, for example, acknowledged that although relationships with peers at St. Thomas were not as close as she wanted (she called these "church friends"), they still helped her transition to high school by supporting her move to a larger school and a larger school community. As her peers 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.

Sydney and James' descriptions of the routines they valued and found supportive illustrate what Healy (2009) mentioned regarding the importance of routines in his discussion of the experience of worshiping God within a community. He argued that routines and rituals create a scaffold for religious experience for people with disabilities, creating a place to experience God's mystery. Although we did not examine the experience of mystery, our participants clearly

found value in these routines and rituals. They indicated that these helped to nurture a sense of belonging in the community and scaffolded meaningful participation in community activities.

Routines and rituals are examples of the dimension of belonging described as "being supported" by Carter et al. (p. 135, 2016) but with an important difference: these routines and traditions are available to all members of the community. Because they are part of the everyday life of the faith community, they can be seamlessly interwoven into worship and community activities and invisible to participants in these settings. Thus, ritual and routines can serve as an excellent medium for clergy, staff, and volunteers looking to make naturally occurring supports available to individuals with IDD but can also be delivered seamlessly or invisibly to others in the community, such as with youth and adults without disabilities who are learning a new leadership tasks or routines, visitors, or other novices in a performative aspect of worship (e.g., what do during communion or baptism, or when to bow, cross, stand, kneel).

The study's findings regarding the importance of routines for participation of individuals with IDD also 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 such as visual guides to the meta structures of worship, specific rites (e.g., baptism, communion), and holiday traditions, would assist worshipers with and without disabilities and enhance their engagement in the life of the church. Not only would such supports encourage active participation, but they would allow for explicit instruction and skills development in areas of communication, social skills, and leadership, to name a few. These supports could be included in curriculum guides, in pre-printed bulletins, and be widely available by publishing houses for faith communities to purchase and use. They could also be developed by volunteers or program staff on site as a support for particular individuals in a congregation.

Leadership: Participating, Belonging, and Holding Valued Roles

Another factor identified in this study as critical to authentic participation and belonging of people with IDD is the importance of holding leadership roles within the typical activities of the faith community, including worship. While Carter et al. (2016) discussed the need to be heard, needed, and known - all qualities or aspects of leadership - we believe that leading in worship is more than the sum of its parts. It may be the key to not only full participation, but also to personal faith development. For our participants, leadership fostered not only a sense of belonging to the community, but a sense of belonging to God and a sense of vocation.

Rather than participating in segregated programs, as is often the case in faith communities, participants in this study were fully integrated into the life of the church (e.g., in worship, in education activities). They were never in separate programs and like other members of this community, they filled visible, valued roles in worship and community life. Further, their faith community intentionally developed and supported these visible leadership opportunities as a strategy to promote inclusion of individuals with disabilities. James and Sydney felt invited and encouraged to participate and well-prepared to perform these highly valued acts of leadership because their participation was facilitated with direct instruction, peer mentors, predictable routines, and repeated practice, and tolerance for less than perfect execution.

Using leadership opportunities to foster inclusion of individuals with disabilities is a somewhat novel approach to disability inclusion in faith communities that breaks with models of inclusion of people with IDD in separated or modified religious education classes, activities, or respite programs. Assuming a leadership role is often seen as a means of increasing participation in faith communities for people without disabilities. Worthington (2016), for example, spoke about the value of leadership in cultivating a sense of purpose and belonging in the faith

community. Assuming leadership roles was also identified as important to individuals with IDD in several prior studies (e.g., Baldwin et al., 2015; King, 1998), but it was not seen as a *strategy* to foster their inclusion (active participation and sense of belonging) in communities of faith. Findings from our study suggest that appropriately supporting people with IDD to assume leadership could be a useful tool to increase full participation and to increase a sense of belonging of these individuals within faith communities and a strategy for faith formation.

In addition to the formal roles outlined in this case study, many communities of faith also include people with IDD as choir members, musicians, teachers and teaching assistants, group facilitators, greeters, in the kitchen, and helping with the physical plant of the church (e.g., landscape, room set-up). Using some of the supportive strategies participants in this study, such as mentorship, could increase independence and a sense of accomplishment for people with IDD in these roles. As described earlier, it may be especially important for religious educators, clergy, and program leaders to examine their own traditions and routines as a medium for the delivery of supports in ways that can feel largely invisible to participants.

Filling essential roles in the community was central to how participants in this study understood that they were a part of the church. Their experience of leadership encompassed a sense of being needed, known, and heard (Carter et al., 2016) but it seemed to go beyond these aspects of belonging to a sense of self-identity and self-image. For example, when asked to show photos of what being a part of St. Thomas meant to them, both participants brought in photographs of themselves in a leadership role in worship for the Photovoice interviews. They seemed to feel that holding these roles provided a place to be seen, to be known, to be heard, and to be respected.

Holding leadership roles may also provide a place to successfully explore and develop passions with support while supporting developmentally appropriate independence, as evidenced by Sydney volunteering in Sunday school and thus gaining practical experience towards her professional goal of working with children. Gaventa et al. (2014) described the value of faith communities for career development through social networks. In this study we found that learning within a context of familiar routines and traditions and with the support of a community, where it is acceptable to take risks and make mistakes, can support pursuit of career development interests for individuals with IDD. The skills that James, for example, developed through routinized social interactions at St. Thomas were certainly a support to him and may have even contributed to preparation that made his success in competitive supported employment possible.

In addition to workforce development, leadership roles also provide opportunities to develop social relationships with peers. Sydney, for example, described that volunteering at the day camp gave her a chance to spend time with peers and provided them with a common experience to talk about and connect over.

Finally, leadership roles appear to be tied to faith expression or how people demonstrate their beliefs. Whether it was James' reading as a support to his mother's preaching, or Sydney's in-depth description of tidying up the acolyte's closet or the moment of serving her mother communion, the first author observed that the rhythm of leadership was not only a support but also a part of how they expressed their faith: Part of what they valued, enacted, and contributed to their community as an act of worship, something that nurtured their faith. Baldwin et al. (2015) described the value of a sense of purpose in faith formation in young people. Leadership in St. Thomas was reciprocal: It was essential and valued by the congregation and essential and

valued by the individuals with IDD. However, it was more than that; it was also associated with a sense of belief and religious experience for the participants in this study.

Establishing Relationships: The Value of Family and Challenge of Peer Relationships

Although much prior research examining participation of individuals with IDD in faith communities has focused on those living in congregate care settings (e.g., Healy, 2009; Minton & Dodder, 2003), participants in this study lived with their biological families. They identified strongly with their families' value of participation in the faith community and the family routines associated with that participation. James, for example, showed a photograph of his family at the church during his Photovoice interview which he titled "Team Evans." His photo illustrated that his family were members of the church and that because he was a part of that family, he was a part of the church, too. For individuals with IDD, faith community participation may be especially significant in strengthening bonds with their families, serving as a source of identity with a tradition or group, and a place to participate in routines and traditions that strengthen bonds beyond the family.

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 way that they get to church, and a factor in where they choose to go to church. They also identified their church experience with particular family members and actions, such as reading Bible stories with a grandmother. Liu et al. also mentioned that their participants moved from a feeling of obligation to their families to attend church to a sense of personal connection with their faith communities. Participants in our study seemed to feel supported by family members in the growth of their personal connection to God and did not express a need to move away from them, something different from Liu et al.'s findings.

In contrast to family relationships, one of the surprising things about the findings around church relationships in this study was the low level of social engagement in peer relationships described by participants and their families. Carter et al. (2016) pointed out this same issue and posited that friendships can be especially hard to support within the confines of a 45-minute weekly program. Participants in the study also described what Sydney labeled "church friends." These were valued social relationships that centered around activities at the church, but they did not extend outside of the church to include a meal or an outing together. Liu et al. (2014) echoed this finding, saying that although some participants identified strongly with a friends at church, they identified others as friendly acquaintances (i.e., "church friends"). Church and community practitioners seeking to strengthen relationships in their churches should learn from this study that even in an intentionally inclusive faith community, with seven years of intentional effort and an articulated commitment to disability inclusion, social relationships between people with and without IDD that extended outside of the faith community were rare. Community leaders in our study mentioned the value of retreats, trips and projects that emphasize increased time together as useful experiences for youth with disabilities and their non-disabled peers. Participants in our study had not taken part in these offerings and could not comment on their efficacy in building relationships. More work remains to uncover ways to foster and support both formulaic social relationships within the community and relationships based on shared interests and experiences that may extend outside of church programs.

Limitations

It is important to acknowledge that there are limitations within this design and in the particular demographics of the study. This case was bound within one community (Yin, 2018) and only two individuals with IDD chose to participate. Using in-depth interviews and

Photovoice produced rich data, but it would have strengthened the study if additional participants with IDD had participated. Having multiple points of view from a wider age range of participants might have contributed a wider perspective of full participation in the faith community. In talking with potential participating families, the time commitment needed for the type of research design we used was identified as a barrier. In future research, offering participants multiple participation options, some with lower time commitment requirements, such as Photovoice only, might increase participation of more individuals with IDD across age ranges.

Further, there were limitations with the site of this case study. St. Thomas has a nearly exclusive focus on ASD in the church. Future research that examines communities with members with a broader range of developmental disabilities might reveal additional critical factors that affect their participation and sense of belonging. Other demographics of this congregation make it difficult to assume that findings would be similar to faith communities in general. Although the state where this research was completed is diverse, the community where this church is located identified as primarily White (i.e., 79% White) and all the participants in this study identified as white. In addition to its lack of racial/ethnic 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 was almost $750,000. This is not representative of most other communities in the United States; future research that explores faith communities with widely diverse populations and more moderate income would add to the literature. Further, the stance of the first author as a member of the Christian clergy makes research outside of a Christian church a challenge. The amplification of the voices of endemic researchers from other (non-Christian) traditions is needed.

Recommendations for Further Research

Future research in the field of faith and disability must consistently include the voices of people with disabilities. Much of the empirical research in faith and disability has been done with parents, educators, and clergy, with few articles including participants with IDD. With a clearly articulated mandate from Eiesland (1994), research *about* people with developmental disabilities should be done *with* people with developmental disabilities. This study models a way to focus on the voices of people with IDD while understanding the context of the community and the work of clergy, staff and other community leaders. Prioritizing their voices and viewing them as experts in faith and disability provides a disability-centered perspective on the questions of faith and disability and is important in this emerging field.

The role of faith community participation and family connection also warrants further study. Further, the role and value of choice and identity should be emphasized in work with congregate care settings around faith and disability. Service providers in these settings should attend to issues of identity (e.g., their clients' faith tradition, preferred worship style/ denomination) and engagement as they provide opportunities for individuals with IDD to participate in faith communities. As providers seek opportunities for individuals with IDD to develop self-determination, they should emphasize personal choice, personal history, belief system and worship preferences when individuals attend faith community activities.

Research tools in this study such as Photovoice and family interviews can be used in research with people with IDD and may provide effective means for individuals to express their thoughts and perceptions. Photovoice data not only triangulated information gained from the in-depth individual and parent interviews but also allowed participants to provide 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, for

example. In addition to its effectiveness in allowing expression of difficult concepts, participants

with IDD seemed to enjoy the Photovoice interview more than the in-depth interviews.

Prospective participants in this study expressed reluctance to participate in a research project that

felt like a formal evaluation similar to those they are required to do in educational or medical

settings. Photovoice may offer an alternative, effective way of obtaining qualitative data in a

manner that is not distressing or aversive to participants. 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.

        Much of the empirical research on faith and disability has been in large, white,

evangelical, Christian churches. This represents a very limited view of the experience of

inclusion in the country's faith communities. It is imperative that more research be conducted in

faith communities of color, in small communities like St. Thomas, in rural communities, and

communities that represent traditions 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 of color, and with various faith backgrounds to more fully describe and

understand the experiences of people with disabilities in all faith communities

        Finally, most of the literature on faith and disability focused on the experience or value of

faith for people with disabilities. Shogren and Rye (2005) and Lifshitz et al. (2009) found that

people with IDD have the same range of experiences of faith as the general population. They

found that people with IDD have the same measures of intrinsic religiosity as the general

population, documenting that people with IDD are just as likely as the general population to have

a strong disbelief, strong belief, or be somewhere in between. Further, people with disabilities

have the same wants and needs, the same desire for learning, relationships, meaning and growth

as their counterparts without disabilities. It is time for faith and disability research to move

beyond questions of *if* people with IDD have faith or faith experiences that are valuable or

important 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 meaning and engagement with strong natural supports

for healthy outcomes for members of all abilities. We developed this case study to examine the

experiences of people with IDD in an intentionally inclusive congregation. Our findings

document that faith communities are well positioned to support people with disabilities and can

be a place for people with IDD to connect, to engage, to lead, and to explore their passions. At

St. Thomas, 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.

Their experiences underscore the importance for faith community leaders, disability rights

advocates, educators, theologians, families, and people with IDD to create communities and

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

can contribute, and where they belong. Expanding the capacity of faith communities

to support a variety of roles for people with IDD in the faith community will allow them to

explore and use their talents and passions while contributing to the function and joy of the faith

community.

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Table 1

Participant Demographics

Participant	Disability	Age category/ethnicity/race/gender	Role in FC
Sydney	ASD, ADHD	15-24, White, non-Hispanic, female	member
James	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. ADHD = Attention Deficit Hyperactivity Disorder; ASD = Autism Spectrum Disorder;

FC = faith community.

Table 2

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	No required credentials for leadership participation and/or not 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
2a. Church relationships	Individuals with whom participants engaged in an activity at the	*Well I'm definitely friends with a lot of, um, kids but there's*

Theme or subtheme	Definition	Key excerpt
	church or someone with whom they shared an interest but not always people with whom they had close personal relationships.	*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	Attending faith community events and activities with their family members, or at the request of family members; holding 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 aave 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