Received as an Angel: A Look at Inclusion of Members with Intellectual and Developmental

Disabilities in Metro East Churches

#### Anna Belmonte

#### Introduction

As an integral part of community life for many Americans, churches are ideally positioned to support individuals with disabilities who may otherwise struggle to be accepted and involved in the larger community (Finn & Utting, 2017; Liu, Carter, Boehm, Annandale, & Taylor, 2014; Mulvihill & Speck, 2009). Despite this potential opportunity, disability literature is largely silent on how churches meaningfully support individuals with disabilities, including those with intellectual and developmental disabilities, in spiritual life (Ault, Collins, & Carter, 2013; Carter, Boehm, Annandale, & Taylor, 2016; Carter, Kleinert, Lobianco, Sheppard-Jones, Butler, & Tyree, 2015; Griffin, Kane, Taylor, Francis, & Hodapp, 2012; Liu et al., 2014). In fact, in many cases, churches are unequipped to support congregants with disabilities to their fullest potential, resulting in further community barriers to this marginalized group (Ault, Collins, & Carter, 2013; Mulvihill & Speck, 2009; Richie, 2015; Vogel, Polloway, & Smith, 2006).

The purpose of this research and project proposal is to address the gap in the literature about intellectual and developmental disability support in local churches and to recommend that the Professional Writing and Rhetoric (PWR) program at McKendree University addresses this need through service-learning scholarship.

In the body of this report, I first investigate the current literature addressing disability in faith communities. Next, I report on my own research about the extent to which individuals with intellectual and developmental disabilities are accommodated and included in programs, activities, and ministries in Protestant and non-denominational churches in St. Clair and Madison Counties in Illinois. Then, using the research data, I develop a project proposal to present the opportunities I found for service-learning scholarship for the PWR program at McKendree University.

## Background

Individuals with disabilities are the largest minority group in the world (Disabled World, n.d.) and represent a large portion of the American population. According to the U.S. Census Bureau, nearly 40 million Americans had a disability in 2015, which is 12.6% of non-institutionalized individuals in the country (Bialik, 2017). Additionally, over 2.8 million children in the U.S. have a disability, which is one in every 20 American children (Richie, 2015). In recent decades, national attention has turned to these individuals, recognizing their right to have equal access to education, the community, and other social services. The Americans with Disabilities Act (ADA) of 1990, amended in 2008, prohibits discrimination against individuals on the basis of disability and guarantees civil rights protections to them, ensuring they receive employment, transportation, government services, and accommodations through institutions, such as schools and workplaces (ADA National Network, n.d.). The purpose of these protections is to achieve equal opportunity for individuals with disabilities to succeed in all areas of life. However, there remains an

area of many Americans' everyday lives that, in many cases, remains inaccessible to people with disabilities: faith communities.

Studies have found that faith is just as important to individuals with disabilities as it is to their non-disabled counterparts, with 84-87% reporting their faith to be very important to them (Carter et al., 2015; Finn & Utting, 2017; Hobbs, Bonham, & Fogo, 2016; Vogel, Polloway, & Smith, 2006). Individuals with disabilities participate in their faith communities to grow spiritually, gain acceptance and friendship, and experience a sense of belonging, which is shown to lead to enhanced quality-of-life and resiliency in the face of illness or disability (Ault, Collins, & Carter, 2013; Carter, Boehm, Annandale, & Taylor, 2016; Griffin et al., 2012; Liu et al., 2014; Mulvihill & Speck, 2009; Sango & Forrester-Jones, 2018; Vogel, Polloway, & Smith, 2006). Furthermore, an inclusive environment and friendships between congregants with and without disabilities are beneficial for the entire faith community (Amado, DeGrande, Boice, & Hutcheson, 2011; Barnes, 2012; Finn & Utting, 2017; Liu et al., 2014; Richie, 2015).

Nevertheless, individuals with disabilities, especially those with severe disabilities, are much less likely to participate in community groups, including churches (Ault, Collins, & Carter, 2013; Carter et al., 2015; Griffin et al., 2012; Verdonschot, Witte, Reichrath, Buntinx, & Curfs, 2009). There is a 13% gap in the participation rate of individuals with disabilities as compared to their non-disabled counterparts (Barnes, 2012). Furthermore, individuals with disabilities who do participate within their faith communities often encounter barriers, stigmas, and a general lack of support and understanding (Ault, Collins, & Carter, 2013; Finn & Utting, 2017; Griffin et al., 2012; Mulvihill & Speck, 2009; Richie, 2015; Vogel, Polloway, & Smith, 2006). According to Iozzio (2018), people with disabilities

"stand literally and figuratively outside of the churches and houses of worship" (Section 5, para. 1).

Churches are morally compelled to extend hospitality, protect human rights, and care for the vulnerable (Gaventa, 2006; Iozzio, 2018; Powell, n.d., Richie, 2015). According to Gaventa (2006), "Including, accepting, and celebrating the gifts of everyone and the diversity of humankind is...not something new, but rather a response that represents the best of religious traditions and beliefs and illustrates the heart of key theological issues" (para. 2). Despite this obligation, faith communities often fail to acknowledge those with disabilities, which results in obstacles for these individuals (Mulvihill & Speck 2009; Richie, 2015). There may be multiple reasons churches do not welcome and include individuals with disabilities in their congregations to their fullest potential, including various barriers, legal exemptions, and a broader model of disability that often "others" people with disabilities. Before looking in more detail at these barriers, it is important to define the population of individuals with disabilities for this research.

## Defining Intellectual and Developmental Disability

Developmental disability (DD) can be defined broadly as characteristics outside of the norm that limit a person's ability to independently participate in society (Odom, Horner, Snell, & Blacher, 2007). More specifically, individuals with DD experience "delays, disorders, or impairments. . . within traditionally conceived developmental domains such as cognitive, communication, social, or motor abilities" (Odom, Horner, Snell, & Blacher, 2007, p. 4). Due to its early onset, DD impairs a person's maturation, learning, and/or social adjustment (Odom, Horner, Snell, & Blacher, 2007). These disabilities affect all racial,

ethnic, and socioeconomic groups, with about one in six (15%) U.S. children ages 3-17 diagnosed with at least one developmental disability (Centers for Disease Control and Prevention, 2018). Some prevalent forms of DD include Autism Spectrum Disorder (ASD) and Attention-Deficit/Hyperactivity Disorder (ADHD); hearing and vision loss that occurs during the developmental stage are also considered developmental disabilities (Centers for Disease Control and Prevention, 2018).

The substance of this study addresses a subset of developmental disabilities known as intellectual disabilities (ID). ID is "characterized by significant limitations in both intellectual functioning and in adaptive behavior" and originate in the developmental period before age 18 (American Association on Intellectual and Developmental Disabilities, n.d., para. 1). ID limits an individual's mental capacity, including their ability to learn, reason, and problem-solve, and inhibits the development of important behavioral skills, such as understanding concepts, navigating social situations, and completing basic tasks (American Association on Intellectual and Developmental Disabilities, n.d.; American Psychiatric Association, n.d.). The DSM-5 refers to ID as "intellectual developmental disorder" to acknowledge that onset begins in the developmental period (American Psychiatric Association, n.d.).

The terms used to label and describe intellectual and developmental disabilities (IDD) are in constant flux. Terms, such as "feeblemindedness" and "mental retardation," are a relic of the past and are no longer acceptable, as scientific research and diagnostic criteria evolve and improve our understanding of these conditions (American Association on Intellectual and Developmental Disabilities, n.d.; Iozzio, 2018). Since DD and ID sometimes overlap in definition and manifestation, it is important to establish the specific population

within IDD research. For this research project, I used the term "developmental disabilities" in the survey. I provided categories of disabilities, examples of each type of disability, and a link to a source that gave greater detail. Though I used the term DD, nevertheless, the population I investigated is characterized by limited intellectual and behavioral competence. DD is commonly used by the general public and by research prior to 2007 to refer to individuals with these limitations. Furthermore, books published before 2000 predominantly use the term DD (Google Books Ngram Viewer, n.d.). Because the term ID has only entered research and common use in the 21st century, ID is still not a mainstream concept. However, in my analysis, I will use the more inclusive term IDD to discuss the results.

I chose to investigate IDD, specifically disabilities that impact intellectual and behavioral functioning, because I have two brothers and two cousins with IDD. One brother has ASD and Obsessive Compulsive Disorder (OCD) comorbidly; the other brother has a learning disability that inhibits his ability to hear, interpret, and respond to audio information. Two of my cousins fall on the Autism Spectrum with varying degrees of functionality. I have experienced first-hand the lack of basic understanding about IDD with my own relatives and recognize the responsibility of the church to minister to the whole body of believers, a responsibility that seems to be misunderstood or left unfulfilled.

## Purpose of This Research

The purpose of this research is to discover to what extent individuals with IDD are included and supported within local churches in two Illinois counties, in order to identify common barriers and gaps in the discourse about disability and to give direction for

further research and service-learning projects for the PWR program. I examined the current literature about disability within faith communities, as well as surveyed a local sample of Protestant and non-denominational churches. As a pilot study seeking to gauge the climate of local churches regarding individuals with disabilities, this research asks the overarching question:

How are individuals with intellectual and developmental disabilities being included and accommodated (or not included and not accommodated) in educational programs, activities, and ministries within Protestant and non-denominational churches in St. Clair and Madison Counties in Illinois?

## **Current Situation**

To discover the extent to which this subject has been addressed in the current literature, I first searched for peer-reviewed research on disability accommodation in churches from 2000 to 2018. The search term "churches and disability" through EBSCO Discovery Service generated 38,100 results and generated 33,900 results through Google Scholar, with varying degrees of relevance. The term "churches and intellectual disability" generated 12,361 entries in EBSCO and 17,700 in Google Scholar, whereas the term "churches and developmental disability" generated 10,967 entries in EBSCO and 19,300 in Google Scholar. The relevance of the articles varied, and I could not access many of them. The research that I found did not address disability accommodations, programs, and ministries within church congregations to the extent that I wanted to investigate.

Approaches to Understanding Disability

The evolving concept of disability "results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on the equal basis with others" (United Nations Human Rights, n.d.). Furthermore, theologians have wrestled with the many ways to interpret disability, and diverse meanings attached to disability are contested in the church (Liu et al., 2014; Richie, 2015; Vogel, Polloway, & Smith, 2006). Four approaches to understanding disability have had an enormous impact on the treatment of individuals with disabilities: the charity, medical, social, and human rights approaches.

The charity approach positions individuals with disabilities as objects of pity and their disability as tragic (United Nations Human Rights, n.d.). They are seen as incapable of caring for themselves and in need of charity (United Nations Human Rights, n.d.). The medical approach considers disability as abnormal and something that needs to be "cured," concentrating on an individual's impairments and positioning those with disabilities as passive patients (Mulvihill & Speck, 2009; United Nations Human Rights, n.d.). Understood this way, individuals with disabilities are seen as unable to live independently and in need of rehabilitation to adequately participate in society (United Nations Human Rights, n.d.).

On the other hand, the social approach acknowledges biases and barriers that prevent individuals with disabilities from full participation in society and affirms that the social environment limits or empowers those with disabilities; disability, therefore, is a societal issue and not an individual one (United Nations Human Rights, n.d.). The focus is on accessibility, inclusivity, diversity, the elimination of barriers, and the increased participation of individuals with disabilities in society (United Nations Human Rights, n.d.).

Going farther than the social approach, the human rights approach to disability focuses on the inherent dignity of individuals, recognizing that those with disabilities are entitled to the same human rights afforded to their "abled" counterparts (United Nations Human Rights, n.d.). Human rights focuses on equal opportunity, social inclusion, respect for diversity, eliminating discrimination, and legally protecting the rights of individuals with disabilities (United Nations Human Rights, n.d.).

With continual advances in disability research, the social and human rights approaches are increasingly common. Consequently, individuals with disabilities are treated with more dignity than they were afforded in the past. Even the terminology with which disability is described has shifted from medical and limits-based language to "people-first" or "identity-first" language that affirms the individuality of each person, regardless of limitations that they experience (Iozzio, 2018).

#### **Barriers**

In their day-to-day lives, families with disabilities often encounter quality-of-life setbacks in relation to health, social, and emotional disparities, and a lack of access in the community compounds upon these adverse effects (Gaventa, 2006; Hobbs, Bonham, & Fogo, 2016; Mulvihill & Speck, 2009).

Section 2(a)(5) of the Americans with Disabilities Act of 1990 (U.S. Congress, 1990) reads:

"Individuals with disabilities continually encounter various forms of discrimination, including outright intentional exclusion, the discriminatory effects of architectural, transportation, and communication barriers, overprotective rules and policies, failure

to make modifications to existing facilities and practices, exclusionary qualification standards and criteria, segregation, and relegation to lesser services, programs, activities, benefits, jobs, or other opportunities."

Though ADA and subsequent legislation have taken strides to reduce these barriers, the reality of social, legal, and institutional exclusion persists today. According to a study of two national congregational programs to socially include individuals with IDD, Amado, DeGrande, Boice, and Hutcheson (2011) describe five types of barriers that prevent full inclusion in faith communities: architectural (or structural) barriers, attitudinal (or stigmatizing) barriers, communication barriers, programmatic barriers, and liturgical (or religious participation) barriers. However, perhaps the most challenging barriers are not financial or architectural, but rather are attitudinal barriers resulting from a lack of knowledge and awareness, which creates an atmosphere of fear and avoidance rather than inclusion and acceptance (Barnes, 2012; Gaventa, 2006; Hobbs, Bonham, & Fogo, 2016; Mulvihill & Speck, 2009; Vogel, Polloway, & Smith, 2006).

## **Legal Exemptions**

Furthermore, there is a tenuous balance between the Establishment Clause and the Free Exercise Clause of the U.S. Constitution. Because of the separation of church and state, laws that would apply to non-religious institutions cannot be enforced on religious organizations, such as churches (Taylor, 2012). Consequently, "churches and places of worship are exempt from ADA and IDEA and can decide how or whether accommodations are made for members or visitors with disabilities" (Mulvihill & Speck, 2009, "Accommodating Disability" para. 3). While churches are relatively free to determine their

own standards and practices, this freedom may result in cases where individuals with disabilities are overlooked or excluded.

#### Method

I used a judgmental sampling of churches for this research project, based on city population and church location, denomination, and online presence. First, I chose the two largest counties in Southwestern Illinois: St. Clair County, with a population of 265,569, and Madison County, with a population of 266,759 (East-West Gateway, n.d.). Within St. Clair and Madison Counties, 12.9% and 12.5% of the population had a disability, respectively (East-West Gateway, n.d.). To the best of my ability, I recorded all cities/towns/villages within these two counties and arranged them by population size. I discarded areas with a population of less than 500. Next, I chose a sample of cities/towns/villages from each county: five large (population of 14,000 or more), three medium (population between 3,000 and 10,000), and two small (population between 500 and 2,500). I found all the Protestant and non-denominational churches in each of these 20 cities/towns/villages, to the best of my ability. I reduced the list of churches by selecting those that had both a website and a means of contacting the church, either through email or an embedded contact form. After these reductions, my final sample consisted of 191 churches.

Next, I developed a survey in Google Forms and sent it to the 191 churches. The churches received a summary of the study, an informed consent notice, and a link to the survey. The survey contained adequate definitions and explanations to inform the participants. I submitted the survey (see Appendix A), the informed consent form (see

Appendix B), and the participant debrief to the Institutional Review Board (IRB) at McKendree University and was approved.

The survey first gave demographic context by asking the size of the congregations, how many individuals had disabilities, and what types of disabilities were present in their congregations. Further, the survey gauged the status of disability ministry for congregants with DD by looking at the presence or absence of accessible programs/ministries, challenges in ministering to individuals with DD, and future plans to implement programs/ministries. Additionally, the survey asked participants whether or not they were willing to follow up with me. The objective of this survey was to give me a snapshot of disability ministry and accommodation in local Protestant and non-denominational churches and to consequently discover where the main difficulties lie in ministering to individuals with IDD.

#### Results and Discussion

After emailing the survey to my sample group, I had to troubleshoot errors, such as unavailable addresses. To the best of my ability, I sought alternative addresses to send the survey through. Three months later, I resent the survey to garner more responses. After about an additional month, I closed the survey.

#### Response Bias and Nonresponse Error

Out of the 191 churches chosen for this study, 24 churches returned a completed survey, representing a nonresponse bias of 87.43%. Additionally, I discarded one survey response because the respondent misunderstood question two on the survey, leaving 23 surveys for the data analysis. Such a low response rate makes it likely that there is

response bias or nonresponse error (Draugalis, Coons, & Plaza, 2008). Only 44% of respondents that indicated they had programs/ministries in place to support congregants with DD included DD in their response to question four, with none of the respondents *only* discussing DD. Evidently, there was a misunderstanding of question four. This is a type of response bias called satisficing, in which respondents "expend little effort in the interpretation and answering of questions" (Sax, Gilmartin, & Bryant, 2003, p. 411).

However, due to the nature of this research project and the sample selected to take the survey, having only a 12.57% response rate is to be expected. Survey response rates, especially to surveys sent through email, have been declining over the decades, with only the most optimized, personalized, and incentivized surveys reliably garnering responses (Fincham, 2008; Holbrook et al., 2007; Sax, Gilmartin, & Bryant, 2003). Time and resource constraints prevented me from incentivizing the survey, completing more follow-ups, and contacting a larger sample of churches, all of which could have improved the response rate (Coggon & Martyn, 1991).

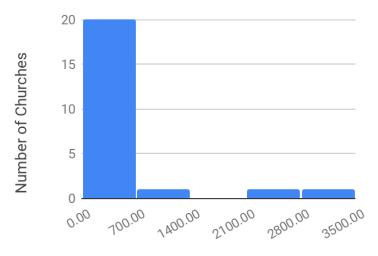
Notably, the sample group consists of churches, organizations that rely primarily on donations and may have few resources to voluntarily complete a survey. Respondents are self-selected, so responses may come primarily from churches that have Internet access, have a staff member to respond to emails, or are willing to discuss disability openly (Draugalis, Coons, & Plaza, 2008).

Despite the possible presence of response bias and nonresponse error, the results of this survey bring to light some possible trends within local churches regarding support for congregants with disabilities that should be addressed. As a pilot study exploring a subject that the current literature remains largely silent on, the results of this research project

could open dialogue in this area of disability studies: the intersection of disability and faith communities. Furthermore, the results of this research provide direction for future research and reveal a potential opportunity for students in the PWR program at McKendree University to help churches communicate about disability and take steps towards implementing accessible programs and ministries in local congregations.

Congregation Size and Disability Representation

# **Congregation Size**



**Number of Congregants** 

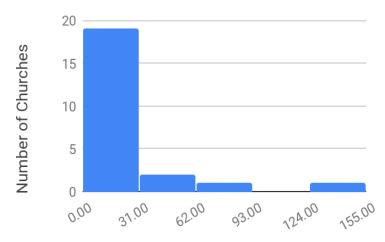
From the churches that completed the survey, there was a total of 9,549 congregants; 568 (or 5.9%) of these congregants had disabilities. The median congregation size was 150 individuals. The median more accurately reflects the average congregation size, due to three congregations with over 1,000 members that skew the mean. Therefore, I will use the median to represent the congregations. See the graphs for a breakdown of the total number of congregants in the churches, followed by the number of congregants with disabilities.

The most prevalent

disabilities were

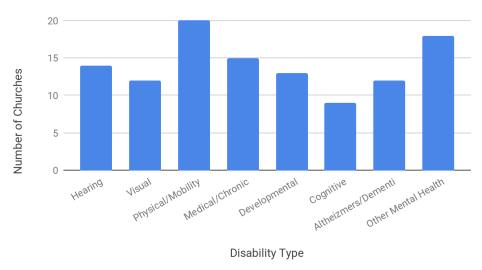
Physical/Mobility disabilities and Other Mental Health disabilities. Thirteen churches marked that they had at least one congregant with DD. The graph below summarizes the distribution of disabilities in the congregations.

# Congregants with Disabilities



Number of Congregants with Disabilities

## Distribution of Disabilities



## **Disability Accommodations**

78% of churches indicated that they had programs/ministries that accommodate congregants with DD. The average size of churches that claimed to provide accommodations was 481.6 individuals, whereas the average size of churches that did *not* claim to provide accommodations was 176.2, which suggests that a church's size predicts its ability to provide supports for congregants with disabilities, with larger churches providing more accommodations than smaller churches.

	Average Church Size	% With Disability
Accommodates (78%)	482	4.25%
Does <b>Not</b> Accommodate (22%)	176	1.98%

Adjusting for church size, 4.25% of the congregants had a disability in the churches that claimed to provide accommodations, and 1.98% of the congregants had a disability in the churches that did *not* claim to provide accommodations. Taken in conjunction with the relation between church size and accommodations, this could indicate that larger churches that provide more accommodations attract or retain more members with disabilities than the smaller churches that do not accommodate their members.

## Developmental Disability Programs/Ministries

It should be noted that, although 78% of churches responded that they had programs/ministries in place to support congregants with DD, 74% elaborated on these programs/ministries, and *none* of them described *only* DD in their elaboration. In fact, only 44% of respondents that indicated they had programs/ministries for those with DD included DD at all in their elaboration, with 56% describing supports for other types of disabilities instead. As noted earlier, this could be due to a misunderstanding of the survey question.

Those that described accommodations, programs, and ministries for congregants with DD had some valuable ideas to share, both in large churches and small churches. The largest church respondent (3000 members) described their "buddies" program for children with disabilities, "Respite Nights" for parents and caregivers, and teacher training.

Similarly, the second largest church has a "Wonderfully Made Ministry [that] provides buddies in the classroom to partner with children. . .with disabilities," two sensory rooms, an "adapted learning environment for children," respite nights, and support groups for parents of children with special needs. Other respondents said their churches provide

counselling, pastoral visits, adapted confirmation classes, tailored ministries, tutoring, and a summer program for students with special needs.

Several churches indicated that their members with disabilities participate in various capacities within the church, such as ministries, office support, educational programs, and potlucks. Although the largest churches noted the most comprehensive accommodations, programs, and ministries, it seems some smaller churches are finding a way to include members with disabilities. One small church has a "Sensory Safe Place for younger children with Autism/Asperger's." Another very small church (64 members) provides "picture worship guides," rocking chairs and ottomans in the sanctuary, fidget toys, and headphones for those who are irritated by sound.

One respondent shared:

"This is a huge weakness in the church in general. We should be making more of an effort across the board to love and care for those who so often get overlooked or mistreated in society. My heart is that we would become more Christlike in this area and love/care for people well."

## Plans for Future Programs/Ministries

When asked what plans they had for starting programs/ministries to support individuals with DD or adjusting current programs/ministries to be accessible, 48% of respondents elaborated. Of those that elaborated, only four churches noted specific plans for developing supports in the future. Only one of these churches was a large church (in the 3<sup>rd</sup> quartile). Therefore, there is no correlation between church size and future plans. Of the

22% who indicated that they did not *currently* have programs/ministries for congregants with DD, none indicated that they had future plans to create inclusive programs/ministries.

Those that indicated they had plans for developing future programs/ministries had some interesting ideas to share. One said their church planned to create a "quiet space" for students with special needs; another church planned to train teachers to start a children's ministry for children with disabilities; and yet another indicated their church is beginning an "Open & Affirming" process to make their church more welcoming to those with disabilities. Another small church planned to advertise on community Facebook pages to attract more families with disabled children.

## **Identified Challenges**

It was clear that not all respondents felt equipped to develop and implement disability supports in their churches; 83% of respondents elaborated on challenges they experienced in supporting congregants with DD. These challenges ranged from resource limitations to barriers from other congregants.

One respondent shared the resource limitations their church faces:

"Ensuring that we have enough buddies/mentors to meet the growing need of ministering to those with disabilities; ensuring that we have enough safe space and tools to meet the sensory needs of different individuals; ensuring that leaders of other teams that minister to these individuals, such as children and student ministry, are comfortable with these individuals and are encouraging inclusiveness as much as possible. . . the ministry has grown because of word of mouth, which often maxes out

our team, as far as having enough help week to week. Because we grow in house, we are not able to spread our ministry out to the community as much as we would like."

Several respondents indicated that other congregants were uncertain about how to interact with those with disabilities. Some recognized attitudinal barriers in their congregations:

"They weren't accepting at all at first, but through intense education they have made great strides towards acceptance and [inclusion] and not simply tolerance."

"We find families are often uncomfortable entering new environments when one of the children has a disability of some kind, and many of those who serve in our ministries don't have special training in various areas, so equipping our people to adequately care for children with disabilities so their families feel comfortable and welcomed is a challenge."

"We have a few adults with developmental disabilities and I would say the most challenging thing actually has nothing to do with the individual but with the rest of the congregation. I find myself often needing to help others to know...how to minister to our members with developmental disabilities."

"Non-impaired individuals often struggle knowing how best to interact/encourage/support those with disabilities."

When prompted at the end of the survey, 48% of respondents supplied additional thoughts. One respondent reflected on the mission of the church:

"The best thing we can do for each person is to give them the gospel of Jesus Christ; reminding them that God loves them and we do too goes a long way as well."

#### **Project Proposal**

This research project presents a possible lack of discourse about the needs of individuals with IDD and a lack of programs and accommodations for people with disabilities in local Protestant and non-denominational churches. However, 11 of the respondents indicated they were interested in follow-up to discuss their responses. This presents an opportunity for faculty and students in the PWR program at McKendree University to develop service-learning projects in partnership with these churches.

In recent years, institutions of higher education have recognized the need to address ableism in higher education, and some call for a pursuit of justice and equity rather than simply checking the diversity box (Stewart, 2017). The rhetoric surrounding diversity and inclusion often fails to promote the fair and equitable treatment of individuals (Stewart, 2017). Individuals with disabilities face this same issue of diversity without equity, as they attempt to participate in communities that favor the abled by design.

As "agents of change" who are responsive to technological, social, and political climates, professional/technical communicators are taking the forefront on accessibility issues (O'Hara, 2004; Redish, 2010, p. 72). Professional/technical writers and designers play a key role in developing user-friendly documents that both theoretically and practically support accessibility (O'Hara, 2004; Ray & Ray, 1998; Redish, 2010; Salvo, 2001). The field of professional/technical writing places people at the heart of accessible communication, which involves understanding individuals' limitations and needs and advocating for all audiences (O'Hara, 2004; Ray & Ray, 1998; Salvo, 2001). Therefore, technical communicators are equipped to assess the needs of stakeholders and adapt

information to reach new, often overlooked audiences (Ray & Ray, 1998; Redish, 2010; Salvo, 2001).

At its core, the PWR program challenges students to address issues in the immediate community and act as advocates through accessible communication design. Students complete coursework for nonprofit, not-for-profit, or charitable organizations as a part of their studies, equipping them with the knowledge they need to take on service-learning scholarship that assists local churches through disability advocacy and support projects.

PWR students could continue investigating the issues touched upon in my research or engage in collaborative service-learning projects, such as writing grants (a requirement of PWR 450) to fund existing or proposed programs. Students may also assist churches with developing and/or implementing steps towards accessibility in various capacities of the church, such as leader and volunteer training, congregational education, accommodation development, and program/ministry development. The following table displays areas where service-learning scholarship or projects could assist churches in accommodating and integrating congregants with IDD. These areas reflect the needs identified in my research, as well as in the literature as a whole.

Leadership Training:

Ministers/elders/deacons

Women's ministries

Sunday school teachers/volunteers

**Program Development:** 

Summer camps

Sunday school

**Vacation Bible School** 

Classroom volunteers/aides

Congregational education about IDD

Accommodations:

Preferential seating

Cry rooms

Sensory-friendly services

Holistic Ministry:

Home visits

Health and wellness activities

Mentorship

The next steps towards developing and implementing service-learning scholarship in the PWR program would be to first reach out to the 11 respondents from my research that supplied their contact information, complete a needs assessment of these churches, and conduct additional research to understand needs and develop potential solutions. PWR faculty can present this to students as a component of their coursework or as an opportunity to develop their skills as professional/technical writers through volunteer work.

As the current situation stands, many local churches, especially small and underfunded churches, face resource constraints, attitudinal barriers, and other challenges with ministering to congregants with IDD. Left unaddressed, barriers that hinder a person's full participation in faith communities can cause individuals with disabilities and their families to feel that they are being turned away at the door. The communities that have a clear responsibility to welcome the entire body of believers, to care for the disadvantaged in society, and to create an environment where every person's value and dignity is upheld are the very communities, in many cases, where access is denied.

# Appendix A: Survey

	agreed to participate in the HON 401 research study. I agree
1. App	roximately how many members/regular attendees are in your congregation?
or mer	llowing questions are about disability in your congregation. A <u>disability</u> is any physical ntal limitation that significantly affects a person's ability to participate in everyday ies. For additional info on different types of disability, click <u>here</u> .
2. App	roximately how many members/regular attendees in your congregation have a lity?
	he best of your knowledge, what types of disabilities do members/regular attendees (You may select more than one)
	Hearing impairment (ex. Deafness)
_	Visual impairment (ex. Vision loss, blindness)
	Physical/mobility handicap (ex. Use of wheelchair and other mobility aids)
	Medical/chronic disability (ex. Cancer, cerebral palsy, spina bifida, epilepsy)
	Developmental disability (ex. Autism, asperger's, Down syndrome)
	Cognitive disability (ex. Difficulty with reading, speaking, math, language use, etc.)
	Alzheimer's/dementia
	Other mental health (ex. Depression, bipolar, PTSD)
4. For	members/regular attendees with developmental disabilities, does your church have
any pr	ograms/ministries that accommodate their disability so that they can participate?
	Yes

□ No
If <u>yes</u> , please list and describe the ministries/programs below:
What challenges have you encountered ministering to members/regular attendees with developmental disabilities?
5. What plans, if any, does your church have to start programs/ministries to support members/regular attendees with developmental disabilities, or to adjust existing programs to be more accessible? Please describe below:
6. Please provide any additional thoughts regarding disability programs/ministry below (such as other disability supports in your congregation, obstacles to ministering to those with disabilities, etc.):
7. Would you be interested in follow-up, as needed, to discuss your responses?  ☐ Yes ☐ No
If <u>ves</u> , please provide your preferred contact information:

Appendix B: Informed Consent Form

**Informed Consent Form for HON 401 Honors Thesis** 

This informed consent form is for the participants who are invited to participate in the

Spring 2018 HON 401 Honors Thesis research project titled, "A study of inclusion efforts

for individuals with developmental disabilities in a Southwestern Illinois sample of

Protestant and non-denominational churches."

Name of Student Investigator: Anna Belmonte

Name of Faculty Advisor: Dr. Stephanie Quinn

Name of Organization: McKendree University

Name of Project: A study of inclusion efforts for individuals with developmental

disabilities in a Southwestern Illinois sample of Protestant and non-denominational

churches

Introduction

I am Anna Belmonte, a Senior Professional Writing & Rhetoric and Honors student at

McKendree University in Lebanon, Illinois. I am engaging in this research project for HON

401 Honors Thesis.

**Purpose of the Research** 

The purpose of this study is to discover to what extent Protestant and non-denominational

churches within two Southwestern Illinois counties are aware of individuals with

developmental disabilities (DD) within their congregations and how they integrate and

support these individuals. This research is investigating an issue that is rarely addressed in

scholarly work, yet has significant ramifications for faith communities and individuals with

DD who desire to participate in these communities.

**Type of Research Intervention** 

This research will involve participation in an online survey that will take approximately 30

minutes to complete.

**Participant Selection** 

You were selected based on your location within St. Clair or Madison County and your status as a Protestant or non-denominational church. Approximately 200 churches within these counties were also selected to take part in this research project.

## **Voluntary Participation**

Participation in this research project is entirely voluntary. You may choose not to complete the survey.

### **Procedures**

Please submit the linked survey within 30 days.

#### Risks

You are being asked to share demographic data about your congregation, although no names or personally identifying information will be requested. You will experience minimal risk, as only aggregated data will be used. Additionally, you may decline to participate in the research.

#### **Benefits**

While there is no direct benefit to you, you may gain insight about your own practices regarding disability by thinking critically about inclusion efforts within your own congregation. Furthermore, your responses may help to open discourse about support for individuals with DD within faith communities.

### Reimbursements

You will not be provided any incentive to take part in the research.

## **Confidentiality**

None of the information gathered will be shared by the researchers: the student investigator and faculty adviser. Individual survey responses will not be used, but aggregated data only. Survey responses will be saved on a password-protected hard drive, accessible only to the student researcher and faculty adviser.

## **Sharing the Results**

The information collected from this research project will be kept private. Only the researcher will have access to sensitive information and will not share this information with anyone. Aggregated data, without personally identifying information, will be used throughout the Honors Thesis course and may be shared with the public.

## Right to Refuse or Withdraw

You have the right to refuse participation in this research project or withdraw your responses once submitted by contacting the researcher.

## **Who to Contact**

Please contact Anna Belmonte or Stephanie Quinn with any questions:
anna.belmonte15@mckendree.edu
smquinn@mckendree.edu
irb@mckendree.edu

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