ABSTRACT

INTERVENTION STRATEGIES FOR THE PARTICIPATION OF PEOPLE WITH AUTISM SPECTRUM DISORDER IN COMMUNAL WORSHIP EXPERIENCES

by

James Thomas Lowery, III

Autism Spectrum Disorders (ASDs) are the greatest collection of communicative disabilities in the country today, and the number of children diagnosed with ASD increases each year. According to the Centers for Disease Control, the number of children identified with Autism Spectrum Disorder is one in eighty. The Centers for Disease Control has also determined, since 1997 that the prevalence of autism in children ages 3-17 in the United States has increased 289.5 percent. Many families of these children, youth, and adults with ASD are not attending worship because it has become such a difficult and exhausting experience. Communal worship strengthens relationships between parent and child, people and the church, and the church with God. Being removed from worship restricts their understanding of self, others, and God's love of for everyone. Worship attendance of people in the autism population is in deficit due to the neglect of their specialized needs by the neurotypical faith community. Creating a worship environment accommodating those special needs will engage the autistic community with the faith community, bringing the faith community closer to resembling the body God intended it to be.

This project was a qualitative grounded research theory. Survey data was used to standardize the collection of personal experiences related to worship and ASD. Results

from surveys of persons, families, caregivers of persons with ASD, and therapeutic professionals were used to compile a list of suggested worship accommodations and shared with current worship planners through an accommodation suggestion survey. Worship planners discerned the effectiveness and ease of implementation of the suggested accommodations. Results of the discerned accommodation suggestions were shared with worship planners to support their inclusion of people with ASD in communal worship services.

Change is a healthy evolution from what *was* necessary to be effective to what *is* necessary to be effective. Churches have seemed reluctant to adapt to the needs, of worshippers with special needs but the changes they are being encouraged to make by people with ASD, their families, and their caregivers are not difficult to make and mostly require a patient and willing spirit. Three major findings were that (1) church leaders who have a negative attitude towards ASD/accommodations drive away people with ASD, their families, and their caregivers; (2) volunteers who are physically present with the individuals with ASD make a positive impact on the communal worship experience for people with ASD, their families, and their caregivers; and (3) accommodations that may provide the greatest impact during a communal worship service for people with ASD may be the least invasive.

DISSERTATION APPROVAL

This is to certify that the dissertation entitled

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CHAPTER 1

PROBLEM

Introduction

"Repent, for the kingdom of God has come near.... Prepare the way of the Lord, make his paths straight" (NRSV,) pleas John the Baptist in Matthew 3:2-3. John may not have been a worshipper in today's congregations, but he seems to have known a great deal about what happens in worship. Some members of God's family are not being prepared for services in church. Some members of God's kingdom have come near but not been welcomed into God's house. Beloved creatures of God's creating have not been nurtured because they are different. The church must repent and respond to John's call for preparation because the church has done little to help those who are disabled find a path to God or a path to worship in God's presence and within God's congregation. The community of adults and children with disabilities grows larger each year, and their participation within a community of faith continues to decrease (Scahill and Bearss 51).

According to the 2010 U. S. Census, 41,259,809 people have disabilities ("Table 1"). These children are born with various forms of intellectual disabilities, nerve and muscle disorders, blindness, deafness, neurological disorders, paralyzation, and missing limbs. The United States government has responded with political compassion in 1990 through the Americans with Disabilities Act (ADA), requiring facilities to become readily accessible to and usable for people with disabilities (*Americans with Disabilities Act*). The government spoke to the disabled population a word of welcome and to the able-bodied population a word of preparation.

Ten years after the ADA was signed into law, an unpublished survey of one hundred churches in Chicago, Illinois, found none of the churches required by law to be accessible to people with disabilities. Based on personal experience, the survey in Chicago is still consistent with the church's preparatory response today. Even though churches are only required to comply with ADA standards if they employ fifteen people or more, "the doctrinal and moral beliefs of many religious organizations suggest that all people should be able to attend communal worship, rather than just able-bodied people" (Vierkant, Hollingsworth, and Stark). Not preparing for all of God's people to participate in worship to a God who loves all people sends a message of lower value, nonimportance, and unworthiness to those who cannot be present and cannot participate.

Though the ADA is directed to all who have functional disabilities, a population frequently neglected are those who have communicative disabilities. Communication deficits impede a person's ability to communicate effectively with another person. This deficit may be one of speech, but it may also extend to areas of social cue comprehension, irregular physical movements such as arm flapping or rocking, and an intuitive understanding of the rules governing shared conversation among others. Autism Spectrum Disorders (ASDs) are the greatest collection of communicative disabilities in the country today, and the number of children diagnosed on the spectrum increases each year. According to the Centers for Disease Control (CDC), the number of children identified with Autism Spectrum Disorder is one in eighty with the Autism and Developmental Disabilities Monitoring Network reporting increases every year since 2000. The CDC has also determined, since 1997, the prevalence of autism in children

ages 3-17 in the United States has increased 289.5 percent ("Autism Spectrum Disorder").

The Autism Society of North Carolina's Outer Banks chapter was established as a place for parents and educators struggling with issues around ASDs to gather and discuss interventions and strategies to help the children for whom they care. The chapter soon began attracting parents and educators of children with varying types of disabilities, ranging from Down's syndrome to Asperger's disorder. While the official topics and public discussions dealt with treatment options, interactions with local schools, and therapist recommendations, many of the side conversations dealt with family dynamics, community support, and church participation.

Many families of these children, youth, and adults with ASD are not attending worship. Worship has become such a difficult and exhausting experience. Many families with disabled children express they were not going to return to church. Many who did return did so for only a few more services and were hiring other caregivers to serve their disabled children, allowing the parents to participate in worship. Eventually, these local families had removed themselves entirely from the faith community of their presence and their disabled children's presence from worship as well as the worshipping community's presence from their children. Further discussion with Jill Scercy of the Autism Society of North Carolina as well as research by John Swinton and Christine Trevett revealed that the absence from worship of children with autism and their caregivers was common throughout the larger autism community.

Communal worship strengthens relationships between parent and child as well as husband and wife by infusing them with significance and meaning (Mahoney 690).

People best understand who they are and how they should live when in the presence of the God who made them and the God from whom they are to live (Dawn, *Royal Waste* 26). Being removed from worship restricts one's understanding of self, of others, and of God's love for everyone.

Worship attendance of people in the autism population is in deficit due to the neglect of their specialized needs by the neurotypical faith community. Creating a worship environment accommodating those special needs will engage the autistic community with the faith community, bringing the faith community closer to resembling the body God intended it to be.

Purpose

The purpose of the research was to describe the specialized needs of a worshipper with Autism Spectrum Disorder and create intervention guidelines that address ASD-related needs during an inclusive worship service.

Research Questions

The following research questions were answered using a spiritual community experience surveys and a predictive accommodation effectiveness survey to direct the creation of worship service intervention strategies, assisting children, youth, and adults with ASD to participate more fully in worship.

Research Question #1

What experiences have caregivers of children, youth, and adults with ASD had in communal worship?

Research Question #2

What interventions do caregivers of children, youth, or adults with ASD predict will make communal worship participation a more positive experience?

Research Question #3

What accommodations may be helpful for the inclusion of a person with ASD into a communal worship service?

Definition of Terms

The following terms may be unfamiliar to the general population or approached with an unhealthy understanding. The definitions provided indicate their use within this research.

Autism is neurological disorder hindering a person's ability to understand social situations and interact within them appropriately. Common difficulties arise in areas of speech, understanding/awareness of social cues, eye contact, and sensory sensitivity.

Asperger's disorder is the highest functioning form of autism available for diagnosis within the previous edition of the psychological diagnostic manual (*Diagnostic and Statistical Manual,* 4th ed. [*DSM-IV*]). People diagnosed with Asperger's were identified as having some of the same social deficits as people diagnosed with autism but did not show evidence of a speech delay when younger as required for a diagnosis of autism. The most recent version of the psychological diagnostic manual (*Diagnostic and Statistical Manual,* 5th ed. [*DSM-V*]) does not include Asperger's disorder.[1] This term is

[1] The *DSM-V* has recently adjusted the diagnostic criteria for autism and ASD while completely removing the diagnosis of Asperger's Syndrome. There is a great deal of debate in the autism community around the autism-related changes in the *DSM* between the fourth and fifth editions.

included in this project because many people participating in the surveys will have received the Asperger's diagnosis under the criteria of the *DSM-IV*.

Autism Spectrum Disorder refers to the understanding of autism as a neurological disorder affecting each person with autism differently, resulting in a range of symptoms from very mild to extremely severe. ASDs include high and low functioning autism as well as Asperger's disorder.

Caregivers are individuals who provide the primary care and nurturing to the children, youth, and adults with autism. They will typically be the child's parents but sometimes may be a grandparent, other family member, or legal guardian.

Communal worship is public worship within a larger group of Christians. Communal worship is traditionally a Sunday morning worship service but may also be a congregational worship service at another time or day of the week.

Faith communities are gatherings of people worshipping, learning, and serving together. Faith Communities are most commonly understood as local churches but also include communities that gather outside of a traditional church facility. Examples of these communities are collegiate ministry groups, home churches, and extension ministry settings.

Levels one, two, and three are the diagnostic severity levels for ASD under the criteria for ASD diagnosis in the *DSM-V*. The work of this project will deal primarily with people diagnosed at levels one and two.

Neurotypical is a description of the general population not found on the autism spectrum. This term is used by the neurodiversity movement as a label for individuals without a developmental disability.

Service providers and educators are therapists, counselors, and classroom teachers who assist caregivers and children, youth, and adults with autism to develop daily functioning strategies that will allow for more successful and fulfilling life experiences. Occupational therapists, speech therapists, cognitive behavioral therapists, and exceptional children counselors are examples of service providers.

Ministry Project

Seventy-five caregivers of children, youth, or adults with ASD were surveyed to discern previous experiences with their children, youth, or adults in communal worship. Caregivers of children, youth, or adults with ASD, service providers, and educators were surveyed to determine which intervention strategies have been found to be effective in helping children, youth, or adults with ASD communicate with the people and the environment around them.

Results of the surveys and research were a list of interventions and accommodations that may be put in place during an established worship service, used to create a worship service especially suited for people with ASD or used to produce guidelines that may assist in the creation of a worship manual for children, youth, or adults with ASD. Worship planners within faith communities were asked to review the interventions and accommodation guidelines to validate their predicted effectiveness.

Context

According to the Centers for Disease Control, the number of children identified with Autism Spectrum Disorder in 2000 was one in one hundred and fifty. In 2004, that ratio increased to one in one hundred and twenty-five. That ratio increased again in 2006 and 2008. In 2010, the ratio was one in sixty-eight. The prevalence of children identified

with Autism Spectrum Disorder has more than doubled since 2000 ("Autism Spectrum Disorder"). People with ASD are generally accepted by their local faith community but not prepared for by their local church for full inclusion in its worship life. My daughter is one of those children with ASD for whom the local church is ill-prepared and ill-equipped for ministry.

The geographical foci of this study were locations where I have lived and had established relationships within the autism community—North Carolina and Tennessee. According to 2015 projections from the 2010 census, North Carolina and Tennessee have similar demographic percentages. A similar geography lends itself to economic similarities as well. Both states contain mountain ranges, plains, and vast amounts of farmland. They are primarily rural states with urban pockets on the cutting edge of research (North Carolina) and manufacturing (Tennessee). These urban pockets contain the higher performing school districts, higher salaries, and higher number of services dedicated to accommodating special needs. Outside of those urban pockets are rural areas dedicated to agriculture. The rural areas of North Carolina and Tennessee contain a struggling infrastructure, lower income families, schools and health care services that perform below average, and fewer services available for people with special needs (see Table 1.1).

Table 1.1. Comparison of NC-TN-US Demographic Projections for 2015

Category	Tennessee	North Carolina	United States
Population	6,600,299	10,042,802	321,418,820
Minorities	21.1%	28.5%	23.6%
Persons per household	2.53	2.54	2.63
Persons with disabilities	11.2%	9.5%	8.5%
Persons without health insurance	14.1%	15.2%	12.0%
High school graduates	84.9%	85.4%	86.3%
Civilian labor force	61.1%	62.1%	63.5%
Persons in poverty	18.3%	17.2%	14.8%

Methodology

Surveys completed by primary caregivers and adults with ASD regarding previously effective worship accommodations are the genesis of this qualitative grounded research design. Surveys completed by speech and occupational therapists affirmed or initiated an adjustment of the caregivers' suggested interventions. ASD-related accommodations and guidelines for worship inclusion are shaped and then shared with local church worship planners. Local church worship planners were asked to predict the effectiveness of guidelines suggested for use in a communal worship service. Finally, the initial ASD-related accommodations were adjusted and a final list of accommodations and guidelines were made available for local church use.

Participants

Participants in the study were seventy-five families identified by the Autism Societies of Tennessee and North Carolina who have children, youth, or care for adults with ASD. Participating caregivers were identified by the University of North Carolina Treatment Communication and Education of Autistic and Related Handicapped Children

(TEACCH) Center and the Autism Societies of Tennessee and North Carolina with a requirement of previous communal worship experience.

Instrumentation

Resulting guidelines and recommendations were determined by the use of three instruments. The first instrument was an adjustment of E. O'Hanlon's Spiritual Community Experiences Inventory (139-54). This instrument asked caregivers and adults with ASD to evaluate their religious experiences, their satisfaction with those experiences, and the rationale behind the rating of those experiences in an open-ended format. The second instrument was a survey distributed to speech therapists, occupational therapists, and educators to determine ASD-related accommodations. The third instrument was a survey distributed to worship planners to determine the appropriateness of the suggested intervention guidelines.

Data Collection

Previous worship experience surveys of caregivers and adults with ASD were conducted online to be as convenient as possible for the participants. The surveys took ten minutes or less to complete per participant. Previous accommodation experience surveys of service care providers and educators were conducted online to be as convenient as possible for the participants. The predicted intervention and accommodation effectiveness survey was conducted online to be as convenient as possible for the participants.

Data Analysis

A chart was used to process the previous worship experience surveys tracking the events affecting the worship experiences of a child, youth, or adult with ASD. The

influencing themes were identified, separated into groups, and appropriately coded. Charts were also used to track responses to the previous intervention surveys with interventions identified, separated into groups, and appropriately coded. Responses offered by the survey of worship planners were recorded and taken into consideration in the creation of the final draft of the intervention guidelines.

Generalizability

This study focused primarily on the children, youth, and adults of eastern North Carolina and middle Tennessee with ASD. Because of the prevalence of ASD and the autism spectrum's symptomatic consistencies, the suggested interventions could be used with children, youth, or adults with ASD in any communal worship environment. Due to the shared visual struggles between many communication deficit disorders, the suggested guidelines in this study may also be used to enhance the communal worship experience of the deaf population as well.

Theological Foundation

Jesus of Nazareth, in his physical ministry on earth, was God's healing hand to a broken and needy people. Jesus encountered the blind, the lepers, the lame, the mute, the ill, the demon possessed, and the dead. With few exceptions, healing only required a spoken word from the mouth of the Messiah. Jesus is known to many Christians as the divine healer but not many understand Jesus as the divine healer of only a few.

Jesus believed in wholeness but not in physical wholeness. The ministry of Christ was one of spiritual health and not one of physical health. Many received miraculous healings, but still more did not. Lazarus and Jairus' daughter were raised from the dead but they eventually died again, and many who were dead were left in their tombs.

Completeness in the eyes of God does not require physical completeness. Even the broken are loved by God, and the Sermon on the Mount may lead them to believe that the broken hold a special place in the heart of God:

> Which one of you, having a hundred sheep and losing one of them, does not leave the ninety-nine in the wilderness and go after the one that is lost until he finds it?… Or what woman having ten silver coins, if she loses one of them, does not light a lamp, sweep the house, and search carefully until she finds it? (Luke 15:4, 8)

Jesus loves the lost and Jesus values that which is of true value. God's people have a lesson to learn from the searching shepherd and the seeking woman of Luke 15: Those whom they may not value are invaluable in the eyes of God (Brown 249). The broken are to be loved as if they were complete. The disturbed are to be loved as if they were steady. The disabled are to be loved as is they were whole.

The United Methodist Church practices open table communion. This earthly feast is shared in expectation of the heavenly one that will include all of God's children, regardless of anyone's earthly opinions of them. The communion table is God's and not humanity's. God determines those who are welcome to the feast and not his earthly ambassadors. The open table brings the community of faith together in ways that will make them uncomfortable because not all gathered look like they do, but at the same time it gives them peace that God's love exceeds all boundaries they struggle to overcome.

People with disabilities remind them that they live in an imperfect world. Thankfully, perfection is not a requirement for being in the presence of God. If it were, God would be very lonely. Imperfections and disabilities should be welcomed into the worshipping community of faith because they remind them God loves the broken and the

piecemeal. According to 1 Corinthians 12 and Romans 12, only within God can they can become the whole body God is calling them to be.

Overview

Chapter 2 reviews selected literature and appropriate research. Chapter 3 presents an explanation of the project's design, the research methods, and the manner of data analysis. Chapter 4 presents the findings of the study. Chapter 5 reports the applications of the major findings that were a result of this study while also offering suggestions for further inquiry and study.

CHAPTER 2

LITERATURE

Introduction

Savannah was a quiet child. Though there was the chaos of concerned physicians all around her, she was quietly born premature in 2007 and spent several quiet days in the neonatal intensive care unit at University of North Carolina REX in Raleigh. Many of the red flags were present from the beginning: small body size, large head circumference, and slow growth rate. Red flags continued to be raised through her second birthday: atypical attachment to doll parts (a shoe, donkey tail), lack of eye contact, echolalia (repeating what others say), atypical attachment to Disney movies (Shrek, Peter Pan), delayed speech development, narrow conversation topics, lack of separation anxiety, walking difficulties, scripting (use of the same verbal responses), and lack of creative play (would only line up toys) to mention a few.

My wife, Eileen, and I considered ourselves to be marvelous parents, especially as Savannah was our first child. When we would leave Savannah in the nursery at church, she never cried or demonstrated any separation anxiety. She would simply move across the floor and play with the books. After worship, we would return to the nursery to pick Savannah up to find out she had remained quiet and had played by herself the entire time we were gone. Savannah never seemed sad to leave the nursery, nor did she seem overly excited to see us again. My wife and I thought we had raised the most well-adjusted child ever to live.

Eileen is a family therapist who had some experience working with families who had children with Autism Spectrum Disorder. She noticed signs of ASD in Savannah and

eventually shared her concerns with our pediatrician who encouraged us to have Savannah evaluated through the TEACCH Center in Greenville, North Carolina. She was diagnosed with ASD in 2007.

We delayed having Savannah evaluated earlier because she presented many traits I displayed Eileen would explain away ASD red flags identified in Savannah by saying, "Well, Trip does that," or, "She inherited that from Trip," or, "She learned that from watching Trip." These observations led to my ASD evaluation and diagnosis later in 2007 by Gary Mesibov[2] at the UNC TEACCH Center in Chapel Hill, North Carolina.

As Savannah grew older, she had many new struggles that impacted her education but also her ability to participate in the life of the church. Bulletins were difficult to understand; music was too loud. Passing the peace (greeting people around her) was uncomfortable, so she would often remain seated as the rest of the congregation mingled. She was uncomfortable with the timeframe of the service movements, never knowing how long we would be praying or listening to the sermon and what service movement was supposed to be next. She would speak out of turn during the children's sermon, answering rhetorical questions and correcting other children who would answer the leader's questions incorrectly. Keeping her seated during the service was impossible as was keeping her from singing songs she enjoyed long after the congregation had finished singing them. Worship, as it is offered in most churches today, does not engage Savannah with the divine. Worship is exhausting and results in raising her anxiety, impacting how she behaves throughout the rest of day.

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[2] Gary Mesibov is one of the leading evaluators of adults with ASD in the United States and internationally recognized as a leader in autism research and practice. He served as editor of the *Journal of Autism and Developmental Disorders* from 1997-2007.

Like my daughter and others with ASD, I struggle to connect to God and the church community through many practices common in worship today. When we lived in North Carolina and were active in the Autism Society of North Carolina, many other parents spoke of struggling with similar issues in the worship services of their local churches. These worship services were varied in the time of day they were offered, worship style, service length, order of worship, and music style. Regardless of the church or worship style, congregations were not implementing accommodations well that would more fully include people with ASD in the communal worship life of the church.

While much is written about the importance of faith communities being hospitable to families with someone who has ASD, not much has been written regarding the importance of accommodations and inclusion in regular communal worship life of the local church. The purpose of this research project was to discern the specialized needs of a worshipper diagnosed with level one or level two ASD in order to recommend accommodations and suggest inclusion guidelines addressing the ASD-related needs of communal worship.

Knowing how anxious and empty I feel at times after worship, I wanted to help people with ASD become as fully a part of the body of Christ as possible and help resource the local church as they strive to be the inclusive body of Christ they know they are called to be. The number of people diagnosed with ASD is increasing rapidly. The level of hospitality shown by the local church to people with ASD needs to increase rapidly as well. Knowing the specialized needs of a worshipper with ASD helps those designing worship to create an inclusive worship experience that more fully reflects what the body of Christ should be.

This literary review focuses on two movements: (1) the divine value of all people, including those with disabilities, and (2) the church's response when considering people with disabilities as part of the body of Christ. The first movement considers God's value of all people and that all people, including those with disabilities, have divine worth. God spoke into creation all that is and declared creation good. Each piece of creation, in all its various shapes and sizes, serves a purpose in the kingdom of God. People with disabilities are not less-than or incomplete. All people are fully and unconditionally loved by God, gifted in unique ways, and designed to make a difference in the world. Holy hospitality should be inclusive of all people. The second movement explores the church's attempts at a hospitable response toward people with disabilities. This movement explores locations where radical hospitality is being offered and where other locations are missing the mark.

Theological Framework

Scripture says that God shaped all of creation and "saw all that God had made, and behold, it was very good" (Gen. 1:31). Each person is shaped into God's good image. John writes, "God so loved the world that he gave his only son, so that everyone who believes in him may not perish but have eternal life" (John 3:16). God is invested in creation; he shaped it, including humanity God continues to love every individual still, without exception.

In the beginning, "God said, 'Let us make humankind in our image, according to our likeness';… So God created humankind in his image, in the image of God he created them" (Gen. 1:26-27). Since this moment, they have differentiated themselves through personal choice as well as through genetics. They are taught to celebrate their differences

because their differences make them unique and their uniqueness makes them special. In the midst of their celebrating, they were reminded that in the beginning their commonality made them special. All of humankind, in all its various shapes and sizes, was first created in the image of God.

God's Spirit is a gift to everyone. Those "many tongues of Pentecost" exemplify the "various sensory capacities" of the people (Yong 15):

> When the day of Pentecost had come, they were all together in one place. And suddenly from heaven there came a sound like the rush of a violent wind, and it filled the entire house where they were sitting. Divided tongues, as of fire, appeared among them, and a tongue rested on each of them. All of them were filled with the Holy Spirit and began to speak in other languages, as the Spirit gave them ability. (Acts 2:1-4)

The Word of God is offered to all, and those words can sometimes sound strange and unfamiliar because they do not sound like the words they may be used to or encounter through the modality with which they are most comfortable. The differences do not discount one another. The differences do not create a hierarchy of importance among gifts. The differences honor their uniqueness and highlight the importance of all gifts to work together to achieve God's hope and advance God's kingdom.

The honoring of imperfection was part of the founding of ancient Israel:

> Jacob was left alone; and a man wrestled with him until daybreak. When the man saw that he did not prevail against Jacob, he struck him on the hip socket; and Jacob's hip was put out of joint as he wrestled with him. Then he said, "Let me go, for the day is breaking." But Jacob said, "I will not let you go, unless you bless me." So he said to him, "What is your name?" And he said, "Jacob." Then the man said, "You shall no longer be called Jacob, but Israel, for you have striven with God and with humans, and have prevailed." Then Jacob asked him, "Please tell me your name." But he said, "Why is it that you ask my name?" And there he blessed him. So Jacob called the place Peniel, saying, "For I have seen God face to face, and yet my life is preserved." The sun rose upon him as he passed Penuel, limping because of his hip. (Gen. 32:24-31)

"Jacob's disability is a mark of his covenant with God" and a sign that God does not value physical perfection over imperfection (Yong 31).

Their disabilities may follow individuals into the heavenly kingdom:

> Jesus came and stood among them and said, "Peace be with you." Then he said to Thomas, "Put your finger here and see my hands. Reach out your hand and put it in my side. Do not doubt but believe." (John 20:26b-27)

After Jesus' resurrection, his scars remained. The marks on his hands and side were distinguishing characteristics, identifying him to the world and "indicative of his solidarity with the marginalized" (Yong 120):

> Then one of the elders said to me, "Do not weep. See, the Lion of the tribe of Judah, the Root of David, has conquered, so that he can open the scroll and its seven seals." Then I saw between the throne and the four living creatures and among the elders a Lamb standing as if it had been slaughtered. (Rev. 5:5-6a)

The Lamb of God, the scars of his slaughter still preserved, stands in the heavenly throne room, passing judgment and offering grace. Amos Yong asserts Jesus' corporeal imperfections are reflections of God's own image as are the disabilities incarnate in them. They are part of who Jesus was, who Jesus is, and who Jesus will always be.

They all have a purpose within the kingdom. They have all been created in God's image and uniquely designed. Pope John Paul II asserts, "It must be clearly affirmed that the disabled person is one of us, a sharer in the same humanity" (Reinders 19). In some cases, this uniqueness creates barriers to full participation in the life of the church because the church, as it is today, is reluctant to embrace people with disabilities.

"Serve one another in love" (Gal. 5:13) is a biblical command that includes everyone. People considered broken are just as important to the community of faith as people considered complete. "To view people with disabilities as flawed and defective,

and possibly a divine mistake, is wrong for a church with Christ-like compassion" ("Ministry to People with Disabilities A Biblical Perspective"). Although people with disabilities are gifted differently, their gifts are still of God and help make the community complete.

Jesus' gospel of unity and wholeness, introduces his followers to the idea that completeness in the eyes of God does not require physical completeness:

> During His time on earth, Jesus walked alongside all types of people, showing no partiality in His ministry. He saw *all* people as bearers of the image of God and desired to share His Kingdom with everyone, especially those whom society deemed unworthy. (original emphasis; White 11)

Jesus' ministry begins, in Luke's gospel account, in Nazareth on the Sabbath as his first public proclamation is one of completeness, freedom, and recovery:

> He stood up to read, and the scroll of the prophet Isaiah was given to him. He unrolled the scroll and found the place where it was written:
> "The Spirit of the Lord is upon me,
> because he has anointed me
> to bring good news to the poor.
> He has sent me to proclaim release to the captives
> and recovery of sight to the blind,
> to let the oppressed go free,
> to proclaim the year of the Lord's favor." (Luke 4:16b-19)

James M. Efird understands the proclamation of the year of the Lord's favor to mean "that *all* people, the poor, the needy, and even the Gentiles are to be included in God's Kingdom. For this, he receives the wrath of the hearers who attempt in a mob-type scene to kill him" (original emphasis; 60). Not everyone is open to hearing of God's hope for the inclusion of all people. Comfort is in thinking they are chosen and favored to receive God's special attention while those on the margins are less than favored because they are less than whole.

Luke uses three parables about recovering lost things of value to convict the religious leaders who objected to the types of people with whom Jesus spent time and engaged in ministry:

> Which one of you, having a hundred sheep and losing one of them, does not leave the ninety-nine in the wilderness and go after the one that is lost until he finds it? When he has found it, he lays it on his shoulders and rejoices. And when he comes home, he calls together his friends and neighbors, saying to them, "Rejoice with me, for I have found my sheep that was lost." (Luke 15:4-6)

The flock was broken and its number was incomplete. The shepherd was willing to risk the safety of the remaining sheep to search for the one who was not part of the whole. The completeness of the body and the value this seems to have for Jesus is worth the risk of fracturing the remaining group further.

According to I. Howard Marshall, the story of the woman searching for the one lost coin has a similar meaning (603). One difference is the lack of risk for losing the remaining coins in the process of searching for the coin that is missing. The message of fracture and wholeness remains that gathering those not included is worth the effort:

> Or what woman having ten silver coins, if she loses one of them, does not light a lamp, sweep the house, and search carefully until she finds it? When she has found it, she calls together her friends and neighbors, saying, "Rejoice with me, for I have found the coin that I had lost." (Luke 15:8-9)

The conviction of religious leaders of the value of the marginalized is more appropriate to this research and the fact Luke uses three parables to emphasize this point (as opposed to Matthew who only shares the parable of the lost sheep) demonstrates the importance Luke places on the value of those others believe have no value.

The parable of the prodigal father follows the same suit as the parables of the lost sheep and lost coin but is more directly aimed at the Pharisees who, like many in their

churches today, were not interested in spending time with those not remaining in the flock, those not already inside the temple, or those not already a part of the whole:

> "Quickly, bring out a robe—the best one—and put it on him; put a ring on his finger and sandals on his feet. And get the fatted calf and kill it, and let us eat and celebrate; for this son of mine was dead and is alive again; he was lost and is found!" And they began to celebrate. (Luke 15:22b-24)

The embracing of the youngest son was not a judgment on the oldest (Craddock 188) but a proclamation of inclusion. It was a statement that the bringing in of those excluded is worth the financial, physical, and emotional risk. The feast they share imagines a table open to all people—the ones present and the ones to come.

The bread and wine are powerful reminders of their need for God and God's love for them all. In the Eucharistic liturgy, the loaf, the body of Christ, is lifted up for all to see. It is not hidden from anyone but is visible to those sitting close to the altar and those further away. It is made available to those close enough to smell it and those who sit in the margins. The bread, the body of Christ, is broken for all. Every break is unique. Every time the loaf is torn, the seam is different, as if this brokenness is not a reminder of something in the past but a declaration of a holy work in their midst at that moment. Christ's body is broken, and they are created in his image. They come forward to receive this gift and in their hands is placed a piece of the torn loaf, torn again and offered to them. This piece is unique as they are each unique. This piece has a torn edge as unique as the states of their spirits are from one another. They are not the same. This is the beauty of the bread. They are all different but still a part of the same body (1 Cor. 12). The cup is also lifted for all to see. A promise is declared that this cup of salvation is from the one God, offered to all those gathered and all those who will gather, even if not this day. It is one cup, a common cup, because the salvation being offered is communal.

The salvation it offers is unconditional for the ones at the altar as for the ones in the margins. The beauty of the Eucharist is image of the bread *with* the cup. Their uniqueness is brought together and re-membered in the communal cup. They are reminded of their individuality at the same time they are reminded of their commonality. Each is loved; all are loved.

People with disabilities remind them that they live in an imperfect world. Perfection is not a requirement for being in the presence of God. If it were, God would be very lonely. Imperfections and disabilities should be welcomed in the worshipping community of faith because they remind them that God loves everyone and created all in God's image.

All people are incomplete and all people are in need of being made whole. Ginny Thornburgh describes the situation:

> Each of us has abilities; each seeks fulfillment and wholeness. Each of us had disabilities; each knows isolation and incompleteness.… Seeking shelter from the vulnerability we all share.… Let the House of God be open to all who would enter and worship. (4)

All Christians confess to this need each time they share in the Eucharist.

Moses met God in the burning bush and received his call to bring God's people out of Egypt. After giving several reasons why he was not gifted or skilled enough to live into this call, Moses answered, "O my Lord, I have never been eloquent, neither in the past nor even now that you have spoken to your servant; but I am slow of speech and slow of tongue" (Exod. 4:10). Moses does not believe he has the ability to serve God's purposes due to his disabilities: "Through a series of questions, God reminds Moses that He determines human abilities and disabilities" (*Ministry to People*). Disabilities can be a part of God's good work.

Disabilities such as ASD do not break the body of Christ. They strengthen it by making it what it was designed to be—a collective of all people, helping each other to love God and neighbor that the kingdom be advanced toward the common good Paul describes in 1 Corinthians 12:7.

Luke's parable of the great banquet in chapter 14 tells the story of invitation into the greater whole. The banquet's host "gave a great dinner and invited many. At the time of the dinner he sent his slave to say to those who had been invited, 'Come; for everything is ready now'" (Luke 14:17). The invitation would not have been a surprise to those being invited. According to Marshall, dinner gatherings such as this one were organized with the number of guests committed in mind. Not to attend when the banquet is prepared is a great discourtesy (588):

> "Go out at once into the streets and lanes of the town and bring in the poor, the crippled, the blind, and the lame." And the slave said, "Sir, what you ordered has been done, and there is still room." Then the master said to the slave, "Go out into the roads and lanes, and compel people to come in, so that my house may be filled." (Luke 14:21b-23)

Luke 14's mandate was for the servant to go out and bring in the poor, the cripples, the blind, and the lame. The call is to reach out to those with disabilities and to bring them in, not out of the kindness of their hearts but because the body is not complete without them (White 12).

Relationships are essential pieces to human personhood: "We cannot be persons apart from our connections to others.… Rejection strikes a blow at the root of healthy human personhood because it strikes at our connection to others" (Seamands 29). Stanley Hauerwas echoes R. Kunz in his belief that the human community is the inner core of Christian worship, not the rituals practiced. Knowing doctrine is not as important as

being a part of the community: "A church would have no way of knowing it is a church without the presence of people with intellectual disabilities" (60). Everyone is needed; all parts are required for the body to be complete and fulfill its purpose.

> Within the life of a congregational community, faith is formed, shared, and strengthened; relationships are forged and deepened; and gifts are discovered, developed, and dispensed.… [U]nfortunately too many people with disabilities do not experience the same opportunities as others to grow spiritually, enjoy community and experience relationships. (Collins and Ault114)

The relationship between those with disabilities and those who are typical is mutual. N. Eiesland is disabled and shares her experience:

> The church is impoverished without our presence. Our narratives and bodies make clear that ordinary lives incorporate contingency and difficulty. We reveal the physical truth of embodiment as a painstaking process of claiming and inhabiting our actually existing bodies. People with disabilities in the church announce the presence of the disabled God for us and call the church to become a communion of struggle. (242)

The disabled are integral to a whole and healthy understanding of God and God's church.

People with disabilities are not marginal parts of the body. They are necessary for the body to function in the way God designed it to. One of the reasons faith communities need the presence of people with disabilities is because they allow the individuals gathered to become a community seeing a purpose beyond themselves (Webb-Mitchell, *Beyond Accessibility,* 38-39). People with disabilities bring unique experiences and an "endless supply of spiritual gifts" (Morris 51). They are all made in the image of God, and in each person, that image is tarnished: "The image of God begins to be restored in the body of Christ when each individual is affirmed for what they have to contribute to the total image" (Swinton, "Building a Church" 59). Even tarnished sections are a part of the greater image.

The Value of Autism Spectrum Disorder

Autism Spectrum Disorder is being diagnosed in children in greater numbers every year. The shear number of people with ASD guarantees someone in every local church has been diagnosed with ASD or knows someone who has. This study is an attempt to help the church embrace people with ASD and their families in a more hospitable and effective way.

Care for those with ASD can cause unique physical and emotional burdens on families. The weight of these burdens impacts where and how often people with ASD engage the world outside of their immediate familial structure. Families with members diagnosed with ASD find regular tasks such as going to the grocery store, visiting friends, and attending weekly communal worship services difficult. Faith and religious practice are important to families and especially to families of someone with ASD because they offer support, a communal foundation, and rationalization for the impact ASD has had on their lives.

A typical worship service is not conducive to the inclusion of people with level one or level two ASD. Modifications and accommodations can be implemented to make communal worship more accommodating and allow people with ASD to participate more fully in the faith community, strengthen their own faith, and be an example to others of the diversity within the body of Christ.

Autism Spectrum Disorder is an umbrella term used to describe various disorders that impact brain development. Social interaction, communication, and repetitive behaviors are difficulties common to ASDs. The term *spectrum* means each person is impacted differently within the scope of the common areas of difficulties mentioned

previously. Symptoms for ASDs can range from mild to severe, manifesting in displays ranging from mild social discomfort to not being able to communicate verbally. Care for those with ASD can range from independence observation to intense assistance required to complete life-sustaining behaviors. The severity and combination of ASD symptoms influence differently a person's ability to function (Baio 4).

Autism Numbers

Current figures indicate one in every sixty-eight children are diagnosed with ASD. These numbers have increased each year since they had begun being tracked by the CDC ("Autism Spectrum Disorder"). Previous numbers had placed diagnosis at one child in one hundred and fifty.

Diagnostic numbers increased for various reasons, and the scientific community is leaning away from any one reason being the leading cause. Better diagnostic tools for earlier detection, more refined diagnostic criteria, environmental changes, and greater acceptance of ASD have all been identified as responsible for an increase in children diagnosed with ASD ("Autism Spectrum Disorder").

People with ASD

ASD is not a new inclusion to the human condition. It has been around longer than many realize, and many leaders from various fields throughout history have been diagnosed or have been considered living with ASD. This list is not all-inclusive nor does it reflect a hierarchy of importance. It is only to be an illustration of the variety of gifts those with ASD offer:

- Wolfgang Amadeus Mozart*—composer
- Tim Burton—film director

- Andy Warhol—artist
- Lewis Carroll*—author
- Temple Grandin—animal rights advocate
- Dan Aykroyd—actor
- Bill Gates**—computer scientist
- Albert Einstein—scientist
- Samuel Beckett—author
- Christopher Knowles—poet
- Matt Savage—jazz prodigy
- Susan Boyle—singer
- Marie Curie*—scientist
- Charles Darwin*—scientist
- Carl Sagan—astronomer
- Nikola Tesla*—scientist
- Hans Christian Anderson—author
- Sir Author Conan Doyle*—author
- Warren Buffet**—investor.

Current diagnostic criteria would place individuals denoted with * on the autism spectrum, though they were not diagnosed by medical professionals in their day. Current diagnostic criteria would place individuals denoted with ** on the autism spectrum though they have not sought an official diagnosis by medical professionals.

Severity Levels in ASD Diagnosis

The diagnostic criteria for Autism Spectrum Disorder severity levels one, two, and three are found in the neurodevelopmental disorder section of the *DSM-V*:

> **Level 1—Requiring support.** Without supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions, and clear examples of atypical or unsuccessful response to social overtures of others. May appear to have decreased interest in social interactions. For example, a person who is able to speak in full sentences and engages in communication but whose to- and-fro conversation with others fails, and whose attempts to make friends are odd and typically unsuccessful.
>
> Inflexibility of behavior causes significant interference with functioning in one or more contexts. Difficulty switching between activities. Problems of organization and planning hamper independence.
>
> **Level 2—Requiring substantial support.** Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions; and reduced or abnormal responses to social overtures from others. For example, a person who speaks simple sentences, whose interaction is limited to narrow special interests, and how has markedly odd nonverbal communication.
>
> Inflexibility of behavior, difficulty coping with change, or other restricted/repetitive behaviors appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress and/or difficulty changing focus or action.
>
> **Level 3—Requiring very substantial support.** Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning, very limited initiation of social interactions, and minimal response to social overtures from others. For example, a person with few words of intelligible speech who rarely initiates interaction and, when he or she does, makes unusual approaches to meet needs only and responds to only very direct social approaches.
>
> Inflexibility of behavior, extreme difficulty coping with change, or other restricted/repetitive behaviors markedly interfere with functioning in all spheres. Great distress/difficulty changing focus or action. (52)

The *DSM-V*'s level of severity label is a change from the diagnostic labels used in the *DSM-IV*.

Autism Causes

The causes of ASD are currently being researched, and the published results of each study falls under heavy scrutiny. The scientific community is not of one mind on the cause of ASD. The CDC's most recent online publication of ASD-related research explains many causes are likely (CDC, "Autism Spectrum Disorder: Research"). According to G. Huquet, E. Ey, and T. Bourgeron, a person's genetic make-up is one of the contributing factors leading to the development of ASD (192). H. Gardner, D. Spiegelman, and, L. Buka's research indicates an environmental influence before, during, and immediately after birth that contributes to the development of ASD (345). Vaccines as a possible cause for ASD development has been a grassroots movement but the evidence for such a claim is not widely accepted though a delayed or modified vaccination schedule for children is growing in acceptance (DeStefano 561).

Autism Diagnosis

I hear often, "I'm pretty introverted. I guess I'm a little autistic too." While many introverts have behaviors in common with those who have ASD, to be diagnosed, markers have to be identified across five behavioral areas over a period of time. The five standardized criteria for an Autism Spectrum Disorder diagnosis are found in the neurodevelopmental disorder section of the *DSM-V*:

> 1) Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history. Diagnostic severity in this area is based on social communication impairments and restricted, repetitive patterns of behavior. The following examples are illustrative and not exhaustive.

a) Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.

b) Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.

c) Deficits in developing, maintaining, and understand relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

2) Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history. Diagnostic severity in this area is based on social communication impairments and restricted, repetitive patterns of behavior. The following examples are illustrative and not exhaustive.

a) Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypes, lining up toys or flipping objects, echolalia, idiosyncratic phrases).

b) Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day).

c) Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).

d) Hyper or hypoactivity to sensory input or unusual interest in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

3) Symptoms must be present in the early developmental period though they may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life.

> 4) Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.
>
> 5) These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. (50-51)

While most individuals display some ASD markers, markers must but identified across the five behavioral areas to receive a diagnosis.

Diagnostic Methods

At the time this dissertation was written, no medical test was available to diagnose ASD. ASD is diagnosed through comprehensive psychological and behavioral evaluations conducted by qualified professionals. According to the CDC's developmental screening recommendations, a child will typically submit to a developmental screen for delays and disabilities during 9-month, 18-month, and 24/30-month well visits. Concerns discovered during these developmental screens may require a more comprehensive evaluation:

> A comprehensive developmental evaluation is a thorough review of the child's behavior and development. These evaluations can include clinical observation, parental reports of developmental and health histories, psychological testing, and speech and language assessments. A range of professionals can conduct comprehensive evaluations, including teachers, social workers, nurses, psychologists, doctors, and speech-language pathologists. ("What Is Autism Spectrum Disorder" 1)

The results from this comprehensive evaluation are used to determine an ASD diagnosis either by a developmental pediatrician, child neurologist, child psychiatrist, or child psychologist according the *DSM-V*.[3]

[3] Research for this project was begun while the DSM was in its fourth edition and concluded when the DSM entered its fifth edition. The fifth edition included many changes to the ASD diagnosis. The research for this project will include those diagnosed with ASD under both the fourth and fifth editions of the DSM.

Autism Treatments

The treatment for ASD can be as varied as the symptoms display. According to Autism Speaks, the leading national ASD-related support organization, treatments typically involve some combination of speech and language therapy, occupational therapy, pediatric neurologist, and/or a gastroenterologist. Early diagnosis and intervention are key to long-term treatment success ("Treatments").

Attempts at Inclusion

Isaiah 56:5 tells his people, "For [the Lord's] house shall be a house of prayer for all people." All means all. No one is left out; no one is left behind. Despite believing Isaiah's words to be true, many churches still hesitate to include all people: "Too often people in the church, while accepting and loving all people, lack the initiative or the insight to provide simple measures that would make the church community more complete, satisfying, and welcoming for those who live with brokenness" (Beates 18). Hesitation to fully include all people is especially true with respect to handicapped members:

> While ethical imperatives of the Gospel seem clear and have never been forgotten by our churches, the direction which that might offer us as community members has not surfaced as a compelling rationale for caring for our handicapped members or for cherishing as an achievable goal their total integration in our community. (Hauerwas 182)

The lack of care extended to the handicapped community may also be impacting worship attendance numbers.

Attendance numbers in every major denomination are decreasing. Space is available in the local churches for more people. Not enough religious leaders without disabilities are creating inclusive space for those with disabilities, but more and more are

beginning "to recognize the unique gifts people with disabilities bring to the Body" (Thornburgh 2). Creating this space requires work on the part of those planning worship, forethought and intentionality, and openness to doing old things in a new way or doing new things that have never been done before. Many leaders are resistant to change the worship patterns with which they have grown comfortable, but straying from their comfort zones may be the disturbance needed to step into something more creative and meaningful (Kouzes and Posner 186; Quinn 65).

The apostle Paul, in 1 Corinthians 12:12, envisions a church body made up of many members: "For just as the body is one and has many members, and all the members of the body, though many, are one body, so it is with Christ." Each person in the body plays a different role, serves a different purpose, and advances the kingdom in a unique way. Each gifting, each role, and each person is needed to move the church and the community around it toward a common good. The body of Christ, the house of God, and the work of the kingdom are weakened for everyone if attitudes and communication prevent those with disabilities from fully participating in the worship life of their congregation (Thornburgh 2). People with disabilities are essential to making the Christian community complete, have been created in God's image, and have purpose (*Ministry to People*).

One barrier to inclusion that George F. White and J. Pierson identify is the congregation's attitude towards people with disabilities. When people with disabilities are viewed as *other*, polarities are established that only further devalue people with disabilities. Inclusion begins when the disabled are seen by the faith community as worthy of being included. "We can only understand the need for change when they

realize that they are making changes in order that the body of Christ can be made whole" (Swinton, Mowat, and Baines 57). After the church understands the need for inclusion, we can reach out to include the missing members of the body.

Jesus taught the importance of inclusion often during his ministry. "As he walked along, he saw a man blind from birth. His disciples asked him, 'Rabbi, who sinned, this man or his parents, that he was born blind?'" (John 9:1-2). The misguided belief echoed by Jesus' disciples in John 9 is a belief many Christians still hold today and only strengthens the distance placed between the different and the typical:

> Throughout its history, the church has interpreted scriptural passages, images, and stories that include persons with disabilities in ways that subtly or explicitly reinforce the assertion that physical and developmental disabilities are caused by or are a consequence of sin and may even be God's punishment visited upon the sinner. This hermeneutical approach assumes that getting rid of their disabilities is the chief concern of people who are disabled and the ideal for all people. (Reinders 34)

Jesus answered the disciples' concern by saying, "Neither this man nor his parents sinned; he was born blind so that God's works might be revealed in him" (John 9:3). Jesus taught the blind man's handicap was not the result of sin and should not keep him from fully participating in the work of the kingdom.

Alienation may cause people with disabilities not only to avoid a particular local church but also the Christian faith (Kabue 115). The church should not resist including people it considers broken because the church already includes people who are broken:

> If we take these biblical affirmations seriously, it is clear that it is not enough for the church to seek to be a place of inclusion and welcome to people with mental illness, as if to do so is simply our Christian duty. Rather, we already participate together—we who carry labels of mental illness and we who do not—in a strange and wonderful body that bears the wounds of crucifixion even after the resurrection. (Kinghorn 12)

Inclusion is not the ultimate goal. John Swinton believes churches must become more than places where the disabled are welcome or tolerated. Churches must become places where the disabled are longed for and missed when not present (*Spirituality* 13)

The church needs to reach out to those whom it has not traditionally welcomed. It needs to reach out more effectively to those who live with disabilities rather than separating and regulating them to a special place or a special ministry: "Rather, I hope, as much as possible we strive to enfold all people completely within the worshipping church" (Beates 127). At the heart of Jesus' gospel, is the inclusion of all people.

The importance of faith in the lives of ASD families. Having a child with a disability remolds a family. The family of someone with ASD lives amidst unique marital, sibling, vocational, relational, and financial stress (Shore and Rastelli 96). The national Autism Society, in its online posting on autism and family issues, emphasizes that faith, prayer, and worship help "families handle the challenges of autism and [provide] a safe, inclusive environment for both the child and family" ("Family Issues"). ASD places stress on the family in many ways, and their community of faith should be a place of refuge, a place where they can be supported and feel belonging. It only adds more stress to discover worship in their faith community is one more place they will not be welcome as a family. Faith enhances the ability for a family to adapt and cope in the face of something distressing such as ASD (Mahoney et al. 233; O'Hanlon 1). Patricia Coulthard and Michael Fitzgerald's research indicates that local churches in general are not being supportive of families who have someone with ASD, and those families are coming to rely on themselves for spiritual formation. The basis of the church, as Paul teaches, is community and individuals coming together to function together for the

common good. A family having to rely on themselves for formation is not the vision Paul or Jesus had for the body of Christ.

Though the focus on inclusion in the faith community is important, the need for inclusion in the worship life of the faith community is being ignored. Eric Carter illuminates the great strides communities have taken to be more inclusive and more hospitable to those with disabilities. Schools have become more inclusive. Workplaces, neighborhoods, and churches have become more inclusive (3-7). One place that has not become more inclusive is the sanctuary. Many practical barriers to participation exist in communal worship for someone with ASD. Communication, liturgy, dress, tradition, architecture, music, sermon style and length, seating, and even the printed bulletin can all be hindrances to including people with ASD in a worship service catering to neurotypical worshippers (13; Vierkant, Hollingsworth, and Stark; Viviano) Like education presentation in the classroom tends to suit one style of learner, worship presentation tends to cater to one style or worshipper (Rognlien 22; Kimball 16; Webber 168; Dawn, *Reaching Out without Dumbing Down* 85-86).

Experiences in worship. The National Organization on Disability reported in 2004 that 84 percent of those with disabilities consider their faith to be important but 47 percent attend worship on a regular basis (at least once per month). This number is 18 percentage points less than people without disabilities (*Key Findings*). Outside of these figures, very little empirical information regarding worship and disabilities exists (Scorgie and Sobsey 195). Even with very little information, community inclusion is understood to be important. “Unfortunately, there are limited studies about families of children with disabilities and community inclusion. However, from the information

available, community inclusion as a social support for children with disabilities was extremely important to these families" (O'Hanlon 40). The lack of available information emphasizes the importance of faith related research within the autism community.

The statistics available are consistent with anecdotal information collected from 184 families who shared their experiences in worship with Mary Beth Walsh, Alice Walsh, and William C. Gaventa in 2008:

> Our son is a part of this community of believers, and they deserve the chance to know him, too. We are not going to hide in the "cry room" anymore. (12)
>
> While sitting in worship with my two young children, an older woman asked me to remove my disruptive toddler. She spoke with a condemning tone, one I would soon become immune to. I took my children to the nursery and cried. (12)
>
> Going to church can be a real struggle for families with autistic children. We have had several moments in church where the boys are too loud, don't behave appropriately when the children are called to the front of the church, etc. (17)
>
> When my son was younger, around 7-years-old, I contacted the CCD department of this parish requesting a viewing of the Special Needs class conducted Wednesday afternoons.… I explained my situation and she felt that they were not equipped to handle my son. (20)
>
> Twin boys were preparing to receive the Sacrament of First Eucharist. One boy was autistic and his twin was not.… The mother came to me with tears in her eyes. I asked her what was wrong, to which she replied, "There is nothing wrong at all! For the first time my two sons are doing something together. They usually go to their separate school and activities and today they are side by side." (21)

Many other stories similar to these are found in this *Autism and* Faith collection.

Many stories exist of families wanting to engage their faith community or deepen their personal faith, but feeling disconnected because the worship environment, among other things, does not allow them to connect to each other or God. Statistics from the

NOD show that families with a child who has a disability do not attend worship as frequently as they would prefer. The stories families tell, show an exodus of worshippers who are not being included because they have needs that may lie outside of the norm. Some faith communities are trying to connect with these families, and these connections hint at the power of inclusion to strengthen the body of Christ as well as the members of it.

Intervention and Accommodation

In 1990, the ADA required buildings to be physically accessible to those with special needs, but physical accessibility is not the barrier to including people with disabilities in worship. R. Kunz identifies unreachable expectations on members as a barrier:

> To be able to grasp spiritual matters, one must understand something about interpretation; one has to be able to talk, to interpret oneself and one's world religiously. Religion is a language game. Or: Religiosity is to be acquired like language and therefore is dependent on the ability to socialize. (22)

Intellectual access is a considerable barrier for the church to address.

Some worshipping communities acknowledge barriers in place that keep those gathered from connecting with God or those outside the church from joining the gathering at all. These barriers may be physical or social but are still hindrances to communal connection between the neurotypical and ASD communities. When children, youth, young adults, and adults with ASD exhibit behaviors that do not fit in with the established worship norms of their community of faith, those families are redirected from the community of faith and encouraged toward secular community resources and support structures (Viviano). Debra Peterson notes that the world is changing and disabilities are

more common, but not much has changed in the hospitality practices of the local church: "Churches must do better offering a heart of welcome, not just an accessible entryway" (qtd. in Viviano). The Roman Catholic church Peterson attends has opened its doors to the disabled population but has not welcomed those with disabilities into communal worship as quickly as they have been welcomed into Sunday school and the children's choir. "The goal is to integrate people with disabilities,… [but s]ometimes separate programs are needed" (Viviano). Separate programs should not but the initial or only response to welcoming people with disabilities.

Congregations open to people with ASD by allowing them to participate in an inclusive Sunday school class or youth group. They are welcomed into a common childcare environment. They may be offered an opportunity to participate in the children's choir, but an invitation into the sanctuary typically comes during a noninclusive worship experience ("What is Sensory-Friendly Worship"; "Mark 10:14 Ministries", Shoudy).

Clergy care for people with ASD and other disabilities. They have compassion toward them. They understand these children are God's children, too, but they do not know how to integrate people with disabilities into the life of the local church (Rose 396). Clergy often have "limited knowledge and [an] unrealistic understanding of the needs of people with disabilities" which impacts their inclusion into full participation (Vierkant, Hollingsworth, and Stark).

Yong identifies three characteristics common in inclusive congregations:

> (1) The church consists of the weak, not the strong which puts people with disabilities at the center instead of the margins of what it means to be the people of God; (2) each person with disabilities, no matter how severe, contributes something essential to and for the body of Christ; (3) people

> with disabilities become the paradigm for what it means to live in the power of God and to manifest the divine glory. (89)

Church members have taken vows through their baptism to be the body of Christ in the world. "The burden of inclusion is not of the people with disabilities. The burden rests on the members of the church to be educated to understand the God-given gifts of people with disabilities, and the necessity of adapting to the presence of people with disabilities" (Webb-Mitchell, "Educating toward Full Inclusion" 257). The priority of traditions and rituals must be set aside for the focus to be on hospitality to those with disabilities (Meininger 348).

Sensory accommodations. Auditory sensitivity is the most common in those with ASD but "there can also be sensitivity to tactile experiences, light intensity, the taste and texture of food and specific aromas" (Attwood 271). They are bombarded with sensory input all the time and especially during worship. Musical instruments, choirs, bands, bells, as well as those speaking over an amplified system contribute to the sensory input for any worship gathering. According to Tony Attwood, people with ASD often notice sounds too faint for others to hear, are overly startled by unexpected sounds, and often find sounds of a particular pitch unbearable. Touching hands, an embrace during the passing of the peace, the stiffness of a pew, or the texture of a seat cushion can provide more sensory input than a person with ASD can process. Bright lights, particular colors, image patterns, or unexpected movements can also distract and provide more sensory input with which a person with ASD is prepared to cope. Many secular accommodations are available for addressing these sensory issues that may also prove helpful in the planning of worship:

- Warning before loud noises,

- Steady illumination levels,
- Clear visual focal points,
- Noise-reduction headphones,
- Quiet room,
- Alternative seating (e.g., chairs, floor, bean bags),
- Visuals matching the conversation theme,
- Touch-free understanding, and
- Clearly communicated expectations.

Structure accommodations. Structure and the predictability it provides is a very common need for someone with ASD. Knowing what comes next provides a sense of peace that a fluid agenda will not provide. Many of the contemporary worship services gather without a bulletin or a printed schedule for the worship service. While non-bulletined worship services seem to provide a relaxed worship experience for many neurotypicals, not knowing what will next or when the current experience will end creates a great deal of anxiety for someone with ASD. Many secular accommodations are available for addressing these structural issues that may also prove helpful in the planning of worship:

- Printed schedules,
- Picture schedules,
- Schedules indicating times,
- Experiences that are the same a majority of the time (i.e., same order), and
- Clearly communicated expectations.

Research Design

This project was a qualitative grounded research theory. Qualitative data was collected through surveys used to standardize the collection of personal experiences related to worship and ASD (Wiersma and Jurs 274). Adaptations of an already successful survey were used to ensure the results were as valid as possible. Theories of accommodations and their effectiveness were developed after the data was being collected (19). Theories were not developed before the surveys were completed to ensure observations were not disregarded without supporting rationale.

Summary

God created all that is seen and unseen. God shaped the parts of them the world can see as well as the invisible mental framework that helps makes them who they are. All of who they are, seen and unseen, is part of the creation God shaped and declared good. Each of them is uniquely created, uniquely called, and uniquely equipped to function within a greater body, to work together within this greater body toward a common good. The body suffers and malfunctions when members are not present.

People with ASD have traditionally been viewed as a part of creation but too unique to be incorporated into the neurotypical flock. Their presence in the larger worshipping community strengthens the work worship does and allows the image their worship displays to be more honest in its reflection of the eclectic creation God formed. Faith is important to the families of people with ASD. The God they seek is a God who touched lepers, brought sight to the blind, and freed the oppressed. The God they want to gather in adoration around is a God of community and not isolation. Not to include people with ASD in the larger worshipping community is to ignore the purpose of

worship and cloud the image of the true body of Christ. Accommodations are used in secular society to include those with ASD in the life of the larger community. The worshipping community can also use accommodations to support deficits manifesting in ASD and help worshippers with ASD be more fully included in communal worship.

CHAPTER 3

METHODOLOGY

Problem and Purpose

People with ASD are not participating in the communal worship life of the church because typical worship services are not accommodating their needs. Faith is important to these families, and modifications can be made to a typical worship service to allow families with a person who has level one or two ASD to be included in the larger community's worship practices.

The purpose of the research was to describe the specialized needs of a worshipper with Autism Spectrum Disorder and create intervention guidelines that address ASD-related needs during an inclusive worship service. The suggested accommodations, vetted by current worship planners, could be used to create worship space conducive to full inclusion of people with ASD into the communal worship life of their faith communities.

Research Questions and/or Hypotheses

Three research questions relate to the experience of caregivers and people with ASD in worship, the observations of service providers and educators of people with ASD in worship, and the predicted effectiveness of suggested inclusion accommodations.

Research Question #1

What experiences have caregivers of children, youth, and adults with ASD had in communal worship?

The worship experience survey aligns to this question. Questions in sections one and two gathered biographical information (#s 1-3, 34-35) and contextual information regarding worship participation (#s 4-8). Questions in sections three collected

quantitative data related to participation (#s 9, 13, 17, 21), level of importance (#s 10, 14, 18, 22), frequency of participation (#s 11, 15, 19, 23), and satisfaction with the experience (#s 12, 16, 20, 24) related to their faith community and its worship. Questions in section four collect quantitative data related to the interaction of the caregiver and the person with ASD with the church leadership and membership (#s 25-33). Qualitative, open-ended questions focused on accommodations (#s 9, 13, 17, and 21). Qualitative, open-ended questions focused on the participant's rationale for their personal experience level responses (#s 12, 16, 20, and 24). Coding organized all qualitative data.

Research Question #2

What interventions do caregivers of children, youth, or adults with ASD predict will make communal worship participation a more positive experience?

The worship accommodation survey aligns to this question. Questions in sections one and two gathered biographical information (#s 1-2), contextual information regarding worship participation (#s 3-6). Questions in section three collected quantitative data related to the opportunity for participation (#s 7, 9, 11, 13) and satisfaction with the experience (#s 8, 10, 12, 14) related to their faith communities and worship. Qualitative, open-ended questions focused on accommodations as part of questions 7, 9, 11, and 13. Qualitative, open-ended questions focused on the participant's rationale for their personal experience level responses as part of questions 8, 10, 12, and 14. Coding organized all qualitative data.

Research Question #3

What accommodations may be helpful for the inclusion of a person with ASD into a communal worship service?

The compiled accommodations suggestions gathered from the worship experience and worship accommodation surveys were used in an online survey. Each accommodation suggestion asked for a quantitative level of predicted effectiveness and ability to be reasonably implemented. Each accommodation suggestion also asked for a qualitative rationale for the participant's response. Coding organized all qualitative data.

Population and Participants

The first participant population was the caregivers of the people with ASD in the case of a minor and the person with ASD in the case of an adult who was capable of personally responding to the survey. These caregivers and people with ASD were identified through the Autism Society of Tennessee, the Autism Society of NC, Surfing for Autism, the TEACCH Center in Chapel Hill, and the TEACCH Center in Greenville general membership rosters and their rosters of those who have indicated willingness to participate in autism-related research. Potential participants were contacted through e-mail and provided the worship experience survey invitation and consent e-mail (see Appendix A).

The second participant population included the service providers and educators of people with ASD. Their participation was important because of their expertise in the area of accommodation implementation. While the caregivers and people with ASD have had experiences of accommodations related only to them, the service providers and educators have had experience with accommodations related to multiple people and in multiple environments. These service providers were identified through the Autism Society of Tennessee, the Autism Society of North Carolina membership rosters, and Surfing for Autism. These educators were identified through North Carolina and Tennessee special

education teacher rosters. Potential participants were contacted through e-mail and provided the worship accommodation survey invitation and consent e-mail (see Appendix C).

The third participant population included the worship planners. They had experiences related to worship acts and provided informed opinions related to the potential effectiveness of ASD accommodations. They also had expertise that allowed further refinement of the suggested accommodations. These worship planners were identified through the North Carolina and Tennessee annual conference clergy offices. Potential participants were contacted through e-mail and provided the worship accommodation survey invitation and consent e-mail (see Appendix E).

Design of the Study

This project studied the previous worship experiences of caregivers of and people with ASD through an online worship experience survey to determine their level of participation and satisfaction with those experiences. Their previous experience with worship-related accommodations was also collected in the same online survey. Service providers and educators of people with ASD completed an online worship accommodation survey to determine the use and effectiveness of ASD-related accommodations in worship. Results from both surveys were used to compile a list of suggested worship accommodations and shared with worship planners through an online accommodation suggestion survey. Worship planners discerned the effectiveness and ease of implementation of the suggested accommodations. Results of the discerned accommodation suggestions were shared with worship planners to support their inclusion of people with ASD in communal worship services.

This study occurred over a period of eight weeks. The timeframe for the worship experience survey was three weeks. The timeframe for the worship accommodation survey was also three weeks and ran concurrent to the worship experience survey. Data gathered from the two worship surveys was processed over the course of two weeks. The timeframe for the worship planner survey was three weeks.

This project was a qualitative grounded research theory. Qualitative data was collected through surveys used to standardize the collection of personal experiences related to worship and ASD (Wiersma and Jurs 274). Adaptations of an already successful survey were used to ensure the results were as valid as possible. Theories of accommodations and their effectiveness were developed after the data was being collected (19). Theories were not developed before the surveys were completed to ensure observations were not disregarded without supporting rationale.

Instrumentation

An online survey was favored for use in this study for several reasons. Online distribution allowed for the survey to be accessed by a larger population as well as provide a means to participate without a large time commitment on the participants' part. Families caring for loved ones with ASD typically have many commitments related to therapeutic care, keeping them from being able to be fully present in a face-to-face survey. An online survey allowed these families to participate at their convenience and when they are in their preferred state of mind. The survey, hopefully, encouraged participants to be more honest in their responses.

Worship experience survey. The worship experience survey was an adaptation of O'Hanlon's Spiritual Community Experiences Inventory (see Appendix B).

Adaptations were made to the Spiritual Community Experiences Inventory to focus the questions more closely on worship experiences than on more general spiritual experiences. Caregiver participants were asked to read statements regarding their experiences in communal worship and then rate their experiences on the respective scale. Participants were also asked to rate the importance of and their satisfaction with those worship experiences. They were asked to identify accommodations they observed to be helpful and accommodations they believe would have been helpful. The rationale for their responses was asked in an open-ended format to encourage a more personal description of the respective experience.

Worship accommodation survey. The worship accommodation experience survey was an adaptation of the worship experience survey (see Appendix D). An adaptation of the worship experience survey was used to keep the questions as consistent as possible while focusing the survey on the accommodations observed and accommodations recommended to improve participation in worship of people with ASD. Service providers and educators were asked to read statements regarding their observations of communal worship and then rate their experiences on the respective scale. They were asked to identify accommodations they observed to be helpful and accommodations they believe would have been helpful. The rationale for their responses was asked in an open-ended format to encourage a more personal description of the respective experience.

Worship planner survey. After gathering results from the worship experience surveys and worship accommodation surveys, suggested and implemented accommodations were compiled and shaped into a survey that could not be created until

the first surveys had been processed. These accommodations were offered to worship planners for evaluation through an online survey for discernment of their predicted effectiveness and ability to be reasonably implemented.

Reliability and Validity

The reliability of the study is secure. The questions in the survey were standardized and asked the same way with the same structure of each participant. Though the questions were asking for subjective personal experiences, the structure of the survey kept the responses as reliable as possible (Wiersma and Jurs 264).

External validity was difficult to secure because ASD displays in various needs (Wiersma and Jurs 266). ASD is a spectrum disorder with an array of needs that may never seem consistent. Accommodations that are effective for one person with ASD may not work with another. The difficulty in securing validity is the reason this study is important. No one person can be an expert in all accommodations because a list of accommodations would be endless. The purpose of this study was to determine best possible accommodations reaching across the most common ASD-related needs and share those with worship leaders in hopes of increasing the probability those accommodations will be implemented in communal worship. Collecting accommodations from caregivers, people with ASD, services providers, and educators that are already known to be successful increased the validity of the final accommodation suggestions offered to worship leaders.

Data Collection

Previous worship experience surveys of caregivers and adults with ASD were conducted online to be as convenient as possible for the participants. The surveys took

ten minutes or less to complete per participant. Previous accommodation experience surveys of service care providers and educators were also conducted online to be as convenient as possible for the participants. The surveys took ten minutes or less to complete per participant. The predicted intervention and accommodation effectiveness survey was conducted online to be as convenient as possible for the participants.

Data Analysis

A chart was used to process the previous worship experience surveys tracking the events affecting the worship experience of a child, youth, or adult with ASD. The influencing themes were identified, separated into groups, and appropriately coded. Charts were also used to track responses to the previous intervention surveys with interventions identified, separated into groups, and appropriately coded. Responses offered by the survey of worship planners were recorded and taken into consideration in the creation of the final draft of the intervention guidelines.

Ethical Procedures

Participants identified by the Autism Society of North Carolina, the Autism Society of Tennessee, the TEACCH Center at the University of North Carolina, and the annual conference offices of Tennessee and North Carolina were known to myself but were not made known to each other. Participants were unknown to me when known participants shared surveys with participants not identified by the previously mentioned organizations. This situation was not a concern because the identity of the participants was not necessary for data collection and may have even increased the number of responses due to an increased comfort level in the participants as a result of anonymity. Data collected by the online surveys was downloaded directly into a private (i.e.,

nonshared) folder on my computer. The only data shared from the surveys were the resulting accommodation suggestions. After completion of the study, raw data from the completed surveys remained in the private folder and disconnected from the public survey. Consent to participate in the study was given in question 7 of the worship experience survey and question 5 of the worship accommodation survey.

CHAPTER 4

FINDINGS

Problem and Purpose

People with ASD are not participating in the communal worship life of the church because typical worship services are not accommodating the needs of worshippers with ASD. Faith is important to these families and modifications can be made within worship services to allow families with a person who has level one or two ASD to be included in the larger community's worship practices.

The purpose of the research was to describe the specialized needs of a worshipper with Autism Spectrum Disorder and create intervention guidelines that address ASD-related needs during an inclusive worship service. The suggested accommodations, vetted by current worship planners, could be used to create worship space conducive to full inclusion of people with ASD into the communal worship life of their faith communities.

Participants

The first participant population was caregivers and people with ASD identified through the Autism Society of Tennessee, the Autism Society of North Carolina, Surfing for Autism, the TEACCH Center in Chapel Hill, and the TEACCH Center in Greenville. Potential participants were provided the worship experience survey invitation and consent letter through e-mail (see Appendix A).

The second participant population, service providers and educators of people with ASD, were important because of their vast expertise in accommodation implementation. Potential participants were provided the worship accommodation survey invitation and consent letter through e-mail (see Appendix C).

Worship planners, the third participant population, had experiences related to worship acts, provided informed opinions related to the potential effectiveness of ASD accommodations, and offer refinement of accommodations. Potential participants were provided the worship accommodation survey invitation and consent e-mail letter through e-mail (see Appendix E).

ASD Participants and Caregivers

In a 2015 study, the Pew Research Center reported the national average for people attending worship at least monthly was 69 percent ("U. S. Public Becoming Less Religious" 70). Participants in the ASD-related survey indicated 73 percent attend worship at least once each month (see Table 4.1). The response rate for this ASD survey supports that families with someone who has ASD, as well as their nonfamiliar caregivers, look to faith slightly more often than neurotypical families. They are actively searching their faith for answers and explanations. Churches need to pay attention to the presence of this population in their midst and their desire to merge faith and present reality.

Table 4.1. Attendance Frequency of Person with ASD or Caregiver (N=97)

Attendance Frequency	n	%	National Average %
Several times a week	3	3.1	no data
Every week	46	47.4	36
About once a month	22	22.7	33
About once a year	11	11.3	no data
Less than once a year	15	15.5	no data

Families and caregivers of people with ASD were asked if they have ever worshipped with a faith community and if they are currently worship with a faith community (see Tables 4.2 and 4.3). Twenty-five percent fewer families or caregivers were currently attending worship than had previously attended. Though the response numbers were lower for the question regarding previous participation in a faith community (n=34 as opposed to n=104), the results support previous research that families and caregivers of someone with ASD seek to make connections with a faith community but remove themselves from the community when their needs are not met.

Table 4.2. ASD Participants Previously with a Place of Worship (N=35)

Response	n	%
Yes	31	88.6
No	4	11.4

Table 4.3. ASD Participants Currently with a Place of Worship (N=104)

Response	n	%
Yes	66	63.5
No	38	36.5

A majority of the persons with ASD were between the ages of 7 and 17 years old (see Table 4.4). This finding was not unexpected. As previously established, most ASD diagnoses are of children on the spectrum. Very few adults are being diagnosed because

high-functioning adults have typically adapted to society. Over time, they have developed social strategies, allowing them to function in a neurotypical environment.

Table 4.4. Age of Person with ASD (N=106)

Age	n	%
6 years old and under	12	11.5
7-8 years old	12	11.5
9-10 years old	16	15.0
11-12 years old	10	9.5
13-14 years old	16	15.0
15-16 years old	11	10.0
17-18 years old	8	7.5
19 years old and older	21	20.0

A strong denominational preference among families and caregivers of people with ASD was unexpected (see Table 4.5). People with ASD typically prefer more structure and routine. The contemporary worship movement within the Protestant church generally presents less structured and more fluidity. A Pew Research Center study on the religious landscape of the United States indicates that 25 percent of the United States population is Protestant while 21 percent is Catholic ("U. S. Public Is Becoming Less Religious" 11).

Table 4.5. Faith Community Affiliation of Person with ASD (N=89)

Affiliation	n	%	National Average %
Catholic	9	10.1	21
Protestant	62	69.7	25
Other	18	20.2	No data

A majority of the people with ASD are male. Research by D. L. Christensen et al. supports that boys are diagnosed at a higher rate than girls with a ratio of 4.5:1. Research is mixed as to why such a discrepancy exists between male and female. The number of survey subjects with ASD fits the CDC diagnostic rate of nearly 4:1 with 80 percent males and 20 percent females (see Table 4.6).

Table 4.6. Gender of Person with ASD (N=96)

Gender	n	%
Male	77	80.2
Female	19	19.8

An interesting gender number discovered in the survey was the gender of the family member or caregiver completing the survey on behalf of the person with ASD. Nearly 90 percent of the family members or caregivers completing the survey were female (see Table 4.7). The survey was not designed to explain this point, but further study would be beneficial in other therapeutic areas.

Table 4.7. Gender of Caregiver Completing the Survey (N=71)

Gender	n	%
Male	1	1.5
Female	70	98.5

The DSM update from the fourth edition to the fifth was probably the rationale behind 74 percent of the survey participants with ASD being diagnosed using the *DSM-IV* (see Table 4.8). *DSM-IV* autism diagnoses are grandfathered into the *DSM-V*, but over time, the diagnostic numbers using the *DSM-V* will undoubtedly increase.

Table 4.8. Diagnosis of Person with ASD (N=96)

Diagnosis	n	%
PDD-NOS	7	7.3
Autism (DSM-4)	54	56.3
Asperger's Syndrome (DSM-4)	17	17.7
Autism, Level 1 severity (DSM-5)	1	1.0
Autism, Level 2 severity (DSM-5)	5	5.2
Autism, Level 3 severity (DSM-5)	4	4.2
Other	8	8.3

Therapeutic Professionals

Therapeutic professionals were defined as those who work with those who have ASD in some capacity to help those with ASD adapt and grow into their particular context. Seventy-five therapeutic professionals participated in the survey. Sixty-eight have a therapeutic role in the life of someone with ASD (see Table 4.9). An overwhelming majority of these professionals identified themselves as speech and language therapists. This type of professional is the most common therapist employed in the public school system. Most of the people diagnosed with ASD are still in the public

school system, which would explain the number of speech and language therapists participating in this survey.

Table 4.9. Role of Therapeutic Professional (N=68)

Role	n	%
Speech and language therapist	39	57.4
Occupational therapist	4	5.9
Special education instructor	4	5.9
General education instructor	3	4.4
Intensive in-home care provider	3	4.4
Other	15	22.1

Ten or more years was the mode of the therapeutic professional's experience with the next most common response being zero to three years (see Table 4.10). This response rate allowed the therapeutic perspectives and responses of the survey to be balanced between youth and experience.

Table 4.10. Length of Experience of Therapeutic Professional (N=47)

Duration	n	%
0-3 years	15	31.9
4-6 years	7	14.9
7-9 years	3	6.4
10 or more years	22	46.8

With 84 percent of the therapeutic professionals reporting to have experience in worship settings and 71.5 percent reporting they attend worship at least once a month, this group brought an experienced eye and unique expertise to the subject of accommodations (see Tables 4.11 and 4.12).

Table 4.11. Therapeutic Professionals Previously with Place of Worship (N=25)

Response	n	%
Yes	21	84
No	4	16

Table 4.12. Attendance Frequency of Therapeutic Professional (N=63)

Frequency of Attendance	n	%
Several times a week	3	4.8
Every week	34	54.0
About once a month	8	12.7
About once a year	7	11.1
Less than once a year	11	17.5

Worship Planners

Worship planners were defined as those who plan for the activities of communal worship services (see Table 4.14). These twenty survey participants represented varying levels of involvement in worship planning as well as varying levels of supervision (see Table 4.13). Three of the worship planners had training experiences related to people with special needs (see Table 4.15). They offered insight into the implementation realities

of the accommodations suggested through the previous two surveys (see Table 4.21). Worship planners responded at a lower rate than persons with ASD, their families and caregivers, or therapeutic professionals. Rationale for this response rate is discussed in Chapter 5.

Table 4.13. Role of Worship Planner (N=19)

Role	n	%
Regional church leadership (bishop, district superintendent, etc.)	1	5.3
Local church pastor	13	68.4
Worship leader/planning committee	2	10.5
Church volunteer	3	15.8

Table 4.14. Frequency of Worship Planner (N=17)

Frequency	n	%
Several times a week	3	17.6
Every week	12	70.6
About once a month	2	11.8

Table 4.15. Previous Special Needs Training (N=13)

Response	n	%
Yes	3	23.1
No	10	76.9

Research Question #1

What experiences have caregivers of children, youth, and adults with ASD had in communal worship?

The focus of this research was to discern ways worship leaders could adjust communal worship services to make them more accommodating to people with ASD. The first step to discerning changes was to discover what experiences people with ASD, their families, and caregivers were currently having.

Anecdotal experiences of caregivers of children, youth, and adults with autism were offered in the first survey. These stories told of church leaders who spoke harshly and cruelly about persons with ASD and their families. They told of people who were giving up on the Christian church because the behaviors of its members were far from Christian. They also told of families and caregivers who only desire the church to be kind toward their loved one with ASD:

> But there's nowhere else to go anyway, so it really doesn't matter now. (There are tons of other churches but it's not worth the trouble to go and be ignored somewhere else.)
>
> Church communities have become ableist. They have tried to hide disability as if it were not allowed by their gods or something. They have failed to provide adequate support or even educate. Because of the lack of help, we see religion as a smaller part of our lives. We are joining a secular community of agnostics because organized religion that discriminates against disability gets everything wrong about both God and Christianity.
>
> We stopped attending church because others viewed his disability in such a negative way. Since this was such a negative experience, we haven't tried to return to church. We will try again when we move in hopes of finding a more accepting congregation.
>
> Asking us how they can include my child would be nice.

> He is not allowed to attend confirmation because of his behavior and we feel it's too late because he's missed out on the regular church experience all these years. I'm crying as I write this because this is one of the biggest losses for our family. I never dreamed I would have a child who would make it impossible for our family to attend church the way we'd like to and it's not his fault. If we're the ones who have to provide all of the support for our son during church, we can't access our own spiritual experience.
>
> Teachers have told us our child is slow, retarded, inattentive, doesn't care, and not Christian.
>
> We've been told by church leaders our child is just a "spoiled brat." Church staff have [sic] made us feel like bad parents because we can't teach our child "proper behavior".
>
> The pastor told us not to come back until we could control our child.
>
> I was told by our church that our child was possibly disabled because of our past sins.
>
> We were once told by an older church woman that our child was possessed by a demon.
>
> Our church has told us they expect our child to just behave and be healed.
>
> Children with disabilities causing them to be non-verbal are not baptized because my church doesn't baptize a person who can't vocalize their beliefs.

People with ASD shared positive and negative experiences within the faith community (see Table 4.16). The implications of surveys such as this one would encourage a participant to share negative experiences where church members and leadership ignored their presence and dismissed their needs but families also wanted to share uplifting and encouraging experiences of the church coming around them and being present with them in meaningful ways.

Table 4.16. General Experiences of ASD Families and Caregivers at Church (N=219)

Response	n	%
Positive	45	20.5
Negative	174	79.5

Families and caregivers of someone with ASD answered survey questions but also shared narratives of their experiences with the local church. Because of the nature of the survey, the comments were critical of the local church and its leaders, both lay and ordained, but still accurately reflected the experiences those families were having as they engaged the worship life of the church.

Because the experiences were unique to each person experiencing them, the terms and phrases were not repeated in exactly the same way. Words and phrases similar in tone and definition were grouped together (see Table 4.17). A majority of local church comments toward families and caregivers of someone with ASD shared in the narratives focused on the church being unaccepting of those with ASD and, sometimes, unaccepting of the family members and caregivers attending worship as well. More than half of the church's behaviors were about excluding families and caregivers of someone with ASD—not simply not including them but directly mentioning these families are not welcome and would not be included. Another group of comments shared by more than half of the participating families focused on words spoken to the families and caregivers of someone with ASD. Participants shared experiences of church members telling them their family member with ASD was "possessed," "retarded," "need to be exorcized." Many other comments in this grouping were bullying terms and terms expressing mean

and demeaning interactions between church leaders (lay and ordained) and the families and caregivers of someone with ASD.

Table 4.17. Negative Terms/Phrases Used by Survey Participants (N=106)

Term/Phrase	n	%
Unaccepting	76	71.7
Not included, not welcome, lack of sensitivity	56	52.8
General discord, mean, possessed, bullied	53	50.0
Doesn't understand	52	49.1
No one to help	52	49.1
Non-accommodating, unstructured	44	41.5
Unsupportive	37	34.9
Judgmental	28	26.4
Consider leaving/left the church	23	21.7
Unwilling, makes no effort, inflexible, uninterested	22	20.8
Doesn't listen, doesn't visit	17	16.0
Made me cry	17	16.0
Overwhelming, stressful	17	16.0
Discriminates	16	15.1
Made things more difficult	16	15.1
Un-Christian	15	14.2
Uncomfortable	13	12.3
Unloving, won't smile	13	12.3
Afraid	12	11.3
Need training	11	10.4

Disappointment in the church and its leadership expressed by people with ASD, their families, and caregivers were sorted into three categories: sensory-related concerns, structural-related concerns, and developmental-related concerns (see Table 4.18). Sensory interests focused on needs related to sight, hearing, touch, and taste concerns.

Olfactory-related concerns were not included in the sensory topics because smell issues are not common in worship settings are were not mentioned by any of the survey participants. Structural interests focused on needs related to the order, routine, and structure of worship. Developmental interests focused on needs related to particular developmental delays in the individual with ASD. These types of delays would include reading, speech, behavior expectations, and social awareness.

Table 4.18. Specific Experiences of ASD Families and Caregivers at Church (N=263)

Response Type	n	%
Sensory	109	41.4
Structural	57	21.7
Developmental	97	36.9

Research Question #2

What interventions do caregivers of children, youth, or adults with ASD predict will make communal worship participation a more positive experience?

Families and caregivers of individuals with ASD have been engaging accommodations in various forms throughout their loved ones treatment. Attempts and plans for accommodation strategies would naturally be brought into the life they live within their faith communities.

Anecdotal experiences of accommodations that caregivers of children, youth, and adults with autism, as well as therapeutic professionals thought would be effective were offered in the first two surveys. These stories told of struggles being encountered with the faith community because the faith community was ignoring the ASD-related need or

because of their ignorance of ASD in general. They did not expect large changes to be implemented within the faith community's structure. They shared stories of the need for people simply to be present or to make an effort to see their loved ones of divine worth and value:

> We attended a church that kept trying to push their special needs service on us even though we preferred him to be in integrated. They wouldn't allow my husband to sit with him during the special needs service and wouldn't allow my son into the regular service. They ended up asking us to leave. After that, we sought an autism friendly service.
>
> Our daughter was allowed to participate in the church life with younger children more her developmental capability. Then, for reasons we don't understand she was moved to a group that fit her age but was beyond her emotional and social capabilities. When we explained to the church leaders the struggles our daughter was having, would continue to have, and asked church leaders why she was moved, we were told there is no one to help her and it's just too much trouble to find helpers each week.
>
> We have tried Sunday School but the teachers don't seem to make an effort. This has been the case at several churches we've been to, so we have just stopped trying.

People with disabilities should be more than just a yearly service project. Simply having someone on a regular basis be present with the individual with ASD during worship would make a meaningful impact on these families.

The accommodations they attempted or planned fell into six categories: visual, auditory, taste, touch, structure, and development (see Appendix G). Visual, auditory, touch, and taste were categories related to sensory experiences, including sight, hearing, feeling, and eating. Structural accommodations related to order and routine experiences. Developmental accommodations related to experiences that were present because of developmental delays (e.g., reading, behavior, social adjustment.)

Research Question #3

What accommodations may be helpful for the inclusion of a person with ASD into a communal worship service?

Interventions and accommodations related to ASD are as varied as the presentation of the disorder they are designed to assist. Accommodations can fit well in one context and be inappropriate in another. The objective to accommodation implementation is to discern which accommodations, of the many available, may be most effective in each context. Those who should understand the appropriateness of accommodations are the therapeutic and worship professionals who implement and adjust accommodations every day.

Anecdotal experiences of accommodations that therapeutic and worship professionals have found to be effective were offered in the third survey. These stories told of good work being done by leaders trying to include all people into the life of the faith community:

> I know their daughter loves to sing and we encourage her to sing the songs she knows with our choir. If she doesn't know the songs, we allow her to stand with the choir or sit near the organist.
>
> I encourage her and tell her what a great job she does singing. This seems to make her feel very proud of herself. Her parents have said this simple act has been wonderful for her self-esteem.
>
> The church is inclusive and while we are careful to note his autism and intellectual disabilities, we still try to make him understand he is a child of God.
>
> We try to include their daughter and our church is very accepting of her. Even if there is a communication barrier, I try to roll with it.
>
> Our pastor has been very supportive of their family. He also encourages their daughter in any way she is able to participate. Even if she's having a difficult day, he always has a kind and supportive word. The family has

> asked several times if they should keep her at home when she's having a difficult day. His response is always, "No. She belongs here just like everyone else."

Empathy on the part of church leadership does not go unnoticed by families with someone who has ASD.

A group of therapeutic professionals were asked to give their opinions on accommodations in the context of communal worship. The accommodations mentioned most frequently were the providing of buddies/partners to be with the people with ASD during worship, clearly communicate expectations for worship participation and behavior, and providing alternative seating in the front and back of the worship space during worship (see Appendix H).

Worship planners reviewed the accommodation suggestions offered by persons with ASD, their families and caregivers, and therapeutic professionals. They identified accommodation inclusions they thought would be possible to implement in a communal worship setting (see Appendix I).

Summary of Major Findings

Charles Kettering, an American inventor in the early 1900s, once said, "The world hates change, yet it is the only thing that has brought progress." Leaders of all types have historically been criticized for not being open to change. Change is a healthy evolution from what *was* necessary to be effective to what *is* necessary to be effective. Churches have seemed reluctant to adapt to the needs of worshippers with special needs, but the changes they are being encouraged to make by people with ASD, their families, and their caregivers are changes that are not difficult to make and mostly require a patient and willing spirit:

1. Church leaders who have a negative attitude towards ASD/accommodations drive away people with ASD, their families, and their caregivers.

2. Volunteers to be physically present with the person with ASD make a positive impact on the communal worship experience for people with ASD, their families, and their caregivers.

3. Accommodations that may provide the greatest impact during a communal worship service for people with ASD may be the least invasive accommodations.

CHAPTER 5

DISCUSSION

Major Findings

People with ASD are not participating in the communal worship life of the church because typical worship services are not accommodating the needs of worshippers with ASD. Faith is important to these families, and modifications can be made within worship services to allow families with a person who has level one or two ASD to be included in the larger community's worship practices.

The purpose of the research was to describe the specialized needs of a worshipper with Autism Spectrum Disorder and create intervention guidelines that address ASD-related needs during an inclusive worship service. The suggested accommodations, vetted by current worship planners, could be used to create worship space conducive to full inclusion of people with ASD into the communal worship life of their faith community.

Negative Attitudes That Hinder Hospitality

Hospitality should be something the church does well, even better than anyone else. The church should be radical in the ways it offers hospitality. From the perspective of the ASD community participating in these surveys, hospitality is not only lacking in the church but it is the most powerful rationale for not being an active member of the church community.

One ASD family member mentioned her child on the spectrum "was once described by an older woman [in the church] as having a demon inside of him.… He's just retarded and all I'm able to do is speak slower to him." This particular family is no longer involved with that faith community. Other families mentioned the unkind

comments made by congregants as the deciding factor to leave one community and seek out another, making "religion a smaller part of our lives." When asked what accommodation they would like to receive most from the church, which accommodation would be the most effective for their family, one participant echoed the spirit of several comments when they responded, "just patience and flexibility at this time,… love and patience." These survey findings supported Patricia Coulthard and Michael Fitzgerald's research, indicating that local churches in general are not being supportive of families who have someone with ASD and those families are coming to rely on themselves for spiritual formation.

Churches, like many organizations, are reluctant to change. Change upsets the current culture and can cause a great deal of discomfort among the members already familiar with the current way of living together. White and Pierson identify the congregation's attitude towards people with disabilities as a hindrance to appropriate and much-needed change in the church. When people with disabilities are viewed as *other*, polarities are established that only further devalue people with disabilities. Understanding all the members of the body as part of a greater whole is important. "We can only understand the need for change when we realize that we are making changes in order that the body of Christ can be made whole" (Swinton, Mowat, and Baines 57). The wholeness of the body should be the vision driving a faith community.

Churches, like many organizations, desperately need to adapt to a new faith climate and congregational culture. ASD is becoming a hard-to-ignore reality in every congregation. With one person in sixty-eight diagnosed with autism, the chances are high persons with ASD are in every congregation in the country. The body of Christ, in the

fullness of its description in 1 Corinthians 12, includes those who are neurotypical as well as those who have ASD. Adaptations should be embraced by the church if their mission is to make disciples of people from every strata of society. If adaptations are not currently being embraced, at the very least, the church should express a willingness to embrace adaptations. The church needs to reach out to those to whom it traditionally has not and more effectively engage those who live with disabilities, not to be separated out and regulated to a special place or a special ministry. Individuals need to be completely enfolded within the worship life of the church as much as possible (Beates 127). The perceived lack of openness to adapt is impacting the ability of local churches to engage with the ASD community and, as a result, hindering its ability to reflect fully the body of Christ.

Clergy are trained and prepared in seminaries and shaped by the ordination process to preach the Word of God and guide the spiritual growth of their local congregation. They are not shaped to understand ASD or another developmental disorder. They cannot be faulted for not having an inclusion skill set, but they can be faulted for not seeking out ways to more fully open their communities up to the diversity of people in the midst of their community. The responsibility to include those on the margins belongs to those in the center.

Several families experienced congregations with members who were not prepared to include or engage with persons who have ASD. What made the greater negative impact was the close-minded attitude of those congregants: “Teachers without training would try to say he was slow, retarded, inattentive, didn’t care, not Christian, etc.” While

any level of training would be helpful, according to the persons with ASD, their families, and caregivers, an open spirit could overcome a lack of training.

Volunteer Presence

John Wesley believed spirituality was not a solitary thing: "He felt that fellowship was vital to Christian spirituality and that there is no such thing as a solitary Christian" (Whaling 13). The church is relational. Relationships are essential pieces to human personhood: "We cannot be persons apart from our connections to others.… Rejection strikes a blow at the root of healthy human personhood because it strikes at our connection to others" (Seamands 29). Connection to others is vital in the understanding of self.

The church is made of people, different people in the same place working toward a common goal in different ways. Paul reminds the church in Corinth that the body of Christ is comprised of many members with different gifts but gifted from the same God. Yong agrees that their differentness and their brokenness are signs that God does not value one gift over another or one person over another but that the God of their differences stand in solidarity with the central and the marginalized (120). Being different should not be about being separate: "The image of God begins to be restored in the body of Christ when each individual is affirmed for what they have to contribute to the total image" (Swinton, "Building a Church" 59). The church is designed to be a place that holds together the tension of being unique and common at the same time. Congregations are meant to be unified in their uniqueness. This unification is accomplished through an open-minded, radically hospitable spirit that accepts those members who are different and includes their differences in the common work of the body.

Families of people with ASD who participated in the survey scored the presence of a volunteer to be with their loved one as the most needed developmental accommodation. The request for a volunteer's presence was the only accommodation lifted up by the persons with ASD, the families and caregivers, as well as the therapeutic professionals. These volunteers did not need to be trained to handle developmental disabilities or to earn an accreditation in special needs care. They only needed to have a heart for others and show patience toward the person with ASD: "We just want a warm, welcoming environment." While many churches mentioned in the survey responses did not offer this warm environment, the ones that did were spoken of highly and with much appreciation from the families and caregivers of those with ASD. People with disabilities are not marginal parts of the body. They are necessary for the body to function in the way God designed it to. One of the reasons faith communities need the presence of people with disabilities is because they allow the group to become a community (Webb-Mitchell, *Beyond Accessibility* 38-39). Neurotypical volunteers physically and intentionally present in worship with someone who has ASD, presents an unavoidable image of what the body of Christ should look like in its fullness, not just to the ASD community but also to the neurotypical one.

A volunteer's presence allows for parents to receive respite while in worship. It allows them to focus on their faith and not giving their loved one the constant attention he or she may need: "We wish they had a buddy system in place. Her brother has to watch her." One worship planner mentioned in survey comments his church uses an incentive program to engage youth volunteers with special needs children in worship. While I am not a fan of paying someone to behave a particular way, depending on how the incentive

program is set up, this method of engaging different children may be a good first step toward sharing deeper experiences.

Many families and caregivers express a sense of isolation when they have a child who is not fully accepted by the community of which they are trying to be members. Without being quickly acknowledged and accepted, these members of the body of Christ move on to other congregations, and sometimes, abandon the search for a church family altogether. As one participant said, "It's not worth the trouble to go and be ignored somewhere else." A volunteer presence can help address feelings of being alone and abandonment many families and caregivers expressed.

Many times volunteers spend time with the persons to whom they are assigned in an effort to help their assignments change to suit the current culture better. My experience has been those who volunteer to work with persons with ASD are often changed themselves. They are softened by people who may be different but also see the world differently, who appreciate the world from a different perspective, and who bring unique gifts to the relationship. Volunteers discover they are not only giving of themselves to the persons with ASD, they are also receiving and both parties are changed for the better. This mutual change is the benefit of the body of Christ—a realization of the need for everyone and that everyone contributes to the kingdom's work in unique ways out of their own unique gifts.

Unobtrusive Accommodations

Recommended accommodations related to senses and developmental delays were 78.3 percent (see Table 4.19). Accommodations for those with ASD, as mentioned in Chapter 2, are most commonly implemented out of these two areas. Typically,

accommodations involving adjustments to sensory input and developmental delays can be costly, not only financially but also in the time needed to implement and maintain the inclusion resources. What made this list of accommodation suggestions interesting was that the most requested were simple to implement, inexpensive, and unobtrusive to the worship practices already present in the community.

The commonly requested accommodations would not require major, if any, invasive changes to the worship service already in place. These changes could be implemented with little effort and little cost. If their disabilities are truly marks of their covenant with God, as Yong implies, every effort should be made to include all people, especially those marked by disability, in the work of the kingdom and communal worship of the King (31). I believe worship planners want to include all people in worship but they do not know how. As Michael Beates also points out, churches may grasp the vision of accepting all people but lack the initiative or understanding to take simple steps that would move the church toward inclusion of all people (18). Participants communicated in the survey results that persons with ASD want to be included, that accommodations in the areas of sensory control and that developmental delays could be most effective toward inclusion, and the accommodations believed to be most effective are also inexpensive and unobtrusive to the worship traditions already in place—simple measures making the church community more complete.

Having a volunteer present, offering seating in the front and back of the worship space, and communicating the appropriate behaviors were three of the most requested accommodations. These would not require changing the order of worship, adjusting the worship length, or purchasing specialized equipment. Debra Peterson says disabilities are

more common in the world today, but church has not made hospitality practices commonplace. Churches must be more hospitable and not only more accessible (Viviano). Offering effective accommodations that extend this heart of welcome would not require much effort, extensive training or an overwhelming volunteer force, or softening or shallowing of theological practices currently in place. Effective accommodations only need forethought by the worship planner and congregants with patience and love. Those with ASD need very little to consider themselves included. Patience and love, as several families expressed, overcome a vast array of inclusion deficits in the church.

Implications of the Findings

Not all people are gifted in the same way. Not everyone is an effective motivational speaker, a skilled mechanic, or an insightful therapist. While some worship planners may feel comfortable with making alterations to the worship environment to be more accommodating, many may not be, which is understandable. Worship planners may desire to accommodate but not have the confidence or the skill set to do so effectively. Resources can be made using results from this project to help worship planners prepare who may not have a natural inclination for hospitality towards those with special needs. Trainings can be made available to help worship planners discuss their particular worship settings and plan for the use of accommodations that would be effective as well as appropriate for them. The requests from the persons with ASD, their families, and their caregivers were not overtly therapeutic. They did not require intensive study or credentialing to understand or implement. The accommodations identified as most effective and most appreciated were accommodations easy to implement with a little

forethought and very little additional resources. Putting many of these accommodation recommendations in place will increase the hospitality of the congregation to other special needs populations as well, not only those with ASD-related needs. Many of the accommodation recommendations make communal worship more approachable by many different populations, including the neurotypical population. For example, adhering more closely to the worship schedule, being mindful of the music volume, and using bulletins that are more user friendly are ways worship planners can be hospitable toward many different populations of worshippers.

Local church leaders can reach out to therapeutic professionals to help plan for appropriate accommodations. Therapists were eager to be involved in the project and responded at a greater rate than did the worship planners. Therapeutic professionals have a passion for the special needs population and were eager to share ways the faith community could include them in new and effective ways. Therapists seek worship communities as well. Involving them in the life of the church can help make worship better and better attended.

A connection is clear between local church behavior and worship attendance by those with ASD, their families, and their caregivers. Families were seeking faith communities that offered experiences that included their whole family or, at the very least, was open to their whole family. Above all, these families are seeking "a warm, welcoming environment that strives for inclusion." If they are not offered the inclusive environment they need, they go elsewhere and sometimes go nowhere. Even if churches are not able to make accommodations at this time, an open spirit will go a long way with families faced with ridicule and rejection in so many other facets of their live. The good

news gleaned from this portion of the project was that these families are leaving *after* attending worship. They are seeking out the church. They are making the effort to bring their family. They are worshipping with the faith community. They are only leaving when the faith community communicates to them that they will not be accepted and their differences are not necessary in the body.

The church cares for others. The work of reaching out to those around who are in need while reaching up to the God who loves all unconditionally has always been the work of the church. Some churches do this kingdom work more effectively than others. Some churches have lost their heart for the other but still have a heart for the God who calls God's people to love their neighbor. Spending time intentionally thinking through these issues of radical hospitality, the prevalence of ASD in their communities, and the desire of God for all people to be a part of the kingdom's work will help the local church develop a better understanding and deeper theological around the body of Christ and the necessity of members who are uniquely created.

Limitations of the Study

This study focused on behaviors of the local church and behaviors of the persons with ASD, their families, and their caregivers objectively reported through surveys. Other methods of engagement, such as focus groups or interviews, would have provided more qualitative information and possibly a deeper insight into the motivation behind the reported behaviors. Extensive insight into those behaviors were not necessary for this project but would have added another dimension to the findings.

This study also focused on participants in eastern North Carolina and middle Tennessee. ASD-related resources are offered at a nominal level in these areas while

other areas of the country have a more developed ASD network. The more developed areas of the country are in the northeast. Areas with more resources and those that have had ASD resources longer may have faith communities more accustomed to ASD inclusion. These more accustomed faith communities may have more effective inclusion practices and better informed worship planners. This study may have yielded different results if offered in better resourced areas such as the northeast.

ASD is a spectrum disorder. It affects each person differently and in varying degrees of developmental depth. This study is able to address ASD with respect to the participants of this project. While the findings of this study can be generalized, the findings are not all-encompassing of the entire spectrum. Many persons with ASD may require more involved accommodations than identified in this study, and some may require accommodations so vast, they may not be able to be included in a mainstream communal worship service. For these persons with lower functioning ASD (level 3 and, in some circumstances, level 2), a separate worship experience may be the best option.

Participants who began the ASD survey did not answer all of the survey questions. One hundred and six participants began the survey, but the number of participants answering each varied from question to question. To require participants to answer all the questions would seem to violate the openness of the relationship and the trust between the survey taker and the survey creator, but not having full participation undoubtedly made the survey results less valid than they could have been otherwise. This same pattern of survey participation and varying response numbers continued through the therapeutic professional survey as well as the worship planner survey.

Unexpected Observations

Response rates varied among the three groups of participants. The highest number of responses were from the ASD participants, including their families and caregivers (N=106). The high response rate communicated they are interested and invested in the work of this study. The therapeutic professional response was about 25 percent less (N=75). Because a response total of 75 was the goal, this rate also communicated an interest in the work of this study. The unexpected observation was the extremely low response rate from the worship planners (N=20). The low response may communicate a lack of interest, a lack of time to engage the survey, a lack of connection to the ASD community, or some other variable. I interpreted the low response rate as support that the opinion worship planners need training and resourcing around the inclusion of special needs populations into the life of their faith communities.

Nearly 90 percent of the persons with ASD, family members, or caregivers completing the survey were female (see Table 4.7, p. 58). This unbalanced participation could be because in many households, the male works outside of the home, spending less time involved in the care of the family member with ASD while the mother's schedule is more conducive to caring for the family member with special needs. This observation is supported only by personal experience within ASD support communities. The surveys were not designed to explain this observation but understanding better how families adjust to provide care for loved ones with ASD may be beneficial to other therapeutic areas.

The most common rationale families and caregivers of someone with ASD gave for leaving a particular faith community to attend somewhere else or nowhere else was

the negative attitude of Christians toward them and their loved one. The *negative attitude* rationale was mentioned 4:1 when compared to the second most common reason for leaving a faith community—lack of accommodations. Christian doctrine is commonly known enough for the general population to have expectations of hospitality from the Christian community. I expected that the lack of accommodations would be a reason for not attending worship but not the lack of Christian hospitality.

Recommendations

Of all the possible responses to the need to include persons with ASD in communal worship, the accommodations identified as more appreciated by those families are relatively easy to implement. The accommodations identified by the worship planners as the easiest to implement were also the accommodations identified as more appreciated. This discovery is exciting. Worship planners only need to prepare differently to begin to be more accommodating. They do not need to budget differently, staff differently, or order worship differently.

Group and Online Training

The lack of hospitality and effort by the local faith communities toward ASD families is encouraging those families out of local faith community participation. Preparation and awareness by the faith community's leadership of ASD has been identified as necessary to encourage the presence of individuals with ASD, their families, and caregivers in the worship life of those faith communities. To help worship planners and other congregational leaders become more aware of ASD and to understand the needed preparations, trainings can be made available in face-to-face gatherings in centralized locations with many people or through online videos where each leader can

participate at his or her own pace and in his or her own space. The online videos would also serve as a way for previous participants to refresh their memory of the material covered in the group gatherings.

The goal of a training would be to educate congregational leadership in the importance of their role as a hospitality ambassador. The responsibility of this hospitality work does not rest solely with the pastor or worship planner but with all congregational leaders and ultimately with each member of the faith community. Those encouraged to attend these trainings would be the clergy person responsible for ordering the life of that faith community as well as those who plan worship and lead volunteers. The goal would be to create buy-in by leaders of the hospitality principles and practices and then encourage those leaders to share those principles and practices with the other people in their faith communities.

Another goal of the training would be to educate those key leaders on the presence of ASD within their communities. The need for general ASD-related education was identified numerous times by surveyed individuals, family members, and caregivers of persons with ASD. These trainings would cover current trends in ASD diagnostic numbers as well as common, widely accepted information related to ASD behaviors and treatment. Because ASD is a spectrum disorder and its manifestations in the people who are diagnosed are varied, the discussion would remain broad and general as it relates to ASD behaviors and interventions. Important for training participants to understand is that no one ASD behavior, treatment, or intervention is common in all individuals with ASD.

Points of information and strategies that could be included in these trainings are

- ASD awareness;

- Simple accommodations such as
    - Seating adjustments,
    - Volume awareness,
    - Bulletin adjustments; and,
- Hospitality strategies, such as
    - Smiling,
    - Kind conversation,
    - General inclusion.

Volunteers

Volunteers can be anyone who is able to be physically present with the person with ASD to assist with needs that arise. These needs could be answering questions about worship order or singing instructions, or helping to find the restroom. Volunteers also model appropriate behavior. Churches can recruit seniors, young adults, or neurotypical peers. These volunteers do not need to be especially trained or have vast experience working with persons with ASD. They only need to have a heart for others and a willingness to be present with them.

Seating

Many persons with ASD have trouble sitting for longer periods of time. Families and caregivers of these persons have fallen into the habit of sitting in the back of rooms so they can exit with honor if the need arises. The back of the sanctuary may also provide additional empty space for these persons to move around outside of their seat without disturbing the view of the worshippers in front of them. Some persons with ASD respond to music. They love the sensory input that comes from hearing instruments and dancing.

Some survey participants mentioned the love their children have for dancing, and they try to sit on the front row in worship each week so their children can dance when the band plays. Reserving seats in the front of the worship space as well as the rear is easy to do and hospitable to the families looking for an easy exit or an impromptu dance floor.

Volume

Many persons with ASD have sensory concerns. Loud noises can be upsetting, especially if those loud noises are unexpected. Worship planners can help the volume concerns of persons with ASD by being diligent with microphone checks before worship and to ensure the soundboard is properly adjusted. Another strategy for volume concerns is to prepare the person with ASD by signaling for impending loud sounds. Many sensory-friendly theatres will use a small light or flag offstage to signal the impending sound so they can be prepared by covering their ears or just be aware that the sound is coming.

Bulletins

Church bulletins are usually filled with information to introduce the reader to the faith community. Every worship planner's objective should be to make that introductory experience a helpful and hospitable one. A simple way to accomplish that objective is to make sure the information in it is correct with respect to the order of worship. Persons with ASD can be uncomfortable in new situations, and having a schedule of the new experience provides a sense of comfort. Knowing what happens first and what items will follow provides comfort because they know what to expect. For experiences they may not enjoy, knowing the timing of the pieces that make up those experiences allows them to know the undesired experiences are coming to an end at a point they can identify.

Because a majority of the persons with ASD are visual learners, pictures in church bulletins can be helpful in communicating not only what experience is at hand but also the expected behavior. The use of an image of praying hands for the pastoral prayer or a singing mouth for the choral response communicates the experience at hand as well as the expected behavior (i.e., praying or singing). The Picture Exchange Communication System (PECS) uses small images to communicate schedules in visual ways (Bondy and Frost). It employs images small enough to fit into a traditional bulletin, and the images are universal enough for most to understand their meaning. Common PECS images are available online and through PECS software.

Expectations

For many persons with ASD, expectations in new situations are extremely stressful. Questions of what to wear, what to bring, what to say, when to speak, where to sit, where to park, whether friends will be there, and many other issues can be overwhelming and possibly paralyzing. Communicating expectation can reduce the stress persons with ASD will experience in new situations. These expectations can be communicated through the bulletin but also through the church's Web site. Having expectations available online allows families and caregivers of persons with ASD to review expectations with their loved one before arriving at church. Having digital copies of PECS bulletins can communicate worship expectations as well. Social stories are extremely effective ways to prepare a person with ASD for experiences and possible responses to different situations. These social stories can focus on worship, singing, Sunday school, offering collections, communion, baptism, or any other experience in the

church. Video social stories are extremely effective and easy to host online for families to view and discuss before arriving at worship.

This study was designed to discern effective accommodations but not how the absence of effective accommodations may impact a person's belief in God. Because the local church is the body of Christ, which is the physical manifestation of God, the action of the local church reflects upon the God it represents. Meaningful to the disability theology conversation is an engagement of ASD-impacted families about how their experience with the local church (positive or negative) has influenced their belief in God.

The rationale behind persons with ASD, their families, and their caregivers for leaving church would also be beneficial to study further, such as the specific reasons for leaving, how many times they attended before deciding to leave, and for what specifically were they looking when researching a faith community. This information would help faith communities better understand the impact of their behaviors on the special needs population.

After implementing inclusion accommodations, an increase in attendance would be expected. Strategies for increasing worship attendance that seem logical and reasonable should increase worship participation but do not always accomplish this. Helpful strategies include offering inclusion accommodations to faith communities, training worship planners on their implementation, allowing a reasonable amount of time for the accommodations to be present, and comparing pre- and postattendance figures to include the worshipping population's demographic information. Making accommodation implementations should increase general attendance numbers and attendance within the ASD community specifically.

A majority of the therapeutic professionals who responded were speech and language therapists. Many other types of therapists work with persons with ASD and were invited to participate in the survey. A greater understanding of this uneven response rate's influencers would be helpful to the work of ASD support communities. Other helpful information to gather would be continuing education experiences most helpful to therapist working with persons with ASD, the professional therapeutic organizations that should be communicated with, and the type of therapeutic interventions parents continue to find most helpful in worship settings.

Postscript

This process has been a labor of love. Depending on the season in which I was working, I might love what I was doing or I might need to labor through. I loved the material. I loved the implications it could have in the local church. I love that the work brought together two pieces of my life that mean a great deal to me—autism and the local church. My own struggles with autism spectrum disorder made this work a very unique labor of self-discovery.

I have learned my hard wiring is extremely helpful in many circumstances but can also be a hindrance in many others. My DMin journey was the first major work I have undertaken since my ASD diagnosis. ASD influenced how I prefer to work, the way I need to structure my work, and the environment in which I work best. This project has taught me more about myself than I ever thought I would teach the local church about ASD. I am a project manager more aware of my oversight deficits, a pastor better able to empathize, and a person of the margins who has been accepted by the center and now is keenly aware of my responsibility to include those not included.

APPENDIX A

WORSHIP EXPERIENCE SURVEY INVITATION AND CONSENT E-MAIL

This letter is an invitation to participate in a worship experience survey I am conducting as part of a Doctor of Ministry degree program at Asbury Theological Seminary. The purpose of this research project is to describe the specialized needs of a worshipper with Autism Spectrum Disorder and create accommodation guidelines that address ASD-related needs during an inclusive worship service. You are invited to participate because you or someone you care for has a diagnosis of ASD.

Faith is important to many of us and has been reported to be particularly important to families with a loved one who has ASD. While faith is important, full participation in the worship life of a spiritual community has also been reported to be difficult because of the spectrum of needs the ASD population has. Many spiritual communities offer separate worship services for special needs populations but few are offering accommodations to allow for full participation in the larger worshipping community's services.

If you agree to participate in this study, you will only be asked to complete a worship experience survey. There is no monetary payment for participation in this study. Your survey will be used in conjunction with surveys completed over the next six weeks by therapeutic professionals and worship service planners to result in a list of accommodations to allow persons with ASD to participate more fully in communal worship services.

This 34-question survey inquires about (1) you/your loved one's diagnosis, (2) your spiritual community participation, (3) participation experiences of you/your loved one with ASD, (4) you/your family's participation in the spiritual community, and (5) basic demographic information about your family.

Your responses are kept in strict confidence.

Your demographic information is only asked to establish your context.

Your participation costs you nothing.

You can stop participating <u>at any time</u>.

Your responses will help me understand your worship experiences on various levels and help me discern what accommodations may help your spiritual community include you/your loved one in worship in a deeper and more meaningful way.

My accommodation recommendations, based on your experiences, will be shared with local church pastors for their input and further refinement. A final list of accommodation recommendations will be made available at the conclusion of this project. That list will also be made available to local church worship planners for use in their own worship services.

Accepting the terms means that you have read this or had it read to you: you want to be in the study. It also means that you agree you have been told about this study, why it is being done, and what to do. If you do not want to participate, do not accept the terms. Being in the study is up to you, and no one will be upset if you do not participate or change your mind later regarding participation.

If you have any questions regarding this survey, or would like additional information, please contact me by e-mail at *trip.lowery@asburyseminary.edu*.

Sincerely,

Reverend Trip Lowery
Director of Young Adult Ministry Recruitment and Enlistment
The General Board of Higher Education and Ministry
The United Methodist Church

APPENDIX B

WORSHIP EXPERIENCE SURVEY

Section 1

The following questions are about your loved one with Autism Spectrum Disorder (ASD). Please respond to these questions by selecting the most appropriate answer.

1. Person's Age
2. Person's Gender
3. What type of ASD diagnosis does this person have?

   ☐ Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS)

   ☐ Autism (diagnosed under the DSM-4)

   ☐ Asperger's Syndrome (diagnosed under the DSM-4)

   ☐ Autism, level 1 severity (diagnosed under the DSM-5)

   ☐ Autism, level 2 severity (diagnosed under the DSM-5)

   ☐ Autism, level 3 severity (diagnosed under the DSM-5)

   ☐ Other (Please describe)

Section 2

The following questions are about your family's spiritual community participation. Please respond to these questions by selecting the most appropriate answer.

4. Which best describes your spiritual community membership?

   ☐ Catholic

   ☐ Protestant (e.g., Methodist, Baptist, Presbyterian)

   ☐ Other (Please define)

5. Do you have a regular place of worship?

   ☐ Yes (If yes, skip to question 8)

   ☐ No

6. Have you attended or been a member of a spiritual community in the past?

   ☐ Yes

   ☐ No (If no, skip to thank you page)

7. How often do you attend religious services at your place of worship?

   ☐ Several times a week

   ☐ Every week

   ☐ About once a month

   ☐ About once a year

   ☐ Never

Section 3

The following questions are about participation experiences of your loved one with ASD. Please respond to these questions by selecting the most appropriate answer.

8. Does this person have the opportunity to participate in religious education activities such as Sunday school or Catechism class within your spiritual community?

   ☐ Yes (If yes, what accommodations were used to aid their participation?)

   ☐ No (If no, why have they not had the opportunity to participate? What accommodations would have been helpful? After explaining your no response, skip to question 13.)

9. How important is it to have this person participate in religious education activities at your spiritual community?

- ☐ Extremely Important
- ☐ Important
- ☐ Not important

10. How often does this person participate in religious education activities within your spiritual community?
    - ☐ Several times a week
    - ☐ Every week
    - ☐ About once a month
    - ☐ About once a year
    - ☐ Never
11. How would you rate this person's experience while participating in religious education activities at your spiritual community?
    - ☐ Positive
    - ☐ Somewhat positive
    - ☐ Somewhat negative
    - ☐ Negative

    Why did you rate this experience this way?
12. Does this person have the opportunity to participate in religious activities such as a music or dance program, youth groups, adult ministries, plays or mission trips within your spiritual community?
    - ☐ Yes (If yes, what accommodations were used to aid their participation?)

- ☐ No (If no, why have they not had the opportunity to participate? What accommodations would have been helpful? After explaining your no response, skip to question 17.)

13. How important is it to have this person participate in religious activities at your spiritual community?
    - ☐ Extremely Important
    - ☐ Important
    - ☐ Not Important
14. How often does this person participate in religious activities at your spiritual community?
    - ☐ Several times a week
    - ☐ Every week
    - ☐ About once a month
    - ☐ About once a year
    - ☐ Never
15. How would you rate this person's experience while participating in religious activities at your spiritual community?
    - ☐ Positive
    - ☐ Somewhat positive
    - ☐ Somewhat negative
    - ☐ Negative

    Why did you rate this experience this way?

16. Does this person have the opportunity to participate in formal spiritual/religious ceremonies such as First Communion or Confirmation within your spiritual community?

    ☐ Yes (If yes, what accommodations were used to aid their participation?)

    ☐ No (If no, why have they not had the opportunity to participate? What accommodations would have been helpful? After explaining the no response, skip to question 21)

17. How important is it to have this person participate in formal spiritual/religious ceremonies or rituals at your spiritual community?

    ☐ Extremely Important

    ☐ Important

    ☐ Not important

18. How often does this person participate in formal spiritual/religious ceremonies within your spiritual community?

    Several times a week

    Every week

    About once a month

    About once a year

    Once

    Never

19. How would you rate this person's experience while participating in formal spiritual/religious ceremonies or rituals at your spiritual community?

    ☐ Positive

- ☐ Somewhat positive
- ☐ Somewhat negative
- ☐ Negative

  Why did you rate this experience this way?

20. Does this person have the opportunity to participate in a regular worship service with your family within your spiritual community?
    - ☐ Yes (If yes, what accommodations were used to aid their participation?)
    - ☐ No (If no, why have they not had the opportunity to participate? What accommodations would have been helpful? After explaining the no response, skip to question 25)
21. How important is it to have this person attend a regular worship service at your spiritual community?
    - ☐ Not important
    - ☐ Important
    - ☐ Extremely Important
22. How often does this person attend a regular worship service with your family at your spiritual community?
    - ☐ Several times a week
    - ☐ Every week
    - ☐ About once a month
    - ☐ About once a year
    - ☐ Never

23. How would you rate this person's experience when attending a regular worship service with your family at your spiritual community?

- ☐ Positive
- ☐ Somewhat positive
- ☐ Somewhat negative
- ☐ Negative

Why did you rate this experience this way?

Section 4

The following questions are about your family's participation in regards to your loved one with ASD. Please respond to these questions by selecting the most appropriate answer.

24. How often have you received support from a religious leader within your spiritual community?

- ☐ Several times a week
- ☐ Every week
- ☐ About once a month
- ☐ Once a year
- ☐ Never (If answered never, skip to question 28)

25. How important is it to have a religious leader to turn to for support within your spiritual community?

- ☐ Extremely Important
- ☐ Important
- ☐ Not important

26. How would you rate the support you received from a religious leader within your spiritual community?

- ☐ Positive
- ☐ Somewhat positive
- ☐ Somewhat negative
- ☐ Negative

Why did you rate this support this way?

27. How often have you received support from one or more members of your spiritual community such as paid or non-paid staff or general members?

- ☐ Several times a week
- ☐ Every week
- ☐ About once a month
- ☐ Once a year
- ☐ Never (If answered never, skip to question 31)

28. How important is it to have support from one or more members of your spiritual community?

- ☐ Extremely Important
- ☐ Important
- ☐ Not important

29. How would you rate the support you have received from one or more members of your spiritual community?

- ☐ Positive
- ☐ Somewhat positive

- ☐ Somewhat negative
- ☐ Negative

Why did you rate this support this way?

30. Have you had any negative experiences regarding this person with ASD within your spiritual community?
    - ☐ Yes (If yes, what are these negative experiences?)
    - ☐ No (If no, skip to question 32)
31. Have you experienced exclusion regarding this person with ASD within your spiritual community?
    - ☐ Yes (If yes, how have you experienced exclusion?)
    - ☐ No (If no, skip to question 33)
32. Have you ever considered switching your spiritual community because of supports or issues regarding this person with ASD?
    - ☐ Yes (If yes, please explain)
    - ☐ No (If no, skip to question 34)

Section 5

The following questions are basic demographic information regarding your family. Please respond to these questions by selecting the most appropriate answer.

33. Relationship to this person with ASD.
    - ☐ Mother
    - ☐ Father
    - ☐ Other (Please describe)
34. Your Age

APPENDIX C

WORSHIP EXPERIENCE SURVEY FOR THERAPEUTIC PROFESSIONALS

INVITATION AND CONSENT E-MAIL

This letter is an invitation to participate in a worship experience survey for therapeutic professionals I am conducting as part of a Doctor of Ministry degree program at Asbury Theological Seminary. The purpose of this research project is to describe the specialized needs of a worshipper with Autism Spectrum Disorder (ASD) and create accommodation guidelines that address ASD-related needs during an inclusive worship service. You are invited to participate because you provide therapeutic services to people with ASD.

Faith is important to many of us and has been reported to be particularly important to families with a loved one who has ASD. While faith is important, full participation in the worship life of a spiritual community has also been reported to be difficult because of the spectrum of needs the ASD population has. Many spiritual communities offer separate worship services for special needs populations, but few are offering accommodations to allow for full participation in the larger worshipping community's services.

If you agree to participate in this study, you will only be asked to complete a worship experience survey for therapeutic professionals. There is no monetary payment for participation in this study. Your survey will be used in conjunction with surveys completed over the next six weeks by families who care for people with ASD, individuals with ASD, and worship service planners to result in a list of accommodations to allow people with ASD to participate more fully in communal worship services.

This 13-question survey inquires about (1) your role with people with ASD and (2) your observations of someone with ASD.

Your responses are kept in strict confidence.

Your demographic information is only asked to establish your context.

Your participation costs you nothing.

You can stop participating <u>at any time</u>.

Your responses will help me understand your observations of people ASD and their experiences within their spiritual community.

My accommodation recommendations, based on the experiences of people with ASD and your observations, will be shared with local church leaders for their input and further refinement. A final list of accommodation recommendations will be made available at the conclusion of this project. That list will also be made available to local church worship planners for use in their own worship services.

Accepting the terms means that you have read this or had it read to you; you want to be in the study. It also means that you agree you have been told about this study, why it is being done, and what to do. If you do not want to participate, do not accept the terms. Being in the study is up to you, and no one will be upset if you do not participate or change you mind later regarding participation.

If you have any questions regarding this survey, or would like additional information, please contact me by e-mail at *trip.lowery@asburyseminary.edu*.

Sincerely,

Reverend Trip Lowery
Director of Young Adult Ministry Recruitment and Enlistment
The General Board of Higher Education and Ministry
The United Methodist Church

APPENDIX D

WORSHIP EXPERIENCE SURVEY FOR THERAPEUTIC PROFESSIONALS

Section 1

The following questions are about your role with people with Autism Spectrum Disorder (ASD). Please respond to these questions by selecting the most appropriate answer.

1. What is your relationship to people with ASD?

   ☐ Speech & Language Therapist

   ☐ Occupational Therapist

   ☐ Pediatric Neurologist

   ☐ Special Education Instructor

   ☐ General Education Instructor

   ☐ Intensive In-Home Care Provider

   ☐ Other (Please describe)

2. How long have you served in the capacity?

   ☐ 0-3 years

   ☐ 4-6 years

   ☐ 7-9 years

   ☐ 10 or more years

3. Do you have a regular place of worship?

   ☐ Yes

   ☐ No

4. Have you attended or been a member of a spiritual community in the past?

- ☐ Yes
- ☐ No

5. How often do you attend religious services at your place of worship?
   - ☐ Several times a week
   - ☐ Every week
   - ☐ About once a month
   - ☐ About once a year
   - ☐ Never

Section 2

The following questions are about your observations of someone with ASD.

Please respond to these questions by selecting the most appropriate answer.

6. Does this person have the opportunity to participate in religious education activities such as Sunday school or Catechism class within your spiritual community?
   - ☐ Yes (If yes, what accommodations were used to aid their participation?)
   - ☐ No (If no, why have they not had the opportunity to participate? What accommodations would have been helpful? After explaining your no response, skip to question 9.)
7. How would you rate this person's experience while participating in religious education activities at your spiritual community?
   - ☐ Positive
   - ☐ Somewhat positive
   - ☐ Somewhat negative
   - ☐ Negative

Why did you rate this experience this way?

8. Does this person have the opportunity to participate in religious activities such as a music or dance program, youth groups, adult ministries, plays or mission trips within your spiritual community?

   ☐ Yes (If yes, what accommodations were used to aid their participation?)

   ☐ No (If no, why have they not had the opportunity to participate? What accommodations would have been helpful? After explaining your no response, skip to question 11.)

9. How would you rate this person's experience while participating in religious activities at your spiritual community?

   ☐ Positive

   ☐ Somewhat positive

   ☐ Somewhat negative

   ☐ Negative

   Why did you rate this experience this way?

10. Does this person have the opportunity to participate in formal spiritual/religious ceremonies such as First Communion or Confirmation within your spiritual community?

    ☐ Yes (If yes, what accommodations were used to aid their participation?)

    ☐ No (If no, why have they not had the opportunity to participate? What accommodations would have been helpful? After explaining the no response, skip to question 13.)

11. How would you rate this person's experience while participating in formal spiritual/religious ceremonies or rituals at your spiritual community?

    ☐ Positive

    ☐ Somewhat positive

    ☐ Somewhat negative

    ☐ Negative

    Why did you rate this experience this way?

12. Does this person have the opportunity to participate in a regular worship service with your family within your spiritual community?

    ☐ Yes (If yes, what accommodations were used to aid their participation?)

    ☐ No (If no, why have they not had the opportunity to participate? What accommodations would have been helpful? After explaining the no response, skip to the Thank You page.)

13. How would you rate this person's experience when attending a regular worship service with your family at your spiritual community?

    ☐ Positive

    ☐ Somewhat positive

    ☐ Somewhat negative

    ☐ Negative

    Why did you rate this experience this way?

APPENDIX E

WORSHIP ACCOMMODATION SURVEY FOR WORSHIP PLANNERS

INVITATION AND CONSENT E-MAIL

Faith is important to many of us and has been reported to be particularly important to families with a loved one who has ASD. While faith is important, full participation in the worship life of a spiritual community has also been reported to be difficult because of the spectrum of needs the ASD population has. Many spiritual communities offer separate worship services for special needs populations but, few are offering accommodations to allow for full participation in the larger worshipping community's services.

If you agree to participate in this study, you will only be asked to complete a worship planning survey related to ASD accommodations. There is no monetary payment for participation in this study. Your survey will be used in conjunction with surveys completed by families who care for people with ASD and individuals with ASD to result in a list of accommodations to allow people with ASD to participate more fully in communal worship services.

This 6-point survey inquires about (1) your role in the planning of worship and (2) your opinion on the implementation feasibility of suggested ASD worship accommodations.

Your responses are kept in strict confidence.

Your demographic information is only asked to establish your context.

Your participation costs you nothing.

You can stop participating at any time.

ASD-related accommodations were gathered from caregivers of people with ASD and people with ASD themselves. They are being offered for your input and further refinement. A final list of accommodation recommendations will be made available at the conclusion of this project.

Accepting the terms means that you have read this or had it read to you; you want to be in the study. It also means that you agree you have been told about this study, why it is being done, and what to do. If you do not want to participate, do not accept the terms. Being in the study is up to you, and no one will be upset if you do not participate or change your mind later regarding participation.

If you have any questions regarding this survey, or would like additional information, please contact me by e-mail at *trip.lowery@asburyseminary.edu*.

Sincerely,

Reverend Trip Lowery
Director of Young Adult Ministry Recruitment and Enlistment
The General Board of Higher Education and Ministry
The United Methodist Church

APPENDIX F

WORSHIP ACCOMMODATION SURVEY FOR WORSHIP PLANNERS

Section 1

The following questions are about your role in the planning of worship services.

Please respond to these questions by selecting the most appropriate answer.

1. Do you currently participate in the planning of worship?

   ☐ Yes

   ☐ No

2. (If #1 = No) Have you ever participated in the planning of worship in the past?

   ☐ Yes

   ☐ No (This selection will remove you from the survey)

3. How often do you participate in the planning of worship?

   ☐ Several times a week

   ☐ Every week

   ☐ About once a month

   ☐ About once a year

   ☐ Less than once a year

4. What is your role in the planning of worship?

   ☐ Regional Church Leadership (Bishop, District Superintendent, etc.)

   ☐ Local church pastor

   ☐ Worship leader

   ☐ Worship planning committee member

   ☐ Other

5. (If #4 = other) How would you describe your role in the planning of worship?
6. How long have you served in that capacity?

    ☐ 0-3 years

    ☐ 4-6 years

    ☐ 7-9 years

    ☐ 10 or more years

Section 2

The following questions are about your opinion of the feasibility of using the suggested worship accommodations in a communal worship service. Please respond to these questions by selecting the most appropriate answer.

7. Which of these visual accommodations could you implement in a communal worship service?

    ☐ Consistent lighting levels

    ☐ Clear visual focus point

    ☐ Visuals fit day's theme

    ☐ Printed bulletins

    ☐ Printed bulletins with pictures of actions (e.g., standing, singing, praying)

    ☐ Projection screen

    ☐ TV in alternate area streaming worship service

8. What visual accommodations not listed would you suggest be offered in communal worship service?
9. Which of these auditory accommodations could you implement in a communal worship service?

- ☐ Warning before loud noises (e.g., small flag raised, leader mentioning change)
- ☐ Noise-reducing headphones (active or passive)
- ☐ Quiet/Crying room

10. What auditory accommodations not listed would you suggest be offered in communal worship service?
11. Which of these taste accommodations could you implement in a communal worship service?
    - ☐ Gluten-free communion elements
    - ☐ Non-bread communion elements
    - ☐ Food allowed in sanctuary (e.g., snacks, motivators)
12. What taste accommodations not listed would you suggest be offered in communal worship service?
13. Which of these touch accommodations could you implement in a communal worship service?
    - ☐ Touch-free understanding when interacting with congregation (e.g., welcoming, passing the peace)
    - ☐ Sensory toys (e.g., fidget sticks, stress balls, coosh ball)
    - ☐ Small trampoline in quiet/crying room
    - ☐ Comfortable seating
    - ☐ Allow baptism by sprinkling in lieu of immersion
14. What touch accommodations not listed would you suggest be offered in communal worship service?

15. Which of these structure accommodations could you implement in a communal worship service?

    - ☐ Alternative seating (e.g., back of the room, front of the room)
    - ☐ Printed bulletins with timing (e.g., 11:00 a.m.—Welcome, 11:30 a.m.—Sermon)
    - ☐ Consistent routine/order of worship
    - ☐ Clearly communicated participation expectations
    - ☐ Alternatives for baptism (e.g., # of people present, method)
    - ☐ Shorter services
    - ☐ Alternatives for communion (e.g., gluten-free elements, longer time allowed)

16. What structure accommodations not listed would you suggest be offered in communal worship service?

17. Which of these developmental accommodations could you implement in a communal worship service?

    - ☐ Social story videos (e.g., navigating the building, singing, order of worship)
    - ☐ Alternative Bibles (picture Bible, storybook Bible, easy to understand interpretations)
    - ☐ Reading partner (read text aloud)
    - ☐ Buddies/partners (general 1:1 assistance)
    - ☐ Videos of previous ceremonies available online (e.g., baptism, communion, confirmation)

- ☐ Clearly communicated behavioral expectations

18. What developmental accommodations not listed would you suggest be offered in communal worship service?

APPENDIX G

ASD PARTICIPANT ACCOMMODATION SUGGESTIONS (N=263)

Accommodation	n	%	Category
Consistent lighting levels	7	2.7	Visual
Clear visual focus point	6	2.3	Visual
Visuals consistent with service's theme	4	1.5	Visual
Printed bulletin	8	3.0	Visual
Printed bulletin with pictures of action (e.g., standing singing, praying)	5	1.9	Visual
Projection screen	8	3.0	Visual
TV in alternative area streaming worship service	3	1.1	Visual
Warning before loud noises (e.g., small flag raised, leader mentioning change)	18	6.8	Auditory
Noise reduction headphones (active or passive)	10	3.8	Auditory
Quiet/crying room	10	3.8	Auditory
Gluten-free communion elements	4	1.5	Taste
Non-bread communion elements	1	0.4	Taste
Food permitted in sanctuary (e.g., snacks, motivators)	4	1.5	Taste
Touch-free understanding when interacting with congregation (e.g., welcoming, passing the peace)	5	1.9	Touch
Sensory toys (e.g., fidget sticks, stress ball, coosh ball)	13	4.9	Touch
Small trampoline in quiet/crying room	1	0.4	Touch
Allow baptism by sprinkling/pouring in lieu of immersion	2	0.8	Touch
Alternative seating (e.g., back of room, front of room)	13	4.9	Structure
Printed bulletin with movement timing (e.g., 11:00am-welcome, 11:30am-sermon)	8	3.0	Structure
Consistent routine/order of worship	6	2.3	Structure
Clearly communicated participation expectations	18	6.8	Structure
Alternatives for baptism (e.g., # of people present, method)	2	0.8	Structure
Shorter services	5	1.9	Structure
Alternatives for communion (e.g., gluten-free elements, longer time allowed)	5	1.9	Structure

Accommodation	n	%	Category
Social story videos (e.g., navigating the building, singing, order of worship)	6	2.3	Developmental
Alternative Bibles (e.g., picture Bible, storybook Bible, easy to understand interpretation)	2	0.8	Developmental
Reading partner	3	1.1	Developmental
Buddies/partners	62	23.6	Developmental
Videos of previous ceremonies available online (e.g., baptism, communion, confirmation)	6	2.3	Developmental
Clearly communicated behavioral expectations	18	6.8	Developmental

APPENDIX H

THERAPEUTIC PROFESSIONAL ACCOMMODATION SUGGESTIONS (N=98)

Accommodation	n	%	Category
Consistent lighting levels	1	1.0	Visual
Clear visual focus point	1	1.0	Visual
Visuals consistent with service's theme	1	1.0	Visual
Printed bulletin	3	3.1	Visual
Printed bulletin with pictures of action (e.g., standing singing, praying)	2	2.0	Visual
Projection screen	4	4.1	Visual
TV in alternative area streaming worship service	0	0.0	Visual
Warning before loud noises (e.g., small flag raised, leader mentioning change)	2	2.0	Auditory
Noise-reduction headphones (active or passive)	2	2.0	Auditory
Quiet/crying room	3	3.1	Auditory
Gluten-free communion elements	0	0.0	Taste
Non-bread communion elements	0	0.0	Taste
Food permitted in sanctuary (e.g., snacks, motivators)	0	0.0	Taste
Touch-free understanding when interacting with congregation (e.g., welcoming, passing the peace)	2	2.0	Touch
Sensory toys (e.g., fidget sticks, stress ball, coosh ball)	3	3.1	Touch
Small trampoline in quiet/crying room	1	1.0	Touch
Allow baptism by sprinkling/pouring in lieu of immersion	0	0.0	Touch
Alternative seating (e.g., back of room, front of room)	10	10.2	Structure
Printed bulletin with movement timing (e.g., 11:00 a.m.—welcome, 11:30 a.m.—sermon)	0	0.0	Structure
Consistent routine/order of worship	1	1.0	Structure
Clearly communicated participation expectations	12	12.2	Structure
Alternatives for baptism (e.g., # of people present, method)	0	0.0	Structure
Shorter services	3	3.1	Structure
Alternatives for communion (e.g., gluten-free elements, longer time allowed)	0	0.0	Structure

Accommodation	n	%	Category
Social story videos (e.g., navigating the building, singing, order of worship)	5	5.1	Developmental
Alternative Bibles (e.g., picture Bible, storybook Bible, easy to understand interpretation)	1	1.0	Developmental
Reading partner	1	1.0	Developmental
Buddies/partners	23	23.5	Developmental
Videos of previous ceremonies available online (e.g., baptism, communion, confirmation)	5	5.1	Developmental
Clearly communicated behavioral expectations	12	12.2	Developmental

APPENDIX I

WORSHIP PLANNER IMPLEMENTATION RECOMMENDATIONS (N=17-20)

Accommodation	n	%	Category
Consistent lighting levels	15	83.3	Visual
Clear visual focus point	15	83.3	Visual
Visuals consistent with service's theme	14	77.8	Visual
Printed bulletin	15	83.3	Visual
Printed bulletin with pictures of action (e.g., standing singing, praying)	13	72.2	Visual
Projection screen	13	72.2	Visual
TV in alternative area streaming worship service	8	44.4	Visual
Warning before loud noises (e.g., small flag raised, leader mentioning change)	10	58.8	Auditory
Noise-reduction headphones (active or passive)	10	58.8	Auditory
Quiet/crying room	13	76.5	Auditory
Gluten-free communion elements	17	100.0	Taste
Non-bread communion elements	7	41.2	Taste
Food permitted in sanctuary (e.g., snacks, motivators)	13	76.5	Taste
Touch-free understanding when interacting with congregation (e.g., welcoming, passing the peace)	13	1.9	Touch
Sensory toys (e.g., fidget sticks, stress ball, coosh ball)	14	4.9	Touch
Small trampoline in quiet/crying room	3	0.4	Touch
Comfortable seating	13	72.2	Touch
Allow baptism by sprinkling/pouring in lieu of immersion	18	0.8	Touch
Alternative seating (e.g., back of room, front of room)	15	83.3	Structure
Printed bulletin with movement timing (e.g., 11:00 a.m.—welcome, 11:30 a.m.—sermon)	8	44.4	Structure
Consistent routine/order of worship	15	83.3	Structure
Clearly communicated participation expectations	14	77.8	Structure
Alternatives for baptism (e.g., # of people present, method)	11	61.1	Structure
Shorter services	11	61.1	Structure

Accommodation	n	%	Category
Alternatives for communion (e.g., gluten-free elements, longer time allowed)	11	61.1	Structure
Social story videos (e.g., navigating the building, singing, order of worship)	7	41.2	Developmental
Alternative Bibles (e.g., picture Bible, storybook Bible, easy to understand interpretation)	13	76.5	Developmental
Reading partner	8	47.1	Developmental
Buddies/partners	11	64.7	Developmental
Videos of previous ceremonies available online (e.g., baptism, communion, confirmation)	10	58.8	Developmental
Clearly communicated behavioral expectations	9	52.9	Developmental

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