

INCLUSION OF THE AUTISM POPULATION IN CHURCHES, SCHOOLS  
AND COMMUNITIES

by

Charlrean Batten Mapson

Duke Divinity School  
Duke University

Date: 3/8/2021

Approved:



Dr. Mary M. Fulkerson, Supervisor



Dr. William H. Willimon, D.Min. Director



Dr. Sarah J. Barton, Committee Member

Thesis submitted in partial fulfillment of  
the requirements for the degree of Doctor of Ministry in the Divinity School of  
Duke University

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ABSTRACT

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## **Abstract**

There is a population of individuals classified as having Autism Spectrum Disorder (ASD). This group of people should be included in places of worship, the schools they attend and the communities where they reside. Consequently, they are sometimes excluded from some occurrences that others experience.

Utilizing personal stories (of successes and sometimes failures), ASD parent interviews and research, I will offer suggestions for inclusion and enlighten the areas where there tends to be exclusion. My focus is the church and how church leaders may become involved in the lives of ASD parishioners to enhance inclusion in not only the church, but the school and the community as well.

My research shows that ASD parents would like their children to experience church as they have. Although willing, most churches, may lack the ability to oblige for various reasons. Schools where inclusion is not encouraged, rests primarily on the shoulders of the principals. Like pastors in churches, principals in schools have influence and can spearhead inclusion efforts in their respective entities. Community entities are willing to accommodate ASD clientele and have done so when approached to comply.

I contend where any of these entities are not willing to foster inclusion, then the church can and most often should become involved to assist, with the necessary training. In other words, the church must do what the church has always done – stand up for those who are unable to do so for themselves.

***Keywords:*** Autism, church, community, inclusion, parents, school

## **Dedication**

I dedicate this project to my teenage son who has Autism, Jadon Hassani Mapson, without whom this work would be incomplete. He is the wind beneath my wings. He is my silent supporter and my rock. I love you son! I write this thesis with the hope that we will help other parents and children like me and my son Jadon.

### **IN MEMORY**

Just toward the end of this journey, I lost two important people in my life, my mother, and my goddaughter – both passed the same week – my last week of intensive study at Duke in August of 2019. When I began this journey, I wanted my mother, Anna Rean Batten, to see me finish it. Unfortunately, she is gone now, but she is the wind at my back, pushing me to complete what I have started. My goddaughter, Anita M. Greene, who passed unexpectedly at the tender age of twenty-eight, the day before my mother. She kept my son, Jadon during my intensive weeks on Duke's campus. She had been his caregiver since he was two years old. She traveled countless miles with us as I spoke all over the country. She was a consistent supporter in anything I ventured to do and was like a daughter to me. She and Jadon were like siblings. Both she and my mother are sorely missed.

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## 1. Introduction

In the spring of 2008, my world was forever changed. My son, Jadon, was three years old and not developing enough language. His pediatrician recommended a local facility for us to have him tested. The facility is utilized by the city for children ages two and under to be evaluated for the potential of having Autism. It was a great suggestion, but there was one flaw. At the time of his pediatrician's recommendation, my son was three years old and had missed the required age threshold. So, it was then suggested that we enroll him in a local preschool for observation. At that time, in our county, children were admitted to the public school system, in self-contained classrooms with special educators, where they could be evaluated for symptoms of Autism Spectrum Disorder (ASD). In April of that year, I was summoned to J.C. Roe Preschool by my son's teacher. She wanted to discuss the findings of her observations. She had been monitoring my son and concluded after about five months that he "Exemplifies the signs of a child with Autism." Upon that news, I was speechless and numb. All my plans for Jadon went hurling out the nearest window and were taken up by a STRONG wind. I immediately burst into tears and asked myself, "What did I do wrong?" In a matter of minutes, I experienced a variety of emotions – rage, frustration, sadness, fear, disappointment, and several others.

After leaving the school, I contacted a dear friend of mine and she in turn introduced me to a friend of hers. Her friend, Jamaye and her husband had three children

– two of them had Autism. She arranged a meeting with me. We sat inside her van at a Salvation Army parking lot. As we talked, she recommended several books for me to read and uttered these words, “All is not lost.” Although I was encouraged by that statement, I still would not accept the diagnosis. I kept looking for signs in my child that he did NOT exemplify “symptoms of a child with Autism.” One of the books Jamaye recommended is entitled, *The Out-of-Sync Child* by Carol Stock Kranowitz. In one portion of the book, a parent describes her child spinning around in circles, sometimes for as much as forty-five minutes, stopping and walking away without any signs of dizziness. That story lingered with me. One afternoon, I was relaxing in a large living room chair. My son, who was about three at the time, walked into the living room, stood in the middle of the floor and proceeded to spin around in circles. He persisted nonstop for approximately seven minutes, stopped and walked away without any signs of dizziness. I immediately remembered the story from the book, but I still had not accepted my child’s diagnosis. Then I was invited by a parent to attend a mothers’ group meeting at the local TEACCH (Treatment and Education of Autistic and Communication related handicapped CHildren) office. I sat at the table with approximately ten other mothers. The meeting was roundtable style, with each mother expressing her daily challenges and victories. I listened, with my arms folded as I attempted to determine why I had wasted my time in attending this meeting. However, as I heard several of the mothers speak, I began to hear descriptions of my child’s behavior as each of them spoke. At that point, I had what I call a LIGHTBULB moment. I realized that I indeed had a child with Autism.

This was all new to me and I was confused and conflicted about what this “Autism” thing was. Autism Spectrum Disorder (ASD), commonly known as Autism, is several disorders that behave in a similar manner. It typically shows up during childhood because much of it interferes with the standard development of a child’s growth. Characteristically, versions of Autism will affect a child’s ability to communicate verbally or non-verbally. Their lack of communication skills can lead to physical aggression. It is for this and several other reasons, that most people shy away from the child with Autism. My own family had to be educated about my son’s condition, because for us, this was new territory. Versions of Autism may also affect a person’s ability to adapt to different behaviors or thinking processes. Finally, some versions of Autism will have children struggle with their ability to relate to other people or to the world around them. For these reasons, and as the pastor in my congregation, I feel it is important to develop a plan of inclusion for those in our churches who have Autism.

Over the years as an ASD parent, of a now teenaged male, it has been challenging to find opportunities for my son’s inclusion not only in church, but in school and the community as well (specifically the rural community, where we most recently resided). If these entities are serious about inclusion of this population, then modifications and accommodations must be made for them. Chantal Sicile-Kira, states in *Adolescents on the Autism Spectrum*, that the area of social communication can be particularly difficult for those on the spectrum and starts to become more of an issue during the teen years. And

for teens with ASD, the social realm – school, community, after-school activities, place of worship – is particularly difficult.<sup>1</sup>

My son is now sixteen years old and I have come to the realization that my son is a *gift*. As an ASD parent, who grew up in the church environment, I, as I am sure, other ASD parents, want for my child to witness the same church experience I have. As a pastor, I am able to utilize my pulpit as a tool to advocate for other parents who are in my congregation and the community at large. Therefore, I will offer suggestions for churches on inclusion – ways to adapt for those with ASD while shedding a light on those issues which can also affect the ASD population in schools and communities.

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<sup>1</sup> Chantal Sicile-Kira, *Adolescents on the Autism Spectrum* (New York: The Berkley Publishing Group, 2006), 145.

## 2. A Historical Account of Autism

Donald T. was not like other five-year-old boys. Leo Kanner knew that the moment he read the thirty-three-page letter from Donald's father that described the boy in obsessive detail as "happiest when he was alone ... drawing into a shell and living within himself ... oblivious to everything around him."<sup>1</sup> Donald had a mania for spinning toys, liked to shake his head from side to side and spin himself around in circles, and he had temper tantrums when his routine was disrupted. When Kanner met Donald, his suspicions were confirmed. In addition to the symptoms the letter described, Kanner noted Donald's explosive, seemingly irrelevant use of words. Donald referred to himself in the third person, repeated words and phrases spoken to him, and communicated his own desires by attributing them to others. Kanner described Donald and ten other children in a 1943 paper entitled, *Autistic Disturbances of Affective Contact*. In this initial description of 'infantile autism' which went on to become a classic in the field of clinical psychiatry, Kanner described children as having a distinct syndrome, instead of previous depictions of such children as feeble-minded, retarded, moronic, idiotic or schizoid. In the words of his contemporary Erwin Schrödinger, Kanner "thought what nobody has yet thought, about that which everybody sees."<sup>2</sup>

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<sup>1</sup> Gerald D. Fischback, "Leo Kanner's 1943 Paper on Autism," *Spectrum*, 7 December, 2007, <https://www.spectrumnews.org/opinion/viewpoint/leo-kanners-1943-paper-on-Autism/>.

<sup>2</sup> *Ibid.*

As early as the 1930s, research into what is commonly known today as “the Autism Spectrum” was being done and the man leading the charge was Hans Asperger. In her article, “Aristotle on the Spectrum,” Audrey Pollnow provides insight on the historical background as it relates to Autism, writing that “Autism was first described in a public lecture in Vienna, given by Hans Asperger, in October 1938. Hoping to protect the children in his clinic, Asperger presented Autism not as a disorder, but as an unusual personality with accompanying superpowers.”<sup>3</sup> To this end, his lecture focused on his high-functioning patients. “For most of the twentieth century, however, Asperger’s research was marginalized, with the dominant paradigm in that of Leo Kanner. Kanner’s work did not acknowledge a spectrum of conditions but focused instead somewhat on the highly particular set of traits manifested by individuals whose social interactions were severely compromised. Rather than observing an autistic spectrum, Kanner simply examined the category of ‘Autism,’ a rarely occurring condition marked by a consistent set of symptoms. Such was Kanner’s dominance in the study of this condition that the syndrome was also referred to as Kanner’s syndrome. So-called ‘classical Autism’ is still sometimes referred to as Kanner’s Autism.”<sup>4</sup>

In his 1943 paper on Autism entitled, *Autistic Disturbances of Affective Contact*, Kanner described the Autism condition as an “innate” disorder. I am inclined to believe his theory. My ex-husband has two relatives on the Autism Spectrum. A nephew who is

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<sup>3</sup> Audrey Pollnow, “Aristotle on the Spectrum,” *First Things*, March 20-17, 59-61.

<sup>4</sup> Grant Macaskill, “Autism Spectrum Disorders and the New Testament: Preliminary Reflections,” *Journal of Disability and Religion* 22, no. 1 (2018): 16.

approximately fifty years old and another nephew who is nine years old, both have Autism, and both are non-verbal. From the very beginning, Kanner appreciated the need for biomarkers. He identified a tendency toward autistic behaviors in some families. He predicted the need for research into the genetics of Autism at about the same time that DNA was being identified primarily as the carrier of genetic information. Today, genetics provides the best hope for discovery of pertinent biomarkers.

It took courage to offer a hypothesis of innate factors in 1943. At that time, Freudian psychology theorized that poor parenting was considered the leading cause for “Autism” in children, with most of the blame being placed on “frigid” mothers who were accused of rejecting their children.<sup>5</sup> Over the years, studies of identical twins have proven that genetics is a powerful force in Autism’s etiology. However, it is also apparent that Autism is not inherited in a simple biological process. Many genes, maybe as many as fifty, could be involved, each gene adding to the risk of the clinical manifestation of Autism. As more of these genes are revealed, clinical descriptions will be further revised, and some may disappear completely. Now, the search for genetic factors that boost the risk of Autism is more prevalent. Evidence of structural rearrangements in DNA, changes in DNA sequence, even epigenetic modifications of DNA, have all been reported recently. Macaskill states, “Success in this effort will lead to a clearer idea about mechanisms that disrupt normal brain development and underlie the onset of Autism.

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<sup>5</sup> Grant Macaskill, “Autism Spectrum Disorders and the New Testament: Preliminary Reflections,” *Journal of Disability and Religion* 22, no. 1 (2018): 16.

Identification of such risk factors and how they might interact with environmental influences will be only the first step in this effort. Progress will speed up once the entire cast of characters is identified.”<sup>6</sup>

In 1944, Asperger added his voice and his research to the field of Autism and articulated the first description of the disorder (which he called “autistic psychopathy”). “Asperger Syndrome” is named for him. Asperger recognized that the phenomenon known as Autism involved a range or spectrum of characteristics that identified certain individuals as developmentally different from the general population. Those characteristics mostly involved the way in which they interacted with other people. Which seemed to be compromised and led to the application of the label “autistic.” Research showed that people with this condition were known to occupy their own worlds and were isolated from ‘normal’ social or environmental interactions. “Individuals with Asperger syndrome share the social deficits, restricted and repetitive behaviors and interests, and impairments in theory of mind and executive function characteristic of Autism.”<sup>7</sup> Because of their normal to high intelligence and lack of difficulty acquiring language, people with Asperger syndrome generally receive a diagnosis in middle childhood or later. Asperger syndrome is a form of Autism long distinguished from more severe forms of the disorder by its lack of cognitive and language deficits; however, new research reveals that there is little difference between individuals with high-functioning

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<sup>6</sup> Ibid.

<sup>7</sup> <https://www.spectrumnews.org/wiki/asperger-syndrome/>.

Autism and Asperger syndrome. As a result, Asperger syndrome was folded into the Autism spectrum in the latest edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) published in 2013.<sup>8</sup>

The symptoms of Autism typically begin to appear around the same age when many vaccines are given. Most of our children experience heightened symptoms of Autism Spectrum Disorder (ASD) after receiving the MMR (Measles, Mumps, Rubella) vaccination. This has led many parents, me included, to blame that vaccine on our children's ASD. For years many of us have felt there is a direct correlation between that shot and the ASD outbreak with a massive increase in the reported incidence of Autism over the past fifty years. Pollnow states that the alleged link between vaccination and Autism has been thoroughly studied and debunked, but its appeal is understandable, which leaves parents with yet more questions about the impetus of the disorder.<sup>9</sup> Today one in sixty-eight American children is diagnosed as having ASD. But one part of the story often goes untold: The diagnostic criteria have changed; a broader group of people now qualifies as having ASD. Because of this, we can't know whether or by how much the actual rate of Autism has increased over time. Three years after Asperger's work, Leo Kanner claimed to have made an independent discovery of what he called, without reference to Asperger's work, "early infantile Autism." (Whether Kanner was really unfamiliar with Asperger's work on Autism is questionable; one of the researchers on

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<sup>8</sup> Ibid.

<sup>9</sup> Pollnow, 59.

Kanner's Autism team had worked in Asperger's Autism clinic as a diagnostician). Given contemporary psychiatric trends in the U.S., Kanner defined Autism much more narrowly than Asperger had, with the result that a very small fraction of American children was diagnosed.<sup>10</sup>

Because Asperger's work was published in German, it was not until 1981 that the English-speaking population was exposed to his writing, when Autism researcher Lorna Wing used the name 'Asperger syndrome' in her publication. Asperger syndrome was first introduced in DSM in 1994, distinguishing it from "autistic disorder" due to lack of significant delay in language and normal cognition. However, with the publication of the DSM-5 in 2013, Asperger syndrome was formally merged into the Autism spectrum and today no longer exists as a separate diagnostic category. Therefore, whether a person has Asperger syndrome or high-functioning Autism, there is no distinction; hence it is all ASD.

From sensory overload, repetitive behaviors, and language challenges, to communication struggles, such as an inability to read social and emotional cues, Autism can be an intensely isolating condition in which the longing for human connection remains locked inside. In the "Whole Body of Christ," Amanda Hendler-Voss writes about Michael L. Ortiz, recipient of his doctorate in mathematics from the University of Texas at Austin. Ortiz describes his own Autism as "unwittingly literal and

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<sup>10</sup> Pollnow, 59.

eccentric...with marked proficiencies and severe deficits, formal and pedantic speech. The social instincts that develop organically in most people are in me replaced with artificially constructed rules applied with rigorous logic,” he states. While others interpret his inexpressiveness as coldness, Ortiz likens the isolation of Autism to living in a soundproof glass box, where one peers into a world in which relationships are simply inaccessible.<sup>11</sup> Ortiz is one of several who has written about their life experiences with ASD.

Parents in the ASD community were given a ray of hope when well-known ASD personality, Dr. Temple Grandin began writing about her condition. Grandin provided hope for those of us who felt hopeless. Her books, and 2010 HBO biographical movie, allowed some of us to see light at the end of the tunnel. I was fortunate enough to meet her after one of her lectures at UNC-Wilmington. It was February 14, 2010 and my son, who was five years old at the time, attended the event with me (photo 1). I was among several who sat awestruck as she spoke of her childhood and adulthood experiences with Autism.

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<sup>11</sup> Amanda Hendler-Voss, “The Whole Body of Christ,” *U.S. Catholic*, March 4, 2019, 33-37.



*Photo 1: February 14, 2010 – Jadon with Dr. Temple Grandin at UNCW*

Born in 1947, Mary “Temple” Grandin, who is known for her work in the area of humane treatment of animals and livestock handling, has numerous degrees, both honorary and earned. She has an earned doctorate in animal science and was once a professor of animal science at the University of Colorado. Dr. Grandin revolutionized practices for the humane handling of livestock on cattle ranches and slaughterhouses, and admittedly, struggled with social and verbal skills unless she was in conversation about her work. Her knowledge in her area of expertise would lend one to assume that she fits the Asperger model for Autism – one who is an expert in a specific subject matter, while simultaneously struggling with socialization. Hans Asperger described children who displayed an intense focus and knowledge of a specific topic or special interest, as “little professors.” This clearly describes Grandin and others who are unable to hold reciprocal conversations but can monologue those ideas and subjects that are of great interest to

them. In the 1980s, Kanner's dominance in the Autism field began to erode, as writings by Dr. Grandin about her own experience with her condition began to surface. I heard what Dr. Grandin and others as they provided a window into the history of ASD. As an ASD parent and a minister of the gospel, I wondered if there is a biblical response to ASD.

### 3. A Biblical Account of Autism

Grant Macaskill, in “Autism and the Church,” states, “We cannot, then, simply find several relevant passages and engage in exegesis, after which we pronounce, ‘This is what the Bible says about autism.’ We need to think more carefully about how the Bible, considered as the normative and sacred Scripture of the Christian tradition, should function to shape our thinking about autism.”<sup>1</sup>

The Gospel of John states, “[Christ’s] disciples asked him, ‘Rabbi, who sinned, this man or his parents, that he was born blind?’ Jesus answered, ‘Neither this man nor his parents sinned; he was born blind so that God’s works might be revealed in him’” (9:2-3, NRSV). This was the scripture that I turned to in the spring of 2008, when I was told by my son’s preschool teacher, that “Jadon exemplifies the symptoms of a child with Autism.” I wondered who or what was to blame, much like the disciples in the gospel of John. When the disciples asked him who sinned to cause the man to be born blind—we need to keep in mind Jesus’ response—“Neither this man nor his parents sinned; he was born blind so that God’s works might be revealed in him.” As a new Autism Spectrum Disorder (ASD) parent, I had to come to the realization that no one was to “blame” for my son’s condition, but ultimately God would get the glory. As a preacher and pastor, however, I wanted to seek further biblical insight on what is detailed for those with special needs, and specifically those with ASD.

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<sup>1</sup> Grant Macaskill, *Autism and the Church* (Waco: Baylor University Press, 2019), 43.

The Old Testament appears to be replete with imagery regarding disabilities as they relate to the exilic Israelites. In Isaiah specifically there is reference to the restoration of those who have disabilities as it relates to their revelation about returning to God. Jeremy Schipper writes, “At certain points, post-monarchic Isaianic oracles use figures with disabilities in oracles describing Israel's eventual glorification, exaltation, or restoration in addition to ingathering.”<sup>2</sup> I found it enlightening that the healings recounted in the Old Testament were merely there for metaphoric reference and not actual physical transformation. The Old Testament speaks of humankind in terms of flesh and soul, therefore, the use of the word “body” in the Old Testament is limited to descriptions of angelic beings (Ezekiel 1:11, 23; Daniel 10:6), slaves (Genesis 47:18; Nehemiah 9:37) and corpses (Judges 14:8-9; I Samuel 31:10, 12).<sup>3</sup>

The New Testament scriptures, however, detail the raising of the whole body from the dead (e.g., Jesus’ crucifixion and ultimate resurrection). Paul speaks of Jesus and the Last Supper prior to his crucifixion in I Corinthians 11, “For I received from the Lord what I also passed on to you: The Lord Jesus, on the night he was betrayed, took bread, and when he had given thanks, he broke it and said, ‘This is my body, which is for you; do this in remembrance of me.’” I Corinthians 12:12-27 appears to be one continuous metaphor. Paul compares the church with a body, then utilizes various body

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<sup>2</sup> Jeremy Schipper, “Why Does Imagery of Disability Include Healing in Isaiah?,” *Journal for the Study of the Old Testament* 39.3, (2015): 327.

<sup>3</sup> Daniel N. Freedman, *The Anchor Bible Dictionary*, vol. I (New York: Doubleday, 1992), 768.

parts to exemplify parts of the body of Christ. Additionally, Paul uses the word “body” in similar language in Romans 12:4-5, where he states, “For just as each of us has one ‘body’ with many members, and these members do not all have the same function, so in Christ we, though many, form one ‘body,’ and each member belongs to all the others.” Likewise, in Ephesians 4:11-12, Paul utilizes the word “body” similarly to the previously cited passage in I Corinthians. He states, “So Christ himself gave the apostles, the prophets, the evangelists, the pastors and teachers, to equip his people for works of service, so that the ‘body’ of Christ may be built up.” In I Corinthians 12:18 Paul writes, “But in fact God has placed the parts in the body, every one of them, just as he wanted them to be.”

In “Wondrously Wounded,” Brian Brock states, “The subject of I Corinthians 12 is the renewal, healing, and opening of genuine communion with God and others called *church*. The chapter is focused on why the body of Christ is fundamentally a political entity that emerges from a distinctive manner of engaging interpersonal relations. Paul understands every member of the church as an active giver or conduit of divine love, a giving that is not reducible to any person’s supposed physiological or intellectual deficiencies. He therefore offers a worked account of what it looks like to live together ‘beyond disability.’”<sup>4</sup>

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<sup>4</sup> Brian Brock, *Wondrously Wounded: Theology, Disability and the Body of Christ* (Waco: Baylor University Press, 2019), 202.

Furthermore, in “Autism and the Church,” Grant Macaskill writes of Paul and the “weaker” things within [Christ’s] body (I Corinthians 12:22). He states, “the things that are naturally or intuitively considered lesser are, in fact, equally important to those that are strong and powerful. They are objects of divine election and love; they are royal gifts to the church; they are functioning members of the body of Christ, without which we would be diminished.”<sup>5</sup>

God has given each of us gifts and has placed us in the body to utilize those gifts. Paul’s words in I Corinthians help ignite the need for inclusion in the church. I view Paul’s writing as a reminder that not only has God given each of us the gifts God wants us to have, but God has also given us our personalities, our abilities and even our different abilities (or inabilities). The question becomes, how do we include those who would typically be excluded? There is room for everyone in God’s church. For most people, the Autism population would appear to be outside and not inside the body of Christ. But Paul’s words in I Corinthians 12:12-27 remind us that this group of people has just as much to offer as any other. At one of my previous pastoral charges, I had an ASD boy in my congregation. He was a very friendly, outgoing young man and I had been told by his mother that he was out in the community often talking about “his” church and inviting people to come to our worship services. I needed a new greeter for our church, so I immediately posted him on the door as the official greeter. I thought that

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<sup>5</sup> Macaskill, 192.

he would be an excellent choice to stand at the door and welcome the worshippers. In I Corinthians 12:14-20, Paul reminds his readers that God's body is comprised of many members (i.e., talents) and each has a vital role to play in the Kingdom.

Neither the Old Testament nor the New Testament give account of specific disabilities. However, in "Autism Spectrum Disorders and the New Testament: Preliminary Reflections," Grant Macaskill writes, "We cannot, in other words, identify a set of passages that describe the condition and tell us what we are to think about it. Rather, we must see our task as one of thinking about this particular issue in dialogue with a broader set of resources found in the New Testament."<sup>6</sup> Macaskill explores how the "New Testament might shape the values of Christian communities in relation to ASD and is offered as a contribution from the discipline of biblical studies to the disciplines of pastoral theology and theological ethics."<sup>7</sup>

When discussing the subject of inclusion, Paul's writing in I Corinthians 12:12-27 is worth noting again. In the first few verses (12 and 13) of the passage, we find these words:

<sup>12</sup>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. <sup>13</sup>For in the one Spirit we were all baptized into one body—Jews or Greeks, slaves or free—and we were all made to drink of one Spirit.

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<sup>6</sup> Grant Macaskill, "Autism Spectrum Disorders and the New Testament: Preliminary Reflections," *Journal of Disability and Religion* 22, no. 1 (2018): 16.

<sup>7</sup> *Ibid.*

Paul is saying here that it does not matter who a person is or what their abilities are, we are all members of the body of Christ. Therefore, there should be a place for the person without Autism and a place for the one with Autism in the body of Christ.

As I read I Corinthians 12:12-27 aloud in its entirety, I noted the overall emotional tone of the passage appears to be aimed at fostering unity. Paul repeatedly emphasizes the oneness that should exist in the body of Christ. One word struck me at the outset – “drink.” In verse 13, Paul says, “For we were all baptized by one Spirit so as to form one body—whether Jews or Gentiles, slave or free—and we were all given the one Spirit to drink” (NIV). Paul is referring to the Holy Spirit, given by God to indwell in all. This is reminiscent of Jesus’ conversation with the Samaritan woman at the well. Jesus offered her a “drink” that would quench her thirst for eternity. The gift of the Holy Spirit is for all, regardless of who they are or what they might have done in life.

Furthermore, the gift of the Holy Spirit is for all, whether they have special needs or not. Verse 22 of the passage states, “On the contrary, those parts of the body that seem to be weaker are indispensable.” This is a reminder from Paul that while others may not regard the “weaker” among us, they are essential to the body of Christ. Paul illuminates this argument in Ephesians chapter four, where once again, he writes about unity in the body of Christ.

In Ephesians 4:16 he writes, “From him the whole body, joined and held together by every supporting ligament, grows and builds itself up in love, as each part does its work.” Paul once again emphasizes that each part is essential to the whole body. In I

Corinthians 12:23 Paul states, “and the parts that we think are less honorable we treat with special honor. And the parts that are unpresentable are treated with special modesty.” This portion of the subject text is a reminder of how some not only in the Autism world, but the special needs environment at large, are treated. Our own United States president once ridiculed a reporter with special needs. Paul, in this portion of the passage, dictates how such persons should be viewed, and ultimately treated by others – with “special honor.” Hence, I contend that those with special needs, and more specifically, those with ASD, are to be treated with “special honor.”

I read I Corinthians 12:12-27 in the waiting room of an urgent care facility. Paul says that the body is a unit made up of many parts. As I awaited to be seen, I noted that each person in this medical facility has a different responsibility (i.e., one unit consisting of many parts). Paul states in I Corinthians 12:15 (NIV), “Now if the foot should say, “Because I am not a hand, I do not belong to the body,” it would not for that reason stop being part of the body.” At this medical facility, the receptionist cannot say, “Since I am not the nurse, I am not part of this facility.” The first question I asked the receptionist when I entered the facility was, “How many people are ahead of me?” Her answer was, “four.” The job of the receptionist is just as important as any other job in that medical facility. If the receptionist were not in place, then we would all be sitting in a room without any order, possibly quarreling about who arrived when and disputing the order in which we are to be seen by the doctor. Each person in that facility has a role to play, and the end goal is for the patient to receive the treatment which will allow him or her to

become better. Each patient enters the facility fragmented, but once we have gone through the process of encountering these people, from the receptionist to the nurse and finally the doctor, each with their own gifts, we will ultimately become whole.

In the church, we each have our own gifts and the end goal is for the body of Christ to benefit from those gifts. If the usher says, “Since I am not the pastor, I do not belong to the body of Christ,” then who will communicate the needs of the congregation to the pastor during the morning worship service? Likewise, we cannot discount those whose needs are different from ours. They too, have gifts that may be used in the body of Christ. On two occasions, my son has left my parishioners awestruck. My son knows the Lord’s prayer. On the fourth Sunday of each month, my young people are in charge and participate in the morning worship service (photo 2). I offered my son, Jadon for the prayer one Sunday morning. He delivered the Lord’s prayer and during the prayer I heard echoes of the word, “WOW” from my parishioners as he prayed.



*Photo 2: October 28, 2018 – Jadon offering the Lord's Prayer*

On a separate occasion, following a week-long vacation Bible school lesson on the fruit of the spirit, Jadon learned to demonstrate the fruit in sign language. Shortly after the vacation Bible school week, there was an afternoon program emphasizing the fruit of the spirit. I suggested to the scripture reader that Jadon could sign the fruit during her reading. The two of them met briefly prior to the service, then during the reading, he signed as she read. The congregation was speechless. Paul reminds us that each person has a role to play as we seek to serve Christ and to win others for Christ. I further contend that those with ASD and other special needs have a role to play and gifts to offer in the body of Christ, just as we do.

Throughout I Corinthians 12:12-27, Paul contrasts the body with many parts, reiterating to his readers that although the body has many parts, it is still one. The passage moves from contrasts between Jew and Greek, body and many parts to questions about

the body's operation should there be one gift and not several. Paul asks in verse 17, "If the whole body were an eye, where would the sense of hearing be? If the whole body were an ear, where would the sense of smell be?" The question for the church becomes, how does the church benefit if everyone were the same? The church must understand that all gifts benefit the one body, and that every gift comes from God. Paul writes in verse 18, "But in fact God has placed the parts in the body, every one of them, just as he wanted them to be." We need each other for the body of Christ to perform effectively. Paul states in 12:20-21, "As it is, there are many parts, but one body. The eye cannot say to the hand, 'I don't need you!' And the head cannot say to the feet, 'I don't need you!'" We cannot discount others because they are different than we are. We cannot say to them, "Because you are not like I am, 'I don't need you!'"

Preceding I Corinthians 12:12-27, Paul writes about spiritual gifts. He writes that there are many gifts, but they are all of the same Spirit; there are many kinds of service but the same Lord; there are different kinds of working, but the same God. This preceding passage is much like the passage cited previously in this writing, I Corinthians 12:12-27. Immediately following that passage, Paul states, "And now I will show you the most excellent way." Then he writes in the thirteenth chapter about how we must love one another. I view the twelfth and thirteenth chapters working in tandem. The twelfth chapter reminds the readers that although we differ, we are all one. While the thirteenth chapter reminds us that we are to love, in my opinion, even in those differences, Paul admonishes his readers to acknowledge and love the differences in everyone.

In his article “Reflections on Autistic Love,” John Swinton writes, “The greatest commandment is to love God, to love one another and to love ourselves. Everything else hangs on that basic premise. Loving God compels us to love others and demands also that we love ourselves. That probably sounds fairly familiar to those coming from the Jewish and Christian traditions. But what exactly does Jesus mean by the term “love”? Love is one of those words which is both powerful and contextually defined. Swinton states, “I love my wife and children, but I also love ice cream. I love my job and I love my friends; I love to ski, and I love to watch cartoons. Indeed, if I have an itch, I really love to scratch it! Everywhere I go I am loving people, things and experiences! But what does love actually mean? Josef Pieper, a scholar of Thomas Aquinas, defines love in this way, ‘It’s good that you exist; I am glad that you are here.’<sup>8</sup> Pieper’s definition is quite helpful. Love is an attitude; an act of will wherein I make a conscious decision to welcome the other.”<sup>9</sup> Swinton proceeds to inquire whether love is a noun or an adjective. I contend that love is a verb. And as we learned in elementary school, verbs are action words. Therefore, if the church is to truly “love one another,” as admonished in the New Testament, then actions are required to love (to welcome) even those with ASD.

I contend that an accurate Scripture regarding children with ASD or any type of special needs issues is found in the gospel of Mark. Recounted in a story of a father who is concerned for his son who is described as one demon-possessed and “has a spirit that

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<sup>8</sup> Josef Pieper, *Faith, Hope, Love* (San Francisco: Ignatius Press, 1997), p. 164.

<sup>9</sup> John Swinton, *Reflections on Autistic Love: What Does Love Look Like?* (Sheffield: Equinox Publishing Ltd, 2012), pp. 262-263.

makes him unable to speak” (9:14-29, NRSV). The description of his symptoms in verse 18 leads me to conclude that the boy is not demon-possessed at all, but merely suffering with epilepsy, for “whenever it seizes him, it dashes him down; and he foams and grinds his teeth and becomes rigid.” In ancient times, epilepsy was often called the “sacred disease,” because according to some, it was believed that the disease was sent by a god; some thought it was inflicted on those who had sinned against a divine entity; and others thought it was because it could only be healed by divine intervention. The Jews and Christians, however, avoided the use of this terminology, because they did not want to associate any deity with such a terrible affliction, so epilepsy was often associated with or attributed to demons.

Once my son reached adolescence, he began to exhibit a pattern of aggressive behaviors. These behaviors were quite similar to those of the epileptic individual described in this biblical passage. He would have a meltdown lasting for approximately thirty minutes or more, then shortly afterward, turn into the laughing and jovial child he was prior to the incident. I describe my response to his actions as one who has to “walk on eggshells” in his presence.

When ASD boys reach adolescence, like other boys their age, their hormones are raging. They, however, are unable to articulate their feelings and therefore, become physical and often violently physical. When my son reached that stage in his life, I thought of the “demon-possessed” boy in the passage. Some of his attacks have happened publicly and for fear of my African American, ASD son’s life, I have had to shout, (while

people were pulling him off me or trying to subdue him), “HE HAS AUTISM!!” On one occasion, he was attacking me in our driveway. My next-door neighbor saw and heard us. He entered my yard with his gun drawn, prepared to shoot my son. I believe the parallel of my son’s condition and that of the boy in the Mark passage is the public’s misconception of each of their conditions. In *Leading a Special Needs Ministry*, Amy Fenton Lee states, “When children are ‘misbehaving,’ researchers have found that they are nearly always trying to communicate a need for one of the following: a tangible object; a physical or sensory need; to escape a demand; an activity or a sensory stimulation; or they are seeking to acquire attention from adults or peers.”<sup>10</sup> My son, Jadon, is no exception. His physical aggression or “misbehavior” often stems from his inability to effectively communicate his wants or needs.

Feeling exasperated, I thought there must be something in the Bible that can help those of us living with these conditions – for those of us who want our ASD children included in a world that sees only their “misbehavior.” In the Pauline passage previously referenced, these words are found in Mark 9:14-29 (NRSV):

<sup>14</sup> When they came to the disciples, they saw a great crowd around them, and some scribes arguing with them. <sup>15</sup> When the whole crowd saw him, they were immediately overcome with awe, and they ran forward to greet him. <sup>16</sup> He asked them, “What are you arguing about with them?” <sup>17</sup> Someone from the crowd answered him, “Teacher, I brought you my son; he has a spirit that makes him unable to speak; <sup>18</sup> and whenever it seizes him, it dashes him down; and he foams and grinds his teeth and becomes rigid; and I asked your disciples to cast it out, but they could not do so.” <sup>19</sup> He answered them, “You faithless generation, how

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<sup>10</sup> Amy Fenton Lee, *Leading a Special Needs Ministry* (Nashville: B&H Publishing, 2016), 122.

much longer must I be among you? How much longer must I put up with you? Bring him to me.”<sup>20</sup> And they brought the boy to him. When the spirit saw him, immediately it convulsed the boy, and he fell on the ground and rolled about, foaming at the mouth.<sup>21</sup> Jesus asked the father, “How long has this been happening to him?” And he said, “From childhood.”<sup>22</sup> It has often cast him into the fire and into the water, to destroy him; but if you are able to do anything, have pity on us and help us.”<sup>23</sup> Jesus said to him, “If you are able!—All things can be done for the one who believes.”<sup>24</sup> Immediately the father of the child cried out, “I believe; help my unbelief!”<sup>25</sup> When Jesus saw that a crowd came running together, he rebuked the unclean spirit, saying to it, “You spirit that keeps this boy from speaking and hearing, I command you, come out of him, and never enter him again!”<sup>26</sup> After crying out and convulsing him terribly, it came out, and the boy was like a corpse, so that most of them said, “He is dead.”<sup>27</sup> But Jesus took him by the hand and lifted him up, and he was able to stand.<sup>28</sup> When he had entered the house, his disciples asked him privately, “Why could we not cast it out?”<sup>29</sup> He said to them, “This kind can come out only through prayer.”

Prior to this pericope, Jesus has taken three of his disciples, Peter, James and John to witness his transfiguration on a mountaintop. Upon their return, they find a crowd of people gathered which includes the remaining nine disciples and the Scribes. They are in such a heated debate that they initially do not notice the presence of Jesus as he approaches. Verse fifteen of the text states that the crowd sees Jesus, and as he descends from the mountain, they are immediately awestruck by him. This is similar to the passage of scripture in Exodus 34:29-35 which describes the people’s awe at the sight of Moses as he descends from Mt. Sinai. In Mark’s gospel, the crowd runs toward Jesus as though they are attempting to have him settle the dispute; much like a parent or an expert who enters the room during a heated argument or debate.

A man in the crowd informs Jesus that he brought his son to the disciples for healing and they were unable to perform the miracle. The text describes the boy as being

demon-possessed, a condition commonly associated with exorcisms. Exorcisms were performed in the day of Jesus, however, if this child were living today, then he would be diagnosed with epilepsy and not a demonic spirit. In verse seventeen of this text, the boy's possessing spirit is labeled or identified as a mute spirit. The verse states, "he has a spirit that makes him unable to speak" (NRSV). The description of his symptoms in verse eighteen, leads one to conclude that he is indeed suffering with epilepsy, "whenever it seizes him, it dashes him down; and he foams and grinds his teeth and becomes rigid." In ancient times, epilepsy was often called the "sacred disease," because according to some, it was believed that the disease was sent by a god. Some thought it was inflicted on those who had sinned against a divinity; and still others thought it was because it could be healed only by divine intervention. The Jews and Christians, however, avoided the use of this terminology, because they did not want to associate any deity with such a terrible affliction, so epilepsy was often associated with or attributed to demons. Regardless, this concerned father wanted his son healed of these "demons," but the disciples were unable to help, therefore he solicited assistance from Jesus. The father describes what happens to the child – he is overtaken by the spirit, thrown to the ground, foams at the mouth, grinds his teeth and his body is stiffened. Jesus addresses the group (which is not specifically defined) and asks how long must he be with them and why do they lack faith. When he announces the rebuke, it is unclear whether the chastisement is addressed to the disciples, the crowd, the Scribes or the entire congregate of people. The spirit recognizes Jesus and throws the boy into a fit. Jesus asks the parent how long has this occurred, and the father

says since the boy was a child. The father further states that sometimes the boy is in the fire and sometimes in the water to destroy him. The father then says, “If you can do anything...” Jesus seems to become sarcastic as he repeats, “If you can!?” Then Jesus tells the father “anything is possible if you only believe.” The father says he does believe but asks for help with his unbelief.

Faith, or the lack of faith seems to be the theme of this passage. The word “faith” is derived from the Greek word “pistis” and predominates as a self-definition of what it means to be Christian. The word “faith” is utilized in the gospels in various ways. In the gospel of Matthew, faith is an attribute that can be quantitatively expressed as greater or smaller. In the gospel of Luke, faith is connected with “conversion.” In the gospel of John, “faith is not the entity that makes miracles occur, but miracles take place in order to make Jesus’ followers believe, although they have periods of disbelief. In the gospel of Mark, the word faith means to hold fast to the gospel; and this passage shows the readers of this text that faith without doubt, was a clear and obvious problem.”<sup>11</sup>

It will take a multitude of faith for those of us who are ASD parents, to get through difficult and trying times. As an ASD parent, and much like this father in the passage, I feel my faith has been tested and has sometimes wavered. When my son began to show his aggressive behaviors, there were days when I did not think God heard my prayers, therefore, even as a preacher, I too have struggled with my faith. Not only that, I

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<sup>11</sup> The Anchor Bible Dictionary, volume II, pp. 754-755.

have also struggled with how to expose my child to the place where he can be introduced to his own faith – the church and more specifically, the church’s congregation.

## 4. A Congregational Account of Autism

As a leader in the church, I believe it is important to navigate and illuminate the church on the need for processes and methods of inclusion, adaptation (accommodations and modifications) for the Autism population. When discussing the subject of inclusion, there is a scripture that bears noting: I Corinthians 12:12-27. In the first few verses of the passage, we find these words:

<sup>12</sup>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. <sup>13</sup>For in the one Spirit we were all baptized into one body—Jews or Greeks, slaves or free—and we were all made to drink of one Spirit.

Paul is saying here that it does not matter who a person is or what their abilities are, we are all members of the body of Christ. Therefore, not only should there be a place for the person with Autism in the body of Christ, but there should also be a place for them in the actual church edifice.

Brian Brock writes in “Wondrously Wounded,” about the church’s response to those who are disabled. He states, “The rarity of churches that genuinely welcome people labeled disabled is a symptom of the fatal transition Jesus warned against, in which his kingdom is turned into ‘religion.’” Brock continues, “Many and gut wrenching are the stories of parents being told in so many words (or actions) that their children are not part of ‘us,’ that ‘the program’ cannot accommodate people with their challenges, of

communion and fellowship being denied to those who cannot understand, and with those presumed not able to comprehend and so maybe even incapable of (or not in need of) being saved.”<sup>1</sup>

Grant Macaskill, in “Autism and the Church,” states, “Within the church, we often form a sense of inclusion through ‘normal’ social practices, and those same practices influence the ways in which we ascribe relative value to other Christians.” He further states, “Autistic people, however, often lack the ability to perform these kinds of skills effectively and are often marginalized. They may not be excluded from church (although those with profound autism and the disruptive behavior that goes with it may well be), but they will probably be marginalized in some way. The decision to label someone as ‘on the spectrum’ is normally a dismissive one, which functions to identify the person as someone we tolerated but would not be sad to see leave our church.”<sup>2</sup>

Erik Carter and Elizabeth Biggs wrote, “Many families impacted by disability enter a congregation for the first time wondering whether they will be accepted. Much more than mere friendliness or common courtesy, young people with Intellectual and Developmental Disabilities (IDD) and their families feel accepted when they are embraced for all of who they are—labels and all. Lily, a 13-year-old with Autism Spectrum Disorder (ASD) and an intellectual disability, had limited verbal speech, used picture symbols to communicate, and required high levels of support throughout her day.

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<sup>1</sup> Brian Brock, *Wondrously Wounded: Theology, Disability and the Body of Christ* (Waco: Baylor University Press, 2019), 234.

<sup>2</sup> Grant Macaskill, *Autism and the Church* (Waco: Baylor University Press, 2019), 100.

Her mother, Katrina, shared that acceptance was needed ‘to make you feel like a person’ rather than being seen primarily for what makes you different. Acceptance is enhanced when church members see differences not as deficits, but in light of God’s delight in diversity and the church’s need for every part of the body. Audrey, the mother of a 19-year-old with Asperger’s syndrome, shared how her daughter’s struggles with working memory and executive functioning skills impacted many areas of her life—including her social interactions, behavior, and independence. When describing her daughter, Audrey noted, ‘I’ve always raised her to know that she is who she’s supposed to be, that God created her with special gifts and talents just like everyone, and not to feel that there’s any value judgment based on that difference’ This type of attitude is also what Audrey hoped church members and leaders would have, saying, ‘I would want them to know that regardless of the person’s differences—be they physical, intellectual, or emotional—just to keep in mind that the person is exactly the same in God’s eyes.’”<sup>3</sup>

Carter and Briggs continue, “When churches adopt this mindset, they begin to demonstrate acceptance of people with IDD in their interactions and programming. Lisa was a 14-year-old with Asperger’s syndrome. Her mother, Heather, personally understood some of the challenges accompanied with having a disability, as she had multiple sclerosis. For her, acceptance meant ‘the person or the family is included in the activities and treated like they are family for the church.’ Several families also expressed

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<sup>3</sup> Erik W. Carter and Elizabeth E. Biggs, “Being Present Versus Having A Presence: Dimensions of Belonging For Young People With Disabilities And Their Families,” *Christian Education Journal*, 2016, Vol. 13, No. 1, 134.

how they felt when their child was accepted without any qualifications or when others in the congregation treated them like family, included them in all aspects of church life, were receptive about their differences, and were not ‘bothered’ or ‘bent out of shape’ if challenges arose. Such actions communicate to young people with IDD and their families ‘there’s a place for you here.’ As Audrey shared. ‘You’re not trying to make a square peg fit a round hole, you’re just saying that there’s a place for everybody here. And also... you belong to something that’s greater than the hole.... [Members at my church] really know and believe in their hearts that we’re all put together differently, and we are all put together in this community for a reason.’”<sup>4</sup>

Sadly, the presence and participation of people with disabilities and their families within faith communities are often described as uneven. While half of all Americans with disabilities attend a church, synagogue, mosque, or other place of worship at least monthly, a clear participation gap exists relative to the attendance of Americans without disabilities.<sup>5</sup> When surveying for this research, I found similar statistics. Only fifty percent of the ASD parents I polled, claimed to have a church affiliation (figure 2), with several parents citing the feeling of discomfort when attending worship, even in their own church homes.

In June of 2019, CNN reported that a British church had to offer an apology for their treatment of a child with Autism Spectrum Disorder (ASD). CNN reports that Paul

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<sup>4</sup> Ibid.

<sup>5</sup> Naomi H. Annandale and Erik W. Carter, “Disability and Theological Education: A North American Study,” *Theological Education*, Volume 48, Number 2 (2014): 83-84.

Rimmer intended to celebrate the end of Father's Day at church with his two young sons in tow. But their time together was cut short for what the church considered a disruption and Rimmer considered a rejection. The family was to attend Sunday's Evensong, a mostly sung-through evening service, at King's College Chapel in Cambridge, England. The event was particularly thrilling for Rimmer's 9-year-old son, Tristan, who loves the 16th-century church's ceilings and famed Latin chorales. And because he has Autism and is nonverbal, he expresses his excitement primarily through laughter and calls (best described as random verbal outbursts). But before the end of the service, an usher asked Tristan and his family to leave on the grounds that he was disrupting fellow parishioners.<sup>6</sup> This is just one of many stories which denote the lack of understanding and need for inclusion of those on the Autism Spectrum in churches. I felt this story was important, because we are reminded that this need for inclusion is a global issue.

Oftentimes, children with ASD have mannerisms which can be difficult for others to comprehend. Rather than reject them, we should seek opportunities to include those who might otherwise be excluded. Erik Carter states, "Churches are called to be places of welcome, belonging and contribution for people with disabilities and their families. This simple statement – which brings both theological and empirical support – is reflected across more than one hundred statements and resolutions issued by denominational and faith groups over the last few decades. It affirms that the presence and participation of

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<sup>6</sup> CNN Europe, <https://www.cnn.com/2019/06/19/europe/boy-Autism-british-church-trnd/> CNN.

people with intellectual and developmental disabilities is vital to the thriving of any faith community. Moreover, it conveys that the Church is incomplete without the gifts and faith of people with disabilities.”<sup>7</sup>

Inclusion in the church is crucial, especially for parents who wish for their ASD children to be involved. So, what does “inclusion” entail? Inclusion is making the necessary adaptations – accommodations, and modifications to ensure that the person with ASD feels like they are part of the church’s congregation. The word “adaptations,” (which encompass both accommodations and modifications), is defined in the educational arena as, “changes permissible in educational environments which allow the student equal opportunity to obtain access, results, benefits, and levels of achievement.”<sup>8</sup> Therefore, we, in our churches need to make the necessary changes which will allow those with special needs an equal opportunity to feel included in our worship and other church related activities.

The ADA (Americans with Disabilities Act) defines accommodations as, “a change the employer can make to ensure that a qualified individual with a disability can perform the essential functions of the job and enjoy equal employment opportunities.”<sup>9</sup> In churches, this means that pastors and/or leaders would make necessary changes which

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<sup>7</sup> Erik W. Carter, “A place of belonging: Research at the intersection of faith and disability,” *Review and Expositor*, 2016, Vol. 113(2), 167-168.

<sup>8</sup> [www.disabledperson.com/blog/posts/what-is-considered-a-reasonable-accommodation-under-the-americans-with-disabilities-act-in-2020](http://www.disabledperson.com/blog/posts/what-is-considered-a-reasonable-accommodation-under-the-americans-with-disabilities-act-in-2020).

<sup>9</sup> Diana Browning Wright, “Common Definitions: Adaptations, Accommodations, Modifications,” *Teaching & Learning*, 2003, 1-2.

will ensure that people with ASD and other special needs are able to participate in worship and other church related activities equally. An example of an accommodation is a sign language interpreter made available for those in the congregation who are hearing impaired.

The word “modifications” in the educational arena is defined as, “those that are made for students with disabilities who are unable to comprehend all of the content an instructor is teaching.”<sup>10</sup> For pastors this means we should ensure that the Sunday School lesson, and the morning message are presented in such a way that those with ASD and other special needs are able to comprehend and/or participate.

Many children with ASD have problems coping in environments like churches, schools and in the community or public arenas. These environments or lack of familiarity with them, can cause many with ASD to have (sometimes violent) outbursts. These outbursts are perceived as bad behaviors. In *Leading a Special Needs Ministry*, Amy Fenton Lee states, “When children are ‘misbehaving,’ researchers have found that they are nearly always trying to communicate a need for one of the following: a tangible object; a physical or sensory need; to escape a demand; an activity or a sensory stimulation; or they are seeking to acquire attention from adults or peers.”<sup>11</sup>

Oftentimes, the behaviors are merely the reaction to what the person is witnessing and other times the reactions may be rejection towards the environment. The child with

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<sup>10</sup> [www.washington.edu/doit/what-difference-between-accommodation-and-modification-student-disability](http://www.washington.edu/doit/what-difference-between-accommodation-and-modification-student-disability).

<sup>11</sup> Amy Fenton Lee, *Leading a Special Needs Ministry* (Nashville: B&H Publishing, 2016), 122.

ASD who displays such outbursts or “misbehavior,” could be labeled “out of sync.” In *The Out-of-Sync Child Has Fun*, Carol Kranowitz addresses this issue. She states that most children on the spectrum are out of sync most of the time, due to a neurodevelopmental problem. She addresses the child who: is overresponsive to touch, movement, sight or sound; has a poor sense of body awareness; has immature fine and gross motor skills; becomes very emotional and quickly frustrated when things are not “just right.” The reason for such confusing behaviors? Sensory Processing Disorder (SPD). Sensory processing is the normal neurological process of organizing sensations for our use in everyday life. SPD, however, occurs when a person with ASD responds in atypical ways to those sensations.<sup>12</sup> SPD is addressed by Joyce Emmons Nuner and Tamara Love in their article entitled, “Church Ministry and the Child with Autism.” In the article, the authors describe aspects of the worship which can prove to be problematic or stressful for the ASD child, such as unfamiliar people, loudness and the need for their participation in the worship.

Furthermore, they offer advice to the congregation for provisions of accommodations and modifications based on individual needs. One example cited in the article involves a child who constantly rocks during the worship service. The church has provided him a rocking chair to be utilized during the services. It is placed on the end of a row just for him.<sup>13</sup> Some churches have embraced other concepts which include those with special needs. Dr. Mary M. Fulkerson, in *Places of Redemption*, writes of a church

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<sup>12</sup> Carol Stock Kranowitz, *The Out-of-Sync Child Has Fun* (New York: Penguin, 2003), 2.

<sup>13</sup> Joyce E. Nuner and Tamara Love, “Church Ministry and the Child with Autism,” *Family and Community Ministries (Online)*, January 1, 2013, 102.

that includes the special needs population in the worship service, while also offering a separate service that is led by and geared toward those with special needs. Fulkerson states, “Some in the congregation are learning a different way to be in relation to those marked as ‘special needs’ members.”<sup>14</sup> Accommodations and modifications can range from the elaborate to the simple. In “Autism and the Church,” Macaskill writes, “The church is a sensory space, to an extent that persons with typical senses seldom register. Occasionally, perhaps, something may have an intense impact on those persons: feedback from the sound system or the smell of halitosis when talking to someone may go through them with a sensory jolt. For most people, though, such things happen only occasionally, and the sensory world quickly returns to normal. For the person with autism, however, each of these elements – and a myriad more beside – has the potential to cause extreme sensory distress. The perfume that one person loves wearing [for example], perhaps because of its emotional associations for them, is painful to the person with autism, who may not even be sitting near them in the church.”<sup>15</sup> A simple accommodation for those who are sensitive to the smells, would be to ask that fragrances not be worn during the service.

Feeling welcomed extends beyond being passively present or simply noticed. When congregations actively welcome people with IDD and their families when they arrive—not with superficial greetings but with authentic friendliness and real gestures of

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<sup>14</sup> Mary McClintock Fulkerson, *Places of Redemption* (New York: Oxford University Press, 2007), 125.

<sup>15</sup> Macaskill, 117.

hospitality—they feel assured their presence is wanted.<sup>16</sup> I pastor in an itinerant church, which means I am subject to be moved once per year. Each time I am assigned to a new charge, I am transparent about the fact that I have an ASD child. And while I am serving the congregation, I attempt to educate the parishioners about ASD and my child's condition (because no two ASD children are the same). We were at my first charge for approximately two and a half years (my son was two years old when we arrived there). At this first charge, there were several young people and older ladies in the congregation who would assist me with Jadon during the worship service.

Then I was transferred to my second charge where I served for seven years. At this charge, there were lots of young people and a few professionals in the field of special needs. I considered myself blessed. I had been sent to a church where my son's Sunday school teacher was a licensed and practicing occupational therapist by the name of Pat. She was also the van driver who would gather neighborhood children for church each week. I was blessed in that I had someone in my midst who was trained and prepared to assist with my child and other special needs children within that congregation. When we arrived at church each Sunday, I merely waved goodbye to Jadon and sent him on his way with "Miss Pat." One year, I held a viewing of the HBO movie depicting the life story of Temple Grandin. Dr. Grandin is a 71-year-old woman living with Autism who has revolutionized practices for the humane handling of livestock on cattle ranches and

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<sup>16</sup> Carter, 133.

slaughterhouses. Upon showing the movie, I was unaware of the effect it would have on my parishioners. After the viewing, I received a call from an adult. She was in tears. She stated that all her life she was dyslexic, and no one had diagnosed it until she was an adult. She was labeled in school as lazy and stupid, and never overcame the ridicule she suffered. She noted that it was not Autism, but she could empathize with Dr. Grandin. Then she offered to assist with the implementation of a special needs ministry at our church. Other calls that day were from children in the congregation who stated that they wanted to befriend my son after watching the movie. I was overwhelmed by the result of one movie night at the church.

There was a parent, Lynn, at that church who had a son with ASD. Prior to my arrival she would “send” her son, David to church with another member. On the first day I spoke from the pulpit, I fully disclosed that I had a son with Autism who, at the time was about four years old. Upon my admission to the congregation, word spread throughout the parishioners and Lynn stopped sending David to church and began bringing him with her. I later solicited Lynn’s help in starting a support group in the church for parents of ASD kids and made her son our official greeter at the church door. The church has long been committed to breaking down barriers to the gospel and promoting full participation in the life of faith communities for all believers. Such barriers may be no more prominent or deeply felt than among people with intellectual and

developmental disabilities (IDD) and their families.<sup>17</sup> An enduring challenge for the church is to welcome these young people and their families enthusiastically, support their meaningful participation, and view them as valued and indispensable parts within the body.<sup>18</sup>

Amanda Hendler-Voss writes about Sadie Thomas who confesses, “I grew up going to church every day of the week – choir practice, youth group, and mission trips. I want my kids raised in that tradition, and I’m sorry we’ve missed out on that.”<sup>19</sup> Hendler-Voss continues this parent’s story, “On their first visit to church, her son Luke struggled to regulate his sensory overload, and she feared his behavior would disrupt worship. They moved to another room in the church, then departed. Years later, they made another attempt. This time, Luke clapped and sang along. She took him to Sunday school later and sat with him. ‘The other kids immediately knew he was different,’ she says. ‘One boy had his mother’s cell phone and asked to take a picture of Luke. Well, he’s not a sideshow. The Sunday School teacher didn’t know how to respond.’ They didn’t return. ‘I’m still very hopeful we will be able to go to church one day,’ she adds wistfully.”<sup>20</sup>

Hendler-Voss states that we should, “Talk with parents of kids living with Autism Spectrum Disorder (ASD) about finding a church home, and one ominous phrase often repeats: ‘A few years later, we tried again.’ Church-shopping to find a congregation that

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<sup>17</sup> Carter and Biggs, 127.

<sup>18</sup> Ibid.

<sup>19</sup> Amanda Hendler-Voss, “The Whole Body of Christ,” *U.S. Catholic*, March 4, 2019, 35.

<sup>20</sup> Ibid.

offers the right fit can be trying for any family. Yet for families with neurodiverse kids or youth – those whose minds are neurologically different, reflecting variation in the human genome – the first visit to a new church might be so traumatizing that a family doesn't try again for years. Early childhood, that crucial season when children's hearts are most open to the rhythms of liturgy and worship and new parents long for God and community, too often passes without the influence or support of the church."<sup>21</sup>

Hendler-Voss writes about a girl named "Emma." She says Emma was four years old and nonverbal. Emma's mother had taken her daughter to childcare at church only to learn that Emma would be refused by the caregiver because she was not toilet-trained yet. So, she took Emma to the church nursery and dropped her off among nearly two dozen toddlers and infants to be cared for by the five nursery volunteer caregivers. Like most ASD children, Emma is easily overwhelmed by sensory stimuli. But her mother was reassured by the caregivers that everything would be fine. Hendler-Voss writes, "Twenty minutes into worship, however, her mother sensed that all was not well. She rushed to the nursery, only to find Emma frozen in the exact spot where she'd left her, her small face filled with fear. Emma's mother took her away. Although church means a great deal to their family, the experience was so distressing that they did not walk through the doors of another church for years."<sup>22</sup> The church needs people who are willing and prepared to

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<sup>21</sup> Ibid., 33-37.

<sup>22</sup> Ibid., 34.

assist parents of ASD and other special needs children. The story of Emma and her mother is all too familiar.

For this research, I solicited several ASD parents, but only ten were utilized, because they returned the required consent form to proceed with the research. I contacted them via email, by phone or in person to determine their interest. Each parent who agreed to participate was given the consent form (Appendix B) to complete prior to my acquisition of information. After they completed the consent forms, I sent them a survey (Appendix C) via email. I solicited ASD parents of various income ranges, geographic locations, professions, and ethnic backgrounds (figure 1). I interviewed parents who had only ASD children and parents who had a combination of neurotypical children and children on the spectrum. Some of the families had ASD children with other diagnoses in addition to Autism. Nine percent of the families surveyed had female ASD children, while nineteen percent of them had male ASD children. I asked each interviewee to choose how they wanted their identity revealed in my research. Some of the parents listed a pseudonym, some listed their first names and others remain anonymous.<sup>23</sup>

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<sup>23</sup> This research was approved by the Duke Campus Institutional Review Board in November 2020.

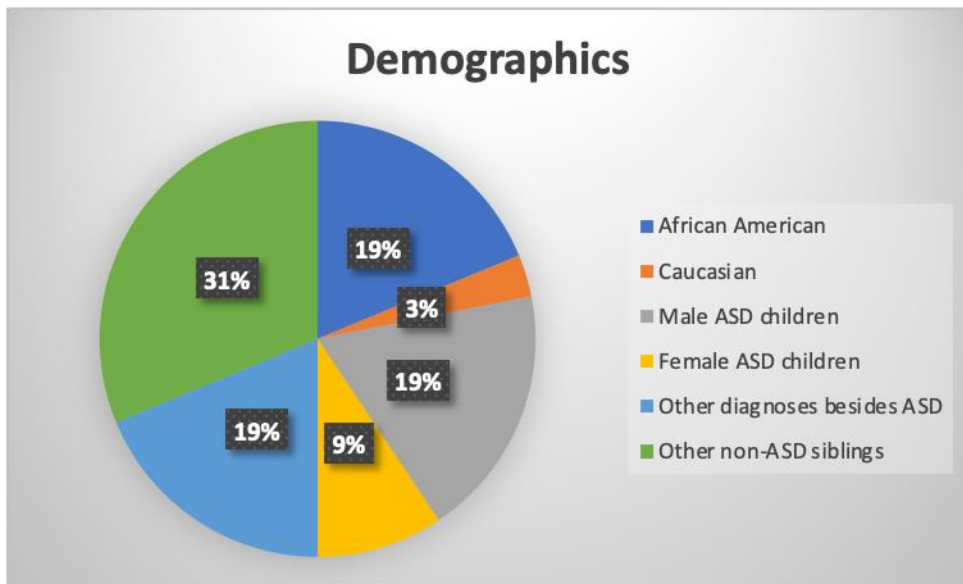


Figure 1: Demographic data of surveyed parents

When I inquired about their church experiences, these interviewees had similar stories. When asked whether or not they attended church on a regular basis (figure 2), 67% of the parents polled stated that they did not attend church on a regular basis, even though 50% of them claimed to be affiliated with a church in some form. They are members of churches, but they are simply choosing not to attend them. Most of the parents polled said in some form that they felt uncomfortable in the church setting as a result of their ASD child's(ren's) condition.

One of the parents, JD (who has three children, two with ASD), expressed that she would often have to remove her eldest ASD child from the worship services and spend that time alone with her daughter in the fellowship hall. On another occasion, JD was attending her sister's funeral with her eldest ASD child. She had to leave the funeral and retreat to the church door while her ASD daughter (overwhelmed by the event) stood

outside. She and her family recently relocated to the west coast and have not yet affiliated with a church. Another parent, Quan recounted that she no longer attends her church. She and her ASD son experience stares “because he loves to move around and make noise” at church and it makes her uncomfortable. When asked about church attendance, another parent, Teresa, simply states that they had bad experiences concerning her (three ASD) children. She states they felt “judged” at church. Another parent surveyed conveyed a recent experience during a church worship service. Shay stated, “my daughter [was] sitting with her hands over her ears and as the service went on, she began to kick clothing off, and scream, and everyone [was] looking at me as if I had hit her or had some real control over what was happening.” Another parent, Keisha stated, “I’m always on pins and needles, because if my child has an outburst, I always feel that people are staring, children speak but they act as if they are afraid or curious...” One other parent stated that they were attending church at a newly built facility, however, the children’s rooms were inadequate – they were too small. She stated that her son felt confined and resorted to spending his worship time in the sanctuary with her, while wearing his headphones. She further stated, “I wanted him to be with other children.”

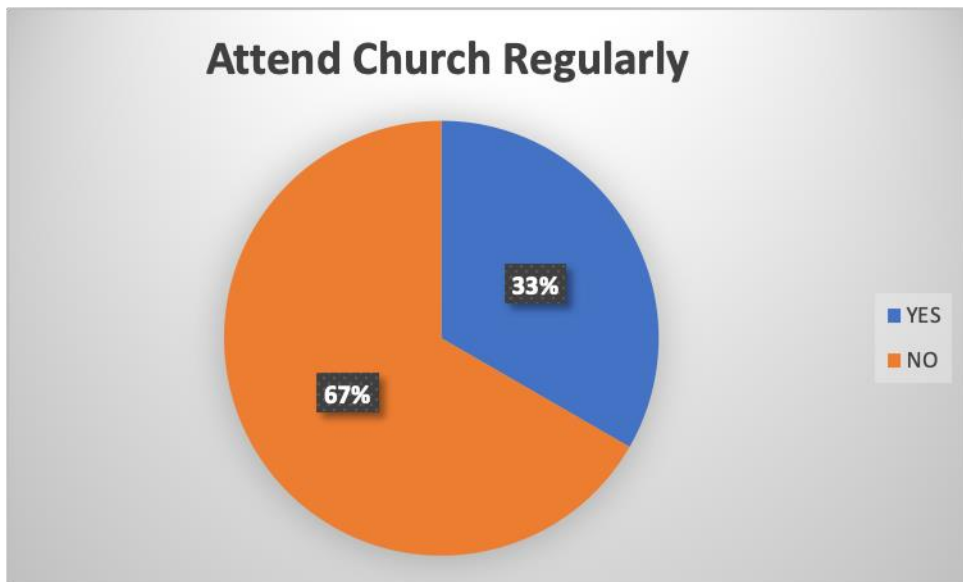


Figure 2: Data from surveyed parents when asked if they attend church regularly

Sadly, my experience is not much different than some of the aforementioned parents. In 2017, I was assigned to my third pastoral charge. At this church there was no “Miss Pat.” And I no longer had the support system that was gifted to me for the first nine and a half years of my ministry and the last seven years of my son’s life. Upon my appointment to the new church, my son struggled to adjust. He destroyed property at the church and repeatedly asked for “Mommy’s other church.” It broke my heart, because we could not return to the former church – the familiarity that he had left behind and longed for. I attempted to explain it to him, but the transition was not easy. While noticing my son’s difficulty adjusting, I exercised my authority as pastor. We had other ASD parents in that congregation and in the community. I wanted them to feel included. So, I initiated and taught a special needs Sunday school and Vacation Bible School class. As a pastor and an ASD mother of faith, I want my child engaged in church. I was hopeful that the

addition of these two classes would help my son feel included in his mommy's new church.

Early on, at this charge, he would accompany me to church and retreat to a special room that had been designated for his use, sometimes with a sitter nearby, but oftentimes not. Then one day I heard something I had not noticed before – the sound of a train horn. The Amtrak station is one block from the church and the door we used to enter and exit the building put the station in full view. As we entered the building one day, a train passed, with horn blazing. My son grabbed his ears and began humming loudly. On another occasion while we were at the church, the trains came so frequently that he had a meltdown. His inability to express those emotions led to several outbursts. Some of his outbursts resulted in physical aggression and property destruction. He destroyed property and left a huge mess in several of the rooms. We paid for all property he destroyed at the church, but the repairs do not erase the memories.

It was difficult for my son to adjust. He did not know how to verbalize his unhappiness with our new environment. The friends he made during my previous seven-year charge, were no longer there. He longed for the company of those we left behind. None of the young people at this new church were willing to reach out to him as they had at other churches where I served. I recall on his thirteenth birthday, I had planned a big party with pizza, cake and all the trimmings – only to have none of the children from the church to show up. Sitters from the congregation who once agreed to sit with him during worship service, eventually all backed away. Surely, it was because they feared what may

have occurred if he had an outburst in their company. I reluctantly made the decision to give him a break from church for a while. And sadly, I never took him back to that church.

Anytime a family is without a church home, i.e., a place for all their family members to worship or participate, it diminishes the body of Christ. Therefore, it is my desire as a minister of the gospel and an ASD parent, to help those with ASD, who want to become part of that body, to accomplish their aspiration. Linda Synder, cofounder of an alternate worship experience for those with ASD states, “If they are not at the table, then we are not a whole body of Christ around the table.”<sup>24</sup> Hendler-Voss writes, “A landmark study by the National Survey of Children’s Health found that the kids least likely to attend church are not those with physical or intellectual disabilities but those with ASD (who are almost twice as likely as neurotypical children to never attend church) or mental health conditions such as ADHD, depression, and anxiety.”<sup>25</sup>

Sadly, the lack of church socialization, to which my child was so accustomed, was a mere memory now. Therefore, he was forced to self-isolate (as a coping strategy) to avoid aggressive behaviors around others in an undesirable and unfamiliar environment. Seemingly, the person with Autism struggles with social skills and appears to most as one who would rather be alone. In *Autism and the Myth of the Person Alone*, Douglas Biklen, through a series of interviews with people on the Autism Spectrum, addresses the concept

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<sup>24</sup> Hendler-Voss, 35.

<sup>25</sup> *Ibid.*, 36.

of “loneness.” This presumed desire for aloneness could lead one to believe that in the community, church and/or school settings, those with ASD would prefer to be isolated. Biklen cites Temple Grandin’s *Emergence: Labeled Autistic* and states, “Where the person labeled autistic is presumed isolated and uninterested, recent autobiographical accounts reveal people in search of connections with the world.”<sup>26</sup> In my opinion, this is why inclusion, such as church involvement (and even school attendance) is so important for the ASD child. For some of them, their only connection with the world is the socialization they receive at these two entities.

In 2019, I was assigned to my fourth and current pastoral charge. This church has quite a few young people. When my son’s fifteenth birthday was looming, I approached a couple of non-ASD parents with my suggestions for Jadon’s party. I wanted to serve pizza, but with such a large group of young people, it could become quite noisy and overstimulating for Jadon. One parent suggested a “silent” pizza party – I think I cried. She further stated that the kids could bring their own devices and listen to their own music, etc. It was the best idea ever! Pictures tell the story...the smile on my son’s face was priceless (photo 3). He was happy and I was happy that we had been placed in a church where he was accepted.

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<sup>26</sup> Douglas Biklen, *Autism and the Myth of the Person Alone* (New York: New York University Press, 2005), 49.



*Photo 3: January 26, 2020 – Jadon’s (silent) 15th birthday party*

As Hendler-Voss writes, “Centering the voices, stories, and bodies of those living with neurological, mental, and developmental differences calls the church to radical hospitality,”<sup>27</sup> as well as radical inclusivity. As one parent has remarked, “A little touch of support would mean so much. Reach out. Initiate contact. Help me connect to others.”<sup>28</sup>

How can the church support the inclusion of ASD parishioners and guests? Amy Fenton Lee offers the following suggestions:

- **One-on-One Assistants (Buddies):** The church provides a personal buddy to accompany and assist the ASD/special needs child inside the typical church or ministry setting and among typical peers. The use of “buddies” is the most common strategy for church inclusion. Many kids with ASD or

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<sup>27</sup> Hendler-Voss, 36.

<sup>28</sup> *Ibid.*

other special needs can successfully participate in the typical ministry setting with the assistance of a one-on-one helper. [This was a strategy that I used at one of my pastoral charges]

- **Self-Contained Special Needs Setting:** The church staffs a room with a lower ratio of participants to volunteers than the typical ministry settings. This room might provide alternate activities that participants with ASD or other special needs may enjoy such as puzzles and toys. The class may also offer a Bible study lesson with enhanced visual curriculum.
- **Hybrid Approach:** A church sets up a “buddy” system while simultaneously providing a self-contained special needs setting. By offering both options, the participants may take part in the environment(s) best suited to their abilities and needs at a given time.<sup>29</sup>

One of the biggest reasons for implementing the buddy system, Lee states, is for the one-on-one helper to accompany the ASD or special needs person should the need arise for them to leave the typical church environment for any reason.<sup>30</sup> As a pastor, who is confined to the pulpit once the service has begun, I find the buddy system to be a very helpful tactic for keeping track of my ASD child. Assigning a buddy to the special needs child at church is a great way to begin fostering much needed relationships for those with ASD who are in need of socialization.

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<sup>29</sup> Lee, 63-65.

<sup>30</sup> Ibid., 67-68.

Church should be the most logical place for anyone to build relationships and to feel accepted, and yet, those with ASD seem to be on the margin of that logic. Hendler-Voss writes, “Perhaps then no one stands in need of the radical communion found at the table of Jesus Christ more than those living with Autism (who struggle socially and relationally in nearly every arena of their lives) and the families who love them. The increasing reality of Autism poses a challenging invitation to today’s church – how can we move beyond the status quo of traditional habits and an exclusive focus on content toward a relational model in which we honor the sacred worth of neurodiversity in the body of Christ?” Hendler-Voss continues, “Inclusivity is the key and parishioners should view ALL ‘children’ of God as actual children of God. Inclusivity in church settings requires effort on all parties – and patience. In worship, neurodiverse children may be seen as too loud or disruptive, but as Timothy Sylvia, pastor and adoptive foster father to children with special needs, insists, such behavior provides a glimpse of God’s kingdom as ‘the spirit shows up in ways we may never understand, sometimes in the guttural sounds of these kids.’ He further states, ‘Children know how to worship. We need to learn from them and tap into their freedom and authenticity. We must get more comfortable with the disruption of the spirit.’”<sup>31</sup>

In *The Child with Special Needs: Encouraging Intellectual and Emotional Growth*, Stanley I. Greenspan and Serena Wieder, address communication issues which

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<sup>31</sup> Hendler-Voss, 36.

can impede the relationships of those with ASD.<sup>32</sup> These relationship impediments can filter into various aspects of life for the one with Autism. Sadly, the result for us and many other families is one of exclusion. Even I, the pastor of a church, felt I needed to leave my own son at home with a babysitter on several Sunday mornings. Linda Synder, cofounder of an alternate worship experience for those with ASD states, “If they are not at the table, then we are not a whole body of Christ around the table.”<sup>33</sup> The question becomes, how does the church, and more importantly, the pastor, provide an opportunity for the whole body (including those with ASD) to feel included “at the table?”

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<sup>32</sup> Stanley I. Greenspan and Serena Wieder, *The Child with Special Needs* (Da Capo Press, 1998), 106.

<sup>33</sup> Amanda Hendler-Voss, “The Whole Body of Christ,” *U.S. Catholic*, Marche 4, 2019, 35.

## 5. A Pastoral Account of Autism

My son is now a teenager and over the years, I have come to the realization that he is a *gift*. The challenge now is to help other parents of children with Autism Spectrum Disorder (ASD) come to the same realization that I have about their own children. I decided that whenever I am assigned to a new pastoral charge, I would be transparent about my son's condition. I also decided to formulate ministries for parents of children on the spectrum. We have initiated support groups, held workshops and I have spoken in several cities about how pastors and churches can work together to include those with ASD.

For this research, utilizing a survey, I communicated with other ASD parents to discuss their experiences with church. One parent remarked that she and her son had stopped attending church prior to the pandemic, because of stares they received from other worshippers, when her nine-year-old son was stemming during the service. Stemming is a technique that is done when a person with ASD is excited or wants to soothe themselves. Some of them will flap their hands, others may make noises, and still others may do both at the same time. The parent stated that the recent pandemic, due to the Coronavirus, has given them an opportunity to begin a new Sunday tradition of attending church in the car while listening to a service online or via social media. She further states that this will likely be their tradition once the ban is completely lifted for

them to return to in-person worship. There are some churches that seem unwilling to receive the person with special needs, even if the child is one of the pastor's children.

I have spoken to churches throughout our denomination and other audiences across this nation, waving the banner of Autism inclusion in church congregations. As senior pastor and leader of my congregation, I have the unique opportunity to enforce change for a group of people who might otherwise be ignored. For most people, the Autism population would appear to be outside and not inside the body of Christ. But Paul's words in I Corinthians 12:12-27 remind us that this group of people has just as much to offer as any other. As a pastor-parent who has a child with special needs, armed with Paul's message, I can "bully" my way into places where my ASD parishioners cannot go. I can become a champion, not only for my cause, but for theirs as well. As a church leader, I intend to do all I can for my child and consequently for other children with ASD who may not be afforded the same opportunities as their peers.

I wanted to involve my son and others with ASD in church. Therefore, at my third pastoral charge, I implemented a Sunday School class (photo 4) with the ASD child in mind.



*Photo 4: May 6, 2018 – Jadon completing a Sunday School activity*

Children on the Autism spectrum thrive on routine. So, I developed a weekly schedule outlining the lesson for the day. Here is an example of one of our lessons:

#### **SUNDAY SCHOOL LESSON SCHEDULE – FORGIVENESS**

- 9:00-9:10 Bible Story & Scripture – 10 minutes  
Scripture – Matthew 18:23-35  
What does it mean to forgive? – VIDEO
- 9:10-9:15 Object Lesson – 5 minutes  
God’s Forgiveness Science Object Lesson
- 9:15-9:18 Hymn Time – 3 minutes  
Veggie Tales Video
- 9:18-9:30 Activity/Craft – 12 minutes  
The Unforgiving Servant Color Sheet
- 9:30-9:35 Closing – 5 minutes  
Matthew West Video – Forgiveness
- 9:35-9:40 Snack Time
- 9:40-9:45 Choice

When my son began to have difficulty adapting to his age-appropriate class at Vacation Bible School (VBS), I utilized the same Sunday School model to teach him the VBS lesson on the fruit of the spirit (photo 5) and it was effective.

When I initially learned of my son's diagnosis, I decided to inform my family members about his condition. Jadon's father has two other males on the Autism Spectrum (two nephews, one age 50 and one age 10); therefore, his father's side is quite familiar with the condition. My family, however, was not. To educate them, I turned to TEACCH (Treatment and Education of Autistic and Communication related handicapped CHildren) and they recommended that I share an excerpt from the book, entitled, *Ten Things Every Child with Autism Wishes You Knew* by Ellen Notbohm.



*Photo 5: June 26, 2018 – Jadon completing a Vacation Bible School activity*

I contend that education is the road to inclusivity in the church. I am willing to do all that is necessary to educate the churches I serve so that my son and others with ASD

will become part of those congregations. At my third pastoral charge my son was having difficulty adjusting and the members had difficulty accepting him. Therefore, during the month of April – Autism Awareness Month, I decided to educate my parishioners, just as I had previously educated my family. So, I published the following *Ten Things* list in our weekly church bulletin. Several members remarked that the list was helpful because it provided them with a first-hand account of what is in the mind of the ASD child:

*Ten Things Every Child with Autism Wishes You Knew (by Ellen Notbohm)*

1. I am first and foremost a child. I have autism. I am not primarily “autistic.” My autism is only one aspect of my total character. It does not define me as a person. Are you a person with thoughts, feelings and many talents, or are you just fat (overweight), myopic (wear glasses) or klutzy (uncoordinated, not good at sports)? Those may be things that I see first when I meet you, but they are not necessarily what you are all about. As an adult, you have some control over how you define yourself. If you want to single out a single characteristic, you can make that known. As a child, I am still unfolding. Neither you nor I yet know what I may be capable of. Defining me by one characteristic runs the danger of setting up an expectation that may be too low. And if I get a sense that you don’t think I “can do it,” my natural response will be: Why try?
2. My sensory perceptions are disordered. Sensory integration may be the most difficult aspect of autism to understand, but it is arguably the most critical. It means that the ordinary sights, sounds, smells, tastes and touches of everyday that you may not even notice can be downright painful for me. The very environment in which I live often seems hostile. I may appear withdrawn or belligerent to you but I am really just trying to defend myself. Here is why a “simple” trip to the grocery store may be hell for me: My hearing may be hyper-acute. Dozens of people are talking at once. The loudspeaker booms today’s special. Music whines from the sound system. Cash registers beep and cough, a coffee grinder is chugging. The meat cutter screeches, babies wail, carts creak, the fluorescent lighting hums. My brain can’t filter all the input and I’m in overload! My sense of smell may be highly sensitive. The fish at the meat counter isn’t quite fresh, the guy standing next to us hasn’t showered today, the deli is handing out sausage samples, the baby in line ahead of us has a poopy diaper, they’re mopping up pickles on aisle 3 with ammonia. . . .

I can't sort it all out. I am dangerously nauseated. Because I am visually oriented, this may be my first sense to become overstimulated. The fluorescent light is not only too bright, it buzzes and hums. The room seems to pulsate, and it hurts my eyes. The pulsating light bounces off everything and distorts what I am seeing—the space seems to be constantly changing. There's glare from windows, too many items for me to be able to focus (I may compensate with “tunnel vision”), moving fans on the ceiling, so many bodies in constant motion. All this affects my vestibular<sup>1</sup> and proprioceptive<sup>2</sup> senses, and now I can't even tell where my body is in space.

3. Please remember to distinguish between won't (I choose not to) and can't (I am not able to). Receptive and expressive language and vocabulary can be major challenges for me. It isn't that I don't listen to instructions. It's that I can't understand you. When you call to me from across the room, this is what I hear: “\*^%\$#@, Billy. #%^\*^%\$&\*. . .” Instead, come speak directly to me in plain words: “Please put your book in your desk, Billy. It's time to go to lunch.” This tells me what you want me to do and what is going to happen next. Now it is much easier for me to comply.
4. I am a concrete thinker. This means I interpret language very literally. It's very confusing for me when you say, “Hold your horses, cowboy!” When what you really mean is “Please stop running.” Don't tell me something is a “piece of cake” when there is no dessert in sight and what you really mean is “this will be easy for you to do.” When you say, “It's pouring cats and dogs,” I see pets coming out of a pitcher. Please just tell me “It's raining very hard.” Idioms, puns, nuances, double entendres, inference, metaphors, allusions, and sarcasm are lost on me.
5. Please be patient with my limited vocabulary. It's hard for me to tell you what I need when I don't know the words to describe my feelings. I may be hungry, frustrated, frightened, or confused but right now those words are beyond my

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<sup>1</sup> The vestibular system refers to our sense of movement and balance. It is located in the inner ear. When we move our heads, the fluid in the inner ears moves around and gives information about where your head and body is in space. The vestibular system also has receptors that help our bodies understand the force of gravity. <https://theautismhelper.com/>.

<sup>2</sup> The proprioceptive system is located in our muscles and joints. It provides us with a sense of body awareness and detects/controls force and pressure. The proprioceptive system also has an important regulatory role in sensory processing as proprioceptive input can assist in controlling responses to sensory stimuli. Proprioceptive input can be very calming for those who are easily overwhelmed by sensory stimulation. Proprioceptive input can be alerting for those who need increased sensory stimulation to facilitate attention and learning. <https://sensory-processing.middletonautism.com/>.

ability to express. Be alert for body language, withdrawal, agitation, or other signs that something is wrong. Or there's a flip side to this: I may sound like a "little professor" or movie star, rattling off words or whole scripts well beyond my developmental age. These are messages I have memorized from the world around me to compensate for my language deficits because I know I am expected to respond when spoken to. They may come from books, TV, the speech of other people. It is called "echolalia." I don't necessarily understand the context or the terminology I'm using. I just know that it gets me off the hook for coming up with a reply.

6. Because language is so difficult for me, I am very visually oriented. Please show me how to do something rather than just telling me. And please be prepared to show me many times. Lots of consistent repetition helps me learn. A visual schedule is extremely helpful as I move through my day. Like your Day-Timer, it relieves me of the stress of having to remember what comes next, makes for smooth transition between activities, helps me manage my time and meet your expectations. I won't lose the need for a visual schedule as I get older, but my "level of representation" may change. Before I can read, I need a visual schedule with photographs or simple drawings. As I get older, a combination of words and pictures may work, and later still, just words.
7. Please focus and build on what I can do rather than what I can't do. Like any other human, I can't learn in an environment where I'm constantly made to feel that I'm not good enough and that I need "fixing." Trying anything new when I am almost sure to be met with criticism, however "constructive," becomes something to be avoided. Look for my strengths and you will find them. There is more than one "right" way to do most things.
8. Please help me with social interactions. It may look like I don't want to play with the other kids on the playground, but sometimes it's just that I simply do not know how to start a conversation or enter a play situation. If you can encourage other children to invite me to join them at kickball or shooting baskets, it may be that I'm delighted to be included. I do best in structured play activities that have a clear beginning and end. I don't know how to "read" facial expressions, body language or the emotions of others, so I appreciate ongoing coaching in proper social responses. For example, if I laugh when Emily falls off the slide, it's not that I think it's funny. It's that I don't know the proper response. Teach me to say, "Are you OK?"
9. Try to identify what triggers my meltdowns. Meltdowns, blow-ups, tantrums or whatever you want to call them are even more horrid for me than they are

for you. They occur because one or more of my senses has gone into overload. If you can figure out why my meltdowns occur, they can be prevented. Keep a log noting times, settings, people, activities. A pattern may emerge. Try to remember that all behavior is a form of communication. It tells you, when my words cannot, how I perceive something that is happening in my environment. Parents, keep in mind as well: persistent behavior may have an underlying medical cause. Food allergies and sensitivities, sleep disorders and gastrointestinal problems can all have profound effects on behavior.

10. If you are a family member, please love me unconditionally. Banish thoughts like, “If he would just...” and “Why can’t she...” You did not fulfill every last expectation your parents had for you and you wouldn’t like being constantly reminded of it. I did not choose to have autism. But remember that it is happening to me, not you. Without your support, my chances of successful, self-reliant adulthood are slim. With your support and guidance, the possibilities are broader than you might think. I promise you – I am worth it. And finally, three words: Patience. Patience. Patience. Work to view my autism as a different ability rather than a disability. Look past what you may see as limitations and see the gifts autism has given me. It may be true that I’m not good at eye contact or conversation, but have you noticed that I don’t lie, cheat at games, tattletale on my classmates or pass judgment on other people? Also, true that I probably won’t be the next Michael Jordan. But with my attention to fine detail and capacity for extraordinary focus, I might be the next Einstein. Or Mozart. Or Van Gogh. They had autism too. The answer to Alzheimer’s, the enigma of extraterrestrial life – what future achievements from today’s children with autism, children like me, lie ahead? All that I might become won’t happen without you as my foundation. Think through some of those societal ‘rules’ and if they don’t make sense for me, let them go. Be my advocate, be my friend, and we’ll see just how far I can go.<sup>3</sup>

I published the above ten items in our church bulletin, because I felt that the information needed to be shared. I was correct. After having read the list, one of my parishioners, approached me and expressed her appreciation for my having shared the information. She

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<sup>3</sup> Ellen Notbohm, *Ten Things Every Child with Autism Wishes You Knew* (New York: Future Horizons, 2005), 4.

further stated that she, and hopefully others, had learned “quite a bit about Autism” and my son. An interesting dynamic regarding my role as ASD parent and pastor, is the fact that I enter a church with a potential ministry already – an ASD ministry. If there are other parents in the congregation seeking support from the church, they have an instant advocate when I – the new pastor – enter the building.

In October of 2019, I was assigned to my fourth and current charge. At this new church, before the pandemic, we were in the process of implementing a ministry for ASD parents. When we were forced into quarantine, I changed my strategy. I offered an online Sunday School class for ASD children. I utilized the same schedule listed above, but I incorporated several videos and an interactive PowerPoint presentation with a variety of activities to engage the young people. My son was a captive audience, and my sole student, however. I was not discouraged, because I realize that anything new takes time to develop. And although there is a plethora of resources for the ASD parent in the county where I now reside, I would like to still implement my plan for the ASD parents in my church and surrounding community.

Nevertheless, prior to the plan implementation, I will conduct an ethnographic study to determine if there is an “itch” for inclusion of the ASD population at my church before I begin to “scratch.” The study will contain questions that will be posed to the general membership regarding inclusion of the ASD population. The purpose of polling the general membership is to determine their level of empathy and support for a special needs or ASD ministry in their church. Here is a sample of some of those questions:

- What ministries, activities, etc. attracted you to your church?
- Have you ever encountered a person with Autism? What was your experience? Did you interact with them? If so, how? If not, what prevented the interaction?
- Have you ever attended a worship service with people who have special needs? If so, describe your experience.
- Do you know a parent or guardian of a child with Autism?
- Have you ever felt uncomfortable in a church setting? Describe your experience.
- What do you think is the best way to include a person with Autism in your church?

If there is an “itch,” then I will start by leading the efforts to initiate a support group for parents or guardians of children on the Autism spectrum. This was an initiative that I led at my second pastoral charge. It was quite effective. We began as a support group for “Parents of Children with Autism,” and quickly had to regroup. Other parents, those of children with Downs Syndrome, Attention Deficit Disorder (ADD), Attention-Deficit/Hyperactivity Disorder (ADHD), and other special needs, expressed an interest in joining our group. We changed our name to “Friends of Exceptional Children” and widened our tent to include them.

Upon initiation of the support group, I did not realize the depth of my involvement when we began, but it was quite rewarding. I was invited by other ASD parents to sit in on their children’s IEP (Individualized Education Program) meetings. I even assisted one grandparent with spearheading a complaint against her grandson’s

school. Her five-year-old ASD grandson was expelled from school because the Columbus county school “had no resources available to assist him.” Once her complaint was formalized, it progressed to litigation. These occurrences are evident that there is need of some support for those who care for ASD children. As a pastor, I was glad to have been in position to lend the support through our ministry.

My motivation for offering ministry to ASD parents is personal. My attendance at the first TEACCH mothers’ group meeting years ago, signified to me that there must have been other ASD parents who needed the same feeling that I had – the feeling that I was not alone. I was reluctant to attend the first meeting. But my reluctance at attending that meeting soon turned into acceptance and then a feeling of relief – a feeling that I was not in this by myself – a feeling that there had to be other mothers, parents out there with the same issues. I offer the ASD ministries through the church because parents need to know that there is a place for their ASD children in the church and a place where they too may feel that they are not in this alone.

Parents that were surveyed for this research affirm that many churches do not offer activities which foster inclusion. Nor do they offer opportunities for parishioners to receive training or resources to assist with the ASD population. When asked if their churches provide activities for children with ASD, 100% of the parents polled answered “no.” When these same parents were asked, “What service(s) can your church or any other church provide for you and your ASD child(ren) that is not being done now,” their answers varied, but included one common thread – each parent emphasized the

importance of having trained people or those who were educated about special needs and/or Autism working with ASD children at the church. One parent, Quan shared, “It would be nice to have children’s church and activities that involve learning about Christ through play. And also educate members about Autism.” Another parent, Grelynn, stated that there should be “Lots of space. Educators with experience and/or patience with children with special needs. It's something a person has to love doing. My son will be able to tell if someone is doing it for the wrong reasons.” She added, “It's all about the person teaching the children. They have to make it so the children want to be there...having a good time while learning and socializing.” Another parent, Teresa suggested, “offer training to staff and volunteers to better support those with ASD.” Yet another parent, Shay stated, “provide training, have support groups.” Churches have mental health awareness and diabetes info sessions but nothing with behavioral health or sensitivity training.” As a pastor-parent of a child with ASD, I recognize the importance of having my child included in the church experience. These parents wish to have their children included also. They are simply in need of a pastor who will support that inclusion.

My plan for inclusion at this new pastoral charge is not much different than those I have executed in years past. Once we determine the need for the ministry, we will invite ASD parents in the church and community to attend a monthly meeting which would benefit parents of children with Autism. Each meeting will feature a subject matter relevant to ASD parents. Examples of subjects that have been well received in the past

include guardianship, wills and living wills, executors of estates, power of attorney, trust accounts, IEPs (Individualized Education Programs), and others. The plan I utilize for initiating ASD ministries has been successful. Here is what I have to offer other pastors who seek to do the same:

*Ten Things Every Pastor Should Know About Starting an ASD Ministry by Charlean B. Mapson:*

1. Survey your parishioners to gauge their empathy or ability for involvement in such a ministry.
2. Pull supporters together and make a plan. It helps if you have parents of special needs children or special needs educators within the congregation. But if you do not, then seek volunteers within the community from a local college/university. There is typically a special needs curriculum offered and students who are willing to provide their assistance, while gaining experience. Furthermore, local elementary, middle, and high schools typically have a special needs program with teachers who may be willing to assist. Or perhaps a local healthcare facility would be willing to offer assistance as well.
3. Upon gaining support, discuss topics of interest with the ASD parents. Develop a plan for a period of 12 months. Assign one topic for each month. We used the months of June and December as “fun” months. In June, we held an event at a park or had a party. In December, we showed a Christmas movie and had arts and crafts.

4. Offer babysitting services. The youth (ages 13-21) volunteered to sit with the ASD children while their parents attended our meetings. Solicit your babysitters from the church, community, local special educators rank, etc. They need to have experience with special needs children or be willing to have training (see chapter six).
5. At each meeting, we offered some light refreshments. In December, we had a covered dish meal. Snacks can be tricky with ASD children. They are typically picky eaters, so seek parental involvement. We solicited a different parent each month to provide snacks.
6. Suggestions for monthly meetings (utilize the resources that are available):
  - a. Sheriff's department – they offer a special device that can be placed on your ASD child, should s/he stray away. I found that this service is limited depending on the county where you reside.
  - b. Attorneys – to discuss living wills, last will in testament, power of attorney, guardianship (important when the ASD child reaches age 18), executor, trust accounts, etc. The time for the ASD parent to plan for the “end” is now.
  - c. ECAC (Exceptional Children's Assistance Center) – I believe they are nationwide. Their mission is as follows: “We help parents navigate the special education system, know their rights, and use their voice. We provide information, support, training and resources to assist families

caring for children with special needs from birth to age 26. We also support young adults with disabilities in becoming self-advocates and leaders and the educators and professionals who serve them.”<sup>4</sup> ECAC has a plethora of topics that are relevant to the special needs parent, for example, “Talking about difficult things with your exceptional child.” We utilized this group for several workshops at our support group throughout the year. Each month they attended they would PAY our “volunteer” babysitters.

- d. Therapists – therapists provide great information for ASD parents. We had an occupational therapy team to do one of our monthly workshops. They displayed items that could assist parents at home with their ASD children and offered suggestions for meltdowns, sensory diets, and sleep disorders.
- e. Nutritionists – since most ASD children are picky eaters, a nutritionist would be a great source to assist parents with offering ways to introduce new foods.
- f. Special Education Director – while serving in Columbus county, we invited the county’s director to a meet-and-greet, so that our parents could engage him in conversation, and he could in turn hear the parents’ needs.

7. Solicit parents or interested volunteers to contact the monthly speakers.

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<sup>4</sup> <https://www.ecac-parentcenter.org/>.

8. Once you have a plan for the year, draft an introduction letter stating the name of your ministry (if you have one), the goal of the ministry (to assist ASD parents), the meeting time and location (it helps to have the same time and location monthly). We made our letter double-sided and published our monthly meeting schedule on the reverse side of the letter.
9. Take the letter to the Special Education Director and ask for permission to disseminate it to the schools. They will tell you how they would like for you to disburse it (sometimes they may even do it for you).
10. Publicize your meetings – EVERYWHERE. I conducted radio interviews, newspaper interviews, and even appeared on a local community college program – however you decide to do it, get the word out! Because, as someone once said, “If you build it, they will come.” But build it right, because as someone else once said, “You never get a second chance to make a first impression.”

I offer this list as a guide for other pastors who are seeking to service the ASD population of their church/community. It is merely a guide and may be modified to suit your needs.

Amy Fenton Lee provides a strategy for churches who wish to provide inclusion and offer accommodations for ASD or special needs parishioners. She suggests intake forms and states, that intake forms are crucial to developing a child’s accommodation plan inside the church. Lee suggests that forms be completed and kept on file at the church. Completion of the forms can be done individually or in an interview with the

pastor or a representative (typically the special needs ministry coordinator) and the family. She highly recommends the interview, and her reasons are simple:

- **Intake conversations allow the church to convey their intention to accept the child.** Even though difficult subjects are often broached that require parents to be vulnerable about their child’s needs, the ministry representative conducting the interview can convey sincerity in the conversation. The interviewer’s tone of voice and response can help the parent of guardian understand that the church is willing to work through any challenges that might arise.
- **Intake conversations invite more candid disclosure.** The church representative conducting the intake interview can ask follow-up questions that may reveal crucial details that would not have been disclosed on a parent-completed form.
- **Intake conversations reveal other family needs.** For many families of a child with special needs, developing a sense of belonging and connection inside a church is every bit as important as developing their child’s accommodation plans.<sup>5</sup>

Lee states, “The real ‘win’ of an intake conversation happens when that church leader recognizes opportunities for connection and then makes relevant introduction to other church members and ministry leaders.”<sup>6</sup> Lee warns that the intake process requires a

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<sup>5</sup> Amy Fenton Lee, *Leading a Special Needs Ministry* (Nashville: B&H Publishing, 2016), 122.

<sup>6</sup> *Ibid.*, 77.

significant amount of time for the church representative. That the person assigned to the task can expect to devote their time to:

- Conducting the parent interview.
- Completing a write-up and formal intake document.
- Contacting assigned buddies and small group leaders who will play a part in the child's accommodation plan.
- Coaching the ASD person's assigned buddies and others (Sunday School teachers, etc.) to help with the specific child's needs.
- Networking and introducing other relevant church leaders to family members.

Familiarity with special education or disability accommodation is helpful. While it is not necessary for the person conducting the parent interview to be credentialed, it is tremendously helpful for the person to be able to pick up on terms used by parents and to know where to interject important follow-up questions.<sup>7</sup>

As a ministry leader in my church, a leader in my son's school, and in my community, I believe it is important to navigate and illuminate not only the church, but the school on the need for processes and methods of inclusion, adaptation and modification for the Autism population.

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<sup>7</sup> Ibid., 77-78.

## 6. An Educational Account of Autism

In *Leading a Special Needs Ministry*, Amy Fenton Lee states, “When children are ‘misbehaving,’ researchers have found that they are nearly always trying to communicate a need for one of the following: a tangible object; a physical or sensory need; to escape a demand; an activity or a sensory stimulation; or they are seeking to acquire attention from adults or peers.”<sup>1</sup> My son, Jadon, is no exception. His physical aggression or “misbehavior” often stems from his inability to effectively communicate his wants or needs. We moved from Wilmington, North Carolina to Wilson, North Carolina in 2017. Unbeknownst to me, this move was a major adjustment for my son. He had several meltdowns over the two-year period we spent in Wilson county. And he did not seem to adjust to our new church. He repeatedly asked for “Mommy’s other church.” It broke my heart because I knew we were not going to return to that church.

Not only was our move to Wilson an adjustment for my son at church, but there was a tremendous adjustment at school – one I never anticipated. Prior to our arrival, I learned of a private school in the city that was founded specifically to educate children with Autism Spectrum Disorder (ASD). I had asked around town and many in the community recommended this school. When we landed in Wilson, I thought we had struck GOLD. It was a private school for ASD kids in grades K-12, and beginning the following year, the school would start a year-round program. My ex-husband and I were

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<sup>1</sup> Amy Fenton Lee, *Leading a Special Needs Ministry* (Nashville: B&H Publishing, 2016), 122.

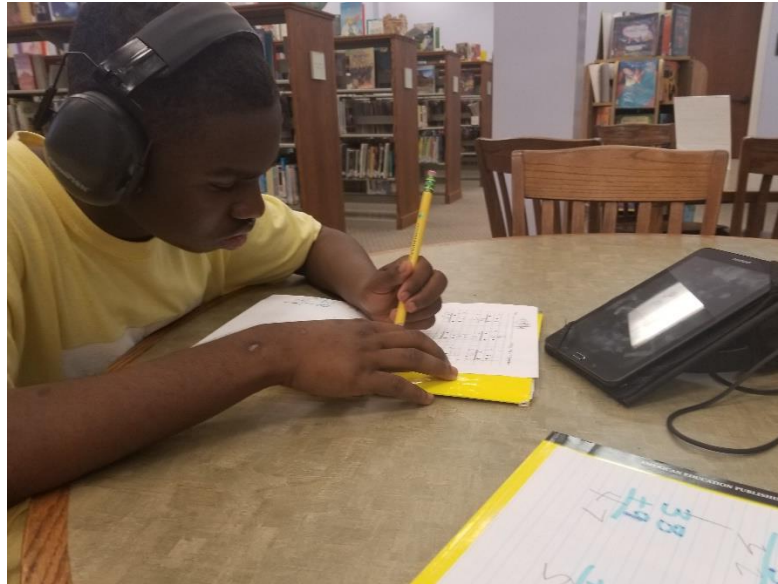
very transparent about Jadon prior to enrolling him. We were assured that the school had handled cases like his in the past and they were equipped to handle Jadon.

Prior to enrollment at the school, I met with the principal-founder and expressed my concern that none of the children seemed to have the same needs as my son. She assured me that they had seen ASD children of all ranges and they were equipped to handle my child. I enrolled my son and hoped for the best. I had heard of many success stories about students who had attended, and I was looking for the same result. Jadon, his dad, his uncle, and I all attended the open house. His dad asked specific questions, because he too seemed to think there might be some disconnect with their efforts to assist our son. The husband of the founder, one of the teachers who would be assigned to Jadon, assured him they could handle it. On the first day – I dropped Jadon off with a gleam of hope in my eye (photo 6), thinking that he would be in the hands of people who were equipped to handle a child with his issues.



*Photo 6: August 6, 2018 – Jadon's first day at Great Accomplishments Academy*

Day one, I received a call that he was aggressive and had ripped the brand-new shirt he wore to school. They told me to bring in a replacement shirt and that they were going to work with him. When I picked him up that afternoon, I learned that, unlike Jadon's former school – Williston Middle School in Wilmington, there was no one-on-one instruction in his classroom. The school was simply not equipped with enough personnel to have that type of instruction. Surely, this was a very big adjustment for him. I asked his teacher to give me the work that he had not completed for that day. The worksheet was multiplication. The sheet had been given to Jadon with no explanation or one-on-one instruction. He had no idea how to complete the assignment, which most assuredly led to his aggressive outburst. I took the incomplete work and promptly escorted Jadon to the public library. We sat there and he completed the sheet as I explained to him how to maneuver the mathematic problems (photo 7). He "got it." He just needed that assistance to get through the first few problems. ASD parent Keisha, when asked to "share any story you wish regarding your ASD child's(ren's) involvement in their school," stated regarding her daughter, "She loves school and I think this year she has a teacher that pushes her to learn and doesn't just give her busy work. I think she is being challenged academically." ASD children can learn, they simply need a teacher who will help them turn on the right switch. Someone who will believe in them and their ability to achieve.



*Photo 7: August 6, 2018 – Jadon finishing his incomplete classroom assignment*

In October 2001, President George W. Bush ordered the creation of the President's Commission on Excellence in Special Education. This commission met and conducted thirteen hearings throughout the country. They listened to comments and concerns from parents, teachers, principals, education officials and the public. The commission found:

- Young people with disabilities drop out of high school at twice the rate of their peers. Upon leaving school the students with disabilities are unemployed and underemployed at a rate higher than those who have no disabilities.

- Too many students with disabilities leave school without successfully earning any type of diploma and attend postsecondary programs at rates lower than their nondisabled peers.
- Adults with disabilities are much less likely to be employed than adults without disabilities.
- Employed adults with disabilities earn markedly less income than their nondisabled peers.<sup>2</sup>

These statistics reflect a failure in the system to educate those with special needs or disabilities.

I recall one of his IEP (Individualized Education Program) meetings from years ago, while he was in elementary school. There was a school official in attendance from the central office. Prior to the meeting, she had observed my child on two separate occasions (academic related not behavior related). At the IEP meeting, when it was noted that my son said his wish was to become a pilot, she remarked, “He can never do that. Sometimes these kids see things on TV and think they can do them. He just needs to find some other job working around airplanes.” I asked her, “How many times have you been with my son?” She said, “two.” I replied, “Then, I’m not talking to you. Because you don’t know my child.” Too often, I have witnessed educators place ASD children in a box. A box I believe stifles their learning abilities. Following that meeting, I emailed the

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<sup>2</sup> Chantal Sicile-Kira, *Adolescents on the Autism Spectrum* (New York: The Berkley Publishing Group, 2006), 158-159.

teacher and expressed my disapproval for the visiting school official's lack of compassion and her negative comments. The teacher agreed. Later that school year, the same official was in attendance at another of my son's IEP meetings. After the meeting, I spoke with her privately to express my concern about her previous comments. She apologized to me and my (at the time) third grade son.

One parent that I surveyed for this research, in the education portion of the survey (Appendix C), said this about her ASD daughter, "I must mention that she is in the Beta Club and they do community service activities that she participates in and she competed in the FCCLA's regional competition sharing her clean up the ocean, save the whales project." FCCLA stands for Family, Career and Community Leaders of America. For an ASD child to become a member of the Beta Club, speaks volumes about their cognitive and/or learning ability. Whenever I am met with doubt about my son's capability, my reply is always, "Jadon LOVES to learn, and he is a sponge. He just needs the right teacher to challenge him."

On day two, at the school in Wilson known for working with ASD students, my son attacked his male teacher, and I was asked to pick him up early. On day three, he attacked the principal, so again I was asked to pick him up early. Later, on day three, I received a call from the principal – she wanted to have a talk with me. When I arrived and took my seat, she and her husband (Jadon's teacher) informed me that he would not be returning to their school. Prior to that day, they had assured me that my "move to Wilson was not in vain." That I was there and had been introduced to their school for a

reason...I am unsure to this day, what that reason was. Jadon had a horrible time adjusting and now in just three days at his new “Autism” school, the principal and his teacher were expelling him from the school I thought would help my son’s dream of becoming a pilot, become a reality. They could no longer have Jadon as a student. My words to them were, “I am heartbroken.” I immediately enrolled him in the Wilson County Public Schools.

After having failed at what was known as the “Autism school” in Wilson, I proceeded to enroll my son in the public school system. Prior to his enrollment, I met with the special education coordinator for the county and was very transparent about my son’s aggression. He entered the Wilson county school system as an eighth grader at a local public middle school – homebound for one hour of school per day. Wilson county’s answer to my son’s situation was to keep him out of school. I believe that ASD children need school as much as they do church, for socialization purposes. There was a short time when he was actually at home with an instructor teaching him there, but after a few weeks, I insisted that my son spend his hour of education at the school among his peers. The school granted my request. I would awaken my son each morning, prepare him for school. Transport him to school for his ONE HOUR session and then return home. The school and more specifically, the special education director had reviewed his previous IEPs and determined that due to his past behavior, homebound was the best option for him.

Children with ASD typically react physically when they are unable to express themselves verbally. Again, my son is no exception. Amy Fenton’s words bear repeating, “When children are ‘misbehaving,’ researchers have found that they are nearly always trying to communicate a need for one of the following: a tangible object; a physical or sensory need; to escape a demand; an activity or a sensory stimulation; or they are seeking to acquire attention from adults or peers.”<sup>3</sup>

Just one year prior to my son’s birth, in 2004, the Individuals with Disabilities Education Improvement Act (IDEA) established a new requirement calling for a “summary of academic and functional performance” to be given to every student who exits special education by graduating with a regular diploma or exceeding the age for special education under state law. The major purpose of the IDEA is to ensure that all children [including those] with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment, and independent living.<sup>4</sup>

During our second year in Wilson, Jadon matriculated into high school. When we gathered for his pre-high school IEP meeting, his dad and I voiced our concern with the lack of academic work he received the previous year given his one hour per school day schedule. The principal at the high school assured us that he would allow Jadon to attend

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<sup>3</sup> Amy Fenton Lee, *Leading a Special Needs Ministry* (Nashville: B&H Publishing, 2016), 122.

<sup>4</sup> <http://www.cpacinc.org/materials-publications/legal-rights/the-individuals-with-disabilities-education-improvement-act-idea-2004/>.

school for more than one hour. He would begin with half a day then add additional hours as he could handle them. The year was off to a great start. Jadon had a teacher who was the sister of an ASD male. Because she had a brother with ASD, she understood. Jadon instantly liked the organization of her classroom, the daily schedule she provided and the reward system she had for him as he completed his daily assignments.

Then picture day occurred. I still am not clear exactly what caused his aggressive outburst, but I dropped him off that morning. Shortly after I arrived home, I received a call that I needed to return to the school to take Jadon home. When I arrived at the school, I was told that an incident occurred after Jadon took his school picture. He was in line waiting for his other classmates to complete their pictures. Something occurred. He had a meltdown and tore another student's shirt. When the principal recounted the story, he informed me that Jadon would be suspended for five days due to his behavior. I have said this repeatedly over the years, "When you suspend a child with Autism from school, you are telling him that if I do this – then I can go home and spend time with my mommy." It makes no sense to me. My son had two other meltdowns at that school, and each time, he was given a five-day suspension. This means he was suspended for fifteen days in one year due to actions relative to his condition – something he cannot control. His dad and I appealed to the principal to have the suspensions removed from his record, but we were refused. I recently recounted this story to a former principal and friend of mine. She has encouraged me to seek litigation. She informed me that the practice against my son was illegal and that the statute of limitations in cases such as these is nonexistent.

Dr. Sarah J. Barton of Duke Divinity School, states, “There is lots of research that highlights disparities with regard to school suspensions and expulsions among children of color, especially those with disabilities.” She recommends the following for further information:

- “Students With Disabilities Disciplined Twice As Often As Peers” by Courtney Perkes<sup>5</sup>
- “Education and Special Education in Juvenile Corrections” by Joseph Calvin Gagnon, Paula Maccini, Brian R. Barber, Peter E. Leone, Loretta Mason-Williams, David Houchins, Candace A. Mulcahy, and Kimber L. Wilkerson<sup>6</sup>
- “Black students and students with disabilities remain more likely to receive out-of-school suspensions, despite overall declines” by Kristen Harper, Renee Ryberg, and Deborah Temkin<sup>7</sup>

My son’s situation seems unique when compared to most of the ASD parents surveyed for this research. It appears that these ASD children managed to avoid suspensions – the principals were not as tough. One parent noted that her ASD daughter was near suspension, “[for] throwing items in the classroom, stripping off clothes in the classroom, ignoring the teacher, and constant screaming.” But the parent noted that the

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<sup>5</sup> <https://www.disabilitycoop.com/2018/02/28/report-disciplined-twice/24783/>.

<sup>6</sup> [https://www.researchgate.net/profile/Peter\\_Leone2/publication/247785101\\_Suspension\\_Race\\_and\\_Disability\\_Analysis\\_of\\_Statewide\\_Practices\\_and\\_Reporting/links/541750600cf2f48c74a40687.pdf](https://www.researchgate.net/profile/Peter_Leone2/publication/247785101_Suspension_Race_and_Disability_Analysis_of_Statewide_Practices_and_Reporting/links/541750600cf2f48c74a40687.pdf).

<sup>7</sup> [https://www.childtrends.org/publications/black-students-disabilities-out-of-school-suspensions#:~:text=Further%2C%20schools%20suspended%20children%20with,without%20disabilities%20\(4.1%20percent\)](https://www.childtrends.org/publications/black-students-disabilities-out-of-school-suspensions#:~:text=Further%2C%20schools%20suspended%20children%20with,without%20disabilities%20(4.1%20percent).).

school “believes in inclusion.” Consequently, her child was not suspended. There was one parent who noted that her son was suspended in 2015. She stated, “His worker left. He was very close to her and when she didn't show up, he had a meltdown. The decision was reversed because there was no B.I.P. in place.” A BIP is a Behavior Intervention Plan. A Behavior Intervention Plan is a written plan that teaches and rewards good behavior. It can be a single page or many pages. The purpose is to prevent or stop misbehavior, not just punish the child.<sup>8</sup> In the school, the principal plays a major role in the inclusion and sometimes *exclusion* of the ASD student. As a contrast to my Protestant experiences, and those of the parents I interviewed for this research, I offer the Catholic school perspective.

In the 2016 publication of the *Journal of Catholic Education*, an article written about the IDEA and Catholic school education, sheds light on the subject of education and inclusion from a different perspective. In the article, written by Michael J. Boyle & Claudia M. Hernandez, entitled, “An Investigation of the Attitudes of Catholic School Principals towards the Inclusion of Students with Disabilities,” they write, “The public-school principal’s attitude toward students with disabilities has a significant impact on the effective provision of special education services. Several studies have noted that for inclusion to be successful, the public-school administrator must display a positive attitude

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<sup>8</sup> <https://www.understood.org>

and commitment to inclusion.”<sup>9</sup> A 2003 study on public school principals’ attitudes toward the inclusion of students with disabilities determined that “positive experience with students with disabilities and exposure to special education concepts are associated with a more positive attitude toward inclusion.” Studies show that principals who possess more positive attitudes and experiences towards students with disabilities are more likely to place them in “less restrictive environments.” In order to qualify as capable administrators, principals should have a basic knowledge of special education as well as some knowledge of current issues in special education. Boyle and Hernandez acknowledge that the need for professional development on special education topics for principals in the public-school arena has been well established through various documentations and writings. However, they note, there is little actual professional development in special education provided for public school principals. In addition to knowledge of special education, their research reveals that the principal—as the school’s change agent and instructional leader—must possess other competencies, such as, “skills in effective instruction, assessment and discipline to provide support and feedback to teachers as they develop environments for teaching heterogeneous groups of students.”<sup>10</sup>

Students with disabilities enrolled in private schools by their parents are not entitled to a free and appropriate public education under IDEA. The IDEA does not require school districts to serve all children with disabilities enrolled in private schools.

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<sup>9</sup> Michael J. Boyle & Claudia M. Hernandez, “An Investigation of the Attitudes of Catholic School Principals towards the Inclusion of Students with Disabilities,” *Journal of Catholic Education* 20, no. 1 (2016): 190-219.

<sup>10</sup> *Ibid.*, 190.

Instead, school districts are required to spend a proportionate share of their federal funds on students who are enrolled in private schools by their parents. If school districts provide this proportionate share, they meet their obligations under the IDEA, even if all eligible children are not served. Hence, when Jadon was expelled from the private ASD school in Wilson, I had no recourse.

Jadon's aggression issue appeared on his former IEP and was duly noted by the Wilson county school system. Their immediate response was to assign him to "homebound" education, which meant he would only receive instruction daily for sixty to ninety minutes. This was unlike our former county of residence, New Hanover, where the public schools dealt with any issues Jadon may have had, while he spent his entire day at the school. The regulations for IDEA assure children with disabilities and their parents the following basic rights: a Free, Appropriate and Public Education – no cost, suitable for the child, paid for by the public school system, including extracurricular activities; Appropriate Evaluation – evaluators must be trained and knowledgeable; Individualized Education Program (IEP) – a written statement that is developed, revised and revised in accordance with the law; Least Restrictive Environment – maximize the exposure to nondisabled peers; Parent and Student Participation in Decision Making – parent and

student help to design the IEP; and Procedural Safeguards – rights of children and parents are protected.<sup>11</sup>

I realized that the Wilson county school system had not afforded my son the most important of these rights – a free, appropriate and public education. Because, as I stated in one of his IEP meetings, “What can he learn in an hour to an hour and a half per day?” I later learned from a source in a neighboring county that Wilson county has a reputation for restricting kids with ASD and other disabilities to homebound education. I wanted to determine if the ASD children of parents I surveyed had been afforded the rights or at least some of the rights detailed in the IDEA. The parents surveyed for this research had ASD children who were attending or had previously attended public schools. I surveyed parents with ASD children in elementary, middle, high school and some that were no longer in school.

In my opinion, IDEA and inclusion are analogous to one another. If ASD inclusion is practiced in schools, then the ASD student will receive those rights outlined in the IDEA. When the ASD parents surveyed were asked, “Has your child’s ASD ever caused your child(ren) to miss school?” Only one parent answered in the affirmative. Quan stated, “If he [her son] doesn’t feel well his sensory needs can become intense and he needs his favorite sippy cup which he’s not allowed to have in school.” I contend that inclusion could be practiced at the school by allowing an accommodation. The

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<sup>11</sup> <http://www.cpacinc.org/materials-publications/legal-rights/the-individuals-with-disabilities-education-improvement-act-idea-2004/>.

accommodation in this case, being to allow her son to bring his favorite sippy cup. Inclusion in schools is as important as inclusion in churches.

ASD parents surveyed for this research were asked, “Prior to the pandemic, did your ASD child(ren) participate in extracurricular activities at school?” And all except one of them answered, “no.” One parent, JD, a former teacher and strong advocate for her two ASD children, fought to have her ASD son and daughter included in what she calls “neurotypical” activities. JD shared that her ASD son participated in JROTC for four years while attending high school. She further stated, “The structure, the student participation/interaction was based on community and respect. It allowed him to be a part of a group of neurotypicals and function without issues.” This is one successful example of inclusion that should be celebrated. Oftentimes, ASD children avoid extracurricular activities at their schools, and other times those opportunities to be included are not offered at all. Posed with the same question about their ASD children’s participation in extracurricular activities at school, parents Quan and Grelynn both stated that there was nothing available at the schools where their children attended. Shay stated that her ASD daughter simply showed no interest in extracurricular activities.

It seems that there is much work to be done concerning the efforts of inclusion for ASD students in schools. Parents surveyed for this research, when asked, “What services can your ASD child’s(ren’s) school provide that they do not already offer,” had some thought-provoking suggestions. One parent, JD, suggested, “A ‘buddy’ program to help ASD kids with social interaction and friends especially at the high school level.

Neurotypicals could volunteer and get community service for it.” Another parent, Quan, suggested, “Events where our kids can interact and have one on one helpers while the parents have a chance to socialize and share resources or find ways to help each other.” Grelynn suggested, “music lessons like piano, sports like tennis and basketball – the same activities provided by Special Olympics.” Another parent stated, “I would like for the school to hire an autism specialist who understands how to work with children on the spectrum.” Then Shay relented, “not sure, not being very social, she [her daughter] only participates in what she deems “OK” so I don’t know a lot about the activities at the high school level.”

When comparing disability types, Boyle and Hernandez state, “Catholic schools enroll a greater percentage of children diagnosed with high incidence disabilities (such as hearing impairment or deafness, developmental delay, speech/language, uncorrected vision impairment or blindness, traumatic brain injury, and other health impairments) than public schools.” However, they also note that low incidence disability categories such as mental retardation, Autism, and emotional disorders have a “significantly lower representation in Catholic schools than in public schools.”<sup>12</sup>

It appears that the Catholic Church is in the forefront regarding support of children with disabilities in education. Boyle and Hernandez write, “Bishops’ statements at the National Conference of Catholic Bishops (NCCB, 1972, 1998) and the United

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<sup>12</sup> Boyle & Hernandez, 190.

States Catholic Conference (USCC 1978) provide an impetus for Catholic schools to serve children with special needs. For example, the U.S. Bishops released a framework of access and inclusion of students with disabilities in which they asserted: Since the parish is the door to participation in the Christian experience, it is the responsibility of both pastors and laity to assure that those doors are always open. Costs must never be the controlling consideration limiting the welcome offered to those among us with disabilities, since provision of access to religious functions is a pastoral duty. The Bishops clearly support the inclusion of students with disabilities in Catholic schools. However, “the financial realities of providing services for children with special needs in our Catholic schools are a major barrier to building effective programs.”<sup>13</sup> The inclusion of students with disabilities presents a moral dilemma. This appears to be the sentiment of not only the Catholic schools, but the public schools and even those private schools like the one we encountered in Wilson, which are designed specifically for children on the Autism Spectrum.

After two years away, we are back in Wilmington and my son is again attending New Hanover County Public Schools. He is able to see some of his old friends and seems to like his new school. When the year began, we were virtual-learning due to the Corona virus pandemic. Then he was allowed to attend school four days per week, with one day reserved for virtual-learning. He has become bored with his schoolwork because it is too

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<sup>13</sup> Ibid.

remedial. He knows the material that is being covered and refuses to engage. I have expressed my concern to his current teacher. I am however, researching a new school for ASD students that is set to open in Wilmington soon. I am somewhat reluctant after our experience with the ASD school in Wilson. I plan to conduct extensive research prior to any attempt to enroll him. I want my son to succeed academically. Sure, he may not be the next Bill Gates, but I believe he can achieve anything he works hard for. Educators have repeatedly stated that he needs to have his behavior modified before they will focus on academics. Since our return to Wilmington, I have assembled a team that has been proactive in providing his services – a qualified professional (formerly known as a case manager), a care coordinator, his psychologist, speech therapist, occupational therapist, (Autism Society of North Carolina) ASNC parent advocate, a behavior specialist, and an attorney on speed-dial. These professionals have helped to make a difference in my son's life. I believe with the necessary tools in place, we can manage his behaviors and help him to achieve better academic goals.

I recently read about an Autism Initiative at Mercyhurst University which helps students socialize, and secure relevant jobs. With these such programs, I still see the light at the end of the tunnel. My son has expressed a desire to become an airplane pilot. His outbursts in recent years have caused most instructors to focus on his behavior rather than his academic abilities. Therefore, he is behind in all subjects. And although he has quite a bit of catching up to do, I believe with my support, the support of the church, a supportive

school, his new team of professionals and programs such as these, he and other children with ASD can do whatever they desire to do.

If an ASD child is to be given an opportunity to succeed in the educational arena, then some accommodations and modifications should be made to assist them. Here are a few strategies that may be implemented when attempting inclusion of the ASD student in the school setting:

- In mainstream classes, homework assignments should be given in writing to the student and a content outline and notes be provided at the start of class.
- A map of the school outlining where the needed classrooms are, and the student's class schedule can be taped inside the first pages of the student's planner or primary notebook.
- A written list of names of classes, room numbers as well as needed supplies and books, and a list of the teacher's expectations and routines for each class can be helpful.
- Sample models of assignment and a list of test assignments will lessen the [ASD] student's anxiety level.
- A cue card for the teacher or aide to place on the desk when s/he recognizes that the student is entering a meltdown or tantrum cycle. This

will prompt the student to leave class and return to a pre-determined established base for de-escalation.<sup>14</sup>

How does the pastor encourage ASD inclusion in schools or become involved with the ASD student academically? Here is some advice to those who are willing to make an effort:

- Volunteer at a local school. I volunteered at my son's library (elementary and middle school).
- "Adopt" an ASD classroom. Offer to run copies for the teacher or assist in other ways (during this pandemic, this may present a challenge, but still inquire).
- Join the PTA and advocate to have funds allotted for the special needs department. I joined and was elected to the office of PTA treasurer at my son's elementary school and then PTA president at his middle school. In both offices, I fought to have some funding directed to the Exceptional Children's department.
- Volunteer to chaperone an ASD class fieldtrip (post-pandemic, after schools go back to "normal").
- At your local church, start an ASD homework clinic. Surprisingly, most school aged ASD children have no homework. Offer a 30–45-minute daily

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<sup>14</sup> Sicile-Kira, 144-145.

homework clinic which focuses on the basics – reading, writing and arithmetic.

- Remember, you do not have to be an ASD parent to be an ASD child's advocate or to perform any of the above suggestions.

When we (the body of Christ) become involved in schools, and advocate for ASD students, then the inclusion component cannot be ignored. Inclusion of those with ASD, is important not only in churches, and in schools, but also in communities.

## 7. A Social Account of Autism

I opine that socialization is as important in the community as it is in churches and schools. As of this writing, we are in the midst of a pandemic that has gripped the world – the Corona virus, also known as COVID-19. For that reason, it is quite difficult to write about the need for inclusion today. However, I offer suggestions about inclusion for the ASD population before and after the pandemic.

Prior to our move from Wilmington to Wilson (and before the COVID-19 pandemic), I involved my son in several activities. My goal was to expose him to as much as I possibly could and allow him to decide what he liked best. When the community is open to inclusion of the Autism Spectrum Disorder (ASD) population, it can be quite rewarding for all parties involved. It seemed easier in previous years to “drag” him from place to place. However, now that he is a teenager, it is quite difficult. Activities that once excited him do not entice him anymore. Chantal Sicile-Kira states, “For teens with ASDs, the social realm – school, community, place of worship, after-school activities – is particularly difficult.”<sup>1</sup> In his book, “Wondrously Wounded,” Brian Brock writes, “The grief associated with a child’s failure to socialize with others is closely associated with our own *longings to connect or communicate* with our child. The

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<sup>1</sup> Chantal Sicile-Kira, *Adolescents on the Autism Spectrum* (New York: The Berkley Publishing Group, 2006), 145.

reciprocated attention that emotionally buoys parents happens more rarely with an autistic child, and a parent cannot help but long for this contact.”<sup>2</sup>

As a parent of an ASD child, I want my son to communicate with me, but I also want him to “have friends” and to engage others socially. In his book, Brock writes about this desire of ASD parents. Brock states that frustration springs from the high aspirations that parents have for their ASD children to join society, and to have friends. Furthermore, he states, “Difficulties functioning as part of a group, difficulties cooperating with other children and obeying simple instructions all apparently leave the child socially isolated. Unreachable expectations from other parents, teachers, or caregivers who have no idea how to deal with such disruptive and antisocial behaviors compound this frustration.”<sup>3</sup>

In earlier years (and pre-COVID-19), in an effort to assist my son with peer socialization, I exposed Jadon to the various Special Olympics programs offered such as the Saturday morning segment, “I Can Do It!” This was a weekly event held locally at University of North Carolina at Wilmington (UNCW). The ninety-minute program was structured so that attendees could enter, participate in several physical activities, take a nutrition break (complete with a healthy snack), and then end their time together with yoga. The program was staffed with volunteers from the Special Olympics and volunteers from the college who were studying special education. Additionally, Special Olympics

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<sup>2</sup> Brian Brock, *Wondrously Wounded: Theology, Disability and the Body of Christ* (Waco: Baylor University Press, 2019), 177.

<sup>3</sup> *Ibid.*, 176.

offered weekly basketball camp, bocce lessons, bowling nights, and dance parties. All of which, I allowed my son to participate in.

Most of the parents surveyed for the purpose of this research report a plethora of community-based activities available for their ASD children. When asked the question, “Prior to the pandemic, did your ASD child(ren) participate in extracurricular activities in the community,” two-thirds of them answered in the affirmative, and referenced activities like: Miracle league one on one sessions and the Tee ball league, Access of Wilmington (a fitness program), Special Olympics, and Top Soccer. One-third of those parents (residents in rural counties) stated there were no activities available. There are several businesses in cities which will offer ASD specific activities. In Wilmington (New Hanover County), we have found the following:

- A trampoline park (Defy Gravity) that offers a monthly “jump” night for ASD patrons. They pay a reduced rate, the music is either turned off or volume lowered, and they are allowed to jump for one hour. Given the layout of their establishment, Defy Gravity is able to offer their service, even during the pandemic.
- Port City Gymnastics (prior to the pandemic) offered a weekly Friday night class specifically for ASD kids. They had several activities that the kids could perform throughout the gym – the session lasted for one hour.
- Years ago, I had heard about a soccer group, so I signed my son up. When I arrived, the group was comprised of “typical” kids. I spoke with the

owner-coach and asked him to consider starting just one special needs class. He did. When the word reached the special needs parents, he had to add four additional classes. If we solicit the help, most often, we will receive it.

- Prior to the pandemic, two of our local theaters offered first-run movie viewings on designated screens for members of the ASD population. The volume of the movie was lowered to a moderate level and the lights were left up. The ASD participants were able to roam around within that room and make noises without penalty or fear of ejection. This allowed them to view the movie on their own terms and in their own way.
- The annual premier summer event in Wilmington is Surfers Healing. It is a group whose mission is to enrich the lives of people living with autism by exposing them to the unique experience of surfing. Their website states, “Though we serve thousands, that mission exists because of one child. Israel and Danielle Paskowitz founded Surfers Healing because of their son, Isaiah. Isaiah has autism, and when he struggled with meltdowns and sensory overload, riding the waves with his father calmed him like nothing else.”<sup>4</sup>

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<sup>4</sup> Surfers Healing, <https://www.surfershealing.org/>.

- During our short time in Wilson county, I ventured out to surrounding counties to seek activities for my son. We joined a new YMCA in Rocky Mount (Nash county). One of the best I have seen in my lifetime. We joined so that my son could utilize their pool. On one of our visits, I noticed a flyer. The YMCA was offering a weekly Friday evening gathering for ASD kids of all ages.
- Therapeutic riding is an equine-assisted activity for the purpose of contributing positively to the cognitive, physical, emotional and social well-being of individuals with special needs. Therapeutic riding provides benefits in the areas of health, education, sport and recreation & leisure.<sup>5</sup> While we resided in Wilson, I learned of a facility in nearby Greenville (Pitt county), that offered therapeutic riding – Rocking Horse Ranch. Their mission is “to improve each participant's quality of life so that they can become more independent, productive, and active members of our community.”<sup>6</sup> The facility will take a child’s IEP and utilize it to structure a plan for them. The riders were asked to call their horses by name and give them commands like “Walk” or “Whoa.” This forced my son to speak – something that can be challenging at times. Albeit a great service, it may not be classified as a community involvement activity, but

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<sup>5</sup> Path International, <https://www.pathintl.org/>

<sup>6</sup> Rocking Horse Ranch, <https://www.rhrnc.com/our-mission>.

therapeutic riding proved to be a very effective resource for my family and other ASD families.



*Photo 8: September 16, 2019 – Jadon riding “Sass”*

For us to locate facilities in rural counties like Nash county (YMCA) and Pitt county (Rocking Horse Ranch), was nothing short of a miracle. ASD parents living in rural counties find it quite challenging to locate activities in their communities. One parent surveyed for this research, stated, “There are no activities outside of school in our town. The nearest would be Wilmington or Myrtle Beach.” ASD parents in larger cities like Raleigh or Durham, North Carolina find it easier to identify activities in their communities which include those with ASD. An ASD parent surveyed for this research, who resides in Wake county, listed several activities in her community – soccer, basketball, tee ball, and pop warner football – all allowing her ASD children to participate. In cases where those counties lack community inclusion activities or

resources, churches can seek to provide some assistance. One local church in Wilmington (New Hanover county) has a gymnasium – once per month, they open that gym to the ASD population to be utilized for activities like those, aforementioned, which were held at University of North Carolina at Wilmington (UNCW) by the Special Olympics.

If a church is planning to pursue holding ASD related activities or any other ASD-based ministries at their facility, then training and a safe environment are imperative. Furthermore, parental consent and initial involvement are extremely vital. Teenagers (I have used them in years past) are generally a great resource for volunteers in special needs ministry. If the church solicits teenagers (or even adults), training is a top priority. Each of the parents surveyed for this research expressed an interest in involving their ASD children in church alongside those who are *trained* to assist them. Amy Fenton Lee reminds those churches that seek to pursue a special needs ministry, that the ministry is first, a calling. She makes suggestions for an interviewer of potential teenaged volunteers. She offers several questions which may be posed to gauge their sincerity about the calling, and to foster dialogue from the trainees. Questions or statements that may be used are:

- Who is impacted by a church's children's ministry?
- Why is this environment important to help people experience Christ?
- We can be a positive or negative influence on every person we come in contact with in the ministry.

- Serving as a volunteer in a special needs environment isn't for everyone (Romans 12:4-8).
- It's okay to decide that serving in this ministry doesn't match your gifts.
- Role-play scenarios for their potential involvement in the special needs ministry.
  - For example: A child is having a meltdown. What do you do?
- Invite the trainees to guess which scenario is a good/bad reason to serve the ministry.
  - For example:
    1. It would be a great place to hang out with my boy/girlfriend or gossip with my best friend.
    2. I am passionate about helping ASD children and helping them experience Jesus' love.<sup>7</sup>

Once volunteers have been trained, Lee offers some practical information for the church to consider:

- **Treat the special needs volunteer role as a job.** Create a job description detailing the expectations of the "job."<sup>8</sup>
- **Safety.** Perception is reality. We do things to be safe and to appear safe. No grabbing or jerking a child who is misbehaving. No horseplay or piggyback rides.

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<sup>7</sup> Amy Fenton Lee, *Leading a Special Needs Ministry* (Nashville: B&H Publishing, 2016), 188.

<sup>8</sup> *Ibid.*, 189.

Only teens over the age of fifteen can pick up children ages three and under. Teens should never be alone with a child except when transitioning in public areas, in plain view. Don't encourage children to sit on your lap – especially male helpers!

- **Toileting and Diapering.** No toileting or diapering by any teens of any participants with special needs.
- **Handling Misbehaving Children.** Role-play or act out one or two common scenarios displaying misbehavior and determine how the helpers should handle it.
- **Do's and Don'ts.** Don't use cell phone while volunteering. Don't take pictures, don't text pictures of the kids, Don't post pictures to social media platforms. Do sign and abide by the church's privacy policy (this should be developed by the ministry director and signed by the parents/guardians also). Don't carry children (see "safety" above). Don't make any physical changes to the room where participants meet without permission from the ministry's director. Do wear a church issued nametag for easy identification. Do protect the privacy of the ASD child and family.
- **Check-in and Checkout.** Don't allow parents or guardians to leave children with you or retrieve them from you without going through proper procedures (these should be established by the ministry director and/or ministry team).
- **Allergies and Medical Issues.** Briefly discuss recognizing and responding to a seizure. Do not administer medication to a child without express written

permission from the parent or guardian. Review emergency response procedure (these should be developed by the ministry director and/or ministry team).

- **Transitions and Taking Children Outside of Facility.** Transitions need to be carefully orchestrated so that each child is visually followed between settings. Make sure all children are identified with an adhesive name tag in case they are lost during the transition.
- **Visitors.** Do not allow parent visitors or other visitors in the room without the lead volunteer's/teacher's approval.
- **Confidentiality.** Only discuss the following with relevant ministry leaders and only on a "need to know" basis: behavior issues, medical issues or special needs diagnoses, and problems in a child's home.
- **Abuse Prevention and Reporting.** Review the signs of abuse, the legal requirements for what to do when those signs are recognized, and who to tell or not to tell.
- **Impact Story or Video.** Be sure to end the training on a positive and inspiring note. Feature a teen volunteer's story talking about the benefits of their service to the ministry. If you don't have any yet, feature an ASD parent who can express the importance of the ministry to them and their family. Through the story or shared vision, answer the questions: Why is it important to serve? How did this

experience shape my life? How can my contribution bring meaning to the lives of the individuals or families I'm serving?<sup>9</sup>

As many ASD parents have expressed, there is a need for properly trained volunteers to work with their children. The lack of trained individuals, or those who are willing to be trained, may point to the lack of available resources in some communities.

One way to involve ASD children in the community is to expose them to their recreational and potential vocational interests. Author Chantal Sicile-Kira suggests, "If your [ASD] teen is into trains or air conditioners, find a person who works in that field who would be willing to help your child realize the different applications of his [or her] interest." She furthered suggests utilizing retired people in the community to serve as mentors. She states developing a relationship with a mentor will improve the ASD child's social skills.<sup>10</sup>

Although there is an existing challenge to find available community resources and activities, some parents are equally met with challenges for available services. Parents surveyed for this research, when posed the question, "Prior to the pandemic, what services was your ASD child(ren) receiving in the community?" Thirty-three percent of the parents cited therapies (speech therapy, occupational therapy, Applied Behavior Analysis therapy and at times physical therapy) as services available for their ASD children. One quarter of the parents polled stated that their ASD children were involved

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<sup>9</sup> Ibid., 190-193.

<sup>10</sup> Sicile-Kira, 136.

in skills development services. The remaining forty-two percent of them stated that their ASD children did not receive any services. Services such as applied behavior analysis, speech, and occupational therapies are offered to those with ASD to help them function in the world. Therapies can be beneficial to the ASD recipient as they may lead to more socialization. Here are just a few that I found to be of common use:

- **Speech Therapy** – is the assessment and treatment of communication problems and speech disorders. It is performed by speech-language pathologists (SLPs), which are often referred to as speech therapists. Speech therapy techniques are used to improve communication. These include articulation therapy, language intervention activities, and others depending on the type of speech or language disorder.<sup>11</sup> Although it has been beneficial to my son, I found it can be challenging to convince someone who does not wish to speak, that they should attend a session which forces them to do otherwise. His speech therapist has begun teaching him some sign language and has ordered a speech assistive device for him to utilize.
- **Occupational Therapy (OT)** – is a branch of health care that helps people of all ages who have physical, sensory, or cognitive problems. OT can help them regain independence in all areas of their lives. Occupational

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<sup>11</sup> Healthline, <https://www.healthline.com/health/speech-therapy>.

therapists help with barriers that affect a person's emotional, social, and physical needs.<sup>12</sup>

- **Applied Behavior Analysis Therapy (ABA)** – is a type of therapy that can improve social, communication, and learning skills through positive reinforcement. Many experts consider ABA to be the gold-standard treatment for children with autism spectrum disorder (ASD) or other developmental conditions.<sup>13</sup>
- **Physical Therapy** – is a branch of rehabilitative health that uses specially designed exercises and equipment to help patients regain or improve their physical abilities.<sup>14</sup> Physical therapy includes activities and exercises that build motor skills and improve strength, posture, and balance. For example, this type of therapy aims to help a child build muscle control and strength so that he or she can play more easily with other children. Problems with movement are common in autism spectrum disorder (ASD), and many children with autism receive physical therapy. However, there is not yet solid evidence that particular therapies can improve movement skills in those with autism.<sup>15</sup>

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<sup>12</sup> KidsHealth, <https://kidshealth.org/en/parents/occupational-therapy.html>.

<sup>13</sup> Healthline, <https://www.healthline.com/health/aba-therapy#how-it-works>.

<sup>14</sup> MedicineNet, [https://www.medicinenet.com/physical\\_therapy/definition.htm](https://www.medicinenet.com/physical_therapy/definition.htm).

<sup>15</sup> US Department of Health and Human Services, <https://www.nichd.nih.gov/health/>.

These are just a few techniques which may be utilized to assist those with ASD and foster socialization, which ultimately leads to inclusion in many aspects of the ASD person's life.

Another avenue for improving social skills for those with ASD, is the addition of a service animal. Service animals have been utilized to assist those with ASD. One resource (there are many) for service animals is Little Angels Service Dogs. Little Angels provides service dogs for ASD, seizure alert and mobility assistance. Their website states that, "Autism Assistance Dogs are not only a living miracle to the affected child, but also to the entire family. These special dogs are trained to assist the child, and the parents of the child, in a variety of ways."<sup>16</sup> There are agencies that will provide the service dogs at no cost, the applicant is simply asked to raise funds through donations for the purchase and training of the dog. However, not all families are positioned to afford or procure a service dog. In these cases, a family pet would be a good substitute. An ASD parent and family friend purchased a dog for her home several years ago. Her ASD son is responsible for caring for the dog and it has helped with his social, and verbal skills.

The service dog or even a family pet, much like the horse in equine therapy, helps the ASD person with socialization leading to effective communication skills. Additionally, it provides them with some level of responsibility as they care for the animal. In Jadon's case, whenever there was a rainy day, he was not able to ride his

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<sup>16</sup> Little Angels Service Dogs, <https://www.littleangels servicedogs.org/autism-assistance/>.

assigned horse, therefore his task was to groom the animal. It taught him to provide a service for the animal that provided him a service.



*Photo 9: November 15, 2018 – Jadon grooming Elliot at Rocking Horse Ranch*

As I learned of other methods and activities to expose my son to socially, I involved him in them. I read that Tae Kwon Do is a practice of discipline which has been helpful for those with ASD. I enrolled him in lessons, and he excelled fairly quickly. Additionally, he loves water and since we live in a beach town, I thought it was important for him to learn to swim. He started swimming lessons at age two and has become quite comfortable around bodies of water. Both the Tae Kwon Do and swimming are activities which cause utilization of his gross motor skills. Furthermore, they are activities which contribute to the ASD child’s “sensory diet.” A sensory diet is a treatment that can help kids with sensory processing issues. It includes a series of physical activities your child

can do at home. It has nothing to do with food. An occupational therapist can design a sensory diet routine tailored to meet your child's needs.<sup>17</sup>

Most communities have professionals who can assist with ASD socialization. For example, a qualified professional (formerly known as case manager), care coordinator, nutritionist, psychologist, etc. Their roles are varied, but together as a team, they can help to progress the person with ASD:

- **Role of the Qualified Professional** – According to Rachel, a qualified professional at a local intellectual and developmental disabilities (IDD) behavioral health provider in Wilmington, the qualified professional is the staff supervisor of those who work one-on-one with the person who receives ASD services.
- **Role of the Care Coordinator** – Care coordinators educate ASD members and families on home and community-based services available in their local area by providing access to behavioral health services, social work services, Meals on Wheels®, exercise programs and other resources.<sup>18</sup>
- **Nutrition Specialist** – It is important that parents and caregivers work with a nutrition specialist—such as a registered dietitian—or health care provider to design a meal plan for a person with autism, who is often

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<sup>17</sup> <https://www.understood.org/>.

<sup>18</sup> Cleveland Clinic, <https://consultqd.clevelandclinic.org/care-coordinators-help-high-risk-patients/>.

unwilling to try new foods. Typically, the ASD client is only willing to eat a limited diet. Such providers can help to make sure the child is still getting all the nutrients he or she needs to grow into a healthy adult. Many children with ASD are on gluten-free or casein-free diets. (**Gluten** and **casein** are types of proteins found in wheat and milk products, respectively.) Available research data do not support the use of a casein-free diet, a gluten-free diet, or a combined gluten-free, casein-free diet as a primary treatment for individuals with ASD.<sup>19</sup>

Several activities mentioned above were available prior to the recent COVID-19 pandemic. When the “lockdown” occurred, activities ceased, and homebound creativity became the order of the day. In “The Out of Sync Child Has Fun,” Carol Stock Kranowitz provides several activities for the ASD kid with Sensory Processing Disorder (SPD) to “feed” their sensory diet. During the pandemic, this book was my “bible” as I sought activities to engage my son while we were in isolation.

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<sup>19</sup> US Department of Health and Human Services, <https://www.nichd.nih.gov/health/>.

## 8. A Journal Account of Autism

The year 2020 will remain in our memory for many years. The recent pandemic has challenged us to develop new and various means of engaging our Autism Spectrum Disorder (ASD) children while confined to our homes.

In March of 2020, the country was stricken with a deadly virus known as the Corona virus (aka COVID-19). Living with Autism during a pandemic has not been easy. It is quite a difficult task. I decided to formulate a schedule for my son to keep him active during the day. I incorporated some games and activities provided by Carol Stock Kranowitz in her book, “The Out-of-Sync Child Has Fun.” Here is a sample of one of those schedules:

### *Jadon’s Monday Schedule*

\_\_\_\_\_ *Prayer*

\_\_\_\_\_ *Brush your teeth and wash your face*

\_\_\_\_\_ *Get dressed*

\_\_\_\_\_ *Yoga (photo 10)*

\_\_\_\_\_ *Eat breakfast*

\_\_\_\_\_ *Today I feel \_\_\_\_\_*

\_\_\_\_\_ *Do indoor chores*

\_\_\_\_\_ *vacuum*

\_\_\_\_\_ *clean my room*

\_\_\_\_\_ *Sort books*

\_\_\_\_\_ *Read books with Mommy*

\_\_\_\_\_ *Dictionary words with Mommy*

\_\_\_\_\_ *JUMP – STOP – JUMP*

\_\_\_\_\_ *Do math*

\_\_\_\_\_ *Hold Up the Wall\**

\_\_\_\_\_ *Puzzle*

\_\_\_\_\_ *Eat lunch*

\_\_\_\_\_ *Paper Bag Kick Ball\**

\_\_\_\_\_ *Computer time*

\_\_\_\_\_ *Tablet time*

\_\_\_\_\_ *YMCA Swimming Pool*

\_\_\_\_\_ *Bubble bath*

\_\_\_\_\_ *Jammies on*

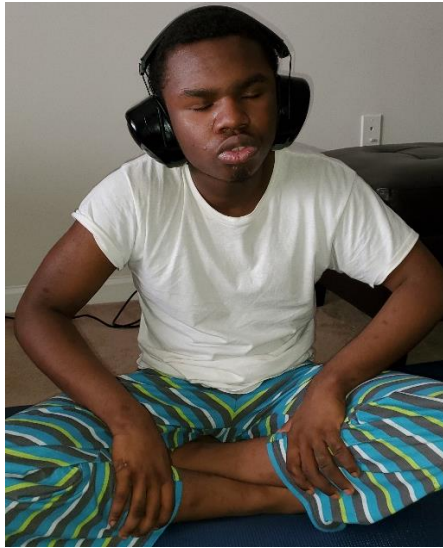
\_\_\_\_\_ *Eat dinner*

\_\_\_\_\_ *Tablet time*

\_\_\_\_\_ *Goodnight Yoga*

\_\_\_\_\_ *Sleep Jazz*

\_\_\_\_\_ *Sleep*



*Photo 10: April 14, 2020 – Jadon practicing yoga*

Hold up the wall, Flashlight tag and Citrus balls may all sound like simple games, however, they are not. They each have a significance to the ASD child with Sensory Processing Disorder (SPD).

- **Hold Up the Wall** – is as simple as it sounds. What the child does:
  - Presses his or her hands against the wall with all their strength, for about fifteen counts or more.
  - Then they press other body parts against the wall:
    - Head and back
    - Hips and shoulders – one at a time
    - Buttocks – together or separately
    - Feet – together while lying on the floor
  - Benefits:

- Deep joint pressure nourishes the proprioceptive<sup>1</sup> system and has a calming effect.
  - Pressing different body parts strengthens body awareness.
  - The preposterous premise of this activity gives kids the giggles, diffuses tension, and helps them feel in sync with their friends.<sup>2</sup>
- **Paper Bag Kick Ball** – another simple, yet effective game.
  - Preparation:
    - Open up the paper bag. To make it ball-like, you can scrunch the opening closed.
    - Option: Remove shoes and socks.
  - What your child can do:
    - Kick the bag up into the air, then kick it again repeatedly.
    - Make a start line, stand beside other kids, and have a kicking competition to see whose bag goes the farthest.
    - Kick the bag back and forth with a partner.
  - Benefits of the activity:

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<sup>1</sup> The proprioceptive system is located in our muscles and joints. It provides us with a sense of body awareness and detects/controls force and pressure. The proprioceptive system also has an important regulatory role in sensory processing as proprioceptive input can assist in controlling responses to sensory stimuli. Proprioceptive input can be very calming for those who are easily overwhelmed by sensory stimulation. Proprioceptive input can be alerting for those who need increased sensory stimulation to facilitate attention and learning. <https://sensory-processing.middletonautism.com/>

<sup>2</sup> Carol Stock Kranowitz, *The Out-of-Sync Child Has Fun* (New York: Penguin, 2003), 122.

- Flexing and extending his leg and foot promotes proprioception (perception or awareness of the position and movement of the body) and kinesthesia (awareness of the position and movement of the parts of the body by means of sensory organs or proprioceptors in the muscles and joints).
- Connecting with the bag provides deep pressure to muscles and joints.
- Running and kicking improve balance, gross motor skills, bilateral coordination, crossing the midline, grading of movement, and motor planning.
- Aiming and kicking improve eye-foot coordination and visual-spatial discrimination.
- Finding a safe and appropriate way to channel his energy strengthens emotional development.
- Playing this game with others builds social skills.
- Being barefoot adds a tactile component (of or connected with the sense of touch) to this multisensory game.<sup>3</sup>

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<sup>3</sup> Ibid., 99.

In addition to the games, I added some household chores and even swimming. Just as the games serve a purpose with the ASD child, so do these activities.

Some activities classified as heavy work are great for the ASD child with SPD. Heavy work is any type of activity that pushes or pulls against the body. It could be something like swimming or vacuuming. With those activities, the resistance of the water or the vacuum cleaner creates the push or pull. Or it could be something like jumping on a trampoline or hanging on playground equipment. In those cases, a child's own weight creates that resistance. Kids with sensory processing issues often seek (or avoid) sensory input. A child who seeks input is looking for proprioceptive<sup>4</sup> input. That's because it can help calm her body and make her feel more oriented in space. Without heavy work activities, she may seek input by crashing into or jumping off things or in other unsafe ways. Heavy work is designed to provide that input in safer, more consistent ways.

When kids do heavy work throughout the day, it can help them feel more organized before they need to seek input. The most effective heavy work activities activate as many muscles and joints as possible at the same time, and for a short period of time. That means not all heavy work is equal. Some activities—like swimming—are

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<sup>4</sup> The proprioceptive system is located in our muscles and joints. It provides us with a sense of body awareness and detects/controls force and pressure. The proprioceptive system also has an important regulatory role in sensory processing as proprioceptive input can assist in controlling responses to sensory stimuli. Proprioceptive input can be very calming for those who are easily overwhelmed by sensory stimulation. Proprioceptive input can be alerting for those who need increased sensory stimulation to facilitate attention and learning. <https://sensory-processing.middletonautism.com/>

more effective and powerful than others. Here are some activities that use movement and resistance to provide sensory input:

### **Household Chores**

- Taking out the trash
- Pushing a vacuum cleaner
- Mopping or sweeping
- Carrying a full laundry basket
- Carrying groceries
- Cooking (such as stirring or kneading bread dough)
- Moving chairs/furniture or rearranging books on shelves
- Shoveling snow or raking leaves
- Pushing the shopping cart in a store

### **Outdoor Play**

- Riding a tricycle or bicycle
- Playing catch (perhaps with a weighted ball)
- Swinging on monkey bars
- Climbing on the playground
- Jumping rope or on a trampoline
- Playing hopscotch
- Wheelbarrow walking (walking on his hands while you hold his feet)
- Swimming

## Inside Play

- Playing Twister
- Squishing play-dough
- Blowing bubbles
- Wrestling (only if your child won't get **overexcited!**)
- Marching or running in place
- Doing push-ups (either on the floor or against the wall)<sup>5</sup>

Clearly, this new schedule was a drastic change from my child's typical day – due to the pandemic. With the change came challenges. Dr. Temple Grandin and Dr. Debra Moore state, “The autistic brain is usually very sensitive to change and novelty. Routines, rituals, and sameness are the preferred status quo. Even introducing what to you seems to be a minor change can trigger major resistance or meltdowns.”<sup>6</sup>

My son had several meltdowns while we were confined to our home. Living with ASD during the pandemic has been tough. Here are some journal entries that I kept over the last few months:

**6/26/20**

*I took a test to determine if I was positive for the Corona virus. In case my test was positive, I took the precaution of having my son leave to stay with his dad and paternal grandmother.*

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<sup>5</sup> <https://www.understood.org/>.

<sup>6</sup> Temple Grandin and Debra Moore, *The Loving Push* (Arlington: Future Horizons, 2015), 60.

7/2/20

*I was told that I was positive. I was instructed to remain at home alone quarantined and isolated. I was alone for one month and one week while Jadon remained with his dad and grandmother.*

9/24/20

*Upon his request, Jadon and I flew to Atlanta to visit my family. While there, I was able to assist with doing some things to my mom's home (she passed last August). After having been shut-in due to COVID-19, Jadon was excited to be on an airplane again. When I arrived at the rental car counter, my car was not available. We took an Uber to my mom's. When I arrived at her house, my brother inquired about my vehicle. I told him what happened, and he agreed to take us back to the airport. On the way to the airport, my brother, who is a smoker, has a cough – one of Jadon's triggers. As we rode, he would warn Jadon before he coughed and that seemed fine. He was also talking to me – another trigger; and playing his radio – another trigger, all of which Jadon cannot control. Jadon and I went inside. While I stood in line, my brother texted that he was still there waiting to ensure that we had the car. They still did not have my car situation resolved. My brother offered to take us back to my mom's. As we were walking, Jadon whispered, "No uncle Carl's car." My brother insisted. I stated that we could take an Uber. He insisted on taking us back saying, "That's a waste of money." At that point, he attempted to physically put Jadon in the car. He resisted. I repeated that I could call an Uber and avoid this. But my brother continued. Eventually, the two of them were in a*

*full-on altercation. My brother had to pin him to the ground and I called 911. The EMS and police arrived, and I told them to sedate my son. They did and we took him back to my mom's house. He was calm and slept the rest of the evening.*

**9/25/20**

*Jadon and I were driving around town in Douglasville, GA. While I was driving, he asked to go to a store. I couldn't understand the name of the store, so I drove in the direction he was pointing. When I stopped, he got angry and had another meltdown. I again called 911. They came and EMS talked with him while he was inside the car. When he calmed down, they left. We stayed in Georgia until 9/28/20 and we were fine after that incident.*

**10/5/20**

*Jadon woke up asking to go to the beach hotel. I called his dad, because he was refusing to go to school. His dad suggested that I go on and take him to the beach. So, he gave me the funds for the room. I took him to Shell Island Resort, and we spent the night.*

**10/8/20**

*I spoke with his doctor at the Duke Autism clinic and he suggested a change in Jadon's medication. I made the change, but he was still anxious and insistent on not remaining at home.*

**10/13/20**

*I helped create a list for Jadon which showed him upcoming events for the remainder of the year:*

- *October is Halloween*

- *October 13th – Tee Tee’s birthday (my baby sister in GA)*
- *October 21st – DVDs*
- *October 31st – Go to Tee Tee’s new house (his choice)*
- *November is Thanksgiving*
- *Fun with friends and family*
- *Springhill Suites hotel (his suggestion)*
- *Hilton hotel (his suggestion)*
- *December is Christmas (the following are all from Jadon):*
  - *“Grammy’s house for Christmas list with Mommy. Big Christmas tree”*
  - *“Grandma’s house for Christmas list with Mommy.”*
  - *“YaYa and YehYeh’s house for Christmas list with Mommy.”*

*He showed me his list, read it, then insisted that we go to Springhill Suites hotel. Referring to the above schedule, during the first week of October, he wanted me to make October become November. He thought my simply turning the calendar to change the month would cause November to appear...I wish I had that kind of power. He reviews the days of the week, months of the year and the date in his class during morning meeting each day. I thought he was comprehending the concept, but he is not. He got angry when I told him the truth – that it was not November yet. He followed me around all day, repeating “Springhill Suites hotel?” We have stayed in the Springhill Suites in Lumberton before. When I was pastoring in Whiteville, we would occasionally stay at that Springhill Suites because they have an indoor pool, which Jadon likes. It was late,*

*probably about 8:00PM. I packed and decided that we would not go to Lumberton. I drove to the Springhill Suites in town at Mayfaire. When I stopped the car, he said, "Want Springhill Suites hotel – THAT WAY," and pointed in the direction of Lumberton. I just wanted peace and NO MELTDOWNS, so I tried to reason with him, explaining to him that it was late, and we could do it the next day. But he persisted, so I drove to Lumberton. We arrived at about 12:04AM. We stayed there for approximately twelve hours and returned home. When I walked in and put our things down, he looked at me and said, "Hilton Hotel?" I convinced him to wait until the following day.*

**10/14/20**

*Jadon insisted on a stay at the Hilton Hotel back in Lumberton again. I called Lumberton and they were booked. So, I booked a room at the Embassy Suites hotel in Wilmington on the riverfront. We went and we stayed for one night only to return home and have him inquire about going to my sister's house again in Georgia – six hours away! I forget how I talked him down. While he was sleeping, I removed all the calendars from the walls of the house.*

**10/15/20**

*At about 7:00PM each evening, I noticed that Jadon was trying to fight sleep. Then he would ask me, "First sleep...then?" So, I typically write a schedule to reflect the next day's activities. His anxiety is EXTREMELY high at bedtime. He could be lying down in the bed, think about the schedule for the next day, then POP up from the bed repeating the schedule over and over and over and over again...on this night, he was lying in his*

*bed, then decided at approximately 11:30PM, that he wanted to get another DVD player, because the current one was not working. He was insistent on going. Changed his clothes and headed for my car. I wrote a note for him that said, "Walmart is closed..." and before I could write another sentence, he took the paper and made a sound of disapproval. I said, "Okay, I'll take you down there, but they are closed, Jadon. They are asleep. You need to go to sleep too." We drove to Walmart; he ran to the door and it would not open. I walked over to him and showed him the sign on the door. Then asked, "Ready for home now?" He said, "Yes." As we were driving towards the house, he began throwing objects at me from the backseat and kicking the back of my seat and the middle section of my car. I drove him straight to the hospital and told the police officers standing outside, "I have a 15-year-old son with Autism. He's having a meltdown in my car. Please do not shoot my son. I just need him admitted to the hospital." He was calm as soon as we drove up to the hospital, but they were going to take him for me in case he started again. The officers and several nurses came over to get him out. He refused. The doctor sent word that she would not come to the vehicle, we would need to go to the 24-hour magistrate for an IVC (Involuntary Commitment) order. I approached the car and asked Jadon, "Ready for home now?" He said, "Yes." We arrived home at about 2:00AM and he went to sleep.*

**10/16/20**

*Day 1 of our virtual annual conference. I am secretary, so I had asked several people to take him for those two days, because I knew Jadon would get restless with me on the*

computer all day long. I had no one to accept. Towards the end of the day's session, about 2:00PM, he came over to my computer, with the look in his eyes that he has prior to a meltdown. I sent a text message to several people (including his dad) with my home address, for them to call 911 in case he began attacking. So, his dad decided to come over and monitor him while I finished the minutes of the conference. He eventually took Jadon to Walmart. Not long after they left, I received a call from his dad that Jadon had had a meltdown at Walmart. He asked me to come, so I did. When I arrived, Jadon was in the EMS truck laughing and talking with two of the EMS team members. While they had him entertained and with his father keeping his distance, I called Jadon's case manager. She stated that she would work on getting more staff support for him. We went home and everything was fine...until later that evening close to bedtime again. He had another meltdown, but I cannot recall the antecedent. I called 911 and they took him to the hospital. Upon his arrival, he repeatedly said, "No hospital." I signed the IVC papers for him. Then we stayed overnight in the Behavioral Health unit. Jadon did not sleep AT ALL that night. Neither did I because he was up. The following morning, Rebecca in the unit tried to find a facility where he could be admitted, and his meds could be evaluated. She said they could not find a site to accept him due to his IQ. She released him to go home.

### **10/20/20**

I had written Jadon's schedule for the evening, which included, "Mommy talks to computer." Well, at about 7:35PM, as I was having a ZOOM meeting with a couple from my church, Jadon threw a television remote control in my office space. I immediately

*gave my address to the couple and told them to call 911. By the time the paramedics arrived, Jadon was in a hyper state. The EMS team had to sedate Jadon, then they took him to the hospital. We stayed one night, and he was released.*

**10/22/20**

*Jadon has two new staff workers – a male and a female. The male was over here tonight, but I asked his dad to come during the time he was here, because I wanted Jadon to know this is not a new boyfriend for mommy. Well, he escorted the guy out and left his dad in place. Later that evening, when we were alone, at bedtime, Jadon asked about getting on a Frontier airplane and going to a hotel. I explained that we did not have airplane tickets or plans to go, but we could go to a hotel. He laid down, and I told him to do some deep breathing with me, because he looked really tense. Eventually, he said or did something which prompted me to ask if he wanted to go to the hospital. At that point, he lost it and scratched my hand, kicked me once and grabbed my clothing (this was mild compared to other attacks). I called 911 and they deescalated the situation. After they left, he persisted about a trip on the plane and to the hotel. I pleaded with him to sleep first, then I would take him; even the paramedics did that when they were here. He said, repeatedly, “No sleep.” So, I said, “Well, mommy sleep.” His response, “No mommy sleep.” We packed and I got in my car at approximately 2:00AM. My intent was to drive him straight to UNC Chapel Hill Behavioral Health Emergency Department and tell them to help with his issues. I was SO TIRED from no sleep, that I was falling asleep behind the wheel, so I stopped at a Hampton Inn in Wilson. I walked into the lobby and called UNC hospital.*

*They said I could bring him, but then I thought I may need a doctor's referral. I was about to go in and get a room. I walked to the car and my son said, "No hotel. Want home." This is what I've been dealing with. I think he needs some serious help. I said "Jadon, come with mommy. We will sleep here and then leave." His response, "No." So, I drove back to Wilmington, and we arrived at about 6:23AM. When we walked in he protested being home and wanted to leave. I told him I was tired and needed sleep. I told him that he needed sleep too. He decided that he was going to sit in my car. I went out to put some things in it, and he has fallen asleep in my car.*

After discussing the above occurrences with my son's case manager (qualified professional), we concluded that Jadon was like everyone else during the pandemic lockdown. He was anxious to get out of the house. The plane trip in September sent a signal to his brain that the virus was over, and things were back to normal. So, he wanted to be anywhere but home at that point.

**10/30/20**

*I just needed a break. I went out of town intending to stay for two nights. One of Jadon's caregivers, Kate, had agreed to spend tonight with Jadon. Later in the evening, I received a call from her. She said he was asking for "fourteen lines." I told her he was asking for "Frontier Airlines." He had been told that I was out of town, so he had determined that we would be traveling on a plane when I returned.*

**10/31/20**

*Tonight, his dad agreed to spend the night with him. I was out to dinner with a friend when I received a call from Jadon's dad that he was having a meltdown. He asked, "What do you want me to do?" I asked what he was doing. His reply was "he's tearing up the house." I asked where he was. He replied, "I left him inside and I'm outside. What do you want me to do?" I said, "Call 911." He called back and asked me to call them. So, I complied. The police arrived, along with the EMS team. His dad (who was still on the phone with me) asked what he should do. I told him to allow him to be admitted to the hospital if his behavior was still erratic. But he would have to accompany him because he is a minor. He then informed me that Jadon was okay. I returned home the following day to find property destruction in the home where we reside.*

During the month of October, we made two trips to the emergency room within a seven-day period. I was at my breaking point. I called my son's qualified professional (formerly known as case manager) and asked her where I could take him because I had had it! I was at a low point, I felt I had no help, and he was out of control and dominating me. I wondered where I had gone wrong. I wondered if I even had anything to offer other ASD parents, given my situation at that time. I felt like I was about to have a nervous breakdown. I prayed, "Lord, You said You wouldn't put more on me than I could bear. I cannot bear anymore." Then November arrived. Like a breath of fresh air. Here is my sole journal entry for the month:

**11/10/20**

7:11AM – I’m sitting at my computer working on my thesis when I hear the sound of birds – I wonder, “When was the last time I heard birds in the morning?” I realize those birds represent the dawn of a new day. And I am encouraged, after all we’ve been through, that God has sent a gentle reminder that better days are coming! I spoke with my friend and fellow ASD mom, Grelynn on last night and she has been experiencing similar struggles with her son during the pandemic. She provided me with some additional resources and activities that I can involve Jadon in like: Fishing with Special Friends, Access Fitness, Beach Bowl Bowling Alley, Jungle Rapids (a water park), and Victory Junction. I felt empowered and more determined than ever. She also said that she has someone with her son from 6:00AM through the evening, or else she cannot get her work done. I was so glad to hear that because I have been struggling with getting my work done while trying to appease Jadon’s whims. I’m so thankful that she and I had that conversation! It helped me immensely. Then following our conversation, I sat down with Jadon’s two staff workers (he has services provided for him through Trillium) to determine their available days and times. I plan to have the maximum hours Jadon is allowed to have per day through his Innovations waiver from Trillium. Prayers are being answered. Also, I’m putting his reward points system in the hands of his teacher, so she can monitor that – that keeps me from having to fight with him so much. I’m so grateful to God for all that He’s doing!! It seems we have a TEAM in place now for Jadon and that is most helpful! With the staff workers, occupational therapist, speech therapist, teacher, qualified professional, and care coordinator all on board, it seems like we can

*finally turn things around or at least begin to. We are also utilizing Integrated Family Services' crisis team, to assist with acquiring Applied Behavior Analysis (ABA) therapy. To God be the glory!*

As of this writing, Jadon has been receiving ABA for two weeks. He has three staff workers who assist with him around the clock for seven days per week. He is at this moment with his dad, because one of his staff workers tested positive for COVID-19. Jadon's two tests were both negative. I tested positive, for a second time in six months. So, I am utilizing this second, less intrusive bout with the virus, and quarantine, to finish this writing.

As of this writing, there is still a need for inclusion of the ASD population in churches, schools, and communities. This population was immensely affected when the pandemic hit. For a group of people who thrive on schedules and routines, this has presented a challenge. The closure of churches has forced congregations to become creative in worship settings. For the ASD child who faces challenges in church settings, going virtual for worship services could prove useful.

In *The Social Media Gospel*, Meredith Gould offers suggestions for the church to include special populations by utilizing social media.<sup>7</sup> Her suggestions for livestreaming and podcasting would be of benefit to the ASD population. Even after the pandemic, if a parent has an ASD child or if an ASD adult is not having a great day, then livestreaming

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<sup>7</sup> Meredith Gould, *The Social Media Gospel* (Collegeville: Liturgical Press, 2015), 62.

the worship service on that Sunday may be their best option – they can attempt to attend again the following Sunday. The same holds true for podcasting – an option that can be utilized to build a virtual Bible study class for those who find it difficult to attend physically. These practices would foster inclusion in church in a different perspective.

Due to the pandemic, schools have been reduced to virtual learning (ZOOM sessions), part-time classroom instruction, or a combination of both. Several parents in my support group have lamented that their ASD kids are “all ZOOM’ed out!” Now that some of them (my son included) are not with their peers at school, they are craving the socialization that is atypical of their personalities. When schools resume their normalcy, there will still be a need for ASD inclusion focus. More involvement by ASD parents or advocates will help to ensure that inclusion takes place.

Most community-based activities have ceased due to the pandemic. The movie theaters, gymnasiums, and other venues which once offered an outlet for the ASD children, have been either permanently closed or temporarily pad-locked. Therefore, it is incumbent upon the ASD parent to ensure that some activity is performed by their children. And then insist that the inclusion come to the forefront after the pandemic.

As a pastor-parent, I will continue to take my message of ASD inclusion to churches, remain an advocate for inclusion in schools and when it is prudent, do the same for inclusion in the community for my child and others on the spectrum, while encouraging other ASD parents/advocates to do the same.

Our days have not been perfect. Jadon continues to have meltdowns, but they have decreased. I track them and they have been once per month since December 2020. I am grateful for the little things. I say this frequently, “Autism parenting is not for the weak.” I do not mean that in a derogatory manner. I am simply saying that I am stronger as a consequence of parenting a child with this condition. My only hope is that the words I have written will inspire some other ASD parent who is living with the same experiences, while encouraging inclusion of the Autism population in churches, schools, and communities.

The suggestions and stories provided throughout this project may be utilized for these entities as they attempt to provide inclusion of a population that is often marginalized and excluded. This research reveals that most of these exclusions occur due to a lack of understanding the ASD population and a lack of properly trained personnel to assist them. I contend that where these entities are not willing to foster inclusion, or are lacking in the necessary training, then the church should become involved to assist. In other words, the church must do what the church has always done – stand up and help those who cannot help themselves.

## Appendix A – Review of Literature

Audrey Pollnow provides insight on the history of Autism, in her article, “Aristotle on the Spectrum,” writing that “Autism was first described in a public lecture in Vienna, given by the Austrian child psychologist, Hans Asperger, in October 1938. Hoping to protect the children in his clinic, Asperger presented Autism not as a disorder, but as an unusual personality with accompanying superpowers.”<sup>8</sup> To this end, his lecture focused on his high-functioning patients. In a 1943 paper entitled, *Autistic Disturbances of Affective Contact*, written by Leo Kanner, he details his Autism findings – the initial description of ‘infantile autism’ which went on to become a classic in the field of clinical psychiatry. Kanner described children as having a distinct syndrome, instead of previous depictions of such children as feeble-minded, retarded, moronic, idiotic or schizoid. In the words of his contemporary Erwin Schrödinger, Kanner “thought what nobody has yet thought, about that which everybody sees.”<sup>9</sup> In 1944, Asperger added his research to the field of Autism and provided the first description of the disorder (which he called “autistic psychopathy”). Asperger syndrome is named for him. “Individuals with Asperger syndrome share the social deficits, restricted and repetitive behaviors and

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<sup>8</sup> Audrey Pollnow, “Aristotle on the Spectrum,” *First Things*, March 2017, 59-61.

<sup>9</sup> Gerald D. Fischback, “Leo Kanner’s 1943 Paper on Autism,” *Spectrum*, 7 December, 2007, <https://www.spectrumnews.org/opinion/viewpoint/leo-kanners-1943-paper-on-Autism/>.

interests, and impairments in theory of mind and executive function characteristics of Autism.”<sup>10</sup>

In “Autism Spectrum Disorders and the New Testament: Preliminary Reflections,” Grant Macaskill explores how the “New Testament might shape the values of Christian communities in relation to ASD and is offered as a contribution from the discipline of biblical studies to the disciplines of pastoral theology and theological ethics.”<sup>11</sup> The gospel of John states, “[Christ’s] disciples asked him, ‘Rabbi, who sinned, this man or his parents, that he was born blind?’ Jesus answered, ‘Neither this man nor his parents sinned; he was born blind so that God’s works might be revealed in him’” (9:2-3, NRSV).<sup>12</sup> If the church embraces biblical principles, like love thy neighbor as thyself, rather than seeking to see who is blamed for disabilities, then perhaps, there could be more acceptance, hence inclusion of the ASD population in church settings.

Many children with ASD have problems coping in environments like churches, schools and in the community or public arenas. These environments or lack of familiarity with these environments, can cause many of them to have (sometimes violent) outbursts. These outbursts are perceived as bad behaviors. In *Leading a Special Needs Ministry*, Amy Fenton Lee states, “When children are ‘misbehaving,’ researchers have found that they are nearly always trying to communicate a need for one of the following: a tangible

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<sup>10</sup> Spectrum News, Spectrum/Wiki, “Asperger Syndrome,” <https://www.spectrumnews.org/wiki/asperger-syndrome/>.

<sup>11</sup> Grant Macaskill, “Autism Spectrum Disorders and the New Testament: Preliminary Reflections,” *Journal of Disability and Religion* 22, no. 1 (2018): 16.

<sup>12</sup> The Holy Bible, New Revised Standard Version.

object; a physical or sensory need; to escape a demand; an activity or a sensory stimulation; or they are seeking to acquire attention from adults or peers.”<sup>13</sup> It has been difficult for him to adjust; therefore, he has had frequent outbursts at the church. Some of those have resulted in physical aggression and property destruction. We have paid for all property he has destroyed, but the repairs do not erase the memories. Sitters from the congregation who once agreed to sit with him during worship service, have all backed away. Surely, it is because they fear what may occur should he have an outburst in their company.

Oftentimes, the behaviors are merely the reaction to what the person is witnessing and other times the reactions may be rejection towards the environment. The child or person with ASD who displays such outbursts or “misbehavior,” could be labeled “out of sync.” In *The Out-of-Sync Child Has Fun*, Carol Kranowitz addresses this issue. She states that most children on the spectrum are out of sync most of the time, due to a neurodevelopmental problem. She addresses the child who: is overresponsive to touch, movement, sight or sound; has a poor sense of body awareness; has immature fine and gross motor skills; becomes very emotional and quickly frustrated when things are not “just right.” The reason for such confusing behaviors? Sensory Processing Disorder (SPD). Sensory processing is the normal neurological process of organizing sensations for our use in everyday life. SPD, however, occurs when a person with ASD responds in

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<sup>13</sup> Amy Fenton Lee, *Leading a Special Needs Ministry* (Nashville: B&H Publishing, 2016), 122.

atypical ways to those sensations.<sup>14</sup> SPD is addressed by Joyce Emmons Nuner and Tamara Love in their article entitled, “Church Ministry and the Child with Autism.” In the article, the authors describe aspects of the worship which can prove to be problematic or stressful for the ASD child, such as unfamiliar people, loudness and the need for their participation in the worship. Furthermore, they offer advice to the congregation for provisions of accommodations and modifications based on individual needs. One example cited in the article involves a child who constantly rocks during the worship. The church has provided him a rocking chair to be utilized during the services. It is placed on the end of a row just for him.<sup>15</sup> Some churches have embraced other concepts which include those with special needs. Dr. Mary M. Fulkerson, in *Places of Redemption*, writes of a church that includes the special needs population in the worship service, while also offering a separate service that is led by and geared toward those with special needs. Fulkerson states, “Some in the congregation are learning a different way to be in relation to those marked as ‘special needs’ members.”<sup>16</sup>

Seemingly, the person with Autism struggles with social skills and appears to most as one who would rather be alone. In *Autism and the Myth of the Person Alone*, Douglas Biklen, through a series of interviews with people on the Autism Spectrum, addresses the concept of “loneness.” This presumed desire for aloneness, could lead one

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<sup>14</sup> Carol Stock Kranowitz, *The Out-of-Sync Child Has Fun* (New York: Penguin, 2003), 2.

<sup>15</sup> Joyce E. Nuner and Tamara Love, “Church Ministry and the Child with Autism,” *Family and Community Ministries (Online)*, January 1, 2013, 102.

<sup>16</sup> Mary McClintock Fulkerson, *Places of Redemption* (New York: Oxford University Press, 2007), 125.

to believe that in the community, church and/or school settings, those with ASD, would prefer to be isolated. Biklen cites Temple Grandin's *Emergence: Labeled Autistic* and states, "Where the person labeled autistic is presumed isolated and uninterested, recent autobiographical accounts reveal people in search of connections with the world."<sup>17</sup> In my opinion, this is why school attendance is so important for the ASD child. For some of them, their only connection with the world is the socialization they receive at school.

In *The Child with Special Needs: Encouraging Intellectual and Emotional Growth*, Stanley I. Greenspan and Serena Wieder, address communication issues which can impede the relationships of those with ASD.<sup>18</sup> These relationship impediments can filter into various aspects of life for the one with Autism. Sadly, the result for us and many other families is one of exclusion. Even I, the pastor of a church, felt I needed to leave my own son at home with a babysitter on several Sunday mornings. Linda Synder, cofounder of an alternate worship experience for those with ASD states, "If they are not at the table, then we are not a whole body of Christ around the table."<sup>19</sup> Having a seat at the table is not always literal, it can be virtual also. In *The Social Media Gospel*, Meredith Gould offers suggestions for the church to include special populations by utilizing social media.<sup>20</sup> Her suggestions for livestreaming and podcasting would be of benefit to the ASD population. If a parent has an ASD child or if an ASD adult is not having a great

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<sup>17</sup> Douglas Biklen, *Autism and the Myth of the Person Alone* (New York: New York University Press, 2005), 49.

<sup>18</sup> Stanley I. Greenspan and Serena Wieder, *The Child with Special Needs* (Da Capo Press, 1998), 106.

<sup>19</sup> Amanda Hendler-Voss, "The Whole Body of Christ," *U.S. Catholic*, March 4, 2019, 35.

<sup>20</sup> Meredith Gould, *The Social Media Gospel* (Collegeville: Liturgical Press, 2015), 62.

day, then livestreaming the worship service on that Sunday may be their best option – they can attempt to attend again the following Sunday. The same holds true for podcasting – an option that can be utilized to build a virtual Bible study class for those who find it difficult to attend physically.

In *The Out-of-Sync Child*, Carol Stock Kranowitz writes about the need for parental communication with the schools of children with SPD. She notes simple distractions – proximity of classmates, sound of rustling paper, movement of children playing outside the window, and even the classroom furniture – which could impede the child’s ability to focus, and ultimately, learn. She warns, however, that not all schools are willing to accommodate the SPD child and that it may be necessary to elevate parental involvement.<sup>21</sup> In 2004, the Individuals with Disabilities Education Improvement Act (IDEA) was passed. The major purpose of the IDEA is to ensure that all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment, and independent living.<sup>22</sup>

In the 2016 publication of the *Journal of Catholic Education*, an article written about the IDEA and Catholic school education, sheds light on the subject of inclusion in schools from a different perspective. In the article, written by Michael J. Boyle & Claudia M. Hernandez, entitled, “An Investigation of the Attitudes of Catholic School Principals

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<sup>21</sup> Carol Stock Kranowitz, *The Out-of-Sync Child* (New York: Penguin, 2003), 245.

<sup>22</sup> Connecticut Parent Advocacy Center, <http://www.cpacinc.org/materials-publications/legal-rights/the-individuals-with-disabilities-education-improvement-act-idea-2004/>.

towards the Inclusion of Students with Disabilities,” they write, “The public-school principal’s attitude toward students with disabilities has a significant impact on the effective provision of special education services. Several studies have noted that for inclusion to be successful, the public-school administrator must display a positive attitude and commitment to inclusion.”<sup>23</sup>

Dr. Temple Grandin addresses teaching and education in her book, *The Way I See It*. Grandin states, that the goal for teaching children with Autism is not to turn them into “normal” kids, more meaningful is to teach them the academic and interpersonal skills they will need to function in the world. She states, “It [Autism] brings with it great challenges, but it can also bring to the child the seeds of great talents and unique abilities. It is the responsibility of parents and educators to find those seeds, nurture them, and make sure they grow.”<sup>24</sup>

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<sup>23</sup> Michael J. Boyle & Claudia M. Hernandez, “An Investigation of the Attitudes of Catholic School Principals towards the Inclusion of Students with Disabilities,” *Journal of Catholic Education* 20, no. 1 (2016): 190-219.

<sup>24</sup> Temple Grandin, *The Way I See It* (Arlington, TX: Future Horizons, 2008), 25.

## **Appendix B – Duke Campus IRB Approved 11/20/20**

### **RESEARCH INFORMED CONSENT FORM**

**INTRODUCTION:** My name is Charlean Batten Mapson, and I am a student at Duke Divinity School, conducting an ethnographic study for my D.Min thesis. My telephone number is: 910-233-0012 and my email address is charlean.mapson@div.duke.edu. My advisor is Dr. Mary M. Fulkerson and her email address is mfulkerson@div.duke.edu. You may contact either of us at any time if you have questions about this study.

**PURPOSE:** The purpose of this research is to study the inclusion of the Autism population in churches, schools, and communities.

**PROCEDURE:** If you consent, you will be asked several questions in an oral interview, focus group via ZOOM in a focus group setting and/or via written survey. The ZOOM session will be recorded, and I may make an audio recording of the interview. All written survey responses, audio and video recordings will be destroyed after they are transcribed.

**TIME REQUIRED:** The interview, survey, and/or focus group/ZOOM session will take approximately 1-2 hours of your time.

**VOLUNTARY PARTICIPATION:** Your participation in this study is completely voluntary. If you choose to participate, you may still refuse to answer any question that you do not wish to answer. You may also withdraw from the study at any time. Should you choose to participate, please indicate whether you would like to be interviewed, join the focus group or both.

Focus Group  Phone Interview  Written Survey

**RISKS:** There are no known risks associated with this interview. However, it is possible that you might feel distress in the course of the conversation. If this happens, please inform me promptly.

**BENEFITS:** While there is no guaranteed benefit, it is possible that you will enjoy sharing your answers to these questions or that you will find the conversation meaningful. This study is intended to benefit the others by enlivening our discourse on the theology and practice of inclusion.

**CONFIDENTIALITY/ANONYMITY:** Your name will be kept confidential in all the reporting and/or writing related to this study. I will be the only person present for the

interview and the only person who listens to the tapes. There will be other Autism parents present for the focus group/ZOOM session. When I write the ethnography, I will use pseudonyms - made up names - for all participants, unless you specify in writing that you wish to be identified by name. Please indicate the first name you would like me to use for you here: \_\_\_\_\_.

**SHARING THE RESULTS:** I plan to construct an ethnography - a written account of what I learn - based on these interviews together with my reading and historical research. This ethnography will be utilized in my final thesis. I also plan to share what I learn from this study with church's denomination. Portions of the ethnography may be printed and made available to the members upon request.

**PUBLICATION:** There is the possibility that I will publish this study or refer to it in published writing in the future. In this event, I will continue to use pseudonyms (as described above) and I may alter some identifying details in order to further protect your anonymity.

**BEFORE YOU SIGN:** By signing below, you are agreeing to an audiotaped interview and/or video recorded ZOOM session for this research study. Be sure that any questions you may have are answered to your satisfaction. If you agree to participate in this study, a copy of this document will be made available to you upon request.

Participant's signature: \_\_\_\_\_ Date: \_\_\_\_\_

Print Name: \_\_\_\_\_

Participant's signature: \_\_\_\_\_ Date: \_\_\_\_\_

Print Name: \_\_\_\_\_

Researcher's signature: 

Date: July 25, 2020

Print Name: Charlean B. Mapson

## Appendix C – Duke Campus IRB Approved 11/20/20

### RESEARCH SURVEY

#### DEMOGRAPHIC INFORMATION

Your First Name or Pseudonym \_\_\_\_\_

Preferred method of contact for further questioning \_\_\_\_\_

How many children do you have with Autism? \_\_\_\_\_

1. What is/are your Autism child's(ren's) gender? \_\_\_\_\_

2. What is/are your Autism child's(ren's) age? \_\_\_\_\_

3. Does your child/ren have another diagnosis? \_\_\_\_\_ If so, what is it? \_\_\_\_\_

4. Does your ASD child/ren have siblings? \_\_\_\_\_ If so, how many? \_\_\_\_\_

5. Do they have an Autism diagnosis? \_\_\_\_\_

6. What is your religious affiliation? \_\_\_\_\_

7. What ethnicity do you identify with? \_\_\_\_\_

8. In what city do you reside? \_\_\_\_\_

#### CHURCH INFORMATION

9. Does your family have a church home? \_\_\_\_\_

10. If so, what is the name of the church? \_\_\_\_\_

11. Do you attend church on a regular basis? \_\_\_\_\_

12. If so, are there activities for your ASD child/ren? \_\_\_\_\_

13. If so, what are those activities? \_\_\_\_\_

14. If you do not attend church on a regular basis, why? \_\_\_\_\_

15. Describe your most vivid experience as an Autism parent in a church environment \_\_\_\_\_

16. What service(s) can your church or any other church do for you and your ASD child(ren) that is not being done now? \_\_\_\_\_

17. Please share any story you wish regarding your ASD child's(ren's) involvement in church. \_\_\_\_\_

### **SCHOOL INFORMATION**

18. Does your ASD child(ren) attend school? \_\_\_\_ If so, is the school public or private? \_\_\_\_

19. If so, what is the name of the school? \_\_\_\_\_

20. Has your child's ASD ever caused your child(ren) to miss school? \_\_\_\_\_

21. If so, what were the circumstances? \_\_\_\_\_

22. Has your ASD child(ren) ever been suspended? \_\_\_\_\_

23. If so, what were the circumstances? \_\_\_\_\_

24. Have you ever had to advocate for your ASD child(ren) at their school? \_\_\_\_\_

25. If so, what were the circumstances? \_\_\_\_\_

26. How has your ASD child(ren) adjusted to the school schedule due to the recent pandemic? \_\_\_\_\_

27. How has this new school schedule affected your ASD child(ren)? \_\_\_\_\_

28. Does/did your ASD child/ren have an IEP? \_\_\_\_\_

29. Do/did you attend IEP meetings? \_\_\_\_\_

30. If so, why? If not, why not? \_\_\_\_\_

31. Prior to the pandemic, what services was your ASD child/ren receiving at school? \_\_\_\_\_

32. Prior to the pandemic, did your ASD child(ren) participate in extracurricular activities at school? \_\_\_\_\_

33. If so, which activities? \_\_\_\_\_
34. If not, why not? \_\_\_\_\_
35. What services can your ASD child's(ren's) school provide that they do not already offer?
36. Please share any story you wish regarding your ASD child's(ren's) involvement in their school. \_\_\_\_\_

### **COMMUNITY INFORMATION**

37. Prior to the pandemic, what services was your ASD child(ren) receiving in the community? \_\_\_\_\_
38. Prior to the pandemic, did your ASD child/ren participate in extracurricular activities in the community?
39. If so, which activities? \_\_\_\_\_
40. If not, why not? \_\_\_\_\_
41. What services can your ASD child's(ren's) community provide that they do not already offer? \_\_\_\_\_
42. Please share any story you wish regarding your ASD child's(ren's) involvement in community activities.

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## Biography

Charlrean Batten Mapson is the daughter of the late Charlie Batten, Jr., and the late Anna Rean Batten. She is a native of Atlanta, Georgia, where she attended the Benjamin E. Mays Academy of Science and Mathematics, and Clark Atlanta University (CAU) where she received a Bachelor of Science Degree in Chemistry with a minor in Engineering. In 1991, the AUC chapter of NSBE honored her with the creation of an annual award and scholarship bearing her name, "The Charlrean Batten Leadership Award."

After six years of service in corporate America, she entered the real estate business. In 2003, she was named Realtor of the Year for the Wilmington Regional Association of Realtors, which had approximately 2,000 members at that time.

In May of 2016, she graduated Magna Cum Laude from Hood Theological Seminary as a Master of Divinity degree recipient and recipient of the "Student Recognition Faculty Award."

She has one publication: "Christianity, Christian Symbolism and the Ku Klux Klan," published in the African Methodist Episcopal Zion Church Quarterly Review, January 2016, volume 129, no.1, page 10.

She is the proud ASD mother of one son, Jadon Hassani Mapson, born to her and Rev. Donald R. Mapson on January 31, 2005.