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## The Spiritual Impact of Disability on Parents and Caregivers

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# DISCERNMENT

*Theology and the Practice of Ministry*

## The Spiritual Impact of Disability on Parents and Caregivers

*Grant Azbell*

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*Abstract: This study was designed to examine the impact of disability on the faith and faith communities of parents and caregivers of persons experiencing disability. This study proceeded by asking nine parents or caregivers of persons experiencing disability a series of seven questions to evaluate the impact of disability on their faith and on their relationship to their faith community. The interviews were conducted on Zoom, and the recordings were transcribed and coded to observe discernable patterns and themes amongst the participants. What emerged from the data is important for ministers, church leaders, and anyone wanting to know more about the spiritual impact of disability on parents and caretakers of persons experiencing disability.*

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### Introduction

In 2010, my wife, Ashley, gave birth to a little boy named Isaiah. We had been married for seven years and had struggled with infertility. Isaiah came with prayers, desires, hopes, and dreams attached to him. He was a perfect little boy by all accounts. He slept through the night, hit his milestones, and hardly ever cried. Many of our friends were amazed at how good he was as a baby. Then, around twelve months, he began to miss his speech milestones. By the time he was two, even though he had a few words, we noticed other issues. We took him to see a specialist, where he received a diagnosis of pervasive developmental disorder (PDD). A diagnosis of autism would come at the age of three.

This experience birthed the question that birthed this project:<sup>1</sup> How does disability impact the faith of parents and caregivers of those experiencing disability and their relationships to their faith communities?<sup>2</sup>

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<sup>1</sup> This article is a summary of my doctoral project, which was accepted by Lipscomb University in the spring semester of the 2021–22 school year.

<sup>2</sup> The wording “people or persons experiencing disability or disabilities” will be used often. Even though it is a bit cumbersome, it is important not to reduce persons to the disability they experience. For this paper, I will seek to use person first language. I will also

I wondered if the journeys of others were like mine. What would I discover by hearing perspectives on faith, parenting, community, and disability from others? I interviewed nine parents or caretakers of persons experiencing disability. What I discovered in my research was—much like the experience of parenting a child experiencing disability—something complicated, nuanced, painful, and beautiful.

Sadly, I also learned of a profound disconnect between parents and caregivers of persons experiencing disability and their faith communities that must be repaired.

### **The State of Disability**

According to statistics from the World Health Organization (WHO), over one billion people worldwide live with some form of disability. The number of people experiencing disability, for reasons not fully understood, is increasing. Almost every person will experience some form of disability, either permanent or temporary, in their life. This highlights the fact that disability is a worldwide phenomenon. Those experiencing disability often do so without proper access to healthcare and other accommodations needed for their difference. In developing countries, accommodations that are taken for granted in industrialized countries, such as wheelchair ramps and handicap accessible bathrooms, often do not exist. Many disabilities that exist are preventable and treatable with access to proper healthcare, such as medical diagnosis, treatment, and therapy.<sup>3</sup>

In the United States, according to the Centers for Disease Control and Prevention (CDC), over sixty-one million people experience disability. Among the United States populace, 13.7% experience mobility limitations, 10.8% have cognitive impairment, 6.8% have independent living limitations, 5.9% are hearing impaired, 4.6% are vision impaired, and 3.6% have self-care limitations. Two in five adults over the age of sixty-five, one in four women, and two in five non-Hispanic American Indians/Alaska Natives experience disability.<sup>4</sup>

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use the terminology of persons “experiencing” disability rather than persons “with” disability as a further attempt not to link personhood with disability.

<sup>3</sup> “Disability and Health,” World Health Organization Newsroom, last modified November 24, 2021, accessed March 10, 2022, <https://www.who.int/news-room/fact-sheets/detail/disability-and-health>.

<sup>4</sup> “Disability Impacts All of Us,” Centers for Disease Control and Prevention, Disability & Health Infographics, last modified September 16, 2020, accessed March 10, 2022, <https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html>.

The United States also lacks proper healthcare access for those experiencing disability. Further data from the CDC is illustrative of this point:

When one factors in the lack of healthcare access, the situation is more dire. 1 in 3 adults with disabilities 18 to 44 years do not have a usual health care provider. 1 in 3 adults with disabilities 18 to 44 years have an unmet health care need because of cost in the past year. 1 in 4 adults with disabilities 45 to 64 years did not have a routine check-up in the past year.<sup>5</sup>

The data are clear: in the United States, the wealthiest nation in the history of the world, people experiencing disability do not have proper access to healthcare.

### **How Is the Church Doing?**

If disability occurs within the church at the same rate that it occurs outside of the church, it is important to ask how the church's efforts are received and measured by those experiencing disability within its boundaries. In this section, the focus will be on the church in the United States. This is also relevant to the church universal, but due to the scope of this project, the focus needed to be narrowed to the United States. If the framing of the gospel by Jesus in Luke 4:16–21 can be applied to those experiencing disability, and I believe it must, then the question "How is the church doing?" as applied to those experiencing disability, is of vital importance.

A study appearing in the *Journal of Disability & Religion* surveyed 266 faith leaders in Kentucky and North Carolina concerning their perception of the inclusion of those experiencing disability within their faith communities.<sup>6</sup> When their perception was compared to the perception of the parents and caretakers of those experiencing disability within said communities, the difference was stark. When asked if families that experience disability left a place of worship where they served because they felt unwelcome, religious leaders responded 95% no and 5% yes, while

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<sup>5</sup> "Disability Impacts All of Us."

<sup>6</sup> Melinda Jones Ault, Victoria Slocum, Belva C. Collins, Maria Mamsell Leahy, and Valerie P. Miller, "Perceptions on the Inclusion and Participation of Individuals with Disabilities in Their Communities," *Journal of Disability & Religion*, DOI: 10.1080/23312521.2021.1932691.

parents and caregivers responded 32% no and 67% yes. When faith leaders were asked if parents of children experiencing disability had left their congregations because they felt their children had not been properly included, 97% said no and 3% said yes, while parents and caregivers of persons experiencing disability responded 53% no and 46% yes. When asked if people experiencing disability had left because they felt like there was no proper support in their place of worship, congregational leaders responded 88% no and 12% yes, while parents and caregivers responded 44% no and 56% yes. When asked if they had ever asked parents or caregivers to stay with a person experiencing disability so the person experiencing disability could participate in a religious activity, religious leaders responded 71% no and 29% yes, while parents and caregivers responded 43% no and 57% yes. When asked if they had ever asked people experiencing disability or their caregivers the best way for them to be included in religious activities, religious leaders responded 34% no and 66% yes, while parents and caregivers responded 46% no and 54% yes.<sup>7</sup> These data clearly illustrate the large discrepancy between the perceptions of religious leaders and the parents and caregivers of people experiencing disability concerning the welcoming atmosphere and inclusion of persons experiencing disability in worship and religious activities.

These data illustrate that churches are failing both their members that experience disability and those members' families. What can be done? The first step is acknowledgment and awareness of this gap. The second step, which this project will address, is hearing more directly from the parents and caregivers of people experiencing disability concerning their experience of faith and congregational inclusion, both in worship and in other religious activities. This gap must be closed if churches are to intentionally steward the gifts that persons experiencing disability have to offer.

## **Research Methodology**

The following section will describe the research methodology of this project. Normate parents and caretakers of persons experiencing disability were chosen for this study.<sup>8</sup> There are four reasons for choosing normate

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<sup>7</sup> Ault, et al.

<sup>8</sup> The term "normate" was coined by Rosemarie Garland Thompson and refers to the socially constructed ideal image "through which people can represent themselves as definitive human beings." Kerry H. Wynn, "The Normate Hermeneutic and Interpretations of Disability Within the Yahwistic Narrative," *This Able Body* (Atlanta:

parents and caregivers. First, persons experiencing disability experience abuse at a higher rate than the normate population.<sup>9</sup> As the primary investigator, I chose normate parents and caregivers to participate in this study—not the person experiencing disability—to avoid any potential harm or unintentional abuse of those experiencing disability.

Second, parents and caretakers are often overlooked in disability and theology studies. However, disability impacts their lives as much as any group other than those directly experiencing disability. There is also a unique aspect of disability experienced by parents and caregivers.

Third, parents and caregivers often have their lives radically altered and understand the life changing reality that disability entails in a unique way. Persons diagnosed with disability as young children only know life that includes disability, while their normate parents and caregivers understand life pre-disability and post-disability. While parents and caretakers experience the segregation and isolation of disability directly, they also experience the impairment, abuse, and physical limitations of disability indirectly. They may have no physical limitations, but the physical limitations of those in their care often become their limitations.

Finally, hearing the experience of parents and caregivers is an essential element in understanding how disability impacts the faith of families and their connection to their faith communities. Parents and caregivers are often the only advocates for their children or those in their care. Interviewing parents and caregivers instead of those experiencing disability is not so they can speak for those experiencing disability. Rather, it is to understand reality from the perspective of parents and caretakers, which, as stated above, is often overlooked. All children must be advocated for because they are not yet actualized adults. Children experiencing disability must be advocated for until they become adults and often much longer. Disability, while not impacting intrinsic value or personhood, can impact one's ability to advocate for oneself. With the eye of a parent or guardian, parents, and caretakers understand the structures that cause harm and abuse to persons experiencing disability. Therefore, their voices should be heard.

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Society of Biblical Literature, 2007), 92; Rosemarie Garland Thompson, *Extraordinary Bodies* (New York: Columbia University Press, 1996), 8–9.

<sup>9</sup> "The Risk and Prevention of Maltreatment of Children with Disabilities," Child Welfare Information Gateway, last modified January 2018, accessed March 26, 2022, <https://www.childwelfare.gov/pubpdfs/focus.pdf>.

## Demographics

In recruiting, the only parameter for type or experience of disability was that it be medically diagnosed, and the diagnosis be received no less than twelve months before the interview. The reason for this stipulation is that interviewing family members impacted by disability within one year of the diagnosis was thought to be potentially harmful. While disability is difficult, regardless of how distant the diagnosis, one year seemed sufficient for parents or caregivers to begin to adjust to their new reality.

Amongst the persons experiencing disability in the care of the project participants, multiple diagnoses were present. However, for the sake of anonymity, I have decided not to name the specific disability. Some of the diagnoses were exceptionally rare and could lead to an identification of parents, caretakers, or those in their care. Therefore, I decided to avoid accidental identification if possible.

The amount of care demanded also covered a broad range depending on the diagnosis and the age of the person experiencing disability. The care responsibilities of parents and caregivers ranged from minimal care to twenty-four-hour care and everywhere in-between. One child was recently deceased, while two other persons in care of participants have terminal diagnoses. Some of those experiencing disability have almost no physical limitations, while the mobility of others is so limited that they are fully dependent upon their parents or caretakers. Some of those experiencing disability are not cognitively limited, sometimes functioning higher than their normate peers, while others have extreme limitations in speech, cognition, and motor function due to neurological impairment.

Of those interviewed, eight were parents and one was a sibling of persons who experience disability. Of the eight parents, six were still married to the biological parent of their child and two were divorced from the biological parent of their child. Four participants were married to a person in the study (though they were interviewed independently). All participants were Christian, with one parent in an interfaith marriage. Participants identified with four denominations: four identify as Church of Christ, three identify as non-denominational, one identifies as Catholic, and one identifies as Presbyterian.

**Table 1: Summary of Participants**

#	Relationship	Age	Denomination	Age of Person with Disability	Age at Diagnosis
1	Mother	30s	Catholic	4	18-19 months
2	Mother	40s	Church of Christ	7	8 months
3	Mother	60s	Non-denominational	37	6 years
4	Father	40s	Presbyterian	Deceased	Birth
5	Father	50s	Church of Christ	7	8 months
6	Father	50s	Church of Christ	26	2 ½ years
7	Sister	70s	Church of Christ	69	Birth
8	Mother	30s	Non-denominational	6	18 months
9	Father	30s	Non-denominational	6	18 months

The impact of disability on the faith of parents and caretakers and their relationships to their faith communities cannot be overstated. This is clear in the research results. At this time, it is enough to say that every aspect of the lives of the parents and caretakers are impacted by disability. Without exception, every person interviewed stated this very fact.

### The Interview

I began the interview by explaining the structure of the interview. I informed the participants that they could stop the interview at any time. I also told them that they could strike anything from the record after the interview if they felt they had shared information with me that they did not desire to go into this project. I began the interview with a prayer and then started recording the session. I set a timer at eighteen minutes for the first question. This was not to limit the amount of time the participant spoke. Rather, it was simply to orient them concerning the time. Having told my personal story multiple times, I have found this helpful. After the first question, I would listen attentively through the interview without interruption except to ask the next question or in the case of a participant needing a clarification.

The interviews were conducted using a semi-structured approach. Participants received the first two questions in advance along with suggestions of how to organize their spiritual autobiography. Initially, it was planned that all the questions would be revealed in the interview without advanced knowledge of the questions. However, the first two questions were so involved that it seemed prudent to send the participants these questions in advance to keep them from feeling overwhelmed. I provided suggestions for organizing a spiritual autobiography to lessen



any sense of anxiety coming into the interview. The seven questions were as follows:

1. Please share your spiritual autobiography with me, highlighting any significant events that have impacted your spiritual journey.
2. By participating in this study, you acknowledge that one or more of your children experiences disability. Please share your and your family's journey, from the time you began to recognize disability up to the present.
3. Could you share more specifically how having a child (or children) who experiences disability has impacted your relationship with God? How has having a child who experiences disability impacted your faith?
4. How has having a child who experiences disability impacted your relationship with your faith community?
5. What could churches do better to support families like yours on their spiritual journey?
6. What are some important things for other people of faith to know concerning disability?
7. What are some important things for pastors to know concerning disability?

### Data Analysis

After finishing each interview, the sound file was downloaded to my laptop, and then the interview was deleted from Zoom's cloud. After downloading the file and saving it to an encrypted file, I then uploaded it to Amazon Web Services and used Amazon Transcribe to transcribe the recorded interviews. After the transcription was complete, I formatted the transcriptions to a Pages file and coded the data.

### Research Results

The following section will report a summary of the research results. The research collected and transcribed totaled over two hundred pages. After editing and coding, the data was still over one hundred pages and

just over twenty-eight thousand words. After coding the data, I organized the data to correspond with each research question.

**Question 1: Please share your spiritual autobiography with me, highlighting any significant events that have impacted your spiritual journey.**

The first question does not reveal anything groundbreaking. The general life trajectory was for the participants to be faithful in church through their childhood, having a salvation experience during early adolescence. This was generally followed by a time of wandering before, relatively early in their marriages, they recommitted to the church. It is important to acknowledge that this is a typical pattern for the participants in this study and not necessarily typical of people in general.<sup>10</sup>

**Question 2: By participating in this study, you acknowledge that one or more of your children experiences disability. Please share your and your family's journey, from the time you began to recognize disability up to the present.**

The responses to question two describe the journeys of the research participants and their families after receiving a diagnosis of disability. All the participants' children or loved ones received an official diagnosis by the age of six or younger. Some learned of abnormalities in the womb. On two occasions, a diagnosis came immediately and was immediately accepted due to the nature of the disability. Several diagnoses were made after months of parents going from specialist to specialist trying to figure out what was different about their child. This experience was full of ups and downs. Often parents would go to one specialist and have something ruled out. This would lead to feelings of relief that their child would be "okay" — that their child would be "normal." Sometimes they would subsequently be referred to another specialist, immediately dashing the feelings of relief. At other times, their child would be cleared and they would celebrate only to later realize, weeks or months down the road, that their child was not developing typically. This medical "roller coaster," as one participant called it, through a long, winding, and arduous process, eventually led to a

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<sup>10</sup> David Kinnaman and Gabe Lyons, *unChristian: What a New Generation Really Thinks about Christianity...and Why It Matters* (Grand Rapids: Baker Books, 2007), 11.

diagnosis of disability. Currently, all participants have a diagnosis for their child or loved one.

Most participants reported feeling devastated upon hearing about their child's diagnosis. Many did not initially accept the diagnosis. Some refused to believe it. Some sought treatments and cures, determining to beat the disability and for their child to be "normal."

Navigating the medical field was a challenge. Many doctors did not take the parents' concerns seriously, often telling them they were overreacting, their child would grow out of it, or to enjoy their healthy baby. One doctor, concerning a child born with disability, advised the parents to let the child die—to "let him go." This same couple also had a doctor tell them their child was like a camera with no film in it. The diagnoses received often came with life expectancies attached. Three of the families I interviewed had children who received terminal diagnoses. One died at twenty. The other two are still living.

Often, coinciding with the diagnosis would be a "desert" or "dry season" of faith. Many participants would feel that God was far from them. All had prayed for their children or loved ones. All had prayed for their healing. Many questioned why this was happening to them.

The diagnosis also corresponded with difficulties in marriage for multiple participants. Partners often disagreed on treatment, with some even rejecting the diagnosis. One partner might do everything possible to get medical treatment or therapy and the other partner might be living in denial.

All participants acknowledged that raising a child who experiences disability is hard. Sometimes, this acknowledgement was paired with very strong language such as: "We felt like we were drowning." "I was at the end of my rope." "This will not be my story." All participants also acknowledged that there is no part of their life that disability does not touch. One participant described it as "relentless."

Getting adequate care for children experiencing disability is taxing and expensive. One participant worked three jobs so that his spouse could stay at home to care full-time for their child. The demand and expense of care forced participants to live life at a different rhythm, which might mean not going on vacation, not going out, not getting invited to events. This, in turn, created a feeling of isolation.

Many participants described how watching their child suffer, especially early on, created a sense of anger at or betrayal from God. Many wondered what they did for their child to experience what they were experiencing. Many wondered if their child was being punished for their,

the parent's or caregiver's, sins. Some developed harmful theology. One participant came to believe in "a God who takes." Most participants went through a season of hopelessness that only lifted when they began to accept their child.

For the parents of children experiencing disability, milestones are a source of consternation. Many live with constant anxiety around unmet milestones, often hoping against hope for their child to suddenly catch up. For parents and caregivers of persons experiencing disability, milestones change, and small things get celebrated. One participant remembers that her brother did not cry for three months after they brought him home from the hospital. One night when they were all sitting around the dinner table, they heard him cry and they all "just rejoiced." Another participant talked about how his child was unresponsive to doctors. But when he, his wife, or his parents touched his son, the boy would move. Another participant had to puree all his child's food and feed it to him until he was eight years old. He recalled how one day after church they went through the drive thru at McDonalds, because going in a restaurant was just too hard, and then took their food to the park to eat it. When they were eating in the park their eight-year-old son picked up a French fry and ate it. He said, "We just sat there and cried."

Some parents interviewed are still learning to navigate their child's medical demands. When the diagnosis of the child is settled, parents seem able to come to a level of peace with the diagnosis. When the diagnosis is uncertain and children are on the "medical merry-go-round" as one participant called it, there is a consistent emotional and spiritual upheaval or "roller coaster." When a child begins to have additional medical complications after the child's medical status had been relatively stable, this can create great emotional and spiritual instability. Ultimately, among the participants interviewed, they all describe disability as increasing their faith. However, there have been moments of spiritual darkness and a feeling of forsakenness.

**Question 3: Could you share more specifically how having a child (or children) who experiences disability has impacted your relationship with God? How has having a child who experiences disability impacted your faith?**

The interviews revealed that having a child who experiences disability is a profoundly spiritual experience. All participants struggled with their faith, to varying degrees, after their child was diagnosed with a

disability. Some went through a stage of anger with God—questioning why God would allow this to happen to their child. Sometimes this was followed by a spiral of doubt that occasionally manifested as destructive behaviors. A consistent theme was the question of why. Why them and why their child? What sin was committed for God to allow this to happen? One participant, whose faith in God was solid, struggled with the actions of other “people of God.” In one instance, a participant’s neighbor—a pastor’s wife—called the police on the participant’s son after she had asked her neighbor for help. All participants felt that unanswered prayers and pleas to God in a sense “seemed to pile up.”

All the participants continually prayed for the person experiencing disability in their care. Watching their child suffering while they were begging for healing was particularly difficult on caretakers. Sometimes, prayers before a doctor’s appointment would appear to be answered. Multiple participants experienced the emotional polarity of praying for their child, going to a doctor’s appointment, and believing their child was okay only to find out later the doctor misread the data, conducted a test that did not adequately address the potential disability, or the doctor was just wrong. One participant talked about how, while actively praying, her child would begin a seizure. One participant remembers praying that “Jesus would heal my brother just like he did the lame man... that was my prayer at that point, and I really thought that [he] was going to do that for a long time.” One participant said that he prayed for his daughter’s healing “so many, many, many, many, many times.” Another participant said that when she hears people talking about forgetting to pray, she cannot comprehend it. She cannot imagine how someone can just “forget” to pray. However, it is also in prayer where many of the participants met God experientially—sometimes for the first time.

There is an intensity in the prayer life of all the participants in this study. The intensity is so palpable that I wonder if any segment of Christianity prays with more ferocity than the parents and caregivers of persons experiencing disability. In the interviews, participants described bringing anger, devastation, or desperation concerning disability directly to God. The participants did not simply have feelings about God, they communicated directly to God. These prayers might involve shouting, cursing, crying, or weeping with their face in the floor. Sometimes, in desperate prayer, participants felt the presence of God. One participant said: “I had felt all along like this was something I had to fix and that I needed to make sure was taken care of and fixed and I had to make sure that he did every therapy appointment and that we pushed him... to make

him normal. And it was like in that moment, God told me he's not normal. That's not his path and that's not your job." During an intense time of prayer, another parent experienced God for the first time: "It was late one night and I'm down on my hands and knees crying and it's the first time I cried out to the Lord and sort of demanded in this ultimatum fashion... that he show up and he did. For the first time in my life, at thirty-four years old, I was experiencing the presence of the Spirit physically [and] emotionally." The peace a parent experienced was often tied to an acceptance of their child, a "releasing" of their child to God. This was often accompanied by the belief that God had gifted their child to them, and it was their job to steward this gift well. Many participants felt they were raising their child to return their child to God.

Many participants, in accepting their child, have also found their child to be a source of inspiration. Often, when their own child's happiness dawned on them, many participants realized: if their child could be happy, they could be happy. One participant said his child "greet[s] the world with kisses every morning." Another participant's brother, who had limited use of his arms, would spend hours reading his Bible every day, turning the pages with his tongue. He became a resource for her because "he knows the Bible backwards and forwards." One participant, whose son never walked or spoke, said that anyone could feel when he was in the room. Another participant's child helped her understand the love of God. When she learned to accept her son as he is, it helped her understand how "God accepts us [and loves us] as we are."

Experiencing disability for these participants was profoundly spiritual. Watching their child or loved one experience disability challenged the way they viewed God. Often, it made them angry with God or it made them doubt God. Some of them still have anger and doubts occasionally. However, their child has also served as a lens for how they see the world.

**Question 4: How has having a child who experiences disability impacted your relationship with your faith community?**

When asked how caring for a child or loved one experiencing disability impacted their relationship with their faith community, all participants had both positive and negative feedback. Most of the feedback, however, was negative. In describing the impact of disability on their relationship with their faith community, one participant said, "I wish I could say more positive things about the church." In reference to the COVID-19 pandemic, another participant said, "When our child, who could

not wear a mask, needed the church to protect her, the church was only concerned about their personal freedoms.” One key desire for parents and caregivers in this study is that both they and their children feel included.

One of the most helpful things that churches did was make children experiencing disability feel welcome. One participant mentioned how nice it was to hear a child ask, “Can [your daughter] sit by me?” It was encouraging for parents to hear other children name their child as a friend. At the same time, the interaction with other kids and their parents could be accidentally harmful. Hearing other parents talk about their children’s achievements was often difficult. It served as a reminder of their child’s limitations. Knowing that they were often not invited to events or out with their friends from church was painful. It was more painful still not to know if it was because others were uncomfortable asking or because they often have to say no due to the care demands of their child or loved one limit their free time.

Getting to their faith communities and participating in worship is hard for families impacted by disability. It can also reinforce the sense of isolation and loneliness that many participants feel in their faith communities. One participant noted how difficult it was to attend a church that did not meet ADA standards due to the law’s grandfather clause exempting older buildings from accessibility standards. They would have to carry their child and his chair up the stairs separately, then disassemble and reassemble the chair to enter the sanctuary. Another parent mentioned having to carry their child up the stairs while the elevator remained broken for months. Many participants were consistently let down because they were faced with situations their child could not handle. Sometimes, when their children had difficulty in the worship service, people would stare at them or even ask them to take their child out. One participant said that he was asked, “Why can’t you keep your child quiet?” Often, they felt like their child’s needs were not a priority. When the needs did feel like a priority, it made a difference.

Multiple parents mentioned how much it meant when church members took initiative and made sure their child was taken care of in class or in worship. Some churches did an excellent job of helping them with their child while they were at church. Some participants had people at their church that made sure their child was 100% taken care of so they could participate in an adult class and the worship service without having to focus on the care needs of their child. One of the participants who experienced this said that their child “knew who loved them and the ones that did made a real difference.” Caring for a person with disability is so

involved that it is literally a full-time job. A break at church might be the only break that parent or caregiver gets all week.

A major desire of most participants was for people to come “get their hands dirty” with them. There were times when people would share about praying for their child, but this was frustrating when what was needed was help. When churches helped, it had an impact. When churches did not show up, it felt like “broken promises.” One participant said the phrase “let us know if you need anything’ is a joke.”

People do not always know how to react to disability. One participant said, “It makes people uncomfortable.” Another participant said that he could tell it made people uncomfortable and often they would not come up and speak to him or his family. He said that he understood because he did not always know how to talk to people about what was going on either. One participant shared that “sometimes the loneliest place in the whole world is in the middle of a crowd.”

#### **Question 5: What could churches do better to support families like yours on their spiritual journey?**

For question five, two dominant desires surfaced for parents and caretakers: the need for education and the need for action. So much harm is done because people do not know and do not make the effort to learn about disability. Additional harm could be avoided and good could be done if churches would be more action oriented. This subsection will begin by describing how participants believed churches could be educated and then offer potential action steps that also surfaced as a result of the interviews.

One desire that surfaced often among participants is for people to ask them about their child. The participants are generally comfortable talking about their child and the disability their child experiences. A rude question or a poor question is better than no question. One participant said, “I don’t get upset with bad questions or stupid things people say because you don’t know what you don’t know. What I get upset with is saying nothing at all.” Participants want their churches to talk about it. One participant said that one of their church’s core values is care for the marginalized. The church has a “list” of marginalized groups and her husband suggested that disability be added to the list. Much time has passed, and disability still has not been added.

All participants mentioned how important it was for people to be educated concerning disability, not just for their child, but for the community in general. Educating congregations concerning disability



might mean learning about common disabilities so that church members would be able to recognize and properly welcome most people experiencing disability. Another point that surfaced was using “people-first” language, so persons are recognized first as persons rather than being identified with the disability they experience.<sup>11</sup> Several participants suggested learning who experiences disability in the community and proactively getting to know them, learning their needs, and engaging with them. Persons experiencing disability attend church less often than persons without disability, even though they consider it more important.<sup>12</sup> There is a large community of persons experiencing disability who have given up on going to church. Churches should learn where persons experiencing disability live in proximity to the church and visit with them and get to know them. The best way to get educated concerning disability is to talk with persons experiencing disability and their caregivers.

The second theme that surfaced was the desire for action. Again, a consistent theme during the interview process was the desire for people to simply show up. One action that churches could do is provide respite for parents and caregivers. As mentioned in the earlier section, parenting a child who experiences disability is exhausting. Churches that host nights out or VBS’s for children experiencing disability so that parents can get a break made a huge impression. Online worship was particularly helpful during the pandemic. Because many of the participants’ loved ones were immunocompromised, they were forced to take extreme lock-down procedures during the pandemic. Everything churches did to help these families worship and stay connected virtually was helpful.

Another important way to help persons experiencing disability and their parents and caregivers feel included is to visit them—again, to just show up. One parent mentioned that “intentionalism” seems to be lacking in the church. Parents often wanted churches to insert themselves more forcefully into their lives. The participants recognized the difficulty in this

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<sup>11</sup> The article, “People First Language,” by Kathie Snow is considered the gold standard for explaining the need to identify the person by their personhood first rather than by their disability. Kathie Snow, “People First Language,” *Disability is Natural*, last modified January 16, 2001, accessed March 27, 2022, <https://nebula.wsimg.com/1c1af57f9319dbf909ec52462367fa88?AccessKeyId=9D6F6082FE5EE52C3DC6&disposition=0&alloworigin=1>.

<sup>12</sup> Gerry Hendershot, “A Statistical Note on the Religiosity of Persons with Disabilities,” *Disability Studies Quarterly* 25 (Fall 2006), accessed March 25, 2022, [https://dsq-sds.org/article/view/813/988#:~:text=Table%20%20shows%20that%20people, respectively\)%3B%20that%20is%2C%20by](https://dsq-sds.org/article/view/813/988#:~:text=Table%20%20shows%20that%20people, respectively)%3B%20that%20is%2C%20by).

but would rather churches err on the side of being too aggressive than on the side of being too cautious. Intrusions can be forgiven more easily than neglect.

**Question 6: What are some important things for other people of faith to know concerning disability?**

Two themes surfaced from question six. The first was participants' desire to be asked about their child or loved one, as also named previously. The second theme that arose was the desire for others to not assume things for which they have no knowledge. These two themes are connected and will be fleshed out in this subsection.

A strong desire among those interviewed is to be known. They want to be known and they want their children and loved ones to be known. Persons experiencing disability and their families often go unseen, unheard, and unknown. Whenever someone lets them feel known, it makes an impression.

Sometimes people make assumptions about participants' experiences because they know others who are impacted by disability, but this can be harmful. These assumptions might be made concerning the life rhythm of a family. The person might know someone with the same or similar diagnosis and thus make assumptions about the participants' child who experiences disability. A quote that came up more than once was, "If you've met one person with autism, you've met one person with autism."<sup>13</sup> This quote is used across the spectrum of disabled experience, not referring only to those experiencing autism, but pointing to the diversity of all persons experiencing disability even when they have the same diagnosis.

Persons in the study wanted people to know that caring for someone with disability is difficult. One participant said it often feels like "drowning." While the experience of disability is unique to each family system that experiences it, disability is always hard. One participant's spouse left, and he had to care for his son for twenty-four hours a day: "For a year after my wife left, I was alone with [my son] and everywhere I went, he was with me every moment. And I can't express what that's like. To be [constantly vigilant] 24-7. I mean, it's just very difficult. It's very stressful... I have been diagnosed with PTSD."

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<sup>13</sup> John Swinton, "Reflections on Autistic Love: What Does Love Look Like?" *Practical Theology* 4 (2011): 269.

Participants all want people to understand how much they love their children and their life even though it is difficult. There is a consistent feeling of blessing that all participants associate with their children and loved ones who experience disability. They have been transformed by the children or loved ones in their care.

### **Question 7: What are some important things for pastors to know concerning disability?**

The last question concerned what pastors or church leaders (depending on the leadership structure of each church) should know concerning disability. One theme predominately surfaced: participants desire their pastors to be assertive in approaching those experiencing disability and their caretakers. This means that pastors and religious leaders should take a strong lead in educating the congregation in disability awareness and advocacy.

Parents had a strong desire for pastors to be assertive, or even “aggressive,” in reaching out to families impacted by disability. One caregiver remembers a former minister who went out of his way to make her brother feel included and how much of a difference that made for him and her whole family. Another participant desired for pastors to have educated themselves so they could come with actual solutions, rather than more questions. One of the participants grew up watching his father interact as a minister. He learned from his father that preaching is not the most important job of the minister. The most important job is getting to know the people. “Once you get to know the people, you’ll know how to serve them.” According to this participant, taking the time to care for the people in the congregation is the essential task for the minister in serving those experiencing disability and their families.

### **Ministry Implications**

#### **Practical Trajectory**

What now? What should churches do that want to better engage families impacted by disability? A few ideas surfaced from the themes of the research conducted for this project.

First, churches must seek out families impacted by disability. Church leaders should not assume that families impacted by disability will tell them what they need. Too often, these families have told churches, church members, and church leadership what they need only to be let down. Faith communities are going to have to build trust with the community impacted

by disability. They should plan to create communication lines and keep them open. They should err on the side of being too assertive rather than too passive. Through getting to know these families and hearing their stories, churches can learn to do community with them.

After getting to know these families, churches must include them. They must find ways to include them and their children, both normative children and children that experience disability, in congregational life. Churches must include the family members who experience disability in any activity in which they are capable of participating. If they are incapable, make sure that this incapability is not imposed by structures, physical or social, within the church. Learn to celebrate different milestones with these families in the way they desire to celebrate them. This demands individualized ministry and new metrics—metrics that are less concerned with efficiency or numbers.

Learning to embrace and include families impacted by disability will force congregations to slow down. Western industrialized society is in a hurry, and it is affecting us individually and collectively. The addiction we have to hurry has been diagnosed as “hurry sickness.”<sup>14</sup> Learning to embrace and include families impacted by disability might also, indirectly, help churches be spaces where spiritual formation happens. Our churches can fulfill their commission to be good-making communities (i.e., communities that form individuals to do good because of inherent good-making qualities within).<sup>15</sup> It is often busyness rather than desire that keeps people from growing spiritually. Families impacted by disability might be the key to resisting the totalism, as Walter Brueggemann has described, of the society that has us imprisoned.<sup>16</sup> Children experiencing disability are immune to totalism. Being forced to resist the pace of the world might help the church stand in opposition to the unhealthy rhythms of life that Christian churches have too easily embraced. Families impacted by disability might be exactly what the church needs to become a space for counter-formation.

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<sup>14</sup> John Mark Comer, *The Ruthless Elimination of Hurry* (Colorado Springs: WaterBrook, 2019), 46–51.

<sup>15</sup> Scott McKnight and Laura Barringer, *A Church Called TOV: Forming a Goodness Culture that Resists the Abuses of Power and Promotes Healing* (Carol Stream: Tyndale House Publishers, 2020), 20.

<sup>16</sup> Walter Brueggemann, “Testimony That Breaks the Silence of Totalism.” *Interpretation* 70 (2016): 276.

### Practical Trajectory for Parents and Caregivers

Both listening to parents and caregivers of persons experiencing disability and being a parent of a child who experiences disability have proven something that I suspected before this process: the impact of disability can only be fully grasped by experience. If that is true, then the best resources for churches to understand and engage with families impacted by disability are families impacted by disability. This demands that parents and caregivers be willing to take the lead in educating religious leaders and members of their faith communities. Again, “You can’t know what you don’t know,” and the families that are impacted by disability are the ones that know. Some responsibility falls on them to educate. Religious leaders and faith communities have the responsibility to listen, but parents and caregivers have the responsibility to educate.

A part of me did not want to write the last sentence. The last thing that families impacted by disability need is more responsibility. These families already have more responsibility than they bargained for—yet they are the ones with experience and knowledge. Most of the harm done in faith communities and by faith leaders is unintentional. All parents and caregivers might not be equipped to be a mouthpiece for the community impacted by disability. However, most parents and caregivers of those experiencing disability have been equipped to advocate for their child and to educate others through navigating the education and healthcare systems and educating others, even if they have only educated friends or family members.

Another helpful practice might be mentorship. Receiving a diagnosis of disability is devastating for a family. It touches every part of their lives. Navigating this season feels like a roller coaster. Parents and caregivers who have been navigating it might be the best resources for families freshly devastated by disability. However, even other parents or caregivers of persons experiencing disability should proceed with caution. Some parents, especially those with a recent diagnosis, do not want to talk about disability. Naming it or admitting a child experiences disability feels like embracing this new reality. Sometimes not naming it can make it feel like this new reality does not exist. Parents engaged in this kind of thinking will not be receptive to talking about the impact of disability. They might even receive such talk with anger and hostility. That is okay. Disability is difficult to process, and everyone deserves room to process in their own way. However, other families impacted by disability will be able to approach and talk to families that have just received a diagnosis more readily than families that have not been impacted by disability. They will also be more

sensitive in considering when to engage and when to disengage. It should be remembered, as one participant in the study said, that “intrusions can be forgiven more easily than neglect.” Developing a mentor program where families impacted by disability might receive mentorship from other families who have navigated disability and are healthy spiritually could make a big difference.

Finally, another helpful tool for families to process disability might be group spiritual direction. Families impacted by disability that continue to engage in their faith and with their faith community are already receiving much of what it is that spiritual direction can offer. They are already learning to recognize what God is doing in their lives. Learning to notice and react to divine activity is necessary for families impacted by disability to survive spiritually. However, group spiritual direction facilitated by a director impacted by disability (or a director sensitive toward and educated about disability) could be a way both to connect families impacted by disability and help families with more recent diagnoses find mentors. This might be more effective than a support group because spiritual direction is designed to deal with the impact of practical matters of life on personal and collective spirituality. Disability entails a spiritual crisis, and finding a community that is seeking spiritual healing for similar crises might fill the gaps that faith communities have left open.

### **Conclusion**

I was surprised by the consistency of the experience among the parents and caregivers. No two stories were exactly alike, and all the stories had elements that went outside of the general experience that emerged. And yet, there was a similar experience connecting each person that participated. Devastation. Pain. Loneliness. Contentment. Acceptance. Love. All these words could describe each story.

What changed my life were the stories and the experiences relayed by the parents and caregivers who participated in this study. It was hard for me to listen and not share parts of my own story and experience with them—because I also get it. And I am so glad that I had the honor to simply listen. Listening changed my life. I hope that others get the chance to listen to these families and their stories. It will change their lives, too.

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