



PASTORING FOR LIFE

DISABILITY

LIVING INTO THE
DIVERSITY OF
CHRIST'S BODY

BRIAN BROCK

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Introduction

Welcome. Gentleness. Presence. Attentiveness. Commitment. This is all Christians need to know about disability. Simple words that sometimes ask more of us than we want to give.

Most Christians have never thought much about disability. This little book is for Christians who want to know where to begin thinking about it. It offers support to Christians with disabilities who want to help other Christians be more welcoming to disabled people.

It is for pastors who are busy and care about ministry but don't have time to read a heavy academic book on disability.

It is for parents who have adopted or birthed a child with a disability and are amid the bewildering process of figuring out what this might mean for their view of God and their life in church.

It is for congregants who are painfully aware that there are people with various disabilities in their churches, whose lives can be a struggle, but are not sure how to extend a better welcome to them in church.

It is for Christians and their families who are struggling to understand how to relate to—and how God relates to—their loved one who has dementia or who has had a stroke or who has had a paralyzing accident.

Christians in all these positions are in a painful place but also one with great promise, because once we begin to think about disability, we find ourselves led into the heart of the gospel in incredibly fruitful ways. Thinking about the disability experience also reminds us that our lives are fragile and vulnerable and that our own disabling may concern us more directly than we had ever considered.

To begin to look directly at the diversity of the disability experience also promises to open our eyes to things in the Bible we had never before seen. In noticing the diversity of the bodily experiences of the people around us, we begin to glimpse aspects of Scripture that we had previously missed. To notice new details in the Bible is almost inevitably to be driven to revisit long-held theological assumptions about disability—and what it means to be a human being.

The aim of this book is to help contemporary Christians to take a journey. The journey begins by thinking about the *experience* of disability. Wrestling with what it might mean for each of us to become disabled offers readers a better vantage point from which to reconsider the unnoticed disability experiences in Scripture and the overlooked capacity of Christian doctrine to shed light on them. The aim of this journey is to help Christians reconceive how we live as church.

A lot of good things are said today in schools and governments and businesses about inclusion. Inclusion is good, but it still presumes that disabled people are a “they” whom “we” need to include. I want to help Christians get beyond this modern habit of assuming that we cannot talk about disability without dividing up humanity into those who have disabilities and those who do not. And I want to do it in a way that helps Christians reimagine the day-to-day activities of the church.

It is important to recognize that books that move directly to telling us how to act and live differently are ones that do not empower us to find our own ways to change. We don’t need to be told what to do but shown how to think creatively about what needs to change in our churches.

The books that actually help us change begin by stimulating creative thought. Stimulating thought, however, very often entails melting down our certainties so that they can re-form in new shapes. Sometimes the only way to provoke and invite creative new insight is to produce confusion in place of misplaced certainties. Sometimes our ways of thinking are so shrunken and dried out that they need the uncomfortable process of roasting or scalding so that they can crack open and come to life again. This roasting and scalding is never comfortable. But it matters. Without spoiling the first chapter, let me urge you not to skip it—though it will be uncomfortable.

Once we see that something is wrong about our world, and our church, we can begin to respond to its inhuman and destructive aspects with real insight. Far too many Christians have never been caught on the horns of the dilemmas posed by the disability experience. The first chapter is designed to reveal the problem of disability for the church in all its complexity. It would be wrong to then immediately offer a formula for how to meet this dilemma.

Once the roasting is done, we have to tackle the job of rethinking how we once understood the disability experience. This is what we will work on in chapters 2, 3, and 4, which draw attention to the biblical threads and theological claims that can help us understand disability better. Having made this disorienting and reorienting journey puts us in the right place to receive some useful hints about how to move, practically, toward being a more welcoming church to all the diversity of humankind. We are in the right place because we will have both the tools to think creatively about the challenges of our own unique situations and a sense of where to look to begin to put these effective but practical hints into practice.

As we proceed, I will point in passing at other things interested readers might like to read among the more recent academic work in disability theology. The main way I will do this is by quoting the sources that have formed my thinking on a given topic.

Make no mistake, my final target is wholly practical. I want to help the church rediscover the power of a gospel that bubbles up in the interactions that the Holy Spirit is calling Christians into with those who today carry the label “disabled.”

ONE

Nobody with Disabilities in Our Church

By chance or by providence, I officially entered middle age while preparing to write this book. The rite of passage was a visit to the emergency room one Saturday morning. I'd finally managed the cliché of injuring myself with a power tool during a weekend do-it-yourself job around the house.

That sunny Saturday morning in November I had been cutting up bits of old furniture and scrap wood for kindling with a circular saw. Next thing you know, I was cutting my finger. For a millisecond I felt nothing. "Whew!" I thought. "None of me is on the ground, really dodged a bullet there!" Then came the blood.

From the instant I saw it beginning to pool dark and red through the tattered gash of my yellow work gloves, my world began to tilt. First a little. Then a lot.

If I was angry at myself when I did it, I felt *really* embarrassed sitting in the emergency room with the other middle-aged guys with hands and arms wrapped in bloody bandages. Turns out that I had managed to sever the tendon on the back of my right middle finger.

I saw all my middle-aged friends again, along with a few new ones, over the next few months as I attended appointments for reconstructive surgery, follow-up care, and physical therapy.

In a flash, with a second's lapse of attention, my world had changed, radically unsettled. I'm right-handed. It's been months now

that I've been *trying* to write this book with that mangled middle finger. It's been getting in the way, not just in my body but in my mind. I am amazed how the loss of a tiny portion of my flesh has so directly affected my capacity to *do* things. Even more shocking is how quickly and deeply not being able to *do* something alienated me from my familiar relationship with the world.

The finger is no longer transparent to my purposes. What I formerly could do without even thinking about my finger I can now sometimes not do at all. Other times I have to think far too much about how I am going to circumvent that darn finger, which not only doesn't work but is sticking out and getting in my way!

More unsettlingly, the loss of capacity has made me begin to worry about my identity. If I'm anything, I think of myself as a writer. I constantly need this finger to type or write longhand. How will I get on if it no longer works?

Only months later does it occur to me that the existential tremors that my damaged finger has unleashed in me might be a sort of gift. The finger has forced me to stop and consider what we're actually saying when we say that someone "is" disabled or "has" a disability.

I am not suggesting that my injury is equivalent to more serious or lifelong disabling conditions. I am grateful that it did not become infected, which could have been life threatening or even led to the amputation of the hand or more. What the injury has done is to help me think more concretely and to listen more closely and comprehend more of what people are really saying when they speak of disability experiences. One of the most difficult aspects of talking about disability is the awkward fact that most people have precious little first-hand experience of it—or think that they don't (more on this later).

Pastors and the Disability Experience

Most Christians today tend to think of disabled people as a class of people with serious physical, sensory, or mental impairments. Good people will extend kindness and a helping hand to them.

Unless it strikes someone close to them, the great majority of churchgoers tend not to think too often, or theologically, about disability in the church. Not having many chances to rub shoulders

with those with disabilities, disability never seems to warrant close thought.

These assumptions explain many pastors' first response to the question of how they think about ministry to people with disabilities. Hans Reinders reflects on the most common way pastors speak about disability in their churches: "The times that I have asked ministers and pastors about members of their congregations who are disabled, the most frequent response is, 'We don't have them.'"¹ This is a remarkable claim. If it is true that most congregations do not have disabled members, huge numbers of people are not in church. If it is false, ministers are widely affected by the serious problem of not seeing what is in front of them. Either way, serious questions need to be asked about why this is such a common response among pastors when asked about disability.

Having little or no regular contact with people with special needs, most Christian pastors are therefore only slightly embarrassed to admit that they haven't thought hard, or theologically, about disability. They are not thinking about it because they are not regularly confronted with it in their church.²

Bethany Fox interviewed pastors from a wide range of Christian traditions in the Los Angeles area. Aside from pastors explicitly responsible for special needs ministries, she found most pastors tended to describe their relationship to people with special needs as "responsive." This is the second most common response from pastors when asked how they might relate to people who would come to their church with special needs. In one pastor's words, "When people come to us, then we try to answer those needs and help them in whatever way we can."³

Some pastors, Fox found, were able to remember having children with intellectual or developmental disabilities in their churches at one time or another. Few, however, could call to mind disabled people who were currently in their churches. Somehow, disabled people seemed to disappear from church after passing Sunday school age—despite the fact that mentally, they still *were* Sunday school age.

The stories pastors told about those with special needs in their congregations were almost always framed in terms of the needs for help or accommodation that those people brought into the congregation.

It seems clear that most pastors perceive the appearance of someone with disabilities in church as a challenge. They create “burdens and practical tasks for the church’s leadership that benefit only the people with disabilities themselves.”⁴ These are the facts on the ground about pastors’ views of what it means to have people with special needs in church. The question is why these views are so widespread and powerful. On closer examination, we discover that they are deformations of the Christian gospel that affect far more than pastors.

Where Are People with Special Needs on Sundays?

The United Kingdom is home to about sixty-six million people. Official government statistics calculate that over eleven million of them have a limiting long-term illness, impairment, or disability. The most commonly reported impairments are those that affect mobility, lifting, or carrying. This hints at why the prevalence of disability rises with age. Around 6 percent of children are disabled, compared to 19 percent of working-age adults and 45 percent of adults over state pension age.⁵ About 13 percent of the population of the United States live with a disability, according to government statistics.⁶

There are clearly many people around with disabilities. Yet people with disabilities are statistically far less likely to attend worship services, Bible studies, and other church activities than those without disabilities.⁷ How can this be? Could people with disabilities need God less? Perhaps they don’t want to worship with other Christians?

Far from it.

One recent US study of more than four hundred churchgoing families with a special needs child found that a third had left a church because they found it unwelcoming. Almost half said that they had refrained from participating in some church activity because they felt their family member was not welcome.⁸

Erik Carter is a social scientist who focuses on the question of what makes a church, synagogue, or mosque successful in welcoming people and families with disabilities. In a large empirical study undertaken in the US, he found that the common denominators expressed by people with disabilities are that they wanted to be present, to be invited, and to be welcomed and known as well as accepted, supported,

cared for, needed, and loved. He also discovered that churches trying to meet these aims in the standard way—through inclusion—have problems reaching these goals. As Carter observes,

Contemporary conversations about inclusion in churches tend to be limited in two ways. First, they frame inclusion as a construct primarily concerned with physical location. Such a narrow lens neglects the primacy of relationships, which can still be limited or altogether absent even when people with and without disabilities navigate the same spaces. Second, they do not place the personal perspectives of people with disabilities and their families at the forefront of the discussions. Such an omission can inadvertently lead congregations to adopt practices that ultimately do not lead people to feel welcomed and valued.⁹

Amy Jacober is a theology professor with over two decades of on-the-ground experience in various capacities with the parachurch organization Young Life Capernaum. Young Life Capernaum hosts weekly events and annual summer camps to share the gospel with and disciple teenagers with disabilities. Jacober has also done extensive surveys of the experiences of children, teens, and families in churches. In her interviews, she asked the neutrally worded open-ended question, What is your experience with church? What she found agreed with other research showing that people with disabilities (and their families) very often experience church as an unwelcoming environment.

Overwhelmingly, the experiences were negative. . . . One mother offered this response, “So I tried to look and every church I called, I asked ‘is there a place for a special needs child?’ every year as he got older—ten, eleven—there was not one church that I found that had a place for special needs kids. . . . I could not believe with all of the programs we have . . . there’s nothing that would have a child with disabilities and stay connected and get taught about Jesus or anything spiritual.” Again and again I was told that families cherished the church, but once they had a child with a special need, they could no longer be involved. I heard stories of being asked to leave as their child was too disruptive. Others were told that no one was able to handle their child. For many, they experienced sitting in pews, working hard

to “handle” their own child and no one came to say hello, let alone help. What all but a few had in common is that they felt unwelcomed in countless small ways. It wasn’t that anyone told them out loud church was no place for a family impacted by disability, but that was the message they received loud and clear. At some point, they just got too tired to keep trying and experience rejection and stress in a place that was established by God to allow us to bear one another’s burdens.¹⁰

In radiating this passive lack of welcome, churches, like most places in modern Western societies, become yet another social space into which people with special needs feel they can’t go. The reasons these social domains are experienced as no-go zones are pretty obvious, as one leader in disability studies joked: “People with disabilities were a cultural minority because they, like other minorities, shared a cultural diet: fast-food drive-throughs. Drive-throughs sidestepped the difficulties of physical and social barriers. Eating and living in private—due to physical and stigmatizing barriers—has defined what it has meant to be disabled.”¹¹ This observation is particularly painful to Christians, since the church’s self-understanding is fundamentally rooted in the idea of being open and welcoming to every human being. Christians like to think of themselves as more welcoming than McDonalds.

Ironically, those who work to give adults with intellectual disabilities a meaningful life are always on the lookout for free activities to which they can take those in their care to give them the chance to mix with, and perhaps even find friends among, the full diversity of the wider public. Activities they can do without paying to join in are incredibly difficult to find.

How often do those in group homes come to our churches?

On Failing to See

The demographic data seems to confirm many pastors’ sense that people with special needs, especially those with learning difficulties, are not in church. The “we don’t have any” view of pastors looks suspiciously like a self-fulfilling prophecy. The aim of this opening

chapter is to examine the psychologically powerful assumptions that perpetuate this self-reinforcing prophecy.

We need to understand why disability lives in the outer reaches of most Christians' consciousness. When disability is assumed to be a marginal human experience, it can only become a conscious topic for pastoral or theological reflection when it befalls a family member or loved one. If we skip asking *why* Christians don't recognize the disabilities of their neighbors as theologically and pastorally significant, we will have little ground to explore the biblical and theological issues that it raises.

It would be saying too much to assert that without discussing experience we cannot read Scripture rightly. But when Christians have considered disability not worth the effort to think well about, they will be forced to cobble together answers to the questions it raises under the pressure of a pastoral dilemma. We can do better. Answers cobbled together under pressure are rarely well thought out.

Here's the amazing truth: once we begin to give a little more concerted effort to thinking well about the disability experience, we discover that what we once experienced as a threatening disability crisis now appears as a promising gateway to a truly life-giving way of following Christ.

The Disabling Experience

I opened with the story of my finger to highlight why the experience of being able-bodied makes it so difficult to take disability seriously as a theme deserving more concerted attention from pastors, theologians, and church people.

My disability experience begins with a finger. Yours might begin with your eyes, your ears, your back, your knees, or even your memory. You will no doubt have already begun to come into contact with disability secondhand as someone you know has mental health issues, a birth defect, or a learning difficulty.

Probably the first thing I learned from my finger injury was how quickly worries arise—and how all-consuming these worries are—about what will happen if the loss of function is permanent. The second realization comes hot on the heels of the first one—you discover

how shockingly distorting intense or chronic pain is on the mind, how disorienting it is. As the pain subsides, one begins to learn how many formerly easy things have become difficult or impossible with one hand—washing your hands, for instance, or carrying an object of any size while trying to open a door, or pulling a trash bag out of a can.

Perhaps for the first time in my life I was experiencing disability firsthand. I had been literally dis-abled. I had been rendered unable to *do* things I had once done without a second thought. The finger, once so useful to me, now constantly gets in the way, bumping into things and making it almost impossible to write.

The injury happened the week before I was to take an international trip. The surgeon told me that it would probably be best to leave the bandages in place for the nearly three weeks of the trip rather than trying to change them on my own while traveling.

The trip was to California, where I had to lecture and go to conferences through the most painful and awkward phase of the recovery process. Often, I had to elevate the hand in order to keep it from pounding with pain. The trip fell just before Thanksgiving. I spent this one as a guest at a pastor's house with several congregants from around the world, including an elderly bishop from an African American Pentecostal tradition.

I'd been to healing services before, but I'd never been cold called for a body part to be grasped and prayed over. At first, I wasn't sure what was going on. It clicked in when I heard the line, "We pray for the enemy spirits to come out."

Having my hand grabbed and prayed over certainly surprised me, though I did not find it offensive. It was not too different from shaking hands, after all. It was, however, my first personal experience of being "ambush healed." For the first time I directly considered how uncomfortable it would be to have the preacher's hands over my ears if I were deaf or, as some have experienced, to have their unseeing eyes anointed with the preacher's spittle (following Jesus's example in Mark 8:23; John 9:6).¹²

About a week later, back in Scotland, a friendly nurse gently unwraps the finger I've not seen in weeks. As the bandages come off, I am shocked.

Disability as Shocking

The finger looks revolting, in the technical sense of the term—it makes my stomach turn. It looks nothing like it used to. Purple, swollen. The skin broken and mottled, and an angry gash and open wound across the knuckle. I am repulsed. This is not “me.” I’d almost rather it be gone. To the nurse, however, the finger is just another body part needing attention. She soaks and scrubs and peels dead skin and picks out stitches. I have to admit it looks a little better. I’m grateful, but boy does the finger still feel odd.

It is odd to say, but in the weeks it has been wrapped up it has somehow become an “object” to me. It has transformed into a stiff, painful, and ugly thing, something that I don’t use but instead work around and try not to think about. What was once one of my most useful bits of flesh first became an object, then a problem to be fixed, “a project.”

My mind whirls with the implications of my ugly metamorphosis. My actual body now challenges my subconscious assumptions about the “beautiful finger” that I never realized I had. (Here the mind boggles. How must the paraplegic feel after an accident that has left their whole body uncontrollable and a barrier to doing what they would like to? How must someone who has been badly burned feel about the pain and disfigurement of their new bodily form?)

Even as my finger heals, its incremental improvements do not reconcile it to me. It stiffens, it is discolored, the nail is lumpy and misshapen—nothing like its twin on my left hand.

I’ve been talking about my personal, subjective experience, but it is important that we pause and sit with this reaction for a moment. What does it mean to experience a part of our *own* bodies as revolting, repellant? First, a part we once related to as likable and functional has been *alienated*. I no longer immediately experience it as “me” because it now feels to me like an “other.” It does not do what I ask it to and instead actively obstructs my goals by sticking out there and constantly getting in my way.

Second, alongside this practical difficulty comes a strange aesthetic reaction. I simply don’t like the way it *looks*. My own body is dragging me one finger at a time into new categories, categories

that Christians do not easily admit they have: between working and useless bodies; between beautiful and unsightly bodies.

My being repelled by my finger is thus a sign of an old, old problem, long ago recognized by the early church. Even when we are not aware of it, we harbor unacknowledged images of beautiful and likable bodies. Body *images* so deeply shape our own aspirations and self-understandings that they almost inevitably color our views of other people's bodies, making it difficult for us to love them.

If we are able to be disgusted by a *part of us* that we once loved as ourselves, how easily will we justify our desire to escape from making eye contact with the burn victim or the person with some other disfigurement? Their unsightliness first repels us and then makes it easy for us to justify our lack of love.

We don't see disabled people around us because we have images of useful and beautiful bodies and attractive minds to which they do not conform. It is easier not to look at them, because if we give them our attention, it makes us anxious.

Disability as Identity Challenging

For a while (several months, in fact) I had to wear a splint to immobilize the most affected joint in my wayward finger in order to protect the surgically repaired tendon from detaching. The splint rubs against the adjacent fingers, making the already stiff and unwieldy digit even more painful and awkward. To add insult to injury, the splint doesn't help me *do* anything. Its only promise is that it will help me regain function in the future—if I keep wearing it.

Immobilizing a joint causes muscles to contract and joints to stiffen at an alarming rate. Anyone with any sort of paralysis will know this better than I do.

I could not but think: What if I was struggling to gain mobility not in a finger but in a hand, not in a hand but in a whole arm, not in a single limb but in my whole body? What would it be like to not be able to control the muscles in my tongue or those that direct my eyes?

My stiffening finger is giving me new eyes for the stiffened knees of the person who has had ankle- or knee-replacement surgery. It is making me reconsider the experience of stiffened ankles and wrists of the

person with cerebral palsy, as well as the awkwardness of the hands limited and drawn into immobility by other paralyzing conditions.

I'm genuinely unsure whether it will ever regain enough flexibility to curl my right hand around a pen. For someone who writes every day, sometimes for hours a day, this is not a superficial worry. The loss of this *particular* bodily functionality threatens my identity.

While I can still write, the hand that once transparently recorded my thoughts has become a cumbersome and awkward barrier to that very process. My body seems determined to upend "me"—or at least that "me" that I have put so much of myself into.

As it heals, the finger begins to recover function—laboriously and incompletely. As it does, I cannot but feel a pang of loss. I've not lost a whole finger, thank God, let alone a limb, but the function will never be the same. It will always hurt and be sore in the cold or if I hit it.

Thus in every waking hour my finger, in all its pain and awkwardness, continually poses a question to me. It holds before me a set of losses; it forces me to grapple with my body's ugliness; it unsettles the certainty that I know who I am.

Ultimately the questions it presses on me are more basic: Will I embrace or fight the alteration of self-image this entails? Is this new unsightliness and unwieldiness really who I am? These are questions that will not be answered without squarely facing how my finger now deviates from my unconsciously embraced ideals and dreams of aesthetic and functional normalcy.

Put theologically, can I really accept my *own* unsightly member? As we have seen, this is a theological question because my own bodily ideals are tied up with how I think of the worth of others' bodies. My finger raises the question: Do I *truly* accept those in the body of Christ who diverge from my ideals? The aesthetic and functional ideals I must confront if I am to accept my finger are not ones Christians can typically admit. Unacknowledged ideals die hardest.

Theologian Frances Young's son, Arthur, has cerebral palsy. It is worth pausing to define cerebral palsy, since we will meet several people in chapters to come with this medical diagnosis. Cerebral palsy is an umbrella term for a condition springing from damage to the brain that usually occurs in the womb. The damage to the brain may cause epileptic seizures, and it is often associated with difficulties in

controlling the muscles. This lack of muscular control often causes sight and communication difficulties, as well as the contraction of large muscles, which can be quite painful. In more severe cases it can also cause learning difficulties. Arthur's cerebral palsy is quite substantial, and he was never able to walk or talk.

Young had raised Arthur to adulthood when she visited a L'Arche community in France. L'Arche is a global movement in which Christians with and without learning impairments live together. At one meal Frances found herself sitting opposite Edith who, like Arthur, had cerebral palsy. She writes, "To my shame, I felt disgusted by her slobbering her food, the red wine she clearly loved splattered all over the napkin round her neck. I was deeply chastened by my reaction—perhaps I was meant to see how people sometimes felt at table with my son."¹³ Frances's bracing honesty takes us to the point of no return in this first chapter. We will get no further if we refuse to admit the disgust, resistance, or discomfort some people evoke in us.

My finger offers me the gateway to a true understanding of disability precisely in its defection from my ideals about what I want it to be. The truth is that I don't like what has happened to me, I don't like how my finger looks or how it works, and if I could bring the old finger back, I certainly would. This is a defining spiritual moment. I can choose to hide from these negative feelings, to bury my loathing of my body part and pretend that I don't feel it. If I take this route, however, I will have to build up defenses against the questions of others about my finger. I will also have to deny or suppress my anger at what I feel I have lost in its ugly metamorphosis.

There is another road. I might admit my vulnerability and discomfort. I might squarely face the challenge to my self-identity my body is forcing on me. Down this road lies transformation.

We've all met elderly people who cannot reconcile themselves to the aging of their body or to the loss of the capacity to drive or live by themselves. Often such refusals to accept loss render elderly people increasingly frustrated and angry. Some of us may have met a pastor or another person with a degenerative disease who refuses to let it be spoken of openly and reacts aggressively to any suggestion that the time might have come to consider letting go of some duties.

The apostle Paul wrote to the Corinthian church: “Those parts of the body that seem to be weaker are indispensable, 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, while our presentable parts need no special treatment” (1 Cor. 12:22–24). Do we have any idea what this really means?

Breaking Disability Down

At the most basic level, my finger injury resulted in what is called an *acquired* disability. It was not a *congenital* disability, one I was born with. From the beginning the surgeon reassured me that the severed tendon would heal in time, and I would regain full functionality. That means mine would be a *temporary* disability. The acute phase of my ordeal lasted about three months. Yet it was an ordeal, a condition that would pass in one way or another. It was not a *permanently* disabling condition, even if it had some permanently function-reducing effects.

The disabilities that come into most people’s minds when they hear the term “disability” are importantly different from mine. When people hear the word “disability,” they think of people who are totally blind or deaf, are in a wheelchair, or have visible conditions such as Down syndrome. The iconic conditions that come to mind when people think of a “disabled person” are only the tip of the iceberg.

Of course, many conditions fit fairly easily with this common imagination of disability: locked-in syndrome, cerebral palsy, and Tay-Sachs disease, to take a few examples. Even these unambiguous cases, however, may have come into people’s lives in very different ways. The same bodily or mental disability may thus raise remarkably diverse pastoral questions.

There are congenital disabilities that exist because a pregnant mother came into contact with an infection from a cat during pregnancy. Other congenital conditions may come from fetal alcohol syndrome or contact with environmental toxins. The different effects on pregnancies can produce a wide range of birth anomalies, including missing or extra limbs, missing or extra digits, or conjoined twins or twins where one has been negatively affected in the womb.

All these disabilities fit comfortably with the popular imagination of disability. But for some conditions, it is much less clear whether the condition is a disability. While certain conditions may be visible, the condition's power to stigmatize a person is more important than the minimal loss of functionality, such as misaligned eyes or a stutter. In such cases labeling the condition a disability may cause offense to people who do not wish to be singled out for their condition.

Also at the margins of the popular imagination of disability are those people who most assume have obvious functional deficits but who resist being labeled “disabled,” such as Deaf or autistic people. Many in both groups are happy to be called Deaf or autistic but *not* disabled.

Some people who wear medical labels of disability have received that label because of their inability to do some things, even though this inability is not immediately visible, such as those with epilepsy, general anxiety disorder, or chronic pain. For them the label “disability” may be crucial for getting the treatment they need even if many people would not recognize them as disabled and they might prefer that other people not know about their disability.

Taking a close look at these different experiences of disability highlights the reality that there is no *one* thing called disability, no *single* disability experience. In fact, in a way few terms are, the term “disability” is an artificial category, a category that does not obviously refer to a single thing. This does not mean that the physical and mental conditions to which it refers are not real—far from it. It means only that the category is so wide and diverse that it can sometimes mislead more than it illuminates.

It can be compared with an artificial category like “things that are in books.” Many things are talked about in books, practically anything you can think of. People put bookmarks and flowers between the pages of books. People write notes in books. Almost an infinity of things are “in books.” So to say that something is “in a book” is not saying much. It is not denying that there are many things in books; it is just not telling us which things are meant.

So even though the term “disability” is not very precise, it is a term that is so widely used that Christians cannot, and indeed will not want to, avoid using it. We just need to use it thoughtfully. When Christians

use the term “disability,” the main trap to be avoided is thinking of “other people” as disabled. A close second is reducing people *to* their disabilities. The advantage of the language of disability is its breadth, its capacity to draw attention to a wide range of human diversity and life challenges. The best way not to let the language of disability trap us is to break it down into its constituent parts.

We also must avoid thinking of all disability as equivalent to *either* disease or injury. My finger was *injured*, but what resulted was a *temporary* disability. I had a *disability experience*, but I did not *become* disabled. I experienced a reduction of my capacity to do things, but, in the end, I did not come to identify myself as disabled. My temporary disablement could well have been formally recognized by my employer giving me a few weeks of sick leave. If I had injured a different part of my body, such as my leg or back, the government might have recognized my reduction of mobility by giving me a special parking permit, officially labeling me “disabled.”

Breaking down the idea of “disability” to reveal the assumptions that support it helps us think Christianly because it teases apart assumptions about disabled people that commonly lump different types of disability experience together. It helps us appreciate the genuine, and important, differences between human experiences. It has also highlighted the fluid boundary between what we commonly assume to be “normal” and the disability experience. Breaking disability down raises the question of whether the term “normal,” which is its linguistic opposite, deserves the same treatment.

Escape from the Norm

The term “disability” functions more like a mean, in the mathematical sense. If we take one hundred numbers, some are nearer to the outer limits of the set, and some are closer to the middle. The one at the very middle is the mean. If we change the numbers in a group, the mean changes.

The same goes for disability. It is a category that defines a shifting set of human experiences. By implication, what we think of as “normal” is really only the name we apply to that group who looks most like they lie nearest the center of all the human beings we’ve ever

come across. The problem is that the numbers one and one hundred are not intrinsically inferior to the number fifty. But if fifty is taken as the norm, suddenly one and one hundred can be perceived as broken, as odd, as weird.

If we want to think Christianly about disability, it is crucial that we not import presumptions about what is “normal” that make us assume that those humans who are “rare” are problems, as natural as this habit may be. “Normal” is always an imagined entity. In earlier centuries theologians like Augustine imagined the norm using the categories of platonic philosophy, in which there was one perfect human form from which each actual human diverged more or less.

Today we think of the norm in statistical terms. What is normal is what most people are like.

We must learn to relinquish from the outset the assumption that most people are “normal.” It is crucial to do so because when we think this way we cannot but assume that those who have a disability are by definition not “normal.” Belief that some people are “normal” generates a basic problem of thinking that runs like this: “If most people have these kinds of bodies and minds, then they are normal/correct, original/healthy. And those whose bodies are different surely wish they were like the rest.”

This is precisely the logic that made me repelled by my finger. My other nine fingers look and work in one way, but now one finger is different. I wish it were like the others. But it is not. In disability theology this is called the “normate assumption.” I simply assume that the best way for a finger to be is like my other fingers. I never pause to think about the fact that I have one finger that is not like the others, and I will have to either accept this or psychologically repress my distaste for it. No matter which road I choose, my finger will never again be like the other fingers. I make a normate assumption when I think of my “normal” fingers as my “real” fingers. This assumption positions my one “damaged” and “unpresentable” finger as the one that will hold me back. This normate assumption stops me from receiving my one different finger as good, even though it remains functional in its own particular and unexpected way.

Grappling with the problems raised by the sheer diversity of the conditions lumped together under the single term “disability” high-

lights the first and most significant theological point to grasp when beginning to think about disability: getting disability right means *paying close attention to particularity*. I am going to have to find out what my finger will do. I am going to have to find out the sense in which my finger and my hand have a new kind of beauty as they are—scar, bent knuckle, stiffness, and all. Behind this acknowledgment I will need to wrestle with the reality that God has at least allowed it to be this way.

When we transfer this insight about my relation to my own body part to relations with other people, we are really saying something very simple. Paying close attention to particularity really only means *listening* to people. People do have different forms of body and mind. But this does not mean that difference, even if rare, is something that needs to be changed. In the end this will have deep implications for us as we negotiate the disability experience in our churches. There will be no single “solution” or “answer” to the ecclesial dilemmas and pastoral questions raised by the many types of life experiences today labeled disabilities.

Inabilities to Imagine

My finger injury was an ordeal. It was only a passage. Painful, worrying, and threatening permanent loss and disablement at the time, but still a passage. The intense experience passed, transmuted into a scar, some unpleasant memories, and a wonky digit. It receded to only a part of a larger life. It was a passage *in* my life, not *a* life. And this is the problem. I find it very difficult to imagine anything more serious, more permanent, more life changing.

People who are born with conditions that I could experience only by losing some of my capacities have a very different disability experience. Those born without any fingers at all, for instance, often live remarkably full lives and eventually forget that some might label their condition a disability.

We come here to one of the most difficult problems in the discussion of disability: the gulf that separates physical disabilities from intellectual disabilities and mental illnesses.

Those who read and write books can relatively easily imagine acquiring a physical disability. But the very fact that we read and write

proves we do not have a (significant) intellectual disability. It is also to be expected that readers with specific disabilities will resonate with some discussions and find others foreign and difficult to imagine.

Many people with physical disabilities find it uncomfortable to be lumped together under the heading “disability” with those who have more severe intellectual disabilities. Paralympians, for instance, are often highly trained and as competitive as any other Olympian. They can find it discomfiting to have their sport compared with the Special Olympics, in which many competitors have learning impairments. Similarly, Deaf people or people with visual impairments can be offended when they are treated as if they are learning impaired. There can be quite a lot at stake practically in such labeling. I have a friend in Aberdeen who spent the entirety of his elementary school years in a school for the learning impaired—even though he only had sight loss.

Churches are often attracted to the testimony of a person with a physical disability whose story fits comfortably within the narrative that Jesus has saved them and helped them to overcome adversity. But those who can’t fit this script because they can’t speak, because they haven’t “won” or “succeeded” in life, or because they live with ongoing mental illness challenge this narrative of salvation as breeding success and performance. To recognize the problem here is to be invited to a much deeper understanding of the gospel.

Who is Jesus to people who cannot be a success in the terms we would like to achieve? Who is Jesus to those who are not “healed” from physical or mental conditions we would like to have removed if *we* suffered them?

Christians are often so busy wanting to be successful, to be part of growing and therefore desirable churches that *within the terms of our gospel* those who seem not to be able to achieve those objectives become a problem. This may be the central spiritual challenge facing contemporary Christians. People with autism highlight why this conflict about what the gospel means is the heart of the problem of disability for the church, as Grant Macaskill observes.

Persons with autism are often treated with a form of contempt within the church, just as they are in wider society. Those whose autism is less

severe—who might have been diagnosed with Asperger syndrome until its removal from the diagnostic categories—are often dismissed as eccentric or are simply undervalued because they are less charismatic or “likeable” than others. They may be marginalized, may be the object of jokes, or may be seen as oddities. They do not conform to expectations; they do not fit in. Those with profound autism, meanwhile, will often exhibit disruptive behaviors that may well lead to exclusion, both for them and for their families. Churches and church leaders will often pray that their numbers will grow by God providing young families, and that their needs will be met by God providing wage earners and promising future leaders; they pray, in other words, for normal solutions to the challenges they face and expect divine blessings to have such normality. The presence of a socially challenged adult with a recent diagnosis of Asperger syndrome or of a disruptive child with profound autism will not necessarily be seen as an answer to such prayers.¹⁴

We find it almost impossible not to pity those who lack some capacity that we would be lost without—our sight or hearing, our capacity to speak or think. Our vision of people who seem not to possess one or more of these capacities is thus deeply skewed. We simply cannot imagine from where we are what their lives are like, because for us to get to their position would demand we *lose* capacities that we love and rely on.

But how would you experience your life if you had never *had* those capacities? Do we feel cheated that an eagle can see far better than the most well-sighted human? Are we embarrassed at our capacity to think just because there are people whose IQs qualify them to join Mensa?

We can envy those with greater capacities than us or pity those we suppose to have less. Yet it is worth noticing that those who tend to be most pitied, those with the most severe intellectual disabilities, are very often the ones most comfortable with who they are, at home in what they can or can't do.

The Gateway to Disability Theology

I can feel my finger and its pain and awkwardness. I can sense my feeling of repulsion at it. And I must look squarely at the sense of loss

it evokes in me. I can also imagine how I would feel if it was my leg so that I could not walk or my eyes so that I could not see. I imagine the desolation I would feel if I were blind or deaf or quadriplegic.

Here is the problem: when I see someone else with one of those conditions, it is almost impossible to avoid projecting the desolation I would feel at such losses onto others who experience the condition totally differently. “Poor you,” I reflexively think. “What a suffering to be like that.” Projecting our fears and pity onto others who have disabilities we would prefer not to experience is totally normal—for sinners. It is not easily surmounted. We are at the gateway to doing disability theology the moment we decide to fight.

The simplest definition of disability theology is this: theological work necessary for us to receive with joy and practical welcome, and without sentimentality or pity, each and every human being as one for whom Christ died.

It is part of being a human to be unable to *do* things. It is part of *our* being human that we will not be able to *do* things. The condition of not being able to *do* what others can is today called “having a disability.” Christians, however, do not know themselves or others in terms of what we or they can *do* but in terms of what God in Christ has *done for us*. We are the sort of creatures for whom God has professed love. This love is never withheld from us because of the capacities we may or may not have. God does not just love smart people. God does not just love people who can do lots of things.

After Frances Young’s first feeling of disgust while sitting at a meal with Edith, whose cerebral palsy made her eating seem so unsightly, Frances gradually began to admit her feeling of repulsion and the pain it caused in relation to her own son. Admitting this disgust was the gateway to transformation:

Sometime later, on another visit, I sat next to Edith on a sofa after the meal, gently trying to restrain her self-abuse as she repeatedly banged her head with her fist. . . . I’d been through the repulsion, I’d reached compassion—the wonderment was still to come. Next time I visited, Edith had just died. I joined the wake where person after person gave testimony to what Edith had meant to them—it challenged my French, but was somehow all the more powerful for being only half-understood. Afterwards a small group of us visitors went . . . to see Edith laid out

in the little chapel . . . , surrounded by flowers and candles, still and at peace, quite beautiful. We simply gazed in wonderment.¹⁵

“The parts that are unpresentable are treated with a special modesty,” writes Paul, “while our presentable parts need no special treatment.” The foundation of the Christian view of disability is contained in the next word: but. “But God has put the body together, giving greater honor to the parts that lacked it, so that there should be no division in the body, but that its parts should have equal concern for each other. If one part suffers, every part suffers with it; if one part is honored, every part rejoices with it” (1 Cor. 12:23–26).

Becoming One Body

To the extent that my finger made me incapable of being like everyone else and doing what everyone else could do, I was disabled by my injury. I discovered through it, however, a more unsettling truth. My injury and disability exposed my disgust at a member of my own body. My misshapen finger also revealed how easily I could be disgusted at others’ bodies.

My injury was a trauma. When I recall the blood welling up through torn yellow gloves, the feeling of dread still rises unwanted in my stomach. I might think that the finger is ugly and want to say that it is somehow “not me”—but my body knows better, viscerally.

Not long after the injury I watched a popular gangster film that included a scene in which a gangster “sent a message” by throwing a grocer who had insulted his daughter to the ground in the street. He then stomped the grocer’s hands on the edge of the curb for good measure.

The image again hit me straight in the gut. How could he wantonly inflict such horrific damage on a hand that would take months or years to heal and that would never be the same? My own disability experience had begun to do its work. I was beginning to glimpse what it might mean to genuinely “suffer with those who suffer.” I was beginning to have an inkling of what it means to be a member of the body of Christ. It was a lesson that had to be learned against the grain of modern definitions of health and disability.

In the contemporary developed world our understanding of disability and healing is biomedical. We think of disability and healing in *mechanical* and *individualistic* terms. Mechanical, because we relate ourselves to other people in terms of what their bodies and minds can and cannot do. Individualistic, because we assume that a disability is a problem of the individual whose body is not “normal.” In this way “biomedicine frames the conversation about what counts as something ‘wrong’ with an individual, and healing takes place when that ‘wrong’ is removed,”¹⁶ as Fox observes. In the biomedical imagination, my finger is a classic instance of a disability in need of healing.

In the first Christian centuries, lepers, with their disfigured extremities, were the paradigmatic image of disabled outcasts. It was in wrestling with the disabled figure of the leper that the Christian church first began to hammer out its theology of disability. By taking on the challenge of the outcast and unsightly leper, these early Christians were asking what it means, concretely, that Jesus died to save every human being.

Yes, Paul admits, there are some in the Christian community who are different, whom we *think of* as weaker. *But the God of Jesus Christ clothes them in greater honor.* Paul immediately goes on to emphasize that because God clothes these ones who seem different in greater honor, a new social order emerges among Christians in which we are empathetically connected with one another. No cure in sight.

Christians follow a healing Jesus, absolutely. But the modern Christian expectation that Jesus’s healing is simply about curing malfunctions in individuals’ bodies is a truncated gospel. Jesus does change peoples’ bodies by healing them. But he changes far more than bodies, as we will see in the next chapter. In changing their relationship to the eternal God, Jesus also changes their social status and their relationships to the religious authorities and their families.

The early Christians grasped the practical force of the biblical good news in rejecting the common, and humanly understandable, practice of shunning lepers as outcasts that was universal in the ancient world. Christians thus realized very early on that a church that cannot admit and root out its disgust at some bodies will not be a church that serves the reconciling and healing work of Jesus Christ.

The early Christians thought about disability because they realized that doing so is nothing more than thinking harder, deeper, and in a more rounded way about what it means to be a Christian.

The healing offered by Jesus Christ goes far beyond what modern mechanized and individualized pictures allow. It even goes beyond the responsivity that most pastors and congregants believe they extend to people with special needs. When Jesus's healing is afoot in a congregation, the surest sign that healing is happening is that the community is discovering creative, boundary-bursting ways to understand one another and live together as church.

The most likely reason why there are not more disabled people in our churches is that our unredeemed feelings and attitudes toward individuals with disabilities have somehow leaked out, through our looks and maybe even our actions, a message that people with disabilities are somehow not *really* welcome in our churches. To stop sending that message we must grasp—emotionally first and then intellectually—what it means to see one another as members of our own body.

This chapter has drawn attention to how critical it is for Christians to examine their own emotional reactions, especially our experiencing another person as unsightly, as unwieldy, as interruptive. The aim of this chapter has been to begin to think about disability where every Christian must, especially those who don't really feel like they know much about disability.

I began with a story about an injured finger to bring home the reality that living in a vulnerable, creaturely body means we are all one accident away from being disabled. And as we age, we are sure to become less able in one way or another. It is essential to start by attempting to get in touch with this truth at a visceral, emotional level if we are to have any hope of getting our theological thinking and practice in relation to disability straight. If we are still stuck in trying to ignore our own vulnerabilities, we will never relate truthfully to the vulnerability of others. The evasion of vulnerability is fatal to the church. It hurts disabled people directly, and this is a travesty. And as we will soon see, it also falsifies the life-giving gospel of Jesus.

My ultimate aim in this book is to convince you that being a church that has become comfortable welcoming people with all sorts

of disabilities into church is just, well, being church. And that being this kind of church is genuinely exciting.

To get there I've tried to dislodge the extremely widespread idea that disability is only a problem sometimes, when someone shows up at church for whom we feel we have to make accommodations—perhaps because they cannot get up stairs or cannot hear or they make funny noises that we find distracting. When Christians think about disability as that kind of problem, they inevitably put it at the end of a very long queue of genuinely pressing problems—who is going to fix the leak in the roof, who is going to visit the shut-ins—the endless list of things that have to get done around churches.

Disability does not belong on that list. As long as Christians approach it in those terms, they will not be able to avoid sending out unwelcoming signals to people with disabilities in their churches. The problem of disability is really the problem of Christians negotiating their sense of discomfort with difference and with the unexpected. Getting it right makes all the difference in the world.