

# Vulnerable Communion

A Theology of Disability and Hospitality

Thomas E. Reynolds



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## Introduction

About nine years ago my family was regularly attending a mainline Protestant church near our home. We had been introduced to the church through the Mothers Day Out program that it sponsored, and gradually grew to appreciate the community there. It was vibrant and socially engaged.

One day a number of concerned mothers met with the minister to express their frustration and anger over the unseemly conduct of a particular boy in Sunday school. They did not want their children exposed to this child and feared what he represented. For it seemed that this boy was modeling “bad behavior”—verbal outbursts that sometimes involved profanity, a lack of sensitivity to other children’s personal space (occasionally biting them when irritated or provoked) and an unpredictably violent imagination when playing with toys. No Sunday school is equipped to handle problems of this magnitude. So upon expressing their indignation, the mothers requested that the minister call the child’s parents and ask that he not return to Sunday school. Obviously, there were family issues that needed serious and immediate attention.

The “problem child” was ours. My wife received the call early one morning. The minister was deeply apologetic and pastoral in his approach. But the damage had been done. What were we to do? Where could we go? Over the years, we had been through behavioral programs, family counseling, and psychiatric care. At this point, we were just beginning to come to terms with our son’s recent diagnosis: Tourette’s syndrome. Later, he would also be diagnosed with Asperger’s syndrome, bipolar disorder, and obsessive-compulsive disorder. But at this point he was about seven years old, and we knew only of the Tourette’s. We stopped attending this church. In fact, we stopped attending church altogether.

The personal connection is important to the aims of this book. Do my wife and I fault the concerned mothers who confronted that Methodist minister? No, for we too have been concerned about our children hanging around the wrong crowd and being harmed or influenced by unruly behavior. Nor do we fault the

minister, for he was in a predicament. Could things have been handled differently? Yes. And other parents did handle it differently, talking with us directly in an effort to understand, even to the point of befriending us and asking what they might do to help. So one of the basic questions of this book is: what could have happened at this church? More broadly, what can happen in our churches and in our daily lives when we encounter not only people with disabilities, but also other people who are different in some way or another? How can we build bridges of understanding and mutuality, fostering mechanisms of support and empowerment instead of barriers that exclude?

The circumstances at this church were complicated by the fact that our son, Chris, had disabilities that were hidden, not readily apparent in physical form, and that we were only beginning to understand. For example, many people with symptoms similar to those of our son remain undiagnosed and untreated simply because they appear “normal,” even precocious, in many other respects. I cannot count the number of times friends and acquaintances of ours have exclaimed, “but he seems so normal!” In fact, this has been a source of great pain. For Chris cannot live consistently under these kinds of expectations. Consequently, when “abnormalities” such as obsessions, angry outbursts, or tics have surfaced, people that he has come to trust have brushed him aside or discounted him altogether. Judgment has also been pronounced against us, his parents, by well-meaning friends, teachers, and family members. Perhaps Chris is simply precocious or gifted, and we are to blame for not accommodating his unique needs; his symptoms then are indications of frustrations that we have caused by not doing right by him. Or worse, perhaps we have created his condition by doing something wrong, harming him. Chris is indeed a charming, intelligent, artistic, caring, and sensitive young person. And he thrives in some circumstances—but not all.

There are very real physiological factors that interfere with Chris’s cognitive and emotional development, complicate his orientation to the world, and frustrate his relationships with other people. Tourette’s syndrome is a neurological disorder of the brain that causes involuntary movements (motor tics) or vocalizations (vocal tics), and in many cases also involves related disorders such as OCD (obsessive-compulsive disorder) and ADD (attention-deficit disorder). Bipolar disorder is psychiatry’s name for manic depression, which entails extreme mood cycling that, in children, often appears in symptoms like prolonged raging, separation anxiety, precociousness, night terrors, fear of death, oppositional behavior, sensitivity to stimuli, problems with peers, and so on. Asperger’s syndrome is probably the most inclusive of Chris’s diagnoses. It is a high-functioning disorder on the autism spectrum that is, in many cases, associated with Tourette’s syndrome and bipolar disorder.<sup>1</sup> With medical care and the support of schools in the form of IEP’s (individualized education programs), Chris is making his way in the world. But the principalities and powers of the world are not set up to make his way easy.

Given this, and without others understanding the biological nature of Chris’s condition, it has been all too easy for others to suspect he is the product of bad

parenting or a toxic home environment. At intervals my wife and I have internalized these possibilities, forging our way through individual counseling and family therapy. We have often blamed ourselves, and thus become caught up in a cycle of shame and guilt. In an effort to cope, we have isolated ourselves by avoiding social situations. Especially when Chris was younger, it was enough that we frequently had to negotiate our way through anxieties or embarrassing eruptions in public places like church, a restaurant, or the local grocery store, which always elicited condescending gazes and suspicious whispers.

Gradually, however, through the supportive presence of others along the way, we are emerging from our self-imposed seclusion and the narcissistic world it generated. Why do I say “narcissistic”? Because, in a real way, isolation is a protection mechanism against the pain of being excluded, against being exposed as an atypical family, constantly bombarded by infelicitous commentary from people whose otherwise well-intended advice serves to reinforce the negative sense of ourselves as bad parents. More importantly, however, we have sought to protect Chris from the pain of being misunderstood. Yet protective walls can be deceptively insidious. In defending against possible suffering, they ironically create further suffering by cutting off the possibility of healing and companionship in relationships of trust. We feared exposure, shirked from making our vulnerability visible, and as a result, disengaged from the very processes that had the power to bring wholeness. It was like a vortex from which we have been able to escape only piecemeal; and even then, only through the tenacious hospitality of friends, an empowering network of medical caregivers, a loving church community, and, through them, the experience of God’s grace.

How easy it is to misunderstand a person whose humanity exhibits itself in unconventional and ostensibly deficient or dysfunctional ways. In turn, how easy it is to misplace the resulting shame and guilt. The effects ripple outward in uncontrollable and potentially devastating ways. Indeed, mechanisms of exclusion, oppression, and hostility are built upon such grounds. There are implications here that stretch far beyond the theme of disability. In this book, however, the central focus is on disability and the human vulnerability it so powerfully manifests. Why? Not simply for personal reasons, but also because disability is an often overlooked and contested “site” that opens up a range of possible resources and interdisciplinary approaches to the vulnerable and relational character of human existence, bringing to the fore issues of difference, normalcy, embodiment, community, and redemption. For this reason, disability has theological power.

In her excellent book *Copious Hosting: A Theology of Access for People with Disabilities*, Jennie Weiss Block suggests that, of all places, the church should be a model of the accessible community, a point of entry into God’s love that is reflected both in thinking and in acting. For, as she puts it, “the Body of Christ presumes a place for everyone.”<sup>2</sup> But place is difficult for persons with disabilities. Far too often such people encounter a symbolic, if not palpably concrete, sign that reads, “access denied.” This is tragic for both persons with disabilities and non-disabled

persons. Certain people are excluded from participation, and thus their humanity is diminished. The result also diminishes church communities themselves, as disabling principalities and powers constrict the redemptive work of God. The humanity of non-disabled people is then diminished, as well.

This book seeks to reflect theologically on how Christians might think differently about disability and act differently toward people with disabilities. Nurturing communities of abundant hospitality is the goal. However, this means more than the courtesy of providing access points for those otherwise unable to enter and find their way. Hospitality involves actively welcoming and befriending the stranger—in this case, a person with disabilities—not as a spectacle, but as someone with inherent value, loved into being by God, created in the image of God, and thus having unique gifts to offer as a human being. Yet we are up against complex social forces and theological assumptions that make the task difficult.

Moving beyond Block's analysis, then, I wish to forge a path forward by rethinking human community in light of the primacy of relation and embodiment, such that the fundamental character of human wholeness through vulnerability and interdependence comes to the fore. It is vulnerability, as I shall argue, that we all share as human beings. Why is this important? Because it provides a way into more firmly acknowledging and experiencing our deep connections with one another, connections that indicate a basic web of mutual dependence but that all too often become obscured by what Stanley Hauerwas appropriately calls "the tyranny of normality."<sup>3</sup> Rather than autonomous self-sufficiency (e.g., the individual's ability to construct, produce, or purchase), our human vulnerability is a starting point for discovering what we truly share in our differences. And, accordingly, it is a source bearing the precious and fragile grace of solidarity with one another, that is, a form of belonging inclusive of disability. There is, in the end, no hard-and-fast dualism between ability and disability, but rather a nexus of reciprocity that is based in our vulnerable humanity. All of life comes to us as a gift, an endowment received in countless ways from others throughout our lifetime. When we acknowledge this, the line between giving and receiving, ability and disability, begins to blur. Theologian Jürgen Moltmann goes so far as to state, "There is no differentiation between the healthy and those with disabilities. For every human life has its limitations, vulnerabilities, and weaknesses. We are born needy, and we die helpless. It is only the ideals of health of a society of the strong which condemn a part of humanity to being 'disabled.'"<sup>4</sup> Conversely, as we shall see, having a disability is not equivalent to being ill and needing a cure.

This is not to downplay or trivialize the real challenges faced by persons with disabilities, but rather to observe just how unstable and malleable the category of disability is. Although we often treat disability as a fixed term with well-defined references, it is inscribed with meanings that are context-dependent and socially derived, varying according to what social groups value and how they understand themselves as a community. Furthermore, the difference between ability and disability is linked broadly to how a society views the difference between normality

and abnormality, notions that shift according to changes in a society's perceptions of bodily functioning and aesthetic appearance. Human abilities tend to be measured in terms of what is considered normal functioning, wholeness, and order, making disability a correlate of dysfunction, incompleteness, and disorder. Sadly, this is why disability is stigmatized so often as a symbolic threat to the social fabric, something to be remedied or excluded. It is this correlation that must be called into question and transformed according to a different way of thinking about wholeness and ability, measured not by productive power and individual completeness but by vulnerability and interdependence.

Transforming our sense of disability in this way entails what Nancy Eiesland calls a theological method of two-way access.<sup>5</sup> On the one hand, persons with disabilities are empowered to participate more fully in the social and symbolic life of the church and wider society. This focus emancipates, seeking to liberate persons from restrictive barriers to public and religious access that are erected as by-products of taken-for-granted beliefs about "normal" conditions of embodiment. Examples of such barriers range from the concrete (e.g., lack of ramp access to above-ground-level buildings or the absence of communication provisions for deaf people) to the more abstract yet equally palpable ways that religious language is used to sanction common human experience and thus ignore, misrepresent, or demean the bodily presence of persons with disabilities (e.g., through metaphors like "walking by faith, not by sight" or "hearing God's word," and through theological views that denigrate or trivialize the experience of disability as something plaguing the "sinful," those "lacking in faith," or "God's special ones"). The point is to become mindful of, reconsider, and alter exclusionary practices and attitudes so as to promote the full inclusion of persons with disabilities into church communities.

On the other hand, the second part of this two-way method gives non-disabled persons access to the social-symbolic world of persons with disabilities, such that the disabling framework of the "normal" becomes questionable. Accordingly, non-disabled persons may gain the capacity to recognize their own complicity in sanctioning social and spiritual barriers to persons with disabilities. As illustrated in the examples above, it is not the impairment itself but the community that is disabling, insofar as it makes rules that draw attention to certain impairments as threats to normal role performances. Furthermore, by way of a critique of normalcy, non-disabled persons are able to acknowledge their own vulnerability, making possible a broader and richer human solidarity.

This being said, what this book is and is not becomes clearer. For instance, this book shall not explore disability solely in personal narrative form. While I shall draw from personal experience at various points to help contextualize the discussion and make important allusions, my overall intention is not to place Chris or my family at the center of the discussion.<sup>6</sup> The main focus will be analytical and theological in nature. Indeed, it is my hope that the book will be sufficiently inclusive in scope to interest readers not immediately connected to disability. Thus,

I seek to speak neither for nor directly to disabled persons. Rather, I speak as an advocate, a father trying to forge a path through an uncertain and painful terrain, but in which I have glimpsed rays of hope. Paul Ricoeur calls hope “the passion for the possible.”<sup>7</sup> And I see possibilities not only for reorienting the way non-disabled persons think about disability and act toward persons with disabilities, but also for altogether reconsidering theological themes in light of human vulnerability. Connecting disability with vulnerability sounds new theological possibilities. It moves the discussion about disability from a minor to a major key. That is, it helps us understand disability not as a human deficiency or tragedy to be pitied, but as a way of living life’s possibilities vulnerably with others and in God.

So I seek broad connections, ways to engage readers who have not thought about disability or engaged persons with disabilities. As Moltmann notes, a “person with disabilities gives others the precious insight into the woundedness and weakness of human life. But a person with disabilities also gives insight into the humanity of his own world. Through persons with disabilities, other people can come to know the real, suffering, living God, who also loves them infinitely.”<sup>8</sup> Reflecting on his work as founder of a community of people with intellectual disabilities, Jean Vanier suggests something similar, namely, that those with disabilities call us into acknowledging our own human weaknesses and thus open us up more radically to God’s grace.<sup>9</sup>

This, however, leads me to make another disclaimer. My purpose in this book is not to marshal examples of how disability can serve a positive function by teaching us what it means to be better human beings or better Christians. While Moltmann and Vanier have their finger on the pulse of something fundamentally important, serious dangers haunt such an approach. I shall enumerate these dangers more fully in chapter 1. Let me simply state from the start that I do not believe persons with disabilities are simply moral lessons or a means of inspiration for non-disabled people. Robert F. Molsberry counters such presumption forcefully: “I resist being seen as inspirational. There’s more to living with a disability than that.”<sup>10</sup>

Speaking personally, while I can think of numerous instances when my son has taught me how to be a better father, a more compassionate human being, and a deeper Christian, he is more than merely a vehicle for my parental and spiritual education. To treat him this way would have the patronizing effect of reducing his person to an object made useful by his disabilities. Not only would this trivialize his real challenges and difficult moments of suffering, it would also mute the fact that his is a life that shines of its own accord and with its own dignity, regardless of whether or not it instructs others. His gifts and abilities far exceed the alleged limitations entailed by one diagnosis or another. The measure of a person is not a factor of their disabilities. That is why I follow the lead of writers in the field of disability studies who speak of “persons with disabilities” rather than “the disabled.” The latter suggests that people with disabilities are all the same and can be wholly defined by their disabilities, unable to speak with integrity for themselves. As Molsberry again states, “I don’t want to allow my life to be the object of hasty

generalizations by those who are not intimately acquainted with it. . . . Disability is not the defining aspect of any life. Disability is just one condition among many that contributes to the richness of living.”<sup>11</sup>

Hence, it is imperative that any book about disability listen to and take account of the diverse voices that make up what has been called the largest minority group, becoming informed by the disability rights movement and by the emerging field of disability studies. The fact that you are reading a book like this is not accidental. It indicates that the hard-won efforts of people with disabilities to bring their experiences of social disempowerment and injustice to the forefront are paying off. While disability has been present through the ages, and is clearly a part of our lives today, until recently it was considered neither something worthy of social activism nor a subject calling for serious intellectual and religious engagement.

The civil rights movement changed that. It opened up new frontiers for rights-based and anti-discrimination legislation. Stimulated by the example of African Americans and women, disability organizations began to claim a political voice and speak out of their own experiences of marginalization, mobilizing as a group to publicly resist societal mechanisms of exclusion.<sup>12</sup> Thus empowered, people with disabilities launched critiques of prevailing social models, formulated new ones, and started creating alternative forms of service provision that were less restrictive and more humanizing. As a result, the field of disability studies developed. Although there is some debate over the character of disability studies, on the whole it is animated by the desire to interpret disability outside of intellectual frameworks that have proven inadequate to the experience of persons with disabilities.<sup>13</sup> Other books have detailed the character and significance of these events, so I will not rehearse their efforts again. Suffice it to say, however, that this book travels a pathway cleared by pioneers who have done the hard work of breaking through barriers of exclusion. As shall become obvious, I write indebted to their labor.

Keeping in line with the general thrust of disability studies, then, this book shall bring literature on disability into conversation with a range of sociological, philosophical, and theological sources in order to challenge non-disabled persons and resist the disabling principalities and powers that afflict our society and our church communities. My particular method, hinted at earlier, is to highlight the theme of vulnerability through a route that privileges disability and brings it to the center of the discussion. Privileging disability in this way amounts to what liberation theologians have called a “preferential option.” It does not simply use the category for theological gain, as if eventually to move on to better or more fruitful territory. Instead, it marks a radical conversion to the afflicted and oppressed as loved of God. Taking such a turn, however, is no easy endeavor.

Disability is a “dangerous memory,” to employ Johann Baptist Metz’s term, that renders our society, our theology, and our church communities accountable.<sup>14</sup> It is not an issue invoked merely when people with disabilities factor into the equation. Rather, it is a ubiquitous element in all social mechanisms that presume “normalcy” as their touchstone and in so doing rule out of play the non-normal

by raising access barriers. Thus, disability has been the occasion for both overt and covert gestures of exclusion, intentional and unintentional acts of oppression. According to the Americans with Disabilities Act of 1990, a disability is defined as (1) a “physical or mental impairment that substantially limits one or more of the major life activities of an individual; (2) a record of such impairment; or (3) being regarded as having such an impairment.”<sup>15</sup> Because the notions of “life activities” and “being regarded” are themselves defined socially and involve culturally communicated perceptions, they open up a wider horizon of investigation. For example, why are certain impairments taken to be disabling and not others? Visual impairment in today’s world is not considered a disabling condition, but needing a wheelchair, an artificial limb, or medication for bipolar disorder is. In these cases, there are real obstructions created by non-disabled persons that prevent social participation and self-definition. The question is why? And, further, how can this be changed? The dangerous memory of disability opens up the possibility of theological and social critique, and the possibility of a theological revitalization that benefits the entire community of faith.

With this in mind, let me sum up the preceding discussion by highlighting the development of the chapters of this book. Chapter 1 enumerates some of the promises and perils of thinking theologically about disability. This will prove instrumental for understanding what it is we are up against, and act as a kind of testing ground for the theological proposals to follow. Subsequently, focusing on vulnerability in light of disability as a dangerous memory, chapters 2 and 3 explore what I shall call the “cult of normalcy.” The task at this point is to expose the false social pretenses upon which exclusionary practices toward persons with disabilities are based, and which are dehumanizing for all people. Following the arc of this critique, chapter 4 then strives to paint a more adequate portrait of being human, a vision grounded in themes of embodied relation, vulnerability, and love. Indeed, being human and whole means more than self-creative autonomy and productive efficiency. And in light of this wider focus, being Christian means more than a fix for our brokenness, a way of maximizing our security and fleeing from our embodied condition of interdependency. Accordingly, chapters 5 through 7 deepen the analysis by examining theological currents that flow from the notions of God and creation (chapter 5), humanity and redemption in Jesus Christ (chapter 6), and the reconciling power of God’s kingdom anticipated in the community we call church, implying a vision of hospitality that encourages a wider praxis of inclusion (chapter 7). These chapters are fruits of the theological method of two-way access mentioned above.

The basic argument of this book is this: wholeness is not the product of self-sufficiency or independence, but rather of the genuinely inclusive communion that results from sharing our humanity with one another in light of the grace of God. To exist as a finite creature is to be contingent and vulnerable. This means we are beings that face limitations and are capable of suffering from a range of impairments. There is a profound theological implication here. It is precisely

such vulnerability that God embraces in Christ, entering fully into the frailty of the human condition, even unto a tragic death. Jesus is Emmanuel, God with us. Sharing the divine self in this way sends a distinct message: God is in solidarity with humanity at its most fundamental level, in weakness and brokenness. This is not to romanticize weakness. Rather, here God reveals the divine nature as compassion not only by undergoing or suffering with human vulnerability, but also by raising it up into God's own being.

Redemption then is a welcoming, an empowering act of divine hospitality. It does not render human beings "weak," in the sense of passivity. Neither does it negate vulnerability by making humans invulnerable and perfectly whole. Nancy Eiesland correctly notes this by calling our attention to the fact that Jesus's body remains scarred after his resurrection.<sup>16</sup> So instead of doing away with impairments and the capacity to suffer, redemption transforms vulnerability into a communion with God, prefiguring the final eschatological horizon to come when all things will become so transformed. An entire "theology of vulnerability" opens up, wherein the marginal and heretofore neglected (i.e., disability) becomes central.

Understanding redemption this way has dramatic implications for living together. It addresses the often hidden struggles of persons whose "deficiencies" relegate them to marginal societal and/or ecclesiological status. But, more broadly, it opens up the christological implications of Paul's paradoxical proclamation in 2 Corinthians 12:9–10; namely, that the saving power of God is made manifest and perfected in weakness or the lack of ability (*astheneiai*). The intent is neither to valorize disability nor to glorify suffering. For Paul's "thorn in the flesh" must be understood christologically, not as a means to romanticize passivity and self-sacrifice. Attending to this, however, requires giving more attention to the theological bearing of notions such as relation, embodiment, wholeness, sin, redemption, hospitality, and the nature of ecclesial existence. It calls also for a rich social scientific and philosophical inquiry into the character of communal life and the ways it can function to marginalize those considered different and deficient in some way or another.

Hence, I come to the fundamental thesis of this book: there is a strange logic to the Christian witness, one that gives testimony to a strength that comes through weakness, a wholeness that manifests itself in brokenness, a power that reveals itself through vulnerability. The logic here is paradoxical and subversive. Rather than idealize vulnerability, it produces what I shall call a "metaphorical reversal" that exposes the false pretenses of the cult of normalcy. For human communities tend to shun what lacks the power to present itself according to common and taken-for-granted values, whether because it is simply foreign and strange or because it manifests some form of alleged corruption or deficiency. Indeed, we grow to fear the abnormal, the different and other. It disrupts the familiar and safe world of commonplace assumptions, and thus makes us vulnerable. Such vulnerability is no panacea; it is anxiety-ridden. A sense of vulnerability can seek shelter in the cult of normalcy and is wont to assuage its insecurity by justifying

the order of things as they are (i.e., the conventions of the cult of normalcy) via all kinds of ideological mechanisms.

The redeemed life, however, exemplifies the reorientation—indeed reversal—of such fear-based anxiety. Such a life marks a conversion (*metanoia*) to God that trades on the experience of vulnerability and inability as a harbinger of divine abundance. This does not mean a mere submissiveness and lack of power in relation to God's utter power. To the contrary, it entails an acknowledgment of creaturely limitation and interdependence that cultivates an active openness toward human differences. A space is made for others, strangers, disabled persons—those without autonomy, power, and completeness measured in terms of the cult of normalcy. It is no accident that the biblical narratives portray a kind of salvation that, far from vindicating the conventional and normal, actually subverts it by pointing to the palpable presence of the divine in human vulnerability as a site of relational interdependence. The power of God is unseemly and strange.<sup>17</sup> It discloses itself paradoxically, not in autonomy but through the stranger's lack of ability. The stranger, however, is not merely a moral lesson. He or she is a person full of dignity, full of humanity, whose call is for us to be present, to listen, and to open up and share our lives.

Jesus Christ is the exemplar of such a stranger, an icon of a vulnerable God. At the heart of the Christian witness is an inclusive love of difference that is christological in shape. In the Christ event God sympathetically enters into our midst and communicates a love that spills over with unconditional regard for all persons. Beyond merely confirming the basic human right to respect, this radical love issues in a recognition and acceptance of human creaturely dependence as a bearer of the image of God. And it does so in a gesture of hospitality.

Reflecting the ancient policy of inviting the stranger into one's home, hospitality is a fruitful metaphor for divine love. In the biblical traditions, welcoming and attending to one who is alien and thus vulnerable, who somehow stands outside the taken-for-granted social world and is thus incapable of reciprocating in like kind, is a moral imperative. Even more, however, hospitality heralds divine presence. It has redemptive power for both host and guest. It bears a relational vulnerability that exhibits the unseemly power of God in human weakness and inability. Such a view emanates from the New Testament remembrances of Jesus's ministry, death, and resurrection. Hospitality is the Christ-shaped character of God's reconciling love, displayed not in power but in vulnerability. Such love is not distributed according to the order of ability, but according to the order of grace, a hyperbolic logic of abundance that functions to reverse the conventions of the "normal" by bearing weakness. For hospitality is a gift offered without preconditions and expectations, an emblem of openness to the other. Accordingly, it is through the practice of hospitality that we participate in God's inclusive embrace, realizing the kingdom of God announced by Jesus.<sup>18</sup>

In this way, we move beyond the cult of normalcy toward living out the presence of God in the praxis-oriented task of being present to and for others. Disability

is more than a handy illustration of God's grace; it is redemptively fundamental. Hence, privileging disability not only makes possible, but also requires, a rethinking of theology from the ground up. Bringing what has been considered marginal to the center of Christian faith has radical consequences. Disability's "dangerous memory" provides a prophetic counter to the cult of normalcy far too often assumed in theological formulations. The focus is shifted from talking about disability as something that affects "them" to representing disability as something that affects "us." Not simply because we are all disabled, though all of us at some point shall experience disabilities as our bodies age, but rather, because we participate in systemic social structures that silence and disconfirm persons with disabilities. And this impoverishes our experience of redemption in Christian communities. Our resistance to human vulnerability calls for transformation if we are to experience the power of the biblical witness and participate more fully in God's inclusive love.

In the end, I come to the conclusion that disability is tragically but redemptively fundamental. Tragic, not in the sense of evoking pity, but because disability entails involuntary impairment and real suffering, much of which is the consequence of social alienation and exile. Redemptive, because disability opens up our vulnerability and dependence upon each other and God. This gets to the heart of Paul's proclamation (2 Cor. 12) that God's power is made complete and perfected in weakness. But I must confess from the outset that it is difficult to estimate the true power of such a paradox, a difficulty made manifestly real not only in the writing of this book, but also more concretely in the everyday realities of parenting a child with disabilities. And the result has transformed my theological perspective and offered fresh new ways of understanding the well-worn landscape of Christian faith.

## Notes

1. For more information, consult Tracy Haerle, ed., *Children with Tourette's Syndrome: A Parent's Guide* (Rockville, MD: Woodbine House, 1992); Ruth Dowling Bruun and Dertel Bruun, *A Mind of Its Own: Tourette's Syndrome: A Story and Guide* (Oxford: Oxford University Press, 1994); Mitzi Waltz, *Bipolar Disorders: A Guide to Helping Children and Adolescents* (Sebastopol, CA: O'Reilly, 2000); Demetri Papolos and Janice Papolos, *The Bipolar Child* (New York: Broadway, 1999); George T. Lynn, *Survival Strategies for Parenting Children with Bipolar Disorder* (Philadelphia: Jessica Kingsley, 2000); and Tony Attwood, *Asperger's Syndrome: A Guide for Parents and Professionals* (Philadelphia: Jessica Kingsley, 1998).

2. Jennie Weiss Block, *Copious Hosting: A Theology of Access for People with Disabilities* (New York: Continuum, 2002), 131.

3. Stanley Hauerwas, "Community and Diversity: The Tyranny of Normality," 37–43, in *Critical Reflections on Stanley Hauerwas' Theology of Disability: Disabling Society, Enabling Theology*, ed. John Swinton (Binghamton, NY: Haworth Pastoral Press, 2004). This essay originally appeared in *Suffering Presence: Theological Reflections on Medicine, the Mentally Handicapped, and the Church* (Notre Dame, IN: University of Notre Dame Press, 1986), 211–17.

4. Jürgen Moltmann, "Liberate Yourselves by Accepting One Another," in *Human Disability and the Service of God: Reassessing Religious Practice*, ed. Nancy L. Eiesland and Don E. Saliers (Nashville: Abingdon Press, 1998), 110.

5. Nancy L. Eiesland, *The Disabled God: Toward a Liberatory Theology of Disability* (Nashville: Abingdon Press, 1994), 20–23.

6. For a personal account, see my essay “Love without Boundaries: Theological Reflections on Parenting a Child with Disabilities,” *Theology Today*, July 2005 (62:2). Readers interested in firsthand, testimonial accounts of disability might consult Francis Young’s *Face to Face: A Narrative Essay in the Theology of Suffering* (Edinburgh: T. & T. Clark, 1990), a moving book by a well-regarded historical theologian who discusses her struggles to parent a child with severe disabilities. In a similar vein, see also Kathleen Deyer Bolduc’s *His Name Is Joel: Searching for God in a Son’s Disability* (Louisville: Bridge Resources, 1999), and *Life as We Know It: A Father, a Family, and an Exceptional Child*, by Michael Bérubé (New York: Pantheon Books, 1996). Also instructive is Robert F. Molsberry’s *Blindsided by Grace: Entering the World of Disabilities* (Minneapolis: Augsburg Fortress, 2004), which chronicles a pastor’s struggle to come to terms with his disabling condition after a bicycle accident.

7. See Paul Ricouer, “Hope and the Structure of Philosophical Systems,” 203–16, in *Figuring the Sacred: Religion, Narrative, and Imagination*, trans. David Pellauer, ed. Mark I. Wallace (Minneapolis: Fortress Press, 1995).

8. Moltmann, “Liberate Yourselves by Accepting One Another,” 121.

9. Jean Vanier, *Becoming Human* (Mahwah, NJ: Paulist Press, 1998), 39–41.

10. Molsberry, *Blindsided by Grace*, 57.

11. *Ibid.*, 84–85.

12. For good treatments of the disability rights movement, see James I. Charlton, *Nothing about Us without Us* (Berkeley: University of California Press, 1998); Joseph P. Shapiro, *No Pity: People with Disabilities Forging a New Civil Rights Movement* (New York: Times Books, 1994); and Doris Zames Fleischer and Frieda Zames, *The Disability Rights Movement: From Charity to Confrontation* (Philadelphia: Temple University Press, 2001).

13. On disability studies, see Colin Barnes and Geof Mercer, *Disability* (Cambridge: Polity Press, 2003); Lenard J. Davis, ed., *The Disabilities Studies Reader* (New York: Routledge, 1996); Mark Nagler, ed., *Perspectives on Disability*, 2<sup>nd</sup> ed. (Palo Alto, CA: Health Markets Research, 1993); Michael Oliver, *Understanding Disability: From Theory to Practice* (New York: St. Martin’s, 1996); Tom Shakespeare, ed., *The Disability Studies Reader: Social Science Perspectives* (New York: Cassell Academic, 1998).

14. Johann Baptist Metz, *Faith in History and Society: Toward a Practical Fundamental Theology*, trans. David Smith (New York: Seabury Press, 1980).

15. American with Disabilities Act (1990), *U.S. Statutes at Large*, vol. 104, 327–78.

16. Eiesland, *The Disabled God*, 98ff.

17. The “strange power” of God is a turn of phrase drawn from Daniel L. Migliore, *Faith Seeking Understanding: An Introduction to Christian Theology* (Grand Rapids: William B. Eerdmans, 1991), 52.

18. See Christine D. Pohl, *Making Room: Recovering Hospitality as a Christian Tradition* (Grand Rapids: William B. Eerdmans, 1999). See also Lucien Richard, OMI, *Living the Hospitality of God* (Mahwah, NJ: Paulist Press, 2000), and Thomas W. Ogletree, *Hospitality toward the Stranger: Dimensions of Moral Understanding* (Philadelphia: Fortress Press, 1985).

# 1



## Theology and Disability

### *Perils and Promises*

As a person with disability I want to turn to every part of human society and God's church and urge them: Let us share your world! Because your world is also my world and every person's world, and because, so far, this is the only world there is.

Arne Fritzson<sup>1</sup>

Some time ago, I was casually describing my interest in theology and disability to a friend who is active in the field of disability studies. I was surprised by his response. He sat back in his chair and smirked awkwardly. After taking a sip of his coffee, he exclaimed with a suspicious tone, "You're venturing into a troublesome area." He proceeded to tell me about the "religious" experience of a female acquaintance who is paralyzed from the waist down and uses a wheelchair. On one occasion, after being subject to considerable pressure, she agreed to accompany a group of Christians to a "healing" ceremony. She was called up to the front of a church during the service. The healing "failed." Not only did she remain paralyzed, she was publicly transformed into an embarrassing spectacle, and made the subject of awkward gazes and whispered questions. This diminished her sense of being welcomed as someone unique and loved by God, the same status as anyone else in that church community. Her impairment had been inscribed with theological meanings that reduced her condition to a lack or blemish, a deviance. The focus

of the community's gaze was on her disability, and as a result features of her personhood fully capable of making valuable contributions to the community were neglected. Such misplacement, certainly not intended, nullified her creaturely dignity as a gift of God. Sadly, she holds a deep resentment toward both Christians and God, as do many persons with disabilities.

This story is disturbing. That it depicts an experience commonplace for persons with disabilities is perhaps even more disturbing. It exposes the rather uncomfortable relationship that exists between Christianity and disability, a relationship that trades on regrettable but all too familiar misunderstandings of what it means to be physically, mentally, or emotionally impaired.<sup>2</sup> While these misunderstandings may involve cultural and social processes wider in scope than Christianity, it is nonetheless true that such misunderstandings have been—and still are—adopted, transmitted, and justified by Christian means, which augment their influence. Because of this an unfortunate irony ensues: among church communities that seek with all due diligence to incarnate the love of God, disabilities are treated as faulted and pitiable anomalies, stigmas to be extricated. Labels and categories are employed that single out and reduce a certain group of people to roles designated for the abnormal and blemished. And such generalized role projections demean and ostracize. How so? By setting up restrictive norms about who and when people are able to participate fully in civic space. Based upon narrowly defined models of individual autonomy, efficiency, or productivity, certain bodily differences and impairments are perceived as liabilities that amount to deviance. Hence, the place where God's welcome should be most evident becomes instead a place of inaccessibility and isolation for some. Persons are disconfirmed.

In this chapter, I shall place disability at the forefront in order to explore the ways in which it exposes major liabilities in theological discourse and practice. The aim is to prepare the way for a counter-discourse that undoes inadequate theological representations of disability by naming and resisting the flawed premises upon which they rest. Clearing semantic space in this regard will help us defamiliarize disability and see more clearly why the example of the paralyzed woman discussed above is so disturbing. Disability does not simply mark a personal tragedy that calls for healing. Neither does it indicate a diminishment of the image of God imprinted upon human beings. Neither does it suggest that people with disabilities are “children of a lesser God,” an ineffective or non-loving God. Rather, it calls into question the Christian community and its understanding of human wholeness, normalcy, impairment, redemption, and God's love and power.

Subverting faulty assumptions will prove critical to the task of systematically rethinking human vulnerability and disability. As Karl Marx once said, the criticism of religion is the beginning of all criticism.<sup>3</sup> Religion commonly relies upon the status quo, which arises and is maintained by mechanisms of social exchange and economic power, reinforcing it with divine purpose. Thus an analysis and critique of theological concepts can aid us in bringing to light the hidden and often faulted practices and attitudes that buttress how we commonly measure what is

normal, valuable, and real. In this way we shall be in the position to open up the prospect of a more adequate theological portrait of God's inclusive love.

## **I. A Disabling Theology or a Theology of Disability?**

More than a few factors make the juxtaposition of Christianity and disability problematic. My intention, however, is not to catalogue every theological framework that is “disabling” or oppressive for persons with disabilities. Nor do I wish to point out flaws by painting an historical portrait of how disability has been theologically interpreted for the past two thousand years. Instead, I seek to usher the reader into the subject matter by highlighting general features in the literature on disability, most especially as they offer critical resources for more adequately framing the correlation between theology and disability, such that their connection leads to a theology “of” rather than “against” or “in spite of” disability. There are two widespread impediments to such a constructive correlation, both of which look for a moral meaning to disability. And this is counterproductive.

### ***Defining Disability beyond the Medical Model***

First, Christians commonly adopt the prevailing medical model of disability.<sup>4</sup> This model is based on what non-disabled people think is best for persons with disabilities. For example, it is assumed that disability indicates a deficient or flawed human condition, a bodily deviation due to a “loss” of capacity in one way or another, which holds a person back from participation in society. Hence, disability represents an inability, abnormality, or disadvantage calling for management and correction in order to restore proper functioning. And from a societal perspective this means that disability is a liability, a dysfunction legitimating professional and welfare services. While this way of approaching the matter is not altogether blameworthy—for many people benefit from corrective measures made possible by modern technology and medical practices—it is nonetheless limited in scope.

The medical model tends to reduce disability to a problem requiring diagnosis and treatment, a broken object to be fixed, made better, or overcome. In so doing, however, the person becomes reduced to a function of disabilities rather than vice versa. Indeed, the personal becomes obscured. Fostering an impoverished, one-way relationship of dependence between healer and patient, caregiver and cared-for, the medical model can effectively silence the patient as a subject of her or his own experience. For it is assumed that the healer has the knowledge to define illness and the power to rehabilitate, the advantages of which are passively received by a beneficiary regarded as someone with nothing to offer. Indeed, the term “patient” has etymological roots in Latin, where it means “to undergo”—one who endures affliction and receives treatment. Seen in this way, reciprocity is annulled by professional control, repair, and supervision. A service is administered to a non-participant, one who plays the role of an otherwise helpless and useless burden.