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Disability and Suffering?— Pastoral and Practical Theological Considerations

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Abstract

"Suffering" is a difficult topic at the crossroads of disability studies and pastoral care. On the one hand, people with disabilities want to clearly distinguish impairments from the sense of suffering, urging that the latter does not necessarily follow the former. This is in part a reaction to historically paternalistic attitudes manifest in and through pastoral care directed to people with disabilities. This paper focuses on how to empower appropriately discerning pastoral praxis so that ecclesial ministry occurs *with* people with disabilities and their families/caregivers rather than only *to* them. Such an approach unfolds in solidarity with the genuine suffering of people with disabilities rather than perpetuates the kind of social stigmatization that causes existential and psychological pain even for those who do not otherwise suffer physically.

Introduction

It is often assumed that disability and suffering are interconnected.² This paper seeks to problematize the connections, albeit not just theoretically or theologically but in order to empower more appropriate religious and especially Christian praxis. Four parts follow:

- A. Clarify why an uncritical equation of the two is problematic especially in light of contemporary disability rights and disability studies perspectives;
- B. Explore how suffering follows disability, although not always as presupposed by those who are temporarily able-bodied (i.e., those who do not have disabilities³);

² This is reflected, for instance, in the title of Larry J. Waters and Roy B. Zuck, eds., *Why, O God? Suffering and Disability in the Bible and the Church* (Wheaton: Crossway, 2011). The contents of the book itself are more nuanced, and the decision on the title may reflect more the publisher's assumptions about how to market the book. But even in this case, that is precisely the point being made.

³ Those in the disability rights movement have developed a new nomenclature regarding those different than they as the "temporarily able-bodied," i.e., those who are born dependent and, if they were lucky or blessed enough to live into old-age, will come again into dependency on others; see Kimberly Willis's guest editorial introducing the term to a theological audience, "Persons with Disabilities and the Temporarily Able-Bodied: Becoming the Body of Christ," *Liturgy* 23, no. 2 (2008): 1–2.

- C. Sketch a pastoral theology of disability in dialogue with disability perspectives that minimizes the explicitly theological warrants for connecting suffering and disability; and
- D. Propose a dual model of disability ministry and praxis in the face of real and perceived suffering.

The goal is to complicate the normate⁴ assumptions linking disability and suffering in order to attend more appropriately—both in theory and practice—to such matters in ecclesial or faith communal contexts.

Before moving on, it is important to briefly define key terms and situate these reflections autobiographically. Disability as understood in the existing scholarly literature is not an obvious notion. It is standard within the field to distinguish *impairment* from *disability*, with the former pertaining to limitation or lack of certain physical, intellectual, or sensory capacities, and the latter involving the social, economic, and other disadvantages experienced as a result. A person could be profoundly deaf or severely hearing impaired, for instance; but if she could afford a cochlear implant or worked at her home computer as a manuscript editor, then she would not be considered as having a hearing disability. Yet the line between impairment and disability is not hard and fast; those who are chronically ill, as another example, may because of their condition perform sub-optimally as an employee but not be able to document their condition to qualify for disability status. The point is that there is both a personal and biological aspect to impairment even as there is a social dimension of understanding how such impinges on human interactions in the broader context of public life.5

The final caveat is the important admission that I approach this topic not from firsthand experience of "suffering disability."⁶ To be

⁴ "Normate" refers to that "socially constructed ideal image" through which definitive humanity is envisaged and the approximation toward which confers authority and power; it is therefore the unquestioned "glasses" through which temporarily able-bodied people see, evaluate, and engage the world, resulting in negative perceptions of and actions impacting people with disabilities. See Kerry H. Wynn, "The Normate Hermeneutic and Interpretations of Disability within the Yahwistic Narratives," in *This Abled Body: Rethinking Disabilities in Biblical Studies*, ed. Hector Avalos, Sarah J. Melcher, and Jeremy Schipper (Atlanta: Society of Biblical Literature, 2007), 91–101, esp. 92.

⁵ On the social aspects of disability, see Colin Barnes and Geof Mercer, *Exploring Disability: A Sociological Introduction*, 2nd Ed. (Cambridge: Polity Press, 2010), ch. 2; cf. Carol Thomas, *Female Forms: Experiencing and Understanding Disability* (Buckingham: Open University Press, 1999), ch. 3.

⁶ Note that when "suffering disability" is used in relationship to people with disabilities, this does not presume (as under normate conditions) that all people with disabilities suffer from or merely because of their condition; instead it is used as shorthand in the rest of this paper to refer to those who actually [*Footnote continued on next page* ...]

sure, the scare quotes around the phrase itself should signal that there is more to disability and impairment than what suffering is assumed to be, precisely what this paper is designed to elaborate. Nevertheless, I myself do not have an impairment, my 20-400 vision notwithstanding (alleviated by my corrective lenses for sure), so in that sense I do not have the same right as a person with a disability to speak to the topic at hand.⁷ The extent of my experience of disability is having grown up with and cared for a younger brother with Down Syndrome. This has led me to reflect extensively on disability, especially from a religious and theological perspective.⁸ The following does not pretend to be the final word at the intersection where disability meets suffering; it is intended merely to be a catalyst for discussion and perhaps a prompt for attitudinal, behavioral, and practical adjustment, especially as that pertains to those ministering not only *to* but also *with* people with disabilities for the cause of the Christian gospel.

A. Why "Suffering" Is a Bad Word in Disability Rights and Disability Studies Circles

For the temporarily able-bodied, that disability and suffering are intertwined seems obvious. These associations are no doubt even stronger within religious, especially Christian, contexts. After all, there is a long history of Christian care for people with disabilities, stretching back through the medieval hospitals to the rise of monastic movements over 1500 years ago, which identified the vulnerable on the margins of society and sought to provide for their needs.⁹ Many

suffer—or perceive themselves as suffering—whether physically, existentially, or in any other way, from their impairing conditions.

⁷ In previous generations, people with disabilities were spoken for by others, but with the advent of the civil rights movement, followed quickly by disability rights awareness, people with disabilities are advocating for themselves and generally are suspicious that those without disability are adequately able to speak on their behalf; see, for instance, the manifesto by James I. Charlton, *Nothing about Us without Us: Disability Oppression and Empowerment* (Berkeley: University of California Press, 1998).

⁸ My scholarly training is in religious studies and theology and my published work has been in systematic and constructive theology; my two books on disability are *Theology and Down Syndrome: Reimagining Disability in Late Modernity* (Waco: Baylor University Press, 2007) and *The Bible, Disability, and the Church: A New Vision of the People of God* (Grand Rapids: William B. Eerdmans, 2011), among other published articles and papers.

⁹ See Andrew T. Crislip, From Monastery to Hospital: Christian Monasticism and the Transformation of Health Care in Late Antiquity (Ann Arbor: University of Michigan Press, 2005), esp. 115–16; cf. Mark P. O'Tool, "The povres avugles of the Hôpital des Quinze-Vingts: Disability and Community in Medieval Paris," in Difference and Identity in Francia and Medieval France, ed. Meredith Cohen and Justine Firnhaber-Baker (Farnham: Ashgate, 2010), 157–73.

of those who were found in such hospice and hospital environments could not care for themselves and were stigmatized if not discriminated against by society.¹⁰ In more recent times, people with disabilities have been publicly portrayed, through the freak-show and other media, in negative terms: as abnormal, even inhuman, objects of the temporarily able-bodied gaze.¹¹ Even with regard to the so-called "invisible disabilities"—i.e., impairments of the brain or the mind, including those related to learning disabilities, which are not obviously perceived—what is experienced of or known about them leaves the temporarily able-bodied anxious, even fearful.¹² Set in historical perspective, then, it may be at least understandable why people generally believe disability is causally related to suffering. The temporarily able-bodied obviously do not want to become dependent on the care of others, be made a spectacle before others, or be subject to awkward behaviors that are socially inexplicable or unacceptable.

The problem, of course, is that temporarily able-bodied presuppositions are shaped by their normate anxieties and biases, and these have been at least relativized, if not challenged, by disability vantage points. The disability rights movement of the last generation has opened up public space for the registration of disability voices and experiences that have questioned temporarily able-bodied assumptions, ¹³ and the epistemological, methodological, and theoretical lenses generated by such perspectives have propelled the recent emergence of disability studies as a scholarly field of inquiry. From this horizon, disability theorists have sought to uncouple the fact of human impairment and the sense of suffering. At least three

¹⁰ Note the play on words in Edward Wheatley's *Stumbling Blocks before the Blind: Medieval Constructions of a Disability* (Ann Arbor: University of Michigan Press, 2010), which is suggestive of the unkind attitudes directed toward and oppressive social realities erected vis-à-vis the—in this case, visually—impaired.

¹¹ I discuss the freak show in my *Theology and Down Syndrome*, 82–86; cf. Paul Martin Lester and Susan Dente Ross, *Images that Injure: Pictorial Stereotypes in the Media* (Westport: Praeger, 2003), and Robert Bogdan, Martin Elks, and James A. Knoll, *Picturing Disability: Beggar, Freak, Citizen, and Other Photographic Rhetoric* (Syracuse: Syracuse University Press, 2012).

¹² This is especially the case with mental illness, for instance, since those so-afflicted often exhibit bizarre behaviors for no identifiable reason; see also Michael L. Perlin, *The Hidden Prejudice: Mental Disability on Trial* (Washington, DC: American Psychological Association, 2000), and Amy Simpson, *Troubled Minds: Mental Illness and the Church's Mission* (Downers Grove: IVP, 2013).

¹³ Fred Pelka, What We Have Done: An Oral History of the Disability Rights Movement (Amherst and Boston: University of Massachusetts Press, 2012).

major problems have been identified with how the temporarily ablebodied link the two.

First, whatever the existential sense of suffering experienced by people with disabilities, temporarily able-bodied perceptions of those with impairments often results in stereotypical and prejudicial attitudes toward them.¹⁴ While perhaps little can be done about personal prejudice, the normate position of temporarily able-bodied persons in society means that they have political and especially economic power over those with disabilities and often exercise the latter in discriminatory ways in employment contexts.¹⁵ So if normate conventions regarding impairment might be innocuous enough at the attitudinal level, they are downright harmful because personal stigmatization is reinforced by what they can and cannot do, and these often lead to exclusion of people with disabilities from employment opportunities. While the temporarily able-bodied may be sentimental about the presumed suffering of people with disabilities, there are real socioeconomic and other structural inequalities that constrain the latter quality of life and intensify whatever other experience of suffering may already be felt.

The second problem with temporarily able-bodied suppositions is that their attitudes toward those perceived as suffering are not actually harmless. Instead, the goodwill intended by temporarily able-bodied people in response motivates a kind of paternalism that can also be dangerous. The movement to sterilize women with intellectual disabilities in the first half of the twentieth century is an extreme but important example.¹⁶ No doubt some were genuinely concerned about the welfare of their friends or loved ones who were susceptible to getting pregnant but without the capacity to adequately raise their children. However, the state, with public backing, acted on this front in ways that violated the dignity and humanity of these most helpless. To be sure, temporarily able-bodied paternalism oftentimes manifests itself not in such violent ways, but is urged as a means to achieve

¹⁴ Douglas Biklen and Lee Bailey, eds., *Rudely Stamp'd: Imaginal Disability and Prejudice* (Washington, DC: University Press of America, 1981).

¹⁵ Peter Susser and Peter J. Petesch, *Disability Discrimination and the Workplace*, 2nd ed. (Arlington: BNA Books, 2011).

¹⁶ See Sharon Morris, "'Human Dregs at the Bottom of Our National Vats': The Interwar Debate on Sterilization of the Mentally Deficient," in *Social Histories of Disability and Deformity*, ed. David M. Turner and Kevin Stagg (New York: Routledge, 2006), 142–60.

other moral goods.¹⁷ But this raises another problem with how the temporarily able-bodied construe suffering in relationship to disability: that people with disabilities are treated as passive recipients dependent on temporarily able-bodied charity and sympathy rather than as having their own agency and personhood.¹⁸

A third concern is understandably related to the very definition of disability, which connotes some kind of inability or incapacity. Here, the proper human response, temporarily able-bodied or otherwise, is to help, to assist with whatever cannot be done. This is all well and good except when the person is reduced to what he or she lacks. Normate discourse thus often does not think twice about talking about "the blind, lame, and deaf" as if that were the only important or essential feature about such individuals.¹⁹ If the "people first" language of "people with disabilities" is designed to respond to such reductionist categorizations by foregrounding the full humanity of those not temporarily able-bodied, 20 that still is insufficient to overthrow the normate postulation that such individuals lack capacity or agency and are helplessly reliant on the charitable benevolence of others.²¹ The point is not to undermine the motivation for acts of kindness and generosity, but to sever the temporarily able-bodied inference that those presumed suffering with disabilities survive merely or only as passive recipients of the aid of others.²²

¹⁷ See the arguments back and forth in *Mental Retardation and Sterilization: A Problem of Competency and Paternalism*, ed. Ruth Macklin and Gaylin Willard (New York: Plenum Press, 1981).

¹⁸ Henri-Jacques Stiker, A History of Disability, trans. William Sayers (Ann Arbor: University of Michigan Press, 1999), ch. 4; Doris Zames Fleischer and Freida Zames, *The Disability Rights Movement:* From Charity to Confrontation (Philadelphia: Temple University Press, 2001); and Nora Ellen Groce, From Charity to Disability Rights: Global Initiatives of Rehabilitation International, 1922–2002 (New York: Rehabilitation International, 2002).

¹⁹ This stems also from scriptural discourse—e.g., S. John Roth, *The Blind, the Lame, and the Poor: Character Types in Luke-Acts* (Sheffield: Sheffield Academic Press, 1997), that is in turn perpetuated unthinkingly by temporarily able-bodied people.

²⁰ See Tanya Titchkosky, "Disability: A Rose by Any Other Name? 'People-First' Language in Canadian Society," *Canadian Review of Sociology and Anthropology* 39, no. 2 (2001): 125–40.

²¹ Even those writing as informed by disability perspectives have difficulty breaking beyond this stereotype. For instance, Lynne M. Bejoian, Molly Quinn, and Maysaa S. Bazna, "Disability, Agency and Engagement: Three Wisdom Traditions' Call to Be Radically Available," in *Disability and Religious Diversity: Cross-cultural and Interreligious Perspectives*, ed. Darla Schumm and Michael Stoltzfus (New York: Palgrave Macmillan, 2011), 177–99, recognize that people with disabilities are agents in their own right (esp. 193–94) but the predominant thrust of this article is directed toward mobilizing the agency of non-disabled people to act inclusively toward the former.

²² Thus societal discourse needs also to shift from that of organizational "agencies" acting on behalf of those passive because of intellectual disabilities—e.g., Paul Wehman, John Bricout, and John [*Footnote continued on next page* ...]

B. Why Suffering Is a Problem for People with Disabilities

Almost three decades ago, a younger Stanley Hauerwas put the question about suffering in relationship to disability, especially to intellectual disability, squarely on the table.²³ To begin, while suffering might include the experience of pain, it ought not be assumed that all suffering involves pain. In fact, some forms of suffering experienced by people with disabilities are devoid of physical pain and have to do instead with the sense of loneliness of alienation from others. Further, while the root meaning of suffering involves being forced to submit to a set of circumstances, human sufferers are not merely passive endurers but can also embrace their lot in a more active sense.²⁴

With regard specifically to those with intellectual disabilities, however (in those days, the acceptable nomenclature was the "mentally handicapped," which is in the title of Hauerwas's book), the point was pressed: should all suffering be avoided? Remember that this was the time in which biomedical technology was increasingly able to identify fetuses with Down Syndrome and other congenital impairments, and the option was emerging about whether women or couples wanted to carry their children through to term or prevent their birth as well as their anticipated life of suffering. Hauerwas' counter, however, was that the suffering of the "mentally handicapped" was less the issue than that of their mothers or parents, especially the stigma of bearing such babies and then the inconveniences of raising these less-than normally developing children in an individualistic society that emphasizes independence and self-sufficiency.²⁵ Within the broader framework of Christian faith, the problem is not the suffering of people (infants/children) with intellectual disabilities or their families but the lack of a sufficiently rich understanding of the church as a truly open-hearted community

Kregel, "Supported Employment in 2000: Changing the Locus of Control from Agency to Consumer," in *Mental Retardation in the 21st Century*, ed. Michael L. Wehmeyer and James R. Patton (Austin: Pro-ED, 2000), 115–50—to recognition that included in this group of people are many capable of self-understanding and self-advocacy to some degree so more of a mutuality than currently exists between such service organizations and those with disabilities and their families can emerge.

²³ Stanley Hauerwas, *Suffering Presence: Theological Reflections on Medicine, the Mentally Handicapped, and the Church* (Notre Dame: University of Notre Dame Press, 1986).

²⁴ Hauerwas, Suffering Presence, 28.

²⁵ Hauerwas, ch. 9.

that is capable of being hospitable to and welcoming of such families so that these children are valued and embraced just as they are.

Still, there is no doubt that with regard to the severely or profoundly disabled, there is some suffering, even pain, involved, just as there is no denying that parents of such infants and children—even those who are only more moderately disabled—are faced with often inconceivable challenges related to their care and provision.²⁶ Further, it is also clear that those with severely debilitating diseases or injuries, including people stricken with chronic pain and chronic illness, not to mention severe mental impairment and profound intellectual disability, suffer at different levels of intensity.²⁷ Last but not least, the experience of later onset disability is particularly challenging since it requires developing or older adults not only to adjust to new bodily or sensory incapacities but also to reorient themselves psychologically and existentially toward a new self-identity.²⁸ In all of these ways and more, it is downright unjust to minimize or overlook the suffering experienced and involved.

While not dismissing the suffering that attends to some, if not many, experiences of disability, I want to challenge the biomedical paradigm within which such suffering is often defined. Following Hauerwas's lead, but extending it variously, what I will argue is that suffering is often individualized according to a biomedical diagnosis: an infant is presumed to suffer because of being born with Down Syndrome; a toddler is thought to suffer because of his polio; the hearing impaired are believed to suffer because of their being hard of hearing; the visually impaired are assumed to suffer because they have to get around using canes or guide dogs; the paraplegic must obviously suffer because she has to use a wheelchair, etc. In each case, the suffering follows from the biomedical impairment, and

²⁶ One of my doctoral students, a mother of a son with disability, writes eloquently from that perspective: Mary Fast, "A Theodicy of the Cross: Where is God in the Suffering of Disability?" PhD diss. (Virginia Beach: Regent University School of Divinity, 2015).

²⁷ See Martin Osterweis, Arthur Kleinman, and David Mechanic, eds., *Pain and Disability: Clinical, Behavioral, and Public Policy Perspectives* (Washington, DC: National Academy Press, 1987), esp. part III; Paul W. Power and Arthur E. Dell Orto, *Families Living with Chronic Illness and Disability: Interventions, Challenges, and Opportunities* (New York: Springer, 2004); and Erin Martz and Hanoch Livneh, eds., *Coping with Chronic Illness and Disability: Theoretical, Empirical, and Clinical Aspects* (New York: Springer, 2007).

²⁸ E.g., Shane Clifton, *Husbands Should Not Break: A Memoir* (prepublication copy available from the author at Shane.clifton@ac.edu.au).

society—those temporarily able-bodied—is mobilized to develop technological and other interventions in order to alleviate the related incapacities and the attendant suffering conditions.

But what if the social model of disability were applied to understanding suffering instead?²⁹ Without ignoring the biomedical aspects of impairment, the social model emphasizes that disability is as much if not more on some occasions a social construction and process of socialization:

List 1. Four Social Constructs of Disability

- Disability defines and responds to impairing conditions according to cultural conventions;
- 2. Disability imprisons those with impairments within economic constraints;
- 3. Disability limits opportunities according to certain sociopolitical structures; and
- 4. Disability confines some people within architectural or geographic environments.

Applied to the notion of suffering, the social model insists that human suffering unfolds socially, often according to interpersonal, relational, and wider cultural dynamics. ³⁰ In this framework, people with disabilities suffer less because of their physical, intellectual, or sensory limitations than because they are unable to live up to normate expectations regarding living independently, achieving life quality, attaining vocational goals, and manifesting economic success.³¹ On the flip side, the temporarily able-bodied make assumptions about those who are different, impose labels on them, and implement social, medical, and other policies undergirded by normate values that constrain rather than enable the flourishing of people with disabilities.³²

²⁹ A brief but substantive overview of the social model is provided by Tom Shakespeare, "The Social Model of Disability," in *The Disability Studies Reader*, 2nd Ed., ed. Lennard J. Davis (New York: Routledge, 2006), 197–204; see also note 4.

³⁰ Ranjan Roy, *Social Relations and Chronic Pain* (New York: Kluwer Academic/Plenum, 2001); cf. Irmo Marini and Mark A. Stebnicki, eds., *The Psychological and Social Impact of Illness and Disability*, 6th ed. (New York: Springer, 2012).

³¹ As depicted by James M. Rotholz, *Chronic Fatigue Syndrome, Christianity, and Culture: Between God and an Illness* (Binghamton: Haworth Press, 2002).

³² Dietmut Niedecken's work not only shows who people with disabilities (the learning impaired in this volume) are reduced to their condition, but also how religious, social, medical, and other [*Footnote continued on next page* ...]

Note then that the sense of suffering has as much to do with the self-perception of failing to live up to the values and expectations of others. More to the point, then, the suffering of people with disabilities in these instances has to do with an internalized sense of failure. Some people with disabilities thus define themselves according to such expectations and self-identify in negative terms as those not able to do—or disabled from doing—this or that. The social model helps us to understand how society's treatment of individuals leads them to view themselves as others see them: they are "disabled"—or incapable of this or incapacitated with regard to that and come to see themselves as helpless, unable, and dependent (perhaps more in their own minds than in reality) on others. Some people with disabilities come to pity themselves, given the sympathy bestowed upon by them by a normate world,³³ while others lose their dignity as human beings through being treated paternalistically as "less than" by the temporarily able-bodied. How do people with disabilities retain their sense of self-esteem when the normate world devalues their existence?34

Religiously and theologically, people with disabilities also suffer because of how their condition is understood and what the community of faith expects of them. Not only do they have to contend with questions (oftentimes not actually asked, but surely thought) like: Why did this happen to you?—as if some sin or demonic etiology could "explain" the presence of impairment—but they also begin to believe that their lack of faith, for instance, is one, if not the primary, contributing factor to their persisting condition. Even if not embracing such a self-understanding, they have to exemplify the Christ-like character expected of those on the path of sanctification, so that means not complaining about their situation, or needing to project an "overcomer's mentality" to those in the community of faith. And if at

presuppositions combine to support eugenic practices (in the Nazi German context) allegedly for the common good; see Niedecken, *Nameless: Understanding Learning Disability*, trans. Andrew Weller (New York: Brunner-Routledge, 2003).

³³ See the discussion of "Pity as Oppression in the Jerry Lewis Telethon," in Beth A. Haller, *Representing Disability in an Ableist World: Papers on Mass Media* (Louisville: The Advocado Press, 2010), ch. 7; for a first-person perspective, see Angela Victoria Lundy, "Off the Pillow of Self-pity," in *Amazing Gifts: Stories of Faith, Disability, and Inclusion*, ed. Mark I. Pinsky (Herndon: Alban Institute, 2012), 188–90.

³⁴ Jenny Morris, *Pride Against Prejudice: A Personal Politics of Disability* (London: Women's Press, 1991).

all successful in this regard, people with disabilities become icons, even sacraments, of divine virtue, patience, and fortitude in the eyes of the temporarily able-bodied faithful, and this results in another set of standards or expectations foisted upon the impaired. After all, if St. Paul said that, "God is faithful, and he will not let you be tested beyond your strength, but with the testing he will also provide the way out so that you may be able to endure it" (1 Cor 10:13, NRSV), and if "you" are impaired, then obviously "you" must have been given a special grace to endure such disability.

C. "Four Fences" in Providence and in Pastoral Theology of Suffering Disability

This section begins to develop a pastoral approach to the experience of suffering disability by focusing on theological reorientation. In previous work, I had initiated reflection related to such a task by retrieving and re-appropriating the Chalcedonian theological method. 35 I compared how the early church fathers protected the mystery of the incarnation utilizing apophatic or negative language about how *not* to talk about the nature of Christ: e.g., Christ's divine and human natures were merely asserted to be without confusion, without change, without division, without separation, known also as the "four fences" of the Chalcedonian confession. So in like manner, rather than deploying cataphatic or positive descriptions of the Christological reality and rather than make presumptive affirmations about what is theologically ambiguous, Christians are better advised to recognize what is not known about disabilities in the context of pastoral care. Hence, I suggested that these "four fences" of the mystery of Christ could translate into "four fences" regarding disability in relationship to divine providence:

List 2. Four Fences of Disability in Divine Providence

- 1. God's will is *not* arbitrary;
- 2. Divine providence and creaturely responsibility are *not* mutually exclusive;
- 3. Divine willing is *not* opposed to the laws of nature; and
- 4. Proper Christian pastoral care should *never* presume to provide any definitive theological explanations for disability.

³⁵ See my *Theology and Down Syndrome*, 167–69.

The point is that a more humble approach is needed, one that acknowledges there is much that is *not* understood theologically, even as trust and faith in God ought to be nurtured.

Building on this platform, let me suggest "four fences" toward a theology of disability in the context of pastoral care for people and their families suffering disability.

List 3. Four Fences on a Theology of Suffering Disability

- 1. God's sovereignty does not mean God is the direct cause;
- 2. Though a fallen world, sins are *not* directly linked to disability;
- 3. All sickness is *not* derived from Satan or demons;
- 4. Pastoral agents should *not* resort to sovereignty, sin, or Satan as the first or foremost cause of any disability.

First, God's sovereignty does not mean that God is the direct cause of disability in any specific case. Yes, scripture periodically suggests that God is the cause of impairments, including as when Yahweh rhetorically pressed Moses: "Who gives speech to mortals? Who makes them mute or deaf, seeing or blind? Is it not I, the Lord?" (Exod 4:11). However, there are many instances of those with sickness or impairment across the scriptures which etiology is not linked with God's sovereign will. Mephibosheth, was "crippled in his feet" because of an accident (2 Sam 4:4), Trophimus is simply said to have been "left ill in Miletus" (2 Tim 4:20), and there are more. My point is simply that we can never know any specific disability as having been directly willed by God-unless God says so explicitlyand therefore we should not tell people with disabilities that their suffering, if such is experienced, is divinely sanctioned. Divine sovereignty does not need to translate into a view that every specific event in the cosmos is part of God's particular intention.³⁶

Second, that we live in a sinful and fallen world does *not* mean that human sins are directly linked to disability in any case. Yes, there might be obvious occasions when creaturely choices bring about impairing consequences, as with fetal alcohol syndrome. Yet even here, the appropriate pastoral response does not make this point and

³⁶ Here I am partial, as a Wesleyan, to the idea that God does not have a blueprint for every single cosmic development, but rather oversees things sovereignly and yet also preveniently and generally; see also Gregory A. Boyd, *Is God to Blame? Moving beyond Pat Answers to the Problem of Evil* (Downers Grove: IVP, 2003), esp. ch. 2.

leave things at that. Sensitivity to the scriptural connections between sin and disability in general³⁷ should alert pastoral caregivers to the reality that many believers continue asking, as did the disciples upon encountering the visually impaired man: "who sinned, this man or his parents, that he was born blind?" (John 9:2). Jesus' response is crucial for present purposes: "Neither this man nor his parents sinned; he was born blind so that God's works might be revealed in him" (9:3). We will return in a moment to the latter clause of Jesus' reply. For now, what needs to be emphasized in the context of pastoral care, especially when interacting with those who are suffering, is that sin and disability are related only in the general sense that we live in a fallen world, and not necessarily in any individual case. If people come to realize, through introspection, that their experience of suffering disability can be gleaned from to make life adjustments and better choices, then pastoral agents can help them process these thoughts; but proper pastoral care should not begin by tying the experience of suffering disability too tightly with sin.³⁸ It is not only presumptive but also judgmental from a normate vantage point.

Third, that there are some scriptural passages that suggest sickness and impairments derive from the work of Satan and his demons does *not* mean that disability is so derivative in any particular case. Even if "the Accuser" tormented Job and even if Jesus responded to the deaf-mute by exorcising an evil spirit, that neither justifies the "devil-behind-every-impairment" notion nor warrants the assumption that epilepsy is of demonic provenance. This is not to say that the human experience of impairment is devoid of a spiritual dimension. Of that, there is no doubt, for the biblical principalities and powers are intertwined with the structural evils that plague the political, social, and economic domains of human life and relationship, ³⁹ and in that sense are entangled also with the disabilities caused by war, famine, and poverty. Yet this general

³⁷ I discuss the scriptural texts that perpetuate these associations in my *The Bible, Disability, and the Church*, 18–24.

³⁸ See A. Wati Longchar, "Sin, Suffering, and Disability in God's World," in *Disability, Society, and Theology: Voices from Africa*, ed. Samuel Kabue, Esther Mombo, Joseph Galgalo, and C. B. Peter (Limuru, Kenya: Zapf Chancery, 2011), 47–58, esp. 50–56.

³⁹ See my *In the Days of Caesar: Pentecostalism and Political Theology—The Cadbury Lectures* 2009, Sacra Doctrina: Christian Theology for a Postmodern Age series (Grand Rapids: William B. Eerdmans, 2010), ch. 4, for explication of these interconnections.

cosmological perspective does not validate pastoral approaches that see Satanic attack as the root cause of suffering disability. Amidst grappling with the challenges of life, people with disabilities and their families ought not to have to bear the additional burden that they are under spiritual assault from dark and destructive cosmic forces. Although such an approach is limited by and large to Pentecostal and charismatic communities, yet the explosive growth of this kind of Christianity worldwide indicates that unless specifically countered, this can become the dominant popular understanding of impairment and disability.⁴⁰

Fourth, last but not least, pastoral agents should not resort to sovereignty, sin, or Satan first and foremost when caring for those suffering disability, and similarly, disability should *not* be presumed to be meant or designed for the sanctification of the afflicted. The point is not to deny that people with disabilities as well as their caregivers are in need of sanctification; all people, especially Christian believers, can use an added dose of divine holiness in their lives. However, popular piety sometimes thinks there must be a rationale for the existence of impairment or disability, and if the blame cannot be put on God, sin, or the devil, then it must serve providential purposes related to the individual's spiritual journey. Perhaps the sanctification of this person's life will also be exemplary for others, or enables solidarity among those so suffering. All that is well and good. But the point to be emphasized is that even if those suffering disability come these conclusions on their own, these conclusions should *not* be first or presumed by the temporarily ablebodied pastors and counselors.

This same caveat of allowing people with disabilities to come to their own informed perspective applies for the other three "fences."

⁴⁰ For further discussion of disability in pentecostal-charismatic Christianity as such interfaces with indigenous cultural worldviews, see Yong, *Theology and Down Syndrome*, 130–40, and *The Bible, Disability, and the Church*, ch. 3. For informed Pentecostal approaches to these matters, see John Christopher Thomas, *The Devil, Disease and Deliverance: Origins of Illness in N.T. Thought, Journal of Pentecostal Theology Supplemental* series 13 (Sheffield: Sheffield Academic Press, 1998), esp. ch. 9. Other Pentecostal theologies of disability and pastoral care are emerging that do not rely on demonic etiologies—e.g., Steven M. Fettke, *God's Empowered People: A Pentecostal Theology of the Laity* (Eugene: Wipf and Stock, 2011), ch. 4; and Jeff Hittenberger, "Receiving God's Gift of a Person with Special Needs: Amos Yong's Theology of Disability," in *The Theology of Amos Yong and the New Face of Pentecostal Scholarship: Passion for the Spirit*, Global Pentecostal and Charismatic Studies 14, ed. Wolfgang Vondey and Martin W. Mittelstadt (Leiden: Brill, 2013; 306 pp.), 141–59.

Those suffering disability can, through earnest wrestling with the scriptures among other resources,

- Come to embrace their experience as somehow providentially ordained;
- Come to the conviction that they are under some kind of spiritual onslaught;
- Take these as prompts to reexamine their personal, moral, and spiritual lives. $^{\rm 41}$

My argument is not that pastoral agents cannot be in conversation about such matters with those suffering disability; rather, I insist that such "explanations" not be where the discussions begins, imposed on people with disabilities by the temporarily able-bodied.

D. "Suffering Disability": Redemptive Pastoral Praxis

How then to proceed? In this final section, I emphasize a pastoral praxis that focuses on redeeming the suffering of disability, that ministers *to* those suffering disability, and that engages in ministry *with* people with disabilities. Each is interrelated with the others, supporting a holistic pastoral approach.

What does it mean to talk about the redemptibility of disability, including the suffering of disability?⁴² Again, temporarily able-bodied pastoral agents should approach such matters cautiously. However, to take off from the preceding discussion about the "four fences" of suffering disability, the main emphasis ought to lie on the fact that while God should not be thought of as sovereignly ordaining or imposing such suffering, whatever the cause of harm, pain, and tragedy, God can bring about something good. As Jesus indicated in response to the disciples' query about whether the man's blindness resulted from his own sin or that of his parents, there is nothing to be gained by attempting to decide what caused the blindness; instead, our focus should be redemptive, following God's overarching intentions: "that God's works might be revealed in him" (John 9:3). The goal is therefore a reorientation from causality or etiology toward redemption

⁴¹ On these matters, Joni Eareckson Tada and Steve Bundy's *Beyond Suffering: A Christian View on Disability Ministry* (Agoura Hills: Christian Institute on Disability, 2011) is exemplary, coming as it does from a woman with quadriplegia and a father of a child with disability; their historically Reformed and Calvinist theological view is front and center although those who come from outside of that tradition may not be as comforted by these perspectives.

⁴² The following extends my prior reflections on redeeming disability: Yong, "Many Tongues, Many Senses: Pentecost, the Body Politic, and the Redemption of Dis/Ability," *PNEUMA: The Journal* of the Society for Pentecostal Studies 31, no. 2 (2009): 167–88.

or eschatology.⁴³ Impairments come about variously—congenitally (through genetic mutations, for instance), incidentally (a fall, a car crash, etc.), as a by-product or casualty of the human condition (e.g., wars or natural disasters)—but salvation is God's business. Christian theology will never be able to provide a fully rational theodicy for those suffering disability, but Christian eschatology can outline the basis for human hope amidst the despair of disability. My suggestion is to focus on the cosmological conditions when talking about causality, but then to shift to the theological hope when attempting nurture and trying to inspire human endurance.⁴⁴

Practically, such an accent on the redemptibility of disability and whatever suffering comes in its trail should also provoke ministry to people with disabilities. Ministry to such and their families should of course not be conducted condescendingly or as if out of duty. People with disabilities and those who care for them are in the best position to identify what their needs are and how best the church or others might be able to assist. The temporarily able-bodied must never presume the form that ministry to those suffering disability should take. Instead, life-giving ministry emerges out of a discerning mutuality between all involved. The model here would be the L'Arche community where core members (people with disabilities) and their attendants relate to one another as equals, but yet also as different.⁴⁵ Even if core members are unable to verbally communicate their needs, attendants take the time to carefully learn about and then discern how appropriate caregiving should unfold.

⁴³ One of Stanley Hauerwas's most recent books, *Approaching the End: Eschatological Reflections on Church, Politics, and Life* (Grand Rapids: William B. Eerdmans, 2013; 269 pp.), has two chapters on disability (pp. 176–91 and 222–36), but readers will have to connect the dots between disability and eschatology in this book more on their own as they are not clearly delineated by Hauerwas; cf. also my paper, "Disability, the Human Condition, and the Spirit of the Eschatological Long Run: Toward a Pneumatological Theology of Disability," *Journal of Religion, Disability, and Health* 11, no. 1 (2007): 5–25, for a different approach to theology of disability from an eschatological perspective.

⁴⁴ Elsewhere I suggest a similar strategy or reorientation from classical approaches to theodicy and suffering, including the suffering of disability, toward a more performative and practical engagement; see Yong, "Disability and the Love of Wisdom: De-forming, Re-forming, and Per-forming Philosophy of Religion," *Ars Disputandi: The Online Journal for Philosophy of Religion* 9 (2009): 54–71 [www.ArsDisputandi.org/], reprinted in *Disability in Judaism, Christianity and Islam: Sacred Texts, Historical Traditions, and Social Analysis*, ed. Darla Schumm and Michael Stoltzfus (New York: Palgrave Macmillan, 2011), 205–27.

⁴⁵ The literature is enormous; a helpful discussion of the reciprocity between core members and attendants is Kevin S. Rymer, *Living L'Arche: Stories of Compassion, Love, and Disability* (Collegeville: Liturgical Press, 2009).

Two aspects are therefore worthy of highlighting. First, most who suffer disability would welcome ministry; however, such ought to be made available in a discerning manner. Second, effective ministry to those suffering disability emerges from out of a genuine human relationship, even friendship. In other words, authentic ministry to people with disabilities opens up when ministers take the time to get to know and even to befriend people with disabilities, their families, and their caregivers, and certainly less out of professional motivation than out of Christian selflessness.⁴⁶

Out of sustained Christian friendship and relationship, ministry to people with disabilities opens up to ministry with them; more precisely the "us" of those temporarily able-bodied and "them" of those suffering disability will itself be overcome. Not that the differences will be erased, since that would itself not recognize or affirm the bodily form of disability as also uniquely in the image of God. Rather, the point is that the ministry of the body of Christ includes each member in his or her particularity, vulnerability, and even weakness, bearing the gifts of the Holy Spirit.⁴⁷ To talk about disability in terms of vulnerability and weakness risks perpetuating able-bodied and normate assumptions that those living with impairments are less strong. However, this is precisely the apostolic counter to the Corinthian presumption about their own nobility, capacity, and intelligence, which included insistence that the ways of divinity involved the mobilization and utilization not of the selfassured but of those who recognized their limitations as creatures made in the image of God.⁴⁸ The point to be made is twofold: first, that people with disabilities, no matter how severe or even profound, ought not to be viewed merely as passive objects of ministry, but can also be welcomed as agents of ministry, even if in some circumstances, how such ministry is carried out will require patience,

⁴⁶ Thus the thrust of Hans Reinder's provocative book, *Receiving the Gift of Friendship: Profound Disability, Theological Anthropology, and Ethics* (Grand Rapids: Eerdmans, 2008).

⁴⁷ Yong, "Disability and the Gifts of the Spirit: Pentecost and the Renewal of the Church," *Journal of Pentecostal Theology* 19, no. 1 (Spring 2010): 76–93.

⁴⁸ See also Yong, *The Bible, Disability, and the Church*, ch. 4, on St. Paul's notion of weakness as providing the rudiments for the first Christian theology of disability; cf. Yong, "Running the (Special) Race: New (Pauline) Perspectives on Theology of Sport," *Journal of Disability and Religion* 18, no. 2 (2014): 209–25.

creativity, innovation, and persistence;⁴⁹ second, and building from this, it is precisely as ministers to others that those suffering disability realize their being created in the image of God, with the capacity to participate in the mission of God, and this itself is redemptive not only for people with disabilities but for all.⁵⁰

Conclusion

This paper intended to accomplish four related purposes:

- 1. To interrogate the normate assumption that all disability brings about suffering;
- To clarify how the suffering of disability oftentimes derives from normate expectations related to and temporarily able-bodied treatments of people with disability;
- **3.** To redirect questions of theodicy regarding suffering disability away from theological causality toward a redemptive praxis; and
- 4. To enable and empower those suffering disability to receive ministry from and be agents of ministry to others.

The foregoing four sections attempted to respond to these objectives. As one who is temporarily able-bodied, I urge others like me to reconsider how their attitudes and approaches to disability not only might be a cause of but also unintentionally perpetuate the suffering that people with disabilities undergo. Awareness of this normate prejudice will take us some way toward alleviating suffering in the world, especially the suffering endured by people with disabilities.⁵¹



⁴⁹ Part II of Mark I. Pinsky, ed., *Amazing Gifts: Stories of Faith, Disability, and Inclusion* (Lanham: Rowman and Littlefield, 2011) provides glimpses of "Ministry by People with Disabilities."

⁵⁰ See my article, "Disability from the Margins to the Center: Hospitality and Inclusion in the Church," *Journal of Religion, Disability, and Health* 15, no. 4 (2011): 339–50.

⁵¹ An earlier version of this paper was presented at the Caring Theologically and Thinking Pastorally Conference on Disability, sponsored in part by the Bethesda Institute and Southern Methodist University/Perkins School of Theology, Dallas, Texas, 16 June 2014; thanks to the audience for helpful questions leading to clarification of various aspects of the paper.