

# Disability

Christian Reflection  
A SERIES IN FAITH AND ETHICS



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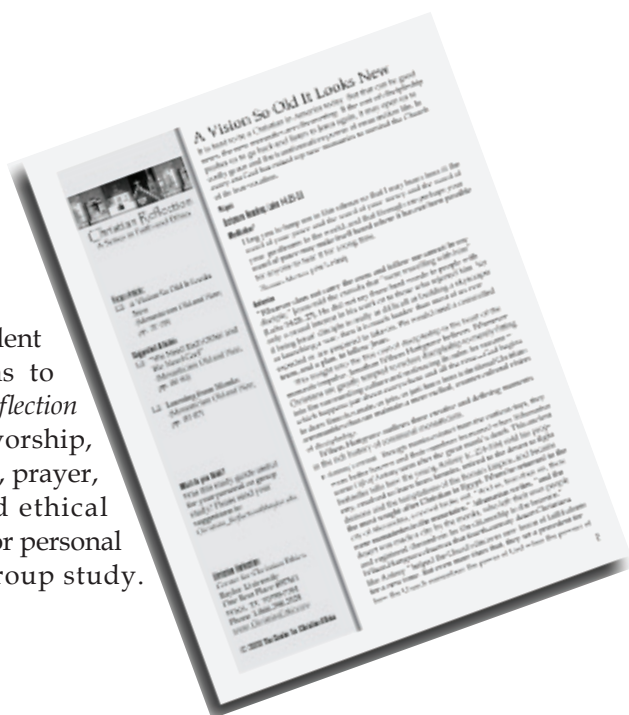
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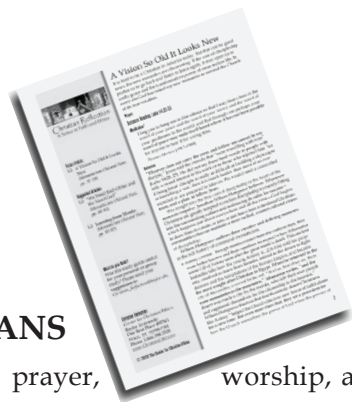


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# Introduction

BY ROBERT B. KRUSCHWITZ

Disability is “tragically but redemptively fundamental” to discipleship, Tom Reynolds notes, for it “opens up our vulnerability and dependence upon each other and God.” How can we walk beside one another in friendship and learn from one another with our disabilities?

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Disability is “tragically but redemptively fundamental” to discipleship, Tom Reynolds has noted. The tragedy is that a wide range of physical, intellectual, and emotional disabilities often involve unwanted impairment and suffering, which then are compounded by social alienation. How easily we exclude those with disabilities in society and church in order to avoid, in Deborah Creamer’s words, “coming face to face with two of our great fears: we are not perfect and we are not in control.” Yet facing disability squarely — our own and others’ — is redemptive, Reynolds explains, when “disability opens up our vulnerability and dependence upon each other and God.” Our contributors help us explore our calling to walk beside one another in friendship and learn from one another with our disabilities.

In *Zacchaeus: Short and Un-seen* (p. 11), Amos Yong warns that “societal fears of disability often warp how we read the Bible.” The ableist perspectives of non-disabled interpreters blunt the biblical message. Yet stories like the one about Zacchaeus clearly challenge “the normate assumption that disability is a problem needing to be fixed or eliminated,” he observes. “All human beings can be accepted as children of Abraham regardless of their physical characteristics or capabilities.”

John Swinton agrees in *Many Bodies, Many Worlds* (p. 18), disability “is not simply a focus for the outworking of compassion and healing; we quickly discover that God uses disabled bodies to carry out the key tasks of the coming kingdom.” Because knowledge of the world depends radically on our bodies, we live in different worlds depending on our disabilities. Swinton concludes,



"It is only as we begin to take seriously the multiple worlds we live in that we can begin to understand what it means to be human and to live humanly. It is only as we learn to listen to all of our worlds that we can learn what it means to live well in that strange new world within the Bible." In *Affirming God in the Midst of Disability* (p. 79), Tom Graves invites us into his world of disability, revealing "the redefinitions of divine power, creation, and human purpose" he has discovered in light of his multiple sclerosis. He writes, "God comes to us in the form of Jesus bearing the wounds and disabilities of a vulnerable human life. If we are called to be a co-creator with God, we also know that God comes to us as a co-sufferer. That is a God truly worthy of worship."

While it usually involves a bodily impairment, human disability is "in no small part...a social construct," Tom Reynolds explains in *The Cult of Normalcy* (p. 25). Indeed, "society disables people by representing impairment as a flaw or deficit, by constructing what is 'normal' and thereby creating the difference between bodies that are 'able' and those that are 'disabled.'" A particularly insidious manifestation of this cult of normalcy is the growing search for genetic abnormalities *in utero*, Brian Brock warns in *The Lure of Eugenics* (p. 68). He writes, "In contemporary society 'prenatal care' and 'prenatal screening' are taken to be synonyms, but they become antonyms in practice when the refusal to test is portrayed as unnecessarily risky and aborting a disabled child is portrayed as a relief." In the context of such attempts to build a wall around "normal" humanity, Tom Reynolds claims that disability, from pre-born to adult life, offers a prophetic challenge: it "exposes the social pretensions of the 'normal' and invites us to see our humanity as vulnerable gifts of God to be received by each other in relationships of mutual giving and receiving."

As one who has lived with multiple sclerosis for half her life, Kay Toombs has experienced life under the cult of normalcy. "I have been very aware of the many ways in which contemporary cultural values with respect to such things as independence, productivity, physical fitness, health, youth, beauty, and so forth, inevitably deepen the sense of vulnerability that accompanies debilitating illness and disability," she writes in *Jars of Clay: Disability in Intentional Christian Community* (p. 34). Yet she has been blessed to be in an "authentic Christian community [that] offers an alternative culture with a radically different value system, thus offering a nurturing context in which it is possible to fully embrace the vulnerability that accompanies disability, to concretely enact our Christian beliefs with respect to the intrinsic worth of all human beings, and to affirm the value of all members of the community."

"The gospel invites us to the greatest stretch of our imagination to see the profoundly disabled as fellow brothers and sisters, members of God's kingdom, who have been given gifts we need and from whom we might learn," Jason Whitt notes in *Baptism and Profound Intellectual Disability* (p. 60). In light of this he confronts a dilemma facing Christians who practice believers' baptism (where baptism follows faith as a person's conscious and voluntary act of obedience to Christ's command). He wonders: "Is there room in the baptis-

mal waters for persons with profound intellectual disability?"

Heidi Hornik explores how three biblical narratives related to disability are depicted in Christian art. In *Desperate* (p. 54), she examines a Byzantine mosaic (on the issue cover) of the woman suffering from a hemorrhage who steals a healing from Jesus. Caravaggio's *The Incredulity of Saint Thomas*, which famously depicts the moment that the disciple probes the wounded side of the resurrected Christ, is discussed in *Lasting Wounds* (p. 56). And in *Unexpected Healing* (p. 58), she reviews Nicholas Poussin's *Saints Peter and John Healing the Lame Man*.

As John Swinton observes in his article, "It is not insignificant that the heart of the Christian faith revolves around a damaged body. It is in the disabled body of Christ on the cross that we encounter our redemption." Terry York reflects on this powerful insight in his new hymn "The Twisted Form upon the Tree" (p. 43). It is part of the liturgy (p. 46) by Debra Dean Murphy that lifts to God our weaknesses and difficulties, and confesses our responsibility for turning them into disabling conditions.

The questions raised about disability and community by our contributors are helpfully focused in the daily life of the L'Arche communities, an international network of residential communities for people with developmental disabilities (core members) and caregiver assistants who live with them. In *Travelling in the Ark* (p. 83), Heiki Peckruhn reviews *Becoming Human* by Jean Vanier, a cofounder of L'Arche, and three books that apply Vanier's insights to other contexts: Stanley Hauerwas and Jean Vanier's *Living Gently in a Violent World: The Prophetic Witness of Weakness*, Kevin Reimer's *Living L'Arche: Stories of Compassion, Love, and Disability*, and *The Paradox of Disability: Responses to Jean Vanier and L'Arche Communities from Theology and the Sciences*, edited by Hans Reinders. These books "compel us to engage in self-reflection about our values, fears, needs, and assumptions about what is 'normal,'" Peckruhn writes. "Hopefully they will spark a desire in us to replace rejection and exclusion with friendship" toward persons with disabilities.

Jackie Mills-Fernald's *Lowering Barriers for People with Disabilities* (p. 89) commends four books that can help us welcome all people, regardless of ability, to participate fully in the body of Christ—Barbara J. Newman's *Helping Kids Include Kids with Disabilities*, Jim Pierson's *Exceptional Teaching: A Comprehensive Guide for Including Students with Disabilities*, Erik W. Carter's *Including People with Disabilities in Faith Communities: A Guide for Service Providers, Families and Congregations*, and the anthology *Special Needs, Special Ministry*. "Becoming a fully-inclusive congregation where all persons are welcome regardless of ability level...may take some time," Mills-Fernald concludes. Yet it is essential that we embark on this "journey that glorifies God and reflects God's view on his people—all made perfect in the divine image." ✠

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# Zacchaeus: Short and Un-Seen

BY AMOS YONG

**Societal fears of disability often warp how we read the Bible. But the Zacchaeus story challenges the normate assumption that disability is a problem needing to be fixed or eliminated. All human beings can be accepted as children of Abraham regardless of their physical characteristics or capabilities.**

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Contemporary understandings of disability are not identical to those of the biblical authors. Nevertheless, some interpretations of the Bible, often based on the normate and ableist assumptions, experiences, and perspectives of non-disabled people, have shaped popular views of disability throughout history.<sup>1</sup> On the one hand, many think that disabilities are ordained by God for God's purposes. But on the other hand, this is often accompanied by the feeling that people with disabilities are or ought to be pitiable and charitable objects of the care of others, and with the judgment that their condition is a sign of divine punishment for sin, or of the presence and activity of an evil spirit. By and large, then, disability has been viewed negatively, as a blot on an originally good creation.

Yet these views of disability can have negative effects. Images of Jesus and the apostles healing the sick, raising the lame, opening the eyes of the blind, and so on, fueled the historic quest for cures for disabling conditions, but they may lead people with disabilities to internalize the normate view and thereby wonder what is wrong with them that prevents their reception of God's healing power. The further assumption that disabilities will be erased in the end—rooted in a belief that the resurrection body will be free from earthly disabilities, which overlooks the fact that the New Testament describes the raised body of Jesus as including the marks of the crucifixion—provides added impetus both to prevent the onset of disability and to

cure or alleviate it if possible in the present life. It is no wonder that people with disabilities are often stigmatized and feel unwanted in public spaces. They remain in back rooms of homes around most of the world as even their families are ashamed by their existence. In technologically advanced societies, there have been initiatives to prevent people with disabilities from reproducing (motivated by the supposition that their children will perpetuate the parents' disability); in the worst case scenarios, eugenic projects have both attempted to select against disability and committed genocide against people with disabilities.<sup>2</sup> Is it any wonder that many people with disabilities do not feel welcome in the Church? Church leaders may claim that there are few people with disabilities in their congregations because there aren't many in the wider community. But up to twenty percent of Americans have disabilities of some sort and most believe that Christians think negatively about them rather than desire to include them in the Church.

In this essay I would like to highlight how our societal fears regarding disability can be seen in the way we read the Bible. Normate assumptions, which lead to the notion that disability is a problem needing to be fixed or eliminated, generate a hermeneutical approach that minimizes what the Bible features about disability.

In a recent book Jeremy Schipper has shown how the normate perspective ignores or even goes so far as to eliminate disability in the biblical message through his treatment of Isaiah 52:13-53:12's reception history (the passage widely known as describing the "suffering servant").<sup>3</sup> Schipper shows not only that the biblical text and context clearly denote that the servant suffered and perhaps even died from a skin anomaly, but also that it was precisely because of this skin condition that the servant was socially ostracized, marginalized, and, in this most fundamental sense, experienced suffering. Yet the interpretation of this passage over the centuries has by and large failed to recognize this, suggesting instead that the servant was injured, in some cases perhaps to the point of death. More intriguingly, what has consistently emerged is a view of the servant as able-bodied, rather than afflicted or plagued. The disability imagery present in the Isaianic text has been lost either in translation or in interpretation. Instead, what has been invented is an able-bodied suffering servant. The irony here is that people with disabilities have long felt the pressure to pass as able-bodied persons, and in this case, the impaired servant has been recreated in the able-bodied image of normate interpreters.

Schipper's study invites reconsideration of other scriptural narratives to see if similar interpretive bias can be identified. Although not a biblical scholar myself, I have spent a significant amount of time on the study of Luke-Acts. A Lukan story that many Christian readers are familiar with is that of Zacchaeus (Luke 19:1-10), a rich chief tax-collector who is described as being "short in stature" (19:3). The Sunday school version has been told with a song:

Zacchaeus was a wee little man,  
and a wee little man was he.  
He climbed up in a sycamore tree  
for the Lord he wanted to see....

A canonical reading of the Zacchaeus story could begin by connecting his short-staturedness to the dwarfism that is identified among a list of disabilities disqualifying priests from offering the sacrificial food or approaching the altar of the Holy of Holies in ancient Israel (Leviticus 21:16-24). Yet interpreters rarely attend to Zacchaeus's shortness, to the point of thinking that "short in stature" refers to no more than his youthfulness. Even when acknowledged, its import is subordinated to the assertion that in the story Zacchaeus seems "exceedingly large in spirit"; in this way his littleness of stature is spiritualized, understood for instance with reference to his humility.<sup>4</sup> Some commentators—even major ones like John Calvin and John Wesley—simply say nothing about Zacchaeus's lack of height. Instead, a great deal of attention is put on debating whether what he says about giving half his possession to the poor or repaying fourfold those he has defrauded (Luke 19:8) amounts to a set of resolutions following his conversion to Jesus or are statements vindicating his practices to local Judeans who would have despised a person in his official governmental position.

Beyond this, the major messages highlighted by scholars, commentators, and preachers appear to be communicable quite independently of Zacchaeus's shortness. His generosity has

been understood as enacting the Year of Jubilee economic vision running throughout the Lukan corpus. Jesus' pronouncement of his salvation as a son of Abraham (Luke 19:9) has been viewed both as contributing to the major theme of Israel's renewal and as an indictment of the crowd's beliefs that certain people, such as stigmatized

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**Interpreters rarely attend to Zacchaeus's shortness, often thinking "short in stature" refers to youthfulness. Even when acknowledged, his shortness is spiritualized and understood with reference to his humility.**

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tax collectors, were excluded from this restoration. Most generally, the conclusion of the pericope has been that "the Son of Man came to seek out and to save the lost" (19:10). Yet, none of these readings are dependent on or even remotely connected to Zacchaeus being a person of little stature, and thus it is warranted to conclude that interpreters think Luke's physical description is a minor, even negligible, part of the story. In effect, then, Zacchaeus's shortness has been overlooked, if not rendered invisible, by normate readers.

But does this dismissal of Zacchaeus's shortness inhabit the spirit of what

Luke is attempting to communicate or reflect instead an ableist bias that literally handicaps readers from engaging the full meaning of the text? I suggest that while it is quite normal for normate interpreters to make little of Zacchaeus's littleness, this dismissal fails to recognize an essential aspect of his humanity and impoverishes our understanding of what is going in this story and in Luke's overall message. Mikeal Parsons's analysis of ancient physiognomic assumptions regarding outward bodily traits expressing inward characteristics suggests that physical descriptions are not throw-away lines in the biblical account.<sup>5</sup> Rather, similar to how contemporary readings have been inspired by the reference to Zacchaeus's littleness to observe the largeness of his heart, so also did Luke deploy the physiognomic conventions of his day only to subvert them in light of the gospel of Christ.

Of the four Lukan characters explored in depth by Parsons – the bent over woman (Luke 13:10-17), Zacchaeus (Luke 19:1-10), the man lame from birth at the Beautiful Gate (Acts 3-4), and the Ethiopian eunuch (Acts 8:26-40) – our focus will be on the smallest one. Though grammatically the *hēlikia mikros* (being short of stature) in Luke 19:3 does not necessarily refer to dwarfism, and the Greeks had other more technical terms for this condition (*pygmē* and *nanos* or *nanosues*), Parsons documents that *mikros* was “also used for pathological dwarfism in texts from the fourth century BCE to the ninth century CE.”<sup>6</sup> He also shows that the contemporary “science” of physiognomy would have read Luke's physical description of Zacchaeus not only as a window into the smallness of his character or of his lowly self-esteem, but also in a derogatory sense as indicative of small-mindedness and greed.

Yet this is only what is most obvious. The assumption of Zacchaeus's pathological dwarfism more provocatively enables Luke to undermine the accepted physiognomic beliefs. The fact that Zacchaeus is later designated a sinner (19:7) would have provided further confirmation for his pathological dwarfism since congenital physical diminutiveness would have been assumed to be the result of sin. The image of Zacchaeus running ahead of the crowd and climbing a sycamore tree (19:4) would have provoked the derision of the crowd. Both those watching Zacchaeus and Luke's readers would have been fascinated by the awkward movements of a pathological dwarf with his less symmetrically proportioned body. My point is this: even if the technical grammatical construct in this passage suggests only that Zacchaeus is relatively short rather than that he is a dwarf (someone under 4'10" by today's measurements), there is nothing to prohibit viewing Zacchaeus as a dwarf and the Lukan strategy of subverting contemporary physiognomic conventions is much more effective precisely if that were the case.

I am not aware of any published readings of the Zacchaeus story by little people, but what if we were to deploy a *littlist* or *shortist* perspective in reapproaching this text?<sup>7</sup> Let me hazard three possible lines of reflection. First, although little people do not agree about whether or not they are part of the wider disability community, there is no doubt that pathological dwarf-



ism across a very broad spectrum brings with it a wide range of physical disabilities and intellectual deficiencies. Beyond this, of course, is the social stigma and public ridicule elicited by their very visible condition resulting in unfair caricatures, discriminatory attitudes, and economic employability (and its concomitant poverty). Little people despair in this hostile climate, to the point that many live in self-denial or even avoid interacting with other little people since they do not want to be reminded of their condition.<sup>8</sup> What transpires, regardless of how physically capable little people might be, is the reality of a “social disability”: they must deal daily with stereotypes of little people as bitter, disagreeable, and vengeful, and with accounts that rarely portray them “as thinking, feeling individuals who were at the center of their own lives, but rather... as adjuncts to the lives of others.”<sup>9</sup> Against this background, however, Zacchaeus emerges not as a passive recipient of pity but as an agent in his own right. It is not so much that he was fully employed – after all, collecting taxes for the Romans was a despicable task that allowed few in the position to live at peace within their community – but that he was capable of and actively sought out Jesus, despite having to contend with the crowds. Further, his desire to see Jesus led him to expose himself to ridicule because “it was considered undignified for a grown man to run, and a man of his importance would certainly not climb a tree.”<sup>10</sup> Yet he persisted and even got the opportunity to host the Son of Man in his own home. In these ways, Zacchaeus becomes a model for what little people can hope to accomplish.

Beyond this, however, little people would resonate with Parsons’s reading of Luke as intending to subvert the physiognomic assumptions of his day. With Jesus’ pronouncement, “Today salvation has come to this house, because he too is a son of Abraham” (Luke 19:9), the (Levitical) prohibition against dwarfs from full participation in the liturgical cult of ancient Israel was lifted. Little people are not only agents in their own right, but also in God’s eyes, regardless of the limitations imposed on them by society or of the lowered expectations that they have to contend with.<sup>11</sup>

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Thirdly, little people would also help us to notice that the structure of this passage results in the salvation or healing of both Zacchaeus and the people in ironic and counter-intuitive senses. On the one hand, normate assumptions would have expected Jesus to heal the sick, impaired, and disabled. Jesus does no such thing in this case, although he definitively acknowledges the presence of full health in the sense of salvation for Zacchaeus. On the other hand, the

prejudices of the people are confronted, and Jesus' acceptance of Zacchaeus just as he is undermines their expectations that those who are impaired and disabled need to be "fixed" or cured in order to participate fully in the renewal and restoration of Israel. Zacchaeus becomes a disciple of the Messiah without having to go through the process of literally being stretched from his diminutive condition. Similarly, little people today need not undergo the various surgical procedures touted to increase the length of their limbs or their overall height in order to fit in with the aesthetic sensibilities of normate culture.

I do not present the preceding as representative of little people's understanding of the Zacchaeus story. Instead, I provide it as a counter to normate readings of Luke 19 that all too often minimize, eradicate, or even render invisible—as impossible as that seems!—Zacchaeus's littleness. It is not that disability and its various features are absent from the Bible; it is rather that normate interpretations are insensitive to their presence and thus overlook them as supplementary to the message that is, for them, obviously meant for normal people (like them). Of course most normate readers are not conscious of the marginalization of disability in their interactions with Scripture. The ableist bias is insensitive to the world of disability and their normative assumption is that the world as it ought to be will not feature any signs or marks of impairment, even those related to littleness. It thus never occurs to them that what they are rendering invisible is actually essential to the message of the gospel that comes to specific human beings. The result is not only an overlooking of important features of a text expressive of the salvific message of the gospel, but the perpetuation of an oppressive social imagination that has negative repercussions for people with disabilities.

My claim, however, is that the Bible really is good news for all people, including those with disabilities and those who are temporarily able-bodied.<sup>12</sup> It is just that normate prejudices have created a chasm between people of varying abilities—separating "normals" like "us" from "them"—so that we are not able to stand in solidarity as human beings created in the image of God. Without such solidarity, normate folk are incapable of understanding the world from the perspective of their friends and therefore think that they need to do what they can to save, heal, or otherwise fix those who have disabilities. Perhaps what the Zacchaeus story teaches us is that human beings are equals both in their sinfulness and need for repentance, and in their being accepted as children of Abraham regardless of their physical characteristics or capabilities.<sup>13</sup>

## NOTES

1 "Normate" in the field of disability studies refers to the assumptions about disabilities held by those without disabilities; "ableism," parallel to *sexism* or *ageism*, thus represents the discriminatory perspectives and practices imposed, sometimes unconsciously so, by non-disabled people, structures, and policies, on those with disabilities. For further discussion, see my *The Bible, Disability, and the Church: A New Vision of the People of God* (Grand Rapids, MI: Wm. B. Eerdmans Publishing Company, 2011), 10-12.



2 The latter was enacted in Nazi Germany, but the Anglo-American world has also been tainted by eugenic assumptions, policies, and practices, especially now that we have the technology to identify disabilities *in utero* and up to 90% of parents (by some estimates) are opting for abortion in these cases. See also Marta Russell, *Beyond Ramps: Disability at the End of the Social Contract* (Monroe, ME: Common Courage Press, 1998), chapter 2.

3 Jeremy Schipper, *Disability and Isaiah's Suffering Servant*, Biblical Reconfigurations (New York: Oxford University Press, 2011).

4 St. Peter Chrysologus, Sermon 54, "On Zacchaeus the Tax Collector," in *Selected Sermons*, volume 2, The Fathers of the Church: A New Translation, 109, translated by William B. Palardy (Washington DC: The Catholic University of America Press, 2004), 207. See also Cyril of Alexandria, Sermon 127, in *A Commentary upon the Gospel according to Saint Luke*, part II, translated by R. Payne Smith (Oxford, UK: Oxford University Press, 1859), 587-590, for another spiritualized view of Zacchaeus's short-staturedness.

5 Mikeal C. Parsons, *Body and Character in Luke and Acts: The Subversion of Physiognomy in Early Christianity* (Grand Rapids, MI: Baker Academic, 2006).

6 Parsons, *Body and Character in Luke and Acts*, 102.

7 While "dwarf" remains the correct medical term, the nomenclature of "little people" or "LP" is the prevalent self-description today; see, e.g., Betty M. Adelson, *The Lives of Dwarfs: Their Journey from Public Curiosity toward Social Liberation* (New Brunswick, NJ: Rutgers University Press, 2005), xvii. The following is inspired by what David E. Orton, "We Felt Like Grasshoppers: The Little Ones in Biblical Interpretation," *Biblical Interpretation* 11:3-4 (2003): 488-502, calls a *shortist* – which is parallel, for instance, to *feminist* – reading or hermeneutic of Scripture, focused particularly on the *mikroi* or little ones who are repeatedly mentioned in the Gospel of Matthew.

8 Joan Ablon, *Little People in America: The Social Dimensions of Dwarfism* (New York: Praeger, 1984), 91-94.

9 Adelson, *The Lives of Dwarfs*, 372; for the reference to dwarfism as a "social disability," see Joan Ablon, *Living with Difference: Families with Dwarf Children* (New York: Praeger, 1988), 7.

10 Leander E. Keck, ed., *The New Interpreter's Bible*, volume IX: *Luke, John* (Nashville, TN: Abingdon Press, 1995), 357. To be sure, besides the ambivalence toward dwarfs in the ancient Greco-Roman world, there was also some degree of acceptance, at least in Egypt and Greece, as documented by Véronique Dasen, *Dwarfs in Ancient Egypt and Greece* (Oxford, UK: Clarendon Press, 1993).

11 On having to live according to the lowered expectations of others, see the moving autobiographical account of Matt Roloff with Tracy Sumner, *Against Tall Odds: Being a David in a Goliath World* (Sisters, OR: Multnomah Publishers, 1999), especially chapter 12.

12 See my *Theology and Down Syndrome: Reimagining Disability in Late Modernity* (Waco, TX: Baylor University Press, 2007).

13 Thanks to David Orton and Vince Le (my graduate assistant) for their encouraging comments on a previous version of this article. I of course am fully responsible for any errors of fact or interpretation.



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# Many Bodies, Many Worlds

BY JOHN SWINTON

Disability is a mode of human experience that challenges our norms and reshapes our most basic understanding of reality as we encounter the rich diversity of what it means to be a human being in God's image.

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The world of disability is a strange place. Entering into that world (or better, as we will see, the worlds of disability), challenges our basic understanding of reality and what it means to live fully as a human being before God. Disability is not simply a space within our humanness where we try to enable people to conform to accepted norms. Rather, disability is a mode of human experience within which our accepted norms are challenged and reshaped as we encounter the fullness of what it means to be a human being in the rich diversity of God's image.

"How can we include people with disabilities?" is not the key question when determining how people with disabilities can be enabled to minister faithfully. As we shall see, inclusion is not enough. Rather, the key question is "What does it mean to be human?" I want to offer a perspective on the latter question that throws important light on the first question.

## THE STRANGE NEW WORLD WITHIN THE BIBLE

Karl Barth has suggested that Scripture is not a place that we go to in order to gather rules, regulations, and edicts for good living, but is rather the doorway into a strange new world.<sup>1</sup> Its stories, images, rituals, and practices invite us to enter this strange new world. As we read the stories of Abraham, Moses, Jesus, and Paul, we come to recognize that their stories are in fact ours. And as we find our place within these stories, they form a lens through which we re-examine the world we thought we knew, and thus begin to transform our understanding of what we previously assumed to be normal.

Within this new world that Scripture reveals to us, disability shifts its shape. It is no longer simply a focus for the outworking of compassion and healing; we quickly discover that God uses disabled bodies to carry out key

tasks of the coming kingdom. Moses, a person with a profound speech impediment, is tasked with delivering the very words of God. Thus Moses begs, "Pardon your servant, Lord. I have never been eloquent, neither in the past nor since you have spoken to your servant. I am slow of speech and tongue" (Exodus 4:10, NIV).<sup>2</sup> God does not heal Moses's disability in order that he can carry out his vocation. Instead, "The LORD said to him, 'Who gave human beings their mouths? Who makes them deaf or mute? Who gives them sight or makes them blind? Is it not I, the LORD? Now go; I will help you speak and will teach you what to say.'" (Exodus 4:11-12, NIV). Within God's providence disability has deep meaning. Disabilities do not prevent one from having a powerful ministry within God's coming kingdom.

The apostle Paul encounters something similar:

Therefore, in order to keep me from becoming conceited, I was given a thorn in my flesh, a messenger of Satan, to torment me. Three times I pleaded with the Lord to take it away from me. But he said to me, "My grace is sufficient for you, for my power is made perfect in weakness." Therefore I will boast all the more gladly about my weaknesses, so that Christ's power may rest on me. That is why, for Christ's sake, I delight in weaknesses, in insults, in hardships, in persecutions, in difficulties. For when I am weak, then I am strong.

### *2 Corinthians 12:7b-10*

We cannot be sure exactly what Paul's disability was. Interpreters have suggested it was depression, epilepsy, or scoliosis. Whatever it was, God did not feel that it had to be removed in order for Paul to work powerfully for the kingdom. Presumably the reason Paul's prayers were not answered was not that he lacked faith! Rather than being healed, Paul discovered a great strength in the disabling condition. While he and perhaps those around him initially thought it was a weakness, God considered it to be a strength.

Surely the mysterious dynamic of God's intricate involvement with disabled bodies is hinted at in this psalm:

For you created my inmost being;  
you knit me together in my mother's womb.  
I praise you because I am fearfully and wonderfully made;  
your works are wonderful,  
I know that full well.  
My frame was not hidden from you  
when I was made in the secret place,  
when I was woven together in the depths of the earth.  
Your eyes saw my unformed body;  
all the days ordained for me were written in your book  
before one of them came to be.

### *Psalm 139:13-16*

This of course raises very difficult questions regarding God's role in disability. While such questions cannot be addressed in this short essay, the important point to note is that disabilities have meaning beyond the mere desire of human beings to eradicate them.<sup>3</sup>

It is not insignificant that the heart of the Christian faith revolves around a damaged body. It is in the disabled body of Christ on the cross that we encounter our redemption. This is wonderfully portrayed in the triptych that Matthias Grünewald painted for the *Isenheim Altarpiece* (c. 1512-1515). The monastery of the Order of St. Anthony in Isenheim (near Colmar in the Alsace region) was a hospice for victims of the plague, and Grünewald's powerful images for its altarpiece have been called "the single most important work of German Renaissance painting."<sup>4</sup> Two things are quite startling about the centerpiece image that depicts the Crucifixion. First, the hands of Jesus nailed to the cross are curled into claw-like shapes to indicate the extreme pain he is experiencing. While earlier artists had focused on Jesus' impassivity, Grünewald indicated that Christ's suffering was real and unromantic, and by implication that God is not impassive. Second, the body of Jesus is pockmarked with red spots. This dying savior identifies not just with human suffering in general, but with the particular infirmity of the plague victims in the monastery. The image reminds us that in the broken body of Jesus we encounter what it means to be a human being before a God who enters into our brokenness, embraces our suffering and our differences, and through his body moves us towards redemption.

In the strange new world within the Bible, human bodies and human disability have meanings that stretch beyond our simplistic biomedical assumptions that we need to fix what is broken and normalize what we consider to be abnormal. Disabled human bodies can carry powerful messages of redemption just as they are.

## THE SOULFULNESS OF HUMAN BODIES

In order to understand the implications of such a suggestion, we need to think through what it means to be an *embodied* human being. To begin with, what exactly is a human body? In the biblical account of creation we find this statement about the constitution of humans: "then the Lord God formed a man from the dust of the ground and breathed into his nostrils the breath of life, and the man became a living being" (Genesis 2:7). God creates the human being out of dust and breathes his *nephesh* (breath, or spirit), into him. Augustine describes human beings as *terra animata*: animated dust. God's *nephesh* is that which makes human beings come alive, and it sustains them in living. When God decides to withdraw his *nephesh* there is no life. Each person, each body is a place where God's *nephesh* continues to sustain life. That being so, it is clear that human beings are ensouled creatures. We are our bodies as we are our souls.

This observation has important implications for the way in which we

view one another and the various bodies that we inhabit. As earth animated by the breath of God, human beings are, in the words of Wendell Berry, “holy creatures living among other holy creatures in a world that is holy.”<sup>5</sup> Each and every body is holy. That is not to suggest that somehow humans beings are perfect, or beyond sin, or in and of themselves holy. My point is that there is something of the divine within each person, and it is that which is holy and it is that which makes our encounters with one another holy.

As we recognize the presence of God’s *nephesh* in one another, we begin to realize that attending to God’s creatures is a mode of attending to God. As the apostle Paul teaches, “Do you not know that your body is a temple of the Holy Spirit, who is in you, whom you have received from God? You are not your own; you were bought at a price. Therefore honor God with your body” (1 Corinthians 6:19-20, NIV). The key point in relation to disability is that all bodies are holy places. Recognizing that is the beginning of understanding what it means truly to be with people who have disabilities. Their bodies, like all bodies, are holy places.

### THE WORLDS CREATED BY OUR BODIES

In his book *Touching The Rock: An Experience of Blindness* and a series of papers on theology and disability, theologian John Hull relates his experiences of going blind late in life.<sup>6</sup> He not only explores what it felt like to go blind, but offers a challenging phenomenological perspective on what we consider to be normal and why we interpret the world as we do. Drawing on the phenomenology of the philosopher Maurice Merleau-Ponty, Hull reflects on the ways human beings gather information and create knowledge.<sup>7</sup>

Hull notices that for sighted people who perceive the world primarily by *looking* at it, the world seems to be “out there.” The world “out there” is then brought within the boundaries of the world “in here” as they use their eyes. This mode of experience undergirds a general assumption that the dynamic of knowledge gathering is a movement from the outside to the inside, with the human body being a passive processor of external facts and conditions. When it is assumed this is the only way for human beings to know the world, then those who do not gather knowledge in this way are assumed to be lacking and in need of help from others to “see” the world similarly to sighted people. Blindness from this perspective will always and only be construed as a deficiency.

However, as he began to lose his sight Hull noticed that his knowledge of the world changed. Indeed, he argues, *his world changed*. As a sighted person he had perceived the world as external to himself. However, as his sight began to fade, so the world moved inward and became the size and shape of his body. Internal feelings and experiences he had never noticed before became primary as his ability to *look* outside began to fade. At first he felt trapped within his own body, but as he began to adjust, his world changed. Gradually he found himself moving outward, but this time the world “out there” was

different. For instance, colors and faces changed their meaning as their ability to inform him of the nature of the world shifted. Feeling a human face is quite different from seeing one; translating colors into words is quite different—though not necessarily inferior—from looking at color. His hands, which were previously used to *do* things, now became vital sensory organs that informed him of the way the world is. Sounds became primary informants, but he discovered that listening without seeing was quite different than listening with sight.

As he learned what it meant to live in this strange new world of blindness, Hull's experience offered a new understanding of how all of us encounter the world. Our bodies allow us to experience and engage with the world in a variety of different ways. Hull became acutely aware that we all encounter the world through our bodies; they are our primary source of knowledge of the world. Because our bodies can be different in fundamental ways, we do not encounter the world in the same way. If that is so, then there is no point at which we can call our experience "normal." All of our perspectives are just that—*perspectives*.

There is no single phenomenal world somehow "out there" awaiting discovery. All of us via our bodies construct and live in phenomenal worlds which may be quite different from one another, but which nonetheless reveal some of the richness and diversity of human experience. If we assume there is just one "normal" way to encounter the world, then we will downgrade other phenomenal perspectives that do not match that one. We will try to make those persons' worlds into as close an approximation to our "normal" world as we can manage. Such colonialism of perspectives inevitably ends up construing people with disabilities as abnormal and requiring some mode of medical or social normalization.

However, if it is true that our bodies generate phenomenal worlds in this way, and if these worlds of knowledge can help us to understand reality more fully and to live well together, then what is required is hospitable conversation and dialogue among us—not with a view to converting one another to our differing worlds, but with a view to listening and learning. For example, what might it mean to take seriously the world of a person with a severe intellectual disability—someone without words or "normal" cognitive capabilities? What could all of us learn by listening carefully to the ways in which their world is created? What would it mean to live well in that world? Or, to take another example, how might we understand the world of people with severe mobility impairments? What could the experience of people whose wheelchairs have become extensions of their bodies tell us about reality?

What can these strange worlds of disability tell us about the strange new world within the Bible, and vice versa? It is only as we begin to take seriously the multiple worlds we live in that we can, together, begin to understand what it means to be human and to live humanly. It is only as we learn to listen to all of our worlds that we can learn what it means to live well in that



strange new world within the Bible.

## FROM INCLUSION TO BELONGING

If this way of thinking is accurate, it has significant implications for what might be meant when we talk about including people with disabilities. Beginning with the suggestion that all bodies are holy and worthy of love allows us to look at one another quite differently. As we gaze upon our different bodies, rather than assuming that there is a need for healing and change, either now or in the future, we can recognize each one is a site of holiness and a place of meeting. If we take seriously the suggestion that the knowledge different bodies offer to us is necessary for understanding the broad range of human possibilities, then our task is to better understand one another's worlds. As we enter into one another's worlds within the context of that strange new world within the Bible, the genuine inclusion of all people becomes a realistic possibility.

However, in this context the goal of inclusion quickly proves to be inadequate. It is relatively easy to include people: they just need to be there. To include people with disabilities or anyone else, we just need to open up a space where they can be in the congregation. But a person can very easily be *in* the congregation and not *of* it! Inclusion is not enough; people need to belong. To be included, one just needs to be there; to belong, one needs to be missed. To belong, others need to long for us to be back among them like the father longed for the return of his prodigal son (Luke 15:11-31). To belong, people need to respect our world and take time to seek out its value. To belong, people need to listen to the challenges and questions that our world raises.

Human beings are not simply included within creation, they belong there. Jesus' mission of redemption and reconciliation is all about helping people to know that they belong to God and that God loves them without end, just as they are. As the apostle Paul puts it, "Don't you realize that *all of you together* are the temple of God and that the Spirit of God lives in you?" (1 Corinthians 3:16, NLT, italics added).<sup>8</sup>

Reflection on the strange worlds of disability as they relate to the strange new world within the Bible helps us to see that when we talk about ministry with people who have disabilities, we are not talking only about things that need to be *done to* a particular group of people or even structural changes that need to be done within our communities. We are talking about seeing the world differently and rethinking disability in the light of our new vision. We are talking about developing the types of conversations, understandings, and relationships wherein our world of multiple worlds can be relearned and in so doing the body of Christ can be re-membered. Our task is to create holy spaces where the forces that seek to dismember human relationships are resisted and healed. In this way our minds can be renewed—no longer "conformed to this world," but "transformed" to "discern what is the will of God—what is good and acceptable and perfect" (Romans 12:2). And our practices of

love for all people can become honed and offered to one another as gifts that reveal the fullness and the breadth of being human and living humanly.

## NOTES

1 Karl Barth, "The Strange New World within the Bible," in *The Word of God and the Word of Man*, translated by Douglas Horton (New York: Harper & Row, 1957), 28-50.

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3 For more on this, see the essays in John Swinton and Brian Brock, eds., *Theology, Disability and the New Genetics: Why Science Needs the Church* (London, UK: T & T Clark, 2007), and Amos Yong, *Theology and Down Syndrome: Reimagining Disability in Late Modernity* (Waco, TX: Baylor University Press, 2007).

4 Christiane Andersson, "Grünwald, Matthias," in *Grove Art Online* (Oxford Art Online, accessed August 23, 2012), [www.oxfordartonline.com/subscriber/article/grove/art/T035179](http://www.oxfordartonline.com/subscriber/article/grove/art/T035179).

5 Wendell Berry, *The Art of the Commonplace: The Agrarian Essays of Wendell Berry*, edited by Norman Wirbza (Berkeley, CA: Counterpoint Press, 2002), 308.

6 John M. Hull, *Touching the Rock: An Experience of Blindness* (New York: Vintage Books, 1992); "A Spirituality of Disability: The Christian Heritage as Both Problem and Potential," *Studies in Christian Ethics*, 16:2 (2003), 21-35; "A Broken Body in a Broken World: A Contribution to a Christian Doctrine of the Person from a Disabled Point of View," *Journal of Religion, Disability and Health*, 7:4 (2003), 5-23; and "Blindness and the Face of God: Toward a Theology of Disability," in Hans-Georg Ziebertz, Friedrich Schweitzer, Hermann Häring, and Don Browning, eds., *The Human Image of God* (Leiden, The Netherlands: Koninklijke Brill, 2001), 215-229.

7 For more, see Maurice Merleau-Ponty, *Phenomenology of Perception*, translated by Donald A. Landes (New York, Routledge, 2012 [original, 1945]).

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# The Cult of Normalcy

BY THOMAS E. REYNOLDS

Against the cult of normalcy, disability foregrounds vulnerability as a fundamental condition of sharing life together. It reminds us that wholeness is not self-sufficiency, but is the genuine communion that results from sharing our vulnerable humanity with one another in light of God's grace.

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A *Sesame Street* ditty that I sang as a child — “One of these things is not like the others; one of these things just doesn’t belong” — aimed to teach children to identify common traits in items and then to note the differences. Now, as a parent of an autistic son, these words trouble me deeply. They mark an insidious human capacity to discriminate and exclude what does not appear to belong, or what has trouble fitting in with what is shared among a group. In fact, we learn to call “normal” what has become familiar, taken for granted, and expected in given circumstances. Alternatively, we learn to name the unfamiliar and strange as deviant and “abnormal.” Associated with unpredictability, the abnormal is disruptive and unsettling.

Disability has long been identified as not belonging, as even advances in disability rights legislation makes discrimination against people with disabilities unlawful. Across many cultures, disability signifies an unruly body that does not conform to familiar expectations. If a disabled body leaks and cannot be contained, it disrupts etiquette expectations and is shunned for lack of “normal” functioning. Indeed, it is commonly perceived as deficient, faulty, and lacking in qualities esteemed by a group. It seems to be a body gone wrong and in need of remediation through cure, healing, or rehabilitative adjustment to participate fully in society. When it cannot be brought into “belonging” through normalizing efforts to contain unpredictable and disruptive displays, such a body is excluded (in “care facilities” that function as hold-

ing places restricting public access) or eliminated (through prenatal screening to offer “preventive” intervention for parents of unwanted children).

In my experience as a parent advocating for my son, Chris, these harsh realities are commonplace. I cannot imagine deciding that his life is not worth being born because prenatal screening deemed his autistic condition somehow “faulty.” I cannot see his body as “wrong” and “lacking,” as just a thing in need of remedy or cure. Certainly, Chris’s way of being does not conform to social expectations. For example, in a grocery store he is sometimes overwhelmed and overstimulated by the crowds, noises, and tight spaces with shelves stacked high with colorful packages. It becomes clear his reactions are “maladjusted” and disruptive for other shoppers, who pass by shaking their heads and staring disapprovingly at both of us. He “should behave” and “contain” himself, someone once said to me. But I wonder precisely “who” it is that should adjust, behave, and contain themselves. When perceived from a different vantage point (Chris’s), the grocery store is in fact an overwhelming place, bombarding the senses with excess noise and enticements to purchase merchandise, far beyond what is needed. Whose reaction is “normal,” and why?

My family has been fortunate over the years to belong to several church communities that welcomed Chris’s way of being into congregational life. His body ticks and verbal outbursts during worship were not scorned, but accepted for what they are: part of Chris’s style of communicating and dealing with the stress of having to sit relatively still for an hour. Church members would speak kindly with him and take an interest in him, even enticing his involvement in the youth program. This experience of welcome marks accessibility in a deep sense, not simply constructing accessible buildings but inviting people with disabilities into full participation, with the community adjusting to different bodies and ways of being. I am reminded of how the Apostle Paul describes the Church as the body of Christ where each member offers gifts to others (1 Corinthians 12:12-27).

In the spirit of furthering this possibility for faith communities, I will consider how disability plays a crucial prophetic role in exposing the social pretensions of the “normal” and invites us to see our humanity as vulnerable gifts of God to be received by each other in relationships of mutual giving and receiving.

## **DISABILITY AS PROPHETIC CHALLENGE**

Frances Young has observed that disability is “a kind of judgment. Clearly it is not some kind of punishment for sin. It is not usually anyone’s fault. But it is a kind of judgment, a *krisis*, because...[s]ociety is judged by the way it treats handicapped people and our society is ambiguous.” She goes on to say disability judges individuals, for it “discriminates between those who rise to the occasion, and those who fail to do so.... It shows up people and their relationships and their values for what they are.”<sup>1</sup> In other words, dis-

ability prophetically holds up a mirror to each society and to each person, reflecting back values, attitudes, and practices that nurture treatments of disability as a tragic flaw, the product of circumstances and bodies “gone wrong.”

Disability, of course, usually involves a bodily impairment—an inability to perform some task or activity considered necessary within a social environment.<sup>2</sup> However, not all impairments are disabilities. For example, today many forms of visual impairment are not considered to be disabling conditions (as in most cases wearing eyeglasses “corrects” vision), but having a mobility impairment that requires a wheelchair is considered a disability. Why is this? Judgments of disability are greatly influenced by social perception. Even physical deformations or speech impediments that are not necessarily impaired may be considered disabilities and trigger restrictive reactions by others based upon aesthetic conventions about what counts as “able-bodied” appearance. North American culture’s way of fetishizing beauty and virility dramatically highlights the aesthetics of disability.

To no small degree, then, disability is a social construct; it is the flip side of the social system of normalcy.<sup>3</sup> Disability is more than an impairment that an individual happens to have: society disables people by representing impairment as a flaw or deficit, by constructing what is “normal” and thereby creating the difference between bodies that are “able” and those that are “disabled.” Medical communities commonly fuel this problem by cultivating curative practices to remedy such flaw or deficiency. Arthur Frank puts it this way: “Society prefers medical diagnoses that admit treatment, not social diagnoses that require massive change in the premises of what that social body includes as part of itself.”<sup>4</sup> Even impairment can be seen as a social construct of sorts, its representation trading on certain definitions of the body that include some features and exclude others governed by a conception of normality.

This social construction is disguised from us when we describe disability as reduced ability and reduced personal fulfillment. This

individualizes disability, rendering it a problem with the body when it is more often the social order that makes an impairment disabling. Further, it makes adaptation and accommodation the responsibility of the individual or family rather than the cultural system or society. It focuses on curative or remediating medical practices (even religious prayers for “healing”), which

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**Disability plays a crucial prophetic role in exposing the social pretensions of the “normal.” It invites us to see our humanity as vulnerable gifts of God to be received by each other in relationships of mutual giving and receiving.**

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depersonalize people with disabilities and overlook the disabling powers and principalities in the system itself.<sup>5</sup>

### **THE RISE OF THE CULT OF NORMALCY**

That some bodies are deemed disabled reflects the exchange values that animate human communities under the sway of what I call the “cult of normalcy.”<sup>6</sup> Society is built upon reciprocity: its members give to and receive from each other items of shared value. They expect predictability in these acts of reciprocity—e.g., when they offer services for payment, or agree on goals for achieving results.

The cult of normalcy takes the exchange values associated with bodily appearance and function—that is, how useful, productive, or valuable certain bodies are in particular social exchanges—and it routinizes them through systems of power and associated rituals. It takes these socially constructed attributions of value from particular situations and holds them up as standards for all people’s bodies. It makes them seem natural and even ideal. Rituals of socialization inscribe these standards across daily life—through media, education, economics, moral codes, and so on. This is why “cult” is a helpful way to understand how normalcy is communicated and internalized by members in a society. We are habituated into mechanisms of normalcy. One only has to turn on the television to see this powerfully displayed.

From inside these systems of normalcy, disability appears as a disruption, a disorienting surprise that throws into crisis what has been taken for granted. Cracks appear. To recover, social mechanisms are put in play to cement the cracks—to contain the damage by attributing the problem to individual bodies, and stigmatizing them as abnormal and in need of care through curative practices, normalizing management, or exclusion.

Consider how two airlines recently treated a family with a teenage son with Down syndrome.<sup>7</sup> The family was removed from one flight after being told that their son could not board the plane with them. They then booked another flight on a different airline, only to discover that their seat had been changed to the back row, several empty rows behind other passengers. Officials for both airlines used language of avoiding “disruption” to defend their action, even when the child posed no threat. Down syndrome “appeared” threatening, unpredictable, and potentially disruptive. In this case, disability was defined by assumptions about what “ability” means, what the “normal” body looks and behaves like. The people who purchased airline tickets expected a smooth and comfortable experience; the airline officials perceived unruly bodies (even those of restless children) as disruptive and threatening. The result was exclusion.

Thinking about disability in terms of the cult of normalcy helps explain the pervasive influence of “ableism,” which privileges certain bodies over against others. By designating certain kinds of bodies as deviant, normalcy serves to uphold communal identities, supporting the basic way a group

of people understand what is valuable among them. It does this by mobilizing representations grounded in binary systems of exclusion—for example, “abled” over “disabled.” We define ourselves by what we reject; the things we exclude outline the identity by creating an “us” over and against “them.”<sup>8</sup> Language itself becomes a vehicle for this process, inscribing the normal into our everyday sense of who we are. For instance, recall how terms like “cripple,” “blind,” and “deaf” are used pejoratively as metaphors of delinquency.

Paying attention to how disability appears as disruptive, then, can expose the illusions of normalcy. And this helps shift attention away from the “problem” of an individual body to the way communities represent disability. The real problem is the normalizing mechanisms that regulate, contain, and exclude people with disabilities. It is therefore crucial to move beyond binaries of “us-them”—especially as couched in terms of “normal” versus “abnormal,” “whole” versus “incomplete” or “faulty”—in order to undo the standard “ability-disability” binary. Even language of “caring for the needy” can still function as a way of maintaining a regulative “us” (giving from an abundance) over against “them” (receiving from scarcity). Unilateral gestures of benevolence in the form of assistance often express a paternalism that remains snagged in the snares of normalcy—as if to say, those “others” need fixing according to ideals “we” hold dear.

Here we must also acknowledge the dangers of being “inclusive,” of opening up access for people with disabilities through accommodation. Often church communities participate in the cult of normalcy inadvertently by treating disability merely as a

“problem” to be included. People with disabilities are seen as tragic anomalies that, according to the good graces of a community, “need” to be brought “inside” and given access and empowerment. A paternalistic and unilateral mode of giving emerges that “does for” others as if they are helpless subjects with nothing to offer. However, this perpetuates an “us-them” or “inside-outside” dualism that ironically retains

a condescending air of pity and normalization. Miroslav Volf agrees, arguing that inclusion “implicitly portrays ‘them’ as the kind of people ‘we’ are not.”<sup>9</sup> Inclusion too easily plays out mechanisms of normalcy, uncritically assuming the rightness of its own position when in fact it is perpetuating the problem.

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**The cult of normalcy takes the exchange values associated with bodily appearance and function—i.e., how useful, productive, or valuable certain bodies are in particular social exchanges—and makes them standards for all people’s bodies.**

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## VULNERABLE HUMANITY BEYOND THE CULT OF NORMALCY

Recognizing the disruption of disability for what it is, however, can help destabilize normative assumptions about what constitutes an “us.” Disability appears within the cult of normalcy as an interruptive force that unsettles our assumptions about what bodies are. This provocation unmasks the familiar and calls into question the standards and governing mechanisms of exchange that produce the “problem” of disability. Differences here become a teacher, opening up the possibility of communities in which bodily diversity is productive of life together, not a deficiency. In the absence of preconceived expectations fueled by dominant visions of what is “normal,” people with disabilities can convey a powerful sense of personhood and dignity and offer many gifts to their communities.

So it becomes a matter of moving beyond inclusion toward something more robust: an accessibility that connects members of the community as equals. This leads to healing, not by “curing” but by empowering creative agency, not by “restoring” bodily intactness but by opening a social space of non-domination and mutuality. We begin to “let go” of normalcy and “let be” by paying attention to disability in its disruptive difference.

Reciprocity between persons involves more than exchanges based on bodily function (ability) and appearance (aesthetics). All human beings share a capacity for giving and receiving, which is grounded in their vulnerability. It is an inescapable fact that human beings are born, live out their lives, and then die as vulnerable creatures exposed to and needing one another. We do not just need others in order to survive as helpless infants, but also to flourish as people who can love and be loved by others, and eventually die in their care. As Kristine Culp suggests, vulnerability does not simply mean susceptibility to harm, as something dire and limiting, but also susceptibility to good, to joy, and to fulfillment through others.<sup>10</sup>

The starting point for discovering what we *share* with one another is human vulnerability, rather than what counts for “ability” — for example, the capacity to think rationally, act autonomously, and look slim, healthy, and agelessly beautiful. What normalcy deems “needy,” “weak,” “deviant,” and so on, is not a flaw detracting from an otherwise pure and complete human nature. Rather, viewed through the lens of vulnerability, it is testimony to the fact that we receive our existence from each other. It is a source of the precious and fragile gift of communion with one another. Jean Vanier, founder of L’Arche, sums up the point: “We do not discover who we are, we do not reach true humanness, in a solitary state; we discover it through mutual dependency, in weakness, in learning through belonging.”<sup>11</sup> We realize genuine wholeness not through “ability” but through an acknowledgment of vulnerability that is made concrete in relations of mutual giving to and receiving from others.<sup>12</sup>

As Vanier goes on to note, “Weakness carries within it a secret power. The cry and the trust that flow from weakness can open up hearts.”<sup>13</sup> The



vulnerability of another is a window into our own vulnerability, evoking a sympathetic relation that eludes the tyranny of the normal, sweeping under the radar of regulated exchange reciprocities. In this way, those who embody “weakness” and are considered “nobodies” in a society – that is, people with disabilities – “have profound lessons to teach us.”<sup>14</sup>

Let me pause to acknowledge a constant danger associated with this recognition of human vulnerability. As we become aware that we are not independent sources of our own destiny with seamlessly complete bodies, but fragile earthen vessels exposed to each other and to the contingencies of finite existence, we may become very frightened. The danger is that in the modality of fear, communities will become a pretext to fortify us against vulnerability: they will invite us to conform to the projected strength and worth of others as though this could purchase validation and social belonging and guarantee immunity from the pain of failure and finitude. This only energizes the erection of protective walls around the “normal.” It then becomes all too easy to judge the different and strange as outside the scripted scheme of things, as “abnormal,” because it exposes our vulnerability. To assuage their members’ fear, communities require a scapegoat – some individual or group or thing to turn into the object of fear, and then contempt – that the community can contain or exclude in order to remove its threat to the order of things. Thus it is that disability is stigmatized and considered a blemish, as it concretely reveals to society what its constituents seek immunity against.

This scapegoating process reflects a communal failure, not only because it falsely represents vulnerability as a flaw, but more because it objectifies the flaw as an attribute of the other person who is different. By projecting our own fear of vulnerability onto another, we become cut off from the wellspring of our own flourishing: mutual dependence. We deny the other and thus ourselves. Disability is a cipher of human limitation and vulnerability, not as a flaw but as a pervasive condition. Of course we can suppress or deny this condition, fleeing from it by pushing away those others whose difference overtly exhibits it as something we deem ugly or dirty or deficient. But in so doing we diminish dimensions of ourselves that are perhaps most human about us – the need to belong and be recognized as of value.

To safeguard against this process of scapegoating, we should remind

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**What the cult of normalcy deems “needy,” “weak,” and “deviant” is not a flaw in human nature. Viewed through the lens of vulnerability, disability is testimony to the fact that we receive our existence from each other.**

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ourselves that full humanity is neither diminished by disability nor confirmed by ability. Instead, it is based on the interdependent relationships we share with one another as creatures loved into being by God and in the image of God. There is a wider horizon in which all persons in their uniqueness and vulnerability coexist, and this horizon is the enfolding presence of a gracious God. The *appearance of disability*, manifest variously through different bodies, calls us prophetically into acknowledging our common human vulnerabilities and weaknesses, and this opens us more radically to God's grace.<sup>15</sup>

It is, in fact, our 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. God's sharing of the divine self in this way sends a distinct message: God is in solidarity with humanity at its most fundamental level, joined with us in vulnerability. Here, God reveals the divine nature as compassion not only by "undergoing" or "suffering with" human reality, but also by raising it up into God's own being. Redemption, then, is a welcoming, a divine act of hospitality. It is not a condescending move of pity. Neither does it negate vulnerable finitude by making humans inviolable and perfectly whole. Nancy Eiesland highlights this point by calling our attention to the fact that Jesus' body remains scarred after his resurrection.<sup>16</sup> So, instead of doing away with the capacity to suffer, redemption transforms vulnerability into a communion with God, prefiguring the final eschatological horizon to come when all things will be transformed in this way. Genuine wholeness is reconciled relationships with others, creation, and the Triune God.

## CONCLUSION

Against the cult of normalcy, disability foregrounds vulnerability as a fundamental condition of sharing life with one another. There is need for healing, not because disability requires "cure" or "containment," but because it entails real suffering, sometimes bodily but in many cases communal and social in the form of alienation, exclusion, and normalizing pressures. Disability, then, invites us to recognize mutual human vulnerability and dependence upon each other and God.

This strikes to the heart of the Apostle Paul's proclamation that God's power is made "complete" and perfected in weakness (2 Corinthians 12:9). And it has subversive implications for living together. Wholeness is not self-sufficiency. Rather, it is the genuine communion that results from sharing our vulnerable humanity with one another in light of the grace of God. Would that our congregations more robustly welcomed all God's children, sharing the radically inclusive love of God without representing some people as "abled" and others as "disabled." This would mean taking a hard look at the humanity we share outside the cult of normalcy. But the effect could be transformative for both Church and society.

## NOTES

1 Frances Young, *Face to Face: A Narrative Essay in the Theology of Suffering* (London, UK:



Epworth, 1986), 142.

2 Nancy L. Eiesland, *The Disabled God: Toward a Liberation Theology of Disability* (Nashville, TN: Abingdon Press, 1994), 27.

3 Lennard J. Davis, *Enforcing Normalcy: Disability, Deafness, and the Body* (New York: Verso, 1995), 2, see also 48-49.

4 Arthur W. Frank, *The Wounded Storyteller: Body, Illness, and Ethics* (Chicago, IL: University of Chicago Press, 1995), 113.

5 I am contrasting what disability scholars call the “social model” to the “medical model” of disability. The former complicates the very notion of disability by identifying the contributing problems in the social environment rather than merely offering medical care for an individual’s biophysical “problem.”

6 See my *Vulnerable Communion: A Theology of Disability and Hospitality* (Grand Rapids, MI: Brazos Press, 2008), chapters 2 and 3.

7 Lewis Griswold, “Family of Down Syndrome Teen Faults Second Airline,” *The Fresno Bee* (September 6, 2012), accessed September 10, 2012, [www.fresnobee.com/2012/09/06/2979927\\_family-of-down-syndrome-son-faults.html](http://www.fresnobee.com/2012/09/06/2979927_family-of-down-syndrome-son-faults.html).

8 The philosopher Michel Foucault famously speaks of binary divisions (mad/sane; normal/abnormal; in/out) and the “power of normalization,” wherein exclusion is not so much ejection from community as it is productive of community. See his *Discipline and Punish: The Birth of the Prison*, translated by Alan Sheridan (New York: Vintage Books, 1979), 29 and 199.

9 Miroslav Volf, *Exclusion and Embrace: A Theological Exploration of Identity, Otherness, and Reconciliation* (Nashville, TN: Abingdon Press, 1996), 58.

10 Kristine A. Culp, *Vulnerability and Glory: A Theological Account* (Louisville, KY: Westminster John Knox, 2010), 2-4.

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

12 See *Vulnerable Communion*, chapter 4.

13 Vanier, *Becoming Human*, 40.

14 *Ibid.*, 45.

15 *Ibid.*, 39-41.

16 Eiesland, *The Disabled God*, 98-105.



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# Jars of Clay: Disability in Intentional Christian Community

BY S. KAY TOOMBS

Living in an intentional Christian community offers a nurturing context in which it is possible to fully embrace the vulnerability that accompanies disability, to concretely enact our Christian beliefs with respect to the intrinsic worth of all human beings, and to affirm the value of all members of the community.

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As a person who has lived with incurable neurological disease (multiple sclerosis) for more than half my life, and with permanent disability for many years,<sup>1</sup> I have been very aware of the many ways in which contemporary cultural values with respect to such things as independence, productivity, physical fitness, health, youth, beauty, and so forth, inevitably deepen the sense of vulnerability that accompanies debilitating illness and disability.<sup>2</sup> We live in a world that places inordinate value on autonomy and that soundly repudiates any signs of weakness and vulnerability. Thus the sick, aging, and those with disabilities find themselves isolated and marginalized, uncertain of their personal and social worth.

In these reflections, I will contrast contemporary social values with the countercultural perspective of intentional Christian community.<sup>3</sup> I will suggest that authentic Christian community offers an alternative culture with a radically different value system, thus offering a nurturing context in which it is possible to fully embrace the vulnerability that accompanies disability, to concretely enact our Christian beliefs with respect to the intrinsic worth of all human beings, and to affirm the value of all members of the community.

## DISABILITY AND CONTEMPORARY VALUES

One of the most important barriers to retaining a sense of self-worth in the face of physical or mental disability is the overriding cultural emphasis on radical autonomy and self-reliance. There is a strong cultural message that we should be able to look after ourselves, make our own decisions, “stand on our own two feet.” While personal responsibility is, of course, important, when radical independence is considered to be the ultimate value, dependence on others is negatively perceived as a form of weakness. As a consequence, those with disabilities (who include, of course, all those living with the limitations of debilitating illness or injury) are reluctant to admit their vulnerabilities, fearing they will be considered a “burden” on others. Paradoxically, this cultural emphasis on self-reliance may also engender reluctance on the part of others to offer assistance when the opportunity arises. My students have shared that, if they see a person in a wheelchair approaching a door, they are uncertain whether they should offer to hold the door, since they are afraid such an offer (and overt recognition of the other’s limitations) may be considered offensive and “politically incorrect.”

Indeed, when society places inordinate value on independence and self-determination, the act of serving another is often negatively conceived as a constraint that robs the caregiver of the radical freedom imagined necessary to achieve self-fulfillment. When caregiving is conceived in these terms, feelings of resentment inevitably arise on the part of the caregiver and incalculable feelings of guilt and self-recrimination on the part of the person receiving care. Thus, in our culture, those with debilitating illness sense they expect “too much” of others, elderly parents constantly worry that they will end up being a “burden” to their children who “have their own lives to live,” and there is a widespread presumption that persons with disabilities are a drain on the lives of their able-bodied partners.

For those living with disability the loss of autonomy is also profoundly disturbing because of the cultural emphasis on “doing” as opposed to “being.” In our society a person’s worth is judged according to the capacity to produce (to be useful) or the ability to achieve a certain professional status. When we say to our children, “You can *be* anything you want to be,” what we mean is that you can achieve worth through *doing*. Given this cultural attitude, a person who is unable “to do” not only feels diminished by the inability to engage in projects that are judged meaningful according to societal markers of “success,” but he or she also feels unable to contribute anything of worth to others.

Recognizing that the assessment of personal worth has as much to do with “being” (or character) as it does with “doing” is a vital step in maintaining personal integrity and countering negative attitudes with respect to disability. As a woman with Parkinson’s disease told me, “I always imagined that when I became a grandmother, I would *do* a lot with my grandchildren. Then I got Parkinson’s.” “However,” she added, “now I realize that I can *be* for my

grandchildren." This was a very empowering realization for her. Similarly, a young woman with a severe congenital physical disability recently told me that she had graduated from law school two years previously and had not been able to get a job. Because of this circumstance, she felt she was not worth anything. Recognizing the importance of "being" versus "doing" was an epiphany for her. "Now," she told me, "I can see that I have personal worth apart from what I can do."

Cultural attitudes with respect to "health" also shape the meaning of disability. In our society we equate "health" with the complete absence of disease and freedom from *any* physical or mental limitation. Moreover, certain ideal standards of beauty, physique, physical strength, fitness, and vigor are often subsumed into this cultural concept of "health." This cultural perspective on "health" makes it difficult for people to accept many unavoidable aspects of being human. Thus, any form of disability is considered an affront—an unnatural and unacceptable state of brokenness—a view that intensifies the experience of loss of control, social alienation, and vulnerability.

Indeed, this perception of "health" and "brokenness" makes it difficult for people to even see beyond the physical manifestation of disfigurement or disability. In the eyes of the "able-bodied" there is the clear assumption that disability is incompatible with living a meaningful life. This prevailing attitude is well reflected in the experience of our friend Perry—a young father of four who died from Lou Gehrig's disease at the age of thirty-five. Emaciated and strapped into his wheelchair, Perry did not meet the worldly ideal of physical beauty and strength. One day a saleswoman, eyeing his physical condition, said to his wife, "I can't believe you've stuck with him!" In judging Perry's worth solely on the basis of outward appearance, this woman completely missed the fact that Perry was a loving father and husband who instilled lifelong values in his children and who is still remembered by all who knew him for his intelligence, humor, thoughtfulness, and steadfast faith even in his difficult circumstances.

I have experienced similar negative attitudes with respect to my disability. When strangers observe I am in a wheelchair, they make the immediate assumption that my situation is an essentially negative one, that I am unable to engage in professional activities, and that I am wholly dependent on others. On many occasions people have said to me, "Aren't you *lucky* to have your husband!" This statement was not so much a comment about my husband's character as it was a perception that my relationship with him was wholly one of burdensome dependence. Furthermore, people overtly treat me as dependent. When I am in a manual wheelchair, people invariably address remarks to my companion and refer to me in the third person, "Would *she* like us to move this chair?" This invariably occurs when we travel through airports. We roll up to the security barrier and the person at the barrier turns to my companion and says, "Can *she* walk at all?" My husband developed a standard response. He would say, "No, but *she* can talk!" These common

responses on the part of others reinforce the perception that disability reduces one's personal and social worth.

### **VULNERABILITY AND CHRISTIAN COMMUNITY**

The experience of illness and disability (a circumstance that strikes all of us at one time or another without regard to worldly status or position) concretely and irrevocably shatters the cultural myth that we are self-sufficient, invulnerable, and in complete control of our lives. In disrupting all our involvements in the world, a problem with the body (or the mind) demonstrates our radical dependence upon our bodies, confronts us with our vulnerability and our limitations, forces us to recognize the fragility of mortality, and reveals to us our need for others. In those moments of vulnerability (even if they are short-lived), we come face-to-face with reality and comprehend in a profound way that the individualistic endeavor, so lauded in our society, is based on an illusion—a false perspective that shapes our views on independence and relationship, on death and dying, on disability and vulnerability, and, ultimately, on our understanding of the transcendent meaning of our existence.

In deliberately rejecting this illusory perspective, a Christian community embraces a radically contrasting paradigm that is grounded in the centrality of covenantal relationship. Rather than pursuing the societal goal of autonomy and self-reliance, we are called to live out our lives in relationship: relationship with God and with

each other. This paradigm shift turns the cultural perspective on individualism versus relationship upside down and transforms the meaning of dependence and independence. In imitating the example of Jesus, the suffering servant, we are called to continually lay down our lives for one another: "No one has greater love than this, to lay down one's life for one's friends" (John 15:13). Since selfless

love, rather than self-determination, is the cardinal value, caregiving (care of and for another) is not considered a burdensome obligation. Rather, it is a form of communion in which both caregiver and care-receiver affirm their mutual need for one another and participate in sharing the love of God. Furthermore, since we are committed to cooperation rather than competition and to setting aside selfish ambition, envy, and worldly success in favor of

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love, humility, and service to others, our lives in community are built upon a basis of trust that enables us to share our vulnerabilities and needs without fear of condemnation from others. As a result, the vulnerability that accompanies the reductions of illness and disability is less a negative life circumstance than it is an opportunity to share in the miracle of relationship.

Living in community permits us to serve one another in very concrete ways: whether it be providing several days of after-birth care for young mothers, caring for elderly parents, assisting with the education of an autistic child, doing housework and garden chores for those who cannot do these things themselves, constructing a wheelchair ramp to make home access easier for a wheelchair user, providing twenty-four-hour care for a friend with Alzheimer's, or working together to give round-the-clock care to those suffering from terminal illness. We have found that these acts of service are not just valuable in and of themselves (although they are surely that), but they are of inestimable worth in bringing us into ever-deepening relationships of love for one another. When my husband was dying from oral cancer, fifteen ladies in our community volunteered to assist me in providing him with round-the-clock care for the last three months of his life. Others prepared our meals, families visited daily, young people came and sang for him, and friends prayed with us at the bedside. The deep relational bonds we formed during this time will never be broken.

Indeed, we have found that one of the fruits of Christian community and the rejection of self-centered values is the breaking down of artificial social barriers that separate on the basis of age, economic status, education, ethnicity, culture, appearance, or physical condition. Furthermore, since we live our lives in close relationship, it is only natural to come together to serve those who have a special need. When an elderly lady in our community was unable to sleep at night due to a terminal illness, young people volunteered to go regularly to her house and sing for her through the night and into the early hours of the morning. They have shared that this experience has impacted their lives in a profound way.

In serving one another on a daily basis, we recognize the undeniable fact that we all need one another. Rather than viewing ourselves as either dependent or independent, we affirm our *interdependence* and celebrate the unique place that each member of the Christian community occupies in the living organism that is the body of Christ. As the Apostle Paul noted:

Even so the body is not made up of one part but of many.

Now if the foot should say, "Because I am not a hand, I do not belong to the body," it would not for that reason stop being part of the body. ... But in fact God has placed the parts in the body, every one of them, just as he wanted them to be. ...

The eye cannot say to the hand, "I don't need you!" And the head cannot say to the feet, "I don't need you!" On the contrary, those

parts of the body that seem to be weaker are indispensable.... If one part suffers, every part suffers with it; if one part is honored, every part rejoices with it.

1 Corinthians 12:14-15, 18, 22, 26 (NIV)<sup>4</sup>

In this context, rather than being marginalized as they are in the wider culture, those “with disabilities” are simply absorbed into community life and find a place of participation where their particular gifts are appreciated. Indeed, so powerful is this shift in perspective that, while writing these reflections, I have actually found myself hard-pressed to identify people in our community under the category of “persons with disabilities.” I simply never think of these individuals as “disabled.” Rather, I think of them only in terms of the irreplaceable part each plays in the relational context of our community life: the young man, paralyzed after breaking his neck, who has a pivotal role in the young people’s outreach ministry in nursing homes; the child with Down’s syndrome who joyfully participates in our children’s choir; the young woman with a congenital physical anomaly who weaves, spins, and cultivates beautiful flowers using one hand; the extraordinary farmer who works with the horses and who, in other contexts, would likely be discounted as a “person with an intellectual disability”; and the autistic child who comes to all meetings and gatherings and who is gradually beginning to reach out to others.<sup>5</sup> I also realize that, since becoming a part of this community, I have not thought of *myself* as a person with a disability. It is not simply that no one here treats me in that way but also, in sharing my life, all are sensitive to any barriers that prevent my full participation in community activities. As an example, if there is no ramp providing wheelchair access into a person’s house, arrangements will always be made for people to meet me there and carry me in and out of the premises.

A central tenet of Christianity is that, since we are made in the image of God, all human beings have intrinsic worth, regardless of any contingent circumstances. This shift in focus from *extrinsic* to *intrinsic* worth turns the cultural perspective on the importance of “doing” versus “being” on its head. The emphasis for the Christian is not so much, “How do I define myself by my role?” but, “How do I live out whatever role God has provided for me?” “What kind of a person am I?” Believers are called to be imitators of Christ, to develop Christ-like character. In stressing that the most important question is, “What kind of a person am I?” we affirm that qualities of character such as compassion, kindness, patience, humility, and courage relate to a way of being in the world that is not dependent on physical or mental abilities and that does not look to the world’s criteria of success. This means, among other things, that it is possible to retain personal integrity no matter how severe the reductions of illness and disability are.

Furthermore, we are reminded that in the kingdom of God (as opposed to the “kingdom of the world”) personal control, physical strength, beauty,



and human capability are not the criteria with which to measure a meaningful life. Rather, “we have this treasure in jars of clay to show that this all-surpassing power is from God and not from us” (2 Corinthians 4:7, NIV). Speaking of his own intractable disability, Paul also reminds us that in the radically distinct economy of the Christian life, God’s power is made perfect in human weakness (2 Corinthians 12:9), for it is in weakness that we

concretely feel our need for God and for each other.

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**In the kingdom of God, personal control, physical strength, beauty, and human capability are not the criteria for a meaningful life. Rather, “we have this treasure in jars of clay to show that this all-surpassing power is from God and not from us.”**

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When I think of the value of “being” reflected in these “jars of clay,” I am reminded of the many people I have known who, in the eyes of the world, would be considered profoundly disabled but who, by virtue of their character, had a powerful impact on the lives of others. As one example, I think of Robert, a forty-nine-year-old father of five who became totally incapacitated

due to a brain tumor. Yet, throughout his illness and dying, Robert continued to minister, not only to those who came under his pastoral care, but to his caregivers and to all who came in contact with him. Indeed, dozens of young people have testified that Robert’s example of grace and fortitude has been a guiding influence in their lives.

In focusing on the centrality of relationship and sharing the daily challenges of life, we see clearly that disease, suffering, disability, and death are givens and an integral aspect of our humanity. In accepting these givens in our lives, we affirm that central to the Christian message is the reality of the cross. The reality of the cross is at odds with the cultural understanding of autonomy. In imitating Christ, believers are called to relinquish absolute control over their lives. Jesus’ admonition is to “pick up your cross and follow me” every single day. Along the way we may well have to face the reductions of illness, suffering, and disability, and inevitably we will face the realities of aging and death. These reductions do not diminish one’s worth as a human being. Consequently, those living with incapacitating illness and disability are not marginalized and separated from the community of the living, but rather they remain at the center of a web of intimate and supportive relationships that continue to affirm the value of their existence. Indeed, it has been our experience that those who are the most vulnerable among us — the dying — have been an incredible gift to all members of our community. In every case these individuals have pressed forward in faith and demonstrated that, no



matter how burdensome the physical circumstances, God's grace is sufficient for every need. We thus have a "cloud of witnesses" who have testified to the truth that one can die in dignity and in tremendous victory, even in the direst circumstances. They have helped all of us to overcome the fear of death that is so deeply rooted in the human psyche.

In speaking of the Christian community's response to the vulnerability of illness, Therese Lysaught contrasts two radically distinct ways of thinking and acting that are identified as either being a "friend of the world" (James 4:1-10) or being a "friend of God" (James 2:23).<sup>6</sup> To be a friend of the world means "to have the same mind, the same outlook, the same view of reality" as the world does.<sup>7</sup> It is, therefore, to buy into the contemporary values that guide actions and shape perceptions—including the emphasis on radical autonomy, productivity, health, youth, and beauty that causes us to marginalize and devalue those who do not meet these cultural ideals. To be a friend of God, on the other hand, is to share "God's mindset" and God's "way of being and acting in the world."<sup>8</sup> It is to live in such a way that we "proclaim this marvelous truth—that God exists, that God is true, and that, consequently, the fundamental context of existence is gift—open, abundant, for-the-other rather than against-the-other."<sup>9</sup>

In living a life based on the foundation stone of self-sacrificing love, and in affirming the centrality of relationship with God and with one another, the Christian community—the *ekklesia*—concretely witnesses to the world that it embodies those values and practices that characterize friendship with God. Responding positively to the vulnerability occasioned by disability, then, represents a particular opportunity for the community to proclaim "the marvelous truth" that God exists, that all human beings have inestimable worth, and that there is a larger wisdom that places disease, disability, suffering, and death within the context of a cosmic narrative of the power of love overcoming even the power of death.

## NOTES

1 I was diagnosed with multiple sclerosis at the age of twenty-nine. Over the years my illness has affected my ability to see, to sense, to move, to maintain my balance, to sit up, to stand up, to walk, and to control my bowels and bladder. With regard to mobility, my disease has progressed through various stages necessitating the use of a cane, then forearm crutches, then a walker, and finally the full-time use of a manual or a motorized wheelchair, since I can no longer walk.

2 S. Kay Toombs, "Vulnerability and the Meaning of Illness: Reflections on Lived Experience" in Carol R. Taylor and Roberto Dell'Oro, eds., *Health and Human Flourishing: Religion, Medicine and Moral Anthropology* (Washington, DC: Georgetown University Press, 2006), 119-140.

3 I have been a member of Heritage Ministries for fourteen years. Our community has found its roots in the 500-year-old nonviolent Anabaptist tradition and has embraced a simple, agrarian lifestyle. This is a tradition that has best served our values and goals and that continues to guide our way of life. While, of course, we do not expect everyone to embrace our religious perspective, we have found that our intentional community provides a context in which all members of the community can live meaningful lives that maintain

a sense of integrity and wholeness. For more information about this community, see [www.homesteadheritage.com](http://www.homesteadheritage.com).

4 Scripture quotations marked (NIV) are taken from the Holy Bible, New International Version®, NIV®. Copyright © 1973, 1978, 1984, 2011 by Biblica, Inc.™ Used by permission of Zondervan. All rights reserved worldwide. The “NIV” and “New International Version” are trademarks registered in the United States Patent and Trademark Office by Biblica, Inc.™

5 The parents of this child have been told by a professional who works with autistic children that the loving, caring, communal environment in which he is growing up is the perfect environment for an autistic child. In other circumstances parents pay many thousands of dollars to send their children to different professionals to work on particular problems, and even to camps where children can interact with animals. As helpful as these interventions may be, an autistic child is thus constantly being thrown into unfamiliar environments and different worlds. In the context of our community life, however, the child is always surrounded by brothers and sisters, adults and children with whom he is familiar, who relate to him and work with him as a part of the wholeness that characterizes our daily life. Nor is he marginalized and set aside with other autistic children.

6 M. Therese Lysaught, “Vulnerability within the Body of Christ: Anointing of the Sick and Theological Anthropology,” in Carol R. Taylor and Roberto Dell’Oro, eds., *Health and Human Flourishing: Religion, Medicine and Moral Anthropology* (Washington, DC: Georgetown University Press, 2006), 159-182.

7 Luke Timothy Johnson, *The Letter of James: A New Translation with Introduction and Commentary* (New York: Doubleday/The Anchor Bible, 1995), 85, cited in Lysaught, “Vulnerability within the Body of Christ,” 168.

8 Lysaught, “Vulnerability within the Body of Christ,” 169.

9 Ibid.



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# The Twisted Form upon the Tree

T E R R Y   W .   Y O R K

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The twisted form upon the tree  
is God in pain,  
as those in pain can clearly see.  
What anguish, Lord, what agony;  
God's loving disability.

His useless arms, not strong or free,  
is God in need,  
as those in need can clearly see.  
He cries in thirst, who calmed the sea;  
God's strength in hard humility.

His legs without mobility  
is God confined,  
as those confined can clearly see.  
He cannot walk, who walked the sea;  
God's presence nailed to one dead tree.

"Why, God, have you forsaken me?"  
is God alone,  
as those alone can clearly see.  
Dark clouds at noon weigh heavily;  
God's Son is God in misery.

The Christ who reigns eternally  
is God with scars,  
as those with scars can clearly see.  
In wounds and disability  
God lives and weeps with empathy.

# The Twisted Form upon the Tree

T E R R Y   W .   Y O R K

C .   D A V I D   B O L I N

1. The twist - ed form up - on the tree is  
 2. use - less arms, not strong or free, is  
 3. legs with - out mo - bil - i - ty is  
 4. God, have you for - sa - ken me?" is  
 5. Christ who reigns e - ter - nal - ly is

God in pain,  
 God in need,  
 God con - fined,  
 God a - lone,  
 God with scars,  
 As those in pain can  
 As those in need can  
 As those con - fined can  
 As those a - lone can  
 As those with scars can

clear - ly see. What an - guish, Lord, what ag - o - ny; God's  
 clear - ly see. He cries in thirst, Who calmed the sea; God's  
 clear - ly see. He can - not walk, Who walked the sea; God's  
 clear - ly see. Dark clouds at noon weigh heav - i - ly; God's  
 clear - ly see. In wounds and dis - a - bil - i - ty God's  
 God

1, 2, 3, 4. 5.

lov - ing dis - a - bil - i - ty. His  
 strength in hard hu - mil - i - ty His  
 pres - ence nailed to one dead tree. "Why  
 Son is God in mis - e - ry. The  
 lives and weeps with em - pa - thy.

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*Tune: GOD IN PAIN  
 12.8.8.8*

# Worship Service

B Y D E B R A D E A N M U R P H Y

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I am struck by how sharing our weakness and difficulties is more nourishing to others than sharing our qualities and successes.

*Jean Vanier*<sup>1</sup>

Power is made perfect in weakness.

*2 Corinthians 12:9b*

## GOD'S PEOPLE GATHER

*Prelude*

*Lighting of the Candles*

*Hymn*

“God Has Spoken to All People” (verses 1-3)

God has spoken to all people  
in each age, throughout the earth,  
in creation and the Scriptures,  
then through Jesus’ human birth.  
God who spoke at life’s beginning  
speaks again with each new day,  
bidding us to hear and follow  
words of life that mark Christ’s way.

Triune God who never leaves us,  
Maker, Savior, Light, and Guide,  
through the water of baptism  
our new life has been supplied.  
Bound by water and the Spirit,  
sealed and marked, empowered by grace,  
known by name as Christ’s disciples  
we can now the world embrace.

Sovereign God of every person,  
different tongues and cultures too,  
many races, many talents,  
many skins of varied hue,  
you have called us to your service,  
help us teach and preach and show  
virtues, practices, and knowledge  
so that seeds of faith will grow.

*Mary Jackson Cathey (2005)<sup>2</sup>*

*Suggested Tunes: STUTTGART or BEECH SPRING*

### *Greeting*

In the name of the Father, and of the Son, and of the Holy Spirit.  
**Amen.**

### *Opening Prayer*

The Lord be with you.

**And also with you.**

Let us pray.

Almighty and Everlasting God,  
who has created each of us in your image  
and through the crucified and resurrected body of a beloved Son  
made of us one body:  
give us hearts and minds, we pray,  
to know the wisdom of human vulnerability;  
to see the beauty in bodies differently-abled;  
to dismantle the barriers erected by attitudes and architecture;  
and to trust the Spirit's power to make us friends, make us whole, make  
us one.

In the name of Jesus Christ our Lord we pray. **Amen.**

### *Call to Confession (based on 1 Peter 2:24-25)*

Christ himself bore our sins in his body on the cross,  
so that, free from sins, we might live for righteousness.  
By his wounds we have been healed.  
Therefore let us turn to the Lord with contrite hearts,  
confessing our sins before God and one another.

### *Prayer of Confession*

For the sin of silence, for the sin of indifference,  
for the secret complicity of the neutral;  
Lord, have mercy.  
**Lord, have mercy.**



For the closing of doors,  
for the closing of hearts and minds,  
for the refusal to see with eyes wide open;

Christ, have mercy.

**Christ, have mercy.**

For all that's been done, for all that is left undone,  
for our failure of nerve, courage, and will;

Lord, have mercy.

**Lord, have mercy.**

Let there be remembrance, regret, and resolve, O Lord:  
that we would know our sins,  
be sorry for them,  
and have the courage to live freely in the light of your grace.

And let there be forgiveness,  
that all your children, at last, may know your peace.

**We pray to the Lord.**

*Silence*

*Words of Assurance and Pardon*

The Spirit bears witness with our spirit that we are children of God.  
As we have confessed our sins, God has been faithful.  
In the name of Jesus Christ, my sisters and brothers,  
your sins are forgiven.

**Thanks be to God.**

## TO LISTEN FOR GOD'S WORD

*First Reading: Isaiah 45:9-12*

Woe to you who strive with your Maker,  
earthen vessels with the potter!  
Does the clay say to the one who fashions it, 'What are you making?'  
or 'Your work has no handles'?  
Woe to anyone who says to a father, 'What are you begetting?'  
or to a woman, 'With what are you in labor?'  
Thus says the LORD,  
the Holy One of Israel, and its Maker:  
Will you question me about my children,  
or command me concerning the work of my hands?  
I made the earth,  
and created humankind upon it;  
it was my hands that stretched out the heavens,  
and I commanded all their host.

The word of the Lord.  
**Thanks be to God.**

*Psalter Reading* (responsively) Psalm 139:1-6; 13-18

O LORD, you have searched me and known me.  
You know when I sit down and when I rise up;  
you discern my thoughts from far away.

**You search out my path and my lying down,  
and are acquainted with all my ways.**

**Even before a word is on my tongue, O LORD,  
you know it completely.**

You hem me in, behind and before,  
and lay your hand on upon me.

**Such knowledge is too wonderful for me;  
it is so high that I cannot attain it.**

It was you who formed my inward parts;  
you knit me together in my mother's womb.

**I praise you, for I am fearfully and wonderfully made.  
Wonderful are your works; that I know very well.**

My frame was not hidden from you,  
when I was being made in secret,  
intricately woven in the depths of the earth.

**Your eyes beheld my unformed substance.**

**In your book were written  
all the days that were formed for me,  
when none of them as yet existed.**

How weighty to me are your thoughts, O God!  
How vast is the sum of them!

**I try to count them — they are more than the sand;  
I come to the end — I am still with you.**

*Second Reading:* Ephesians 2:17-22

So he came and proclaimed peace to you who were far off and peace to those who were near; for through him both of us have access in one Spirit to the Father. So then you are no longer strangers and aliens, but you are citizens with the saints and also members of the household of God, built upon the foundation of the apostles and prophets, with Christ Jesus himself as the cornerstone. In him the whole structure is joined together and grows into a holy temple in the Lord; in whom you also are built together spiritually into a dwelling-place for God.

The word of the Lord.  
**Thanks be to God.**

## *Hymn*

### *“When Hands Reach Out”*

When hands reach out and fingers trace  
the beauty of a loved one’s face,  
we thank you, God, that love relies  
on gifts of grace not seen with eyes.

When fingers spell and signs express  
our prayer and praise and thankfulness,  
we thank you, God, that hands can sing;  
you bless the silent songs we bring.

When broken bodies will not mend,  
we thank you, God, for Christ our Friend.  
In him, our healing can begin:  
he welcomes all the wounded in.

And when the ways we learn and grow  
are not the ways that others know,  
we thank you, God, that we have learned  
you love’s a gift, and never earned.

Your Spirit gives us differing ways  
to serve you well and offer praise.  
When all are joined as one, we’ll be  
your able, strong community.

*Carolyn Winfrey Gillette (2001)<sup>3</sup>*

*Suggested Tunes: O WALY WALY and TALLIS’ CANON*

## *Gospel Reading: John 9:35-41*

Jesus heard that they had driven him out, and when he found him, he said, “Do you believe in the Son of Man?” He answered, “And who is he, sir? Tell me, so that I may believe in him.” Jesus said to him, “You have seen him, and the one speaking with you is he.” He said, “Lord, I believe.” And he worshiped him. Jesus said, “I came into this world for judgment so that those who do not see may see, and those who do see may become blind.” Some of the Pharisees near him heard this and said to him, “Surely we are not blind, are we?” Jesus said to them, “If you were blind, you would not have sin. But now that you say, ‘We see,’ your sin remains.

The Gospel of the Lord.

**Praise to You, Lord Jesus Christ.**

## *Sermon*

## AND TO RESPOND IN FAITH

### *Prayers of the People*

In peace, let us pray to the Lord.

**Lord, have mercy.**

For the blind and those who cannot see well;  
and for those who have sight but little vision for God's good future;  
let us pray to the Lord.

**Lord, have mercy.**

For the deaf and those who cannot hear well;  
and for those of sound hearing who block out the cries of injustice;  
let us pray to the Lord.

**Lord, have mercy.**

For the lame and those who cannot move well;  
and for those whose haste and speed deny them the joys of creation;  
let us pray to the Lord.

**Lord, have mercy.**

For all who suffer in mind, body, or spirit;  
and for those who think they have no woundedness, no need of healing;  
let us pray to the Lord.

**Lord, have mercy.**

For your Church: where it is faithful and where it is not;  
where it perpetuates patterns of brokenness,  
and where it glimpses the goodness of the kingdom of God;  
let us pray to the Lord.

**Lord, have mercy.**

For the world and its people:  
that a spirit of respect for all would triumph over conflict and violence;  
that the dignity and worth of all persons might be acknowledged and  
upheld;  
let us pray to the Lord.

**Lord, have mercy.**

For all of creation, that groans as it awaits the fulfillment of your shalom;  
and that we your people might wisely steward its gifts;  
let us pray to the Lord.

**Lord, have mercy.**

*(Other petitions may be spoken.)*

In the fellowship of the Holy Spirit and of all the saints,  
let us commend ourselves and one another to the living God  
through Jesus Christ our Lord. **Amen.**

## *Presenting Our Gifts*

*Monetary gifts are collected, if appropriate to the occasion, and are brought forward with the communion elements. A Doxology may be sung. The presider may offer a prayer of thanksgiving for these gifts: the fruit of our labor and the work of human hands.*

## *Communion*

*The worshiping community's texts and traditions should guide this part of the service: the Invitation, the Peace, the Eucharistic Prayer (or Prayer of Thanksgiving), the Lord's Prayer and the distribution of the elements.*

## *Communion Hymn*

*"The Twisted Form upon the Tree"*

*Terry W. York (2012)*

*Tune: GOD IN PAIN*

*(See pp. 43-45 of this volume.)*

## *Prayer After Communion (unison)*

**For your body – blessed, broken, and shared – we give you thanks, O Lord; and for the cup of blessing that satisfies our thirst for you.**

**From this table of welcome and plenty may we go forth to bear witness to your goodness, and to be signs of hope and reconciliation in the world you have made and loved.**

**All glory is yours, we pray, now and forever. Amen.**

## **THAT THE WORLD MAY KNOW**

## *Closing Hymn*

*"Let it Be Said of Us"*

*Steve Fry (1994)<sup>4</sup>*

## *Dismissal with Blessing*

**The Lord be with you.**

**And also with you.**

**May Almighty God bless us, Father, Son, and Holy Spirit.**

**Amen.**

**We are sent in the name of Christ our Lord to love and to serve.**

**Thanks be to God.**

## Postlude and Meditation

Even when they call us mad,  
when they call us subversives and communists  
and all the epithets they put on us,  
we know that we only preach  
the subversive witness of the Beatitudes,  
which have turned everything upside down  
to proclaim blessed the poor,  
blessed the thirsting for justice,  
blessed the suffering.

Oscar Romero (1917-1980)<sup>5</sup>

### NOTES

1 Jean Vanier, *Community and Growth*, second revised edition (New York: Paulist Press, 1989), 185.

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5 Oscar Romero, *The Violence of Love*, ed. by James R. Brockman, SJ. Copyright © 2011 by The Plough Publishing House. Used with permission. Available online at [www.plough.com/ebooks/violenceoflove.html](http://www.plough.com/ebooks/violenceoflove.html) (accessed September 17, 2012).



### DEBRA DEAN MURPHY

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With great economy of expression, the mosaic in San Apollinare Nuovo depicts the desperate woman who stole a healing from Jesus.



# Desperate

BY HEIDI J. HORNICK

Perhaps no one in the Gospels is more aggressive, less passive, in seeking Jesus' aid than the woman who suffered with a hemorrhage for twelve years (Mark 5:24b-34; Luke 8:43-48). Literally sneaking into another story (of Jairus begging Jesus to help his dying daughter), the woman tries to steal a healing from Jesus by touching the fringe of his clothing as he is walking in a large crowd. The woman is desperate: her physical disability renders her socially ostracized, and she has "spent all she had on physicians" (Luke 8:43) who cannot help her.

Jesus becomes aware that someone has touched him when he notices "that power had gone from me" (Luke 8:46). Unable to deny what she has done, the trembling woman falls at Jesus' feet, admits why she has touched him, and declares to the crowd that she had been healed immediately. The sixth-century mosaic from San Apollinare Nuovo depicts the moment when Jesus blesses the woman, saying "Daughter, your faith has made you well; go in peace" (8:48). The physical healing has restored her to the community.

The mosaic is part of the earliest known cycle of scenes from the life of Christ: thirteen small mosaics (on the left lateral wall of the church nave) depict Jesus' miracles and parables, and thirteen (on the right wall) depict the Passion and Resurrection. The scenes are presented in chronological order. Since the mosaics are located at a great height—above the clerestory windows—the actions had to be clear, the gestures exaggerated, and the number of figures reduced to a minimum.

The Byzantine figures are flattened; they lack the three-dimensionality of earlier Roman wall paintings. The person to Christ's right may be Jairus, the synagogue leader who appears in the framing narrative. The other three figures (male and female) represent the community to which the woman can now return. The woman's prostrate position is emphasized, with her body covering half the foreground. The gold background is common in Byzantine mosaics, which were created from cut pieces, or tesserae, of glass or stone.

The mosaic cycle has been preserved in excellent condition in San Apollinare Nuovo, the leading church in Ravenna, which was the seat of the Byzantine Empire in Italy before it fell to the Lombards in 751 and to Charlemagne in 777. The city was later donated to the Roman See.<sup>†</sup>

## NOTE

<sup>†</sup> P. J. Nordhagen, "Ravenna," in *Grove Art Online* (Oxford Art Online, accessed September 6, 2012), [www.oxfordartonline.com/subscriber/article/grove/art/T070902](http://www.oxfordartonline.com/subscriber/article/grove/art/T070902).

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Caravaggio depicts the risen Christ with the marks of his  
earthly disability—those wounds that so terribly defaced  
Jesus' body during life and contributed to his death.

# Lasting Wounds

BY HEIDI J. HORNICK

Caravaggio's *The Incredulity of Thomas* depicts the risen Christ with the marks of his earthly disability. Touching those wounds, which so terribly defaced Jesus' body and contributed to his death, are imperative for Thomas to believe in the resurrected, bodily Christ. Granting Thomas's demand, Jesus says to his disciples, "Blessed are those who have not seen, yet have come to believe" (John 20:29b).

This episode challenges what Amos Yong identifies as "the normate perspective [that] ignores or even goes so far as to eliminate disability in the biblical message." Among other things, this perspective assumes "that disabilities will be erased in the end – rooted in a belief that the resurrection body will be free from earthly disabilities." It reduces the biblical view of disability to an "impetus both to prevent the onset of disability and to cure or alleviate it if possible in the present life."<sup>1</sup>

Caravaggio, an Italian Baroque painter known for his meticulous attention to nature and detail during the period of the Catholic Reformation, emphasizes the corporeality of the risen Christ. The painter conveys the sensation of touch as we watch Christ guide the finger of Thomas into the gaping wound.<sup>2</sup> Psychological tension is evidenced in the wrinkled brows of Thomas, yet neither of the other two apostles turns away in disgust. Instead, they are transfixed on bodily proof being exhibited by Jesus to them – and to us as viewers of Caravaggio's image.

The painting belonged to Vincenzo Giustiniani (1564-1637), an aristocratic Italian banker and art collector, before entering the Prussian royal collection. Today it is located at the Sanssouci Palace (former summer home of Frederick the Great) in Potsdam, near Berlin, Germany. There are many theories as to why this is one of the most frequently copied of Caravaggio's paintings. Perhaps artists have recognized that, as John Swinton states, "It is not insignificant that the heart of the Christian faith revolves around a damaged body."<sup>3</sup>

## NOTES

1 Amos Yong, "Zacchaeus: Short, Saved, and Un-Seen," *Disability, Christian Reflection: A Series in Faith and Ethics*, 45 (Waco, TX: The Center for Christian Ethics at Baylor University, 2012), 11-17, here citing 11.

2 For more on Caravaggio, see John Gash, "Caravaggio, Michelangelo Merisi da," in *Grove Art Online* (Oxford Art Online, accessed September 6, 2012), [www.oxfordartonline.com/subscriber/article/grove/art/T013950](http://www.oxfordartonline.com/subscriber/article/grove/art/T013950).

3 John Swinton, "Many Bodies, Many Worlds," *Disability, Christian Reflection: A Series in Faith and Ethics*, 45 (Waco, TX: The Center for Christian Ethics at Baylor University, 2012), 18-24, here citing 20.

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only available in the print version of  
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Poussin deploys conventions of classical art—such  
as brightly colored draperies, majestic columns, and  
exaggerated gestures—to depict the disciples healing  
the lame man.

Nicholas Poussin (1594-1665), *SAINTS PETER AND JOHN HEALING THE LAME MAN* (1655). Oil on canvas. 49 1/2 x 65 in. Marquand Fund, 1924 (24.45.2). The Metropolitan Museum of Art, New York, NY. Photo Credit : © The Metropolitan Museum of Art; image source: Art Resource, NY. Used by permission.

# Unexpected Healing

BY HEIDI J. HORNICK

**T**o “a man lame from birth” who was carried to the Temple to beg alms, the Apostle Peter says “I have no silver or gold, but what I have I give you; in the name of Jesus Christ of Nazareth, stand up and walk” (Acts 3:6). As Loveday Alexander explains, “Peter’s lack of ‘silver and gold’ (v. 6; perhaps due to the community’s policy on property, 2:44) highlights both the unexpected character of the miracle (the beggar is looking for money, not healing, v. 5) and the apostles own dependence: only ‘in the name of Jesus Christ of Nazareth’ can healing take place.”<sup>1</sup>

When Nicholas Poussin interpreted this story from Acts 3:1-10 late in his career, he was a well-established Baroque painter who preferred the revival of classicism in art rather than the realism of his contemporary, Caravaggio. For instance, Poussin depicts the story’s setting – “the Beautiful Gate” of the Temple – with classic architectural columns. The lame man reclines in a typically classical pose. He has a malnourished body, but it is not obvious that he cannot walk; indeed, no deformity or disability is evident in his figure. Poussin employs the conventions of classical art in other ways: the figures are heavily draped in robes of highly saturated colors (as in the Roman wall paintings that had recently been discovered), and are posed in rhetorical, animated gestures. The gestures are exaggerated whether the figures sit or stand, turn from or face us.<sup>2</sup>

Poussin prepared his compositions by organizing their primary narrative elements on small stages with wax figures and arranged draperies. For this one, he borrowed compositional ideas from Raphael’s version of the scene in the Sistine Chapel tapestries and the *School of Athens* (1509), a fresco painted in the Stanza della Segnatura for Pope Julius II. He also borrowed from Michelangelo’s *Creation of Adam* (1508-1512) the gesture between God and Adam, applying it to Peter’s touching the lame man. The Apostle John the Beloved, who is only a supporting character in the biblical story, has a similar role (rather literally) in the painting as he holds the elevated arm of the lame man.

## NOTES

1 Loveday Alexander, “The Acts of the Apostles,” in John Barton and John Muddiman, eds., *The Oxford Bible Commentary* (New York: Oxford University Press, 2001), 1033.

2 Mary Sprinson de Jesús, “Nicolas Poussin (1594-1665)” (October 2003), in *Heilbrunn Timeline of Art History* (New York: The Metropolitan Museum of Art, 2000-) (accessed September 5, 2012) [www.metmuseum.org/toah/hd/pous/hd\\_pous.htm](http://www.metmuseum.org/toah/hd/pous/hd_pous.htm).

# Baptism and Profound Intellectual Disability

BY JASON D. WHITT

Is there room in the baptismal waters and at the Lord's Supper table for persons with profound intellectual disability? For Christians who practice believers' baptism, the question goes to the heart of what it means to be the Church and to welcome the giftedness of each person in our midst.

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Is there room in the baptismal waters and at the Lord's Supper table for persons with profound intellectual disability? For some within the Christian tradition, there is a quick answer to the question about baptism: infants are baptized on the confession of faith of their parents. The dilemma, from their perspective, is whether persons with profound intellectual disability can mature in discipleship and be confirmed later in their faith. But how should Baptists and others who practice believer's baptism address the question? According to their practice, baptism is supposed to follow faith as a person's conscious and voluntary act of obedience to Christ's command. Baptism is symbolic of what has already happened in the person's life; it is a response (by the person and in a faith community) to what is already the case. This act of obedience serves as the initiatory rite into the Church. Consistent with this, the Lord's Supper is reserved for baptized believers—those persons who by baptism have become members of the Church.

So what is the place of those with profound intellectual disabilities in churches that practice believer's baptism? If they are unable to consciously and freely turn to Christ and follow him in baptism, must they remain outside of the Church and not share the table with those who are followers of Christ?

Let me focus the issue. The concern is not with the eternal salvation of

the profoundly disabled. There is a confidence that these children and adults are held firmly within God's love. They are loved by their church families and will be welcomed within the community even though they are not baptized. The default circumstance is that they will remain perpetually in a child-like position in the Church because of intellectual limitations. They will be nurtured and loved, but never fully belong to the community of believers.

Yet this situation is not entirely satisfying. It seems to betray the gospel that demands a place for the "least of these" because Christ has broken down the barriers that separate us—including the one between able-bodied and disabled. So, is there a way to remain true to Baptist convictions on believer's baptism and sharing of the table while making room for those who can never act on their own volition or understanding to confess faith in Christ? Two fundamental questions must be considered: how do we understand baptism and the Lord's Supper, and what is the nature of the Church? By taking these in turn, we may gain clarity for answering the question about the place of the profoundly disabled in our congregations. I write as a Baptist with the hope of sparking reflection among those who share similar convictions concerning baptism and the Lord's Supper.

### **THE "ORDINANCES"**

Baptists often emphasize the symbolic function of baptism and the Lord's Supper, which are called the "ordinances" of the Church. Through these practices of the faith community, a believer signals, or outwardly expresses, a spiritual reality. The noted Baptist theologian Augustus Hopkins Strong (1836-1921) explains, "By the ordinances, we mean those outward rites which Christ has appointed to be administered in his church as visible signs of the saving truth of the gospel."<sup>1</sup> Regarding baptism, he writes, "Baptism symbolizes the previous entrance of the believer into the community of Christ's death and resurrection."<sup>2</sup> His student, W. T. Conner (1877-1952), adds, "While baptism does not save, nor is a condition of salvation, it does symbolize a salvation that comes to us by faith in Christ."<sup>3</sup> Baptism, in their view, is an act that symbolically portrays a spiritual reality that is already accomplished—namely, salvation. Likewise, in taking the Lord's Supper believers remember Christ's sacrifice and testify to their constant appropriation of Christ's saving grace.

Contrast this to a more sacramental view of the ordinances. While agreeing that these actions have great symbolic significance, the sacramental view would add that God's grace is conveyed through them. Whereas Strong and Conner highlight the believer's role of obedience in openly confessing the divine salvation they have experienced, the sacramental view (as we will see below) offers a more complex account of who is doing what in the ordinances.

When we examine Baptists' practice of the ordinances, they are not merely symbolic; something more is taking place, something that changes those who receive the water and the meal. The first Baptists in the early seventeenth century (and others who would later practice believer's baptism) were con-



vinced that the basis of a regenerate Church must be baptism into membership and the partaking of bread and cup only by those who freely confessed to their faith in Christ. They rejected infant baptism because infants cannot choose to follow Christ and so voluntarily join the community of disciples. Congregations that practice believer's baptism today remain adamant that it is the act of immersion in obedience to Christ's command that *makes* a person a member of the Church. Only members share the meal, and they do not eat alone: believers are now in community with God and with one another.

So, what is happening in the water and the meal? To hold an initiation rite reserved for only those who believe suggests that baptism is more than mere symbol. Something takes place: a person is brought into the community of the Church and a new identity as one baptized begins to be formed. Likewise, taking the meal is not only a symbolic reminder of Christ's sacrifice, but in eating and drinking together, a shared identity is forged among those around the table.

To articulate this feature of the ordinances, Stanley Grenz draws upon the work of social theorists who note how members of particular communities

tend to have a similar outlook toward life, view the world in a similar manner, and construct the symbolic world they inhabit using similar linguistic and symbolic building materials, even if they are not of one mind as to the meaning of their shared world-constructing symbols.<sup>4</sup>

This shared identity develops through the common narrative that is told and lived through the language and practices that are peculiar to the group.<sup>5</sup> Thus, individual members of the group are formed by the community even as they contribute to the further shaping of the community.

Baptism and the Lord's Supper are such "acts of belonging."<sup>6</sup> Christ gave these practices to the Church and his Spirit works through them for the initiation and edification of all believers. Thus, they are more than mere symbols: they help to form the identity of the individuals who have accepted the saving grace of Christ. The bodily practices with the water, bread, and cup are constitutive parts of the story into which believers live. Baptism is a person's initiation into the Church where the gospel narrative—the way of living according to the life, death, and resurrection of Christ—is the identity-forming account of the community. The person now belongs to this group, yet initiation is neither the end nor the fullness of their identity. Thus, the Lord's Supper is a repeated reaffirmation of each member's belonging to the group, and so continues the shaping of their identity in the body of Christ.

Since the ordinances are acts of belonging that are constitutive of identity, they cannot be personal acts of symbolic remembrance. Baptism and the Lord's Supper are acts of threefold agency: God, the Church, and the candidate.<sup>7</sup> Because they are given by Christ to the Church, there must be a body of believers gathered together who can offer them.<sup>8</sup> When people turn to Christ in faith and become new creations, it is the Church that forms them into the

new identity discovered in the gospel narrative. Grenz explains, “For this reason, baptism points beyond initiation into the Christian life to the goal of God’s saving activity, namely, the eschatological transformation of all believers within the context of the establishment of the new creation.”<sup>9</sup> It is within the community that is being shaped by God’s future that a person takes on the identity of the new creation.

## THE COMMUNITY OF BELIEVERS

If the Church is an identity-forming community, it must be more than simply a voluntary association of believers (if “voluntary association” means that believers may or may not be part of this community depending on their preferences). Where the Church properly may be called “voluntary” is in each believer finding faith apart from coercion from earthly powers. This was the message of the early Baptists who rejected infant baptism as a matter of course for everyone who happened to be born in a particular political region. They understood the Church as a community of the regenerate – those who in faith had accepted God’s grace and were now living as disciples of Christ.

Believers learn what it means to be disciples as they are formed within the community that lives the gospel story. The Apostle Paul offers a compelling picture of this process when he describes the Church as “the body of Christ” (1 Corinthians 12:12-31). In the context of discussing spiritual gifts, Paul notes that each member is necessary to the body because each has gifts that are given for the benefit of all.

Indeed, those who seem weakest or of least value may be the most indispensable (12:22-23). In this Paul hints at the subversive nature of the Church.

Accepted barriers are broken: Greek and Jew, slave and free, male and female have all been given gifts that the Church needs. This means that people who outside of the Church would have little interaction with one another – much less

acknowledge a need for one another – discover in the body of Christ that they are dependent upon those they disregarded.

Life together in Christ reveals that at the heart of what it means to be human is a dependence on one another, because each has been gifted by God for the good of everyone else. It is easy to imagine what believers might learn from the great saints: the spiritually powerful have much to educate the weak.

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**If baptism and the Lord’s Supper are given by Christ to the Church for the initiation and edification of believers, they are more than just symbols. They help to form the identity of those who have accepted the saving grace of Christ.**

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More challenging is imagining how the seemingly weak are gifted with offerings necessary for the apparently strong. So, Paul's account suggests the incomprehensible: the master finds himself in need of the gift of a slave. God's economy of gift giving overturns the world's economy of merit. The Church is the community in which this eschatological vision is lived in the world.

## **THE PLACE OF THE DISABLED IN THE BODY OF CHRIST**

On this way of understanding the Church, baptism, and the Lord's Supper, is there any place for the profoundly mentally disabled in the water or at the table? One might think that if these practices require a conscious and reasoned assent to the call of Christ, then the answer must be "no." To the extent they are unable to understand a decision to follow Christ and the implications of that decision for their lives, the profoundly mentally disabled are not able to comprehend the "belongingness" of these acts, and thus to enter voluntarily into the community. To give them the ordinances would be akin to baptizing infants.

Yet is this last metaphor really appropriate? Infant baptism is rejected on the assumption that the child will come to an age where the choice for faith can be made. But what if, because of intellectual disability, the person will never reach a cognitive level where that choice is possible? In reflecting on this issue, Michael Taylor, a British Baptist educator and parent of a mentally disabled child, offers an important reminder: "It is true that we look for a response to the Gospel in those who come to join the church, but we are made members of Christ far more by what is given than is expected."<sup>10</sup> That is, Christians who practice believer's baptism already recognize that salvation is something accomplished in us by Christ. The human part is not primary, but it is not insignificant. Perhaps how we account "a response to the gospel" should be reinterpreted in instances where intellectual assent is not possible.

If, as argued above, baptism accomplishes something — namely, the conferring of membership and belonging to the community of faith — withholding baptism from those whom we believe Christ has accepted but who cannot consciously respond entails the Church excluding the most vulnerable in our world. Such exclusion is not, of course, intentional. We intend to love and care for these. Yet, by denying baptism on the grounds that they have not accepted Christ, the clear message is sent: "Because you are limited, you can never be fully a member of this community."

I can imagine some fellow Baptists will raise an objection at this point. "If the Church is a voluntary gathering of those committed to discipleship, by definition the profoundly intellectually disabled cannot belong," they would say. "This does not mean God or the Church does not love them. If we are convinced that the profoundly mentally disabled have their place in God's kingdom and rest comfortably in the grace of Christ, what concern is there if they do not receive the water and the meal?"

The idea that continues to haunt me, however, is that the concern is not

just for them, but for all of us in the Church. What is lost to the community of faith in our refusal to baptize and share the table?

Reflecting again on the nature of the Church as the body of Christ in which each member is uniquely gifted for the good of the whole, we may need to consider what gifts the profoundly mentally disabled have been given for the benefit of the whole body. Often, the relationship to those with disabilities is seen as going only one way: the able-bodied Christians serving and caring for those who cannot do for themselves. A sense of Christian service and virtue is evident in the self-sacrifice of those who would care for such persons. However, the disabled person is reduced to a piece of spiritual exercise equipment on which able-bodied Christians can develop spiritual virtues by serving the “least of these.”

The gospel invites us to the greatest stretch of our imagination to see the profoundly disabled as fellow brothers and sisters, members of God’s kingdom, who have been given gifts we need and from whom we might learn.<sup>11</sup> Our learning comes not by what we do for them, but from what they teach. What if their presence in the community of believers is essential to our coming to understand more of who God is, who we are, and who we are to be? They challenge us in our self-sufficiency, reminding that to be human is to be dependent. Perhaps they also teach about patient perseverance, or living in a moment without concern for tomorrow. For some people with profound cognitive disabilities, their gift to us may be simply presence—being and not doing. Other gifts may be gentleness, peace-fulness, joy, wonder, or simply silence.<sup>12</sup>

All of this leads to a suggestion, which I offer here with no small amount of fear and trembling: those in the tradition of believer’s baptism should baptize persons with profound intellectual disabilities—not all such persons indiscriminately, but those children and adults who are already present in our congregations, the sons and daughters of faithful parents who have included them in the life of the Church. We

offer this baptism into the community with the full conviction that believer’s baptism remains the norm for most. The intention is not to turn from this conviction, but rather to recognize that there are cases where baptizing one who cannot confess faith is a proper affirmation of that person’s place in the body of Christ.<sup>13</sup>

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**As we reflect on the nature of the Church as the body of Christ in which each member is uniquely gifted for the good of the whole, we need to consider what gifts the profoundly mentally disabled have been given for the benefit of the whole body.**

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In this baptism, we confirm their belonging to the body of Christ because we acknowledge that Christ has accepted them. And we baptize because we understand that the community of believers needs the gifts that God has given these members. They are not halfway members or junior members of the body—they are brothers and sisters with those who suppose themselves to be able-bodied. And finally, we share the Lord's Table, coming together to eat and drink, and in so doing remember what Christ has done in us and what he makes of us as a new people—people who see in our most vulnerable a beauty and worth that the world cannot account.

As a final caveat, I add that this answer is really only a beginning point, the spark to a much larger and more challenging conversation. The spectrum of human intellectual capacity is broad, and so what is suggested here leaves untouched the great middle ground between the profoundly intellectually disabled and what we believe to be normal intelligence. How should we share the ordinances with the high functioning Down syndrome child who has only a very basic grasp of sin but loves Jesus, or the mentally disabled adult who functions at the level of a preschooler? As noted above, there must be significant discernment about what is understood by response to Christ's call. My hope is that more congregations will begin having these important conversations not simply at pragmatic levels, but with serious theological reflection on what it means to be the Church, to baptize, to share the Lord's Supper, and to account the worth and giftedness of each person in their midst.

## NOTES

1 Augustus Hopkins Strong, *Systematic Theology*, revised (Philadelphia, PA: The Griffith & Rowland Press, 1907 [1866]), 930.

2 Ibid., 940.

3 W. T. Conner, *Christian Doctrine* (Nashville, TN: Broadman Press, 1937), 278.

4 Stanley Grenz, "Baptism and the Lord's Supper as Community Acts: Toward a Sacramental Understanding of the Ordinances," in Anthony R. Cross and Philip E. Thompson, eds., *Baptist Sacramentalism* (Eugene, OR: Wipf and Stock, 2003), 85.

5 James K. A. Smith offers important reflections on bodily practices and the formation of Christian identity, particularly through the liturgy, in *Desiring the Kingdom: Worship, World-view, and Cultural Formation* (Grand Rapids, MI: Baker Academic, 2009).

6 Grenz, "Baptism and the Lord's Supper," 92.

7 James Wm. McClendon, Jr., *Doctrine: Systematic Theology, Volume 2* (Nashville, TN: Abingdon Press, 1994), 389.

8 This commitment produced much consternation for early Anabaptists and Baptists who became convinced of believer's baptism. How could they, who had been baptized as infants, rightly administer baptism and the Lord's Supper before a congregation consisting of baptized believers existed? The uncomfortable solution they adopted was that one person must go first and be baptized as a believer by another person who was not a baptized believer. That first one would then baptize the rest.

9 Grenz, "Baptism and the Lord's Supper," 93.

10 Michael Taylor, "Include Them Out?" in Faith Bowers, ed., *Let Love Be Genuine* (London, UK: The Baptist Union, 1985), 47. This collection of essays is among the earliest reflections on disability and the Church produced by Baptists.

11 Stanley Hauerwas sees the Incarnation as the key to stretching our imagination. "The

humanity of that God," he writes, "has made it possible for a people to exist who do in fact, as Nietzsche suggested, exemplify a slave morality. It is a morality [David Bentley] Hart describes as a 'strange, impractical, altogether unworldly tenderness' expressed in the ability to see as our sisters and brothers the autistic or Down syndrome or disabled child, a child who is a perpetual perplexity for the world, a child who can cause pain and only fleetingly charm or delight." Stanley Hauerwas, "The Politics of the Church and the Humanity of God," ABC Religion and Ethics (June 19, 2012), [www.abc.net.au/religion/articles/2012/06/19/3528056.htm](http://www.abc.net.au/religion/articles/2012/06/19/3528056.htm) (accessed September 6, 2012).

12 For more on recognizing the giftedness of the profoundly mentally disabled, see Henri Nouwen's account of his close friend, teacher, and confidant, Adam Arnett, in *Adam: God's Beloved* (Maryknoll, NY: Orbis Books, 1997). Adam was a profoundly disabled young man in the Daybreak Community. Though Adam was unable to care for himself or communicate, Nouwen came to understand their relationship as a deep friendship in which Adam articulated the deep mysteries of God simply in his presence.

13 I am grateful to my friend Scott Bullard for helping me to articulate this ideal.



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# The Lure of Eugenics

BY BRIAN BROCK

In contemporary society “prenatal care” and “prenatal screening” are taken to be synonyms, but they become antonyms in practice when the refusal to test is portrayed as unnecessarily risky and aborting a disabled child is portrayed as a relief.

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**T**he science of prenatal testing is reaching its maturity with the development of a non-invasive blood test that can detect genetic conditions such as Down syndrome cheaply and safely.<sup>1</sup> Just as it now seems perverse not to test pregnant women for conditions that are potentially catastrophic for the health of the child, such as for toxoplasmosis, AIDS, or hepatitis, it will soon seem nonsensical not to check if our nascent children have genetic defects.

It will be hard for modern states that face mounting healthcare costs not to strongly encourage this routine fetal testing regime, and it will be difficult for parents to resist using it. Who, after all, would willingly choose the hardship, financial challenges, and social stigma associated with raising a disabled child? With the advent of painless genetic testing which “just happens” to young parents as a matter of routine, every new parent will begin life with their children having had to make a choice about whether to continue or abort each pregnancy.

I will cast light on this new landscape from two directions. First I will explore how self-protective walls can become destructive, cutting off the lifeblood of human communion. The Berlin wall is a classic case. It was both physical—constructed of concrete, topped by barbed wire, and surrounded by exclusion zones—and very human. Humans guarded its gates and ran the vast ancillary system of tracking people that certified who was allowed to cross the wall and who was not. The physical wall was only the most visible part of a highly developed apparatus for segregating people. Because it rested on the continual efforts of vast numbers of soldiers, police (secret and



explicit), and a judicial and legislative system as represented by immigration officers, this wall penetrated every nook and cranny of the society that it regulated. The East German theologian Wolf Krötke came to see its brutalizing presence as a paradoxical living nothingness—a type of human living driven by death, separation, and lies.

When I looked through the window I could see the Berlin Wall scarcely five hundred meters away. ...What was playing itself out before my eyes was absurd. A boundary which threatened the natural communication of its citizens, families, and friends was drawn right through the middle of a vibrant city. It was spectral, but exactly as such also real in brutal ways. In itself it was *nothing*, but exactly as such it was dreadfully significant. And yet, it was passed off as something truly good by a great mass of shameless lies. The same structure clearly repeats itself wherever people do that which we call “evil.”<sup>2</sup>

As a second way of casting light on the landscape of prenatal testing, I will ask what it means to live, procreate, and parent in the mode of praise or doxology to the Trinitarian God. Does this mean that we, as Christians, should welcome these new techniques, or is something problematic in their proliferation?

Martin Luther characterized human sin as organizing our daily lives by way of anti-doxologies (acts of praise of self and idols) that are the antithesis of doxology (praise of the true God).<sup>3</sup> Sin is made up of concrete, aberrant responses to God’s gifts, which are personified anti-doxologies. In contrast, the saints are drawn together by songs that refuse to praise any other God, magnifying the Lord alone: “The LORD’s right hand has done mighty things” (Psalm 118:15-16, NIV).<sup>4</sup> “Singing” thus names the cast of all speaking that properly marks the Christian ethos. “Under ‘singing,’” says Luther, “I include not only making melody or shouting but also every sermon or public confession by which God’s work, counsel, grace, help, comfort, victory, and salvation are glorified before the world. ... As [Psalm 118:14] puts it: ‘The Lord is my Strength and my Song; He has become my Salvation.’”<sup>5</sup>

Those who are caught up in God’s work are learning to see and praise the manifold works of God, and thereby coming to live an embodied recognition of God’s grace and care. This contrasts with faith in human works that is sustained by idolatrous anti-doxologies that exalt the salvific power of other persons and forces. Thus by looking at what people praise we can expose their self-protective walls. I will employ praise-analysis as a mode of social criticism of the eugenic practices of our age, making audible our own reasons to resist praising the Lord for some lives he has created.

## **PRENATAL SCREENING: POLICING THE BORDERS**

The evil of the Berlin Wall was invented neither by the guards who stood at the border with guns, nor the officials who issued passports, nor the legislature that decreed the norms for entry and exit. But all upheld it. Similar

social dynamics are visible in prenatal screening. Medical researchers develop diagnostic tests. Legislators – acting on the advice of managers, accountants, lawyers, and physicians – legislate permissible modes of policing the boundary of human life. Genetic counselors explain and validate the notion of borders to parents who often have ambivalent feelings about bearing a disabled child. And at the end stands the techniques of violence wielded by the medical practitioners who perform abortions.

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**It is very difficult to separate strong claims about the benefits of testing and aborting fetuses with genetic anomalies from judgments about the perceived negative impact of citizens currently living with those conditions.**

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Here I am distinguishing between abortion on demand and *selective* abortion. Selective abortion destroys human community at its foundations by setting up a criterion against which every human life must justify itself before being granted the right to enter human society. Because violence undermines the political nature of human life, by definition there can be no genuine freedom to destroy humans whose genes

appear to differ from that which we currently take to be the norm. Prenatal screening and abortion of the disabled is a classic case of what Wolf Krötke calls “nothingness,” in that if one is labeled “disabled” one is forcibly denied entry into the community of the living. It is never solely a parent’s choice to bar the gates to an individual life: such denials can only be carried out by a wide range of humans oriented by intertwining anti-doxologies.

Some have protested that testing and aborting fetuses with genetic anomalies is not necessarily a judgment about citizens currently living with those conditions. Addressing these objections, Hans Reinders concludes that it is very difficult to separate strong claims about the benefits of screening out the disabled from judgments about the perceived negative impact of the living disabled on society. To “test” implies making “selections” that rest not only on judgments about the health of the human genome, but also on judgments about the quality of life experienced by disabled persons who already exist.<sup>6</sup> Empirical studies confirm that, when faced with a diagnosis of genetic anomaly, virtually every mother or couple draws on anecdotal experiences and accounts of the lives of the disabled and their caregivers in deciding whether or not to abort.<sup>7</sup>

These two strategies – setting up criteria to judge the unborn and then attempting to disengage these criteria from living disabled citizens – are general forms of what I have called embodied anti-doxologies. But more specific anti-doxologies attract us today. In order to discern what is being praised

as salvific, we must listen to how people in our society understand themselves and where they go to gain control over their lives. On this theme Rayna Rapp's detailed anthropological account of the rationales behind what is called genetic screening is highly illuminating. Her *Testing Women, Testing the Fetus: The Social Impact of Amniocentesis in America* draws on extensive research in the late 1980's and 1990's on the main participants in the drama of amniocentesis in New York. Though the techniques of prenatal screening have been improved significantly since the time of her study, the aims of the screening process are essentially unchanged today.

Before any of the physical barriers that make up walls can be constructed, societies must reach collective agreements about boundaries between "us" and "them" that need to be protected. This "wall in the mind" thus *precedes* and *sustains* any techniques of prenatal testing. How do such boundaries form in the collective consciousness, what makes them solid, and what drives the final decision to deny a supposedly substandard human entry into the body politic? Tracing the paths of three actors in this drama—the geneticists and laboratory technicians whose technical expertise supports the claim that there is a clear boundary *here at this point*, the genetic counselors who lead pregnant women to this boundary and explain to them what it entails, and the woman (and perhaps father) who will make the decision about whether to end a particular pregnancy—will allow us to discern the more specific doxologies that drive their investment in maintaining a barrier between those who may enter life and those who are denied. Many other supporting actors—like the medical personnel who carry out the decision to abort, the researchers and technologists who push testing techniques forward, and the legislators who frame laws on abortion, prenatal testing, and the social provision which would support parents raising a disabled child—will have to remain in the wings even though they play vital roles in sustaining the environment in which these three main actors meet to police the border between "us" and the disabled.

### **GENETIC COUNSELORS: INTERPRETING TEST RESULTS**

Prenatal diagnosis through amniocentesis is a complex affair. Amniotic fluid must be extracted, cells cultured from it, chromosomes separated, and then a judgment made about the health (or otherwise) of the fetus's genes. The aim of these complex processes is to produce a clear genetic diagnosis from what are essentially grey areas and judgment calls, leading Rapp to call testing labs "laboratories for fact construction" (p. 192). Most of the bench work in this process is undertaken by less educated women while the geneticists who oversee the work and make the final diagnoses are usually highly trained males specializing in cell biology, embryology, and pediatrics. Though both lab workers and expert doctors are very aware that each stage of the process involves craftwork and that false moves may be made which may invalidate the final diagnosis, Rapp discovered that all parties involved had strong reasons not to admit the interpretative nature of their work (p. 208).

This problem is compounded by the fact that medical science still has very incomplete knowledge of how any given genetic anomaly will be expressed as a child matures. This is why autopsies are routinely carried out on selectively aborted fetuses to determine the actual effects of the diagnosed genetic anomaly. Heartbreakingly, it is only at this point that some parents become aware that prenatal diagnosis is far from foolproof, despite its having been so presented. Rapp quotes one woman's response as she realized that her aborted fetus was being sent to pathology:

When the doctor took a tissue sampling I asked him why, and he said, "To send to pathology to confirm the diagnosis." And I started howling, I was just screaming my head off: "If there's anything that even possibly needs confirming, what am I doing here?" (p. 241)

Geneticists used to deal directly with parents, but now this work has been handed over to genetic counselors whose stated aim is to assist women's reproductive choice by providing information about hereditary risk to prospective parents. In practical terms they prepare parents to take the test and to explain the meaning of the laboratory results to others. Counseling sessions therefore have four main goals: establish the primacy of scientific discourse, establish the authority of this discourse, communicate risk, and construct a family history narrated in medicalized terms. Again, the vast majority of practitioners (95%) are female (pp. 56-57).

Rapp notes an inherent confusion in these activities of the genetic counselor who thinks of herself as value neutral even as she plays the role of gatekeeper. The biomedical and public health establishments that employ genetic counselors presume that some conceptions are expendable or even burdensome. Thus genetic counselors are prone to reproduce this bias in an unreflective manner that "assumes that scientific and medical resources should be placed in the service of prenatal diagnosis and potential elimination of fetuses bearing chromosome problems. In principle, then, counselors are trained to offer a value-charged technology in a value-neutral manner" (p. 59). Prenatal diagnosis thus expresses a biomedical picture of healthcare in which prenatal *screening* precedes and is more fundamental than prenatal *care*. During genetic counseling the prospective parents must learn to evaluate themselves and their growing offspring within the screening framework *before* making what is termed an "informed" decision for or against embracing a given pregnancy.

Theologically we need to note that the paeans of praise to concepts like value-neutrality, individual choice, risk avoidance, and the authority of expertise are problematic in themselves, and they become a deadly cocktail when unreflectively teamed with decisions about whether to eliminate humans perceived to be a burden. While each concept might conceivably find a place in a song of praise to the creating and redeeming God, in the contemporary usage just described they clearly preface any sense of wonder and thankfulness for the gift of conception with a prior anti-doxology lifting up the prom-

ises of perfect control, benevolent expertise, and a life free of “accidents.” Not only is this to praise the gods of fertility and quality assurance who are bound to disappoint us with children who do not conform to our expectations, but also it is to undermine with a benevolent smile the hurdles facing the socially marginalized for whom “genetic risk” is a very small part of the life challenges they daily face. In systematically directing attention away from the concrete life-barriers facing mothers and suggesting that their hopes and fears are most appropriately attached to a realm of *possible* choices, genetic counseling illustrates a classic instance of how evil is a non-reality even as it is embodied in concrete words and actions. The substitution of the imagined for the concrete is a familiar political ploy, in this case played out by perhaps unwitting genetic counselors speaking for a state (or for-profit medical system) whose offer of help to those mothers who most need social support has been reduced to the offer of an abortion. This political role is sustained by genetic counselors’ embrace of the psychologists’ self-understanding as non-directive (and therefore apolitical) precisely as they serve the widespread use of the technologies of elimination. In theological and pastoral terms, the net effect of this anti-doxology is the loss of attentive empathy and concern for the whole of life in service to the state’s interest in minimizing economic cost.

## PARENTS: MAKING CHOICES

Rapp’s detailed descriptions of how pregnant women made the decision to undergo amniocentesis and then chose to abort a conceptus diagnosed as abnormal is by far the most difficult terrain to summarize. I will set out what I take to be the findings most relevant in our search to understand the anti-doxologies of our age.

Prenatal testing presents mothers with a bewildering set of social pressures. As it is currently configured, amniocentesis yields a diagnosis late in pregnancy, demanding that mothers take up a stance of distance from someone in their womb whom they may have wanted and are certainly beginning to experience as an independent living being (p. 179). Often mothers face subtle and not-so-subtle moral disapproval if they do not test, or refuse to abort a fetus diagnosed as abnormal (p. 263). Many women who had borne live disabled children told of having been the object of anger and disappointment from medical staff (pp. 266-267), and expressed their own amazement and disgust at the rapidity with which adoption or institutionalization of their children was offered (pp. 269-270). In addition, Rapp found that women from lower socio-economic strata often opted out of testing simply because the prenatal care available to them was so poor and time consuming to procure that they gave up in frustration (p. 109).

The new forms of prenatal genetic testing will resolve the problems of expense and danger that are associated with amniocentesis, as well as its relatively late verdict on a pregnancy. But they will not make interpreting test results any less difficult for less educated mothers—for whom comprehend-

ing the language of science and risk is daunting. The sexual politics of the decision to test or abort will also remain highly complex: for example, some women seek tests in order to garner greater paternal involvement, while some men invoke patriarchal privilege to deny testing—here the permutations are myriad and unsettling. For all these reasons and more, mothers deserve compassion and social support.

Yet the fact remains that they too have been drawn into the role of gatekeepers, whether by choice or as participants in a culture that demands the final judgment on a pregnancy to be pronounced by the mother or both parents. Our interest in the remainder of this section is in discerning the doxologies that orient parents, especially mothers, as they digest a diagnosis of a fetus with an anomalous genetic inheritance.

In our society women are positioned to approach their reproductive choices as private individuals. In this space of privacy Rapp found many women undergoing transformations of self-understanding and new levels of self-reflection in being forced to articulate their reasons for continuing a pregnancy or not. This is not to imply that prenatal testing forces women to become more reflective about their relationships with medicine and their conceptus; as testing becomes wholly routine the sense in which a woman has any choice in the matter will become less evident. As we will see, the theologically critical innovation is that women are expected either to collate the information on which a “rational” choice to continue a pregnancy can be made, or to give reasons, against the grain of the medical establishment, why they ought not be asked to make such a decision at all.<sup>8</sup> Rapp came to view the vast majority of mothers who confronted the issues raised by prenatal screening as “moral philosophers of the private” who struggled to discern the way forward in their state of isolation from any tradition of explicit thought about these issues. Living within an enforced but at times empowering privacy, they are surrounded by the cacophonous opinions of medical professionals, newspaper pundits, friends, family, and other children (pp. 306-307).

Rapp found a range of reasons given for pursuing amniocentesis and potentially aborting a fetus diagnosed as anomalous. Two priorities recur: the capacity to mother a disabled child, and the impact of a disabled child on the mother’s most intimate relationships with the child’s father, other children, and extended family members. Four broad types of justification solidified the boundary being constructed against a genetically anomalous fetus. The first was a discourse of “selfishness,” which narrates killing as an act of love in praise of “protecting the children.”

Some people say that abortion is hate. I say my abortion was an act of love. I’ve got three kids. I was 43 when we accidentally got pregnant again. We decided there was enough love in our family to handle it, even though finances would be tight. But we also decided to have the test. A kid with a serious problem was more than we could handle.



And when we got the bad news, I knew immediately what I had to do. At 43, you think about your own death. It would have been tough now, but think what would have happened to my other kids, especially my daughter. Oh, the boys, Stephan and Alex, would have done ok. But Livia would have been the one who got stuck. It's always the girls. It would have been me, and then, after I'm gone, it would have been the big sister who took care of that child. Saving Livia from that burden was an act of love. (*Mary Fruticci, 44, white homemaker*) (p. 247)

Prenatal testing is forcing women, concludes Rapp, to become "philosophers of the limit": in order to take the test they needed to imagine the outer limits of their maternal embrace (p. 308). Under the shadow of their perceived responsibilities as mothers and women, and imagining life with a disabled child, they were forced to articulate a set of values ostensibly located in the private realm but formed by (and forming in turn) the life of society as a whole.

The anti-doxologies that we have just heard sung are as pervasive as "commonsense." The praises of "protective limits," "knowledge as power," "acting to improve life," "protecting the children," and "free private choice" are ubiquitous in our age, explored and lived into as salvific promises by parents and many others in all walks of life. Lost to the singers of this anti-doxology is the notion that new life is a gift that is inherently enriching. Rapp found it remarkable that among those considering abortion, the focus on limits almost always excluded any consideration that positive effects might accrue to siblings of a disabled child or to themselves as parents (p. 248). These anti-doxologies also subvert the collective will to support women, parents, and families, which leaves them with the sense that the decision to embrace a disabled child is tantamount to economic and personal suicide. The anti-doxologies of these women thus mesh with the anti-doxologies that demonize the desire to share medical costs or the cost and labor of childrearing. They likewise hide the voices of parents who have raised children with disabilities and understand their experiences in terms of a journey toward acceptance, appreciation, and enrichment (p. 264).

From a theological perspective, prenatal testing is built on the assertion that in order not to take on more than we can bear, we must choose who we will accept into the human community. We can now see what a shameless lie and self-justifying evasion it is for those of us living in liberal democracies to believe that iron curtains were only a problem in communist states. In our joyous praise of the free market system, we are not well placed to resist the anti-doxology of prenatal testing. John Swinton explains:

Neo-liberal capitalism offers a picture of human beings as fundamentally individual beings who choose to join together to form societies, the primary purpose of which is to attain the greatest benefits for the largest number of individuals. In other words, the individual *precedes* the community. ... Thus we begin with individuation, separation, and

distancing and move towards unity and relationship, a unity and relationship that is *optional, tentative, and dependent* on the child fulfilling certain criteria....<sup>9</sup>

The marketers, political spin-doctors, and MBA-trained pastors who are so influential in neo-liberal societies are deeply invested in an account of freedom that rests, finally, in the supremacy of choice. In such a landscape, prenatal testing is one more mechanism serving the worship of freedom defined as "choice." It therefore sounds nicely like the many other praises we sing of the techniques that can save individuals and families from "accidents" that will destroy the lives we have imagined for ourselves. But if human beings are never "accidents," then instructing people that they have a choice and insisting on how they should make it is an induction into an anti-doxology that refuses to praise the Trinitarian creator for fertility and new life. Thus when they entail the elimination of human beings, philosophies of limit are, by definition, anti-doxologies. They cannot be glosses on the song "The LORD's right hand has done mighty things"; rather they sing "we must act to save ourselves from 'them' or be drowned."

### **THE DISABLED: SINGING SONGS OF ANNUNCIATION**

In the face of these anti-doxologies, it makes sense for Bernd Wannewetsch to suggest that the disabled are "angelic messengers" who invite us to see God's working anew. The fetus we label disabled is not silent, but is a positive word of grace and liberation to those praising their own fetters. Remarkably, it was the annunciative character of a genetically anomalous fetus that transformed Raya Rapp from an abortion activist and privileged academic into a genuine inquirer. She ends her study of amniocentesis with this elegiac dedication to her aborted offspring:

Mike named the fetus XYLO, or X-or-Y for its unknown sex, LO for the love we were pouring into it. Together, we watched XYLO grow; together we chose to end his life after a prenatal diagnosis of Down's. My personal pain and confusion as a failed mother led me to investigate the social construction and cultural meaning of amniocentesis.... XYLO's short life pointed me toward these vital concerns; his ending marked the beginning of my search for contextualized knowledge. If the work accomplished in this book helps others to think about these evolving issues, his short life will have been a great gift. (p. 318)

In the light of God's self-annunciation from the manger in Bethlehem, the Christian is enabled to say in faith (without the intervening and instrumentalizing "if") that XYLO was indeed a great gift in exposing the shameless lies permeating the culture that united to refuse him entry into life with his parents. With the cultural landscape Rapp has described now fully in view, we too can now hear XYLO's repetition of the angel's message to Mary and the shepherds: "Fear not." In this annunciation our enslavement to the con-



trol that wishes the disabled not to exist ends. The “fear not” that they speak, writes Wannennwetsch,

implicitly feeds on the resurrection of the one *angelos tou theou* who did not recoil from having his wings clipped (Philippians 2:5-8) or from sharing the human life of fear and anxiety, yet was triumphantly raised from the dead to offer transformation and new life to those who recognize him and their own existence as human beings in the faces of his most dependent brothers and sisters (Matthew 25:40).<sup>10</sup>

The disabled, whether born or unborn, announce an end to our need to draw boundaries between them and us, for community is not maintained by violence, but by openness to being surprised by the birth of the unexpected.<sup>11</sup> These babes speak Jesus Christ’s own message: “For he is our peace; in his flesh he has made both groups into one and has broken down the dividing wall, that is, the hostility between us” (Ephesians 2:14). What we call “disability” is thus central, rather than peripheral, to theological conceptions of personhood or the image of God. The disabled, from embryo to old age, invite us to give up self-definition by violently separating ourselves from those who seem unlike us.

In contemporary society the terms “prenatal care” and “prenatal screening” are taken to be synonyms, but they become antonyms in practice when, as we have seen, the refusal to test is portrayed as unnecessarily risky and aborting a disabled child is portrayed as a relief. Christians, of course, should welcome the fact that technologies developed to aid screening can now be used in the service of care. The essential ethical insight to grasp, however, is that there is a vast difference between using those technologies to care for children in the joyous receipt of a divine gift, and deploying them as an expression of the ideologies of control, management, expertise, and risk avoidance. Given our internalized fears of the other and the ever-growing imperative to control chance and deviance, the witness to the divine annunciation “fear not” can only be proclaimed by a Church that has been confronted by liberating grace and thereby had its idolatrous praise of “freedom of choice” exposed.

We must undertake the intellectual and practical work of unlearning the patterns of exclusion and denial of the other as we discover what it means to inhabit Christian praise. Confessing in worship that the sinful man still lives – resisting life with the disabled and pining for an easier life – protects us from undue deference to expert calculators of risk. The self-annunciation of Jesus Christ remains the lifeblood of the Church which as a community has been freed to name the forces that enslave it, and can serve society by bringing them to light as anti-doxologies.

## NOTES

1 For a survey of the technological state of the art, see “A New Safe Blood Test to Diagnose Down Syndrome,” *Laika’s MedLibLog* (March 13, 2011), accessed August 28, 2012, [laikaspoetnik.wordpress.com/2011/03/14/a-new-safe-blood-test-to-diagnose-down-syndrome/](http://laikaspoetnik.wordpress.com/2011/03/14/a-new-safe-blood-test-to-diagnose-down-syndrome/).

2 Wolf Krötke, *Sin and Nothingness in the Theology of Karl Barth*, Studies in Reformed Theology and History New Series, 10, translated and edited by Philip Zeigler and Christina-Maria Bammel (Princeton, NJ: Princeton Theological Seminary, 2005), x-xi.

3 For a more detailed discussion, see Brian Brock, *Singing the Ethos of God: On the Place of Christian Ethics in Scripture* (Grand Rapids, MI: Wm. B. Eerdmans, 2007), chapter 7.

4 Scripture quotations marked (NIV) are taken from the Holy Bible, New International Version®, NIV®. Copyright © 1973, 1978, 1984, 2011 by Biblica, Inc.™ Used by permission of Zondervan. All rights reserved worldwide. The “NIV” and “New International Version” are trademarks registered in the United States Patent and Trademark Office by Biblica, Inc.™

5 Martin Luther, “Psalm 118,” translated by George Beto, in *Luther’s Works, Volume 14, Selected Psalms III*, edited by Jaroslav Pelikan (Saint Louis, MO: Concordia Publishing House, 1958), 81.

6 See Hans Reinders, *The Future of the Disabled in Liberal Society: An Ethical Analysis* (Notre Dame, IN: University of Notre Dame Press, 2000), chapter 4, and “Life’s Goodness: On Disability, Genetics and ‘Choice’,” in John Swinton and Brian Brock, eds., *Theology, Disability and the New Genetics: Why Science Needs the Church*, (London, UK: T & T Clark, 2007), 163-181.

7 Rayna Rapp *Testing Women, Testing the Fetus: The Social Impact of Amniocentesis in America*, (New York: Routledge, 2000), chapters 3 and 6. Further citations to this book will be in the text.

8 Barbara Katz Rothman, *The Tentative Pregnancy* (New York: W. W. Norton & Company, 1993 [1986]), 51, 83-85.

9 John Swinton, *Raging with Compassion: Pastoral Responses to the Problem of Evil* (Grand Rapids, MI: Wm. B. Eerdmans, 2007), 200.

10 Bernd Wannenwetsch, “Angels with Clipped Wings: The Disabled as Key to the Recognition of Personhood,” in Swinton and Brock, eds., *Theology, Disability and the New Genetics*, 182-200, here citing 195.

11 Hannah Arendt, *The Human Condition* (Chicago, IL: University of Chicago Press, 1958), chapter VI.

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# Affirming God in the Midst of Disability

BY THOMAS H. GRAVES

An encounter with personal disability brought Tom Graves to a perplexing impasse. As a philosopher of religion, how could he talk of God in words that were both true to his faith and honest with his disabled condition?

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**I**t began innocently enough as I stumbled and tripped while playing tennis. When that clumsiness was repeated several times, I longed to find a reason for my loss of athletic prowess, other than the fact that I was never that good anyway. My concern grew as I noticed a great deal of numbness in my left hand and my feet began to feel as if I were walking through sand. An orthopedic specialist diagnosed the problem as a result of bone spurs on my upper spine, but surgery did nothing to alleviate the symptoms. A neurologist then began a series of tests to determine if I had a brain tumor or some other serious malady of the nervous system.

I was thirty-six years old, at the prime of my life, with a loving wife and two young daughters. A few months earlier I was playing tennis, golf, softball, and jogging. Now I was scared to death, or I should say, I was scared of death. I wondered if I would live long enough to teach my daughters how to ride a bicycle. When the doctor concluded lengthy tests and informed me that I had multiple sclerosis, I remember thanking him, knowing what else he was looking for.

At that same time, the spring of 1983, I was teaching a course on the problem of evil. Suddenly I was no longer a spectator looking objectively at the many instances of chaos and suffering in human life. Now I found myself to be a very fragile participant in the game of life, wounded and afraid like so many others. One lives and thinks differently when one experiences the harsh limitations of human life.

My job as a minister and a professor of philosophy of religion was to

speak of God in a meaningful way. How could I now learn to talk of God in words that were both true to my faith and honest with my disabled condition? Like the biblical exiles I needed to learn to sing the Lord's song in a very strange land. My illness challenged and changed my thoughts at several points. Just as importantly, it led me to a much deeper spiritual experience.

As sophisticated as I thought I was, one of the first impulses that came to mind upon learning that I had multiple sclerosis was the question "What have I done to deserve this?" There was enough Calvinism in my background to make me aware of my inescapable sinful nature, if not human depravity. There was also something within me that insisted on the orderliness and fairness of creation. But to claim that all misfortune is retribution for our sin is not true biblically, is not true always in the world around us, and I felt was not an adequate explanation for my own situation. Bad things do happen to good people. Surely a faith that worships a man of sorrows who died on a cross cannot deny that fact. Evil, particularly natural evil, cannot be reduced in every instance to the realm of human sin.

Most importantly, my encounter with personal disability brought me to a refined definition of divine omnipotence. How we describe the character of God is distorted if we begin that discussion from the standpoint of absolute power. The central revelation of God throughout Scripture is that God is relational love, not manipulative power. When viewed from this vantage point we understand the nature of God, the creation of the world, and the purpose of human life in a dramatically different fashion.

First, the doctrine of the Trinity teaches us that the nature of Christ is consistent with the nature of God. The God we see in Jesus Christ is one who uses power perfectly, not one who monopolizes all power. God enjoys that degree of power that is commensurate with there being other effective agents of power in creation. God has so limited divine power as to allow freedom for persons so that we may come into relationship with God without coercion. A love compelled by force is no love at all. Isn't that what the Crucifixion is telling us? God is willing to sacrifice power in order to demonstrate God's love. God would rather die than stop loving us. It is God's love and not God's power that is omnipotent. The physical agony of human life is not the direct result of God's loving will. If neither my own sinful character nor the perfect character of God is the source of my disability and anguish, what is its source?

In dealing with the issue of natural evil I begin with two presuppositions: the environment out of which God creates is a realm of primordial chaos; and creation is not completed but is an ongoing process. Genesis 1:2 tells us that when God began to create "the earth was a formless void (*'tohu wabohu'*) and darkness covered the face of the deep." As Karl Barth insists, the "nothing" out of which God created was in fact "something." Barth refers to it as "*das nichtige*," or that to which God said "no" in the process of creation.<sup>1</sup> Edgar Sheffield Brightman refers to it as "the given" from which "surd evil" arises.<sup>2</sup> Nicholas Berdyaev uses the mystical imagery of "meonic freedom"

or “the ungrund” to describe this realm of freedom prior to creation.<sup>3</sup> David Ray Griffin, disputing the doctrine of *creatio ex nihilo*, postulates a primordial chaos out of which God creates.<sup>4</sup> Whatever philosophical image one may choose to describe the environment of God’s creative act, it is clear that the language of Genesis refers to an unformed realm of chaotic existence from which God calls forth creation. The process of divine creation is one of bringing both order and intensity out of a realm of chaos. Nature at the point of creation is not yet perfected; chaotic elements and remnants of disorder remain in our unfinished universe.

Genesis 1:26-28 speaks of persons being created in the image and likeness of the creator and given dominion over all that was formed by God. Persons are charged with the responsibility for caring and having dominion over the earth, bringing all creation to its fullest expression. In keeping with the loving character of God, the biblical model rejects domination by power and the crude abuse of nature. Persons are invited, indeed have a duty, to join with God in an “eighth day of creation,” fulfilling our calling, in our feeble human way, to be co-creators with God. As Henri Nouwen commented, the most radical teaching of Jesus Christ is to strive to be like God.<sup>5</sup> Our vocation as persons of faith is to express ourselves as fully as possible in our likeness to God, through loving creativity. Nature is an unfinished realm waiting on persons for its true destiny to be accomplished. This makes the natural order an arena in which the creative capacities of humanity can be fully and freely expressed.

Understandably our harsh encounter with the evils of this world can give rise to a cynical atheism insisting that a God of love and power would want to create a paradise of blissful perfection and that anything less is not worthy of our worship. On the contrary, I have found reflection on the issue of evil to be a pathway toward belief. As stated by John Hick, “human goodness slowly built up through personal histories of moral effort has a value in the eyes of the Creator which justifies even the long travail of the soul-making process.”<sup>6</sup>

Given our redefinitions of divine power, creation, and human purpose, one can argue that to allow human freedom, God accepts the agony and consequences of human sin; to provide an arena in which human creativity can be expressed, the natural order remains unfinished; and to provide meaning for human existence, persons are given responsibility to work with God in bringing the created order toward completion. Is that not the pathway to salvation? Rather than indicting God for the evils of human life and the shortcomings of the natural order, it is possible to see it as part of the divine plan to provide all that is necessary for free and creative personal life. I prefer living in that arena, even given all of its evil, to an antiseptically clean and perfected order where human life would be left without freedom or challenge.

From this perspective we can see the importance of the gospel proclamation: you are not alone. God is with us in our suffering. Our pain is felt in

the very heart of God. The Christian faith is a form of radical humanism, worshiping a God who provides all that is necessary for meaningful human life. That same God comes to us in the form of Jesus bearing the wounds and disabilities of a vulnerable human life. If we are called to be a co-creator with God, we also know that God comes to us as a co-sufferer. That is a God truly worthy of worship.

## NOTES

1 Karl Barth, *Church Dogmatics*, III.3, (*The Doctrine of Creation: The Creator and His Creature*), edited by G. W. Bromiley and T. F. Torrance (Edinburgh, Scotland: T. and T. Clark, 1969), 293.

2 Edgar Sheffield Brightman, *A Philosophy of Religion* (New York: Prentice-Hall, Inc., 1940), 314.

3 Nicholas Berdyaev, *Spirit and Reality* (New York: Charles Scribner's Sons, 1939), 145.

4 David Ray Griffin, "Creation Out of Nothing, Creation Out of Chaos, and the Problem of Evil," in Stephen T. Davis, ed., *Encountering Evil* (Louisville, KY: Westminster John Knox Press, 2001), 108.

5 Henri J. M. Nouwen, *The Return of the Prodigal Son: A Story of Homecoming* (New York: Image Books, 1994), 121.

6 John Hick, *Evil and the God of Love* (New York: Palgrave Macmillan, 2010 [1966]), 256.

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# Travelling in the Ark

BY HEIKI PECKRUHN

With whom are we being human together? With whom are we living together into our potentialities? These questions of community and humanity, central to the L'Arche communities, are explored in four books reviewed here.

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What does it mean to be human? What must we do to live into our best human potential? In theological and philosophical discussions these questions are often answered by first defining minimum markers of humanity, and then coming up with strategies for developing these qualities in living human beings. In other words, we make a claim about what defines a human being first (made in God's image, or capable of reason and empathy), and then we muse about what it might look like to pursue the full potential of our humanity (to love and serve God and others, or to use our intellectual and emotional capacities in a moral fashion).

Jean Vanier strikingly reframes these questions in *Becoming Human* (Mahwah, NJ: Paulist Press, second edition, 2008 [1999], 166 pp., \$12.95) comprised of his 1998 Massey Lectures, part of a prestigious radio series commissioned by the Canadian Broadcasting Corporation and the University of Toronto. *With whom* are we being human together? *With whom* are we living together into our potentialities? Vanier invites us into his personal reflections on becoming human, reflections which center on befriending others, especially those who are marginalized, dehumanized, and excluded. Through living in relationship together we come to discover our common humanity and potential for a good life.

The Canadian philosopher Vanier is best known as the co-founder, with Father Thomas Philippe, of L'Arche (French for "The Ark"), an international network of residential communities for people with developmental disabilities (core members) and caregiver assistants who live for varying lengths of time in a L'Arche community. Vanier's reflections on friendship and sharing lives are deeply grounded in his Christian faith and his more than forty years



of experience living with men and women who have intellectual disabilities. What makes *Becoming Human* stand out is that it is neither a handbook for how to “deal” with persons with disabilities nor a defense of their value. Rather, it is Vanier’s invitation for us to reflect deeply on our own humanity. In his view, such reflection is best done in relationship with those commonly found on the margins of society, who are denied full humanity and opportunity for

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**Reflection on our humanity, Jean Vanier suggests in *Becoming Human*, is best done in relationship with those found on the margins of society, who are denied full humanity and opportunity for reflection due to their developmental disabilities.**

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reflection due to their developmental disabilities.

We discover the meaning of becoming human on the road with others, Vanier argues. Concerned with the liberation of all persons from loneliness and fear, he describes how a sense of belonging can set one on a journey toward healing and forgiveness. At the heart of exclusion lies fear: we exclude others because we are afraid

of difference, of being challenged, and of losing what is important to us, including our image of ourselves. This fear prevents us from being open with others and from growing and changing in relationship with them. Yet growing and changing are intrinsic to being alive. By beginning with inclusion and friendship with those we have been taught to fear and exclude because of their disability, Vanier explains, we all become human together. By sharing our needs for intimacy, changing and adapting in light of each other, and being vulnerable and trusting, we discover together our unique contributions to our communities.

Vanier’s book is rich in insight and wisdom, drawing on personal experiences, biblical stories, theological themes, and philosophical and psychological perspectives. It is a book that should be read often, and read together with others. Most importantly, it should be read with an open heart and mind.

Vanier speaks of inclusion that is grounded in a sense of belonging, which is brought about by gaining trust that we are valuable as persons, and deeply listening to each other. So what is it that those of us not living in a L’Arche community can learn from listening to Vanier? Three recent books seek to provide a response, with authors from different fields reflecting on the wisdom of Jean Vanier and other insights gained by engaging persons with disabilities.



Theologian Stanley Hauerwas and Jean Vanier help us pursue the question “What does L’Arche have to say to the Church” in their dialogue in *Liv-*



ing *Gently in a Violent World: The Prophetic Witness of Weakness* (Downers Grove, IL: InterVarsity Press, 2008, 115 pp., \$15.00). The authors seek to model a prophetic ministry of transformation and hope, which John Swinton describes in his introduction as “taking seriously the ‘world of the disabled’ and allowing our perspectives to be shaped and changed by listening carefully to those who see things differently” (p. 11).

Vanier recounts how L’Arche came into being in 1964. His story makes it obvious that L’Arche homes are first and foremost built around people, taking seriously that “Jesus is calling us from a pyramidal society to become a body” (p. 35). Like any human body, these communities are fragile; Vanier does not shy away from recounting the difficulties of living in and sustaining them.

Becoming the body of Christ means taking seriously when “Paul says that those parts of the body that are the weakest and least presentable are most necessary to the body and should be honored” (p. 36). Honoring those in our communities considered weak or unpresentable is not simply about “bringing them up to speed” in a push towards autonomy and independence. Valuing independence often serves to reinforce separation and loneliness and does not address the need for belonging and relationships. This is where L’Arche can be a powerful sign to congregations today, Hauerwas says, because churches too often fall into the temptation of conforming to the speed and placelessness that marks life in the modern age (p. 51). L’Arche “helps the church find the gospel” (p. 57) by embodying gentleness, being present for one another, and caring for each other in physical ways through mutual patience, profound interdependence, and honesty.

Because people with disabilities are among the most vulnerable and the most marginalized, it is in friendship with them that we learn the meaning of love. L’Arche is not meant to be *the* solution, the prescription for a better world. Rather, it is a *sign*, an embodiment of the hope that a more just world is possible (p. 45). Hauerwas challenges the Church to become the embodiment of hope as members embrace their own and one another’s vulnerability, and seek to live gently and hospitably with each other (p. 79).



In *Becoming Human*, Vanier insists that the friendships between core members and caregiver assistants at L’Arche is changing and transforming for all involved. The caregivers are not moral heroes or persons with a special calling, but ordinary people who are open to being changed in intimate friendships. But is there warrant for this claim? What does this care and intimacy look like, and how does this transformation manifest? Kevin Reimer’s *Living L’Arche: Stories of Compassion, Love, and Disability* (Collegeville, MN: Liturgical Press, 2009, 184 pp., \$26.95) is a behavioral psychological study of “compassionate love” within L’Arche communities through interviews and

observation. It is the first ethnographic study of United States L'Arche communities, providing a close look at the relationships and challenges in the residential communities. Reimer explores how compassionate love manifests in assistants, and how its development leads to personal transformation.

Reimer takes seriously the task of listening to his interviewees, and he writes captivating narratives that provide a glimpse into the everyday life of several L'Arche communities. He inquires into the motivations and consequences of those choosing downward mobility in a materialistic and individualistic Western culture. Reimer is able to have his own conceptions and assumptions challenged by what he observes, and presents the fullness of life in L'Arche, including both joyful and painful experiences. He uses the interviews and observations to reflect on the nature of moral development itself.

This engaging and enlightening study would be a great companion read to Vanier's *Becoming Human*. It can serve congregations that are interested in pursuing more inclusive life styles and compassionate ministry practices as a testimony to the power of life centered on Christ-like compassion. Reimer's interviews and observations will correct some common presumptions about L'Arche caregiver assistants. They are not super-human heroes; they are flawed yet beautiful persons who learn about themselves and about living together in friendship with core members. This serves as a reminder that all of us, with our flaws and our abilities, have the need and capacity to live in radical friendship.



*The Paradox of Disability: Responses to Jean Vanier and L'Arche Communities from Theology and the Sciences* (Grand Rapids, MI: Wm. B. Eerdmans Publishing Co., 2010, 183 pp., \$18.00), edited by Hans Reinders, is a wonderful compilation of engagements with the work of Jean Vanier. In an opening essay by Vanier about learning from being on a journey with persons with disabilities, we hear again his reflections on being human as grounded in love. It is living in loving relationships (which are necessarily mutual), rather than physical or cognitive capacities, that marks humanity. The responses to Vanier include essays from the fields of psychology, medicine, anthropology, and theology. They ask probing questions such as these: What would happen if we adopted Vanier's understanding of being human and took seriously his idea that we can only do something *for others* if we learn how to receive the gift offered by them *to us*, which crucially involves accepting our own neediness (p. 4)? What if we began to understand disability as a resource to examine, understand, and claim the good life—rather than following the more commonly (even if covertly) held assumption that disability is the opposite of what is good and desirable (p. 176)?

In these varied essays the social psychologist Roy F. Baumeister reflects on the emotional and biological effects of social exclusion, physician Christi-

na Puchalski explores the need for spirituality in the care for dementia patients, and the social justice and peace studies professor Pamela Cushing sees the need for disseminating more stories that exemplify the value of persons with disabilities in order to expand the cultural imagination. Despite the contributors' diverse interests and approaches, all of them seriously engage Vanier's challenge to hypercognition, the attitude pervasive in Western society that privileges cognitive abilities and makes strong connections between intellect and being human. Rather, as Stephen Post argues, humanity is constituted by "other-regarding" love, love that brings to life persons with disabilities and caregivers alike (p. 31).

The theological responses presented here inquire about the embodied practices modeled in L'Arche such as peacemaking, prayer, and knowing God. Brian Brock uses prenatal screening and the concept of supererogation ("beyond the call of duty") to demonstrate how different perspectives on being human and moral obligations can influence ethical frameworks and decision making. Brock argues that the call to duty is commonly framed only in regards to the "normal." But Christian hospitality must not consist of laws or duties; it goes beyond good intentions and beyond what is considered "normal" charitable behavior. It is attentiveness and neighborly love that inspires a social ethic that witnesses to the voices of the most vulnerable who challenge our politics as usual (p. 138).

Many essays in this book help to dispel our prejudiced attitudes and stereotypes of the disabled and their caregivers (e.g., as holy innocents and unflawed heroes). Certainly we all need to experience mutual love and to overcome our own challenges in receiving and extending it. Yet Bill Gaventa also alerts us to the crucial component of honesty and self-reflection. Without these the value of people with disabilities "becomes that of helping us discover who we are" and the people themselves are used by us to work out our own issues (p. 107).

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**Kevin Reimer's interviews correct some misperceptions of L'Arche caregiver assistants. They are not super-human heroes; they are flawed yet beautiful persons who learn about themselves and living together in friendship with core members.**

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Disability is a paradox. On the one hand, disability is *culturally created* via social structures and habits that turn impairments into disabling conditions and lead to experiences of oppression. On the other hand, impairments are *natural* conditions, and we are all experiencing our bodies and minds in flux and deterioration over the span of our lives. The paradox of disability reminds us that we are neither fully nor eternally able, in control, self-suffi-

cient, and healthy. The gift of this paradox of disability is that it allows us to live into our humanity with the challenges and gifts presented to us on our journey; it allows for transformation of human relationships, our values, our questions, and even our understanding of love. The latter point is powerfully made by Christopher Newell, who reflects on suffering, the disabled body, and human brokenness through his own experiences. He shares his realization that the more important issue is not *whether* but *how* brokenness will be valued. Love can turn into a threat if it seeks to alleviate suffering by eliminating it from sight, rather than transforming it by embracing the brokenness of all. He writes, “part of the cultural context of suffering is the ubiquitous tendency to worry about its adequate representation rather than actually allowing it to be present...to create a space so that we may listen to the *still* voice of those with disability” (pp. 174-175).

This book, though decidedly academic in approach, is a great resource for readers who are already interested in reflecting on the many directions that engagement with Vanier and L’Arche narratives can take. It provides little concrete, how-to guidance for those feeling the impulse to act upon the charges presented by Vanier. However, given that each individual and congregational situation is unique, this is one of the book’s strengths because it helps us to change our perspectives and examine our specific situations with new eyes.

All of these books are great resources not only for beginning to think about disability, but also for deeply engaging questions of community and humanity. They compel us to engage in self-reflection about our values, fears, needs, and assumptions about what is “normal.” Hopefully they will spark a desire in us to replace rejection and exclusion with friendship.

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# Lowering Barriers for People with Disabilities

BY JACKIE MILLS - FERNALD

**If the Church is a place where all are welcome regardless of ability, why is the disability population so poorly represented in our congregations? The resources reviewed here can help us lower the barriers that prevent people with disabilities from participating fully in the body of Christ.**

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**O**ne in five persons in the United States has a disability, which equates to about 54.5 million people. However, if we were to take a look within our congregations, we probably would not see the disability population well represented, which begs the question, “Why?” Throughout the Bible God calls his people to care for and defend the needy and the sick, to be a voice for those with no voice. We are God’s image bearers and are called to love like God does. The Church is all inclusive, a place where all are welcome regardless of ability.

Often there are physical barriers that make it challenging for a congregation to be inclusive, such as older buildings that do not have elevators or handicap accessible facilities. There may also be communication barriers, such as not providing Braille or large print for the visually impaired, or sign language interpretation or closed captioning for the deaf community.

However, the biggest barriers that keep congregations from seeking and welcoming those with disabilities are not physical or communication hurdles, but those of attitude. Frequently, church leaders, staff members, and volunteers have incorrect information, stereotypical views, or are simply fearful of those who are different from them.

Many resources have been developed to assist congregations in developing a Christ-like view and love for those with disabilities. There are videos, blogs, articles and books on the theology of disability, and step-by-step guides

on development of special needs ministry and outreach. Four excellent books — Barbara J. Newman's *Helping Kids Include Kids with Disabilities* (Grand Rapids, MI: Faith Alive Christian Resources, 2001, 95 pp., \$29.99), Jim Pier-son's *Exceptional Teaching: A Comprehensive Guide for Including Students with Disabilities* (Cincinnati, OH: Standard Publishing Company, 2002, 240 pp., \$19.99), Erik W. Carter's *Including People with Disabilities in Faith Communities: A Guide for Service Providers, Families and Congregations* (Baltimore, MD: Paul H. Brooks Publishing Co., 2007, 264 pp., \$27.95), and the anthology *Special Needs, Special Ministry* (Loveland, CO: Group Publishing, 2004, 176 pp., \$18.95) — are reviewed here.

Barbara Newman's *Helping Kids Include Kids with Disabilities* is an excellent resource to equip children's ministry teachers, volunteers, and children without disabilities by providing information and tactics on creating an inclusive community. Newman gives accurate information regarding disabilities so we, as the body of Christ, are able to broaden our perspectives and change our hearts to be welcoming and inclusive like Jesus.

The book features guidelines to help children include those with disabilities. For instance, Newman offers crafts and activities that supplement Bible lessons highlighting the uniqueness of each child created in God's image. She provides a series of template letters, designed for unique disability categories, which children's ministry leaders can distribute to parents to help them create disability awareness in their children. She also gives many relevant tips, such as how best to communicate with children with disabilities, and how to better understand and empathize with them. When understanding and empathy are present, inclusive friendships become possible.

The sections of the book each focus on a disability category such as autism, attention deficit hyperactivity disorder (ADHD), visual and hearing impairments, emotional impairments, and cognitive handicaps. Each has a handy fact sheet, lesson plan, and letter to families. Newman does a great job showing that each child is an individual, and that the categories used to label children are only helpful in explaining general characteristics. It is important that our views of disability are not reduced to stereotypes.

The lesson plans are well thought out, full of interactive components and hands-on learning. They include scripture passages to reinforce that God is the master creator and does not produce junk. With great sensitivity, the lessons explain specific disability categories, awareness of those disabilities, and how to include children with those disabilities into the classroom, when appropriate. There are activity sheets, visuals, and a follow-up letter to families. The follow-up letter includes a recap of the child's lesson, opportunities to discuss his or her particular disability further, and approaches to facilitating friendships among all children in the classroom, regardless of a child's ability level. A concluding section of the book has family devotions infused with Scripture to unpack at home; these help families to better understand God's heart and to change their mindsets to be more inclusive.



Newman, who is Director of Church Services for Christian Learning Center Network ([www.clcnetwork.org](http://www.clcnetwork.org)), brings her wealth of knowledge of disability and special education into this concise nuts-and-bolts book. She gives the reader practical, easy-to-understand information about disability and how to embrace those with disabilities in Sunday school classes. Teachers, volunteers, and parents will find her book invaluable.

Jim Pierson's *Exceptional Teaching: A Comprehensive Guide for Including Students with Disabilities* is meant to be read and reread by Sunday school teachers, volunteers, and church leaders as persons with different or new disabilities periodically show up in their churches. Pierson, a special educator and Johnson University instructor, has produced a must-read resource that all can understand without being overwhelmed in the process.

The book covers over seventy of the most common disabilities and special health care needs, including their definitions, suspected causes, and common characteristics. In each case Pierson offers tips on creating welcoming environments and teaching strategies. He is thorough in his approach without going overboard on explanations and medical jargon and terminology. This book is designed for the individual who desires to create inclusion but is not sure how or has limited knowledge or experience in the world of disability.

The chapter on Christian education and spiritual formation has assessment forms that help the teacher understand each student's functioning level and then map out a teaching plan for spiritual truths that takes into account the student's unique strengths and deficits. This type of plan is called an Individual Christian Education Plan (ICEP).

The latter part of the book focuses on practical ways to care for families impacted by disability. This section includes feedback from parents who stress their need to be accepted for who they are and loved like Jesus loves. Several mention they need other church members to refrain from judging or criticizing them, but instead come alongside them in prayer and encouragement. Pierson describes how to develop several different programs of respite for families, so parents are able to receive breaks from the constant care of their children with disabilities.

In the *Exceptional Teaching 2011 Supplement*, Pierson and his co-authors discuss understanding autism, behavior management, and making the congregation fully inclusive, to name just a few sections in this information-packed resource.

Jim Pierson's education and personal experience encompass over forty years of service. His strong passion for and knowledge base of disability enable him to share his story and suggest ways church leaders and their programs can include all God's children.

After meeting Erik Carter at a conference where he and I were speaking, I knew that any book he authored would be a must read. I picked up a copy of his *Including People with Disabilities in Faith Communities: A Guide for Service Providers, Families and Congregations* and was unable to put it down.

Carter begins by describing how persons without disabilities can set up reciprocal relationships with persons with disabilities: each has so much to give and receive. He goes on to identify the many barriers – architectural, attitudinal, communicative, programmatic, and liturgical – that prohibit a person with disabilities from developing such relationships and fully participating in the faith life of their congregation. Not only do barriers exist within congregations. Often there are barriers within their surrounding communities as well, such as limited transportation, stereotypes based on past negative experiences, unwillingness of existing support staff to help special individuals get to church, and the barrier of fear from persons with disabilities not knowing what to expect in a new environment.

To open its church doors and create opportunities for persons with disabilities to live out their lives of faith, a congregation must expand its commitment to seek out and welcome individuals and families impacted by disabilities. Carter includes a checklist of “indicators of welcome” to aid a church in increasing its hospitality level. He urges members to use the checklist annually to identify both areas for improvement and continued focus.

The book offers an effective strategy to becoming an inclusive community – from creating planning teams and developing a vision statement to creating messaging for getting the word out to the community. It suggests ways for including persons with disabilities in service opportunities, and other ways for them to use their gifts and skills to support the congregation’s work. It is important for people with disabilities to be giving and not just receiving members, so they may be fully integrated into the body of Christ.

In the chapter titled “Designing Inclusive Religious Education Programs,” Carter covers the first steps of identifying a team and coordinator, choosing or developing a curriculum, initiating parent connections, knowing what questions to ask, and creating individual religious education plans complete with worksheets. He describes what sorts of support are needed and how to create specific roles for volunteers, such as lead teachers and individual buddies. Carter emphasizes the importance of being known by actions and not just the words of a well-written mission statement.

Many congregations get Sunday morning programming for persons with disabilities down pat: they run well, and persons with disabilities and their families feel included and loved. But what happens the other six days of the week? Carter challenges us to create connections seven days a week through leisure, recreational activities, vocational or volunteer opportunities, and providing transportation to adults with disabilities. For special family support the other six days of the week, Carter urges creating a respite program, instituting special support groups, and sharing other resources with families, much like the role of a social worker.

This guidebook ends with a chapter on creating community partnerships that go beyond congregational walls in a collaborative effort to enhance the life of a person with disability. Carter includes a list of inclusive congrega-



tions, as well as a detailed resource list of potential community-based partnerships and training resources.

*Special Needs, Special Ministry* is written by a group of writers – Jim Pier-son, Larry Shallenberger, Louise Tucker Jones, Mary Ann McPherson and Pat Verbal – with varied backgrounds ranging from professional to volun-tee, parent to ministry worker. It is designed for children’s ministry staff and volunteers as a practical guide on how congregations can include children with disabilities and their families.

The book offers a step-by-step approach to designing a special needs min-istry, including a launch checklist, first steps, volunteer recruitment and train-ing, getting the word out, and liability considerations. Case studies and anecdotal stories are dispersed throughout the book. The reader gets a broad view of ministry development in a book that is well laid out. It is an infor-mative and entertaining read.

To help create disability awareness and facilitate inclusive culture, there are sermons to be used by church leaders, reproducible bulletin inserts, and fact sheets on how persons with disabilities can serve and impact the world. The chapter on volunteer recruiting and training volunteers is information-packed, looking at how and where to find the right people in the church and beyond who have servant hearts and a passion for those with disabilities. The author of this chapter – Pat Verbal, who manages curriculum development for the Christian Institute on Disability at Joni and Friends – does a good job explaining how to identify the right people and equip them to be effective in special needs ministry.

Becoming a fully-inclusive congregation where all persons are welcome regardless of ability level is an exciting journey and may take some time. There are many good resources in addition the ones reviewed here. Many churches also have insights and tools to share as you network with practitio-ners from across the country for a journey that glorifies God and reflects God’s view on his people – all made perfect in the divine image.



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