The Witness of Disability in a Medicalized World

Daniel Rempel

Until recently, Mennonite theology has spent little time examining the place of people with intellectual disabilities in our ecclesial practices and confessions of faith. Kathy Dickson, in her essay "Disability and Mennonite Theologies: Resisting 'Normal' as Justice Anytime and in a Global Pandemic," outlines some of the ways that Mennonite theology and disability theology, when read together, offer complementary visions of human worth and resistance to Western cultural concepts of what it means to be a normal human being.[1] She also describes how communal efforts guide the work of justice, focusing particularly on the most vulnerable people within unjust societal systems.[2]

Dickson's essay moves in four parts:

1. She begins by describing the current landscape of unjust societal systems in her own American context, noting that, in light of policies centered upon caring for "normal" bodies, being diagnosed with conditions such as "mental retardation" or "dementia" could hinder one's ability to access care through being denied care on the basis of such conditions.[3]
2. Then she notes that the biases at play in Western medical diagnoses[4] are actually indicative of larger societal perceptions of disabled people, which scholars like Rosemarie Garland-Thomson have described as

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1 Dickson here is herself speaking from a Western mindset, so this resistance must be understood as a resistance from within.

2 Kathy Dickson, "Disability and Mennonite Theologies: Resisting 'Normal' as Justice Anytime and in a Global Pandemic," *The Conrad Grebel Review* 38, no. 2 (Spring 2020): 107.

3 Dickson, 108.

4 Future references in this article to the medical model are referring to a Western, allopathic perspective and practice of medicine.

"normate biases."[5]

3. Next, Dickson argues that inherent to Mennonite theology is a tendency to push back against the "normal." This is evidenced most particularly by the way that Mennonite confessions of faith call us to ongoing resistance in a culture of violence, power, and wealth that pervades Western society, and to hold the value of living simply so that others may simply live.[6]
4. Finally, she describes the emphasis of both disability and Mennonite theologies on a communal interdependency as the appropriate way of being in the world—an interdependency that values the place of all members in the community.

Dickson suggests that reading Mennonite and disability theologies together can offer immediate responses to our medicalized world, especially in light of the recent COVID-19 pandemic. Trained by these two complementary disciplines herself, she contends that Christians—and Anabaptist theology in particular—can offer a better way forward for those trained in normate understandings of the world, while working toward a better and more just medical imagination for all.[7]

I draw on Dickson's essay from the outset here because of the exemplary way she weaves together not only Mennonite theology and disability theology but also personal experience; her theological integration follows from the way she frames her essay around the experience of her aunt's final days in the hospital and how her aunt's diagnosis with Down Syndrome affected the doctors' care and response. From Dickson's perspective, the doctors' medical gaze landed first on her aunt's Down Syndrome before seeing her aunt's person, which, in turn, affected how they proceeded with treatment. Where Dickson saw a loving

5 Dickson also notes that Amos Yong has adapted and expanded Thomson's definition, suggesting that for him, "'Normate biases' denote the 'unexamined prejudices that non-disabled people have toward disability and toward people who have them,' and that these assumptions function so normatively that the inferior status of people with disabilities is inscribed into the consciousness of society. He argues that 'non-disabled people take their experiences of the world as normal, thereby marginalizing and excluding the experiences of people with disabilities as not normal'" (111–)12. Cf. Amos Yong, *The Bible, Disability, and the Church* (Grand Rapids, MI: Eerdmans, 2011), 10–11.

6 Dickson, "Disability and Mennonite Theologies," 114.

7 To follow Dickson on this account is also to recognize the manner in which Christianity itself has contributed to the rise of what we will come to understand as the "medical model" of disability. It is not the case that Christian theology will only reform that which is "out there" in what Anabaptists have tended to understand as "the world"; our theologizing must also serve as a corrective to the ways in which Christian theology has erred and even led to the oppression of people groups within our own history.

family member, the doctors were trained to see a disabled woman. Dickson's personal encounter with a loved one's intellectual disability provided the foundational ground for her perspective; without the story of her aunt framing the essay, Dickson's argument would lose some of the force it carries in responding to Western medicine's normate biases.

In a similar vein, I argue that encountering the voices and experiences of people with intellectual disabilities is imperative for instructing Mennonites in particular, and Christians more broadly, in navigating medical systems. It is also how we come to understand what "good health" really is. In focusing on intellectual disability, the intent is not to discredit or disavow other non-intellectually disabled experiences but to focus on a particular group of people[8] who are commonly ostracized as a result of our perception of their inability to conceive rational thought. People with intellectual disabilities face unique challenges that those able to self-advocate do not, and their experiences also provide unique opportunities for reflection in light of both theology and our Western medical systems. It is thus my contention that by opening ourselves to being confronted by the lives of people with intellectual disabilities, we can learn to not only actively resist common-yet-harmful cultural conceptions of good health but also glimpse better understandings of health in the twenty-first century that have merit for all people in all bodies, mirroring life in the kingdom of God along the way.

Medicalizing Disability: The Birth of the Baconian Method

Disability has not always been pathologized. As Henri-Jacques Stiker argues, "There is no dis-ability, no disabled, outside precise social and cultural constructions; there is no attitude toward disability outside a series of societal references and constructs. Disability has not always been *seen in the same way*."[9] In other words, according to Stiker, the category of disability has been created. It is not objective. It has not always existed. It shifts and evolves with the times, and people did not always understand the category of disability as they do now. Stiker's work is an attempt—and he is clear that it is *an* attempt, not *the* attempt—to trace these shifting cultural conceptions toward what we now

8 Yet, to make even such a distinction between physical and intellectual disability is not to raise awareness of the polyphony of experiences that are grouped under the label "intellectual disability." That is to say, there is not a unique positive characteristic that unites all people labeled as "intellectually disabled," for as the old colloquial saying goes, "If you've met one person with Autism, you've met one person with Autism." Such a remark highlights that there may be more that distinguishes individuals labeled as "intellectually disabled" than what unites them under the same label.

9 Henri-Jacques Stiker, *A History of Disability*, trans. William Sayers (Ann Arbor, MI: University of Michigan Press, 1999), 14.

understand to be disabled bodies, noting the ways in which societal conceptions have changed and evolved over time. We will return to Stiker's work below, but for now it is important to recognize that the way disability is understood today is not the way it has always been conceived.

To get a sense of how disability fits into our modern, medicalized world, it is imperative that we note how disability came to be pathologized.[10] To do that, it is helpful to begin with an examination of what has come to be known as the Baconian project.[11] According to Jason Reimer Greig, "The Baconian project remains the dominant mode of health care in Western, late modern society."[12] It represents the transition in moral discourse from the pre-Enlightenment vision of the "good life" to a commitment to eliminate suffering while expanding the capacity for human choice.[13] Exemplified in the work of Francis Bacon, the created order was seen as neutral raw material that can be molded in order to alleviate suffering in human beings. For Greig, "Although humanity's relationship with nature previously concerned discerning and contemplating God within life, Bacon now saw the vocation of humanity as one of God-given dominion over the Earth. Whereas the contingency of life had previously resigned people to a passive fate, humans could now seize the means of nature for the ends of a utopian future."[14] The Baconian project represents the movement from receiving life as a gift to an attempt to control and shape our life toward our own ends—ends that attempt to transcend our own finitude and vulnerability by mastering the world through newly conceived technological methods.

Such a claim is not to presume that people before the Baconian project never sought to control and shape their lives toward their own ends, or that those living in a post-Baconian world never seek to receive life as a gift. The historical situation may not be quite as distinct as we could be reading Greig to suggest. What Greig clearly gets right in addressing the Baconian project is that the at-

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10 To say that disability is "pathologized" is simply to recognize that the medical gaze has sought to understand disability as a condition that can be cured rather than as a variation of human embodiment or expression.

11 Like Stiker's claim above, it is important to recognize that the Baconian project is but one way of narrating the story of how disability came to be pathologized. This article is not an attempt to craft a comprehensive narrative account but to serve as merely one telling of the story by highlighting a particular facet that is imperative for understanding the plight of people with disabilities today.

12 Jason Reimer Greig, *Reconsidering Intellectual Disability: L'Arche, Medical Ethics, and Christian Friendship* (Washington: Georgetown University Press, 2015), 52.

13 Here, Greig's is drawing heavily on Gerald P. McKenny's *To Relieve the Human Condition: Bioethics, Technology, and the Body* (Albany: State University of New York Press, 1997).

14 Greig, 53.

tempt to control and shape our life toward our own ends via the use of technology came to operate as the predominant mode of functioning in the world and is the dominant mode of perception for those captivated by the medical gaze. The problem of the Baconian project is not simply the attempt to orient life toward our own ends but also the way it encourages us to transcend our own finitude and vulnerability—the very facets of our being that make us human.[15]

Alongside the rise of humanity's perceived ethical responsibility to eliminate suffering through dominating nature, Greig notes the manner in which the rise of the Romantic ideal of "authenticity" was permeating Western culture and contributed to the ends of the Baconian project. In this context, "self-determination and self-definition increasingly became highlighted as imperatives for human flourishing. One increasingly could (and should) choose one's life, as opposed to simply accepting it from someone or something else."[16] Insofar as this emphasis on self-determination and self-definition related to the body, one began to see their body as their possession that can be manipulated to fulfill one's desires. This control over the body then becomes imperative to controlling one's existence.

Ultimately, in the Baconian project the body "becomes a 'project' that can be made and remade to fit the norms both of individual authenticity and social acceptance."[17] And as this happens, deviations from the norm become not only devalued but also a potential threat to personhood. "Persons began to fear less the illness itself than the loss of control that the illness engenders. When control of the body means mastery over any unchosen limitation, the constraints of illness look increasingly like dangers to the self."[18] Thus, as modern biomedicine began to emerge, it developed as a means by which human beings could eliminate individual suffering and increase autonomy and choice.

There is no question that the Baconian understanding has resulted in significant positive developments for humanity, both individually and collectively. However, a dark underside of the project eventually emerged—one that disability rights activists have come to know as the "medical model of disability," which began to appear in the mid-nineteenth century alongside the newfound

15 We can see how such tendencies would be damaging to disabled bodies when they are primarily understood through a pathologized gaze. Bodies that often display finitude and vulnerability so publicly are sought to be transcended in any way possible, and such possibilities do not prohibit the use of matters such as eugenics in medicine's attempts at mastery.

16 Greig, 55.

17 Greig, 55.

18 Greig, 55.

eugenics movement.[19] This medical model of disability is an understanding of disability that focuses primarily on a person's impairment. One's disability is rooted in their inability to perform or participate in certain tasks because of skills or abilities they lack, particularly regarding motor, sensory, or intellectual functioning. According to Greig, in the medical model "disability is an inherently *biological* reality that relates less to the surrounding environment than to individual, pathological bodies. The medical model locates the 'problem' of disability solely with the impaired body, whose dysfunction characterizes its lack of 'normality' and 'health.'"[20] In the medical model, disabled bodies are defective bodies, unable to accomplish the skills that "normal" bodies are able to.

In the Baconian project, biomedicine's response to disabled bodies is attempting to craft interventions that cure, repair, or rehabilitate individual impairments in an attempt to bring people "back" to "normal functioning." Such a mindset draws upon our conceptions of what a "normal functioning body" is and the presupposition that disabled bodies are deviations of this norm that must be returned to their normal functioning state. One may (rightly) interject that because of conditions that are "incurable" or possessed since birth, not all people are able to "return" to their "normal functioning state," and thus the medical model of disability is rendered inadequate on such grounds.

Such interjections remain inconceivable to the bastions of biomedicine, however, as evidenced by the account of disability activist Vic Finkelstein. Recounting his own medical encounter with paraplegia, Finkelstein notes, "If, as happened to me following my spinal injury, the disability cannot be cured, normative assumptions are *not* abandoned. On the contrary, they are reformulated as that they not only dominate the treatment phase searching for a cure but also colour the helper's perception of the rest of the person's life. The rehabilitation aim now becomes to assist the individual to be as 'normal as possible.'"[21] Under the fundamental Baconian presuppositions, realities such as Finkelstein's do not fuel alternate imaginations about the purpose and goal of biomedicine. Rather, these situations are seen as nothing more than challenges in the biomedical project—ones that must be assuaged to meet Baconian ends.

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19 Lennard Davis has helpfully tied the means of pathologizing disability to the discovery of the concept of an average or "norm." Yet, in doing this he also posits the bold claim that those who sought to further the concept of a norm in relation to the human body were all eugenicists in that they sought to improve humans so that deviations from the norm would diminish. See Lennard Davis, *Enforcing Normalcy: Disability, Deafness, and the Body* (London: Verso, 1995), 30.

20 Greig, 59.

21 Greig, 60. Cf. Michael Oliver, *The Politics of Disablement* (London: Macmillan Education, 1990), 54. Italics added.

Ultimately, in this medical paradigm abnormality becomes pathologized, evaluated through the lens of illness and disease. "When a fully functioning body and a complete lack of sickness come to be defined as the standard for human flourishing, impairments can only stand as deviations and flaws of normality."[22] If normal functioning bodies have become the means to further the Baconian project's ends, bodies that do not function normally are seen as threatening to normalized ends and must be remedied as quickly and efficiently as possible. Those whose bodies cannot be remedied to a certain level of functioning have faced segregation or extermination, for society cannot bear to gaze upon such "disordered" bodies. The implication of the Baconian project is for bodies to become normalized, and its powerful grasp may result in shaping attitudes toward people with impairments in all facets of life. Disability has not always been pathologized, but under the influence of the Baconian project it has become difficult to see disability in any other way.

Returning now to Stiker's claim in light of the medical model of disability, we are given the freedom to challenge this model as being the best way of perceiving people with disabilities.[23] If disability has not always been seen in the same way and there really is no disability outside precise social and cultural constructions, then we have the opportunity to create new and more just visions of not only the category of disability but also health in general. Just because the medical model of disability has become the predominant conception of understanding disability in the twenty-first century does not mean we are without alternatives.

The Social Model of Disability

The most common proposal for reconceptualizing disability emerged in the latter half of the twentieth century and has come to be known as the social model of disability.[24] In the social model, disability advocates suggest that it is not one's impairments that render one disabled but society that disables people because of the way it is constructed. Fueled by the colloquial phrase "nothing about us without us," the social model of disability attempts to move away from defining disability as a pathology and move instead toward something bound by social conceptions of the built environment. In doing this, advocates for the social model of disability suggest that social transformation is the "cure" that disabled

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22 Greig, 60.

23 To be sure, there are certainly times when people with disabilities do benefit from the medical system, and such a telling of the medical model is not to suggest that people with disabilities ought to never seek medical care. However, this telling is an attempt to parse out our deep-seated assumptions about human lives and the differences that we encounter within other bodies.

24 Tom Shakespeare, *Disability: The Basics* (London: Routledge, 2018), 14–15.

people really need. Rather than therapies and treatments, disabled people need barriers to be removed and access to be increased. In the social model, society needs to change, not disabled people. Disabled people do not need a cure; they need access and the ability to determine their lives for themselves.

The social model has been a valuable resource for the disability rights movement in reforming and reframing conversations around disability, but it is not without its limits.[25] While the social model gives us proper cues about how we should conceive solutions to the problems that plague disabled people—most notably via the emphasis to listen to disabled people, or, "nothing about us without us"—it does not adequately address what those solutions are.[26] Partially, this is because what we conceive broadly as the social model is intentionally vague in an effort to be "big tent" regarding whom it seeks to include. It also was not intended to address *all* problems disabled people face. So, with the insights of the social model on our side, we now move to imagining alternatives to the Baconian project in relation to the medicalization of disability—alternatives that provide a more holistic vision of how our understanding of health can be conceived through the lens of disability.

Health in a Fallen World[27]

In his book *Wondrously Wounded: Theology, Disability, and the Body of Christ*, Brian Brock offers an alternative vision for understanding health by making the provocative claim that his son Adam is "the healthiest person I know."[28] He makes this claim not because of Adam's ability to avoid illness or injury but because "he reflects and disseminates the claim of the One truly healthy one, the One who lives at the heart of wonder."[29] This claim is startling, not only because

25 For more on the limits of the social model of disability, see Tom Shakespeare, *Disability Rights and Wrongs Revisited* (New York: Routledge, 2014), 11–46.

26 It should be noted that while the social model *qua s*ocial model does not give us constructive solutions, those who follow the social model do offer solutions. This is simply a disclaimer that the social model is not a distinctive approach. Rather, it's a broad categorization of approaches to disability that reject the medical model and attempt to source solutions to the "problem" of disability by reevaluating society and its systems through a disability lens.

27 This section draws from an argument I develop in Daniel Rempel, "The Healthiest Person I Know? Disability and Health," *Vision: A Journal for Church and Theology* 22, no. 1 (Spring 2021): 45–51; https://press.palni.org/ojs/index.php/vision/article/view/729/634. Thanks to the publishers of *Vision* for permission to repurpose that material here.

28 Brian Brock, *Wondrously Wounded: Theology, Disability, and the Body of Christ* (Waco, TX: Baylor University Press, 2019), 145.

29 Brock, 45.

in it we see Brock attempting to redefine the boundaries of what constitutes a healthy person but also because Adam has Down Syndrome and Autism, along with a host of other medical ailments.

Brock's claim that Adam is the healthiest person he knows comes in a chapter entitled "Health in a Fallen World." Here, we find Brock attempting to redefine conceptions of what health may mean to those claimed as citizens of the kingdom of heaven, disabled and able-bodied alike. Brock's account is starkly different from the account of the medical model of disability via the Baconian project surveyed above. The most noticeable difference comes from where one begins in assessing health and what makes a person healthy. For the Baconian project, health is a product of the norm, a regulated yet ultimately culturally contingent assessment of what commonly holds collective bodies together (contrary to the views of advocates of the medical model). For Brock, a proper understanding of health does not begin with a collective norm but is established by one's particular situatedness as a finite and sinful creature under God.

Guided by the work of the Jewish theologian Franz Rosenzweig, Brock argues that "God's merciful address *only* comes to people caught up in lies about themselves."[30] He notes a similarity in the work of Dietrich Bonhoeffer, who argued that the love of God drives deep into Christians," "particularly figured fallen personas."[31] Drawing on the work of Rosenzweig and Bonhoeffer, Brock makes the staunch claim that our particular situatedness in the world is inherently compromised by sin, and thus our fallen state as sinful human beings compromises our speech about health. If we are to assess our own conceptions of what makes someone healthy, we must recognize the way that sin has co-opted our ability to conceive these understandings. As a result, any appropriate Christian conception of health must first begin by wrestling not with our physical ailments but with our spiritual condition.

Because Brock begins his chapter on health by directing his reader to the topic of sin, one may anticipate him following a line of thought that argues illness is the result of the fall as one of the curses God places upon humanity in Genesis 3. Such a line of thought would be remarkably similar to the Baconian project, which determines illness as deviation from the norm.[32] However, this is not the case. For Brock, the primary result of the fall was not physical cursedness manifesting as illness or disease but rather separation from God and a distorted view of the self.[33] While the topic of sin does not figure overtly in

30 Brock, 143.

31 Brock, 143.

32 In this instance, the "norm" would be the original created status of human beings, and the deviation would be the sin that altered this original state.

33 In saying this, Brock is not attempting to answer questions about how and when biological illness and/or disease entered the human sphere. Rather, he is directing our

the rest of the chapter, it is important for Brock to locate its influence from the outset, understanding that sin, not illness, is the primary challenge that those who want to be healthy need to wrestle with. Sin is the reality that affects our health, a suggestion that runs starkly against the Baconian project.

Returning to Rosenzweig, Brock notes that in the midst of living with the muscular degenerative disease commonly known as Lou Gehrig's disease or ALS, Rosenzweig "believed most physically healthy modern people are suffering from a mortal illness. That illness is an incapacity to appreciate and receive their creaturely lives with all their individual peculiarities—including their physical illnesses and incapacities."[34] Rosenzweig is clear: what is most damaging to a person is not any physical illnesses or incapacities that may come their way but rather an inability to live "in the heart of wonder." Wonder draws human beings into deeper engagement with their everyday lives. It orients the Christian's gaze—that is, the way they perceive the world—seeing all of creation as God's gift to the world. Wonder may thus be the foremost way for Christians to combat out own sinful state and enter life in the kingdom of heaven.

Wonder is a task manifested properly in everyday life rather than primarily in extravagant circumstances. In an attempt to overcome such impulses for the extravagant, Brock argues that humans have a tendency to attempt to escape our current realities, even when those realities are ones we have been liberated to enjoy. He cites the Israelites complaining in the wilderness only months after being freed from Egypt as being a paradigmatic example of "captivity to the idea that satisfaction will be had in being somewhere else."[35] Ignoring their situatedness as creatures under God, Israel lost their sense of awe toward God's wondrous work of liberative mercy as they complained about their current situation. As Brock points out, it is exactly there—in the everydayness of life—where God wondrously breaks into our lives. "God breaks in on this situation of inner estrangement by revealing them to be *alongside* human beings, *in* the world, and *with* God."[36] Those who are attuned to the closeness of God in the everydayness of life are those who live by the sustenance given by relation to God. It is these people who, Brock argues, recognize health as life with God.

This example of the Israelites suggests that wonder and liberation are inherently interconnected. If creatures currently find themselves in a state limited by sin and the first step of moving oneself from sin into the kingdom of heaven is the practice of wonder, then to experience freedom is inherently connected to the practice of wonder. To further this claim, Brock shifts his focus from

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attention away from illness and disease as being the primary markers of our fallenness and toward separation from God being the primary marker of our distorted state of being.

34 Brock, 146.

35 Brock, 152.

36 Brock, 152.

Rosenzweig to Bonhoeffer to suggest that while creatures were created to be free, freedom "is a relation and nothing else."[37] This relation is manifested in our turn toward others, toward creaturely reality (our situatedness on earth), and ultimately in relation to God. Freedom is "being-free-for-the-other," recognizing that the fullness of our being is found in mutual cooperation and dependence. "To be a creature is to be dependent on and to depend on other creatures." However, such dependence is not arbitrary allyship; it comes about by "concretely depending on God's enlivening Spirit." Ultimately for Brock, our creatureliness—a true vision of the human person—is constituted in our dependence upon God and all that God has given as good gifts to those created by God.

Brock's final move in his chapter, after clearing the necessary ground through the work of Rosenzweig and Bonhoeffer, is to put forth his provocative constructive claim that his son Adam is the healthiest person he knows. He transitions by positing the following: "Taken together, Rosenzweig and Bonhoeffer offer a compelling conceptual explication of what is being said when Christians confess that to be saved is to be liberated to be free creatures. Being made free means continually being confronted with sin, and precisely so, invited into the kingdom of heaven. Here disability appears in a remarkably different light."[38] This difference, for Brock, is found not in the way he is to welcome his son into life in the kingdom of heaven. Rather, he strikingly states that it is Adam who welcomes *him* into the kingdom of heaven.

Brock notes four ways in which Adam's witness welcomes others into the kingdom of heaven:

1. Adam has an ability to live without worry of the future. Brock views this as a manifestation of Jesus's command to his disciples in Matthew 6:24–26 to not worry about their life or how they will survive, for their heavenly Father will provide all their needs. Adam's distinct ability to live solely in the present tense witnesses to people molded by a society obsessed with future goals, retirement funds, and hoarding possessions. He is a staunch manifestation of life devoted to the everydayness in which wonder takes place.

2. From Brock's perspective, there is no gap between what Adam says and what he does. Again, Brock draws on Jesus's words in Matthew, where he commands his disciples to let their yes be yes and their no be no (Matt 5:36–37). Adam "liberates everyone around him from suspiciously watching for signs of hidden motives, for other selves peeking out from

37 Brock, 156. Cf. Dietrich Bonhoeffer, *Creation and Fall in Dietrich Bonhoeffer Works* vol. 3, ed. John W. de Gruchy (Minneapolis: Fortress, 2004), 63.

38 Brock, 163.

behind masks."[39] Adam is who he is, and thus lives truthfully in a world that has become far too comfortable with distorting the truth. Thus, Adam may have a particular capacity to confront false narratives that sin thrusts into our lives.

3. Adam has a heightened level of emotional sensitivity. He is attuned to both the highs and the lows of those around him, yet at the same time has a remarkable tendency to position himself regarding ongoing social converse. Here Brock notes the way in which Adam embodies the Apostle Paul's teaching that members ought to have the same care for one another, where if one member suffers, all suffer together with it, yet if one is honored, all rejoice together (cf. 1 Cor 12:24–26). "Neither a loner nor an attention seeker, with absolute innocence he gravitates to the force fields of human converse. . . . I can only wonder at his attention to fields of interpersonal communion of which I never even dreamed."[40] Again, here we see a commitment to the everydayness in which wonder takes place. Adam's attentiveness to human emotion offers a picture of the way that members of the kingdom of heaven ought to be attuned to one another's needs.

4. Adam enjoys many people. Brock emphasizes this final point: "If the kingdom of heaven is a new social order whose characteristic is joy, I have most powerfully glimpsed what this might mean because I have lived with Adam."[41] Joy is imperative to life in the kingdom, for, as the Apostle Paul notes in Romans 4:16, "the kingdom of God is not food and drink but righteousness and peace and joy in the Holy Spirit." Wonder is not possible without joy, for joy often can be the outcome of a life lived at the heart of wonder. It is with this joy that Adam welcomes others into the kingdom.

In this chapter, Brock is attempting to claim that "a theological definition of health goes beyond this catalogue of bodily vulnerabilities in asking how people enact their creaturehood."[42] What is at stake is not how many doctor appointments one has to attend or how many prescriptions or treatments one is prescribed but how creatures operate in the world. It is in this way, in light of the examples listed above, that Brock can claim Adam is the healthiest person he knows. Adam's health is not represented by the absence of illnesses or diagnoses; on top of his Down Syndrome and Autism, Adam's life has been subject to sepsis, significant brain injury, inability to speak, and aversions to textures of certain kinds of food. The Brocks are unsure of how well he hears,

39 Brock, 163.

40 Brock, 164.

41 Brock, 165.

42 Brock, 168.

and at six months of age it was discovered that he had a pair of holes in his heart. Adam contracted leukemia at the age of eight, which resulted in over two years of chemotherapy. For years he has had problems with gastric reflux, which often keeps him up at night, and, most recently, he has contracted keratoconus, which results in loss of vision in addition to eye pain. Yet, not only despite this but exactly in light of all of this, Brock continues to claim that Adam is the healthiest person he knows.[43]

Ultimately, what is significant about Adam's health is the way he witnesses to an alternative social order, manifested in the everydayness of life, contrary to the Baconian model of health and normativity. Brock testifies that "it often interrupts me through the acts that Adam performs in which an alternative social comportment appears that is both extremely beautiful and a strikingly deep challenge to the social order of this fallen world. In this way his life *evokes* the almost unthinkable social dynamics to which Jesus pointed, and as he does so, he constantly *provokes* our world."[44]

Adam is both an exemplar and a witness, yet not of the ways we may traditionally think. He is an exemplar of life lived in an alternative order, and he witnesses to a reality that is possible beyond the snares and traps of our fallen world. This is not to claim that Adam is without sin or "wholly innocent"—a sort of divine creature who is distinct from all other human beings—but rather that perhaps the Apostle Paul was correct when he claimed that God has chosen those who the world views as foolish to shame the wise (1 Cor 1:27). It may just be that Adam (and people like him) have been chosen to witness to the alternative reality Jesus spoke about as the kingdom of heaven, drawing those around them into the heart of wonder.

To accept Brock's claim of Adam's health is to be confronted by Adam's invitation to life in the kingdom of heaven. It is to accept that Adam, alongside a host of others living with what we understand to be intellectual disabilities, may be a herald of the kingdom, calling others to faithfulness under God. The challenge presented to able-bodied individuals—and here I include myself and likely many readers—by this welcome is to evaluate our being in the world and how we conceive ourselves in light of our own sin, our capacity to wonder, and our pursuit of freedom. It is a challenge presented not in life's extravagant moments but in the everydayness of our existence—in the mundane, repetitive

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43 To be clear, we must note that it is not *because* Adam is understood as disabled that he represents the healthiest person that Brian knows. Such logic could be read as reinstating a logic of subordination by simply reversing the bifurcation of disabled and non-disabled humans. Rather, Adam's disability is incidental to being understood as healthy. Nothing in the four points Brock notes above is predicated on Adam's disability, yet despite his disability, he remains the healthiest person Brock knows.

44 Brock, 165.

nature of our daily existence. The alternative social order to which Adam witnesses may not be one without sin (Adam as a human being is a sinner just like anyone else), but it is one that lives life presently, full of truthfulness, emotional sensitivity, and joy. Such a life may offer us glimpses of the kingdom of heaven in the places we least expect to find them.

It is worth noting the conditional statement in Brock's concluding chapter "Health in a Fallen World":

> *If the kingdom of heaven is anything like Jesus teaches,*
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> *and* Adam displays in significant ways the tenor of this kingdom in his form of life,
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> *and* it is the state of our hearts out of which the social order of our world flows,
>
> *then*, to recognize the true health of those we call disabled, we will have to have our hearts assayed to see how deeply they welcome this kingdom. To genuinely receive the presence of another person means not to pity them, be repelled or frustrated by them, but to welcome them without regret.[45]

Adam's witness is one of welcoming others into the kingdom of heaven. His is a life lived with God, the true sign of health. As Christians, we are called to join Adam and those like him in the kingdom of heaven, journeying alongside the God who liberates us from our false pretenses into a life full of wonder and freedom. For Brock, this is what it means to be healthy.

Receiving the Witness of Disability in a Medicalized World

Between the Western medical model of disability as a product of the Baconian project and Brock's conception of health exemplified by his son Adam, we find two starkly different conceptions of health. While both may have merit in certain contexts, it is clear that the medical model, as the dominant model of our day, has often resulted in the oppression and marginalization of people with disabilities. This oppression occurs not only when people with disabilities are set to receive medical care (although surely then as well)[46] but also as medicalized conceptions of disability have emerged as the dominant gaze by which ableist societies come to understand disabled persons. Thus, while recognizing the inherent

45 Brock, 167.

46 The case of Michael Hickson gained international attention when he was denied treatment for COVID-19 as a result of his disability. See Joseph Shapiro, NPR Morning Edition, Special Series: The Coronavirus Crisis, "One Man's Death Raises the Worst Fears of Many People with Disabilities," July 31, 2020, https://www.npr.org/2020/07/31/896882268/one-mans-covid-19-death-raises-the-worst-fears-of-many-people-with-disabilities.

benefits of the medical system, this final section seeks not to portray a synthesis between the Baconian model and Brock's reconception of health but to (1) note the ways in which Brock's understanding of health can witness to the Baconian system, (2) offer a call to reform the harmful ways that the medical system has treated people with disabilities, and (3) seek a better way of conceiving health in the twenty-first century that accounts for the experiences of all people.

The claim I want to advance is heavily related to the social model of disability noted above, in the sense that disability is a cultural construct and that what is most important in disability identity is not one's physical or intellectual impairments (defined in the broadest sense of the term) but rather how one's body is perceived by those embedded in particular cultural narratives (the stories we tell ourselves to make sense of the world). Recognizing the imperfections of the social model, and taking up the claim above posited by Stiker, we must recognize that there are better accounts of disability and health than the medical model, such as those posited by Brock. But how can we come to understand, like Brock, that those who carry the label "disabled" are worthy of being identified by such alternative conceptions of health?

Disability theorist Rosemarie Garland-Thomson has argued in her work on cultural narratives that shape structures story.[47] What Garland-Thomson means by this is that the shape our bodies take—in other words, our experiences as particular bodies in the world—form the narratives that our identities are bound up in. Such an argument, she posits, runs counter to the cultural impulse to standardize the body through medical technology. For Garland-Thomson, "Normal is the central concept governing the status and value of people in late modernity. It is the abstract principle toward which we are all herded by a myriad of institutional and ideological forces."[48] In this way, the predominant cultural narrative has become that the concept of normalcy structures our shapes—for instance, the way we understand our bodies. Bodies must submit to the structure imposed by normalcy—the center from which deviation departs—lest they be cast out from the prevailing cultural fantasy of bodily stability.[49]

To insist that shape structures story rather than story structuring our shapes means that particular accounts of human lives form and reform the way we come to see the world. For Garland-Thomson, the stories of disabled bodies offer an immediate counternarrative to the dominant cultural norms. They liberate us from the tyrannical imagination of the norm to a new way of perceiving the world. "Narratives do cultural work," she argues. "They frame our understandings of raw, unorganized experience, giving it coherent meaning and

47 Rosemarie Garland-Thomson, "Shape Structures Story: Fresh and Feisty Stories about Disability," *Narrative* 15, no. 1 (2007): 113.

48 Garland-Thomson, 114.

49 Such as we saw in reference to Davis's account of eugenics above.

making it accessible to us through story."[50] In insisting that shape structures story, Garland-Thomson argues that these stories always begin with particular bodies. To be faithful to narratives pertaining to disability, we then must begin our perception with bodies we have come to understand as disabled.

Similarly, Brock argues that if we want to recognize the true health of those we call disabled, we will have to have our hearts assayed in order to be able to perceive the world in the way they do. He notes elsewhere that the so-called challenge that disability presents is not so much the impairment that our normate gazes perceive but the structure of the normate gaze itself, which renders us unable to fully receive the life of the person we have come to understand as disabled. In this way, those in need of Jesus's liberation are not so much the people with disabilities but those possessed by the ableist gaze of Western society. Indeed, Brock suggests that "perhaps it is *Adam* who is the provocateur revealing the resistance of the church and world to lives like his, and drawing *us* in."[51] For Brock, the lives of his son Adam and those like him can witness to a new way of perceiving a world that looks different from the one that society trains us to see. Ultimately for Brock and Garland-Thomson, the problem lies not in disability itself but in society's inability to perceive people with disabilities for who they truly are.

For Christians, then, if we are to take the charge of Brock and Garland-Thomson seriously, we must recognize that if shape structures story, and particular bodies and particular lives confront our false perceptions of the human, we are in need of encounters with lives different from our own to shake us out of our false perceptions and into a renewed vision of life lived in the kingdom of God. And we know that there is one Living Body who continues to confront us and shake us out of our false (and even sinful) perceptions by offering us glimpses of the kingdom of heaven. If Brock is right that what makes a person healthy is communion with God and participation in the "heart of wonder," then, placing that understanding alongside Garland-Thomson's, we are charged with the claim that Christians need Christ's invading power to come in the form of his own scarred and wounded resurrection body to help us realize the fullness of the vision of the kingdom of heaven that he has to offer. It is only this wounded body that has the capacity to draw us out of our separation from God and place us in communion with the One capable of setting us free. And, as Matthew 25 tells us, sometimes Christ's appearance comes to us in the forms of bodies that we would least expect.

In saying this, we are drawn back to the account of Kathy Dickson that we began with in the introduction. As noted, Dickson deals with a wide array of themes present in both Anabaptist and disability theologies to craft an account

50 Garland-Thomson, *Shape Structures Story*, 122.

51 Brock, *Wondrously Wounded*, 240.

of how we can resist the problems of normalcy that plague the lives of people with disabilities. However, it is my contention that if Dickson had not been confronted by the witness of the life of her aunt with Down Syndrome, her essay would lose the force of its argument and Dickson herself might not have been trained to see the world as she now does. Here is how Dickson recounts the story of her aunt:

> Words spoken in the critical moments that led to my aunt's death haunt me to this day. I can still see the doctors in blue surgical coverings standing in the cove outside the ICU, facing us, her family. "Look, we have a woman with Down Syndrome here," were the first words out of the lead doctor's mouth. I heard everything else that was said, but those words punctuated every sentence for me. She was suffering; they needed to decide on a path and act quickly. Based on the doctors' picture of what was happening, we agreed that we had to say goodbye, then held her and sang to her. One solitary tear lay on her cheek as she took her last breath. I recount those moments in my head like all of us standing there that day, convinced in the moment that it was the right choice. But the framing the doctor's words gave to her death is the beginning of the haunt: "We have a woman with Down Syndrome here."

Here, we see the reality that many disabled people face—the desire of the medical gaze to pathologize people with disabilities rather than see the particularity of each person. It is my contention that what enabled Dickson to perceive the life of her aunt differently from the medical professionals was that they were looking primarily at Down Syndrome while Dickson was looking at her aunt, the person she had come to know and love. In this relationship, Dickson was trained not only to see her aunt as a person with intrinsic value but to also understand the entire medical apparatus as called to value the lives of all people, especially those with Down Syndrome. It may even be the case that it was Jesus revealing these things to Dickson through the very body of her aunt.

Dickson is thus right to suggest that Anabaptist theologies are well equipped to resist the dominant cultural gazes that lead us to pathologize disability under the medical model. And to take her claim seriously, we must be willing to grapple with Anabaptist theology in a manner that allows it to resist these dominant cultural gazes in the first place. In doing so, however, we must emphatically suggest that this resistance will only come to fruition if we let people like Dickson's aunt assay our hearts by welcoming their lives and witnesses into our own, the way they themselves demonstrate such a welcome of us. If we want to work for the liberation and justice of people with disabilities, especially as this liberation and justice pertains to the medical enterprise, we must only do so as we allow the lives of disabled people to come into our own and shape our stories. Such a welcome is not a conforming one where those welcomed in must assume a certain type of being in line with our cultural ideals. Rather, it is one in which the dominant group allows outsiders to enter and, in turn, is confronted and

shaped by those entering for the transformation of the dominant group. Personal vulnerability is essential in the task of welcoming.

An alternative vision of health is available that prioritizes welcome into the kingdom of God over conforming to a predetermined norm. However, it may just be the case that recognizing this alternate understanding of health is only possible if we allow ourselves to be confronted by the witness of people with disabilities and, in these confrontations, recognize where we have conformed our vision of health to ableist biases that reject the lives of those different from us. For, if Brock is right, then the one who is unhealthy is not the one with impairments but the one who is unable to recognize the way that God is at work around us. And it just may be the case that God is choosing to speak through the lives of people like Adam Brock and Kathy Dickson's aunt in order to drag us out of our old ways of being and conform us to a life that is more in line with Christ.

Responding as Anabaptist Communities

This essay argues for a new understanding of health that runs counter to the predominant mode of perceiving people with intellectual disabilities under the gaze of the Western medical apparatus. And if we want to modify our conceptions of health and the medical system, we cannot do so by privileging abstract accounts of theoretical possibilities; rather, we must be confronted by those whose lives are different from our own. In this case, the lives we identified as being different belong to people whom society has chosen to understand as "intellectually disabled." To conclude, I offer brief remarks about the way Anabaptist communities may respond to these confrontations and how we can work to create more faithful accounts of both health and disability.

As Karl Koop has argued, "All Christian communities hold to doctrines even if certain communities claim to be creedless or primarily praxis oriented."[52] Within Mennonite traditions, however, the abundance of confessions of faith suggests that Mennonites have at least been willing to change their views on matters of doctrine and faith throughout our history. In response to questions about the nature and place of doctrine in such an ever-evolving tradition, Koop suggests the modified statement of *lex orandi, lex vivendi*—the law of what is prayed is the law of what is lived. This, he suggests, "places what the church believes, teaches, and confesses in the context of Christian experience that is embedded in prayer, liturgy, and discipleship. . . . This ancient ordering also assumes a Christian imagination shaped by an encounter with the living God."[53]

52 Karl Koop, "Putting Doctrine in Its Place: Confessions of Faith, Modernism, and the Lex Vivendi," *Direction: A Mennonite Brethren Forum* 48, no. 2 (Fall 2019): 138.

53 Koop, 139.

In this view, doctrine is important, but it is secondary to encounters with the living God. Doctrine is shaped and understood through these encounters as we attempt to live and believe in a manner more faithful to the living and active God. These are not unhinged encounters; they are discerned in and through worshipping communities collectively striving to seek greater faithfulness and adherence to the revelation of God among us.[54]

Following Koop, I suggest that if God is indeed choosing to speak through the lives of people with disabilities we ought to be willing to change our beliefs and practices for greater adherence to the revelation of God through them. To live in this way is to continue taking belief and practice seriously while recognizing there may be places where we have erred in our doctrine and practice.[55] Humility is needed to recognize these errors and strive for a new way forward. Reconceiving our perceptions about health and disability may not require a wholesale overhaul of our confessions of faith, but we do need to be honest with ourselves about the way that our beliefs and practices may have negatively affected the lives of people with disabilities—and thus the larger community—not only in the past but also today as well.

If we take seriously Koop's charge, Mennonite communities are presented with a unique opportunity to respond to the faithful witness of people with intellectual disabilities, especially in the medical arena. It is likely the case that we have misdiagnosed the "problem" of disability and that what needs to change is neither the behavior nor abilities of people with intellectual disabilities but rather our ableist perceptions of them. We can never truly know who people with intellectual disabilities are if we keep them at a distance, refusing to be encountered by them and their witness. Our churches ought to be open to encounters with people who have intellectual disabilities, taking time to listen to them. Our health may depend on it.

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54 Such a framing is aligned with Brock's conception of health above, where he suggests that to be a creature is to concretely depend on God's enlivening Spirit.

55 For example, in a recent volume on Anabaptism and disability, both Jason Reimer Greig and Melissa Florer-Bixler raised concerns about the implications of believers baptism for people with intellectual disabilities, although each propose different accounts of how Mennonite communities can approach baptism in a theologically responsible way that takes into account the lived experiences of people with intellectual disabilities. See Jason Reimer Greig, "Re-Imagining Narratives: Anabaptist Baptismal Theology and Profound Cognitive Impairment," *Conrad Grebel Review* 38, no. 2 (Spring 2020): 120–34; Melissa Florer-Bixler, "Believers Baptism as Supported Decision," *Conrad Grebel Review* 38, no. 2 (Spring 2020): 135–46.