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# Disability and Christian Theology

*Embodied Limits and Constructive  
Possibilities*

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## Understanding Disability

Before we consider the various ways in which disability might intersect with theological reflection, we must first try to make sense of disability itself. Our first significant challenge comes from a rather benign resistance to this task: to most people, defining disability seems unnecessary. As Rosemarie Garland Thomson notes, disability and able-bodiedness seem to be “self-evident physical conditions.”<sup>1</sup> It seems strange to even ask what disability is. We can describe it, draw pictures of it, point out examples of it. We think that we know (or can imagine) what it means to “be disabled.” It is a category that makes sense to us. Perhaps most tellingly, we often think that we know (usually just by looking) if someone is disabled, and we think that we know if someone is not. Disability seems to be a self-evident category. But is it?

### What Is Disability?

#### *Definitions and Statistics*

In the current scholarship of disability studies, distinctions are often drawn between terms such as “impairment,” “disability,” and “handicap.” “Impairment” usually signifies an abnormality or loss of physiological form or function. For example, a damaged optical nerve

is classified as an impairment. "Disability" describes the consequences of the impairment, which may be an inability to perform some task or activity. In this example, the disability might be an inability to see. "Handicap," literally meaning "to hinder" or "to place at a disadvantage," denotes the disadvantage that results from an impairment or disability. A person is considered handicapped, for example, when the damaged optical nerve or the inability to see makes one unable to distinguish floor numbers on elevator buttons, thus hindering navigation without additional assistance. While we may most often think of these three terms as inextricably linked (i.e., that a person with a significant impairment is both disabled and handicapped), it is important to note that an impairment does not necessarily result in a disability, and a disability need not be a handicap. Our hypothetical friend with the damaged optical nerve (an impairment) would not be handicapped if the elevator buttons were marked in Braille and would not be disabled (the impairment would have no consequences) in the dark.

In the United States today, our use of the term "disability" often draws on the language of the Americans with Disabilities Act of 1990, which defines disability as "a physical or mental impairment that substantially limits one or more of the major life activities" of an individual.<sup>2</sup> According to the U.S. Census Bureau, "a person is considered to have a disability if he or she has difficulty performing certain functions, or has difficulty performing activities of daily living, or has difficulty with certain social roles."<sup>3</sup> While these definitions usually exclude temporary illnesses, they encompass a wide variety of physical, cognitive, and psychological impairments. Using such definitions, it is currently estimated that 51.2 million Americans have some level of physical or mental disability (18 percent of the population), and 3.2 million have a severe disability (12 percent of the population).<sup>4</sup>

Even though disability is found in all age-groups, issues of disability should be of particular concern as the population ages due to worldwide changes in fertility and mortality (fewer children are born, and more people reach old age) and as the baby boom generation approaches retirement.<sup>5</sup> For example, the World Health Organization projects that by the year 2020, the proportion of population aged sixty and over will reach 23 percent in North America, and the total number of elderly people worldwide will reach more than 1 billion. In addition to other social and economic implications, population aging means that "more and more people will be entering the age when the risk of developing certain chronic and debilitating diseases is significantly higher."<sup>6</sup> Not only, then, do we need to attend to disability today, but we must also consider the growing impact it will have in years to come.

*Disability beyond the Statistics*

While they may give us a starting point in terms of understanding the frequency of disability, statistics fail to represent the diversity found within the category “disabled.” If we pay attention, it does not take us long to see that disability takes many forms and affects human lives in a wide variety of ways, to the point that using the single term “disability” to lump together people who experience mobility impairment, sensory loss, disfigurement, chronic pain, long-term illness, developmental difference, dyslexia, schizophrenia, depression, and more, is to create a deceptively simple category. Moreover, even within any single particular condition, there is often a great deal of variety. For example, disability (impairment) may be temporary or permanent. It may affect all aspects of an individual's life or may be a fairly minor inconvenience. Impairment may result from accident, illness, or genetics, or the cause may be unknown. Some people have their conditions from birth; others acquire them in youth, adulthood, or old age. Certain impairments are relatively stable, others become progressively worse, and some improve with time or medical intervention. People with disabilities may use very different technologies to adapt to their situations or may “pass” without any apparent aid. In addition, it is important to recognize that people with disabilities are not all treated the same by the nondisabled, especially since some disabilities are more socially acceptable than others, and individuals may have very dissimilar attitudes toward their own conditions. In these and many other ways, the “experience of disability” is diverse indeed!

Beyond this, it is important to remember that people with disabilities have other characteristics as well. Disability crosses all lines of race, gender, sexual orientation, class, age, and so on. These and other life experiences affect each person's experience of disability. Sometimes the relationship between disability and other identities is direct, as when poverty or malnutrition leads to a disabling condition or prevents a person from receiving medical treatment or adaptive technologies. Conversely, disability can lead to poverty if a person either is physically unable to work or is denied the right to work by barriers of access or attitude. Other times the relationship between identities is less immediate but still important. A young person and an older person might respond to a similar disability in very different ways. A businessperson may have an easier time adapting to mobility impairment than a professional athlete. Issues of race, class, gender, and sexual orientation affect the sorts of barriers and obstacles a person with a disability will face, and people who experience oppression or exclusion as members of one or more of these minority

groups may find themselves doubly (or triply) oppressed as a result of their disability.

One particular area of concern in contemporary scholarship has been the interaction between sexism and disability.<sup>7</sup> Until recently, research has paid little attention to women with disabilities; most studies on disability have focused on men's issues and have used male subjects, with results (at least, until recently) assumed to be normative for both men and women. The omission of women's health issues from medical research has recently come to the attention of the general public (e.g., we are only beginning to learn about causes and characteristics of heart disease in women); these gaps in research are particularly significant for women with disabilities. In addition to medical issues, women's narrative experiences of disability have also received less attention in scholarship than those of men. Some propose that this is because disability is culturally interpreted as more traumatic and life changing for men than for women, especially insofar as disability in men, at least within Western culture, is seen as a lack of ability (a tangible loss, with specific economic implications), whereas disability in women instead is seen as a loss or lack of beauty (and, often, a loss of potential as a wife or mother). Others propose that disability in men has been seen as more significant insofar as disability often is equated with dependency, and traditional stereotypes seem to suggest that it is more acceptable for a woman to be or appear dependent than it is for a man. It is clearly erroneous, however, to assume that disability is less traumatic for women than for men. For example, compared with both nondisabled women and men with disabilities, women with disabilities typically have a lower level of educational achievement, a higher rate of unemployment, and, for those who are employed, a significantly lower annual income. Noting the limited role choices and limited role models available to disabled women, Michelle Fine and Adrienne Asch go so far as to conclude that "disability is a more severely handicapping condition for women than for men."<sup>8</sup>

The needs and issues of women with disabilities have largely been ignored by the disabled rights movement; men have held the power in these organizations and have, intentionally or not, determined which issues are to be given priority. As Mary Jo Deegan and Nancy Brooks note, "Like many other social change movements, the disability movement has often directed its energies toward primarily male experiences."<sup>9</sup> Concerns of women with disabilities—including discrimination as a result of gender and disability, violence against women with disabilities, and sexism within their organizations—have been disregarded. While this is beginning to change as women take leadership roles and demand that our concerns be addressed, change is slow.

Unfortunately, the feminist movement has been no better than the disability rights movement at attending to or engaging with disabled women. Events and meetings are often not physically accessible, and women with disabilities who are present are frequently encouraged to work on "their own issues" with "their own kind."<sup>10</sup> As Pat Israel recounts: "Years ago when I attended a national women's conference I had to use a dirty, foul-smelling freight elevator to get to the workshops. There was garbage on the floor and walls. I felt degraded and dirty every time I had to use it. I wonder what would have happened if the black women had been told to use the freight elevator because they were black."<sup>11</sup> While organizations are now more aware of and sensitive to issues of access, necessary adaptations are still often made only after a member requests such services (e.g., meetings are rarely interpreted into sign language as a matter of course, and convention sites still frequently include barriers to mobility). Going beyond issues of access, areas of tension arise between disabled and nondisabled feminists over issues such as abortion, caregiving, and technology. For example, many women with disabilities identify themselves as feminists but reject a pro-choice position on abortion, arguing that abortion is too often used as a form of eugenics against disability; this position is difficult for many nondisabled feminists to understand or accept.<sup>12</sup> Thus, even when issues of basic accessibility are addressed, other diversities of identity and political commitments are frequently overlooked.

This nascent literature on women and disabilities also reminds us of the lack of attention to disability in relation to other identity concerns. For example, little has been written to date on disability and race or on disability and sexual orientation. We must be mindful that disability is not an exclusive category but rather one that intersects all other identity and interest groups. Similarly, we must take care that we not assume one individual or group experience of disability to be typical or representative of all people with disabilities. People with disabilities are as different as people without disabilities. Alan Gartner and Tom Joe perceptively write:

It is mistaking the diversity of persons with disabilities to expect or desire that they all will have the same views or values. Some are Yankees fans, others favor the Mets; some are men, others women; some are black, others white; many are poor but some affluent; some politically liberal, others conservative; some see gains won primarily from individual efforts, others from group action. On many, indeed most, issues, it will be these (and other) factors, not the fact of the person's disability, which will have the most salience.<sup>13</sup>

People with disabilities are individuals—individuals with different attitudes toward their disabilities, individuals with different sociological influences and characteristics, individuals with different political positions, individuals with different tastes and interests. It is important that we remember that there is no one perspective that can be called “the disabled person’s perspective.”

It is a challenge to be mindful of this diversity: it is too easy to assume one perspective—usually our own—to be normative and to create interpretations and doctrine based on experiences that do not represent the full diversity of the people to whom, or for whom, we speak. However, as feminist and liberation theologians so clearly demonstrate, diversity includes a richness that can be an asset, not a liability, to our understandings of ourselves and of God.<sup>14</sup> The same is true for the diversity of disability. Each perspective is different, but each offers us a piece of the puzzle. Susan Brooks Thistlethwaite and Mary Potter Engel remark that “people look alike only when you cannot be bothered to look at them closely.”<sup>15</sup> Beyond the most obvious signs of accommodation (wheelchair, hearing aid), many people choose not to look closely at those with disabilities. By ignoring these differences, we not only miss truly encountering one another but also miss important truths about ourselves and the world.

Finally, in addition to seeing disability as a category that holds immense diversity within it, we must note that the category itself is an unstable one, with no neat differentiation between “us” and “them.” The most obvious example of this is seen when we consider that disability will likely impact each of us during the course of our lives. Disability has been called an “open minority” because it is a group that most of us will “join” at some point in our lives.<sup>16</sup> Even if one does not live long enough to experience a significant disability, most of us will have some sort of firsthand experience with impairment, whether it be a sprained ankle, the need for eyeglasses, or the “normal” limitations that come as we age. As Elizabeth Stuart notes, “The contrast is not between the able and disabled but between the temporarily able and the disabled.”<sup>17</sup> However, while the recognition of this fluidity can be valuable in expanding our perspectives and breaking down some of the dichotomy between able and disabled, it is also important that we do not appeal to this fluidity to minimize the legitimate justice concerns of people with disabilities. Using a wheelchair for a week can teach an able-bodied person a lot about what it is like to be disabled, but it cannot teach her what it is to be a lifelong wheelchair user; it would be inappropriate to say a person could understand everything about the experience of disability from an isolated experience of impairment. At the same time, the wheelchair user-for-a-week might have a better understanding of mobility impairment than a person who has been deaf from birth and has always been



identified as disabled. As we recognize these sorts of interweaving connections and differences, we can begin to realize a significant truth: we may in some important ways be more alike than different, even though we are different in significant ways.

### *Disability and Activism*

While it is outside the scope of this work to present a complete history of disability and disability studies, a brief overview of this topic may be helpful.<sup>18</sup> Throughout much of history, people with disabilities have been oppressed and repressed as individuals and as a social group. People with disabilities have been isolated, incarcerated, institutionalized, and controlled. Without entering into any sort of “oppression derby” over which minority group has been the most oppressed in history, it is important to note that people with disabilities, especially those who experience double or triple oppression based on other categories of gender, race, class, and so on, have experienced some of the worst that history has had to offer. People with disabilities have been defined as many things: deserving victims of divine punishment, objects of scorn, sideshow freaks, medical case studies, recipients of charity, and poster children. In movies and in literature (and perhaps most clearly in children’s stories), disability has been used as a metaphor both for evil and for childlike innocence, and disabled people have frequently been portrayed as malevolent, comical, or victims of a fate worse than death.<sup>19</sup> As has been the case for other minority groups, rarely have people with disabilities been viewed first as people.

Examples of prejudice and discrimination are too numerous to mention, but a few instances will set the scene. In the nineteenth and early twentieth centuries, many states passed laws forbidding people with particular disabilities to marry, and some disabled people were forcibly sterilized. In 1927, the U.S. Supreme Court heard arguments on the forced sterilization of people with disabilities who were wards of the state.<sup>20</sup> In an eight-to-one decision, the Court allowed the sterilization to proceed, with Chief Justice Oliver Wendell Holmes writing that “it is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind.”<sup>21</sup> In addition to such attempts at eugenics, people with disabilities have been routinely incarcerated, sometimes for life, in institutions and nursing homes, solely because of their disabilities.<sup>22</sup> A 1911 Chicago city ordinance (known as the “Chicago Ugly Law”) went so far as to make it a crime for anyone who was “in any way deformed so as to be an unsightly or disgusting object” to appear in public.<sup>23</sup>

People with disabilities in the United States have been organizing for more than a century to fight such injustices. As early as the 1850s, local organizations were established to advocate for the interests of deaf people, leading to the formation of the National Association of the Deaf in 1880. During the Great Depression, the League of the Physically Handicapped staged sit-ins at federal offices to protest antidisability discrimination by government programs. The National Federation of the Blind and the American Federation of the Physically Handicapped were organized in the early 1940s, and disabled soldiers returning home after World War II founded the Paralyzed Veterans of America. Around the same time, parents of disabled children began to form self-help groups that later grew into national advocacy organizations. Polio and spinal cord injury survivors asserted their right to study, work, and live in communities, and people with psychiatric disabilities protested custodial institutions. Inspired by the African American civil rights movement and the women's movement, various disability communities began to coalesce in the 1960s, giving rise to the modern disability rights movement. Finally, in the early 1970s, a series of legal cases, first and foremost *PARC v. Commonwealth of Pennsylvania*, crystallized disability as a civil rights issue.<sup>24</sup> In the decades since, disability rights advocates have scored numerous significant legal and legislative victories, culminating in passage of the Americans with Disabilities Act of 1990.

Alongside these political movements has been the growth of a disability culture that challenges traditional notions and assumptions about disability. Disabled artists, writers, performers, and activists celebrate disability as a facet of human diversity. It is now easy to find television and movies that focus on issues of disability and/or include characters with disabilities.<sup>25</sup> People with disabilities are also gaining unprecedented access to public life and serving in significant roles in business, government, and education. However, as millions of disabled Americans remain locked in poverty and as barriers of attitude and architecture keep people with disabilities from full participation in society, the disability movement still centers on legal challenges, protests, and activism of all sorts.

### *Disability and the Academy*

A significant addition to the disability movement as a whole has been the development of the academic discipline of disability studies, giving the opportunity for theoretical reflection, critique, and construction that not only contributes to the academy but may also act to sustain the movement as it looks beyond legal issues of access and inclusion. The field grew out of the work of disabled scholars and activists in the 1980s and 1990s who found that disability, as a

socially constructed phenomenon, was not being critically addressed within traditional academic disciplines. Disability studies emphasizes the articulation and theorization of the political, social, and ideological ways in which disability is understood, treated, and experienced. Current work focuses on a critique of the "essential" disabled person and an exploration of the various ways in which people are socially constructed by disabling environments. While access remains a primary issue of concern, many of these more recent scholarly productions are concerned with identity construction beyond actual experiences of limitation. For example, Rosemarie Garland Thomson, one of the key figures in disability studies, describes a recent project as an attempt to "go beyond assailing stereotypes to interrogate the conventions of representation and unravel the complexities of identity production within social narratives of bodily difference."<sup>26</sup> Others emphasize "the implications of disability representations from the perspective of the disability rights movement,"<sup>27</sup> or how "the disabled use, elude, resist, or rewrite the culturally authorized scripts of disability identity."<sup>28</sup> This cross-disciplinary enterprise of theorizing experiences and constructions of disability draws from a wide variety of fields, including sociology, anthropology, political science, literature and film studies, philosophy, psychology, architecture and design, and the arts.

Like any other discipline, disability studies requires a base of knowledge and a familiarity with discursive terms and methodologies. While defining itself as a scholarly academic pursuit, it also sees itself as a logical progression from the disability rights movement and as such is careful not to lose its grounding in praxis. Lennard Davis writes, "It is not as if disability studies has simply appeared out of someone's head at this historical moment. It would be more appropriate to say that disability studies has been in the making for years, but, like people with disabilities, has only recently recognized itself as a political, discursive entity."<sup>29</sup> As has been the case with the civil rights movement or the feminist movement, there is understood to be a reciprocal connection between political praxis by people with disabilities and the formation of a discursive category of disability studies.

However, like race and gender studies, disability studies is not a monolithic undertaking but rather is the site of internal struggle and debate over its desired identity, methodology, and commitments. One particularly heated topic at present regards what qualifies one as an expert. For example, it is frequently argued that some degree of personal involvement with the experience of disability is necessary. People without disabilities (sometimes playfully or pejoratively referred to as TABs—temporarily able-bodied) are often regarded with suspicion as to their motivation or ability to understand the full scope of the field. For example, one author writes that "the apparent ease of intuitive

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knowledge is really another aspect of discrimination against people with disabilities."<sup>30</sup> While rarely articulated as such, the legitimacy of an epistemic privilege of people with disabilities is becoming a central concern in the field of disability studies.

At the same time an argument is made by some that disability studies ought to be limited to those with personal experiences of disability, the work of many other scholars who have investigated various aspects of the body and related issues is also being appropriated by the field of disability studies. Examples of these sources include Sander Gilman's work on disease, David Rothman on asylums, Erving Goffman on stigma, Leslie Fiedler on freaks, Susan Sontag on the metaphors of illness, Mikhail Bakhtin on the grotesque, Michel Foucault on disease and sexuality, Jacques Derrida on blindness, Judith Butler on gender and sexuality, and Susan Bordo on anorexia.<sup>31</sup> As the field of disability studies evolves, it works backward to incorporate historical writings on disease, the body, freakishness, and so on, while it simultaneously looks forward to a new generation of writers and scholars interested in feminist, Marxist, postmodern, and cultural studies models for understandings of the relation between the body and power.

As those who work with issues of disability in the academy and on the picket lines continue to define and defend their goals and commitments, they, along with those who watch them, still return again and again to our first question: What is disability? We turn now to two very different answers to that question, as seen in the medical and minority models. We will discover that these perspectives are only partially adequate, which will lead us to the limits model as an alternate way to attend to the experience of disability.

## Models of Disability

### *Medical or Functional-Limitation Model*

As suggested previously, disability may be best seen less as a precise category (where one either is or is not disabled) and more as a broad descriptive term for a cluster of somewhat related experiences or situations. Two distinct models for this cluster can be identified in the literature of disability studies. First is the medical or functional-limitation model, where attention is focused around what one can or cannot physically or functionally do. This model is closest to the commonsense idea that a disability is what someone has when his or her body or mind does not work properly. The medical model emphasizes body parts that do not function. Labels such as "invalid," "cripple," "spastic," "handicapped," and "retarded" all stem from this model. As we will see later,

disability rights advocates note that such terms, originally designating a functional loss, also typically connote a lack of worth.

Two interrelated assumptions constitute the medical model. First, this model sees disability as primarily a medical or biological condition (what we defined earlier as impairment). It claims that the disabled person's functional ability deviates from that of the normal human body. As a result, this model accentuates ways that people with disabilities are dis-abled and are dependent on others for help. Conversely, it designates disabled people as heroic when they participate in what otherwise might be considered ordinary activities such as sports or careers. Second, according to the assumptions of the medical model, if one displays any of a number of physical conditions, one is automatically labeled "disabled." According to this model, it would be nonsensical to suggest that a person who is unable to walk or hear might not be disabled. Key to the medical model is the presumption that disability is a problem that is experienced by an individual (making it a uniquely Western model)<sup>32</sup> as a deviation from an assumed state of normality.

The development of this model can be seen best in the historical relationship between disability and numerous professional and academic disciplines that concentrate upon the management, repair, and maintenance of physical and cognitive capacity. Medicine, rehabilitation, special education, sociology, psychology, and a number of other subspecialties have all, according to David Mitchell and Sharon Snyder, "established their scientific and social credentials (as well as their very professional legitimacy) through the 'humane' study and provision of services to disabled populations that are at the outermost margins of social interest and cultural value."<sup>33</sup> These authors suggest that such service professions have defined and been defined by the experience of disability. In other words, disability is a construction that anchors one end of the continuum between healthy and ill. Disability (which, in this case, includes illness, age, and other diminishments of ability) is an undesirable condition that helps to define the opposite and desired condition of health. Thus, although these professions and disciplines do not focus entirely on disability, their primary emphasis is restoring function and ability, and they aspire to move individuals toward health and nondisability. From these professions, we are shown that disability is a lack or deficit that must be restored by medical or surgical means wherever possible. Medical professionals have the duty of correcting or curing the deficit so as to achieve a state of normality for the individual. When such restoration is not possible, social workers and other service professionals have the job of creating that "state of normality" through help such as personal aids and assistive devices (mainstreaming) or by removing the individual from the normal world altogether (institutionalization).

The perspective of the medical model is that the body is a biological machine that functions to a greater or lesser extent. Disability, then, is located solely within the body, with no appeal to societal or environmental factors. It is an individual rather than societal condition. Under this model, barriers of architecture and attitude do not cause disability, but rather disability is simply a defect of the body. Physical, cognitive, and psychological disabilities may have environmental causes (abuse, physical or emotional trauma, malnutrition, etc.), but cures are available through repair: "treating" bodies through medicine or rehabilitation. According to Christopher Donoghue, the defining characteristic of the medical model is that the state of people with disabilities "is generally considered to be undesirable and, for that reason, they are expected to seek professional assistance to bring relief to their situation."<sup>34</sup> This model rests on notions of deviance, proposing that disability is in conflict with society's morals or values. Erving Goffman and others have successfully demonstrated the ways the "abnormal nature" of people with disabilities serve as a source of stigma among the nondisabled.<sup>35</sup> Building from this, Eliot Freidson proposed that the underlying assumption of rehabilitation is that people with disabilities need to be changed (normalized) in order to become accepted by the nondisabled.<sup>36</sup> The medical model has this principle of normalization at its core, attempting to modify, repair, or relocate individuals with disabilities until they are congruent with societal expectations of normalcy and acceptability.

The medical model falls under great suspicion by the disabled community because of this identification of individual impairments or deficiencies as the source of disability. By imposing definitions of disability based on criteria of deviation from an assumed norm, the model creates clear categories of normal and abnormal. Activists note that it is only a short step from saying that "you have a problem" to believing that "you are a problem." As a result, it is argued that the medical model has contributed to the disenfranchisement of people with disabilities from society. In addition, this model creates impediments to alternative understandings of disability. As long as we define disability as being an issue solely of individual impairment, there is no great need to attend to architectural and attitudinal barriers in society, and little or no obligation for a community to change its exclusive practices toward people with disabilities. For example, the medical definition of disability used in the Americans with Disabilities Act protects people with disabilities only to the extent that their rights of access and employment do not cause "undue hardship" to those from whom they seek relief (employers and businesses, for example). This marks a dramatic difference between disability rights and other civil rights legislation that allows no such exception for discrimination.

The medical model pervades our legal, therapeutic, financial, political, and social worldviews to such a degree that we barely see it as an interpretation. This perspective, with its emphasis on normalization, seems so “normal” to most of us that it is difficult even to think of disability as anything other than a functional loss, which itself creates an impediment as we try to explore alternative perspectives (as will be seen in discussions of theology later in this book). However, when we begin to attend to experiences rather than just to an abstract notion of disability, other options come into focus. Surely impairment, pain, and loss have something to do with many individual and communal experiences of disability. There is, however, something more than just these aspects. Political and social implications, not accounted for by the medical model, are also unavoidable.

### *Social or Minority Group Model*

The second model common to reflection on disability is often called the social or minority group model, in which shared experiences of discrimination and oppression are emphasized. Under this model, individuals are considered disabled insofar as they experience prejudice and exclusion. It is from this perspective that Nancy Eiesland can claim that Jesus himself was disabled, in much the same way James Cone has claimed that Jesus was black—it is the experience of oppression that is central.<sup>37</sup> The minority model begins with the notion that disability is a sociopolitical category. It argues that disability is not so much about what one can or cannot do but rather is about how individuals are treated in their daily lives and by society at large. In other words, “to be disabled means to be discriminated against.”<sup>38</sup> Disability under this model is socially constructed and results from society not being organized according to the needs of disabled people. The “problem” is no longer identified as the physical, cognitive, or psychological characteristics of the individual, but rather is identified as prejudicial, exclusive, and oppressive attitudes and barriers—aspects that are related to social or political concerns rather than individual diagnoses. This model highlights the fact that individuals are often more handicapped by the physical and attitudinal barriers in society (e.g., lack of access to employment, education, and health care) than by their own abilities. The recognition of such barriers makes disability into more than just a functional (medical) or theoretical concern—it becomes an issue of justice as well. Built in to this model, then, is a sense that addressing the “problem of disability” means working against unjust social structures and instances of bias and exclusion.

Key to the minority group model is the notion of ableism. Like sexism, racism, and other isms, ableism can be described as “the set of often contradictory

stereotypes about people with disabilities that acts as a barrier to keep them from achieving their full potential as equal citizens in society."<sup>39</sup> Among these stereotypes are the beliefs that people with disabilities are inherently unable to manage their own lives, embittered and malevolent, and morally, intellectually, and spiritually inferior to able-bodied people; or, conversely, that people with disabilities are saintlike, cheerful, asexual, childlike, and unusually heroic. Fred Pelka describes ableism as "the belief that people with disabilities are different from 'normal' people, and that their lives are inherently less worthwhile than those of people without disabilities."<sup>40</sup> Under the minority group model, ableism, rather than any physical impairment, becomes the cause and the problem of disability.

In the United States, the development of the minority group model is historically linked to the Independent Living Movement in Berkeley in the late 1960s and early 1970s.<sup>41</sup> At the end of the 1960s, a group of significantly disabled people attending Berkeley (a central locus of other civil rights movements) was attempting to integrate their individual experiences with what they were learning in the university. From their reflections, these people came to see that disability was not so much a matter of impairment as it was one of discrimination; their personal characteristics were not the problem but rather the discriminations they faced within society itself. As a result, they saw that disability, redefined as "social oppression," could be remedied by political activity, lobbying, and direct action. Slogans such as "Nothing about Us without Us" were developed to highlight the political nature of such resistance, articulating the position that "if we have learned one thing from the civil rights movement in the U.S., it's the sense that when others speak for you, you lose."<sup>42</sup> For the first time in the public eye, politically active people with disabilities were proclaiming that they knew what was best for themselves and were presenting "a demand for self-determination and a necessary precedent to liberation."<sup>43</sup>

The recognition of disability as a human rights issue also clarified for disabled people the means necessary for gaining those rights. In addition to protests and public actions, this model accentuated the need for protected minority status, including legal support for civil rights and protection against discrimination. Claims were made that services for disabled people had to be based on the concept of equal opportunity and nondiscrimination rather than on the traditional solutions of segregation and specialization. National and international initiatives were proposed and eventually achieved, including the Americans with Disabilities Act of 1990 and the United Nations declarations of the International Year of Disabled Persons (1981) and the International Day of Disabled People (annually on December 3), all of which focus to some degree on the fundamental human rights of equal opportunity and full participation.



### *Inadequacies of These Models*

Many in both the disability rights movement and disability studies see the minority model as superseding the medical model. In fact, most definitions of the minority model are set up in contrast to the medical model. However, scholars and activists alike are beginning to realize that the minority model itself is not without flaws. One significant concern is that the minority model ignores the very real bodily experience of impairment. By focusing primarily on ableism and experiences of discrimination, the minority model fails to take into account the physical and emotional reality of impairment. When a nondisabled person suddenly becomes disabled as the result of an accident, for example, coming to terms with a newly acquired impairment can create a whole host of emotional and practical difficulties. By emphasizing the social and political nature of disability, the minority model devalues these individual challenges. When the experience of impairment is deproblematized, there is little room for people with disabilities to have a negative or even ambivalent relationship to their impairment. The minority model suggests that all people with disabilities should accept and even embrace their own disabilities/impairments—after all, the impairment is not the (or a) problem. Many people with disabilities, including, for example, those who experience chronic pain, have a much more complex relationship with their disabilities than this model would allow. As Roy McCloughry and Wayne Morris note, “In an attempt to address the fact that the medical model is a deficit model, the social model can go so far as to elevate impairment to a place beyond regret.”<sup>44</sup> In the effort to counter the medical model, which focuses primarily on impairment, proponents of the minority model sometimes choose to disregard impairment. In doing so, they disallow a wide variety of lived experiences of disability.

One way activists and scholars have tried to negotiate these two models is to heighten the distinction between disability (as socially created) and impairment (as a physical attribute of the body), thus allowing the medical model to speak to impairment while the minority model addresses disability. In this way a paradigm is established for disabled people in which impairment/disability becomes similar to sex/gender and race/ethnicity. This construct does have advantages for the lived experience of disability, allowing for political activism even when one has an ambivalent relationship with one’s own impairment. However, the distinction between disability and impairment becomes dangerous insofar as it can be presented as an unconquerable dualism or dichotomy—one part of which (disability) tends to be valorized and relevant to the public sphere and the other part (impairment) privatized or silenced. In this way, each model “produces and embodies distinctions of value and power.”<sup>45</sup> In addition, as Mairian

Corker and Sally French describe, since disability and impairment are discursively related (it is very difficult to “talk” about disability without referring to impairment), “such practice marginalizes the role of discourse in creating and challenging disability oppression.”<sup>46</sup> The presupposition that the boundary between disability and impairment is solid does not allow us to explore adequately the experience of disability, because this experience is “in between.” This leads Margrit Shildrick to observe that “at best, we have ‘leaky bodies and boundaries.’”<sup>47</sup> Trying to work with the medical and minority models in a dichotomous fashion ignores the leakiness of our bodies and misses the full richness of the experience of disability.

In addition, focusing too heavily on either of these constructs leads us to forget, as was noted at the beginning of this chapter, that disability is only one of a number of experiences that contribute to the identity of people with disabilities. These other identity experiences are ignored by both models altogether. Susan Peters describes the shortcoming in this way:

Until recently, I viewed disability through the lenses of social injustice and societal oppression. I committed myself to a disability rights movement in the United States that demanded unity and strength, derived from collective identities and promoted in the common experiences of oppression. Within the last few years, however, I have felt that something was missing—my sense of self. I began to feel the need to re/define myself as an individual and to validate my personal biography of unique lived experiences in multiple communities—only one of which was my disability network of political affiliations. I began a search for self-identity that is more complex and personalized, and more grounded in sense of physical and psychological self-image than in the political identity that had previously consumed my thoughts and activities.<sup>48</sup>

The medical model emphasizes body parts, ignoring the identity of the whole person and dismissing the role of society or culture in the experience of oppression. The social model emphasizes minority group status, stressing the similarity of people with disabilities without making a place for individual differences, and ignoring the sometimes negative bodily experiences of people with disabilities. Even if we try to hold the two together in tension, we see only categories of impairment and oppression. Both models fail to capture fully what it really means to be a *person* with a disability.

An especially important challenge to both the medical and the minority group models comes from the Deaf community.<sup>49</sup> Many Deaf people do not consider themselves as people with disabilities but rather as members of a lin-

guistic minority.<sup>50</sup> The Deaf argue that their difference is not about function or public perception but is actually a communication difference—they “speak” in sign language rather than English or other aural languages. As a result, they see their situation as radically different from that of people with disabilities. For example, one author points out that the Deaf are not disabled when they are among others who communicate through sign language, “whereas a group of legless people will not transcend their motor impairments when they become part of a legless community.”<sup>51</sup> Similarly, being Deaf is not defined by experiences of discrimination or exclusion, or even by a person’s ability to hear. People who are Deaf can have a range of hearing abilities from “perfect hearing” to “profoundly deaf”; conversely, there are people with severe or complete hearing loss who do not identify as Deaf and do not participate in the community of Deaf people. The issue of whether Deaf people are a linguistic minority or are disabled (within the context of either the medical or the minority model) has generated intense debate and discomfort among disability rights activists as well as within Deaf communities.

A striking example of the challenge to define deaf/Deaf identity may be seen in the debate over cochlear implants. In the cochlea (a part of the inner ear) of a hearing person, sound waves are translated into nerve signals. Some types of deafness result from sound waves failing to reach the cochlea or from the cochlea failing to make the translation into nerve signals. The cochlear implant (CI) is a piece of technology that helps to compensate for the hearing loss with a bundle of electrodes surgically implanted into the cochlea combined with a body-worn speech processor. Like other medical interventions, this procedure has both benefits and risks. In many cases, the CI provides the recipient with the ability to identify and distinguish a wide variety of sound frequencies, enabling the individual to function with fewer barriers in society at large. From this perspective, the CI is seen to restore what was lost in terms of relationships and experiences as well as auditory function. At the same time, the CI requires extensive auditory therapy, can be painful, and, in most cases, does not restore full hearing but only offers the recipient more cues to help make sense of the Hearing world. Some members of the Deaf community have vigorously challenged the use of these implants, especially in children who are not yet able to make such a decision for themselves, seeing the CI as contributing to a sort of genocide against Deaf Culture.<sup>52</sup> The extreme side of this movement also exerts pressure for deaf people to give up hearing aids—“sort of a Deaf-liberation equivalent to bra-burning”—and resists any attempt to conform or adapt to the expectations of Hearing culture.<sup>53</sup> While this debate touches on many issues, it also highlights the inadequacy of both the medical and minority models to address the experience of the Deaf community, who see their “disability” as

neither a medical impairment nor a minority experience (at least not one that has a reason to work politically with other "disabled" groups), but rather as a unique and legitimate cultural form.

Critiques such as these that come from Deaf Culture, along with the awareness of the multiplicity of responses to disability and the multidimensional character of human life, now lead some to question the existing models of disability. For example, Corker and Shakespeare state:

We believe that existing theories of disability—both radical and mainstream—are no longer adequate. Both the medical model and the social model seek to explain disability universally, and end up creating totalizing, meta-historical narratives that exclude important dimensions of disabled people's lives and of their knowledge. The global experience of disabled people is too complex to be rendered within one unitary model or set of ideas.<sup>54</sup>

The existing models of disability are both totalizing and limited in scope—neither is adequate to fully capture or explain the lived experience of disability. From our contemporary perspective, we can see that both essentialize (either physical attributes/function or social location/minority status) and privilege one group over another (healthy over disabled or oppressed over oppressor). Moreover, the move from modernism to postmodernism shows us that these essential categories are constructions. In this way, we might suggest that "the disabled" is not a natural category but rather is one that has been and continues to be constructed and, thus, can be deconstructed. This is a move that disability studies is only beginning to note. As Branson and Miller write:

What we are exploring is the discursive construction of a category with shifting referents and shifting significance, a concept that demonstrates *par excellence* that its meaning lies, in Derrida's terms, in "*différance*," in the establishment of meaning through the assertion of difference. No finite meaning is ever achieved, but meaning is constantly deferred as people manipulate it for their own strategic ends. The meaning of "the disabled" is elusive but dramatic, vague in its specificity, and destructive in its application as this label is applied to others and as "the disabled" are defined by difference, with the boundaries of their identity deferred. It is a label that threatens us all but one that is assumed by the majority of the population to be embodied in others.<sup>55</sup>

These authors are among the first to note that the exploration of the concept of disability is at the core of the construction of "normal" subjectivity, part of an

attempt to define and understand oneself in relation to the embodied other. This observation, that our understanding of "disability" is in direct relation to any understanding of "normal" or even of "self," makes clear the need to analyze and critique our models and their consequences in thought and action.

### *The Limits Model*

It is my contention that we must attend to both the medical and minority perspectives but also be willing to go beyond them and be open to new models.<sup>56</sup> As we have discovered, the term "disability," as it is commonly used in the two existing models, is too often an absolute category without a level or threshold. One is either disabled or not. As noted earlier, from this perspective "one cannot be a little disabled any more than one can be a little pregnant."<sup>57</sup> Yet reflection on the lived experiences of people who identify as disabled, as well as those who do not, shows the category of disability to be a fluid construction. As discussed previously, ambiguity in my own identity is part of what leaves me dissatisfied with both the medical and minority models. Today, as I sit to write this text, I may feel disabled—aware of the pain and limitations of my body and of the barriers imposed by the physical environment that surrounds me. Tomorrow, sitting comfortably in a chair discussing this work with a friend, I may feel not-disabled. Though this fluidity may not be the primary experience for all people, either with or without disability, most of us experience some situations where we feel more or less disabled than in other situations. Such fluidity reminds us that disability is not just an either/or—it is also a "when," "where," and "how." Lived experiences of disability like these have no home within either the medical or minority models.

Attention to fluidity, as well as to the commitment that disability is as much an identity statement as it is a biological or sociopolitical condition, leads me to a consideration of disability as an instantiation and reminder of human limits. The limits model differs from the medical and minority models in that it does not attempt to divide participants into one of two categories (either disabled or not-disabled) but instead offers a new way to think about what disability is. It attempts to engage in critical reflection on embodied experience and offers us a way to think about the limits of each person and situation and of what such limits may enable or make difficult. Where the medical model begins with an evaluation or assessment of limitations, the limits model begins with the notion of limits as a common, indeed quite unsurprising, aspect of being human. Unlike the minority model, the limits model avoids categorization and instead encourages us to acknowledge a web of related experiences, suggesting, for example, that a legally blind person may in some ways be more similar to a

person who wears glasses than to a person who uses a wheelchair. The medical and minority models offer valuable perspectives; the limits model offers a companion piece that emphasizes reflection on the experience of embodiment in its various formations, including disabled embodiment.

Sallie McFague suggests that the test of a model is in looking at what it allows us to see and what it allows us to say, knowing that every model is partial and is only one square in the quilt. We can see and say that the limits model has potential insofar as it highlights the fact that we all experience limits, that these limits differ, and that these limits are accepted, rejected, accentuated, complicated, degraded, and lived in many different ways. It offers us the ability to think of the presence of limits as a natural and good aspect of being human that at the same time is inherently difficult and challenging. It provides us with a new paradigm to make sense of ability and disability. This perspective of limits does not universalize, relativize, or minimize individual experiences but instead proposes an area of common ground in the midst of the recognition of exceptional incarnated and environmental differences. It gives us a place for some very important conversations to begin. It does not dismiss the insights of the medical or minority models but offers a needed theoretical perspective that helps make greater sense of "the experience of disability."

Key to the limits model is the recognition that "disability" is actually more normal than any other state of embodiedness. As such, disability should not be an afterthought to models of embodiment. As Stuart notes, "In truth the human body is only ever temporarily-abled and hence reflection on the disabled body should be central to any theorizing on the body."<sup>58</sup> As a starting point, the limits model notes that good health is never a permanent state, so the "exception" (disability) is perhaps actually more "normal" than the norm (able-bodiedness). Beyond this, however, the limits model highlights the ways and degrees to which we all experience limitation as an unavoidable aspect of humanity. Limits are not an unusual experience and might even be considered an intrinsic element of being human. Some limits are more profound than others, and many are not accommodated by our physical and social environment, but I argue that limits are more common than we typically consider them to be. We must recognize the existence and prevalence of limits and begin with disability or limits as central to our theoretical and theological reflection rather than as exceptions. The limits model proposed in this work attempts to do just that: to start with the human variations of ability as the norm, and to build theory and theology from that starting place.

Beyond offering an important complement to medical and minority models in disability studies, the limits model has a number of direct implications for theological reflection. As we will see in the chapters that follow, the limits

model highlights the fact that all people are limited to varying degrees, and offers this perspective as a foundation for theological reflection. When understood as part of what it means to be human, limits are no longer something to be overcome in search of perfection or something that is experienced as a punishment for sinfulness. From the limits perspective, sin might now be redefined as an inappropriate attitude toward limits as we both exaggerate and also reject our own limits and the limits of others. Disability might be understood as limits that are not accommodated by the environment.<sup>59</sup> Rather than minimizing the experiences of disability, this perspective allows us to identify areas where our limits become disabling due to physical or social barriers, relocating sinfulness. It also identifies prejudices we hold about limits—that is, how we see some limits as “natural” (we cannot fly) and others as “defective” (I cannot run)—and offers an opportunity for a critical reexamination of such views. Moving away from such prejudices, we might instead explore the relationship between limits and creativity, or wonder what the existence of limits tells us about the nature of humanity. Through this new lens, questions may also be raised about images and understandings of God.

Christian theology has not, until now, looked at disability from a perspective anything like that of the limits model. When disability has been considered at all, such attention has been based primarily on medical or minority understandings of disability, raising questions such as: Is the reason for my disability my own sin or that of my parents? How might my congregation work to better include people with disabilities in worship? Under these models, disability has rarely been used as a source for theological reflection. In the chapters that follow, we will continue to attend to all three models as we examine our past inheritance and future potential for disability in the Christian tradition. In addition to discovering a long history of attention to disability and other “unusual” forms of embodiment, we will see that the medical, minority, and limits models each has value as a square in the quilt we make as we consider future constructive possibilities for disability and Christian theology.