2016

The unheard voices of people with disabilities: practical theology in conversation with the spiritualities of Julian of Norwich and Teresa of Avila

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http://hdl.handle.net/2144/16325

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THE UNHEARD VOICES OF PEOPLE WITH DISABILITIES: PRACTICAL THEOLOGY IN CONVERSATION WITH THE SPIRITUALITIES OF JULIAN OF NORWICH AND TERESA OF AVILA

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Submitted in partial fulfillment of the requirements for the degree of

Doctor of Philosophy

2016
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One can never consent to creep when one has the impulse to soar.

– Helen Keller
DEDICATION

I dedicate this work to the one who said to me,

“You are my hero,” and the three “Cs” in my life.
ACKNOWLEDGMENTS

I would like to thank Dr. Claire Wolfteich for being my mentor and guide over the years of my journey to become a theologian. During our years together, through her quiet but steady direction I have learned how to know and express the truth of God as a practical theologian in our pluralistic society. I can think of no other sacred gift I would have rather received. As I embark on my future path, I can only hope to pass on this blessed gift to others as she did to me. I would like to thank Dean Mary Elizabeth Moore her careful reading of this dissertation, as she provided many thoughtful comments and edits. Thanks goes out to my defense committee members for their helpful suggestions andattentive reading of this dissertation. To my other professors at Boston University, please know that your help and support has taken fruitful root within me and in this dissertation.

This dissertation and my work in general has many supporters, some from my Chicago days at the University of Chicago where I was taught by some great theologians, namely: Don S. Browning, Anne Carr, Kathryn Tanner, Stephanie Paulsell, and of course my good friend David Tracy. My debt to him and his work is tremendous; it is here that I would like to thank David Tracy for his unequivocal support of me and of my quest to find my distinctive voice as a theologian. To my good friend, Dr. Elizabeth Musselman-Palmer, thanks so much for supporting me and my work. A very special “thanks” goes to Dr. Peggy Hothem for nurturing my young intellectual life, for teaching me how to live the life of faith, and for always encouraging me to believe in myself as a woman of God. To all of my many supporters, family, friends, neighbors and colleagues, I say, “Thank
you! This dissertation would not have been written without your kind encouraging words, and numerous favors.” Among these wonderful supporters are my friends and colleagues at the Center for Biostatistics in AIDS Research at Harvard University who cheered me on and encouraged me during my dissertation writing. Of course, all of the wonderful people at New England IRB are among those who also deserve my many thanks and gratitude.

I had a group of key supporters during the writing of this dissertation and throughout my degree program. Dr. Dawna Thomas served as an honorary advisor to my work, providing me with an “insider” view of important next steps throughout my degree program. Karen’s friendship and weekly outings for sharing nourished me and encouraged me to keep writing. On Carole I bestow an honorary doctoral degree for her unparalleled nurturing support during the writing of this dissertation. Thanks to my siblings and other family members for letting me know, “You can do it!” Lastly, to my parents, who now gaze upon me from the other side of the universe, you taught me how to fight and how to dream: thank you. Now I know I have surpassed your wildest expectations of me, and that you are both very proud of me.

Thanks to all my many supporters. Now onward to the next great adventure!
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ABSTRACT

This practical theological study draws on the theological method of Don S. Browning to implement a mutually critical correlation between the everyday experiences of people with disabilities depicted in six case study narratives and selected texts of two mystical authors, Julian of Norwich and Teresa of Avila. The study brings to light the harsh everyday reality of living with a physical disability, articulates disability as a practice, and outlines the operative effective history of the United States associated with physical disability. This operative history has long kept the harsh reality of embodied vulnerability hidden from view and thus has contributed to the marginalization of people with disabilities. The critical dialogue between the narratives of persons with disabilities and the selected mystical texts provides a new hermeneutical lens through which to read mystical theology and reveals insights into embodiment and marginalization that bear implications for spirituality studies, disability studies, and practical theology.
This dissertation argues that scholars in disability studies neglect embodied vulnerability when they define disability only as a social construction. Chapter One proposes that disability is both a social construction and a biological reality. The next chapter illustrates that people with disabilities still experience existential absurdity and that predominant norms in the United States (however unconscious) continue to try to conceal or avoid the negative effects of embodied difference. The study then analyzes the themes of embodiment and marginalization in the mystical theologies of Julian of Norwich and Teresa of Avila. Chapter Three reveals that Julian’s relational conception of the Trinity and God’s immanence in the humblest of needs offer ways to establish dignity for people with disabilities. Chapter Four shows that mystical prayer provides impetus for Teresa’s work as a social reformer, which challenges sixteenth century Spain to welcome conversos and value women. The final chapter shows that the mutually critical conversation offers a starting point for building theological constructs of embodied spirituality to respond to the avoidance of embodied vulnerability and the challenges of living with physical disability.
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LIST OF ABBREVIATIONS

ADA ...................................................................................... Americans with Disability Act
BU ............................................................................................................ Boston University
CP ................................................................................................................... Cerebral Palsy
DVT ................................................................................................. Deep Vein Thrombosis
F ............................................................................................. The Book of Her Foundations
GBS ............................................................................................... Guillain-Barré Syndrome
IC............................................................................................................. The Interior Castle
IRB ............................................................................................. Institutional Review Board
L .......................................................................................................... The Book of Her Life
LE ............................................................................................................... Collected Letters
LT .......................................................................................................................... Long Text
ST .......................................................................................................................... Short Text
WP..................................................................................................... The Way of Perfection
CHAPTER 1
INTRODUCTION TO DISABILITY AND THEOLOGY

Introduction

David Tracy writes, “The final indignity is to be forbidden one’s own voice and robbed of one’s own experience.”¹ For centuries people with disabilities have been deeply marginalized and excluded from participating in life and public discourse.

Through the centuries, people with disabilities have been perceived as subhuman, evil, scapegoats, and entertainers (as in the circus or freak shows), as demonic or imbued with extraordinary spiritual powers.² The exclusion of people with disabilities from public education and the public square contributes to the dearth of texts that depict the experience of disability. People with disabilities did not receive the right to be included in public schools in the United States until 1975 with the passage of public law PL 94-142.³ Disability rights advocates still seek to end the social marginalization, stigma, and negative attitudes wrongly attached to those with disabilities so that they are properly included as full participants in their respective communities.

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In an effort to address the marginalization of people with disabilities from the public square, this dissertation listens to the unheard voices of people with disabilities. This study integrates the voices of people with disabilities depicted through qualitative interviews into the academic discourses of practical theology, spirituality, and disability studies to address the problem of inadequate conceptions and definitions of disability. The interview narratives examine disability as a social construction, a form of social oppression, and a form of impairment and limitation. Moreover, the narratives are embodied texts of lived religion that can be placed in dialogue with embodied mystical texts to reshape theological constructs of embodied spirituality. My hope is that a two-way conversation between the everyday experiences of disability and two mystics will offer rich insights into the everyday lives of people with disabilities while providing new hermeneutical lenses for reading mystical theology.

The disability studies literature predominately defines disability as a social construction. Yet disability as a social construction comes nowhere close to accurately portraying the physical and social challenges that people with physical disabilities confront every day, and merely perpetuates the experience of embodied life with a disability in a way that is out of touch with the actual embodied life of disability. To offset the overreliance of disability defined as a social construction, this study instead

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4 Barbara J. Lutz and Barbara J. Bowers, “Disability in Everyday Life,” *Qualitative Health Research* 15, no. 8 (October 1, 2005): 1051. An example of an everyday challenge for someone with a physical disability might be the struggle to find a wheelchair accessible bathroom.

5 Disability theology here refers to attempts to integrate a discussion of disability into theological discourse.
draws on the everyday lived experience of physical disability as a theological source.\(^6\)

Nancy Eiesland makes the point that sometimes it is advantageous to distinguish between physical and intellectual disability because of differences in experience. Thus, for this study disability will mean physical disability unless otherwise specified.

The narratives of people with disabilities collected through qualitative interviews will add complexity to current definitions of disability that are operative in disability studies and disability theology literature. Interviews in this study will reveal how physical disability interacts with social realities and with the everyday lived religion of people with disabilities. Furthermore, this study brings the interviews among the unheard and historically marginalized voices of people with disabilities into a mutually critical theological conversation with the writings of Julian of Norwich and Teresa of Avila, both of whom drew upon their own lived experience in crafting their theologies. The dissertation will illustrate this conversation through a limited sampling of “case studies” drawn from qualitative research and brought into dialogue with Julian and Teresa. I will argue for the significant implications of this approach for practical theology and spirituality studies, and I plan to develop a larger set of qualitative research data in future writing, but that is beyond the scope of this dissertation. For now, in chapters 1 and 2 this dissertation uses the case study narratives to describe and critique the theoretical literature of disability studies.

It is important before advancing into the chapter to clarify some basic distinctions concerning the definition of disability. The definition offered here is the operative definition used in this dissertation. It is distinct from the disability studies debate concerning the definition of disability offered below. In this dissertation embodied impairment is understood as a set of biologically based physical limitations that prohibit normal bodily function. Able-bodied people and people with disabilities experience embodied impairment. The primary distinction between being disabled and non-disabled is that people with disabilities experience marginalization and oppression because of their embodied impairments. Furthermore, people with disabilities fit within the legal definition of disability, whereas other forms of embodied impairment do not. The legal definition of disability according to the Americans with Disabilities Act (ADA) is as follows:

A person with a disability as a person who has a physical or mental impairment that substantially limits one or more major life activities. This includes people who have a record of such an impairment, even if they do not currently have a disability. It also includes individuals who do not have a disability but are regarded as having a disability.\(^7\)

Thus, a blind person fits within the legal definition of disability and the embodied impairment is the inability to see. On the other hand, someone with a broken arm experiences embodied impairment because of the immobility of the arm. However, the broken arm does not fit the legal definition of disability and it does not lead to marginalization. Thus, in this study people with physical disabilities are defined as people

who fit the legal definition of disability, as they also experience marginalization because of their embodied impairments.

The current chapter introduces disability and disability studies in an effort to describe how the unique characteristics of disability relate to the development of a practical theology of disability. First, this chapter will describe the interviewees who participated in this study through qualitative interviews. Next, the discussion moves to the decades old debate concerning the definition of disability. The important issue of whether or not to include those with cognitive impairments follows the section on the debate concerning the definition of disability. The discussion advances to consider the relationship between the current literature in disability theology and the construction of a practical theology of disability for this dissertation. Lastly, in an effort to frame the initial discussion of the contemporary situation of people with disabilities, the chapter begins to explore the social frameworks that contribute to the marginalization of people with disabilities.

**Who are the Interviewees in this Study?**

This study will integrate data from six qualitative interviews used as case studies. Below is a brief description of the interviewees to contextualize who they are and how they are socially located. The names, locations, and some particular details have been altered to allow the interviewees’ identities to remain anonymous.

Desiree is a 59 year-old Cape Verdean black woman who earned a Ph.D. and now teaches as an associate professor on topics of gender and race with some disability studies
at an institution of higher education in New England. Her interests in cultural diversity grew out of her own experience as a member of a Cape Verdean family and community that exudes diversity. Her interest in teaching disability began through her own experience of congenital heart disease. Desiree literally grew up in the hospital where she had to learn to contend with having Ebstein’s anomaly of the tricuspid valve.

Lisa is a 55 year-old white woman with cerebral palsy. She can walk independently with no assistive devices but sometimes she uses two crutches to walk in order to prevent frequent falls that have caused medical problems. She has a master’s degree in education and she currently works as an Independent Living Skills Trainer. As a Skills Trainer she helps people with disabilities live independently in their homes and helps people with disabilities obtain critical resources to function in their daily lives. She currently collects Social Security Disability and works part-time up to the limited number of working hours that Social Security allows. A few years ago she was able to work full-time but the pain in her legs became too much for her to tolerate, so she cut back on her work, now collects Social Security benefits, and experiences much less pain. Lisa grew up in a devout but also strict Catholic home. She describes herself as a recovering alcoholic who has been sober for the last sixteen years. Lisa now attends the Unitarian Universalist church near her home, which provides her with a sense of community and support.

Maria is a 42 year-old white woman who was born with cerebral palsy, which impacts her balance and walking gait. Maria ambulates without crutches or a cane; however, her different gait is noticeable to others. Maria is a sophisticated beautiful
woman who pays particular attention to her appearance and is impeccably dressed for her interview. She is married and has an 8 year-old son Andrew. Maria is now in a Ph.D. program in nursing to advance her career as a nurse educator and pediatric nurse. Maria describes herself as a Christian who was recently baptized because she wanted to be sure of her salvation; she notes that this isn’t necessarily because of a deep evangelical faith, but rather because of her realization of the presence of God in her midst. Maria’s mother sought to have Maria baptized as a child but the Catholic priest refused and the family surmised that the refusal had something to do with Maria’s disability.

John is a 59 year-old white man who has the equivalent of two years of college education and was a social worker prior to becoming disabled as a consequence of contracting Guillain-Barré Syndrome (GBS) at the age of 43. The GBS is a rare paralyzing condition that effects a person for years or for life. In John’s case, he is paralyzed from the waist down and is not expected to improve in this regard. He suspects (and some medical literature supports him in this claim) that the GBS was caused by a flu shot that was required for his job as a social worker. He currently collects Social Security disability. John describes himself as a “born-again” evangelical Christian who now infrequently attends a non-denominational church.

Mary is a 54 year-old white woman with cerebral palsy. She earned a BS degree in business from a university in Rhode Island. She worked for over 35 years in the banking and customer service industry. After a shoulder injury, she experienced a near deadly blood clot and has been unable to work due to severe medical complications. At this time she is waiting to hear from Social Security as to whether she is eligible to
receive benefits. She recently married a man whom she met while participating in a choir at the Episcopal Church that she regularly attends in Rhode Island.

Tom is a 47 year-old white man with very severe cerebral palsy that leaves his muscles contracted and very tight. He has some control of his left hand with which he moves a “joystick” control to operate an elaborate motorized wheelchair. Tom has a master’s degree in education from a university in Boston. He works as an unpaid activist at the Massachusetts Statehouse to initiate the passage of legislation to improve the lives of people with disabilities. Tom does this work in spite of a very severe speech impediment that makes him very difficult to understand without practice and focused attention. During my interview with him, his personal care attendant was present (with his consent and IRB approval) because his interview would have been impossible for me to understand without the extra translating assistance.

At the conclusion of this summary of the interviewees, I would like to acknowledge my own lifelong disability of cerebral palsy. My cerebral palsy distorts my walking gait, and other people immediately know that I have a physical disability. For the most part, I ambulate through my daily activities without any assistive devices, although sometimes now because of my age I use a cane. I have a lifetime of knowledge about what it means to live with a disability and this is part of what sparked my interest in this dissertation topic. For the most part I have tried to allow my interviewees to speak freely without my interrupting, as my role in this work is to listen. My hope is that through my listening, I have allowed the voices of the interviewees to be heard with authenticity in
the academy. However, I also hope that my voice as a theologian will speak throughout this entire dissertation.

**The Definition of Disability Debate**

As the discussion throughout this chapter will show defining disability is complex. Furthermore, this chapter will reveal that conceptions of disability influence the trajectory of theoretical discussions which in the end impact academic discourse. For this reason the discussion of the definition of disability is critical to the development of a practical theology of disability. The academic field of disability studies is engaged in an important decades-old debate as to whether disability is an individual or a social construct. The debate has implications for this dissertation and for negotiating the conversation between theology and the experience of disability because the manner in which disability is defined determines the trajectory of theological constructions. The medical model of disability defines disability as an individual construct that deems people as disabled based on physical impairment and closely follows medically-based conceptions of disability.\(^8\)

Disability as a social model emerged in the mid-1970s in Britain.\(^9\) The social model grew out of a response to the medical model and the use of medical definitions of disability and the derogatory connotations of defining disability as lack, abnormality, or


impairment. This social construction model defines disability not as a physical impairment but as a function of complex social and political dynamics that set a standard of normalcy. Philip M. Ferguson and Emily Nusbaum point out that the social construction and medical model definition debate of disability is “one of the most influential contributions to the theoretical study of disability in the last 40 years.” The definition of disability is critically important to developing a theology of disability that considers the everyday lives of people with disabilities because it identifies the starting point that shapes theological constructions. Is the definition of disability as a social construction adequate?

The social construction model makes it difficult to enter into a conversation about embodied impairment, for it neglects the truth that many people with disabilities depend upon the medical model and medical treatment to sustain their lives. The social model of disability argues that disability is only socially constructed rather than biologically derived. The consensus for many years within the field of disability studies is that disability is a social construction. However, recently a few disability scholars have addressed the issue of embodiment. Bill Hughes and Kevin Paterson, scholars in the disability studies field argue that the experience of impairment has not been completely

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11 The number of sources that cite the social construction model far outnumbers the few that consider the aspects of embodiment, Anne Finger, Elegy for a Disease: A Personal and Cultural History of Polio, 1st ed. (New York: St. Martin’s Press, 2006); Thomas Shakespeare, Disability Rights and Wrongs (New York: Routledge, 2006); Tobin Siebers, Disability Theory, Corporealities (Ann Arbor, MI: University of Michigan Press, 2008).
ignored but that its consideration “remains theoretically embryonic.” Furthermore, Hughes and Paterson, citing the work of Thomas Shakespeare and Nicholas Watson, point out that, “there has been little or no engagement between disability studies and the sociology of the body.” The work that considers embodiment within disability studies still remains very small; the majority of literature in the field still holds firmly to the primacy of the social construction model to describe disability. Shakespeare argues that the definition of disability as a social construction separates bodily function from societal attitude, and in so doing, removes embodied experience from disability discourse. This neglects the experience of various kinds of everyday pain, suffering, and trauma associated with living with a disability. In light of this, Tobin Siebers calls for a new realism regarding the disabled body, one that takes seriously the daily routines of the disabled body, and that invites a change in attitudes toward the disabled body.

The disability rights movement used the perspective of disability as a social construction to curtail the categorization of people with disabilities as sick or unable to carry out the tasks of human life in society. Ironically as a result of this stance it became

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12 Bill Hughes and Kevin Paterson, “The Social Model of Disability and the Disappearing Body: Towards a Sociology of Impairment,” *Disability & Society* 12, no. 3 (1997): 326; It is also important to note that a lack of attention to the body also exists in the discipline of sociology, Michael Kelly and David Field note, “However, in most types of sociological narrative about chronic illness, the body remains theoretically elusive. Its existence is seldom explicitly denied, but its presence has a kind of ethereal quality forever gliding out of analytic view,” in Michael P. Kelly and David Field, “Medical Sociology, Chronic Illness and the Body,” *Sociology of Health & Illness* 18, no. 2 (1996): 242.


increasingly difficult for people with disabilities to discuss and bring to the forefront the actual physical difficulties their disabilities created in their lives. The social construction model when employed in the context of people with disabilities leads to a denial of the experience of disability and its biological origin. Feminists were the first to point out the irony that when people referred to the social construction of disability (rather than the medical model) it disembodies disability discourse. It stands to reason that disability discourse should involve embodiment. Susan Wendell believes that disability activists propose a liberatory vision of social constructionism because it is “safer and more comfortable for disability activism to focus on people who are healthy disabled.”

Furthermore, Wendell explains, “Yet some people with disabilities are sick, diseased, and ill.” Wendell makes the point that the social construction stance neglects the unhealthy disabled body because it analyzes oppressive structures, policies, attitudes, and other social injustices as the primary causes of oppression of people with disabilities and this reduces the attention on those with disabilities that do in fact fit into the medical model.

Two of the case studies used in this dissertation shed light on the medical model and how it actually operates for people with disabilities, at least as one part of the total picture. Maria recounts a confrontation with her doctor over extreme pain in her foot caused by her cerebral palsy. Maria explains:

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17 Ibid.

18 Ibid., 163–164.
I went to my primary care physician about a year ago about my foot pain that was really bothering me. I suppose I knew that the real cause of the foot pain was related to cerebral palsy in the back of my head. But it kind of had an acute onset, so I wasn’t definitely sure. To me I could’ve had a broken bone in my foot. So of course I waited until I realized it wasn’t going to go away on its own. Before you can go see somebody else you need to go to your primary care physician, so I went to the primary care physician. I had my son with me because I figured it was my foot, I didn’t think it would be a big deal to take him with me to the doctor. And the doctor was actually kind of mean to me, and he said to me my foot wasn’t designed to walk that way and so there was nothing that he could do about my foot pain. Nor did he know who to refer me to, so if I could figure it out he would be happy to refer me to anyone who could help me. You have to be your own advocate. Fortunately, for me I had enough resources to be able to figure it out and get what I needed. But when he said, “Your foot wasn’t designed to walk that way,” and I have this foot that’s killing me, you’re not even going to take an x-ray to make sure that there is nothing that you can help me with?”

Maria did in fact receive the medical treatment she needed for her foot related pain due to her cerebral palsy but it came through a great deal of effort on her part to find the right medical care. Once Maria found the proper medical professionals to attend to her foot pain, her primary care physician did make the referral for treatment and Maria’s pain has now subsided.

The point is that proper medical care is essential for people with disabilities to carry on with their daily lives, but that care does not always come with ease or without extra effort on the part of people with disabilities. In Maria’s story we see the doctor throwing up his hands and in a sense saying, “You’re foot is not normal, I can’t treat you.” The disability studies debate over the definition and critique of the medical model fails to see the obvious dependence of people with disabilities on medical advancements and technology. Thus, disability studies scholars do not recognize the obvious
dependence of people with disabilities on medical care when advocating for the social construction model. Scholars in disability studies would likely take issue with Maria’s doctor describing her foot as abnormal. However, Maria’s doctor is correct on one level in pointing out the truth that Maria’s foot is abnormal. Another vantage point shows that Maria’s doctor could have treated her with more sensitivity. The challenge is to help doctors and other medical professionals to develop more sensitivity to the unique needs of people with disabilities while delivering proper medical care. The important critique is to find ways to step into the important issues of the medical model and not to deny its importance.

Desiree’s life with a rare congenital heart condition, further illustrates the dependence of people with disabilities on medical care. People with Desiree’s condition often experience heart arrhythmias, low exercise tolerance, easy fatigue, brain abscess, and the chance of sudden death increases. Desiree notes, “I always need to live close to a really good hospital.” Desiree’s condition requires regular medical evaluations from cardiologist experienced in the treatment of patients with congenital heart disease.

In her 59 years of life, she has endured two major heart surgeries, had six pacemakers implanted and underwent about twenty cardiac catheterization procedures. Thus, Desiree’s life from an early age was filled with hospital visits. During her interview she told the following story regarding her frequent trips to the hospital:

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I think as a child I grew up kind of semi in the hospital. I always went to the hospital. I thought everyone went to the hospital until I was 14. I was having a cardiac catheterization at fourteen and I went to get homework because I was going to miss school and this girl said to me, “Aren’t you afraid?” I said to her, “No, it’s kind of routine.” She said, “I’ve never been in the hospital.” And I looked at her and said, “How do you live?” because I thought everybody lived in the hospital like me. I didn’t know the difference.

The critique of the medical model by the disability studies discipline criticizes the idea of defining people as “abnormal.” However, the narratives attest to the fact that Maria’s foot and Desiree’s heart are not “normal.” Disability studies also takes issue with framing disability in individualistic medical terms. However, the truth is clear from the two narratives that there is an ongoing dependence on individualized medical care to address the unique needs of people with disabilities. Disability studies misunderstands the need for the medical model and that the specification of abnormality in defining disability is accurate.

Most people with disabilities need ongoing medical care regardless of whether disability is conceived of as a social construction or not. Regardless of the definition of disability, the medical need cannot be eliminated. Medical care and even the definition of “health” is complex. A specific treatment provides relief and a “cure” while it may compromise another area of health. In a compilation of essays entitled The Meaning of Health, Paul Tillich points out that, “Successful surgery may produce a psychological trauma…Particular healing is unavoidable, but it has the tendency to provoke diseases in
another realm.” For this reason, Tillich argues that, “The concept of health cannot be defined without the relation of its opposite: disease.” Tillich’s argument concerning health and disease has to do with “unhealthy health,” by which he means that sometimes the intervention is worse than the disease itself.

The challenge in understanding health in relation to disability is to discern what within the impairment itself (limited function of limbs, senses, or other capacities) constitutes ill health. The difference is not as clear as those in the medical profession would have us believe. The concepts of normality and health are complex and difficult to define with precision. People can develop individualized concepts of what “normal” or “healthy” means for their individual bodies. The fact that someone with cerebral palsy walks around with extremely tight muscles is “normal” for them, but in terms of the medical model such muscular tightness needs medical intervention to improve health. And it is very true that increased flexibility for those who struggle with spastic muscles is a grand health benefit that leads to the amelioration of some functional limitations and improves daily living. However, Paul Tillich’s concept of “unhealthy health” is somewhat shortsighted in that it assumes that there is a complete whole health to be had, when in reality we all have aspects of ourselves that are healthy and those that are not. We are all in a perpetual state of “unhealthy health,” and perfect health is a misnomer. Tillich says that our health has to do with our finitude and our finitude is inescapable, so

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22 Ibid., 173.
some measure of ill health is afforded to us all. Some obviously have more disease and ill
health than others, but our health is always dynamic over time.

Even with the ebb and flow of health and illness, it seems appropriate to claim
that no one would choose disease over being healthy. So in examining the concept of
health, it is plausible to argue that it is always better to be healthy than to be in a state of
ill health or disease. It is also true in some sense that people are more impaired than at
other times, but no matter the removal of the social constructs of disability, people with
disabilities will always experience disadvantages because of their impairments and it will
always be more advantageous to live without a disability than to have one. In defining
disability exclusively as a social construction, scholars engaged in reflection on disability
take the stance that disability is similar to other oppressions, meaning simply there is
nothing wrong with being disabled. However, Thomas Shakespeare points out the error in
this type of stance when it comes to disability:

There is nothing intrinsically problematic about being female or having a
different sexual orientation, or a different skin pigmentation or body
shape. These other experiences are about wrongful limitation of negative
freedom. Remove the social discrimination, and women and people of
color and gay and lesbian people will be able to flourish and participate.
But disabled people face both discrimination and intrinsic limitations.23

Shakespeare explains that disability is different than the other “isms” in which
people argue that experiences are socially constructed. With race, gender, and sexual
orientation, when the social construction is removed people can go on with their lives and
experience social justice. Yet even if the social construction of disability is removed,

people with disabilities experience many hardships that others do not experience; and these difficulties cannot be completely alleviated through social justice movements. Shakespeare explains “it will remain disadvantageous to have many forms of impairments.” The social construction model by itself does not adequately describe the contemporary situation of disability. The focus on the healthy disabled and the disembodied approach of the social construction model prohibits the concrete attention upon the embodied challenges of living with a disability. A practical theology of disability seeks to integrate a more embodied approach into theological conceptions in order to more adequately describe and address the challenges of living with a disability.

A portion of Mary’s case study illustrates how the social construction model functions in the minds of people with disabilities. Mary decided early in her life not to give anyone her time and energy if they could not understand her disability.

My friends were my friends and my dorm mates, the ones that I didn’t freak out I was friends with and the ones I freaked out we steered clear of each other. I was never put in a difficult position. I knew people at school ahead of me like the choir director’s son was in the fraternity that was closest to my dorm. So he came over a few times and said hey we are having a party why don’t you come. So I went a couple of times to that house…. so I was just “normal,” “normal” they just treated me like all the other girls. They would have parties and someone would say, “Call her up, call her up.” So I would go and someone would come to meet me at the front door and they would say to me, “I’ll take you downstairs this way but after tonight, make sure someone lets you out downstairs.” Because the same room as the dancing and the social room there is an entrance that came out to the parking lot. So then I learned that way, so I would send someone to the front door to open up the back door and get them and they would let me in on the bottom. So it was all good because I learned at a young age to speak up for myself, or I was made stronger either by all of

24 Ibid.
the physical therapy and stuff I did and by being allowed to be a normal child and play with my sister and friends that got off the school bus near us. So I never had a communication problem describing myself. I don’t ever remember feeling low about myself or less.

Mary’s narrative makes an important point about adaptability to a “new normal” among able-bodied people and people with disabilities. Because Mary is present at the school and out in her community, people get to know her and in gaining knowledge of what she needs, people around her adapt to help her. Marginalization exists in our society but there is also a sense of a desire to be helpful, kind, and compassionate.

Mary’s exclamation of being normal reveals a denial of difference that operates at times in her life. However, there is a difference, for example, when Mary is let into the party through the back door. The denial of difference holds at bay the actual everyday experience of disability. This perhaps helps Mary carry out her daily activities with more ease than if she lives with complete awareness of her daily challenges. It is important to consider what the social model gives to people with disabilities. In some ways the harshness of living with disability can be too much to cope with on a daily basis. In this way the social model and the denial of embodied difference provides a temporary way out of the harshness of disability. This denial of the difficulties of disability enables people with disabilities to live and work unimpeded by complete awareness of their physical limitations. In this way the social model is helpful. However, it is important to consider, the denial of embodied difference and its difficulties does not make the harshness go away. Instead, denial temporarily masks the problems and difficulties. What is interesting about Mary’s narrative is what is in the white space and margins that is not
articulated about her experiences of difference. It is difficult to break through the denial of difference. Physical difference often does not show itself until the physical difference confronts the person with a disability in a harsh way.

Two case studies illustrate the confrontation of embodied difference in everyday life. Tom as a lifelong wheelchair user articulates the harsh reality of disability, when he says, “A bad day is when, I have a plan in mind and I can’t do it.” Maria explains that her disability is usually “no big deal” until, “I can’t do something that I want to do.” Maria conveys a story of one such situation:

When I was a kid I used to ride bicycles all the time. So this summer I decided I was going to get a bike and I was gonna take Andrew (Maria’s 8 year-old son) and will go riding on these bike trails. So I got a bike and I can’t ride it. I don’t have the balance anymore to ride the bike that I used to have. So that was really frustrating to me. So first of all I needed a bike that I could get on, so I’d be able to lift my leg high enough and wanted to be able to get on the bike. And not all bikes are made the way they used to be anymore, so it was hard to find a bike. So we went to a bike store and we looked around and we couldn’t find one. So we ended up ordering this bike online and my husband ended up putting it together. And I took it out for the first time at the top of my driveway where was kind of flat. I was able to coast around but I did it when I was all by myself, which might’ve been kind of stupid, because if I had fallen and broken my hip then there would’ve been no one to help me…. but I didn’t want anybody to see me I was hoping the neighbors weren’t watching. If I could’ve practiced in a black box I would’ve. So I was able to coast around but the area was only so big. So I really couldn’t peddle but I felt pretty good I was scared I could feel my heart racing but I was able to coast around. When I tried it the second time again by myself I fell. And I jammed my pinky finger back pretty hard, I probably did do something to my finger but it doesn’t hurt now but it did for about five weeks. So I definitely did something to my pinky finger but I wasn’t even going to admit to anyone in my house that I had done that. And then I realized that I probably needed some help with the bike, so I enlisted my husband. And then when I tried to ride the bike with his help, helping might not be the right word because he wasn’t helping me in the way that I wanted or something. I wanted him to hold the bike more, or like I was learning to ride a bike for the first time, even
though I used to be completely competent at bicycle riding. And so he wasn’t I don’t think he was realizing how much help I really needed because of course he didn’t know this background story of me already falling. I didn’t tell him. So I think I tried with his quote on quote help. I think I ended up falling about three times. And the last time he was like, “You need to [stop] you can’t do this right now you need to get off the bicycle.” So then I was hysterical crying, this was in the privacy of our own driveway so it was not really public, but I made my son stay in the house because I didn’t really want him to be watching his mother fail at this….So I cried and was upset and when I get upset like that my husband I guess knows that I usually like to just deal with it by myself and I kinda had this get away from me mentality like don’t come near me….I need to deal with it by myself.

Maria confronts her disability when she tries to create a situation of fun and normalcy for her and her son through bike riding. Maria seeks to ride the bike as a way of being a “normal” mom. She imagines in her mind her and her son riding on the bike trails. She is concerned with her son seeing his mom fail as she attempts to ride so he is told to stay in the house. When the attempts at riding fail, Maria is confronted with her disability in a way that she does not want to admit. Maria cries alone as she contends with her embodied difference.

The social construction model of disability neglects the reality of embodied difference and in doing so negates the embodied reality of disability. However, such models tend to diminish the capacity of persons to fully consider the harsh reality that is involved in a life with a disability, and in this way the models only provide a partial way to battle oppression. They do not address the real issues of embodied difference. The difficulty of accepting the harsh reality of disability as embodied impairment is that it seems to provide no way for people with disabilities to end their marginalization. There are inherent disadvantages of living with a disability with no available corrective in a
society that misunderstands the meaning of that embodied difference while it elevates beauty and athleticism. The corrective begins through naming the embodied experience of physical disability as it is truly experienced in daily life with its physical and social complexity. A brief discussion of rehabilitation literature is necessary to comprehend what is at stake in accepting the harsh reality of disability.

This dissertation draws upon studies from the allied health professions in order to grapple with disability as embodied difference. Disability studies tends not to rely upon rehabilitation research in its conceptions because of the association of rehabilitation with the medical model. Scholars in rehabilitation research point out that, “Successful psychosocial adaptation has been implicated as a powerful correlate of successful rehabilitation, vocational adjustment, perceived well-being, overall life satisfaction, and improved quality-of-life among people with chronic illness and disability.”

The predominant perspective among rehabilitation researchers is that denial of disability or chronic disease is a maladaptive response linked to psychological maladjustment, poor health outcomes and diminished quality of life. The social model’s inability to allow for a discussion concerning embodied difference creates silence concerning the embodied challenges of living with a disability. While it is not completely clear that this silence directly facilitates a lack of self-acceptance among the everyday lives of people with physical disability.


disabilities, it seems plausible to argue that the silence is at least not as helpful as open discussion. It is not possible to draw a direct link between the denial of embodied difference within the social model and a lack of self-acceptance among people with disabilities. However, this study moves in the direction of self-acceptance of embodied difference as a potential way of fostering a healthy response to disability.

Another detrimental fall out that originates from the social model and the denial of embodied difference is the neglect of embodied wisdom and knowledge of those with physical disabilities. Louise Thibodaux notes that rehabilitation literature amply documents that disability generates specific knowledge of the physical and social self, and yet that often, especially in medical settings, the determination of what disability means originates from able-bodied outsider perspectives. Knowledge generated from an outsider perspective is not completely accurate in its portrayal of the lives of people with disabilities. The disability studies discipline neglects both the positive and negative consequences of the embodied difference of disability. This dissertation seeks to tap into the embodied knowledge and wisdom of people with disabilities that derives from acknowledgement of the biological and embodied nature of disability.

The call is not to shy away from impairment but to step right into the difficult issues that disability brings to the surface. We see that these difficulties can even be

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27 Louise R. Thibodaux, “Habitus and the Embodiment of Disability through Lifestyle,” The American Journal of Occupational Therapy 59, no. 5 (2005): 507; Disability as a social construction downplays the knowledge that the experience of disability offers because it is seen as playing into the medical definitions of disability as a “special case.” Part of the move away from the “special case” is to limit the spotlight on embodiment and individual difference. Thus, some people with disabilities view this special knowledge of disability as oppressive. I see this special knowledge as a positive contribution people with disabilities make by offering a hermeneutic of suspicion to strictly able-bodied perspectives.
semantic in nature as we distinguish disability and impairment. For example, the British 1976 UPIAS law that provided some rights for people with disabilities in the United Kingdom distinguishes the concepts of disability and impairment, impairment being defined as, “Lacking part or all of a limb, or having a defective limb, organism or mechanism of the body.”

That law defines disability as, “The disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from the mainstream of social activities.” Of course the words “lack” and “defect” stand out. In digging a little deeper into what “defect” actually means, more troubling words rise to the surface. Defect, according to the Merriam-Webster dictionary, means “Imperfect in form or function,” or “falling below the norm in structure or in mental or physical function.” “Imperfection” and “below the norm” are words and concepts the disability community usually avoids. Such avoidance does not change the way that people in their respective bodies are treated as “being disabled,” nor does it change the biological reality that makes specific people “fall below the norm.” It merely avoids or masks the truth. Hughes and Paterson point out that the avoidance of the biological reality of disability recreates a type of dualism similar to the mind/body split, in that disability studies ends up with a “disembodied subject, or more precisely a body devoid of history, affect, meaning and

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29 Ibid., 3–4.
Disability studies makes the impaired body disappear, which ironically revives a mind body dualism. In seeking to develop a practical theology of disability this study seeks to address the neglect of embodied difference to avoid the current mind body dualism of disability studies.

Disability is both a biological reality and socially constructed. In this study, I listen to both types of experience in the everyday lives of people with disabilities in the hope of unraveling the complexity of difference and sameness of what it means to live with a disability in today’s society. Some might see this examination of impairment and embodiment of people with disabilities as moving directly into an examination of distorted cultural representations of the body. Yet actually I am undertaking this move to listen more intently to what has been disregarded and ignored in an effort to understand more deeply what is taking place in the experience of embodied impairment and disability. Entering into awareness that the experience of embodied impairment is painful and harsh while also acknowledging that Western culture names the disabled body as “worthless” invites a conversation with God and initiates new self-understanding and awareness.

In exploring and naming the negative and challenging aspects of disability, and even emphasizing what many in the disabilities studies community do not want to admit, I have said elsewhere, “It is better to walk on two sturdy healthy legs than two disabled

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It is to come out into the open with the truth of experience in order to challenge society and ourselves to encounter what is “other” and come to a new understanding of ourselves and the meaning of difference and of life. In finding new terms to describe what it means to have a disability—physical, intellectual, or emotional—is to challenge society to reimagine and reconstruct its categories of “worth,” “ability,” and “disability.” We have seen this happen with the education of those, for example, with Down Syndrome who now enjoy life on different terms than they did a few decades ago. Instead of being deemed worthless and locked up in institutions to sit in their own feces, they enjoy life and employment as integrated citizens of society. Those of us without intellectual impairments learn from them how they conduct their lives. All of this happens because we as a society decide to see the “other” in a new light. Thus, in seeking to respect the biologic reality and the social construction of physical disability, this study seeks to consider the entirety of disability in order to build new theological bridges to address the cultural dangers when people with disabilities are labeled “less-than” or “worthless.” This means not shying away from the real and substantial differences among those who are disabled and those who are able-bodied.

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31 Diana Ventura, Our Fractured Wholeness: Making the Courageous Journey from Brokenness to Love (Eugene, OR: Cascade Books/Wipf and Stock Publishing, 2010), 2. In making this statement I am reiterating concepts I developed previously that, “Physical brokenness is always an unwelcome, tragic event, no matter what its origin.” The argument in this book in a nutshell says, disability and physical brokenness starts out as a tragedy but it does not need to remain that way, the life of faith provides the power to transform what begins as a tragedy into a blessing.
The notion of being “less-than” as associated with disability is similar to the existential absurdity that James Cone describes in his book *Black Theology and Black Power*:

> [A]bsurdity arises as man confronts the world and looks for meaning. The same is true in regard to my analysis of the black man in white society. It is not that the black man is absurd or that white society is absurd. Absurdity arises as the black man seeks to understand his place in the white world. The black man does not view himself as absurd; he views himself as human. But as he meets the white world and its values, he is confronted with an almighty No and is defined as a thing. This produces the absurdity.  

People with disabilities hear the same almighty “No” and are defined as objects and this produces absurdity in their lives. Cone points out that this absurdity comes to the forefront when people realize a contradiction of self-identity: “When he first awakens to his place in America and feels sharply the contradiction between what is and what ought to be or recognizes between his view of himself and America’s description of him as a thing, his immediate reaction is a feeling of absurdity.” People with disabilities feel absurdity when they experience the same type of contradiction in their own lives. The narratives of the lives of people with disabilities speak of this absurdity and in doing so depict the marginalization they experience in their everyday lives.

In sum, the strategy of ignoring the biological basis of disability does not work. Defining disability as a social construction is not adequate. Disability is not only a social reality, it is also biological in nature. In defining disability as a social construction, I

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33 Ibid., 8–9.
suggest that disability studies inappropriately disembodies its discourse. Disability is unique among the “-isms”, for after all the social barriers are removed people with disabilities still must struggle to live with physical limitations that cannot be relieved through social intervention. The disembodied approach makes it difficult for people with disabilities to express the actual physical difficulties that their disabilities create in their lives. Disability studies avoids the medical model in an effort to disregard embodied difference as a way to alleviate the marginalization of people with disabilities. Yet avoiding the biological aspects of disability is, I suggest, the wrong approach to address the marginalization of people with disabilities. Instead of ignoring the medical model, the response from the disability studies discipline would be more effective if it faced head on the difficulties of the medical model. For this reason, this study steps directly into the challenges of the biological basis of disability in order to move toward a theological response to the harsh difficulties of living with a disability in the hope of ameliorating some of the marginalization of people with disabilities.

**Cross Disability Analysis**

Building on this discussion of physical disabilities, we now need to consider how cognitive impairments relates to the current discussion on physical disability. In her book, *Copious Hosting*, Jennie Weiss Block takes what she calls a “disability-neutral” or “cross-disability” approach within her analysis. This means that her work does not make distinctions concerning the nature of disability, for example whether a disability is physical or mental. Specifically, the cross-disability or disability-neutral approach refers
to all people with disabilities the same way, without identifying their disability as being physical or mental in nature.\textsuperscript{34}

Block advocates for the disability neutral approach whenever possible because making distinctions concerning disability types she believes, “often lead[s] the most vulnerable people to further stigmatization.”\textsuperscript{35} The stigmatization comes from the idea that to exclude from analysis people with cognitive impairments is to further marginalize those with such impairments. Joseph Straus notes that disability studies concerns itself with those with physical limitations but neglects those with cognitive or developmental disabilities.\textsuperscript{36} Straus also correctly explains that the reason for this neglect is the lack of an autonomous subject capable of constructing and formulating a narrative in the case of those with cognitive impairments.

In advocating for the “most vulnerable” Block does not realize that disability-neutral analysis may not be supportive or helpful for proper analysis of disability, whether physical or intellectual. Caution must be taken when “lumping” together the lives of people with physical disabilities with those who have intellectual disabilities. Able-bodied individuals sometimes view people with physical disabilities as “automatically” having intellectual impairments. This leads people with physical disabilities to be unfairly characterized as having intellectual disabilities along with their


\textsuperscript{35} Ibid.

physical challenges. This is an unfair characterization and is seen by some with physical disabilities as an oppressive assumption. Tom is a good example of how this misguided assumption works. Tom’s severe speech impairment creates a great deal of difficulty for him, he explains, “People do not have patience to understand me.” When people misunderstand Tom’s speech, they make-up their minds about what he needs before he asks and in doing so often treat him like a child even though he is a grown man.

Although people within the disabilities studies discipline may view the exclusion of people with intellectual impairments as inappropriate, it is also important to separately examine subgroups of the larger disability population. Nancy Eiesland in her book, *The Disabled God* keeps her focus on physical disability and excludes people with intellectual disabilities from her analysis noting, “To be sure, it would be a worthwhile and much-needed project to examine the experience of persons with intellectual, social and emotional disabilities within the church. However, such endeavors are outside the scope of this work.”\(^{37}\) Eiesland provides two reasons for the exclusion. First the literature that she wishes to employ in constructing her theology of disability deals almost exclusively with physical disability.\(^{38}\) Second, Eiesland explains that the stigmatization of people with intellectual disabilities, although similar to people with physical disabilities, also differs in significant ways, and such additional work was beyond the scope of her work.\(^{39}\) Yet to her credit, Eiesland considers the neglect of people with intellectual disabilities to


\(^{38}\) Ibid., 28.

\(^{39}\) Ibid.
be “scandalous.” One of Eiesland’s hopes in penning *The Disabled God* was to stimulate more work concerning disability and theology regardless of whether the disability was physical or intellectual.

It is important to consider that many people with disabilities have a multiplicity of physical and cognitive impairments. In making the distinction between physical and intellectual impairments the intent is to direct attention to what is the primary challenge while considering secondary influences when necessary. The truth is that the challenges of disability are similar among people with cognitive and physical disabilities but, at the same time, that they are also not the same; in some cases they are entirely different. The effort to include everyone without consideration of disability type wrongly assumes that the experience of disability is exactly the same for those with cognitive impairments as those with physical disabilities.

Given the complexity of disability, this study focuses primarily on physical disability while also considering intellectual and emotional impairments when necessary. This stance is neither the disability neutral stance of Block nor the perspective of Eiesland. Rather it takes a person-centered approach that respects that the challenges and difficulties might blur the lines of distinction between disability types, while also being cautious not to define experiences as the same when each person’s experiences are likely to be markedly different and unique. My focus is primarily on disability as physical, and I have focused on that literature and engaged with interviewees who are challenged physically. At the same time, I recognize that some people with disabilities may live with

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40 Ibid.
secondary cognitive issues. I seek to respect the complexity of disability and the human person. All the interviewees in this study were free of secondary cognitive issues. This approach allows for proper analysis of physical disability while not naming it as the “same” as intellectual impairment. It also addresses Block’s concern about further stigmatization of those with intellectual impairments by their exclusion, while allowing me to draw as needed on literature concerning those with intellectual impairments.

**Disability Theology and the Social Construction Model**

The social construction model of disability is the most common conception of disability among the small number of books written on disability theology. Brian Brock and John Swinton, Sharon Betcher and Thomas Reynolds are in strong agreement with defining disability as a social construction; as a result, their respective theologies significantly downplay the difficulty and personal experience of disability. Nancy Eiesland and Jennie Block, while advocating for disability as a social construction, both state the need to keep in mind the physical difficulties of disability. Deborah

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45 Block, *Copious Hosting*, 27–31, 85.
Creamer takes a step in what I suggest is the more appropriate direction when, at the same time as pointing out the difficulties with defining disability as a social construction, she calls for integrating the personal experience of disability into disability theologies. Creamer proposes a limits model as a way out of the debate. The limits model calls for critical reflection on embodiment; it contends that limits are not exceptional but an intrinsic aspect of human existence. However, Creamer softens the meaning of the limits model when she states, “Key to the limits model is the recognition that ‘disability’ is actually more normal than any other state of embodiedness.” Creamer seeks to integrate limitation as a theological construction, but the move to call disability “normal” eliminates or downplays the true reality of disability as embodied difference. Thus, her move has the same effect as the social construction models of disability; her turn of phrase makes nearly everyone disabled. The social construction of disability seems to pave the way for a society that includes everyone regardless of physical difference, so it is an attractive model for those thinking and writing about disability.

In *Disability in the Christian Tradition: A Reader*, Brian Brock and John Swinton define disability as a “perceived impairment.” They suggest that the way to inclusion and social justice for people with disabilities is to adhere to a conception of disability that

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47 Ibid., 32.

48 Ibid.

49 Brock and Swinton, *Disability in the Christian Tradition*, 1.
is similar to the social construction model as a way to overcome “best-case anthropologies.”

Best-case anthropologies say that the concepts of normal and abnormal are accurate conceptions of humanity while the social construction model of disability argues that these distinctions are inaccurate, oppressive, and socially constructed. In a recent review of the conceptions of disability used in Brock and Swinton’s edited collection, Elizabeth Antus explains the two divergent conceptions of the theological anthropology of disability that emerge in the text.

The first perspective that is less popular Antus calls “enfolding,” which appropriates texts using a “normative theological anthropology,” which is akin to the “best-case anthropologies.” This normative anthropology suggests how people with disabilities can be fully included in accounts of the human in spite of their impairments. This perspective holds that there is a pre-existent able-bodied anthropological ideal functioning body and mind. People in this approach are considered either normal or abnormal. In other words, the normative theological anthropology approach holds that there is an able-bodied ideal that people with disabilities do not meet and therefore the person with a specific type of impairment is deemed disabled on the basis of medical criteria. The normative theological anthropological stance also takes issue with the disembodied approach to disability when the consequences of impairments are removed.

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50 Ibid.


52 Ibid.
from analysis and disability is conceived of as entirely a social construction. This means that impairments are seen as part of disability, and therefore should be fully considered in analysis and consideration of how the person with a disability interacts within society. The normative theological anthropological approach, as conceived by Antus, would not subscribe to the idea that disability is completely a social construction; instead this approach demands that the experience of impairment be integrated into the discussion of disability. This dissertation takes a normative theological approach.

The second approach adhered to by Brock and Swinton, and used by most authors in their collection of essays, is the expansionist conception. The approach attends to people with disabilities and their impairments in order to emphasize and expand what it means to be human, rather than to focus on the daily experience of disability. The alternative to maintaining the best-case anthropologies according to Brock and Swinton is that disability is entirely a social construction and therefore the difference that disability creates is considered a universal aspect of human life and thus not a difference at all. The social construction model reflects and attends to impairments and illnesses of people with disabilities in order to “rethink and expand an account of being human.” The emphasis is on what it means to be human, not what it means to endure a life with a disability. Antus explains that the move to view disability as a social construction allows people

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53 Ibid.
54 Ibid., 246.
with disabilities to offer the truth of what it means to be human, thereby allowing them to speak from the center of theological anthropology rather than the margins. Swinton and Brock argue that the definition and distinction of able-bodied and disabled that exists in the normative theological anthropologies leads to the exclusion of people with disabilities. Inclusion is a primary value within the disability community. Thus, from Brock and Swinton’s perspective maintaining the distinction between able-bodied and disabled is considered to be oppressive. The attention to impairment from the expansionist model or from the perspective of disability as a social construction is not to view disability from the vantage point of a lack or deficit but to bring it in line with an expanding view of humanity that includes everyone regardless of difference. The expansion of what it means to be human means de-emphasizing difference as a lack or deficit while emphasizing inter-dependence. The consequence of the expansionist perspective is that it denies the consequences of embodied difference. This study seeks to show that the expansionist model is inadequate because it denies the true reality of the experience of physical disability. The denial of the true experience of disability means that theological constructions based on the expansionist and social construction models only go part way in providing a response to the contemporary situation of disability.

When disability is only viewed as a universal aspect of all human life, it diminishes the capacity to fully consider the harsh reality and difference that is experienced in disability. In primarily adopting the social construction model,

\[55\] Ibid.
theologians engaged in reflection on disability take the stance that disability is similar to other oppressed groups. They argue essentially that there is nothing especially wrong with being disabled; it is just another human condition. In the introduction of *Disability in the Christian Tradition*, Brock and Swinton write, “Any approach to the topic of disability leads inexorably toward the ‘problem of the human.’” Other scholars writing disability theology also echo this point, reiterating that disability tells us something about what it means to be human. It is true that a review of the essays in Brock and Swinton’s book of Aquinas, Augustine, and Bonhoeffer will surely reveal the consideration that we are all human, while also taking a normative approach. For the most part, however Brock and Swinton’s book moves in the direction of disability as a social construction and this obscures as it seeks to obliterate the experience of disability while attempting to make everyone “normal.”

The removal of “disability” and able-bodied distinctions does nothing more than mask and systematically deny the real and experienced difference among people. The denial may be far more dangerous than maintaining proper distinctions. The social model, while it seeks to end the oppression of people with disabilities by “normalizing” and moving disability off the margins by defining disability as part of the universal human experience, in so doing dismisses the true reality of difference among disabled and non-disabled people. I too want humanity to include everyone regardless of difference. The point is that those who invoke an expansionist view of humanity fail to name disability as the deviation and harsh impairment that it truly is. This denies the reality of difference,

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56 Brock and Swinton, *Disability in the Christian Tradition*, 1.
which is critical for truly understanding and appreciating the difficulties of being
disabled.

No matter the approach to disability, we all seek the same outcome: to maintain
and preserve the dignity of every human being regardless of their physical or mental
status. The discussion of disability does not depend upon answering questions about what
it means to be human but what it means to embody difference and what it means in light
of that difference to preserve the dignity of every human being. Brock and Swinton say
that the real issue that we need to ask ourselves is: “Why am I unable to love everyone
regardless of ability?”57 I agree with Swinton and Brock that we need to ask ourselves
this question in order to bring about social justice and equality for people with
disabilities. But to deny the difference between able-bodiedness and disability is not the
way that this will be accomplished. In seeking to be inclusive, those who wish to expand
the definition of what it means to be human removes the reality of embodied physical
difference. The emphasis for this dissertation will be less on what it means to be human
and more on what it means to endure a life with a disability. Thus, I disagree with Brock
and Swinton when they contend that disability theology resists dividing people into
categories of disabled and able-bodied.58

The perspective of the disability rights movement and most scholars who
currently write in disability studies and disability theology is to emphasize the

57 Ibid., 12; Here I paraphrase the actual question posed in the text, “What sort of people do we
have to become in order to rightly perceive and love all people, including those whom we might wish to
shun?”

58 Ibid., 19.
“sameness” of all human beings, underscoring that people with disabilities are just like everyone else in spite of their impairments. The argument of the social constructionists is that disabled and able-bodied people are the same because impairments are merely perceived and socially constructed differences. Thus everyone regardless of embodiment should be viewed as fully human. The concern about making distinctions between normal and abnormal is based in past history and its relationship to disability. The thought among disability scholars is that, if impairments and deficits of those with disabilities are emphasized, then society will act as it has in the past by labeling and construing people with disabilities as “less than” those with able bodies. The concern is that the “less” becomes “less” valuable, less human, literally more “worth-less” than everyone else.

The concern to preserve the humanity of all persons is understandable within many social contexts of the twentieth century. For example, the concern was palpable among those who witnessed the eugenics movement, which unjustly sterilized those with intellectual impairments and systematically exterminated those who were deemed “less-than” and thereby were expendable and not worthy of life. The eugenics movement originally took form in the United States from approximately 1890 to the late 1930s, its ideals and proposed methods were then adopted by the Nazis. Kim Nielsen explains the idea of the eugenics movement took hold through the drive to uphold democracy through

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a competent citizenry, “For the nation to succeed… it must limit its already dangerously expanding pool of intellectually, physically, and morally defective citizens.”

Christine Rosen explains how even some religious leaders supported the eugenics movement:

They genuinely believed that eugenics would increase human happiness….Religious leaders pursued eugenics precisely when they moved away from traditional religious tenets…Theologically, these men were creative, deliberately vague, or perhaps even, as their critics contended, deeply confused. In terms of solving social problems, however, their purpose was clear: They were dedicated to facing head-on the challenges posed by modernity. Doing so meant embracing scientific solutions….Looking back, one might expect to find a little more hesitation from religious leaders before they offered their support to a movement that appeared to lack both humility—in that it replaced God with science as the shaper of the human race—and respect for the inviolability of the individual, a hallmark of the Judeo-Christian tradition.

The Holocaust began its mass murder of human beings through doctors determining the worth and value of people with cognitive and physical disabilities. Suzanne Evans explains: “The first category of the Nazis began exterminating as part of their quest to build a master “Aryan” race was the so-called Ausschusskinderer, “garbage children” or “committee children,” who had been born with certain supposedly hereditary disabilities.” Hitler issued a decree in 1939 that required doctors to report children that showed signs of physical deformity or cognitive impairment, “a panel of ‘medical

60 Ibid., 101.


experts’ decided which of those children should live or die. The children selected for death were transferred from their homes or institutions to a pediatric killing ward. There, shortly after their arrival, they were killed by lethal injection or so-called hunger houses in which they died slowly and painfully from malnutrition.”

In light of the “pediatric killing wards” that occurred less than a century ago, David Tracy’s plea for theologians to remember the “tremendum” of the Holocaust and to address the massive global suffering of our world takes on a new sense of urgency and meaning.

Some believe that the Holocaust, with its judgments and horrors against certain groups of people, brought about the postmodern era. David Ford cites Edith Wyschogrod’s work to make this point, “If there were just a single factor to be named in the widespread disillusionment with modernity it would be the impact of what Edith Wyschogrod calls that period’s ‘man-made mass death’ – the Armenian genocide, the First World War, Soviet exterminations and terror, Japanese massacres, and Nazi killings and death camps.” These massacres in terms of people with disabilities occurred because people were designated as a burden to society, James Glass explains, “Eliminating deformed children and mental patients was not so much a phobic reaction to their presence, but the result of a culture of belief that genetic deformities were a burden.

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63 Ibid.


on the nation.”66 The problem that precipitated the mass extermination of people with disabilities is in deeming some people as worth less and burdensome to society and thereby only worthy of being put to death. Frances Young expresses the value of people with severe cognitive impairments: “They challenge the slogan which generated modernism: *cogito, ergo sum* (I think; therefore I am). We need a stranger to hold up a mirror to ourselves…those with limited capacity to learn and think…. [to] enable a shift in values, away from individualism, dominance, competitiveness, to community, mutuality – a human ecology that has the potential to be ‘angelic’.”67 Thus, even the weakest among us who in their limited power to speak and think and who seemingly have nothing to contribute to society offer a profound witness. People with severe physical and cognitive impairments who are unable to move and speak critique our success oriented culture by asking through their embodied difference and limitations: “What is the meaning of life if there is no way to succeed?”

In an essay Bernd Wannenwetsch takes the normative anthropological approach. Wannenwetsch explains that Bonhoeffer offers a perspective on disability in a sermon about strength being made perfect in weakness. In that sermon Bonhoeffer expresses his belief in the epistemological advantage of the weakest among us, and that the weakest


have something significant to teach society. Embracing the normative theological anthropologic approach and entering into awareness of embodied life with a disability with all of its harsh impairments invites a conversation with God to discover new measures of truth. Taking hold of the epistemological advantage also offers a way out of the problem of maintaining the best-case anthropologies and the feared negative consequences it may pose, if some bodies are deemed inferior to others. The danger of revisiting the pediatric killing wards is alleviated by realizing the value of every human life and the epistemological advantage of the weakest among us, to teach all of us something about how to live.

We are all the “same” in our humanness in being fearfully and wonderfully made by God. For that reason alone we have a human right to live and not be led off to the gas chamber because of embodied difference. Furthermore, Bonhoeffer’s emphasis on the epistemological advantage of weakness shows that every human being has something sacred to offer the world, regardless of their physical or mental status. So yes, we are all the “same” in being human and having our God-given right to live. But that does not mean that embodied impairments make no difference in the lives of the people that have to endure life with a physical disability, and that disability is thereby only perceived or socially constructed.

Ironically, it is because of the shift brought on by the Holocaust and postmodern thinking that people with disabilities who previously would have been deemed worthless

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and put to death are now beginning to cry out and have their voices heard. In light of our humanity and value as persons, we need to speak of our uniqueness; we cannot simply remove the conceptions of able-bodied and disabled in order to make everyone the “same.” We are not in fact the same. Embodied impairment and disability does in fact make a “difference.” It is not removing the distinctions between able-bodied and disabled that will change the marginalization of disability but rather realizing that we can maintain concepts of the “normal.” We must also be willing to realize that we have misunderstood the cultural meaning of these concepts and that they need to be reconstructed, not simply collapsed in upon each other as Brock and Swinton do when they say impairments are merely perceived.

**The Hegemony of the Normal**

This dissertation seeks to understand the social influences that do in fact socially construct disability, while also recognizing the full complexity of disability as embodied impairment, limitation, and suffering. Disability, when defined as entirely a social construction, inappropriately reduces everyone to sameness. It is true that, by making this move, those in disability studies and disability theology wish to undo what people with disabilities for centuries have historically endured—that is, being on the margins of society and being the face of the “other.”
David Tracy explains that the face of postmodernism is in the face of the other. Tracy argues that the ethics of resistance in postmodernity is to listen to the voice of the other. To listen to the voice of people with disabilities is to listen to people who have been deeply marginalized and viewed as insignificant throughout history. For Tracy welcoming the other has to do with coming to know truth. Tracy explains that understanding involves interpretation, and interpretation involves conversation. Teasing out similarity and difference within the context of defining disability is critical for carrying out the conversation proposed in this dissertation. In *The Analogical Imagination*, Tracy explains that all conversation with the “other” involves analogy. In locating and understanding similarity in difference of those who are other we learn of one another and do not slip into more of the same. By this, Tracy means to point out that the careful work of sorting out and respecting similarity and difference among those that we view as “other” will open us to new perspectives of truth and understanding.

This type of careful teasing out of similarity and difference needs to take place in order to understand disability. Taking this stance is valuable in developing a practical theological study of disability because it seeks to respect and appreciate individual difference. A practical theology of disability respects individual embodied difference in the hope of opening up new knowledge of the everyday experience of disability, and not

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70 Tracy, *Plurality and Ambiguity*, 20.

yield more of the “same” perspectives of disability and its relationship to theological discourse. Acknowledging the importance of difference breaks us out of the grand narrative of the social construction model, this opens up the way for unexpected disclosures of truth. Tracy exposes the lie of the grand narrative when he writes, “There, I like you, am other and different.” Tracy also quotes Emmanuel Lévinas who says, “Do not kill me.” By this, Lévinas means to say: do not try to force me and my experience into the grand narrative.

The grand narrative in terms of the social construction model of disability unfortunately remains intact. John Hull suggests that there is another operative concept within theology and philosophic constructions, which he calls, “the hegemony of the average.” Hull explains that the Bible, for example, and the concept of being made in the image of God carries a conception of the average or “normal.” Hull’s conception of the hegemony of the normal extends past philosophic constructions as it spills over into society. I prefer to make the distinction that the hegemony of the normal applies to philosophical and theological constructions. The able-bodied centric position and ableism includes a broader social framework that holds within it a historical tradition of cultural

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72 Tracy, “Theology and the Many Faces of Postmodernity,” 108.

73 Ibid.

74 John M. Hull, “Blindness and the Face of God: Toward a Theology of Disability,” in *The Human Image of God*, ed. Hans-Georg Ziebertz (Leiden: Brill, 2001), 215. Hull himself does not use the term the hegemony of the normal but this is the particular connotation that is implied in his use of the terms, “hegemony of the average.” Thus, I will use the terms, “hegemony of the normal” because it better describes what is operative in our philosophical conceptions, as it is also more descriptive of what Hull actually meant.

75 Ibid., 215–226.
and political forces that determine expectations and norms about how people with
disabilities are to be treated. So ableism is the broader social framework in which the
hegemony of the normal fits.

Hull uses Lévinas as an example of the hegemony of the normal. Hull explains
that Lévinas, in his plea for all to consider the “face of the other” actually fails to
consider that those who are blind typically don’t know the “face” of the other, except
perhaps by feel. In making this point, Hull calls for scholars to realize the hegemony of
the normal within philosophical and theological discourse. Hull further argues for
philosophical inclusion of disability, which means that we are completely open to the
plurality of perspectives, or “plurality of worlds” that come to light when the experiences
and differences of people with disabilities are included in philosophical and theological
discourse. For Hull no dialogue between able-bodied people and people with disabilities
can occur in a meaningful way until the hegemony of the normal is properly addressed
because:

There can be no dialogue between the disabled and the non-disabled until
the plurality of human worlds is recognised. As long as the non-disabled
world retains its hegemony, the relations which it has with the world of
disability will be those of care for the helpless, and of patronisation. The
relationship will be that of charity, of condescension, and not that of
mutual respect based upon acknowledgement of otherness.

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76 Ibid., 227.

77 Ibid.

78 Ibid., 229.

Hull views the hegemony of the normal as disempowering the self-esteem of people with disabilities; yet this ascribes too much power of being “normal” to determine the self-esteem and agency of those with physical disabilities.

Just because the world does not accept or fully understand the bodily condition of those with physical impairments does not mean that those with physical disabilities need to give in to what the world inappropriately and unjustly ascribes to those with disabilities. For some in disability studies, breaking the hegemony of the normal means having no concept of the normal operative in society, and this rips too far into the underpinnings of scientific knowledge and the advancement of health related discoveries that people with disabilities rely upon to live to be even remotely tenable. 80

To offset the hegemony of the normal Hull proposes accepting the “plurality of worlds,” which for Hull, who is blind, is an epistemological gift. According to Hull, it is through opening oneself up to the plurality of worlds and thereby individual difference that we open ourselves up to new self-understanding. This new understanding truly accepts the differences of the other while breaking the faulty notion of the “average” or normal. Moving forward with Hull’s “plurality of worlds” allows us to distinguish and embrace our embodied differences while not simply naming the difference of disability as only socially constructed. This allows the theology of disability in this study to consider the everyday lives of people with disabilities. The hegemony of the normal will not end; it can only be shifted to be more inclusive. Shifting the hegemony of the normal is not

80 See Dudley-Marling and Gurn for more information on the argument that the concept of the “normal” is a misnomer. Curt Dudley-Marling and Alex Gurn, The Myth of the Normal Curve, Disability Studies in Education 11 (New York: Peter Lang, 2010).
done by removing the concept of normalcy or by defining disability to make everyone the same. Instead it is done by embracing the plurality of difference. Reconceiving the meaning of “being normal” shifts its significance so that having a lesser and impaired body does not mean “lesser” as a human being or not worthy to live with dignity.

This discussion highlights the importance of valuing difference. Hull suggests that the “plurality of worlds” points to the difference in experience between the disabled body and the athlete but the difference does not imply worth or value but fullness and emptiness. In light of the emptiness, Hull points out that, “Emptiness understands fullness in a way that fullness cannot understand emptiness. It is true that the empty desires the full, and the full fears the empty, but in its transfigured state the broken body may learn to be beyond desire and fear.”81 The truth is that we all need to live out the fullness of our own embodiment no matter its form, the cultural dictates of what stands for beauty, soundness, and normalcy aside. Hull’s concepts of fullness and emptiness are not as clear cut as he might believe, physically disabled dancers, dance with a great deal of beauty, and disabled athletes at times exhibit more internalized physical control than their able-bodied counterparts because they need to push past limitations that the able-bodied athlete does not encounter. The key to teasing out how the concepts of normalcy and difference operate and play out is to negotiate the complexity of difference by focusing on the meaning and consequence of the difference.

Conclusion

This chapter has explored the current perspectives of disability, theology, and the importance of the everyday experiences of people with disabilities. It is clear from this discussion that there is more to addressing the marginalized lives of people with disabilities than employing the social construction model of disability. Establishing the importance of embodied difference and the biological basis of disability is critical in illustrating the difficulties that disability brings to individual lives. The next chapter will develop a practical theological methodology for a theology of disability, which considers how disability relates to spirituality in everyday experience.

Also included in this chapter will be excerpts from qualitative research interviews to begin the conversation between people with disabilities and theological and theoretical discourse. Chapter 3 explores the writings of Julian of Norwich in terms of her bodily illness, her perspectives on embodiment, and Trinitarian perspective of theological anthropology. Using the Showings, both Long and Short texts, along with secondary sources, in order to develop points of contact for a mutually critical conversation with the voices of people with disabilities collected as interview data. Chapter 4 then examines the writings of Teresa of Avila, as well as secondary sources in terms of her bodily illnesses, and her work as a social reformer in order to develop points of intersection between her life and the six narratives of contemporary people with disabilities. Finally, chapter 5 brings the unheard voices of people with disabilities into conversation with the mystical writings of Julian and Teresa. The conversations will focus on embodiment and marginalization in order to develop proposals for transformation.
CHAPTER 2
TOWARD A METHOD FOR A PRACTICAL THEOLOGY OF DISABILITY

Introduction

This dissertation utilizes the practical theological method of mutually critical conversation between the everyday experiences of disability and two mystics, Teresa of Avila and Julian of Norwich. In undertaking the mutually critical conversation this study will utilize Browning’s four submovements\(^1\) first proposed in his classic book, *A Fundamental Practical Theology: Descriptive and Strategic Proposals*. This dissertation explores the everyday lives of people with disabilities through listening to and integrating three disciplines: disability studies, spirituality studies and practical theology. The integration of the three disciplines raises the question: “What are the specific methodological concerns for developing a practical theology of disability that integrates practical theology, spirituality studies and disability studies?” This chapter will explore the answer to this question. The chapter will explore the how practical theology relates to spirituality studies, as well as disability studies to begin to construct a practical theology of disability that integrates spirituality and the experience of everyday life. Next, the chapter discusses how to utilize Browning’s submovements of practical theology to construct a practical theological method of disability. The next section begins the

\(^1\) Don S. Browning, *A Fundamental Practical Theology: Descriptive and Strategic Proposals* (Minneapolis, MN: Fortress Press, 1991), 8; Browning uses the specific word of submovements to describe his conception of fundamental practical theology. The word submovement is used here when referring specifically to Browning’s work. However, the terms movements and submovements are utilized interchangeably throughout the text.
descriptive movement that develops the concept of disability as a practice using case study narratives from qualitative interviews and disability studies literature. Lastly, the descriptive movement constructs the concept of operative effective history as it relates to disability.

The Mutually Critical Conversation and Transformation

The hope in initiating the mutually critical conversation between the everyday lives of people with disabilities and Teresa and Julian is to bring about transformation. In order to explore the potentially transformative power of the mutually critical conversation we must first come to terms with what that conversation means for this study. Claire Wolfteich proposes a definition of practical theology that is helpful here: “Put simply, practical theology entails critical thinking about what we do and how we live out our faith. It entails the study of practices, contexts, cultures, and communities in dialogue with faith traditions and informed by the best human knowledge available.”\(^2\) The “what we do” analysis in this dissertation is an examination of everyday life. The “how we live out our faith” in this study entails critical thinking about the implicit ways in which faith shows up in our lives in the context of the unexpected trials and tribulations of daily living with disabilities. The “dialogue with faith traditions” occurs when practical theologians engage texts of various faith traditions as conversation partners—in this case, Teresa of Avila and Julian of Norwich.

A practical theology of disability in this dissertation explores the everyday challenges of living with a disability as what Tracy would call the contemporary situation. David Tracy defines practical theology as a “mutually critical correlation of the interpretation and theory of the Christian fact and the interpreted theory and praxis of the contemporary situation.” Broadly conceived, the mutually critical correlation takes place between the contemporary situation, defined as the lived everyday experience of disability as depicted through the interview data used as case studies, along with current scholarship in disability studies, and the Christian fact as depicted in the writings of Julian of Norwich and Teresa of Avila. In other words, Wolfteich’s “what we do” is the contemporary situation, “how we live out our faith” is the Christian fact, and “dialogue with faith traditions” is the mutually critical correlation. This study will attend to the “contemporary situation” and the “Christian fact” using an adapted form of the method proposed by Don S. Browning in *A Fundamental Practical Theology*. Browning’s method is important because it integrates disciplines of the social sciences and theology and this allows for a concrete examination of the experience of limitations, suffering and triumph in the everyday lives of people with disabilities. The goal of the mutual and critical correlation is to develop wisdom in the hope of bringing about transformation. The definition of transformation used as a goal in this dissertation derives itself from practical theology and spirituality studies.

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Spirituality scholars debate about whether personal transformation is the goal of the work of spirituality studies. Scholars such as Bernard McGinn and Walter Principe argue that transformation is not the goal of the work, whereas, Mary Frohlich and Sandra Schneiders do identify personal transformation as part of the goal of spirituality studies. Douglas Burton-Christie argues that to engage adequately in and investigate in spirituality studies “one must be willing to enter into it, even be transformed by it,” although personal transformation is not the goal of spirituality studies for Christie. Yet, Christie does expect deep personal engagement with one’s work to occur, “One’s love for the subject, far from being a hindrance to careful academic work, constitutes an initial and enduring interpretive key, informing our work at every step along the way.” The discipline of spirituality studies is often cited as being self-implicating. Thus there is a level of personal involvement with the task that lends itself to taking on personal risks associated with obtaining new knowledge and insights. Engaging in the discipline leads to

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9 Ibid., 103.
personal transformation. Wolfteich explains that the concept of transformation is shared by the disciplines of practical theology and spirituality studies, “The transformative aim—a dimension of all practical theology—is present here from the beginning. Indeed, practical theologians and many spirituality scholars share a concern with transformation.”

Thus, undertaking a mutually critical conversation that combines the work of practical theology and spirituality studies provides some measure of personal transformation for the author because of the self-implicating nature of spirituality.

People with disabilities may also experience transformation through offering their narratives for the construction of a practical theology of disability. Don Browning describes David Tracy’s definition of practical theology in the following way: “Practical theology, Tracy believes, has primarily to do with the criteria or norms for the transformation of human brokenness.” Engaging people with disabilities in the interview process is transformative in itself, opening a pathway for people with disabilities to voice their experience. This dissertation moves outside the church and into the everyday lives of people with disabilities in the hope of developing proposals for transformation. Tracy believes that it is the vocation of all theologians to respond to the concerns of global suffering.

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include all of the voices of the oppressed into the theological conversation. In the new preface in *Blessed Rage for Order* published in 1996, Tracy presses for all of theology to be made public and available to “all intelligent, reasonable, and responsible people.”

How does a practical theology of disability answer Tracy’s plea to make theology public while also listening to the unheard voices of people with disabilities?

A practical theology of disability nuances a commonly used term from the disability community— inclusion. The term inclusion in the context of disability studies means including people with disabilities as full members and participants of their respective communities. An example of inclusion may involve moving a meeting location so people with wheelchairs can attend, but more than this it means allowing people with disabilities to participate as full members of the community. Inclusion within a practical theology of disability means including the unheard voices of people with disabilities into academic discourse. In order to properly respect Tracy’s call to listen to the voice of the other, respond to the intense suffering in the world and create theological constructions that are truly public, a practical theology of disability seeks to include people with disabilities as participants within the process of constructing theological discourse; ultimately, this involves allowing people with disabilities to express the truth of their everyday lives through qualitative interviews.

The interviews conducted in this study may be transformative as the work may result in a shift in the misguided attitudes of some people toward people with disabilities.

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In communicating their stories, people with disabilities impact the misguided attitudes of other people. Even though the doors of public schools are now open to them and inclusion in academic discourse is beginning to emerge, people with disabilities continue to struggle with misguided and negative attitudes of able-bodied people. Research in disabilities studies shows that increased personal contact and accurate information concerning disability diminishes anxiety and awkwardness regarding disability among disabled persons and able-bodied people, while improving attitudes toward people with disabilities. Positive attitudes toward disability naturally lead to efforts to end societal oppression and cultural barriers to full inclusion and participation in society. Mårten Söder argues that it is incorrect to assume that attitudes toward people with disabilities are always prejudicial, and reminds us that instead ambivalence may be involved. As a result Söder proposes using qualitative research to provide the essential contextual vantage point to determine what is happening in the everyday experiences of people with disabilities. The inclusion of the unheard voices of people with disabilities in this study will serve as an approximation of the close personal contact with people with disabilities that research shows is transformative. Thus, the hope is that the mutually critical

14 Lisa Schur, Douglas Kruse, and Peter Blanck, People with Disabilities Sidelined or Mainstreamed? (Cambridge: Cambridge University Press, 2013), 120.


17 Ibid.
conversation in terms of disability will be a transformative process for everyone involved. The transformative work of this study conducts the mutually critical conversation using Browning’s method and submovements.

**Developing a Practical Theology of Disability Using Browning’s Method**

*Introduction to Browning’s Method*

Browning proposes a turn to practice integrating practical philosophy into a practical theological method which widens the scope of practical theology to outside the church through the utilization of the social sciences.\(^{18}\) Browning’s move to open up a method that integrates the social sciences is helpful for this dissertation because this study will examine the everyday lives of people with disabilities through qualitative interviews and disability studies literature. In order to construct a method for a practical theology of disability, we will first examine the two issues Browning seeks to address through widening the scope of practical theology. In developing his proposal for practical theology in *A Fundamental Practical Theology*, Browning seeks to address two issues he believes contributed to practical theology’s beleaguered state, namely, the clerical paradigm and the theory to practice model. A brief glimpse into the history of practical theology will help explain the relevance of these two issues for constructing a practical theology of disability.

At the time of the publication of his book *A Fundamental Practical Theology* in 1991, to admit that one was a practical theologian was to subject oneself to embarrassment. Practical theology at that time to use Browning’s word was in a “beleaguered” state.\(^{19}\) In response, Browning proposes the move to practical philosophy in order to move the discipline of practical theology away from a “beleaguered state” within the academic community, and the predominant model of the clerical paradigm and a theory to practice model. Farley explains universities of Post-Enlightenment Europe wondered about the need for theology as an academic discipline.\(^{20}\) In response to this question Schleiermacher wrote a book entitled *A Brief Outline on the Study of Religion*.\(^{21}\) In the book Schleiermacher argues that theology is a positive science similar to law and medicine. Just as society needs doctors and lawyers for the benefit of society, so also society needs trained clergy to carry out the ministerial duties of the church. Schleiermacher structured the discipline of theology into philosophical, historical and practical. In this framework the role of practical theology was to *apply* theory obtained from the other two disciplines to practice the tasks of ministry. The theological disciplines functioned as separate entities, each seeking to justify their position in the academy. The separation of theological disciplines led to what is known as the clerical

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\(^{19}\) Ibid., 3.


paradigm, which in this view of practical theology based on Schleiermacher is that practical theology exclusively involves the training of clergy. This exclusive focus on the training of clergy restricts the scope of practical theology to only influencing clergy’s role within the church. The hyper-focus on the training of clergy also perpetuated a theory to practice model. Browning explains that Schleiermacher contributed to the theory to practice model.

Although Schleiermacher saw practical theology as the teleological goal and “crown” of theology, his view of theology still had a theory-to-practice structure. He understood theology as a movement from philosophical and historical theology to application in practical theology....Schleiermacher saw theology in general as moving from historical knowledge to practical application; he had little idea how the practices of the church form the questions we bring to the historical sources.²²

Browning believes that Schleiermacher had a theory to practice model because Schleiermacher’s theology moves from philosophical and historical theology in one direction to practical theology. Browning turns to Gadamer and practical philosophy to address the inadequate theory to practice model. Browning believes that the theory to practice model and the clerical paradigm contribute to the “beleaguered state” of practical theology.

Browning turns to the work of Hans-Georg Gadamer and practical philosophy to address the inadequate theory to practice model. Browning’s turn to practical philosophy is important to us because it holds within it important issues concerning the nature of practical theology and establishing the everyday lived experience with a physical

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²² Browning, A Fundamental Practical Theology, 43.
disability as a practice. Practical philosophy distinguishes *phronesis* (wisdom) from *theoria* (theory) and *techne* (technique) in the philosophy of Aristotle. According to Browning, Gadamer seeks to establish the disciplines of “philosophical ground for academic disciplines such as history, philosophy, psychology, sociology, and law,” to provide justification for the humanities in light of the growth of the academic disciplines of the natural sciences. In order to justify the need for the disciplines of the humanities, Gadamer argues that in all of the “cultural disciplines” human understanding involves conversation or dialogue. If all human understanding involves conversation then it follows, according to Gadamer, that all human understanding is influenced by history and tradition. This raises the question, “Is objective knowledge possible?” According to Browning, William Dilthey believes that the influence of history and tradition can be self-emptied. Edward Husserl, on the other hand, thinks that history and tradition can be bracketed. According to Gadamer, neither the approach of Dilthey or Husserl work because, for Gadamer, the past is always operating in the present whether we acknowledge it or not. History and tradition are always at work to comprise effective

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23 Ibid., 34.

24 Ibid., 37.


27 Ibid., 37–38.

28 Ibid., 38–40.
histories that operate within all conversations.\textsuperscript{29} Thus, according to Gadamer, Aristotle’s \textit{phronesis} breaks the theory to practice model because all conversation is theory laden practice.\textsuperscript{30} This enables Browning to reformulate the theory to practice model, to a practice to theory to practice model, which means that theory and practice are completely integrated. The alignment of practical theology with practical philosophy allows practical theology to establish itself as operating beyond the paradigm of training clergy and into the wider-world considering the influence of religion and practices outside the church.

\textbf{Browning’s Submovements to Develop a Practical Theology of Disability}

Browning adopts Tracy’s mutually critical correlational method, and it is this methodology that will be used in this dissertation.\textsuperscript{31} The mutually critical correlation method brings together the interview data from people with disabilities into conversation with Teresa of Avila and Julian of Norwich. The hope of this work is to construct new spiritualities and practical theologies of liberation to address the challenges of living daily with a disability. Mystical texts of Teresa of Avila and Julian of Norwich do not speak directly to the experience of disability. Integrating mystical text into a practical theology of disability requires a dual understanding of both disability and theology in order to extrapolate the necessary content to devise the appropriate relationships between the two. Of course, specific concerns arise for developing criteria for the selection of specific

\textsuperscript{29} Ibid., 40.

\textsuperscript{30} Ibid., 38–40.

\textsuperscript{31} Ibid., 44.
portions of mystical texts, and there are questions concerning how to engage mystical
texts with the experience of disability. Preliminary work is necessary to discern the links
between mystical texts and disability before undertaking the usual mutual critical
correlations in practical theology.

The transformative practical theological work of this dissertation is adapted from
Browning’s traditional four submovements of practical theology: descriptive, historical,
systematic, and strategic. For Browning, practical theology moves from descriptive
theology and its formation of questions to historical theology, systematic theology and
theological ethics (which systematics includes), and finally to a strategic or fully practical
theology. The historical and systematic analyzes classic texts in relationship to the
content of the descriptive movement. Finally, the strategic movement involves tying
together the threads from the previous movements in the hope of developing proposals
for positive transformation. This dissertation adapts Browning’s four movements into
three, descriptive, historical/systematic and strategic practical theology. This next section
will consider the three movements of practical theology used in this dissertation. The first
movement will be the descriptive movement.

The Descriptive Movement for a Practical Theology of Disability

This first movement involves the cultural analysis of religious practices, while it
also provides a space to employ the social sciences. The descriptive movement captures

\(^{32}\) Ibid., 8.
“in all their richness the basic questions practical theology takes back to its classics. Its interests are practical because, in the end, it wants to appreciate and criticize current, social, cultural and ecclesial practices.” Browning believes that objectivity in the social sciences is a fallacy, because the social sciences are emerged in their own social scientific traditions. Browning also points out that implicit values influence the drive to particular research questions which defines what is acceptable and viewed as appropriate for research. Browning also believes that implicit religious values of Christianity exert an unacknowledged influence upon the social sciences because of Christianity’s pervasive influence in the West.

Adopting a hermeneutical perspective allows those engaged in the social sciences to also acknowledge the mutual transformation brought about by research and clinical processes, thus in psychotherapy both client and therapist are transformed by the clinical engagement. Ada María Isasi-Díaz argues that conducting interviews is a form of liberatory praxis, because of the mutually transformative experience of the interview process. The same holds true for social scientific research where both interviewer and interviewee change through the research process. For these reasons, Browning challenges those engaged in the social sciences, as well as, practical theologians to acknowledge their operative effective histories. Thus, Browning believes acknowledgement of one’s effective histories is crucial to understanding the complex interplay between research and practice.

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33 Ibid., 93.
34 Ibid., 88–89.
35 Ibid., 84–85.
effective history is critical to adequately perpetuate truth claims. Therefore, Browning seeks to restore the adequacy of truth claims within the social sciences through challenging those engaged in the work to acknowledge the operative implicit religious values and effective histories.

Harold Garfinkel of Harvard University makes a similar point as Browning when he argues that objectivity in the social sciences is not possible. In developing ethnomethodology Garfinkel criticized sociologists for not having a subject with a history and a biography, and instead employing an “ideal dummy” subject that turned out to be a mere “stand in” for the ideas of the sociologist.\(^{37}\) Garfinkel’s ethnomethodology acknowledges reflexivity in collecting narratives, as it recognizes the value in analyzing everyday experiences, and it also contends that social interactions can and should be documented.\(^ {38}\)

For these reasons during the descriptive movement the author of this dissertation will avoid the use of an “ideal dummy” as a stand in for the actual narratives of people with disabilities. Most of the current literature in disability theology does not use individual narrative accounts to depict disability.\(^ {39}\) This neglects the everyday embodied experience of disability that can be obtained through qualitative research methods.


\(^{38}\) Ibid., 1–115.

Creamer explains that this is important because “generalizations fail.” Yet scholars in disability theology, allied medical professions, and disability studies all call for the utilization of accounts of disability narratives within their respective discourses.

Social scientific objectivity can also be used as a form of “othering” because it has a tendency to “objectify” actual lived experience. Isasi-Díaz brings this point to the forefront when she asserts the point that she is careful to respect the actual voices of her interviewees. Isasi-Díaz explains that the intent is not to distort the voices of her interviewees to force their voices to fit the values of academic theology. Why is Isasi-Díaz so careful not to distort the voices of those involved in her project? For Isasi-Díaz distorting the voices is to further oppression and perpetuate marginalization and “othering”. It is only the authentic that will truly provide the power of liberatory praxis. Anything short of this Isasi-Díaz argues perpetuates the status quo because it allows the actual everyday struggle of her interviewees to remain unheard. Isasi-Díaz’s care for the voices of her interviewees issues a word of caution to all of us not to perpetuate

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41 Ibid.


45 Ibid., 45.
“othering” through the manipulation of texts. For this reason this dissertation will be careful to maintain the authenticity of the voices of interviewees by utilizing whenever possible verbatim text from interview data. Thus, the descriptive movement utilizes theoretical texts from disabilities studies to develop the concept of disability as a practice, along with narrative texts gleaned from collected interview data to describe the contemporary situation of the everyday lives of people with disabilities.

To maintain the authenticity of the voices of the interviewees I propose adding an aesthetic–ethical correlation to this study. In his article a Correlational Method Revisited, David Tracy stands by his 1983 article in Don Browning’s Practical Theology: The Emerging Field in Theology, Church and World, however now, Tracy adds an aesthetic–ethical correlation. This addition can aid the development of mystical–prophetic practical theologies by healing the unfortunate split between theology and spirituality. The discipline of theology separated itself from being defined as a way of life and being properly integrated with spirituality when the study of theology moved from the monasteries to the universities.

Philip Sheldrake in his book Spirituality and Theology describes the advancement of the split: “It is difficult to be precise about the date when the rational or ‘scientific’ approach to theology in the West was born. This is because change is always an extended

46 Ibid., 62–72.

process rather than an event. However, from approximately 1100 onwards, scholars such as Peter Abelard (1079-1142) began to understand theology to be essentially a process of intellectual speculation.”

Sheldrake sees the divorce between spirituality and theology as advancing until a completely antagonistic relationship developed by the time of the Enlightenment.

Tracy calls for the healing of the split between theology and spirituality by paying, “virtuous attention to particular realities outside of ourselves: a call to the Other as other.”

Through adding the aesthetic–ethical correlation to the method used in this dissertation, I open myself up to virtuously and prayerfully attending to the “Other as other” in the work of collecting interview data and the writing of practical theology in the hope of bringing about human transformation and flourishing. This means grabbing a hold of Christie’s “enduring interpretive key” of being deeply engaged and loving one’s subject, and embracing the full breadth of the self-implicating nature of spirituality studies. For this reason, a practical theology of disability integrates spirituality and theology by establishing opportunities for people with disabilities to theologically reflect on their everyday lives through participating in interviews. This places some of the transformative power of theological reflection directly into the hands of people with

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49 Ibid., 40.

50 Tracy, “A Correlational Model of Practical Theology Revisited,” 82.

disabilities. So in adding the aesthetic–ethical correlation to this dissertation I add this dimension directly into the process of employing interview data as a form of liberatory praxis to follow in Isasi-Díaz’s prudent and wise footsteps. In doing so I will do something that Tracy suggests practical theologians are best suited to do, and that is, “to help people discern the significant moments that occur in each human life that manifest the direction of our lives.”

The way to do this is to attend to “something more” that is embedded into ordinary everyday life. This act of spiritual attending not only operates within the descriptive task of the practical theological work but also in the critical conversation within the systematic and historical movements. In doing this work of retrieving spirituality within the critical correlational model, it is true that much of what we have are only fragments and mere “hints” and “guesses” to bring us to closer approximations of truth. In the interviews people with disabilities tell their stories to reveal the hidden and yet aesthetic beauty and trauma of living with a disability. It is critically important that people with disabilities bring their authentic voices into the academy as a critique of social structures and oppressive ways of thinking.

Interviews provide a means for addressing social oppression. Isasi-Díaz argues that providing a platform for the authentic voices of Hispanic women is an effective

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52 Tracy, “A Correlational Model of Practical Theology Revisited,” 72.


54 Tracy, “A Correlational Model of Practical Theology Revisited,” 54.
means of challenging the ideological and societal structures that are oppressive. In a similar manner, this dissertation will use interviews to bring the unheard voices of people with disabilities into conversation with theological discourse with the expectation that this potentially will ameliorate some of the oppression that people with disabilities experience. Until recently the thoughts and feelings of people with disabilities have been muted or disregarded. Darla Schumm and Michael Stoltzfus point out people with disabilities are beginning to “tell their own stories, and identify their own desires and ambitions.” The interviews in this study will attend to the experiences of disability and everyday spirituality to provide a potential means of attending to the social attitudes both positive and negative, and to the experience of embodied impairment as it relates to social marginalization within everyday life.

Nancy Ammerman defines lived religion as, “the embodied and enacted forms of spirituality that occur in everyday life.” This study will examine the “embodied and enacted forms of spirituality” in the lives of people with disabilities. In addition, R. Ruard Ganzevoort defines lived religion as: “the actions and meanings operant in the ways

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55 Isasi-Díaz, En La Lucha, xii.


57 Schumm and Stoltzfus, Disability and Religious Diversity Cross-Cultural and Interreligious Perspectives, xxvi.

humans live, interact and relate to the divine.”⁵⁹ In order to capture the operant meanings and actions that also exist in lived spirituality, this study will provide participants with an opportunity to articulate perspectives on their lived spirituality in an attempt to uncover hidden and the implicit sacredness embedded in ordinary life activities, for Ganzevoort rightly reminds us that, “In one way or another human stories are connected with stories of and about God.”⁶⁰ In providing a platform for people with physical disabilities to articulate their everyday experience of spirituality and physical impairment it will be possible to obtain narratives that depict how social marginalization and embodied life interact and are embedded in the particularity of an individual’s social context, and then to determine whether the theoretical frameworks of disability studies used to define disability are even operative in everyday life.

The narratives in turn will provide more accurate theological sources with which to conduct a conversation between theology and disability because the interview content will describe the embodied life of disability within the particularity of individual social contexts. The assumption is that when practical theology listens to the authentic voices of those who are marginalized the act of participation of interviewer and interviewee are engaged in a form of liberatory praxis that leads to the transformation of human brokenness and thereby the work leads to human fulfillment and flourishing. Attentively

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theologically listening to the lives of people with disabilities prevents errors that occur through overgeneralizing the experience of people with disabilities into a “dummy” research participant who is a stand in for the ideas of the researcher.

To illustrate the everyday experiences of people with disabilities, this study will use a narrative approach focused on the stories of disability and spirituality as articulated by interviewees. Margaret Honey points out that, “the interview has a beginning, and an end and it stands as a structured whole. The [semi-structured] interview is certainly more than a sentence, it is an attempt to tell a story about a particular topic or issue.” Thus, the interviews in this study serve as a mechanism for telling stories. The interviews are also a meaning-making device for interviewees. This involves alternative modes of thinking, “the form of thought that goes into the construction not of logical or inductive arguments but of stories or narratives.”

This is a preliminary study that for the first time proposes to bring together interviews of people with disabilities and mystical texts. To keep interview content manageable in relationship to the conversation with the two saints, the sample size is on the smaller side but within the normal limits for this type of study. More qualitative research is necessary to grasp the complexity of disability as it relates to theological discourse. A variety of new interview cohorts could be collected in the future, for example, conducting interviews of mothers of children with physical disabilities, people

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with multiple disabilities such as cognitive impairments as well as physical disabilities, or collecting interviews of people with disabilities with ethnically diverse backgrounds. Thus, it is important to consider that this is a preliminary investigation with the intent of putting together an initial study that places case study narratives of people with disabilities into conversation with theological discourse and mystical texts. To keep the conversation between the interviews of people with disabilities and the mystics focused and manageable, specific portions of narrative texts will be gleaned from interview content and brought into conversation with the mystical texts. The narrative portions ground and challenge the theoretical concepts concerning disability in conversation with real lived experience and are the “hints” and “guesses” Tracy suggests are necessary to orchestrate the aesthetic–ethical correlation. Thus, this study will use theoretical literature from the discipline of disability studies and history in terms of the practice of disability and the operative effective history (developed below) as its descriptive movement.

The Historical Movement for a Practical Theology of Disability

The historical and systematic movements in this dissertation will develop a synthesis of the mystical texts in terms of the central issues of disability. The central issues of disability are the theology of embodiment and the response to marginalization. This study integrates historical analysis into the descriptive and systematic movements

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63 Tracy, “A Correlational Model of Practical Theology Revisited,” 79.
because of the limited availability of historical texts that deal with the lives of people
with disabilities. This study utilizes historical information (as available) to contextualize
the lives of people with disabilities in American culture and the two mystics within their
respective time periods. The use of historical information in this way allows for the
proper appropriation and interpretation of the mystics and the lives of people with
disabilities within their respective contexts. Browning’s second movement historical
theology places the questions that emerge from the movements of descriptive theology
into conversation with the central classic texts of the Christian faith.64 Browning states
that the historical theology movement asks, “What do the normative texts really imply for
our praxis when they are confronted as honestly as possible?”65 Browning utilizes history
to understand practice and as a tool to properly enter into and acknowledge the
hermeneutical process that is operative in effective histories. According to Browning,
history provides “technical, explanatory, and distancing maneuvers ... designed to gain
clarity within a larger hermeneutic effort to understand our praxis and the theory behind
it.”66

Multiple effective histories are operative in this dissertation. These are important
to consider as Browning expresses Gadamer’s ideas concerning our effective histories as,
“The past lives in the present whether we realize it or not.”67 There are the operative

64 Browning, *A Fundamental Practical Theology*, 49.
65 Ibid., 49.
66 Ibid.
67 Ibid., 41.
effective histories of people with disabilities. This history is addressed in two ways. First, interviewees are encouraged to express their individual lives within the particularity of their histories. Second, and perhaps more importantly, this study constructs disability as a practice that has an operative effective history within the context of American culture and disability studies. This operative effective history situates itself as a tradition which operates in the lives of people with disabilities interviewed for this study.

The Systematic Movement for a Practical Theology of Disability

According to Browning, systematic theology is “the fusion of horizons between the vision implicit in contemporary practices and the vision implied in the practices of the normative Christian text.”68 The mystics do not speak directly concerning the experience of disability. Thus, to understand what disability means in terms of Christian texts, in this case the mystical works of Julian of Norwich and Teresa of Avila, we first need to explore the writings of the mystics in terms of marginalization and embodiment. Marginalization and embodiment are two broad concepts that relate to contemporary definitions of disability. Thus, the concepts of marginalization and embodiment form a link between the mystics and the contemporary situation of disability. Secondary Christian resources of spirituality and theology are useful here. To keep the work manageable, the analysis of Julian and Teresa will be limited to the broad themes of

68 Ibid., 51.
embodiment and marginalization, because these two themes represent the central issues concerning the everyday lives of people with disabilities.

The question remains, “Why engage people with disabilities in qualitative interviews and then bring those reflections into conversation with mystical texts?” Mystical texts are a neglected form of content and mode of knowledge in the field of practical theology. Wolfteich points out that, “While some recent writing takes steps to weave spirituality into a framework for practical theology, mysticism generally falls outside the scope of the discourse.”69 This dissertation seeks to remedy that neglect by engaging the mystical texts of Teresa of Avila and Julian of Norwich as conversation partners. Wolfteich argues that practical theology should engage mystical texts; furthermore she asserts that Certeau’s analysis “of ‘mystic speech’ and ‘practices of unsaying’” suggest a needed corrective to practical theological method and discourse because de Certeau’s work “problematizes the reading of history and historical texts,” pointing out that mystical texts are “of exile, nostalgia, and irreducible difference.”70 Certeau’s perspective on history calls practical theologians to realize that “the hermeneutical ‘conversation’ is perhaps more elusive, fragmented, riddled, and silent than perhaps practical theologians have envisioned.”71 Given the problems that Certeau points out, Wolfteich proposes turning to poetics within practical theology as a way to


70 Ibid., 162-163.

71 Ibid., 164.
grasp and speak of God, to heal the unfortunate split between theology and spirituality. This healing helps move practical theology toward mystical–prophetic practical theology as proposed by David Tracy.

In his “Revisited” article, Tracy calls for the integration of mystical texts into practical theologies. Since he sees the integration of mystical texts as very important to an aesthetic–ethical correlation that leads to mystical–prophetic work. David Tracy’s method of mutual critical correlation provides the best opportunity to construct a practical theology of disability because it offers the opportunity to explore the mystical dimension of the Christian experience with his call for the addition of the mystical–prophetic correlation fully integrated into the practical theological method. This raises the question of why the addition of the mystical–prophetic correlation is important to creating a practical theology of disability? What is important for us is that Tracy affirms the integration of aesthetic–ethical as occurring in an encounter with the spirituality of everyday. Tracy tells us that we need to attend to the natural revelations and gifts that occur to us in the course of our everyday interactions. After all, the challenges of living with disability occur in everyday life.

A practical theology of disability seeks to acknowledge and create opportunities to experience the presence of God within the practice of theological reflection. Tracy properly asserts in his “Revisited” article that in our daily lives revelatory events and

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72 Tracy, “A Correlational Model of Practical Theology Revisited,” 72.

73 Ibid., 76.
experiences are available to all of us, and that mysticism does not involve hallucinations and visions.\textsuperscript{74} It is helpful here to recall McGinn’s complete definition of mysticism in his book \textit{The Foundations of Mysticism}. McGinn writes, “The mystical element in Christianity is that part of its beliefs and practices that concerns the preparation for, the consciousness of, and the reaction to what can be described as the immediate or direct presence of God.”\textsuperscript{75} According to McGinn’s definition, mystical does not mean God is inaccessible; we all have access to the presence of God and it is this acknowledgement of God as operative within theological reflection that offers possibilities for healing the unfortunate divorce between spirituality and theology.

Mystical texts do not speak directly to the experience of disability; this means that, as much as possible historical context must be considered in direct relationship to the mystics in order not to project one’s own views onto past events or figures. Spirituality scholar Elizabeth Dreyer is uneasy at some scholars’ retrieval of the medieval woman mystics in feminist studies, which, she argues, gives “short shrift” to historical context.\textsuperscript{76} Dreyer suggests that the way to do this work is to “cross-over” into the world of the mystic under consideration.\textsuperscript{77} The aim in analyzing historical texts is to respect the

\begin{itemize}
\item\textsuperscript{74} Ibid., 85.
\item\textsuperscript{77} Ibid., 155.
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authentic voice of the mystic allowing it to “speak out of their own time and context to the extent that we know what these are.”

Literary scholar, Catherine Willits, unknowingly provides an example of how this “short shrift” occurs. Willits paints a portrait of Julian of Norwich as one concerned for blind people of the Middle Ages because of the importance of physical sight in medieval lay Eucharistic devotion. Willits argues that in her *Showings* Julian addresses the marginalization of those who are blind, “by intentionally obfuscating her discussion of bodily sight and by equalizing bodily and ghostly sight as modes of understanding God.” Willits argues that Julian intentionally manipulates her use of these terms to address the marginalization of blind people who are unable to participate fully in the Eucharistic devotional practices of the day. However, her argument is not supported by current scholarship, Julian’s *Showings*, or historical writings. Nicholas Watson, scholar of Julian’s writings, believes that “bodily sight” and “ghostly sight” are used in such a variety of ways in Julian’s writings that they cannot be used in any form of analysis. He further explains, “The flexibility with which she deploys words depicting her apprehension of the revelation—words such as ‘understood,’ ‘showed,’ ‘took,’ ‘conceived’ and especially ‘saw’—indeed renders her own (or any other) system of

78 Ibid., 166.


80 Ibid.
categorization virtually useless for the purposes of detailed analysis.”\textsuperscript{81} Willits fails to realize that the aim in analyzing historical texts is to respect the authentic voice of the mystic allowing it to “speak out of their own time and context to the extent that we know what these are.”\textsuperscript{82}

Sometimes the authentic voice or intentions of an author are obscured by a lack of relevant facts, because so little is written concerning the history of disability. Dreyer’s point is that we should not automatically jump to the conclusion that Julian’s stance on people with disabilities is either positive or negative, but rather to consider the information in light of Julian’s writing and vantage point. The reality is that we cannot know Julian’s actual perspective; instead, following Tracy’s suggestion, we can take clues as “hints” and “guesses.” In light of the fragmentary nature of historical texts in relationship to disability and the importance of considering history whenever possible this study joins the historical movement with the systematic movement in the hope of placing historical information in equal footing with the systematic movement.

Julian of Norwich (1342-1423) is a perfect conversation partner to employ with the everyday lives of people with disabilities because she integrates everyday embodied experience into her intensely personal and highly practical theological reflections. Julian asks God for a near-deadly illness out of devotion, and she receives it. Julian’s near-death experience begins her odyssey of theological reflection to explore the meaning of her


\textsuperscript{82} Dreyer, “Whose Story Is It?,” 166.
revelations received in the midst of bodily illness and relationship with God. Julian writes of this experience as one who is oppressed, and from this margin gives intellectual voice to her theological insights. Julian, in what Bernard McGinn calls an unprecedented text on digestion\textsuperscript{83} integrates embodied everyday life and theological reflection.\textsuperscript{84} Julian’s theological reflection seeks to makes sense of suffering, theological anthropology, cosmology, and what it means to be made in the image of God. All of these theological concepts relate to the experience of disability. Furthermore, Julian reflects upon these broad theological topics through Christological and Trinitarian lenses with an eye to providing these insights for future centuries, thus providing fruitful ground for investigating the hidden and yet to be uncovered theological intricacies of the everyday embodied lives of people with disabilities.

Teresa of Avila (1515-1582) is included as a further conversation partner in this dissertation because a single mystic cannot adequately cover a conversation concerning the multiple and complex issues of disability. Whereas Julian provides strong connections to embodied life, Teresa addresses issues of marginalization and social reform. Teresa experienced multiple bodily challenges and illnesses, including a period of paralysis.\textsuperscript{85} However, issues of embodiment take on a less central focus in her writing than in Julian’s


Showings. Therefore, Teresa’s illnesses will play a part in the proposed conversation but more emphasis will be placed on Teresa’s work for social justice. Carole Slade describes Teresa of Avila as a social reformer. Slade mentions six narratives in the Foundations (F) that depict deplorable situations women were in because of the pervasive antifeminism of sixteenth-century Spain. Slade points out that Teresa sees the antifeminism of her day as an ignorance that will one day be revealed. Teresa discerns from her intimate relationship with Christ in mystical prayer the misguided patriarchal social order of her day and subsequently uses wisdom obtained in prayer to establish necessary social reforms through the establishment of religious communities. Thus, it is in initiating the conversation between the everyday lives of people with disabilities and Teresa and Julian that new theological insight will take form on how to hold up the reality of embodied disability in the midst of social marginalization. Thus, I analyze Julian of Norwich and Teresa of Avila in terms of their perspectives on embodiment and responses to marginalization to form a theological synthesis of the points of contact that will be used to form the starting point for the conversation between the interviews gleaned for significant moments. From that conversation the “significant moments” of the lives of people with disabilities will be placed in conversation with the synthesis of the mystical texts.

In choosing Julian of Norwich and Teresa of Avila for this study, the question becomes: Why not Thérèse of Lisieux? After all Thérèse suffered from a bodily illness

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and was a saint. Mary Frohlich in her article, *Desolation and Doctrine*, explains that Thérèse’s spirituality at times is characterized as, “sentimental, privatized, overly subjective, and disconnected from the world of theology.” It is true that Thérèse upon an initial reading makes this impression; however a more in depth analysis allows her true theological insights to come to light. For this reason, Frohlich argues that Thérèse may find new significance if examined in light of the onset of postmodernity. To this point, Ann Astell argues that Thérèse and Lévinas share an “extraordinary confluence of themes” and this brings together the writings of two different characters of religious discourse Saint Thérèse of Lisieux and Emmanuel Lévinas. Astell explains that in the end for both Lévinas and Thérèse “holiness reveals itself finally in a relationship of extreme inter-dependence and receptivity, and in ultimately finding the Other of the parent or child in one’s self.” If this is true, then Thérèse would seem on the surface to operate positively for people with disabilities given the need for acceptance and “otherness” of one’s own body. However, the stumbling block to bringing Thérèse into the conversation of this study is the “little way” which calls people to littleness and

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88 Ibid.
90 Ibid.
The call to insignificance and littleness is problematic for the lives of people with disabilities in that for centuries they have been ignored and deemed insignificant. The call for people with disabilities is to find their significance, voice and dignity before God and society, the little way is not helpful in this regard. That said Thérèse’s theology in the future will provide an excellent conversation partner in dealing with the apophatic name for God and its relationship to suffering, illness and disability.

There are also other bedridden mystics and stigmatists to consider as conversation partners, such as, Thérèse of Neumann, Marthe Robin, and Marcel Van. Although these bedridden mystics mention St. Thérèse of Lisieux as a source of their experiences in their testimonies, they do not offer theological content that would allow for an in depth conversation with interviewees. The content of the bedridden mystics mentioned above are primarily testimonies of mystical experiences, thus the theological insights in the texts are difficult to extrapolate and use in a conversation with interview data. Furthermore, the experiences detailed in these testimonial accounts while perhaps helpful in discerning how the everyday experience of physical disability relates to the disciplines of spirituality and practical theology, these texts are not vetted in the Christian

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theological tradition as authoritative. For these reasons, Teresa of Avila and Julian of Norwich have been selected as the conversation partners for this study.

Theology is unique among academic disciplines because it acknowledges “something more”\(^\text{95}\) namely; God is present with us in our work and in the world. We are not completely on our own. So what is it that we are actually trying to do in all of our analysis of the everyday lives of people with disabilities and our engagement with the qualitative interviews? For in all of our “doing” of practical theology, we are attending with the presence of God in mind in relationship to the contextual situations that interest us. Practical theology attends to God, the text of the Christian tradition and the contemporary situations of the world. Attending in the manner I am suggesting here integrates theology and spirituality as a way of life. Theology cannot fulfill its function without spirituality and spirituality does not work properly without theology. Theology without spirituality separates itself from the experience of the presence of God, whereas spirituality without theology becomes sentimental individualistic piety uninformed by the communal life of the church. It is important to remember that the work of the mystics is a social endeavor and is not an illustration of individualistic piety. It is crucial for both spirituality and theology to be properly integrated in order to carry out the theological task. Evagrius of Ponticus expresses the essence of this integration when he says, “If you are a theologian you truly pray, and if you truly pray you are a theologian.”\(^\text{96}\) For this

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\(^\text{95}\) James, *The Varieties of Religious Experience*, 394.

reason, a practical theology of disability integrates spirituality and theology by placing the reflections of the everyday lives of people with disabilities at the center of theological inquiry while also seeking to establish the embedded spirituality that permeates everyday life. Attending to the experience of the “other” in this case people with disabilities provides an opportunity for a disclosure of truth and this according to Tracy is always transformative. David Tracy reminds us in the *Analogical Imagination*, “there is never an authentic discloser of truth which is not also transformative.”¹⁷ In order to reach the measure of transformative power suggested by Tracy we must consider something of which Rowan Williams reminds us: that is that *apophasis* undergirds all theology calling it to silence, prayer, contemplation, and communion.⁹⁸ The relationship between disability and mystical texts resides in the unknown; thus using texts as a dialogue partner with the experience of disability requires an openness of attention on the part of the theologian to letting the lives of people with disabilities speak, as well as, listening and interpreting the writings of the two mystics to properly hear what the mystics have to say in relationship to the experiences of people with disabilities.

*The Strategic or Full Movement for a Practical Theology of Disability*

The strategic movement involves tying together the threads from the previous movements in the hope of developing proposals for positive transformation. In the final

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¹⁷ Tracy, *The Analogical Imagination*, 78.

movement, the fusion of horizons influences and changes the perspectives originally proposed within the descriptive and historical/systematic movements. For Browning, the strategic practical theology is the defense of validity claims for concrete praxis. This proposal to defend validity claims will be adapted to consider the everyday lives of people with disabilities. Furthermore, these specific considerations will be discussed in chapter 5.

The strategic movement creates a dialogue between the interview data and Christian resources in terms of relevant themes developed in the previous movements, as deemed appropriate. The work in this dissertation will consider that Julian and Teresa did not speak directly to the experience of disability (as we know it) and will extract common themes from the lives of the two saints, such as embodiment, social oppression etc. and bring those into conversation with the concrete experiences depicted in the interviews. Initiating a conversation between mystical texts and the experience of disability requires juxtaposing common links between the mystical text and the experience of disability. For example, if social marginalization emerges as a theme from the interview data, the dialogue would turn to the writings of Teresa of Avila and Julian of Norwich and their insights concerning this theme. Attempting to bridge the gap between disability and mystical texts requires a balance between properly attending to the writings of the theologian, in this case Julian of Norwich and Teresa of Avila, along with the experiences of disability as depicted by the interviewees. A theologian engaged in such a conversation

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must properly attend to the historical context of the mystic in order to not to distort or misappropriate the historical text simply to use it for twenty-first-century purposes.

**Summary of the Mutually Critical Method for a Practical Theology of Disability**

In sum, the goal of this study is to develop new proposals for transformation based upon the theological work that happens through mutually critical conversation while integrating practical theology, spirituality, and disability studies. I use Tracy’s method of mutually critical correlation to set up a conversation between the everyday experiences of disability and the writings of Julian of Norwich and Teresa of Avila. I use Browning’s descriptive sub-movements to describe the contemporary situation of disability using the case study narratives and current scholarship in disability studies. This will be helpful in developing a practical theology of disability because it integrates the social sciences. This in turn facilitates a contextual examination of important experiences that influence the everyday lives of people with disabilities, experiences like limitations, suffering, and triumph. Furthermore, the practical theology of disability under construction here seeks to heed Tracy’s call to all theologians to address massive suffering. The response is to listen to the voices of the other in a theological conversation in order to address the issues of marginalization in the everyday lives of people with disabilities.

This study adapts Browning’s method as it combines the historical and systematic movements because of a lack of historical data concerning people with disabilities. It is critical in trying to bridge the gap between the contemporary situation of disability and
the mystics to take care not to misappropriate mystical texts for contemporary purposes. The engagement of the two mystics in terms of the central issues of disability, namely marginalization and embodiment within the particularity of their own historical contexts, allows for a more focused and manageable conversation in the final chapter.

Browning’s turn to practical philosophy emphasizes the importance of practice for practical theology. Thus, it is important to determine the role of practice in building a practical theology of disability. The next section of this dissertation will explore disability as a form of practice and finds that people with disabilities and able-bodied people strive to maintain a sense of “normalcy” in everyday life and in social situations. The value of normalcy, I argue, stems from an operative effective history of disability that derives from the American history of disability. Thus, the practice of disability situates itself within a larger framework. The exploration of disability as a form of practice within the context of its effective history provides a unique vantage point for the examination of the everyday lives of people with disabilities. This vantage point of the everyday lives of people with disabilities provides the framework for the conversation with the two mystics in chapter 5. In developing disability as a practice within the context of its operative effective history, this next section integrates theoretical literature from disability studies and case study narratives.
Part II: Constructing Disability as a Practice

Disability as a Problem and Limit Experience

In the field of disability studies Tanya Titchkosky and Rod Michalko take a phenomenological approach to examining disability to argue that disability within the able-bodied dominant culture is predominantly viewed as a problem to be solved. The interviewee Tom describes a little bit about how this works. Tom with his severe speech impairment is very difficult to understand. His body at times gets contorted and twisted in his wheelchair. He explains that during his visits to the Massachusetts statehouse for his advocacy work, some people who know him understand him for who he is but others simply pat him on the head and treat him like a child. Michalko and Titchkosky further contend that defining disability only as a problem to be solved serves to maintain definitions of normalcy, and keep the value to “normalize” the bodies of those with disabilities firmly in place. The main avenue by which Tom is treated like a problem to be solved even though he independently moves in his motorized wheelchair is to pat him on the head and treat him like a child, while he is 47 years old and has a master’s degree. The experience among the able-bodied people who pat Tom on the head is as if they think of him as a problem, most likely unconsciously thinking: “I really don’t want to deal with this man. I don’t know what to do so I will pat his head and simply move on.


101 Ibid., 127.
about my day.” The people who pat Tom belittle him and his intelligence, whereas others who ignore him and his wheelchair make him completely invisible. Either way the able-bodied people at the statehouse that do not consider the fullness of who Tom is merely see him as a problem to their able-bodied world. Michalko and Tichkosky’s main point is that disability defined as a problem upholds the hegemonic structures of the normal and that knowing and acknowledging this truth and then initiating a phenomenological approach to the question of disability allows for a more accurate portrayal of what is happening in the lives of people with disabilities and why.102

An example of disability experienced as a problem in theological literature can be found in Fulkerson’s book Places of Redemption: A Theology for a Worldly Church. This postmodern analysis of Good Samaritan United Methodist Church offers liberatory lessons for secular society.103 Good Samaritan seeks to be a welcoming and inclusive church of all people. The church is a diverse community which includes people of color, white people, global citizens, and people with disabilities from a local group home. Fulkerson develops the idea of theology as a response to a wound. She tells us that the inspiration for this idea comes from Charles Winquist’s statement that, “creative thinking originates at the scene of a wound”104 Fulkerson uses the conception of a wound to help Good Samaritan address the wounds of able-ism and racism. Fulkerson describes how

102 Ibid.


104 Ibid., 14.
she is disturbed by an encounter with a man with a contorted twisted body in a wheelchair, her tentative approach of him, and her struggle to know what to do—for example, whether to stand and thus talk down to him, or squat down in order to meet him face-to-face. Even when Fulkerson is approaching the situation of disability with compassion and openness, her encounter with the physically disabled man in a wheelchair becomes a problem for her. Disability indeed does resonate in our culture as a problem, which I will argue needs to be considered in a practical theological way in order to develop a method to explore disability.

The challenge in developing a methodology for a practical theology of disability is tying together multiple, and seemingly contradictory stances. One of these is the hegemony of the normal and the dominance of the able-bodied centric position within society that marginalizes people with disabilities for their “abnormal” non-conforming bodies. The biological basis of disability brings to the forefront issues that cannot be alleviated by social action. For example, no social action can address the pain and difficulty of Desiree’s arrhythmias. If we are to admit the reality of embodied impairment among people with disabilities and not simply state that we are all the same, then it is difficult to address the hegemony of the normal for it implies the removal of the normal which does not solve the problem. Yet for the most part this is what the social construction model seeks to do: establish that everyone is the same—when they are not. The reality is that there is a difference between being disabled and able-bodied, because disability makes a significant difference in how one goes about living everyday life and

\[^{105}\text{Ibid., 16.}\]
this is a concrete biological fact that cannot be addressed through mere adjustments to the
definition of disability. For Michalko and Titchkosky the solution to the “problem” of
disability is not asserting a definition of disability but asking a different question based
on phenomenology, thus they ask, “What is the phenomenon called disability?” By
asking the question Michalko and Titchkosky seek to address how disability “makes an
appearance in the world and is lived.” Michalko and Titchkosky call for the examination
of disability as it is lived but there are few studies that actually examine the embodied
everyday experiences of people with disabilities. This is a gap this dissertation seeks to
address. The argument here is that disability “appears” to the able-bodied majority that is
afraid of its own vulnerability and finitude as a problem to be ameliorated. Disability
reminds humankind of what it most often wants to forget—its finitude and limitations.
Our finitude and limitations confront us with the reality that as humans we are not in
complete control of our lives. Lisa conveys this as she describes her multiple trips to the
doctors as a young child of six because of her cerebral palsy:

I can remember being six and being really angry about my situation….I
was angry that my own life was out of my control. I was angry that my
dad had died. I was angry that the doctors ran my life, that’s what it felt
like, the doctors run my life…and that I have to go to the hospital and I
hate it there. And they are always doing stuff to me that I don’t like. I
would often be mad at my mother … we would often go to the doctors and
she’d come in … and I would downplay whatever was going on… but
then my mother would speak up for me ….and she would make it
perfectly clear that she “has this or that going on” and I’d be like [yelling
in my head], “shut up!”

Lisa’s physical limitations left her completely out of control of her physical body at the
hands of the medical doctors. Her narrative about going to the doctors brings home in a
very meaningful way how our limitations can leave us out of control of our physical bodies. Such limitations or limit situations are comprised of, “two basic kinds of existential situations: either those ‘boundary’ situations of guilt, anxiety, sickness, and the recognition of death as one’s own destiny, or those situations called ‘ecstatic experiences’— intense joy, love, reassurance, creation.” Of course disability locates itself on the negative side of the limit situation as somewhat comparable to sickness, given our unwillingness to embrace the negative aspects of embodied difference. According to medical anthropologist Kleinman, the limit experience of sickness brings up a common question, “Why me?” Disability although not completely comparable to illness and sickness, disability raises the same sorts of questions. Tracy explains:

Such experiences (sickness, guilt, anxiety, recognition of death as one’s own destiny) allow and, when intense, seem to demand reflection upon the existential boundaries of our present everyday experience. When an announcement of a serious illness – whether our own or of someone we love – is made, we begin to experience the everyday, the ‘real’ world, as suddenly unreal: petty, strange, foreign to the now real world. That ‘limit’ world of final closure to our lives now faces us with a starkness we cannot shirk and manages to disclose to us our basic existential faith or unfaith in life’s very meaningfulness.

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106 Tracy, *Blessed Rage for Order*, 105.

107 In affirming the negative aspects of embodied difference throughout this dissertation, it is important to note that the negative aspects of limit situations are not completely static or unchangeable. In time one’s relationship to the embodied difference of disability can shift to a more positive, meaningful and life affirming experience, although the permanence of the unchangeable biological reality that comprises the limit situation of the disability remains the same.


It is this sort of confrontation with the limits of our existence that we tend to want to avoid, because, as Schillebeeckx explains, such limits and suffering raise questions of ultimate meaning:

….apart from some forms of suffering which can for the most part be removed by man, there are forms of suffering and threats to life on which man can have no influence through technology and social intervention. This is where the question of meaning of humanity emerges. The historicity and thus the finality of man, which he does not know how to escape so that he can adopt a standpoint outside of time, makes him understand his humanity as a hermeneutical undertaking, i.e., as a task of understanding his own situation and unmasking critically the meaninglessness that man brings about in history.\textsuperscript{110}

In other words, the suffering that cannot be removed by human innovation and technology forces the question of meaning to emerge because when one is confronted with suffering that cannot be alleviated by human intervention it forces us to consider what we most want to avoid, that is our limitations and finitude. A disability positions a person on the borders of finality providing a “boundary perspective” which is not ordinarily available to those who do not have to confront physical limitations on a daily basis. Those with disabilities cannot help but live in constant confrontation with their limitations, which opens up a unique hermeneutical perspective that is not ordinarily available to those without disabilities. This boundary perspective affords those with disabilities the unique task of unveiling interpretations that originate from the meaning of physical limitation. Therefore, being disabled serves an important purpose to unveil what humankind prefers to overlook: its finitude and limitations. Those with disabilities have

no choice but to integrate life lived on the boundary with its limitations into their experience because a life in a disabled body is a constant confrontation with finitude. People with disabilities therefore provide theological discourse with a hermeneutic of suspicion that integrates the meaning of physical limitation into its vision of the world. Disability challenges academic discourse to break out of its neglect of embodied difference and limitations.

The hermeneutic of suspicion associated with disability involves vulnerability, finitude and confronting limitations. Kirmayer points out, “Sickness challenges cultural clichés and facile explanations. It poses anew the problem of Job, latent in every life, made personal and immediate by the insistence of bodily suffering.”111 When one lives with a disability the limitations of humanity are undeniable and questions of meaning are constantly raised. Those with disabilities cannot help but live in everyday confrontation with their limitations. For people with disabilities these encounters with limit experiences occur in the practice of everyday life. The neglect of the examination of the meaning of physical limitations and suffering that cannot be alleviated through human intervention among people with disabilities challenges academic discourse to consider how human finitude and frailty influences theological interpretations. Wolfteich reminds us that practical theology “attends closely to context and culture” while it is also concerned with comprehending the experiences of everyday life.112 David Tracy prompts us to listen to

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the voice of the other and to attend deeply to the massive amount of suffering in our world today. The practical theology of disability in this dissertation attends to the concrete experience of limitations and suffering while it conveys the unheard voices of the “other” as people with disabilities to the academy. The limit experiences of physical disability prompts theological questions such as: “Why do I have to suffer this way while others do not?” An interviewee Lisa sheds light on what it is like to ask this question of God concerning her suffering and embodiment:

My mother was very Catholic….and so was my father and we grew up in the Catholic church and it was very strict….I went to Catholic school starting in kindergarten right up through college, so I really bought into [being Catholic] because people and the nuns would say to me, “Oh you’re really special to God” … you know… “God really loves you” … “you have to be brave”… “offer it up for people less fortunate than you…”

The adults around Lisa told her to offer up her suffering to God, as she explains that phrase “offering it up” means that “You’re suffering for other people.” Lisa further elaborates what this meant for her:

I being the “goody-two shoes” that I was….I really bought into that because that was the only way I could make any sense out of what was happening to me….but at the same time I would think to myself, “Why is God punishing me like this?”…. On the other hand, I would be like “wow, if I can be good enough and brave enough, I could be a saint someday.”

Lisa’s belief that God may be punishing her brings home the point that disability is not peripheral to theology. People with disabilities also need theological interpretations

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and insights to help them in the struggle of everyday life. Mary provides insight into the daily struggles of disability as it relates to physical limitations.

Mary describes the difficulty with her having rotator cuff surgery, “The thing about the rotator cuff surgery I literally was flat on my back because they would not let me walk.” Mary explained that her husband, Robert could start doing things in two or three days after his rotator cuff surgery, when he felt like he could stand up and move. One of the concerns for Mary was that she needed her arms and crutches to walk, the shoulder surgery thereby prevented her from walking. As a result of being on her back for a long period of time, she developed a deep vein thrombosis (DVT), in other words a huge blood clot. The clot ran from her groin on her left side all the way down to the top of her calf.

So what that left me with was a huge upper left thigh, so not only does my system initially not work well [because of my loss of muscular strength from my cerebral palsy] but it is compromised by the huge blood clot that I had…. in the long run it made it very difficult for me to get around because my leg was so big [almost a third more of its normal size] and it was so heavy, my other leg started to look the same, [the right leg] was not as bad but you could tell that it was not average like it used to be. So I want to the doctor to see what was going on because I could not walk very far.

After 10 to 20 yards Mary would have to sit down halfway, because she started to lose the feeling in her legs when she walked. She would “muscle her way” to a place to sit using mostly her upper body and crutches to get there. After her lymphedema therapy Mary got to what medical professionals describe as a “manageable” size. In order to keep her condition under control and at a “manageable” size Mary must don thigh high compression socks and use a lymphedema pump.
So right now what I do is I wear thigh-high socks every day. I also have a lymphedema pump, which is an electronic pump unit. I have two leg sleeves and they mimic the muscles and it's an hour in the morning and an hour at night. Yes I do, do it and it does work, but if my husband were not off [from work] right now [because of his own rotator cuff surgery] I would only be doing it at night. As it is right now we are up at six [in the morning] to get me dressed in the socks. On a normal day [when he is working] he is out the door by 7:15 am. It is not a process that I can do for myself. Most of the work has to happen from the other side of me, meaning someone needs to be on the other side of me so I can do it. Before I was married, [and] I had my braces, [and] I had my knee socks, it would be the same process but the socks only went up to the knee, I would put them on with the sock donner. I would put the sock on the sock donner and then struggle to put the sock on because that’s my max coordination. And some days I couldn’t get my left foot into the sock donner. But my thing is that I was frustrated with people in the medical profession and the manufacturers, for the fact that there seems to be no one out there that has thought of the wearers or users point of view. So here I was trying to work, I was single, only my income and I was trying to work 40 hours a week, to make my everything and I had doctors on the other hand saying you really need the thigh-high [compression socks] and I'm looking at my doctor (who I love and see every six months) and my leg is growing, growing, and growing, wider, wider, and wider and he says to me you really need the thigh-high. And I say to him, “I'm doing the best that I can I get to work. I get my socks on, I get my braces on, I get my shoes on, I get to work, so you can’t have it all,” that is what I’m telling the doctor, “You can’t have it all.”

Mary confessed to me that when she was using only the knee high socks when she lived alone, it would take her about an hour and forty-five minutes just to get ready to go to work in the morning and that was on a good day. On a bad day she would have to enlist the help of her mother who lived nearby to help her put on her socks so she could go to work. Ultimately the lymphedema and the thigh-high compression socks ended her working life because she was no longer able to get herself ready and out the door to keep a full-time job.
It is difficult to imagine the inability to work as a consequence of it being physically impossible to dress. Physical limitations in the lives of people with disabilities prevent them from excelling and maintaining their careers. The biological basis of limitation and impairment rush to the forefront as it situates itself within the context of everyday life. No social reconstruction can ameliorate Mary’s lymphedema and the painful and frustrating consequences it has upon her life. How are people with disabilities to deal with their everyday lives when confronted with the harsh reality of their embodied limitations? Employing a method of mutual critical correlation to develop a practical theology of disability opens up the way for the necessary conversation between daily life and theological texts to address the limit questions that arise from the everyday challenges of disability.

*Practical Theology and Disability as a Practice*

As mentioned above practice is central to the discipline of practical theology. Browning proposes a turn to practice while integrating practical philosophy into a practical theological method which in turn widens the scope of practical theology.114 Practical theology traditionally turns to practice as a primary source for its analysis. Colleen Griffith reminds us of this when she writes, “In the absence of paints, a watercolorist cannot work. Minus a bow, a violinist cannot make music. Divorced from

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the realm of practice, one cannot speak as a practical theologian." The emphasis on practices within the discipline of practical theology usually typifies practices of faith related to specific religious communities.

This study will take practical theological analysis in a new direction by analyzing the everyday lives of people with disabilities and their implicit religious beliefs and practices. I will argue that an examination of everyday life calls for an analysis of disability as a form of practice. Practical theologian Ted Smith explains that practical theology turned to culture and in doing so practical theology’s attention to practice is one of its best conceptual tools for attending to culture. The emphasis on practices within the discipline of practical theology usually typifies practices of faith of religious communities. I argue along with rehabilitation specialist and scholar, Louise Thibodaux that the daily lives of people with disabilities “constructs the experience of disability,” and this gives rise to the “logic of practice.” This for Thibodaux is the occasion to allow people with disabilities to “embody their own discourse” and to “teach it to others.” Thus, the daily experience of disability can be viewed as a practice available for analysis in the discipline of practical theology. The neglect of the struggles of embodied life among people with disabilities in the discipline of disability studies calls

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117 Ibid.
for a more engaged emphasis on the daily experiences and practices of living with a physical disability.

In providing a platform for people with physical disabilities to articulate their everyday experience this study depicts case study narratives that show how the challenges of embodied life with a disability can be conceived as practices. Smith explains that in considering the role of practice within practical theology three thinkers contribute most widely: Bourdieu, MacIntyre and Gadamer. Lastly, Ted Smith explains that theologians Mary McClintock Fulkerson and Joan Martin integrate the role of practice and embodied life in the context of practical theological work: “Both Martin and Fulkerson adapt Bourdieu’s theory to make visible the bodily wisdom of people often overlooked by methods that pay less attention to practice.”¹¹⁸ Joan Martin’s book, More Than Chains and Toil, depicts the moral agency and Christian work ethic of enslaved women through an analysis of the slave narratives of women. Martin explains that the narratives obtained by interviews or written text by the slaves themselves, “set free the lives of women who were propertied objects and artifacts of others’ history; the narratives made them the subjects of history.”¹¹⁹ According to Martin, Bourdieu underestimates the power of individuals to resist, furthermore she also contends that


resistance takes social and individual forms. I will argue along with Martin that Bourdieu underestimates the ability to resist. Fulkerson in her book *Places of Redemption* integrates the work of Bourdieu and Macintyre to account for the role of “place” in the context of a multiracial congregation that seeks to be welcoming toward all people including people with severe cognitive and physical disabilities. Fulkerson analyzes the practices of congregational life through the lens of bodily performance, arguing that our embodied habitus embeds itself into our experiences of place which involves our enactment of tradition and storytelling.

Bourdieu’s approach to practice is more embodied than MacIntyre; thus, Bourdieu’s work is more influential for the purposes of this study; however MacIntyre’s work is important for considering the role of tradition in maintaining stereotypes of and prejudices against disability. Lastly, Gadamer is important for retrieving the concept of effective history. Smith describes Bourdieu’s use of practice as “to describe human action in a way that highlights its embodied, social, and habitual qualities.” Bourdieu explains that practice is the combined effect of field, capital, and habitus. For

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120 Ibid., 69.

121 Smith, “Theories of Practice,” 249.

122 Ibid., 246.

Bourdieu, the habitus is a practical conceptual schema that operates in the logic of practice.

Habitus according to Bourdieu, operates in everyday life to shape practices, and is defined as:

systems of durable, transposable dispositions structured structures predisposed to function as structuring structures, that is, as principles of the generation and structuring of practices and representations which can be objectively “regulated” and “regular” without in any way being the product of obedience to rules, objectively adapted to their goals without presupposing a conscious aiming at ends or an express mastery of the operations necessary to attain them and, being all this, collectively orchestrated without being the product of the orchestrating action of a conductor.124

The concept of habitus helps explain the largely unconscious knowledge of how people are expected to conduct themselves in various social contexts of everyday life. An understanding of practice is derived from habitus. Bourdieu and Wacquant describe habitus as the following:

to speak of habitus is to assert that the individual, and even the personal, the subjective, is social, collective. Habitus is a socialised subjectivity … neither the individual… nor groups as concrete sets of individuals sharing a similar location in social space, but in relation between two realisations of historical action, in bodies and things.125

The embodied and unconscious socially and spatially contextualized nature of practice comes to life through habitus because habitus dictates the usual ways of relating to social environments and relations with others. These expectations of conduct form into


predictable patterns of social manners and these social manners are driven by hegemonic social structures and social hierarchies which determine social positioning. Social locations are for the most part inherited; people acquire their habitus from childhood. Social disadvantages are incorporated into the habitus and behaviors are adjusted to meet the expectations of the anticipated life-chances inherent in one’s social positioning.126

Habitus, according to Edwards and Imrie, “offers a way of bringing an analysis of the body to bear upon an understanding of the social inequalities which are core to the lives of disabled people.”127 Furthermore, Edwards and Imrie explain how this works in the everyday lives of people with disabilities through citing a narrative from Stephen Kuusisto’s memoir, Planet of the Blind, “for example, [Kuusisto] notes the hours of practice and bodily re-orientation necessary when, after living for years with a visual impairment was given a guide dog. As he [Kuusisto] writes of moving around: ‘The street is more my own. … I’m walking without the fight-or-flee gunslinger crouch that has been the lifelong measure of blindness … at age thirty-nine, I learn to walk upright.’”128 What Edwards and Imrie do not mention in this quote is that Kuusisto in this text is describing negotiating walking on a train platform as a blind man who once had his sight and now he is challenged with learning all the new habits associated with


staying safely on the platform and not falling in front of an oncoming train. Thus, we can see from this example that disability requires daily habits to negotiate the physical landscape of society primarily built for able-bodied people. These daily habits establish themselves as habitus and intuitive know how to function through everyday activities. This gives credence to Fulkerson’s point that embodied habitus situates itself in the context of place. The context of place in the lives of those with physical disabilities shows itself in the landscapes of everyday places such as train platforms, unanticipated stairs, slippery sidewalks in the wintertime and alike.

Bourdieu conceptualizes the objective world where all human action and practices take place between individuals and groups as fields, and a field is:

. . . a network, or a configuration, of objective relations between positions objectively defined, in their existence and in the determinations which they impose upon their occupants, agents or institutions . . . the structure of the distribution of power (or capital) . . . that [is] at stake in the field, as well as by their objective relation to other positions.

In other words, fields are social institutions such as law, education, family, medicine etc. that constitute social life. People inhabit various social locations based on the power of their habitus and practices in a given field. People compete for social position and status within particular fields according to particular social norms of behavior and manner of practice. Bourdieu notes that obtaining power within a particular field takes on a game-like character. The players and the rules of the game comprise the logic of practice with

130 Fulkerson, Places of Redemption, 41–49.
131 Bourdieu and Wacquant, An Invitation to Reflexive Sociology, 97.
in a particular field. The concept of *illusio* for Bourdieu is the ability to identify what in a particular field counts as capital. Furthermore, Bourdieu emphasizes within this concept that there needs to be a serious commitment to “taking the rules of the game” seriously in order to obtain capital.  

*Illusio* in the form of knowledge and acceptance of the rules of the game allows for the commitment and investment in obtaining various forms of capital largely set by social positioning and habitus. The concept of *illusio* for Bourdieu is our commitment to participating in a particular field and making the investment in the stakes of the game. The game becomes critically important because it defines privilege and social status.

The critical importance of Bourdieu’s work to developing a practical theology of disability becomes clear when examining Bourdieu’s notion of capital, which introduces the consequence of embodied inequality in relationship to understanding practice as socially derived. Arthur Frank explains that Bourdieu claims that privilege in the past was passed down through monetary capital or class title, whereas now, “privilege is transmitted through complex investments and reconversions of capital; education is paramount, but health enhancements are increasingly relevant.” Bourdieu uses multiple conceptions of capital in his work:

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132 Ibid., 117.

133 Ibid.

134 Ibid.

Depending on the field in which it functions, and at the cost of the more or less expensive transformations which are the precondition for its efficacy in the field in question, capital can present itself in three fundamental guises: as economic capital, which is immediately and directly convertible into money and may be institutionalized in the forms of property rights; as cultural capital, which is convertible, on certain conditions, into economic capital and may be institutionalized in the forms of educational qualifications; and as social capital, made up of social obligations (‘connections’), which is convertible, in certain conditions, into economic capital and may be institutionalized in the forms of a title of nobility.\textsuperscript{136}

Bourdieu believes that it is impossible to understand the social world without including a conception of capital.\textsuperscript{137} In \textit{Forms of Capital}, Bourdieu uses the example of the game of roulette to illustrate a system where at each spin of the wheel there is an equal opportunity for the miraculous gain or loss of money. By contrast, “Capital, which, in its objectified or embodied forms, takes time to accumulate and which, as a potential capacity to produce profits and to reproduce itself in identical or expanded form, contains a tendency to persist in its being, is a force inscribed in the objectivity of things so that everything is not equally possible or impossible.”\textsuperscript{138} Furthermore he explains, “And the structure of the distribution of the different types and subtypes of capital at a given moment in time represents the immanent structure of the social world, i.e., the set of constraints, inscribed in the very reality of that world, which govern its functioning in a durable way, determining the chances of success for practices.”\textsuperscript{139}


\textsuperscript{137} Ibid., 46.

\textsuperscript{138} Ibid.

\textsuperscript{139} Ibid.
determine the chances of success of practices at functioning well within a particular social and economic system.

Interviewee Tom illustrates how all of these forms of capital work in his own life. In terms of economic capital Tom’s only source of income is Social Security because he is unable to work because of the severity of his cerebral palsy. Thus he has limited resources to build and obtain economic capital because his physical body prevents him from being gainfully employed. Tom has a master’s degree in education with an emphasis on disability and rehabilitation. Tom’s educational accomplishments show that in spite of his physical disability he was able to obtain some cultural capital. However, because of his severe physical limitations, he is unable to convert that capital into economic capital. Lastly, Tom is an example of how people with disabilities can create social capital even when cultural misunderstanding creates constraint and an extreme obstacle.

Tom developed a health issue and was taken to the hospital. Tom knew that the doctors had misdiagnosed his medical problem because of his severe speech impairment. The medical professionals at the hospital wrongly assumed that he had a cognitive impairment, so they made little effort to understand his garbled speech. Finding that his medical situation was deteriorating and becoming more desperate, Tom began to fear for his life. While he was in the hospital he used his specially adapted laptop to send emails explaining his situation to medical professionals who knew his medical history. The medical professionals Tom emailed then contacted the doctors at the hospital so Tom finally got proper medical attention that saved his life. Tom converted this horrible
situation into social capital. Tom secured a grant from a nearby university to develop a medical form for people with severe communication issues so that this sort of incident would not happen to other people with disabilities. Tom explained to me during our interview, the form Tom designed is now being used with people with speech impairments, as well as, people with autism and downs syndrome. Thus, Tom’s life illustrates Bourdieu’s forms of capital and shows that physical limitations constrain his ability to convert the cultural capital of his education into economic capital. Tom’s tenacity in light of being misunderstood and ignored by medical professionals was able to create some social capital through initiating the creation of the new medical form that is being used by many other people with disabilities. In order to do this Tom had to resist the predetermined ideas the medical professionals had of him, and he needed to devise a workable plan to free himself from the situation. Lastly, he took the further step of resistance through working to devise the new form, and then fought to get the form utilized among those who needed it.

Frank analyzes narratives of illness and sickness. In doing so he develops a conceptual understanding of cultural expectations concerning sickness and illness. In using Frank to establish this point, it is important to note that many in the disability studies discipline take issue with defining or relating disability to sickness or illness. On the other hand there have been a number of feminist who have noted the importance of wanting to acknowledge being an “unhealthy” person with a disability rather than deny health-related issues in order to distance oneself from the medical model. This study in seeking to explore the everyday lives of people with disabilities does not hesitate in utilizing the literature of medical sociology where it seems appropriate. Since there is little scholarship establishing disability as a practice per se, the work of Frank here is used as the closest match to the experience of disability that exists in the literature. I agree with those in disability studies that disability is not exactly comparable with sickness and illness but in this case I am simply using the experience of embodied impairment and physical limitation as a common thread between illness and disability to begin to conceptually establish disability as a practice.
argue in the pages that follow that cultural expectations concerning sickness and illness that operate in our culture limit opportunities of people with disabilities to obtain economic, cultural, and social capital. I contend that limited opportunities to obtain capital (in whatever form) are due in part because of the able-bodied social world and the fallout of living with physical limitations that cannot be ameliorated or helped through social action or medical interventions. I will also argue that a tradition of dealing with people with disabilities as a “problem” is born out of American history and exists to foster (whether consciously or intentionally or not) to the continued marginalization of people with disabilities.

**The Practice of Disability, Tradition and Operative Effective History**

As mentioned above, Browning uses Gadamer to make the argument that there is an effective history that operates in the present whether we acknowledge it or not. I argue below that there is a specific effective history that originates from the American history of disability. This operative effective history influences the practice of disability and the everyday lives of people with disabilities and thus is critical to understanding the contemporary situation of disability.

Fulkerson employs the work of Alasdair MacIntyre to account for the dynamic character of place and the narrative nature of tradition where individual acts are

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141 This point is related to the earlier argument established in chapter 1 by Thomas Shakespeare that disability is unique among oppressed groups given that impairment of disability will always require extra intervention. Thus, the oppression of disabled people cannot be fully alleviated through the revision of social structures.
intelligible in their larger contexts. Fulkerson points out, “My act makes sense in the larger story of my life, which is embedded in many larger stories.”\(^{142}\) The source of the good is discovered through the communal wisdom which emerges through tradition and the layering of individual stories upon communal stories. It is tradition that determines what a community defines as its ends and its good. According to Fulkerson tradition is “the mediation of ends, which are found according to MacIntyre in the practices of a tradition.”\(^{143}\) According to MacIntyre a practice is:

> Any coherent and complex form of socially established cooperative human activity through which goods internal to that form of activity are realized in the course of trying to achieve those standards of excellence that are appropriate to, and partially definitive of, that form of activity, with the result that human powers to achieve excellence, and human conceptions of the ends and goods involved, are systematically extended.\(^{144}\)

MacIntyre is important in considering our effective histories but it remains to be seen if his definition of practice really is situated within the hegemony of the normal. What is important to grasp at this point concerning MacIntyre is that there is a notion of tradition operative in the playing out of daily practices and these practices are driven and defined by social goods defined by operative traditions and effective histories. Recent studies among rehabilitation professionals that integrate Bourdieusian analysis with disability indicate that the principle good operative for people with disabilities is in obtaining as

\(^{142}\) Fulkerson, *Places of Redemption*, 38.

\(^{143}\) Ibid., 39.

much normalcy as possible. Patricia McKeever and Karen-Lee Miller explain that: “In Bourdieu’s terms, mothers demonstrated both logic of practice and illusio. Their responses ranged from resistance to appeasement of powerful pediatric professionals, adhering to hegemonic definitions of body normativeness and development, as well as cherishing their children despite social suffering.” Mothers of children with disabilities seek social capital for their children, for example, by making the extra effort to dress their disabled children to, “control the presentation of children’s bodies, and hence the interpretation of their worth and ability extended to the symbolic uses of dress.” This drive to normalcy among people with disabilities reveals the operative able-bodied centric position within our culture. Meaning one way to obtain social capital is to “normalize” the look of one’s appearance to coincide with acceptable forms of dress to appear as normal as possible. Maria is a good example of this, because she purposefully avoids using a cane because it would call attention to her disability and make her look less normal. Mary tells a story about how her parents took measures to help develop her physical strength with a motive that she stand for long periods of time and thereby ambulate more “normally”:

My dad built a standing table that is what they called it. It was like a box with four sides, literally a tall rectangular box that they would put me in and I had full leg braces. I could stand in the “box”, like when my mother


\footnote{Ibid.}

\footnote{Ibid., 1187.}
was cooking dinner, and I could help because it had a counter attached to it at my level and I could do stuff she would give me to do. Mary explains that she had the “box” while she was in first or second grade. These narratives depict an embodied habitus driven by a tradition that seeks normalcy.

Fulkerson puts together tradition and embodied habitus in a way that is helpful in beginning to understand physical disability as a practice:

Whatever form of gospel one learns, racialized incorporative practices will accompany it, whether for Christians habituated as ‘whites’ or those habituated as ‘blacks’. Everyday knowledge, the wisdom to maneuver, is racialized. In the case of Good Samaritans, as we will see, people ‘of color’ from outside the US will be racially habituated in very different ways from African Americans. Whites will have been habituated into illusory proprieties that, being ‘without race’, they are simply human beings. All of these racialized habituations will be gendered as well. Many of the participants, black and white, will have been habituated into bodily proprieties, everyday knowledges, around ‘normal bodiedness’. They will, in other words, most likely participate, however unconsciously, in aversive postures toward people with disabilities.148

Fulkerson’s point is that there are multiple habituated practices that are unconsciously embedded into our traditions and practices. Stories layered upon stories builds the able-bodied perspective of disability throughout the centuries attests to the fact that people with disabilities are often viewed as objects of pity, in need of charity and either being ascribed as having holiness or being demon possessed.149

Historian and author of *An American History of Disability*, Kim Nielsen points out that the Puritans viewed the world as ordered by God. Nielsen explains, “The Puritan


social ethic pervaded all aspects of life in early New England. Believing that God had created the world to be orderly and hierarchical, the Puritans sought to replicate that design in their social structure and community covenants. Thus, the Puritans established laws to prevent those deemed incompetent from serving in public life.

Nielsen explains, “In 1641 the Massachusetts ‘Body of Liberties guaranteed that no one would be made to perform public service if they were unable to due to ‘want of years, greatness of age, defect in mind, failing of senses, or impotency of limbs.’” It is important not to look at the laws through a twenty-first century lens, whereby it is hard to pinpoint exactly the laws intention, however, it does seem that these laws were believed to be an act of Christian compassion by the Puritans on behalf of those who were deemed by the community as unable to serve and thus provided an avenue for relief of social responsibility. Massachusetts law at the time did protect those who did not understand the law due to a lack of mental capacity; Nielson explains that this protection was common practice in the English homeland. Whether the law to exclude people with disabilities from public service was to serve as an act of compassion or not, the consequence was that the law served to perpetuate marginalization of people with disabilities, whether due to a determination of physical or mental incapacity. Nielsen’s book examines the lives of people with disabilities as it steps through American history and it reveals continued

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152 Ibid.
marginalization of people with disabilities out of a desire for an orderly society mixed with an ebb and flow of a misplaced sense of compassion or charity and hateful distain.

The misplaced charity and hateful distain originate from the determination of the inferiority of slaves and a conflation of slavery and disability. Nielsen explains, “The racist ideology of slavery held that Africans brought to North America were by definition disabled. Slaveholders and apologists for slavery used Africans’ supposed inherent mental and physical inferiority, their supposed abnormal and abhorrent bodies, to legitimize slavery. Indeed, slaveholders argued that the bodies and minds of those they enslaved were disabled to such an extent that slavery was a beneficial kindness owed to those in need of care.” Furthermore, slaves with visible infirmities were deemed “refuse” slaves and were often left to die. Slavery in America illustrates the mixed bag of hateful distain and charity. The central theme emerges here of the body being deemed as “worthless” and then leading to the belief that a slave as subhuman was only worthy of charity. Nielsen explains that how people with disabilities were treated prior to the birth of the American nation depended upon individual circumstances, “The experiences of people with disabilities in colonial America varied tremendously according to one’s familial resources (economic as well as physical), race, legal status, gender, and class.”

The birth of America set in motion the national desire for creating a citizenry that could keep the new nation growing and flourishing. Nielsen points out that between 1776

153 Ibid., 42.
154 Ibid.
155 Ibid., 47.
and 1865 the new nation sought to determine the value and worth of its citizens in order to determine that it had what it needed to “run” the new democracy. In light of the concerns of having enough human “capital” some advocated for the education of women.\textsuperscript{156} Nielsen explains:

For example, in 1791 an unnamed contributor to the \textit{Universal Asylum and Columbian Magazine} warned of the deleterious effect of limiting women’s education. No one should be surprised, the author wrote, at the “pale-faced, decrepit, weak, deformed women, daily presented to view, who have been tortured into a debility which renders their existence wretched.” The nation required women’s education, the author insisted, in order to ensure able-bodied women that it might succeed in its grand experiment of democracy. How could women—if deformed and decrepit—help the new nation at such a critical moment? Embedded in these arguments was the unstated premise that good citizens were citizens able and competent in all ways.\textsuperscript{157}

Advocating for the education of women at the time was not for the sake of the women but for the sake of the nation and developing citizenry to contribute to the ends of the democracy. Nielsen argues that through the notion of developing a competent citizenry the various “isms,” began to take root in making distinctions between fully competent citizens and others.\textsuperscript{158} She explains: “The new, expanding, and solidifying republic required the maintenance and policing of competent citizens. Ideologies of racism, sexism, as well as ableism supported and contributed to the demarcation of full citizenship.”\textsuperscript{159} In this framework of a nation demarcating citizens as competent and

\textsuperscript{156} Ibid., 52.
\textsuperscript{157} Ibid.
\textsuperscript{158} Ibid.
\textsuperscript{159} Ibid.
incompetent it was in the best interest of citizens to downplay or overcome embodied aspects that would deem a citizen as incompetent, thus, whenever possible at least in terms of disability that had some variability in interpretation, for example, passing as someone who has a slight limp as opposed to someone who is labeled with a disability.

The era of 1865-1890 Nielsen marks as a time of educating the citizenry.\textsuperscript{160} While people with orthopedic disabilities were not educated until later in American history, people who were deaf were educated under the ideal of “oralism” which meant deaf people should not use sign language. This emphasizes the fact that throughout early American history the intent was to “normalize” defects in order to build and maintain a competent citizenry. There were some detractors to the “oralism” movement who argued that sign language was important because it enabled the deaf community to receive Christianity. Nielsen explains the push-pull of this era where the ability to be educated and the growth of institutions to warehouse people with disabilities took root, “The period from the Civil War until the 1890s is one in which disability became increasingly institutionalized. The solidification of the federal government that developed in this period, along with emerging technologies and urbanization, aided the creation of institutions and the development of policies pertaining to people considered disabled.”\textsuperscript{161} The embodied difference of disability in America was to remain hidden and locked away.

\textsuperscript{160} Ibid., 78–99.

\textsuperscript{161} Ibid., 98.
People with disabilities who were not locked away in an institution were to be kept out of public sight. Nielsen describes the “ugly laws”:

As Civil War veterans returned home, as urban areas expanded and the number of industrial accidents increased, cities across the United States began to pass what have been referred to as “ugly laws.” People with disabilities were to be made invisible. In 1867 San Francisco banned “any person who is diseased, maimed, mutilated, or in any way deformed so as to be an unsightly or disgusting object” from the “streets, highways, thoroughfares or public places of the city.” Chicago and many other cities adopted similar bans.\(^\text{162}\)

Hiding away embodied difference also took place among people who had cancer and other incurable diseases. Some people had relatives literally locked away in attics and basements never to be seen by children living in the same house.\(^\text{163}\) Nielsen points out that the ordinances unwittingly distinguished poor people with disabilities from people with disabilities who had wealthy families. The assumption here is that people with more wealth could pass with more dignity than those who lived in poverty. This brings to the forefront the deeply contextual nature of disability and that much of how a disability is perceived and what comes of a personal situation of disability depends upon family resources and cultural attitudes. During the time between 1890 throughout the early 1920s America as Nielsen points out that in its efforts: “to study, regulate, and improve


\(^{163}\) Ken Burns et al., *Cancer: the Emperor of All Maladies*, 2015. In episode one, Dr. Vincent DeVita, former director of the National Cancer Society explains, “When I was growing up I had an aunt who had cancer. She was hidden in the attic.” Sherwin Nuland, surgeon-writer points out the reason for the isolation, “Cancer was thought of as a contamination that was one of the reasons some people with cancer isolated themselves. They were aware of what it meant to some others. It was a reason some people wouldn’t let their children go near a relative who had cancer. People were ashamed if they had cancer and no one wanted to be seen if they had it.”
society had neither eradicated bodily difference nor prevented misfortune.”164 The effort was to simply eliminate disability and embodied difference from cultural sight.

Institutionalization of people with physical and mental disabilities, according to Nielsen served to control the reproduction of social norms. In the midst of this national desire to lock away disability was also a sense of benevolence especially toward disabled veterans of war. People who became disabled either through industrial accidents or war helped uphold this cultural benevolence because of the able-bodied starting point of these individuals. Furthermore, veterans posed another problem to the cultural distain toward people with disabilities because they fought heroically for their country. Thus, disabled veterans fit squarely into the narrative of the heroic soldier who lost their able-bodiedness for the good of the country. Disabled veterans helped prevent the complete removal of people with disabilities from the sight of society. In order to discover the status of veterans of World War I, Nielsen points out that the Cleveland Cripple Survey was implemented. The survey showed about 65 percent more instances of disability than expected.165 Furthermore, Nielsen explains, that the researchers assumed that all people with disabilities would be incapable of financial support but the “results astounded them,”166 for among the examples of people with disabilities that they found was a “District Court judge who had taken his bar examination by ‘holding a pencil between his

164 Nielsen, *A Disability History of the United States*, 89.
165 Ibid., 128.
166 Ibid.
teeth.”  This judge is an example, of a person deemed by the Cleveland Cripple Survey as a “successful cripple,” and it is these sorts of individuals who have orchestrated resistance in the midst of this cultural misunderstanding and distain. People with disabilities throughout American history resisted the culture that sought to lock them away to develop and nurture a sense of dignity and a worthiness to “fit in” to the culture and affirm themselves as Americans. It is this continued marginalization and resistance among people with disabilities and their loved ones that forms the tradition of disability in America. Helen Keller and President Franklin D. Roosevelt are notable examples of this resistance because they overcame physical limitations in order to assume leadership roles.

In resisting people with disabilities say “no” to the current conventions of what living with a disability is supposed to mean and instead decide to live as “normal” of a life as possible. Ultimately up until 1975 if you had a disability you were deemed as unworthy of a public education, unable to work and marginalized from everyday life. The reason for painting this brief picture of the tradition of disability in American culture is to suggest that the hegemony of the normal and the able-bodied centric position is essentially part of American tradition and this tradition is part of our effective history. This American historical tradition gives rise to our current conceptions and values that as Fulkerson suggests operate on an unconscious level.  There is still the desire, (however

\footnote{Ibid.}

\footnote{Fulkerson, \textit{Places of Redemption}, 6–21.}
unconscious) to marginalize people with disabilities making them invisible from the public square, to treat people with disabilities as a “problem” to solve, or in the name of misplaced compassion to absolve the disabled person of social responsibility. Thus, the culture continues its desire to sanitize the negative effects of embodied difference.

The American tradition of disability operates in our society defining roles and expectations of people with disabilities. Talcott Parsons in developing the concept of “sick-role”¹⁶⁹ comes under fire within the disability studies discipline because it is believed that his work focuses on an individualistic model of disability that aligns itself with the medical model. However, Parsons’ concept of “sick role” is widely cited in academic circles and this concept is a powerful descriptor of what it means to be sick in our society. Parsons’ concept of sick role asserts that there are specific social expectations of someone who is deemed medically sick. A sick person is expected to be relieved of his/her work duties and expected to follow doctor’s orders until which time the person is deemed well and able to work. In the effort to return to work people who are sick are expected to view their current status of being sick and unable to work as unacceptable.¹⁷⁰ The sick person then is expected to seek and follow a regimen of medical treatment in order to return to working status. It is important to consider that for Parsons the expectations were institutionally defined, whereas Parsons’ student Harold Garfinkel, the originator of ethnomethodology, established that the roles people play are

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not defined institutionally but rather as context specific interrelationships between various roles and expectations. Frank explains Garfinkel’s view:

Garfinkel’s most enduring contribution can be described as shifting the pride of place from institutions, which were paramount for Parsons because they guarantee continuity of normative expectations, to individuals who are understood as artful in how they play with and sometimes against what is expected of them. Role thus becomes a form of performance, and normative expectation is reconceptualised as the work of rendering orderly a reality that requires constant ordering. Garfinkel makes the point that our everyday experiences have a specific order and structure to them. Garfinkel must assert this argument because this is the basis on which his method of ethnomethodology rests; ethnomethodology studies the structure and order of everyday experiences in detail. Garfinkel further points out that to keep social situations ordered and structured people in social situations work to create order and maintain structure.

This ordering is critically important in examining the everyday lives of people with disabilities. The ordering of the everyday lives of people with disabilities in the context of the tradition of disability and the able-bodied centric position creates interplay between able-bodied people and their disabled counterparts to downplay disability. People with disabilities in social situations where their disabilities are brought to the

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forefront resist the negative conceptions of their bodies. To do this people with disabilities may systematically deny or downplay the consequences of their physical limitations while also seeking to “fit” their lives and bodies into the able-bodied world. In order to negotiate the landscape of their everyday lives people with disabilities must project as “normal” image as possible into their social worlds. Michael Kelly and David Fields explain that people do not want to hear the details of a chronic illness in public discourse, “Most public accounting practices help direct attention away from the potentially stigmatising nature of illness, and much social interaction is geared to repairing or overlooking faux pas, to covering up misunderstanding and generally making interaction work.”¹⁷⁵ This directs attention away from delving directly into the difficult aspects of disability, such as the true reality of embodied difference and instead brings the situation back into a projected or felt normalcy. The point is that this not only operates within our conversations about illness and disability but it functions in our experience of illness and disability to always seek a sense of normalcy when social situations bring the harsh biological differences of disability to the forefront, such as when a disabled person falls unexpectedly in a room full of people.

In a nutshell, the social ordering of situations and making them workable in everyday life is subjected to this operative American tradition of disability, so that when able-bodied people encounter people with disabilities in everyday life both parties negotiate the landscape of this tradition asserting their own cultural vantage points,

¹⁷⁵ Kelly and Field, “Medical Sociology, Chronic Illness and the Body,” 251.
beliefs and understandings onto the situation to bring the situation back to a sense of normalcy. Frank explains that in the midst of living everyday life where roles and performances are operative, there is a lack of reflection on how playing out our roles in terms of traditional expectations weaves together our collective lives. Frank writes:

> What our times condition people to lack is a reflective sense of how engagements in their own practices weave the nets that impair their freedom. People are generally clear about the immediate intended effects of their actions. They are less clear about how an aggregation of actions brings about a particular kind of world, especially in terms of the primacy of certain sources of value and the complementary neglect of others.\(^{176}\)

This dissertation involves engaging people with disabilities to tell their stories in order to discover the meaning of disability in their lives, render that which is not ordinarily reflected upon and currently incoherent into the coherent, to discover the stakes of the game that are to be taken seriously. Comprehension of the meaning of everyday life and practice is caught up in our story telling and meaning making. The argument here is that there are unique roles, performances and practices that are inextricably linked to living with a disability, and the long history and tradition of relegating people with disabilities to the margins. This dissertation seeks to discover the yet to be examined intricacy of everyday life of living with a disability in order to investigate more closely the relationship between disability and practice within the operative frame of reference of our effective histories and predominant and largely unarticulated values of normalcy. The assumption here is that there is unexpressed practical wisdom, namely a functioning know how operating in the everyday lives of

\(^{176}\) Frank, “From Sick Role to Practices of Health and Illness,” 21.
people with disabilities, while there are also practices among their able-bodied counterparts. Through providing those with physical disabilities an opportunity to tell the stories of their everyday lives some of that practical wisdom will come to light.

Maria’s depiction of various events in her everyday life experience with cerebral palsy illustrates some of how disability functions as a practice in the midst of the drive to normalcy. Maria falls down more regularly than an able-bodied person. She explains that because she falls often she hardly ever gets hurt. She knows how to protect her body from harm in the way that she lands on the ground. Maria explains that, “I fall and I don’t usually get hurt. It’s pretty rare that I would get hurt but sometimes. I actually don’t mind if I fall in my own house. It’s if I fall outside of the house in public that makes me feel incompetent or incapable, and all sorts of negative words.” Maria confesses that there is no rational reason to see herself as incapable or incompetent for her falling but this is what comes up for her in the event of a public fall. The public fall takes on a different sort of significance for Maria because it is public. The reason for Maria’s preference for falling at home is that in public she must contend with the response of others in relationship to her falling. Kelly and Fields explain what is happening for Maria when she falls in public, “when bodily demands conflict with desired self-presentation the individual becomes acutely aware of the divergence between body and self.”177 In light of a public fall Maria must reestablish herself in the social context and renegotiate her sense

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177 Kelly and Field, “Medical Sociology, Chronic Illness and the Body,” 245.
of self in relationship to the event that forced into focus her embodied difference as a woman with cerebral palsy.\textsuperscript{178}

What counts as social capital in the field of the everyday experience of disability for Maria and others with physical disabilities is being as “normal” as possible and eliminating the reality of physical difference from view. This I believe stems from the American tradition of disability. As an American in the past people with disabilities needed to hide or eliminate defects and limitations. To be a “successful cripple” in American culture one needed to resist the able-bodied centric culture and this meant working against insurmountable odds to eliminate one’s limitations to pass as “normal.” Thus, this renegotiation Maria’s sense of self and her sense of dignity when she falls is born of her American context which seeks to keep disability and its negative effects out of sight and hidden away.

Maria experienced a situation where she fell with a plate of food during a professional conference. Maria’s experience further illustrates the social drive to minimize one’s experience of disability. There on the floor with food sprawled all over the conference room carpet people rushed to see if Maria was okay. The fall left Maria horrified and humiliated. Maria assured her frighten colleagues that she was okay and that she would be able to get up on her own. People rushed to get her a fresh plate of food, others helped pick up the broken shards of glass, while others alerted hotel staff, still others sought to help Maria get up. People sought to help Maria as she rolled on all fours and crawled to the nearest chair as she reassured people that she indeed could get

\textsuperscript{178} Ibid.
up on her own. Once seated she quickly reassured people that she was okay and that others should simply go back to their “normal” activities. In Maria’s story of the fall at the conference we see the social ordering of everyday activities and the drive to normalcy. The fall is disruptive to all in the room and the situation works toward reestablishing social order and what in the particular context is perceived as “normal.” In disability there is habitus. In other words, personal embodied wisdom helps the person negotiate living with a disability. In other words, Maria’s habitus helps her use her embodied wisdom (established from years of falling) to physically fall and not get hurt. In Maria’s situation there is also a social habitus partaken by people with disabilities and able-bodied people to reestablish the social order. In social situations when disability becomes disruptive people with disabilities often take the lead offering their years of wisdom, conveying what they need and what they don’t need from able-bodied helpers. Thus, those who are able-bodied who encounter people with disabilities on a daily basis have more established “know how” on what to do and not to do in social situations when disability and physical limitations are disruptive in a social environment.

Once left to herself and those she was attending the conference with Maria scanned the room to see if her boss was in attendance and witnessed the event. Maria was somewhat relieved to see that her boss did not witness the devastating fall, she pleaded with her colleagues not to tell her boss what had happened. Maria’s colleagues did in fact divulge the event to her boss, which devastated Maria because she wanted to keep her experience of disability from her boss. Although Maria could not articulate her experience in terms of social capital, it seems that Maria’s desire to keep the fall hidden
from her boss might be an attempt to maintain social capital and prevent the loss of social position among her colleagues and her boss. Maria’s manner of dealing with her disability is one of almost complete denial. Maria would deny her disability completely if she could. In our interview together she described her disability as “no big deal” and that she sought others to see her disability in the same way. Maria does not use handicap parking tags or plates, she confesses that she spoke to the doctor one time about obtaining the necessary medical clearance to obtain the parking privileges. Maria has an obvious physical disability of cerebral palsy that disturbs her walking gait. She sways from side to side and there is an obvious limp to her walk. She cannot hide her disability from anyone and yet she refuses to accept it as part of her life. She explains her use of denial in the following way:

I do a very good job of ignoring it actually and choosing not to make it a big deal. Even though there are a lot of things that I could do to make my life easier that I choose not to do. A perfect example of this is I do not have a handicap parking placard or handicap plates. Because there is something about that label that I do not want to attach to myself. And I don’t want to display this to my child…As time is gone by I’ve considered it more seriously even the other day when I had to park in a visitor spot at my school and had to pay. I noticed that the handicap spots were free of charge. In the wintertime especially when it’s icy and I have to park far away that’s probably not smart…on my part because I am making it so much harder for me, but I guess my pride gets in the way because I don’t want that label. This is an internal battle that I have with myself from time to time…I got as far as asking my doctor about it once, which it was actually a huge step for me, to even have those words come out of my mouth…but that is as far as I got. I never did anything about it.

Maria’s strong sense of denial of her disability originates from her own distain over having the label of disability attached to her and this indicates a desire to hold on to the illusion that her disability is not a “big deal” and that she can pass as “normal” in an able-
bodied society. Maria becomes devastated when her disability confronts her and reveals the true nature of her embodiment so that her next response is to minimize and hide this aspect of herself from others, even though it is obvious to others who encounter her in public. Maria’s disability is more acceptable to her in private it is easier to contend with alone and on her own terms, than it is socially around others because in a communal context the true nature of her limitations always stands a chance of being brought into the open and the threat to her maintaining and keeping her sense of self and capital is omnipresent. The case study of Maria reveals that disability does in fact function as a practice within the operative effective history of disability.

**Conclusion**

In summary we can glean from this chapter that adapting Browning’s methodology into three submovements: descriptive, historical/systematic and strategic will help facilitate a mutually critical conversation between the everyday lives of people with disabilities and the mystical texts of Julian of Norwich and Teresa of Avila. The goal of the conversation is to develop proposals for transformation to address the challenges of living daily with a disability. Practical theology inextricably involves an analysis of practice. Thus, this chapter establishes that disability functions as a practice in the everyday lives of people, with individual and social forms of habitus operating to order social situations to maintain a sense of normalcy as conceived and maintained through the operative effective history in American culture. The operative effective
history of disability demands that people with disabilities resist their embodied limitations to appear as normal as possible, while also minimizing the effects of their disabilities upon everyday activities to increase the chance of obtaining and keeping social capital. The minimization of physical limitations among people with disabilities can take the form of almost complete denial even when disability is visibly apparent. The denial of disability shows in a preliminary way that some people with disabilities seek to be the “same.”
CHAPTER 3  
JULIAN OF NORWICH AND DISABILITY

Julian of Norwich Introduction

Spirituality scholar Bernard McGinn points out that, “During the past century Julian has become a cultural phenomenon, being used (and perhaps misused) not only by students of mysticism but also by poets and novelists (e.g., Charles Williams, T. S. Eliot, H. F. M. Prescott, Denise Levertov, Annie Dillard, and Iris Murdoch).”¹ This chapter will explore the writings of Julian of Norwich in relationship to physical disability in order to develop a practical theology of disability. Rather than misuse Julian’s text to serve a twenty-first century worldview, I will attempt to respect Julian’s cultural situation and to consider what her true intentions were in writing the way that she did. Julian of Norwich leaves us with two mystical text that describe her experience of sixteen revelations or showings in the Short Text (ST) which is an initial reflection on the revelations she received from God in May 1373. The Long Text (LT) is an expanded theological reflection on the events originally described in the Short Text. I draw upon secondary scholarship in addition to these two primary sources in order to establish the relationship between Julian’s writings and physical disability. The previous chapters established that the issues of disability are best situated within the broad topics of embodiment and marginalization. How does Julian’s theology respond to the marginalization of those with physical disabilities? Does her cosmic positive theology offer hope to those with

physical disabilities or does it fall short of providing a hopeful message? This chapter will explore several areas of Julian’s theology that may provide points of connection with the challenges of living with a disability, specifically Julian’s bodily sickness, along with Julian’s conception of God being with us in our humblest of needs as expressed in LT 6. Next this chapter will explore Julian’s Trinitarian theology and the theology of the ongoing suffering of Christ to determine where disability and embodied impairment fit within Julian’s theology. Lastly this chapter will explore what it means to be made in the image of God in terms of Julian’s theology in order to determine what Julian’s theological anthropology brings to the experience of disability. All of this theological work is undertaken in the hope of determining how Julian’s theology addresses the marginalization and the daily challenges of living with physical disabilities.

Julian’s love for God compelled her to carry on in the task of writing the LT after nearly twenty years of trying to make sense of her embodied revelations before God. Julian’s writing is intensely personal and highly practical. The text is an intricate blend of theological reflection, visions of God, personal insight and imagination. Elizabeth Dreyer notes, “Julian’s aim is not to present tightly argued, systematic theology, but rather to be faithful to the revelations she received, her style is circular rather than linear, suggestive rather than categorical, poetic rather than discursive.” Julian describes herself as “unlettered,” (LT1) as she insinuates that she is uneducated, but her text shows a high degree of theological acumen and insight. In her introduction to Julian of Norwich: A

Book of Essays, Sandra J. McEntire explains, “Although the source of Julian of Norwich’s learning cannot be known, her Showings attests to a learned author, one familiar with some of the most important patristic texts and commentaries.”

McEntire sheds light upon Julian’s writing style:

The Long Text represents Julian’s allegorical and tropological reading of her own earlier text, and, as such, of her represented self in that text. Fully aware of her lettered and unlettered audience, lay and churchly, and of her culture’s political and social boundaries, and just as fully committed to the inerrancy of her revelations, Julian’s Long Text is a brilliant excursus in medieval thought, spirituality, and poetics.

In the LT Julian performs a hermeneutical task of making sense of her earlier religious experience of bodily illness and the sixteen showings, to make known what she came to know within her embodied self and the truth that love is the Lord’s meaning. To do this Julian strikes a fine balance between presenting a theology that critiques what she sees as the theological inaccuracies of her day and conveying the message in a way that will not get her into trouble with the religious authorities. In creatively and carefully confronting what she sees as theological inaccuracies of her day, Julian’s writing is an act of radical resistance, for women were not allowed to write or teach in the fourteenth century. Julian’s confession of being “unlettered” some view as a defense against any accusation that she is disdaining cultural expectations by teaching as a woman.

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4 McEntire, Julian of Norwich: A Book of Essays, xii.

5 Ibid., 9.
Julian’s Life in Context

Julian wrote the *Showings* in the 14th century during a time of considerable suffering. Julian and her neighbors experienced plagues, and the ravages of war.

Sheldrake describes Julian’s context as influenced by the following historical events:

“The Hundred Years War between England and France caused a continual death-toll from every social class and growing taxation to pay for it…At the same time, was the age of plague. Norwich first succumbed to the Black Death early in 1349 and there were two other outbreaks in the 1360s. Overall about a third of the population died.”

Sheldrake notes that the, “combination of war, taxation, and plague contributed to economic depression and growing social instability.”

Jantzen notes that even though the popes and bishops “denounced the hostilities” of the war the “bearing of arms was, after all, an honourable profession; and the chivalric ideals of truth, honour, freedom and courtesy were semi-religious in inspiration….the military ideals, at least in theory, had the hearts of the religious population.”

Jantzen explains that the location of Norwich as a port city left it vulnerable to pirates during the war but it also allowed the city to become a key gateway to important other key cities of England, such as, London, York, and Lincoln. This means that Julian’s anchoritic cell


7 Ibid.


9 Ibid.
was located near a main avenue where the hustle and bustle of this key port would transpire day in and day out.10 Jantzen explains that there was more exchanged in this commerce than just exotic materials, “there was a flourishing trade of ideas, not the least of them religious.”11 Julian entered into this exchange of ideas through her writing. Dreyer believes that part of Julian’s intention in writing the *Showings* is to “correct the image of a wrathful God that generates fear of damnation, and partly to offer hope and encouragement to a community ravaged by plunder and plague.”12

The Black Death meant that people were literally surrounded by death with little means to prevent the continual and devastating losses. Jantzen also notes that the Black Death might have brought an experience of the Beguines to Julian.13 The Beguines were an informal sisterhood who were sometimes accused of heresy. In spite of the stigma attached to them, the Beguines were known for caring for the poor and the sick.14 Jantzen notes that the Beguines were probably more welcomed into communities during the Black Death because of the limited resources to care for the dying.15 Jantzen explains:

10 Ibid.

11 Ibid., 7.

12 Dreyer, “The Trinitarian Theology of Julian of Norwich,” 86.


14 Ibid.

15 Ibid.
Yet in the Norwich of Julian’s youth their devotion to care for the sick and dying would have been urgently needed and appreciated, because of the violence of the plague commonly known as the Black Death which swept through the land. In the absence of any concrete evidence, one can only speculate about what, if any, Julian’s relations to the Beguines might have been: certainly she shared their compassion for human wretchedness (but so, of course, did many others), and it is not impossible that she might have been more closely affiliated to them.\textsuperscript{16}

Whether Julian was affiliated with the Beguines or not, through this brief gaze into Julian’s context, we gain a glimpse from Jantzen’s point here of some of the compassion toward sickness and death that was operative in Norwich and perhaps right outside the window of Julian’s anchoritic cell. This sort of compassion may have also been helpful to the newly injured from the ravages of war or those contending with physical disabilities for other reasons.

Julian’s revelations coincided with a near deadly bodily illness and in the context of being ill Julian received revelations that allowed her to have an embodied experience of Christ’s suffering. I suggest that Julian’s experience of bodily illness may speak to the experience of disability, because the experience involves embodied impairment and religious revelation. Furthermore Julian’s experience as embodied religious revelation allows her experience to speak even more profoundly to influence a theology of disability. Lastly, Julian reflects theologically on her embodied experience and places it in a cosmic frame. Before delving into Julian’s theology to explore how it relates to disability, it is important first to establish the nature of Julian’s illness to help determine

\textsuperscript{16} Ibid.
the relationship between Julian’s bodily illness, embodied impairment and physical disability.

**Julian’s Illness and Disability**

What is the nature of Julian’s illness and how does it relate to disability and embodied impairment? In his article, *The “Bodelye syeknes” of Julian of Norwich*, James T. McIlwain explains that in spite of rigorous and plentiful examination of the religious and literary aspects of Julian, little attention has been devoted to understanding the exact nature of Julian’s bodily illness, “Scholars have concerned themselves primarily with the religious and literary aspects of Julian’s writings, while her illness has received little systematic attention beyond speculation about psychopathological states which might have engendered the ‘shewings.’”

Furthermore, Maria Lichtmann points out that any discussion of embodiment in Julian’s *Showings* is virtually left out of scholarly inquiry. McIlwain compiles the portions of text concerning Julian’s illness in order to address the lack of scholarly work. Most of the work done to determine the nature of Julian’s illness focuses on Julian’s general state of mental health and her psychological state at the time she received her visions. Several scholars suggest that a hallucinatory or psychological state introduced by the illness brought to Julian’s awareness visions of the Passion readily accessible to Julian’s mind because they were so much a part of common

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devotional practices of the Middle Ages. Paul Molinari asks whether Julian suffered from some sort of psychological neurosis, or whether their origin and nature has to be explained by a special intervention of God. Molinari concludes that Julian’s visions were not a result of a psychological disturbance, he explains, “Perhaps the strongest indication of the divine origin of her sickness is her behaviour—her spiritual attitude—during its course and particularly at the crisis. In the midst of severe pains, when she was convinced that the shadow of death was upon her, she remained in an attitude of spiritual peace, of self-detachment, of readiness to do God’s will in suffering and dying.”

McIlwain also excludes the idea of Julian having a mental illness noting that scholars have emphasized the mental soundness of Julian’s writings and that Margery Kempe’s account of visiting Julian shows no signs that Julian had a disturbed mental state.

Through his work, McIlwain seeks to identify a medical diagnosis that corresponds to Julian’s illness. McIlwain summarizes the full medical description of Julian’s illness in the following way:

In summary, then, we have a thirty year-old woman who, after one week of unspecified symptoms, developed a symmetrical, ascending paralysis affecting limbs, neck and trunk. Her complaints also signal abnormalities of visual and oculomotor function. She experienced shortness of breath,

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20 Ibid., 23; Molinari also points out that, “modern psychology, far from abolishing the classic principles of St Ignatius of Loyola and St John of the Cross on the discernment of spirits, rather confirms their value and even postulates a greater care in their application.” Ibid., 26.


difficulty speaking, pains of unspecified type and location and, possibly, tinnitus. At one point in the illness she may have had a sore throat associated with fever, a sense of strangling and a foul odor. Her mental state was alert from time to time during the illness, but apparently she retained vivid memories of what occupied her mind during these episodes. There must have been great prostration, since she and those around her thought her to be so near death that the last rites were administered and her mother, at one point, attempted to close her lids, believing her to have passed away. The duration of her illness and convalescence is not known. Happily, she survived apparently with no permanent sequelae, and lived at least another forty years.  

McIlwain rules out a permanent condition of the central nervous system as a possible diagnosis for Julian’s illness because there is no reoccurrence or permanence of the symptoms, while he rules out Guillain-Barré Syndrome (GBS), and a tick borne illness. Instead he leans toward botulism as the cause. He does point out however that if Julian lived as part of a Benedictine community it would have been unlikely that Julian would have consumed the meat that would have contained the potent and deadly bacteria, because of the dietary restrictions of such religious communities. Colledge and Walsh seek a medical diagnosis for Julian’s illness without intending to use the diagnosis to explain Julian’s mystical experiences. Through consultation with heart specialists Colledge and Walsh determine that Julian probably suffered from “severe heart failure.”

From McIlwain’s description it is clear that Julian experienced embodied impairment  


24 Ibid., 174.

25 Ibid., 176.

through paralysis, a loss of vision, and difficulty speaking. However, her illness was temporary and she was not marginalized because of her illness.

In the Middle Ages sickness and impairment were very much part of everyday life. Irina Metzler argues that because of this there was not a specific conception of disability as we have it today. Metzler also explains that “Medieval people were less ‘politically correct’ and more direct in their terminology, so a wide variety of descriptions of physical impairments that we would now reclassify as disabling exists in this period.”27 Furthermore, Metzler points out that because modern connotations of disability did not exist in the Middle Ages, it is, “preferable to speak of ‘impairment’ during the medieval period, rather than of ‘disability’, which implies certain social and cultural connotations that medieval impaired persons may not have shared with modern impaired people.”28 This is not to say that Metzler believes that impairment can be studied without its cultural context: rather she desires to study physical impairment without the modern overtones of current definitions of disability. Instead, Metzler proposes looking at disability as it would be envisioned in the cultural context of the Middle Ages, where embodied life centered around four categories whether someone was living or dying and whether someone was ill or healthy. Disability in the Middle Ages forms what Metzler calls a limbic or in between status that did not fit a specific definition for the time. She writes:


28 Ibid., 2.
Medieval concepts of health and illness in relation to physical impairment have shown that the impaired body was neither sick nor healthy, since according to medical thinking the course of an illness was to either improve, in which case the patient was deemed healthy, or to take a turn for the worse, resulting in the death of the patient. The disabled person fits neither model, since the functional loss renders a body not truly ‘healthy’, yet the disabled person never recovers that loss.\textsuperscript{29}

Thus, it is historically accurate to conceive of Julian’s bodily sickness as a physical or embodied impairment rather than through the lens of modern conceptions of disability. The temporary nature and the lack of marginalization due to the illness exclude it from being conceived as a permanent physical disability. Julian’s experience of embodied impairment is a point of contact between her theology and people with disabilities. The next step in conducting the mutually critical conversation is to place Julian’s illness into perspective according to her historical context and theological writing.

**Julian’s Bodily Illness – Theologically and in Context**

McIlwain’s work is a kin to looking at Julian’s bodily illness through the lens of the medical model. Elizabeth Leung contends that McIlwain views Julian’s illness, “through a medicalized lens that renders Julian’s physical sensations as belonging to a narrative of illness.”\textsuperscript{30} The conception of Julian’s account exclusively from the lens of the rationalistic medical model strips Julian’s *Showings* of mystical content and power, and it calls into question the authority of religious experience. Roberta Bondi poses the question


of whether there is an either or choice in terms of being rational or standing behind the validity of religious experience, she asks herself: “What if, at the end of my work, I would have to choose between religious experience and a rationally structured universe? If I were to embrace one all the way to the bottom, would honesty not compel me to give up the other?”31 If one stands merely on rational structure looking at Julian’s text through the lens of the medical model, then one has to ask: What really happened to Julian? And why? Furthermore, was there anything truly religious about Julian’s experience or were her visions mere symptoms of botulism or some other illness? The modern tendency is to silence mysticism in the name of its apparent irrationality. Kees Waaijman notes:

It had to eliminate mysticism — precisely to the degree that mysticism lays bare man’s inner powerlessness — as an unproductive element, often falsely labeled as quietistic, irrational, and occult. In reaction, mysticism — a living indictment against every form of self-interest, self-will, and technicalism — developed a language and a logic of its own which in turn rendered it unintelligible to cultural rationality.32

The rationalistic stance turns quickly to a scientific and systematic structure that sets aside the mysterious aspects of life that are yet unknown as it seeks to make predictions and formulates explanations. To submit to a mere medical diagnosis in the name of maintaining a sense of rational structure is to mute the voice of Julian’s theology and mystical experience. Obviously there is more to Julian’s story than mere conclusions of the medical model. A host of intangibles come into view in terms of religious experience,


divine intervention, the meaning of faith in the midst of illness in the face of death, and what it means to reflect upon illness. This cannot be boiled down to McIlwain’s medical description. Whether the cause of Julian’s illness was botulism or cardiac arrest it is important to acknowledge that there is more to Julian’s experience of illness than a mere clinical diagnosis. There is a space in the middle between Bondi’s dichotomy of giving up entirely on religious experience for rational structure or ditching all rational structure in favor of religious experience. By considering a mixed approach to the issue there is freedom to acknowledge that Julian probably did have some form of botulism but also to acknowledge that in the midst of that illness God bestowed on Julian the gifts she asked for in the midst of that illness.

When Julian’s illness is examined merely through a medical lens it loses its religious power but if the information that can be gleaned from an innovative modern medical vantage point is placed into dialogue with religious experience new potential insights into Julian’s experience can come to light. What is far more interesting to consider than Julian’s actual diagnosis is the exercise of placing Julian’s embodied experience into the framework of the medical model and looking more closely at the actual symptoms and how they may have influenced her visions. For example, Julian’s experience of Christ’s thirst may have been influenced by her own; furthermore, Julian mentions the smell of Satan, which could have been influenced by the foul smell associated with botulism. The potential influence of the symptoms of botulism upon Julian’s visions does not detract from God’s ability to communicate to Julian’s understanding in the context of the symptoms of bodily illness. Of course concrete
conclusions cannot be made regarding the potential influence of botulism (since we don’t know this is what was affecting her) and botulism’s relationship to the content of Julian’s visions. What is called for is an acknowledgement of the potential relationship between Julian’s embodied experience of illness and what takes place in her visions. Julian’s visions may be a result of her asking for three gifts.

Julian asks for three gifts from God: “The first was recollection of the Passion. The second was bodily sickness. The third was to have, of God’s gift, three wounds.”33 The desire for the first gift originates from Julian’s longing for a deeper understanding of the Passion of Christ. From the second gift Julian desires to have a bodily sickness so that she can experience the sufferings of Christ. The third gift is to receive three wounds: contrition, kind compassion, and the wound of steadfast longing for God. In the Long Text Julian explains that she asks for the first two gifts only on the condition that receiving the gifts are God’s will. Julian desires the first gift to have the mind of Christ’s Passion and to experience it with others who loved Christ, Julian writes “so that I might have seen with my own eyes the Passion which our Lord suffered for me, so that I might have suffered with him as others did who loved him. Therefore, I desired a bodily sight, in which I might have knowledge of our savior’s bodily pains…”34 In desiring this bodily sight Julian was asking for an embodied experience of Christ. But not just any experience: one that is severe and a near deadly bodily illness through which, she would


34 Ibid., LT 2, 178.
experience every kind of bodily and spiritual pain so that she would receive the rites of Holy Church and yet not die. Metzler points out in Middle English that, “‘Sickness’ (siknes[se] ) was also a blanket term for an abnormal or special state of health, and could sometimes signify a specific mental or physical disorder.”35 This implies that Julian was asking for a specific bodily state, and it seems that in terms of Metzler’s argument for the four concepts of death/life and illness/health that predominated the worldview in the Middle Ages, Julian desired to be close to death by way of illness and then to be returned to health and life.

Julian wants a “bodily sight” so she can experience the sufferings of Christ as if she were with Mary Magdalene and others during the crucifixion. Julian’s prayer for bodily sickness seems odd to us from our twenty-first century perspective. However, Metzler points out that in the Middle Ages it was believed that “sickness/impairment could bring spiritual healing” and was therefore viewed as having positive characteristics if the illness was seen as being sent by God. Metzler suggests that the attribution of being holy by being ill and having visions imputed a kind of power to the person in the Middle Ages because of the preference for the vita comtemplativa verses the active life.36 Julian echoes the desires and actions of other mystics of her time when she asks for a bodily

35 Metzler, Disability in Medieval Europe, 5.

36 Ibid., 48.
illness. Caroline Bynum notes that many medieval mystics viewed illness as a way to grow closer to God and obtain salvation.\(^\text{37}\)

It may seem curious that Julian wanted to experience the Passion of Christ by way of her bodily illness; however, if we consider that devotion to the Passion of Christ was common in the Middle Ages, Julian’s request becomes much easier to grasp.\(^\text{38}\) Ellen Ross explains that cultural artifacts of the Middle Ages focused on the humanity of Christ and that, “growing numbers of theological texts pondered the nature and effects of Christ’s crucifixion, in painting and sculpture, depictions of the suffering Christ in agony replaced the majestic Christ of resurrection and judgment, and liturgical dramas reenacted the circumstances of Jesus’s suffering and death.”\(^\text{39}\) Furthermore, in relationship to practices of devotion that were preoccupied with the human body and the Incarnation of Christ in the Middle Ages, Ross writes “This understanding of Christ afforded Christians the comfort of kinship; his human suffering paralleled, and thus validated, their own. The obvious incongruity of equating Christ’s passion to ordinary worldly suffering cannot but be noted; to make sense of their own humanity, these Christians emphasized Christ’s.”\(^\text{40}\) Michael Raby explains that, “Julian participates in the trend of late medieval devotional


\(^{40}\) Ibid., 46.
practice that embraced pain for the sake of coming closer to Christ. The danger, though, is that pain will produce the contracting effect observed by Aquinas and Augustine, and the soul will shrink inside of itself, away from God. Illness then has the potential to either to distract from or to enhance the experience of God. It is impossible to explore here what the characteristics are that lead a person toward or away from God in the midst of pain and suffering, what is important to note here is that Julian experienced illness and in the midst of it she received mystical revelations from God. The revelations were not a passing or insignificant experience for Julian; she spent the next two decades of her life making sense of her embodied experience. Thus, in the devotional and theological context of the Middle Ages Julian’s request for a bodily illness does not seem out of place, whereas from our twenty-first century perspective Julian’s request is not as comprehensible.

Julian wishes to have witnessed the Passion, and that she might suffer with him, so that she can have knowledge of Christ’s bodily pains. Even so, Julian realizes that her request may be contrary to God’s will so she makes her request conditional adding to her prayer the qualification, “if it be God’s will.” Julian’s act of contrition might mistakenly be viewed as a desire to despise or punish her body, but Julian merely wants her experience to imitate as much as possible the suffering of Christ. Thus she wanted no comfort during her illness because her Lord had none. Julian believes that the bodily sight will provide her with a way to suffer with Christ. Julian desires the bodily sickness

as an act of contrition and an act to grow closer to Christ. Marisa A. Klages argues that the writings of Julian of Norwich along with other fourteenth century mystics, Richard Rolle, Margery Kempe and Walter Hilton “develop a rhetoric that allows them to use pain and/or desire as a catalyst through which their writing becomes embodied.”\(^{42}\) The embodied rhetoric Klages suggests helps the writers obtain union with God, as the writers integrate embodied experiences of pain and desire as an “ultimate conduit for divine contemplation….For Julian of Norwich, the practice of physical pain serves as the essential coupling of the corporeal and the spiritual.”\(^{43}\) Lichtmann suggests further that Julian’s desire for a near mortal bodily illness stems from a desire to intimately incarnate her theological knowing of Christ, known previously in her prayer life and meditations.\(^{44}\) Thus, Julian seeks to enhance her experience of Christ’s embodiment and this is the driving force behind Julian’s desire to experience Christ’s passion, suffer a bodily illness, and receive the wounds of contrition, compassion, and longing for God. This confirms that Julian’s desire for bodily illness was driven by a deep devotion and a longing for contemplative intimacy with Christ. Thus, in her text Julian confesses that the bodily illness is a way of offering herself to God, so that she could be purged and upon her recovery after live more to God’s honor.

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\(^{42}\) Marisa Klages, “Rhetorics of Pain and Desire: The Writings of the Middle English Mystics” (PhD diss., West Virginia University, 2008), ii.

\(^{43}\) Ibid.

\(^{44}\) Lichtmann, “‘I Desyrede a Bodylye Syght’: Julian of Norwich and the Body,” 13.
Julian received her bodily sickness as she requested at thirty and a half years of age. It is important to note that Julian believes that her illness is sent to her from God, she writes, “God sent me a bodily sickness in which I lay for three days and three nights.”

During her illness Julian desired no comfort from anyone, only that she might receive the rites of Holy Church and yet not die. During her illness when those around her thought she would die, the curate was sent for and he held a cross before Julian’s face, so that as she was dying Julian could take comfort from the image of Christ on the crucifix. We read in her text that everything was dark around her but light shone upon the crucifix, and then she subsequently experienced sixteen revelations from God.

Julian did not seek to hide from her embodied nature, although her female body would have been perceived as inferior in the Middle Ages because she was female. Lichtmann believes that in her desire for bodily illness and the gifts Julian is “entrusting her conversion to her body,” and that Julian seeks to incarnate her theology in asking for the serious illness and all manner of pains bodily and ghostly. Clearly, this desire means that her female body is not something Julian wishes to escape. Instead, for Julian embodiment is, “the locus of spiritual enlightenment” and the temple of the Holy Spirit. Furthermore, Lichtmann suggests that, the body is the means by which a deepened spiritual experience of transformative character takes form and that in Julian’s experience and theology, “the transformed body is the means through which she comes to know

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47 Ibid.
This transformation unifies the body and soul, and as a result of this unification Lichtmann argues that Julian lives in a new wholeness of embodied soul, being “oned” with Christ who joins together the spiritual and physical worlds. Lichtmann solidifies her perspective on Julian’s *Showings* in the following way: “In conclusion, what Julian offers us is not only a non-dualistic epistemology of the body as a vehicle for knowing God, but a theology of the body and a somatic revelation of God in and as body.” Julian longs to embody theological devotion as she integrates body and soul; this allows her bodily illness to be a point of contact to receive mystical revelations. Thus, Julian and other mystics like her show us that embodied impairment and the body in illness can be a point of contact with God. Julian interacts with Christ through her embodied impairment. In Julian’s revelations Christ does not reject Julian because she is ill or undergoing states of blindness or paralysis. Instead through that illness Julian is given contact with the divine.

Petro Muro Hendry squarely centers the transformational power of Julian’s theology upon her bodily illness. Hendry writes, “Julian revises the experience of being acted on by illness, of being a prisoner to a body that suffers; passivity turns to passion as her wounded body is conflated with Christ’s. This union becomes the center of her autobiographical reflections in which she represents herself as an active agent in relation to the Divine.” Julian’s embodied experience coincides with some of the other mystics

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48 Ibid., 12.

49 Ibid., 17.

of the time. Leigh Gilmore explains that “through their remapping of the body, mystics represented it as a network of possibilities and not simply as biological fact.”\textsuperscript{51} This movement beyond mere biological fact empowers Julian to critique the predominant patriarchal tradition of the fourteenth century. Lichtmann explains, “In her incarnational affirmation of the self as God-informed sensuality, Julian brings to the foreground a principle of the body much neglected in the patriarchal tradition.”\textsuperscript{52} Hendry agrees with Lichtmann’s understanding that Julian is issuing a critique of the patriarchal tradition, Hendry explains, “Thus, for Julian, her bodily illness which results in her revelations and union with Christ, becomes a site of transformation in which gender is reconceived.”\textsuperscript{53} Hendry argues that the struggle of women mystics to obtain their authority shaped the way they told their stories:

Thus, it was through mystical experience that women of the 12th to 15th century found the authority to speak, write, and teach. And, they were not merely content to claim their experience, they challenged deeply entrenched church doctrines that contested normative gender roles through actually reinscribing gender in more complex and destabilizing ways. Consequently, Julian’s life story as a 14th century mystic provides a window into the ways in which women have struggled to authorize themselves as knowers. The shifting nature of who counts as a knower and how gender shapes this construction is one part of the tale Julian’s story tells.\textsuperscript{54}


\textsuperscript{52} Lichtmann, “‘I Desyrede a Bodylye Syght’: Julian of Norwich and the Body,” 17.

\textsuperscript{53} Petro Muro Hendry, “Disrupting the Subject,” 103.

\textsuperscript{54} Ibid., 97.
Hendry makes the argument that Julian’s embodied knowing allowed her to have a transformed consciousness and that transformation permitted Julian to bypass and subvert the oppressive patriarchy of her day. Hendry also argues that Julian’s experience evolved from, “the body in pain, through the body on the cross, to the ecstatic and risen body….Like Christ, her body is capable of miraculous transformation. It is a body that can resist the logic of gender and map a contradictory discourse.” Hendry is in good company. Liz McAvoy makes a similar argument concerning the Showings that Julian’s desire for a bodily illness was not an act of asceticism but rather an attempt to grow closer to her God and address culturally derived oppression of women. Julian through entering into an embodied relationship with Christ sets the stage for her writing to have authority.

Julian through her writing unknowingly or knowingly breaks the existing dominant patriarchal frameworks and discourses that claimed women were inferior and had no authority to teach. McEntire argues that in Showings, Julian negotiates a balance between combating the authoritative patriarchal discourse and her individual experience, and that Julian has far more then self-representation of her revelations going on in the LT. McEntire explains, “That these assumptions and conclusions about woman, the flesh, and the inferiority of the body were widely appropriated can be assumed for the

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55 Ibid., 101.

medieval audience.” McEntire also contends that Julian made a profound shift between the Short and the Long Text by removing all signs of misogynistic thinking. She explains, “With the exception then of Julian’s incredulity regarding her interpretation of her uniquely revelatory moment, a credulity which results from a deeply interiorized set of assumptions, the misogynistic teachings undergirding the authoritative discourse are conspicuously absent from the Long Text.” This shift in Julian’s work is not a mere oversight. According to McEntire the absence of the misogynistic thinking in the Long Text, “reflects not that such assumptions failed to impress upon her their weight and import but that she carefully and consciously resists them as a result of her own experience and revelation.” In the negotiation between the cultural dictates of patriarchal authority and her experience, Julian removes a reference to female inferiority in ST chapter 6 from the LT.

The years of contemplation on her embodied experience of illness and divine revelation between the writing of the ST and the LT empowers Julian to write as an act of resistance and social justice to address the patriarchal authoritative discourses of her day. In writing her text Julian’s embodied experience of bodily illness and divine revelation moves Julian’s work from the private to the public spheres. Macario Ofilada Mina in *The Textuality of Mystical Experiences*, explains that, “mystical experiences that form part of

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57 Ibid., 7.

58 Ibid., 11.

59 Ibid.

60 Bynum, *Fragmentation and Redemption*, 167.
public history, those that are fully human in the sense that they are shared with and appraised by the community ... cease from being private and become part of the human drama when they appear as writing texts for a reading community. From the reading and writing community arise writers, who consign to the collective archive the experiences of individuals who are taken as prototypes, models or paradigms by the community.”

Julian’s embodied experience moves into the social realm through her writing down her theology and thereby becomes a vehicle by which to critique the marginalization of women. Women were marginalized and defined as inferior or “worth-less” in Julian’s day, and people with disabilities share in a similar marginal experience as they are defined as inferior simply because of their embodied difference.

Julian’s request for a bodily sickness appears unusual to us but it is not so strange when we consider the devotional practices of the Middle Ages and that Julian desired the bodily sickness as an act of devotion to grow closer to God. Julian uses her bodily illness as a way to share in the experience of Christ. In this way Julian uses her bodily illness as a means to convey the message that she and thereby her body – even in its weakened and vulnerable state – is worthy to receive revelations from God. Julian desires a bodily illness so she can enter into the suffering of the Passion of Christ with all its implied embodied vulnerability so that she can share with Christ in his suffering and embodied human vulnerability. For example, Julian writes, “And at this, suddenly I saw the red blood running down from under the crown, hot and flowing freely and copiously, a living

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stream, just as it was the then when the crown of thorns was pressed on his blessed head.” 62 And it seems that there is an emotional and spiritual response that Julian wishes to conjure up in us, Brandolino explains that, “Julian does not merely take note of the fact that Christ is bleeding; she uses language that prompts the reader to a very sensory understanding of that fact. The description of the blood forces the reader to see and feel it, and is all the more lifelike for its presentation in the present tense.” 63 Julian appears to want to give us a close representation of her experience so that we can enter into a similar experience of the suffering of Christ. Through entering into Christ’s suffering with our own vulnerability and embodied impairment we have an opportunity to understand Christ’s Passion in relationship to our own human ordeal and circumstances. The power of Julian’s theology to address the concerns of people with disabilities originates in her entering into this relationship with Christ in shared embodied vulnerability and then using that experience to reconstruct in writing what it means to embrace suffering. In the Long Text she expresses how her embodied experience relates to God’s goodness being found in our humblest of needs, in the Holy Trinity, and in the ongoing suffering of Christ.

God’s Goodness and Our Humblest of Needs

If the body is an important point of contact for developing a practical theology of disability, thus it is important to explore the relationship between embodiment and God in


Julian’s theology by examining the neglected text concerning a man and his purse in the Long Text chapter 6. Julian writes, “The highest form of prayer is the goodness of God and it comes down to our humblest of needs.” Julian writes, “A man walks upright, and the food in his body is shut in as if in a well-made purse. When the time of his necessity comes, the purse is opened and then shut again, in the most seemly fashion. And it is God who does this, as it is shown when he says that he comes down to our humblest of needs.” The purse is our body and the opening and closing is our natural process of digestion. For Julian, God is in even our humblest of digestive functions because this is how God created us and God does not disdain what God has made. God’s goodness is present in every aspect of our embodied life. McGinn believes that the passage in LT6 concerning the purse is unprecedented in the history of Christian mysticism. The passage occurs in two of the four existing manuscripts of the LT, yet, McAvoy points out, the discussion of this text is largely neglected in scholarly literature. McAvoy also notes that the authenticity of the authorship of this passage is not called into question; she believes that it was edited out of two manuscripts for reasons of decorum, and that the centrality of the text was not understood by those copying the original LT manuscripts. McAvoy comments that recent editors of Julian’s Showings, for

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64 Julian of Norwich, Julian of Norwich: Showings, LT 6, 186.

65 Ibid.

66 McGinn, The Varieties of Vernacular Mysticism 1350-1550, 450.
example, Glasscoe, and Colledge and Walsh, fail to mention the omission of this important passage in two of the existing manuscripts of the Long Text.\(^6^7\)

While McAvoy discusses the purse passage of LT 6 in terms of what she sees as Julian’s drive to contextualize femininity within male dominance, she also emphasizes that in this passage Julian expresses the radical immanence of God. McAvoy explains: “humankind is never separated from him. Such a radical perception of God’s immanence serves to accentuate for Julian the beauty of all God-given human activity, even that arising from ‘the lowest parte of oure nede.’”\(^6^8\) Julian expresses God’s radical immanence as she points out how we are enfolded in God, “clad in the cloth, flesh in the skin, body in the bone, heart in the trunk, and so we are soul and body, clad and clothed in the goodness of God.”\(^6^9\) This means that in our embodied vulnerability as humans we are wrapped and clothed in the love of God, as it were held by God in our deepest and most intimate vulnerability. Through this passage Julian allows the “flesh” to be completely embraced by the love of God. As McAvoy notes, this is contrary to what Julian’s contemporaries would believe, among them Walter Hilton who in the *Scale of Perfection* depicts the body as corrupt. McAvoy also points out that Julian similarly contradicts the *Ancrene Wisse* that describes the female body as weak.\(^7^0\) In order to do


\(^{6^8}\) Ibid., 101.

\(^{6^9}\) Julian of Norwich, *Julian of Norwich: Showings*, LT 6, 186.

\(^{7^0}\) McAvoy, “‘... a Purse Fulle Feyer’: Feminising the Body in Julian of Norwich’s A Revelation of Love,” 102.
this Julian reconstructs a vision of humanity that allows the female body in all of its vulnerability and bodily need to be fully embraced and clothed by the love of God. McAvoy points out that Julian’s mention of defecation is, “thus wholly in keeping with her ability to transform the earthy and ugly into the beautiful and sublime.”\textsuperscript{71}

Furthermore, McAvoy argues that, “By imposing none of the traditional blame upon Eve, Julian implicitly restores her and her ‘open’ womb to the hierarchy of salvation alongside that of the corporeally ‘sealed’ Mary. Thus, the startling image of the ‘fine purse’ of the body becomes a symbol of Eve, of Mary, of Christ, of Julian and of general humanity.”\textsuperscript{72}

So we see here that the purse becomes a space where the messy, seemingly unbecoming, and perhaps grotesque becomes a bodily sight of love and transformation. What is important in this passage in terms of physical disability is that a body in all of its everyday messy vulnerability (perhaps even inferiority) receives a welcoming embrace of divine immanence that is coupled with the redemptive and transformative power of God. In other words, God embraces everyone in their embodied vulnerability and this is a liberating word for those with physical disabilities.

This text intersects with the everyday lives of people with disabilities because it expresses God’s relationship to our everyday bodily functions. Life with an embodied impairment or physical disability is often dictated by specific bodily practices and needs within the context of everyday life, which often go unnoticed or unexamined, and yet these bodily practices often drive or at least contextualize the everyday practices of life.

\textsuperscript{71} Ibid., 105.

\textsuperscript{72} Ibid., 109.
with a physical disability. For example, when a person who uses a wheelchair needs the assistance of someone else to use a public bathroom, there are specific practices involved with how the person with a disability and his/her helper negotiate the routine of getting situated in the bathroom, dealing with whether the bathroom is accessible or inaccessible, how the person in the wheelchair is transferred to the toilet, what happens when the disabled person is finished, and how the person with a disability is helped with their clothes and back into the wheelchair. According to Julian God is right in the midst of the most vulnerable and difficult parts of all of it. Julian’s words about our humblest of needs bear repeating here. She writes, “The highest form of prayer is the goodness of God and it comes down to our humblest of needs.” This suggests that Julian would place God’s love in the midst of all of those everyday bodily practices and vulnerabilities. In light of McAvoy’s argument concerning the purse and its implications for transforming ideas about woman’s inferiority, it is plausible (although we can’t be exactly sure because the concept of disability as such is absent missing in the Middle Ages) that Julian would not consider the person with a disability as inferior because of their inability to take themselves to the bathroom. Instead it is likely that Julian would follow the line of thinking that she writes of in LT 6 that and would see all the bodily needs as the highest form of prayer. Thus, Julian shows us how God relates to the very fabric of our bodies and everyday functions. The text opens up the possibility of God being with us in our most intimate, vulnerable, and embarrassing moments of our everyday lives, leaving us to prayerfully consider how the highest of God’s goodness is in the humblest of our bodily

73 Julian of Norwich, Julian of Norwich: Showings, LT 6, 185.
needs. In writing the mystical experiences in the Long Text, Julian critiques the
patriarchal structures that perpetuate the ideal that the male body is superior. In this first
glance at the theological consequences of Julian’s illness we see that God does not
abandon Julian because of her embodied impairment but instead offers her a sacred
embrace. Julian tells us of a God who enfolds us in goodness even at our most vulnerable
and humble moments and this provides tremendous hope to people with disabilities.

Julian through her embodied impairment enters into an experience of Christ’s
Passion. Julian desires the bodily illness (which she believes was sent to her by God) so
that she can enter into the suffering of the Passion of Christ with all the embodied
vulnerability of her humblest of needs and impairment so that she could share with Christ
his suffering and human embodied vulnerabilities. Ultimately, for Julian it is in the space
of our most intimate human needs that the love of God encloses us; it is in this sacred
space where she shares Christ’s Passion and experiences the bodily sight. In and through
her illness, the love of God comes to life in the form of the sixteen revelations. The only
way to discern how Julian’s experience of entering into the suffering of Christ addresses
the needs of people with disabilities is to explore Julian’s conception of the Trinity and
Christ’s suffering. It is true that Julian’s theology is Trinitarian as it situates itself within
a conception of God as love. In the first showing, for example, Julian sees the bleeding
head of Christ and the Trinity fills her with joy. Julian makes the declaration in her text,
“the Trinity is God, and God is the Trinity.”74

74 Ibid., LT 4.
Julian’s Conception of the Trinity

In order to fully understand Julian’s statement, “the Trinity is God, and God is in the Trinity,” we must first examine Julian’s overarching view of reality or cosmological framework. McGinn notes that Julian is not so much concerned with cosmology but what interests Julian, “is the universe's dependence on God's sustaining love, something that God reveals to her in two images found in both the ST and the LT: the world as the size of a hazelnut and the seeing of God in a pointe.”

To understand Julian’s vision of reality and cosmic vantage point, we will first examine the now famous hazelnut image in LT chapter 5, and second we will consider, Julian’s seeing God in a point. McGinn notes that, “Julian’s teaching about creation in general and specifically the creation of humanity as the goal of God's work. Julian's understanding of the created universe is Christocentric not only in terms of its making, but also in its redemption through Christ’s death.” In that revelation God showed Julian that God is to us everything that is good, and that God comforts us and enfolds us with love. The Lord in this spiritual vision showed Julian a ball no bigger than a hazelnut. Julian thought that the ball would not last, but God replied to Julian’s understanding, “It lasts and always will, because God loves it; and thus everything has being through the love of God.”

For Julian, God is the Creator, Protector, and Lover even of this little thing that is a ball the size of a hazelnut. And Julian questions, what may this be? The answer comes generally thus: “It is all that is...

75 McGinn, The Varieties of Vernacular Mysticism 1350-1550, 443.

76 Ibid.

77 Julian of Norwich, Julian of Norwich: Showings, LT 5.
made."\(^{78}\) Meaning that even in the smallest of things God shows his properties; God made it, God loves it, and God preserves it.\(^{79}\) And yet Julian emphasizes another aspect in the hazelnut passage and that is we are not to rely on created things but on God. Julian writes, “The little thing which is created seemed to me as if it could have fallen into nothing because of its littleness. We need to have knowledge of this, so that we may delight in despising as nothing everything created, so as to love the uncreated God.”\(^{80}\)

Thus, we are not to rely upon the created order of things but God who both created everything but also exists beyond as uncreated God. Julian believes that it is our reliance on created things and not God that disturbs our rest, she explains, “For this is the reason why our hearts and souls are not in perfect ease, because here we seek rest in this thing which is so little, in which there is no rest, and we do not know our God who is almighty, all wise and all good, for he is true rest.”\(^{81}\) Julian tells us that it is in finding ourselves in God who is love that we find spiritual rest.

In the third revelation Julian says, “I saw God in a poynete [point].”\(^{82}\) Spirituality scholar Ritamary Bradley notes that word “point” is sometimes also translated as an

\(^{78}\) Ibid.

\(^{79}\) Ibid.

\(^{80}\) Ibid., LT 5, 183.

\(^{81}\) Ibid., LT 5, 183–184.

“instant in time,”83 this is true for Jantzen84 and Colledge and Walsh.85 God is in a point has spatial and temporal implications which impact Julian’s anthropological conceptions. Thus, in order to understand Julian’s theology in relationship to disability we need to delve into the conception of God as in a point. McGinn explains the spatial aspect of Julian seeing God in a point, “So God is both ‘in a point,’ that is, at the center of all things, and the ‘point beyond all points.’ This paradoxical ‘seeing’ of the infinite in the least spatial category, the dimensionless location of a point, can be described as a cosmic coincidence of opposites.”86 The temporal aspect of Julian’s “point” as an instant in time also reveals that we are always facing suffering and death.87 Our suffering comes as points in time until the time of our death. At death our suffering is transformed to joy. All of the points comprise one continuum of time.88 McGinn explains how Julian’s temporal and spatial aspects of seeing God in a point indicates an ongoing cosmic unfolding of Julian’s theology that involves even us today: “As the original vision of LT 11 and subsequent uses of ‘point’ show, the word always has both spatial and temporal dimensions. In LT 11, immediately after the reference to seeing God in a quasi-spatial


84 Jantzen, Julian of Norwich, 180.

85 Julian of Norwich, Julian of Norwich: Showings, LT 11, 197.

86 McGinn, The Varieties of Vernacular Mysticism 1350-1550, 444.

87 Ibid., 445.

point, there follows a meditation on ‘the foreseing wisdom’ by which God from all eternity governs the whole temporal process that we only see as a result of chance and happenstance.\textsuperscript{89} Thus for Julian human events are comprised of a series of points that come to us as part of God’s wisdom although for us the events feel like they come to us haphazard and by chance. Julian tells us that what she teaches is for all fellow Christians.\textsuperscript{90} Thus, Julian’s theology is a process of unfolding reality that involves the human world today. Furthermore, the discussion above shows that Julian’s God of love is with us through time and space, in the midst of the events of our lives until our death. This allows us to know that the intention of Julian’s theology is to help us experience the embrace of God’s love for suffering humanity. In response to that embrace Julian calls us to open ourselves in our vulnerability to accept that love. Julian shows us this in her own response to suffering and bodily illness.

According to Julian, we human beings are made in the image and likeness of God and that we are who we are, and have our true nature by the blessed Trinity.\textsuperscript{91} What is the relationship of Julian’s Trinitarian theology to, physical disability and embodied impairment? McAvoy argues that Julian joins her female body with Christ in her desire for a bodily sickness so that she might share in Christ’s passion.\textsuperscript{92} Julian conflates her

\textsuperscript{89} McGinn, \textit{The Varieties of Vernacular Mysticism 1350-1550}, 445.

\textsuperscript{90} Julian of Norwich, \textit{Julian of Norwich: Showings}, LT 37, 241.

\textsuperscript{91} Ibid., LT 10.

body with Christ’s suffering body and this occurs within Julian’s Trinitarian conception of God. McAvoy notes that, “Julian leaves us in no doubt that she is conflating her own pain-wracked body with that of the crucified Christ who simultaneously begins to materialize before her eyes in the chamber. As she tells her audience: ‘for I would that his peynes were my peynes.’”\(^{93}\) In the pages that follow I will argue that Julian uses this sharing of bodily pains between herself and Christ to critique the patriarchal structures of her day through her conception of God as Trinity; consequently a theology of disability based on Julian’s work that critiques the social structures that oppress people with disabilities will need to be placed in the same type of Trinitarian framework.

Julian’s Trinitarian theology relates to her theological anthropology. According to Julian, our human nature is understood as double, having two parts; a higher part, substance, and a lower part, sensuality. In our substance, we are united with God in creation, and we are the noblest of creatures. In the higher part God, the Creator, made us so noble and rich in our substance that all people who will be saved will always, “achieve his will and glory.”\(^{94}\) When the higher part, our substance, meets God continually, it does the will of God without fail and will do God’s worship. The substance portion of the soul is undisturbed by life and the Fall and in our substance we are full, and we are knit to God and God is knit to us.\(^{95}\) Christ holds our substance within the Father as it was originally created. Our substance then is the mystery of our true being undisturbed by the

\(^{93}\) Ibid., 72.

\(^{94}\) Julian of Norwich, *Julian of Norwich: Showings*, LT 57, 290.

\(^{95}\) Ibid., LT 57, 291.
pitfalls, the suffering, the pains, and the weakness and sin of this world. Our sensuality is the part of ourselves that still experiences weakness, limitation, and the everyday suffering of this world. For this reason I believe that Julian would place embodied impairment and disability squarely within the lower part of the Trinity. In our sensuality we fail, but in such failing God will restore us by mercy, grace and natural goodness, Julian explains, “…by the operation of mercy and grace, plentifully flowing into us from his own natural goodness.” The natural goodness comes to us through Christ, as defined in Trinitarian relationship of the higher and lower parts. God is also knit to the lower part—our sensuality—which is our body and the sensual soul is grounded in Christ incarnate, who for Julian is divine Wisdom. Thus, Christ’s two natures of substance and sensuality are joined or “oned” to us. Whereas the first person of the Trinity is united to us in creation by the Father Almighty, the second person is united and tied together with us in Jesus Christ. Julian explains that, “our nature, which is the higher part, is joined to God in its creation, and God is joined to our nature, which is the lower part in taking flesh.” Thus, Christ ties together the substance and the sensuality within us. Julian explains, “And so in Christ our two natures are united, for the Trinity is comprehended in Christ, in whom our higher part is founded and rooted; and our lower part the second person has taken.” For Julian there is an ongoing process of integration of sensuality

96 Ibid.
97 Ibid.
98 Ibid.
into substance, this is a process of being enfolded into the love of God through finding rest in God and not the created world.

Julian’s higher and lower parts of the Trinity are thereby intimately connected to how our experiences of suffering and limitation (the lower part) are enfolded and embraced by the love of God. How this process may work in the lives of people with disabilities will become clearer in the pages that follow. Dreyer sees Julian’s higher and lower parts of the Trinity as operating in a relational way as a corrective to views of God as wrathful: “In its fourteenth-century context – partly to correct the image of a wrathful God that generates fear of damnation, and partly to offer hope and encouragement to a community ravaged by plunder and plague – Julian’s text reveals a triune God whose members relate to each other and to the world in a generous, reliable, loving, mutual, and life-giving way.”\(^9\) In Dreyer’s view this conception of God supports “feminism’s rejection of a strictly hierarchical model of God that has encouraged an understanding of community in which one group is seen as subordinate to another.”\(^10\) Nicholas Watson, for example, believes that Julian has an “optimistic and intimate expectation of knowledge” as she goes about the hermeneutical task of making sense of her revelations, which situates itself from a Trinitarian vantage point.\(^11\) This optimism plays a critical role in Julian’s Trinitarian conception of God. Watson conceives of the optimism as

\(^9\) Dreyer, “The Trinitarian Theology of Julian of Norwich,” 86.

\(^10\) Ibid.

indicative of Julian’s ability to reconceive the typical theological conceptions of her contemporaries. In reformulating her contemporaries Julian uses the Trinitarian conception to critique the patriarchal structures of her day.

Julian takes on the typical conceptions of her contemporaries, such as Walter Hilton, and this pushes Julian into the realm of critiquing cultural perceptions of the female body as inferior. Denise N. Baker, McEntire, and McAvoy collectively argue in various ways that Julian bypasses the traditional blame of Eve for the Fall of humanity. Each scholar goes about this argument using different points of entry. McEntire agrees with Baker that Julian reconstructs Genesis 1-3 and Augustine’s conception of original sin. Baker believes that Julian, “offers an alternative to the doctrine of original sin crucial to Augustine’s juridical theodicy,” and that Julian disagrees with “the Augustinian premises about the nature of sin and the character of God’s response to it,”

Furthermore, McEntire argues that “Julian appropriates the inferior female body for an image of humanity and its salvation and hereby reverses Augustine’s anthropology.” This critique of Augustine fits squarely within Julian’s theological conception of reality (mentioned above). McAvoy sees the critique of the inferiority of the female body as taking place in the context of the Long Text chapter 6. In her analysis of the “purse” passage, McAvoy uses the association of food and the female body within the work of

102 McGinn, *The Varieties of Vernacular Mysticism 1350-1550*, 649n96. It is important to note here that McGinn does not take issue with Baker’s stance on Julian but rather notes her stance in his text.

103 Baker, *Julian of Norwich’s Showings*, 86.

Caroline Bynum to make the argument that, “the digested food here which is expelled by the ‘feyer’ purse of the body is likely to have been devised to have more than a passing association with the feminine. Thus, the ‘soule’ held within a possibly feminized human body is represented by Julian as being as much a reflection of God’s glory as is his maternal caring for the homophonic human soul.”\textsuperscript{105} The approaches of Baker, McEntire and McAvoy to Julian’s writings reveal an incarnational embodied approach as a way of offering a critique to the authoritative discourses that Julian is presumably trying to address. Why is this important to our task of finding and developing points of contact between Julian’s theology and disability? The discovery of how Julian reconceives the female body will likely reveal what Julian’s response to disability might be, and will also provide the building blocks to begin to construct a conception of being made in the image of God that will provide a way to address the central concerns of disability.

Baker describes how Julian disentangles the historical theological threads used to maintain and enforce the ideas that females were inferior to males. Baker explains that both Julian and Hilton to some extent follow the line of argumentation in some fashion Augustine’s \textit{De Trinitate} or \textit{On the Trinity} (400-416). Baker explains that Hilton provides a “recapitulation of Augustine” while Julian innovates upon the traditional Augustinian perspective.\textsuperscript{106} Baker believes that Augustine in \textit{De Trinitate} proposes a model of the soul

\textsuperscript{105} McAvoy, “‘... a Purse Fulle Feyer’: Feminising the Body in Julian of Norwich’s A Revelation of Love,” 105.

as image of God to which Julian adheres but which she also modifies. According to Augustine, humanity embodies the same Trinitarian likeness as God. Augustine’s conception is based upon Genesis 1:26-27, “Let us make man in our own likeness, And God created man to his own image; to the image of God he created him. Male and female he created them.” In being created by God according to Augustine people have the ability to grow more divine and into the likeness of God. For Augustine without God’s intervention people are not likely to meet their destiny of growing into the likeness of God because of Adam’s sin. Baker points out that according to Augustine humankind is “born with their essential nature deformed.” Baker explains Augustine’s perspective on ending the deformity of the soul, “Only through a process of sanctification, enabled by Christ’s atonement and enacted by grace, can humanity be re-created in the image of God and perfected to his likeness.” Metzler crucially notes here that, “A common theme in medieval thought has been the imagery of human bodies as the microcosmos, that is, the human body represents in the small scale the ordering and hierarchy of the wider world outside – the macrocosmos – on the large scale.” Thus, Julian appears to be offsetting the deformity of body and soul in order to address the deleterious effects of our deformed nature. Adam’s sin is inadvertent and not willful according to Julian. Thus, according to McEntire, “Adam’s ‘kyrtyll’ or corporeal humanity, is hereby dignified, not rejected, not

107 Ibid., 38.
108 Ibid.
109 Ibid.
110 Ibid., 39.
gendered, not split. The Incarnation, according to Julian, restores the dwelling place of God within humanity.”

So in the traditional Augustinian perspective, the deformity of our souls cannot be addressed because of Adam’s sin unless God intervenes. Furthermore, if McEntire’s reading of Julian is correct, then Julian believes that the Incarnation heals the deformity of the soul, because through Christ God has a dwelling place within humanity. Baker surmises that Julian sees “contemplative union as the culmination of a process of self-examination which leads the mystic to see the imago Dei within.”

Baker’s perspective makes sense in relationship to McEntire’s reading of Julian, because contemplative union leads to intimate contact with Christ from within and this is exactly what Julian experienced in her revelations.

Watson’s hermeneutic of “optimistic and expectation of knowledge” in Julian’s writing seems to be at work in what Baker understands as this contemplative union as operating in the Trinity “as bidirectional, either from God to the soul or from the soul to God…” The bidirectional nature of the Trinity clears up some confusion about whether Julian has a hierarchical understanding of the Trinity. Dreyer argues that it is relational, while the fact that Julian retains the distinction of the higher substance and the lower sensuality leads Lichtmann to argue that Julian conceives of the Trinity as having a

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111 McEntire, Julian of Norwich: A Book of Essays, 16.
hierarchy. Baker makes the point that although Julian uses the traditional higher and lower distinctions for aspects of the Trinity, Julian’s use of the higher and lower parts does not model traditional uses of the Trinitarian distinctions. Julian’s conception of the bidirectional nature of the soul and God curtails the deformity of the lower or sensual part of the Trinity and in turn makes the Trinity less hierarchical. Although there is a higher and lower part it seems that the relational nature of the Trinity takes precedence. This is important because the relational nature of the Trinity makes it easier to embrace individual and embodied difference within the *imago Dei*. This makes sense when considering Julian’s embodied approach to entering into the Passion of Christ; she seemed to fully embody the relational nature as well.

Baker specifically sees this relational aspect in Julian’s theology when Julian employs the metaphors of being enclosed. Baker views this as an indication of “the indivisible bond between humankind and God.”\(^{115}\) This enclosure works in a bidirectional and relational way, Baker explains: “Julian insists, the *imago Dei* is enclosed within the individual soul at the same time that the individual soul is enclosed within God.”\(^{116}\) Julian not only defines the operations of the substance and sensuality as relational but she orchestrates another bold theological move which adds to her divergence from the Augustinian tradition by not adding a gendered description onto the higher and lower parts and failing to label the higher (male part) as superior, and inferior to the lower (female part). Baker explains that Julian makes a significant shift from Augustine when

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\(^{115}\) Ibid., 41.

\(^{116}\) Ibid., 53.
she asserts that higher reason, “informs the sensuality or lower part of the soul,” and that higher reason is not simply relegated to the higher part. This is a radical move because the Augustinian perspective of the female connected with Eve submitting to temptation and eating the forbidden fruit is conflated with the lower and thereby inferior reason. Baker explains that, “The lower reason, directed toward the corporeal, is the medium of temptation between this sensuality and the higher reason.” This separation of sensuality and substance into higher and lower forms of reason became integrated into the Christian tradition and was used to support the idea that women were inferior to men. McEntire explains the full implications of Julian’s leaving out Eve as being a deliberate critique of Augustine, “Julian articulates an internally persuasive discourse that distinctly revises that prior view and embraces imagery that opposes Augustine’s view of the body as limitation.” The female body is associated with the lower reason. Thus, McEntire explains that according to Børresen, a “woman is nearer to the devil and further removed from God.” It is this cultural perception of the inferiority of the female body

117 Ibid., 45.

118 Ibid., 42.

119 Ibid.; Baker explains, “The lower reason, directed toward the corporeal, is the medium of temptation between this sensuality and the higher reason. This tripartite construction gains wide currency in the high Middle Ages because Peter Lombard incorporates it into his Sentences (1.24.6-13), where he divides the soul into the sensuality or inferior power and the reason or superior power, which itself consists of higher and lower parts.”

120 McEntire, Julian of Norwich: A Book of Essays, 19.

viewed in the traditional Augustinian sense that prevents a female from being held within the all-encompassing embrace of God, which can offset the “deformity” of the soul. While her medieval contemporaries equate the sensual part of the soul as a deformed image of God through human sinfulness, Baker argues that Julian instead “claims that the substance of the soul inextricably rests in God as the ground of being on which its existence depends just as the imago Dei resides in the soul.”

This once again brings Julian to a state of positive optimism as she rests in the assurance that the sensuality will one day become fully integrated into the substance which has its being in God. Julian takes a much more positive stance on the soul’s sensuality; she does not label it as inferior but rather sees it as involved in a process of sanctification and participating in an ongoing relationship with the humanity of Christ. Knowingly or unknowingly Julian’s positive stance toward the lower part of the Trinity, namely the sensuality softens the idea that illness in the body leaves a person estranged from and unloved by God. Instead, Julian’s conception of the Trinity that obliterates the inferiority of women based on cultural views of their embodiment. This prompts the question of how to locate the distinction of superiority and inferiority of the body as it fits within the embodied difference of disability. In order to answer this question we need to turn back to the specifics of how the substance and sensuality operate in order to properly situate embodied impairment and disability within Julian’s Trinitarian theology.

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The soul exists in our substance, and also is in our sensuality. Julian explains, “[O]ur substance, it can rightly be called our soul, and as regards to our sensuality, it can rightly be called our soul, and that is by the union which it has in God.” So our sensuality includes our bodies as well as a portion of our soul that is not yet fully integrated into our substance. The fact that Christ dwells within the sensuality as well as the substance means that according to Julian’s theology Christ dwells within embodied impairment and disability. It is important to note here that embodied impairment dwells in the sensual part of Julian’s conception of the Trinity because it is embodied and not necessarily because it is associated with sin. In the Middle Ages if an illness or sickness was not deemed as coming from God it was not automatically assumed to be a result of sin as historians have supposed, but rather, as Metzler points out, “The emerging picture shows the ambivalence and fluidity of medieval attitudes to the physically impaired, revealing it was not necessarily viewed as being primarily caused by sin, as many historians have previously assumed.” Historian Henri-Jacques Stiker agrees that there is no definitive way to describe disability in the Middle Ages, he suggests, “Christianity never found an entirely stable position, no effective praxis to address disability.” Julian’s theology through reforming the largely inferior conception of the female body could also be used to offset the negative aspects of embodied impairment and disability.

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124 Metzler, *Disability in Medieval Europe*, i.

Furthermore, because Christ dwells in both the higher and the lower parts of the soul, the body is wholly integrated into who we are as human beings and Julian does not perpetuate a body/soul split. The body cannot be split off from the soul and labeled as evil because body and soul are intimately joined in God through Jesus Christ in Trinitarian relationship. In the Middle Ages, even though the naming of impairment as sin is unclear, it is likely that the conception of deformity of the soul still existed and the person would likely be conceived as “less-than” someone without a disability.

### Ongoing Suffering of Christ and Disability

Julian’s lower part of sensuality locates the suffering of the Passion squarely within our bodies, and this is helpful for people with disabilities, because it provides a way to understand the suffering and challenges of everyday life. Brandolino points out that, “Julian took comfort in Christ’s suffering, leaving the body in a position to negotiate a path to God based as much on his goodness as its own.” 126 Julian’s willingness to take such a positive and embodied stance to entering into the suffering of Christ through her bodily illness communicates healing power to people with disabilities. This healing power is available today because for Julian the ongoing suffering of Christ occurs as part of the ongoing enfolding of life, as depicted in Julian’s overall vision of reality. Furthermore, Christ in His sensuality still suffers with us sharing in our embodied

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126 Brandolino, “The ‘Chiefe and Principal Mene,’” 110.
impairment through his embodied impairment, thereby Julian’s God is one who embraces and intimately knows our human suffering.

Jesus Christ as second person of the Trinity took our human nature at the same time he was completely divine. As far as Christ’s substance (namely, his divinity) is concerned, “he is glorious and impassible.”\(^{127}\) In terms of his sensuality, “to which all his members are joined, he is not yet fully glorified or wholly impassible.”\(^{128}\) This means that Christ is able to suffer as he exists in our sensuality, but that in divinity, he is unable to suffer in substance. In the eighth revelation, Julian sees a vision of Christ’s passion when Christ is near death. This vision was painful for Julian to watch, for Christ was, “completely changed and transformed from his naturally beautiful, fresh and vivid complexion into a shrivelled image of death.”\(^{129}\) Julian’s vision tells her that we are so united with Christ, that “when he was in pain we were in pain.”\(^{130}\) Having had this vision, Julian reflects on the meaning of Christ’s suffering as it relates to us. At the very moment in her vision when she believes Christ will expire in the ninth revelation, the appearance of the cross changed from the anguish of near-death to joy.\(^{131}\) Then Julian understands the Lord’s intention that, “[W]e are now on his cross with him in our pains, and in our sufferings we are dying, and with his help and his grace we willingly endure the same


\(^{128}\) Ibid.

\(^{129}\) Ibid., LT 16, 206.

\(^{130}\) Ibid., LT 18, 209.

\(^{131}\) Ibid., LT 21, 215.
cross until the last moment of life.”\footnote{Ibid.} According to Julian, when we are on the cross with him, his appearance will eventually change for us and we will be with him in heaven and “all will be brought into joy.”\footnote{Ibid.} This means that Christ continues to suffer with us in our sensuality so we can rise to be with him. The reason for this ongoing suffering is that, “[H]e still has that same thirst and longing which he had upon the Cross.”\footnote{Ibid., LT 31, 230–231.} What does this thirst mean? Julian tells us that Christ’s thirst is “his longing in love.”\footnote{Ibid., LT 31, 231.} According to Julian, this longing in love is to gather us all into him. Right now we are not gathered but one day we will be. And why does Christ continue to suffer? According to Julian, “in his divinity he is himself supreme bliss.”\footnote{Ibid.} Christ suffers with us because he wants all souls to be saved and come into his bliss and he wants to make us all heirs of his joy.\footnote{Ibid., LT 21, 215.} When we are in this joy, Julian tells us, “there is no pain on earth or anywhere else which could trouble us, but everything would be joy and bliss for us.”\footnote{Ibid., 215.} This is not what we know here on the earth. We know suffering. We know hardship. Julian informs us that

\begin{footnotes}
\footnotetext[132]{Ibid.; Some may believe that Christ’s ongoing suffering connotes the notion of, “The Disabled God,” first coined by Nancy L. Eiesland in her book, The Disabled God. Christ’s affliction on the cross cannot be classified as a disability, but is more accurately portrayed as embodied impairment, because Christ did not experience marginalization because of physical limitation such as blindness, but suffered for the redemption of the world. Therefore, Christ’s suffering cannot be equated with disability.}
\footnotetext[133]{Ibid.}
\footnotetext[134]{Ibid., LT 31, 230–231.}
\footnotetext[135]{Ibid., LT 31, 231.}
\footnotetext[136]{Ibid.}
\footnotetext[137]{Ibid., LT 21, 215.}
\footnotetext[138]{Ibid., 215.}
\end{footnotes}
Christ does not show us his joy but “his suffering countenance,” and as Christ carried his cross we are to suffer with him. As we suffer with him, Christ longs for us to be in bliss. What does it mean for people with disabilities that Christ continually suffers out of a longing and thirst to bring them more deeply into his everlasting bliss? Is this the kind of God who would turn people away because they were unable to see, hear, move, or speak? No, Julian’s God is a God of great kindness who out of the deepest of all loves continues to endure suffering in the hope of bringing all people into endless and everlasting bliss. This is a God who would likely love people with disabilities just as they are. In this way it seems that Julian’s Trinitarian perspective is able to address the marginalization of people with disabilities. This will be explored in chapter 5 through a conversation with the narratives of people with disabilities.

**Julian and Embodied Worthiness**

It seems that Julian’s relational conception of the Trinity only brings us part way to addressing the issues of disability. Julian went through a time when Christ revealed, “a supreme spiritual delight,” in her soul. At this time, Julian was filled with, “everlasting surety, powerfully secured without any painful fear.” She was completely at peace, ease and rest, and she says at this time, “there was nothing upon earth which could have

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139 Ibid., LT 21, 215.
140 Ibid., LT 15, 204.
141 Ibid.
afflicted me.”\footnote{Ibid.} The blissful feeling lasted for a time. Then Julian was filled with dread and she was weary of her life, so much so that she could hardly want to go on living. Then the blissfulness returned, but so did the painful dread. As Julian moved between extreme feelings of joy and dread she realized that, “This vision was shown to teach me to understand that some souls profit by experiencing this, to be comforted at one time, and at another to fail and to be left to themselves.”\footnote{Ibid., LT 15, 205.} Even though we are left to ourselves for a time in our suffering and pain, Julian tells us that, “God wishes us to know that he keeps us safe all the time, in sorrow and in joy; and sometimes a man is left to himself for the profit of his soul, although his sin is not always the cause.”\footnote{Ibid.} So there are times that God leaves us to ourselves to experience the pain, sorrow and dread of our lives for our own profit, but God wants us to know that we are always safe.

What is the profit of which Julian speaks? Julian suggests that we are asked to endure for no other reason than it is the Lord’s will. And we are left to ourselves to learn of our complete dependence on God. According to Julian, God has pity and compassion over all our trials and times of great humiliation and over our being rejected by this world. Julian writes:

Yes, I even saw that our Lord rejoices with pity and compassion over the tribulations of his servants; and he imposes on every person whom he loves, to bring him to his bliss, something that is no defect in his sight, through which souls are humiliated and despised in this world, scorned and mocked and rejected. And he does this to prevent the harm which they
might have from the pomps and the pride and the vainglory of this wretched life, and to prepare their way to come to heaven, into endless, everlasting bliss.\footnote{Ibid., LT 28, 226.}

These things through which we are scorned, mocked and humiliated in this life are “no defect in his sight.”\footnote{Ibid.} People with disabilities are mocked and humiliated for their embodied difference; and Julian says that it is in these things that we have no defect in God’s sight. I who have limped and stumbled through my entire life, “have no defect in God’s sight.” For a person with a disability this word by Julian opens a sense of their worthiness before God. Here we are reminded that Julian said, “Sin is necessary,”\footnote{Ibid., LT 27, 225.} so as we encounter the sinfullness of humankind in the form of being humiliated and despised, and when we put away within ourselves our pride and vainglory, we move closer to union with God. In light of this Julian wants us to know of our status as blameless and guiltless children.

And he wants us to see that his pains and his tribulation exceed all that we may suffer so far that it can be comprehended in full. And if we well contemplate his will in this, it keeps us from lamenting and despairing as we experience our pains; and if we see truly that our sins deserve them, still his love excuses us. And of his great courtesy he puts away all our blame, and regards us with pity and compassion as innocent and guiltless children.\footnote{Ibid., LT 28, 227.}

We are like innocent and guiltless children no matter what, whether someone is born able-bodied or disabled. Here, Julian calls us to remember the great expanse of
God’s love. Overarching everything, our sinfulness and innocence, our broken bodies and our wholeness, God’s love permeates all making us “innocent and guiltless children.” The remembrance of God’s love “keeps us from lamenting and despairing as we experience our pains.” We have a tendency instead to dwell on remembering our sin, our failings and weakness rather than the magnitude of God’s endless love for us. The depth of God’s love, according to Julian is so great that God wants us to, “forget our sins.” We must forget anything that distracts us from the love of God. Julian writes, “He [God] wants us in all things to have our contemplation and our delight in Love.”

We are to remember that we are safely held within the Trinity, because Christ is knitted together with us in our ongoing suffering, and we are united with Him in his ongoing suffering of the Passion. Through God’s grace and mercy, we become more holy through the integration of our sensuality into our substance through the love of God. Julian writes, “our sensuality by the power of Christ’s Passion can be brought up into the substance, with all the profits of our tribulation which our Lord will make us obtain through mercy and grace.”

Humanity is engaged in an ongoing process of becoming more holy and integrated into our true selves, found in the substance of the Trinity through Jesus Christ. And although our blamelessness is freely given by God, it only is a help to us if we

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149 Ibid.
150 Ibid.
151 Ibid., LT 72, 321.
152 Ibid., LT 73, 323.
153 Ibid., LT 56, 289.
remember that Christ’s pains taken on for us exceed anything we could possibly endure, and that it is Christ’s will for us to know his willingness to suffer for us, to bring us fully into his substance and endless bliss, as it is in the blessed Trinity.

In Julian’s Trinitarian theology Christ’s substance is impassible, but in his sensuality Christ is still able to suffer. For Julian we suffer with Christ on the cross, and Christ continues to suffer because we have not completely been restored to our true substance through Christ’s mercy. Julian wishes to be in intimate contact with Christ and to share in His Passion, his embodied experience of suffering. This is the mystical knowing of those on the margins. For Julian this means, for example, understanding the experience of women. McEntire explains that Julian embraces, “extreme physical suffering in her own body, but she also goes much further than other female mystics by representing the divinity as having a female body that groans and moans, endures wounding and torture.” Through this act of shared suffering with Christ, Julian sends the message to people with disabilities that Christ dwells with them in their pain. This truth it seems can serve as a source of comfort for people with disabilities. Christ is with us in the pain and suffering we endure in life enfolding us in love and fixated upon our most intimate needs in order to provide some measure of relief from our ongoing suffering. The truth that Christ dwells in pain will perhaps provide comfort the next time

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154 Ibid., LT 27, 225.

uncontrollable painful physical limitations confront a person with a disability preventing them from doing what they want to do, or inhibits who they imagine themselves to be.

What does it mean that Julian was willing to go to these extremes? The culture of Julian’s day believed in the inferiority of the female body and yet according to Julian’s theology, in His death Christ assumes the female body even with its culturally implied inferiority. McAvoy argues that dominant to Christianity is the trading of bodies with salvation. McAvoy believes that Julian is trying to address this, “by exploiting the link between bodily transaction and female sexuality and allying it to her treatment of God’s motherhood, Julian was able to effect both authority and a powerful redemption of the female body in her texts by inscribing upon the Second Person of the Trinity a type of sacred whoredom, which in turn was rendered central to the salvific process.”\textsuperscript{156} Thus, McAvoy explains that, “This collapse of Julian’s own suffering body into that of Christ’s has the effect of transforming their merged corporeality into a female site of negotiation, a primary commodity of exchange and a feminized route to salvation.”\textsuperscript{157} McAvoy argues that in attempting to legitimize the female body, Julian conceives of Christ as Mother, so that Christ can then become embodied as the holy whore for the world. McAvoy believes that Julian is trying to convey that Christ offers himself as a lover to the world by asking that others enter into the wound of his side. What McAvoy thinks Julian is doing in her theology is to completely legitimize the female body and equalizing it with the male body and thus legitimizing the female person. This illustrates the breadth

\textsuperscript{156} McAvoy, “Julian of Norwich and the Trinity of the Feminine,” 71–72.

\textsuperscript{157} Ibid., 73.
of Julian’s response to the marginalization of women. Christ taking on the characteristics of a “common-woman” seems plausible from Julian’s perspective but McAvoy’s “holy whoredom” seems to step over a line that Julian would have drawn for herself. McAvoy in her eagerness to make the argument that Julian’s conception of Christ seeks to share in all of the vulnerability of being female in a male-dominated culture, appears to overlook that the use of the holy whore imagery actually is not likely to have fit into Julian’s purview because Christ in his humanity from Julian’s standpoint has no sin. If the holy whore aspect of McAvoy’s argument is set aside, the Christ as Mother is enough to critique the inferiority of the female body. Implied in Julian’s entering into suffering with Christ along with her critique and re-conception of sensuality is the radical immanence and acceptance of extreme embodied vulnerability and marginality by Christ as conceived by Julian as our Mother. Christ as Mother is thereby sufficient to provide important insight into how Julian’s theology interacts with the inferiority of embodied impairment.

Disability always stands juxtaposed to the normal able-body as the ideal; it is common for those who are disabled to long for a normal body, but Christ as embodied vulnerability offers a critique to the desire to be normal. That is, to enter into Christ’s embodied impairment is to be enfolded and embraced in our embodied difference and thereby to remove its inferiority. Of course Julian employs Christ as Mother whereas in the discussion of disability we draw upon the notion of Christ’s embodied impairment as what is shared between Christ and people with disabilities. Julian tells us that this goodness is found in our Mother, “Jesus, who opposes good to evil, is our true
Mother.” Julian writes, “We have our substance in the Father, God almighty; and the second person of the Trinity is our Mother [Jesus] in nature in our substantial creation. Jesus is our Mother of mercy in taking our sensuality.” So Julian in taking the non-gendered approach developed by McEntire and Baker adds the notion of gender back into the Trinity by describing Jesus as our Mother. Thus, Jesus is united in our sensuality as our caring merciful Mother. And so the suffering and pain of this earthly life is to bring us more closely into union with our merciful Mother Jesus Christ. Because God is all goodness and in Him we are worthy, precious, and blameless, we are to put aside all things that would have us turn away from Him so that we can trust and fall directly into the loving arms of our Mother Jesus. Instead of dwelling on the implied unworthiness that will always be given to us by the world through enduring the hegemony of the normal, instead people with disability should reflect upon how the love of Christ, merciful Mother is present in times of suffering and humiliation, considering that all of the events of life may be necessary to come to know and be “oned” with God in Love. Julian tells us that in the Trinity we are knitted together with Christ in his humanity. Christ continues to suffer with us, loving us and longing to bring us to bliss. Thus, Christ loves us in our bodily pains and the struggles of our soul to become more intimately united with Christ. Because of this, and because we are loved so intimately with Christ in our bodily pains, and we are found blameless, whether we sinned to bring them on or not, knowing our embodied worthiness before God through Christ’s ongoing suffering in the

158 Julian of Norwich, Julian of Norwich: Showings, LT 59, 295.
159 Ibid., LT 58, 294.
Trinity calls us to leave behind negative self-images of ourselves given to us by society and to embrace and be found fully in the merciful arms of our Loving Mother Jesus Christ.

**Summary of Julian of Norwich**

Julian’s bodily illness does not fit the definition of disability because Julian does not endure social marginalization because of her illness. As a result of her bodily illness Julian receives sixteen revelations from God. Julian’s bodily illness or embodied impairment does not prevent intimate contact with God. According to Julian God’s love encloses us in our humblest of needs, and this is important for people with disabilities because the everyday life with a disability involves much that is messy and humbling, the notion that God’s goodness is in those very needs is a great comfort for people with disabilities. Julian conceives of the Trinity differently than her contemporaries, such as Walter Hilton. Julian enhances the relational aspects of the Trinity through taking a non-gendered and bidirectional approach. Scholars argue that Julian takes the bidirectional and non-gendered approach to the Trinity to critique the patriarchal structures of her day. This is important for people with disabilities because in taking this Trinitarian approach Julian critiques the predominant idea of her day that women were inferior because of their embodiment. Julian’s re-conception of the Trinity may be relevant for people with disabilities in establishing their worth. Julian’s Trinitarian conception of God is also helpful to people with disabilities in terms of the higher part, the substance, and the lower part the sensuality, because in Julian’s conception of these parts, we continue to share in
Christ’s suffering through His sensual part. According to Julian we are knit together with Christ in the Passion, while humanity today is still in the process of becoming holy and integrated into our true selves, when our sensuality is integrated into our substance through the love of God. This ongoing process allows Christ to enclose us in our suffering and pain, for we do not have a God who abandons us in our suffering but shares in it with us. However, there are times when according to Julian God leaves us to ourselves in suffering, for Julian believes that God believes that it is best for us at time to be left to ourselves. Even as we are at times left to ourselves to endure suffering, Julian explains that God wants us to know that we are safe. That safety seems to be in knowing and clinging to the idea that we are enfolded in God, sharing in suffering with Christ. Through this theology Julian conveys that a word to people with disabilities that Christ dwells with them in their pain. This message might serve as a space for people with disabilities, in that they can know that they are not alone in the painful limits of their everyday lives.
CHAPTER 4

TERESA OF AVILA AND DISABILITY

Teresa of Avila Introduction

This chapter will analyze texts considered to be spiritual classics: Teresa of Avila’s, *The Book of Her Life* (L), the *Way of Perfection* (WP), and the *Interior Castle* (IC), along with selected letters written by Teresa. I will draw from the *Foundations* (F) to develop the notion of Teresa as a social reformer. Secondary sources will also be used to establish the relationship of Teresa’s writings and common themes of disability developed in chapters 1 and 2 to prepare for the mutually critical conversation with the unheard voices of people with disabilities. Thus, this chapter will tease out and refine the theological points of contact between Teresa’s theology and physical disability, in so doing laying the foundation for the constructive work of chapter five. To that end, this chapter investigates the general concepts of embodiment and the response to marginalization in Teresa’s work. First, Teresa’s life will be properly situated within its historical context. Next, Teresa’s bodily illnesses will be explored in an effort to discover her perspective on embodiment. Lastly, Teresa’s perspective on embodiment will be examined in relationship to Teresa as a social reformer and her founding of convents and monasteries.
Teresa of Avila (1515-1582) was canonized in 1622; almost 350 years later in September 1970 she became the first woman to be named a doctor of the Roman Catholic Church.¹ Teresa of Avila lived when the Spanish Inquisition was in full swing and this meant that persons like her—a woman who had mystical religious experiences—were viewed with intense suspicion. Teresa was born to a *converso* family. Her grandfather Juan Sanchez was accused of practicing Judaism by the Inquisition, and was forced to endure public humiliation by parading himself in the streets of Toledo for absolution.² The process of absolution at the time required one to walk “on seven consecutive Fridays, through the streets of Toledo wearing a *sambenito*, a bright yellow knee-length tunic embroidered with black crosses and flames identifying him as a heretic.”³ The act of humiliating himself did bring Sanchez pardon, and he subsequently moved his family to Avila to create a new beginning, yet from that point on he kept his Jewish heritage a family secret. Indeed, it remained so until the mid-1940s.⁴

Teresa grew up in a volatile environment at the center of religious and political struggles. Rowan Williams explains that Teresa of Avila was “reacting to a particularly

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difficult epoch in the history of the Spanish state and Church.” He continues, “She lived in a society whose tensions and anxieties were more like those of modern South Africa than Europe in the last quarter of the twentieth century: though she would have recognized all too readily the horrors of Germany in the 1930s, and the threat of resurgent anti-Semitism in the France of 1990.” The point that Williams is trying to make is that there was a lot of anxiety about individual differences that led to oppression during Teresa’s lifetime. Jodi Bilinkoff explains that Teresa’s life spanned some of the “great movements in European culture now known as Renaissance, Reformation, and Counter-Reformation. Her experience of these movements, and the changes and conflicts they brought, had an enormous impact on her life and work as a mystic, a writer, and a religious reformer.” Most notable was the time Teresa spent in Avila, Bilinkoff explains: “Here, in this urban setting, she found many of her models for the religious life, as well as the individuals and institutions that helped to shape her concepts of prayer and monastic reform.” This was a setting of immense religious and political change, Bilinkoff explains: “Teresa was born one year before Ferdinand of Aragon died and two years before Martin Luther initiated his revolt.” She “grew up in the age of Charles V,

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6 Ibid., vii.


8 Ibid.

9 Ibid., xii.
when Spain was emerging as a major European and overseas imperial power and the
defender of Catholic orthodoxy in a religiously divided Europe.”

Individual differences, family bloodlines, and religious practices were under intense scrutiny, positively and negatively. In this context, Teresa’s status as “minor nobility” was no doubt extremely helpful in many respects, as was being of high moral character. Still the Spanish Inquisition played a critical role in Teresa’s life, something from which not even her status as minor nobility could shield her. Because the inquisitors regarded all deviations from pure Catholicism with suspicion, Teresa wrote with her confessors in mind, knowing that they were obliged to authenticate that Teresa’s religious experiences were from God and not the devil in order to keep her from the Inquisitors’ attentions.

Sanchez’s son Alonso became Teresa’s father, unbeknownst to him the father of a saint. Her piety had early beginnings. Already as a child of seven, Teresa played at being hermits and martyrs for Christ with her brother. Yet during adolescence Teresa’s religious piety grew cold; instead she read romantic tales and began to cultivate her feminine charms in hopes of marriage. Teresa began to “meet with opposition at home” when she started showing what her father felt were untoward affection for her cousins,

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10 Ibid.


12 Ibid.

13 Ibid., 38.

namely sons of her aunt. To thwart that relationship, Alonso entrusted her to the care of
the Augustinian nuns of Our Lady of Grace, who ran a sort of finishing school for
adolescent girls to prepare them for their future life in marriage. A devout nun, Doña
Marie Briceño turned out to mean more to Teresa than all her former friends, and Teresa
began to consider a vocation in the religious life. Yet things took a turn when Teresa
became ill at Our Lady of Grace and needed to leave the school. While she recuperated
at the home of her uncle Pedro, she read the Letters of St. Jerome and this tipped the
balance in favor of Teresa committing to a religious vocation. Yet the decision was not
easy. So difficult was it for her to leave her father, who was against the idea of Teresa
becoming a nun that she slipped away in the middle of the night to the Carmelite
Monastery of the Incarnation. Teresa became ill several years after her profession at the
Incarnation. No one knows the exact nature of the illness, though Teresa herself
attributed the illness to the food and lifestyle at the Monastery of the Incarnation. The
next section will explore the similarities and differences of Teresa’s numerous illnesses to
disability.

15 Kieran Kavanaugh, introduction to The Book of Her Life, by Teresa of Avila in The Collected

16 Ibid.

17 Ibid., 17–18.

18 Ibid., 18.

19 Ibid.

20 Ibid., 19.
Teresa’s Illnesses and Disability

As Teresa’s recorded illnesses were many, it is somewhat surprising that little has been written concerning the impact that Teresa’s bodily illnesses may have had on her theology. Teresa experienced fainting spells, heart palpitations (likely from heart arrhythmias), three years of paralysis, traumatic healings, and a broken shoulder that was not set correctly, and she probably suffered with bulimia. Imagine for a moment being Teresa paralyzed in the bed and not being able to move, as she here describes a time when she nearly died from her illnesses after four days of torment:

The result of the torments of those four days was that I was unable to stir, not an arm or a foot, neither hand nor head, unable to move as though I were dead; only one finger on my right hand it seems I was able to move. Since there was no way of touching me, because I was so bruised that I couldn't endure it, they moved me about in a sheet, one of the nuns at one end and another at the other.

Think of the level of vulnerability and dependence involved in being carried around by the four corners of a sheet and only being able to move one finger. Now consider enduring this in the sixteenth century with no modern comforts. When scholars gloss over Teresa’s paralysis, they negate the influence of Teresa’s illnesses upon her theology.

Teresa does not elaborate much on her illnesses in her texts, and this could be part of the reason that her illnesses have not been the subject of more scholarly inquiry. Yet a

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careful examination of the text of her *Life* (*L*) and *Letters* (*LE*) does provide some clues about how she interpreted her illnesses and disability. In the *Life* Teresa explains that she sees her illness as coming from God. She writes, “During this time, although I did not neglect my spiritual improvement the Lord was more determined to prepare me for the state that was better for me. He sent me a serious illness so that I had to return to my father’s house.”\(^{23}\) This passage reveals that Teresa does not believe that her illness is a whim or punishment from God, but rather than she sees it as means to an end, a way to create in Teresa a state that was better for her. During the first year of her very poor health, Teresa wonders whether her illness is a result of offending God.\(^{24}\) Yet her writing has a practical tone too: she blames the food and the lifestyle at the Incarnation as being detrimental to her health.\(^{25}\) The illnesses concerned Teresa’s father deeply and he searched desperately for a remedy. Because doctors could find no cure, Teresa’s father sent her to a faith healer. Teresa explains, “Since the doctors there had no [cure] to offer, [my father] sought to bring me to a place very famous for the cure of other sicknesses; and also mine they thought could be cured.”\(^{26}\) Teresa tells us, “I remained in that place almost a year, and for three of those months suffering such severe torment from the harsh cures they used on me that I don't know how I was able to endure them. And, finally,

\(^{23}\) Ibid., L 3.3, 62.

\(^{24}\) Ibid., L 4.5, 66.

\(^{25}\) Ibid., L 4.5, 66.

\(^{26}\) Ibid., L 4.5, 66.
even though I endured them, my bodily make-up could not…”

The treatment she was given likely was indeed severe. “Besides the usual treatment of bleeding, Teresa was given injections, poultices, and pills in odd numbers as well as being rubbed with scorpion oil and brick oil to open her pores.” Teresa explains that psychologically she could have endured more but that the physical treatments themselves nearly killed her:

[F]or the cure was too harsh for my constitution. After two months, because of the potent medicines, my life was almost at an end. The severity of the heart pains, which I went to have cured, was more acute. For sometimes it seemed that sharp teeth were biting into me, so much so that it was feared I had rabies. With the continuous fever and the great lack of strength (for because of nausea I wasn't able to eat anything, only drink), I was so shriveled and wasted away (because for almost a month they gave me a daily purge) that my nerves began to shrink causing such unbearable pains that I found no rest either by day or by night–a very deep sadness.

Teresa’s father brought her back to the doctors after seeing the poor results of the healer. Yet the doctors had no hope for Teresa. Their diagnosis of tuberculosis was one that she cared little about because of her bodily state at the time: “The pains were what exhausted me, for they were like one continuous entity throughout my whole body, from head to foot. Pain of the nerves is unbearable, as doctors affirm, and since my nerves were all shrunken, certainly it was a bitter torment.” For three months Teresa endured

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27 Ibid., L 4.6, 66.

28 Marcelle Auclair, Teresa of Avila (New York: Pantheon, 1953), 64.

29 Teresa of Avila, The Book of Her Life, L 5.6, 73.

30 Ibid., L 5.8, 74.

31 Ibid.
this horrible state and she explains that it “seemed impossible to be able to suffer so many ills together.”\textsuperscript{32} Teresa believed that the patience to endure all of this illness came from His Majesty/God; she also considered it important that she read Job as presented in St. Gregory’s *Morals*.\textsuperscript{33} According to Teresa, the Lord used all of this to prepare her to “bear the suffering with so much conformity to His will. All my conversations were with Him. I kept these words of Job very habitually in my mind and recited them: *Since we receive good things from the hand of the Lord, why do we not suffer the evil things?* This it seems gave me strength.”\textsuperscript{34} Teresa used the experience of her suffering to grow closer to God through prayer.

With her health not improved, Teresa was brought back to Avila. Teresa explains that “the one they expected to be brought back dead they received alive; but the body, worse than dead, was a pity to behold. The state of my weakness was indescribable, for I was then only bones. I may add that the above condition lasted for more than eight months. The paralysis, although it gradually got better, lasted almost three years.”\textsuperscript{35} Teresa describes an experience common to those with disabilities when she senses her paralysis getting better, “I began to go about on hands and knees, I praised God.”\textsuperscript{36} She

\textsuperscript{32} Ibid.

\textsuperscript{33} Ibid.

\textsuperscript{34} Ibid.

\textsuperscript{35} Ibid., L 6.2, 77.

\textsuperscript{36} Ibid.; Teresa’s praise is likely from a sense of gratitude that often accompanies regaining bodily function that once was lost. People with disabilities such as, cerebral palsy often find themselves crawling around after an unfortunate fall. There is often a praise mixed with a sense of humiliation that goes along
continued to try to live in conformity with God’s will, and her patience in doing so amazed those around her.\textsuperscript{37} She had not given up. “For I still desired my health, even though I bore the illness with much happiness. And I thought sometimes that if in being well I were to be condemned, I would be better off this way. But nonetheless I thought I would be able to serve God much better if I were in good health.”\textsuperscript{38} Though she considered herself better able to serve God in health, she nonetheless abandons herself to the will of God, which she considers to be central, “for He knows best what is fitting for us.”\textsuperscript{39}

In the midst of her illness, Teresa in her writing explains the push/pull of managing and living with an illness as a believer. As Teresa understood her physical illness as being a manifestation of God being “determined to prepare me for the state that was better for me.”\textsuperscript{40} This means Teresa needs to seek conformity to God’s will in the midst of the incomprehensibility of illness. As she wishes to be set free from her ill body, she must also be willing to be limited in her body for the will of God. Conflicted between desiring relief from suffering and obedience to God, she beseeches Saint Joseph for healing. Saint Joseph is the target of Teresa’s prayers because “as the ‘Lord’s’ tutor, with the experience of crawling around as an adult. The praise comes from the realization that one is okay and not hurt after a fall. The humiliation is from finding oneself suddenly on all fours, while most everyone else in the world manages to continue to walk upright on two legs.

\textsuperscript{37} Ibid., L 6.5, 79.

\textsuperscript{38} Ibid.

\textsuperscript{39} Ibid.

\textsuperscript{40} Ibid., L 3.3, 65.
Joseph could give the Child a command—so in heaven God does whatever he commands."\(^{41}\) In time, Teresa regained her ability to move and resumed life in the monastery.

Among the few scholars who have engaged the subject of Teresa’s illnesses, some speculate that Teresa’s mystical experiences could be a byproduct of epileptic seizures. For example, Marcella Biro Barton points out scholars have not considered the progression of Teresa’s illnesses.\(^{42}\) Barton argues that Teresa’s illnesses might fit into "the pattern of her life."\(^{43}\) As a result Barton suggests that Teresa’s mystical experiences were a result of temporal-lobe seizures or major motor seizures. In Barton’s opinion the temporal-lobe seizures are not to discount mystical experiences but present a means to scientifically understand what may have been happening in Teresa’s brain at the time of some of her religious experiences. Barton writes, “If one accepts the possibility of her temporal-lobe seizures, then it is possible that Saint Teresa, through temporal lobe seizure-induced experiences, was led to a further search for truth, a developing mystical experience, and finally a closer union with God.”\(^{44}\) Thus Barton argues that, “Saint Teresa's visions and voices could have been the result of a combination of her temporal-

\(^{41}\) Ibid., L 6.6, 80.


\(^{43}\) Ibid.

\(^{44}\) Ibid., 592.
lobe seizures and her mysticism." Barton suggests: “Temporal-lobe seizures can be seen as part of the development of Saint Teresa's mysticism, and at the same time do not distract from her ultimate service to the Church and to God. They should be viewed as only one possible vehicle of transformation.” What is interesting about Barton’s argument is that a bodily illness or ailment is used as a vehicle for the mystical communication of God. In this way there is a similarity to Julian, who through her bodily illness received her revelations from God. This reveals a unique connection between embodiment and spiritual experience. Barton explains, “Her contemplation and love of God seemed to interlock with physical changes in her body, producing a unique spirituality.” Ultimately although we cannot know whether Teresa suffered from a form of epilepsy or temporal-lobe seizures, what is clear is that there is a potential relationship between embodied experience and the mystical experiences of both Teresa and Julian.

Although Teresa’s illnesses show some similarities to physical disability, they are not exactly comparable to the modern definition of a physical disability in that Teresa does not suffer from marginalization because of her illnesses. Even though Teresa’s embodied experience has largely been overlooked by scholars, she did experience embodied impairment. Furthermore, we can glean from this discussion that although Teresa did not experience the marginalization associated with physical disability, she did

46 Ibid., 598.
47 Ibid.
for a time experience trauma similar to the medical trauma experienced by people with disabilities. Teresa’s embodied impairment not only likely colored her life experience, but, if Barton’s argument is accurate, it also influenced her mystical experiences. Further exploration of Teresa’s theology in relationship to her illness reveals some of the potential influence her illnesses had upon her theology.

**Teresa’s Illnesses – Theologically and in Context**

In this next section we will explore Teresa’s bodily illnesses theologically in the context of 16th century Spain. To do this we must first briefly discuss Teresa’s most classic book, the *Interior Castle*. Teresa begins the *Interior Castle* by stating that the soul is like a castle or mansion, a single diamond very clear in which there are many rooms. The many rooms refer to John 14:1-6 and that “In my Father’s house there are many mansions…” The rooms are not arranged one after another in a row but some are above and some are below, and there are other rooms to the sides. This signifies that there is not just one way to reach the center but there are various ways. E. Allison Peers clarifies Teresa’s use of the word mansion. Peers explains, “Each of the series of *moradas* [mansions] (use the plural throughout, especially in the title of each chapter, is noteworthy) may contain as many as a million rooms; all matters connected to spiritual progress susceptible of numerous interpretations, for the grace of God knows no limit or measure.”

Ruth Burrows tells us that each “*moradas*” is a staging-inn where travelers

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stop for a while on a journey. At the center of Teresa’s metaphorical castle is God’s dwelling place. In God’s dwelling place the most secret things are experienced between God and the soul. The metaphor of the interior castle is employed throughout Teresa’s book marking the soul’s progress from imperfect sinfulness to the seventh mansion and spiritual marriage with Christ. The door through which one enters the castle is prayer. Upon entering the castle through prayer, the way to make progress for Teresa is to develop self-knowledge and humility. The first three mansions of the *Interior Castle* involve human effort to nurture the life of prayer. The fourth through seventh mansions rely on less human effort as the mystical life of prayer advances to the later stages. Teresa places “crippled souls” outside the castle on the outer courts.

Teresa of Avila herself seems to echo the commonly held derogatory views toward people with disabilities in sixteenth-century Spain when she metaphorically uses the term “crippled souls” to signify those who are cut off from God. At first glance the “crippled souls” term seems like a disparaging statement against people with disabilities. What does Teresa use of the term “crippled souls” really mean? The exact term “crippled souls” or “*almas tullidas*” appears once in Teresa’s collection of writings. The term is used in the *Interior Castle* to describe those who have souls turned toward the self and worldly things and not toward God. Teresa writes, “Well now, we are not speaking to these crippled souls, for if the Lord Himself doesn’t come to order them to get up— as He

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50 See note 58 below.
did the man who waited at the side of the pool for thirty years—they are quite unfortunate and in serious danger. But we are speaking to other souls that, in the end, enter the castle.”

Teresa’s use of the term “crippled souls” seems initially to refer only to the immobility of the soul to turn from self to enter into the door of the castle through prayer, and not a loss of bodily control. Teresa’s writing in the *Interior Castle* supports the idea that the emphasis of the term is upon the inability of the soul to move and not the body:

Not long ago a very learned man told me that souls who do not practice prayer are like people with paralysed or crippled bodies; even though they have hands and feet they cannot give orders to these hands and feet. Thus there are souls so ill and so accustomed to being involved in external matters that there is no remedy, nor does it seem they can enter within themselves. They are now so used to dealing always with the insects and vermin that are in the wall surrounding the castle that they have become almost like them. And though they have so rich a nature and the power to converse with none other than God, there is no remedy. If these souls do not strive to understand and cure their great misery, they will be changed into statues of salt, unable to turn their heads to look at themselves, just as Lot’s wife was changed for having turned her head.

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52 Teresa of Avila, *Interior Castle*, IC I, 1.6, 286; “Decíame poco ha un gran letrado que son las almas que no tienen oración como un cuerpo con perlesía o tullido, que aunque tiene pies y manos no los puede mandar; que así son, que hay almas tan enfermas y mostradas a estarse en cosas exteriores, que no hay remedio ni parece que pueden entrar dentro de sí; porque ya la costumbre la tiene tal de haber siempre tratado con las sabandijas y bestias que están en el cerco del castillo, que ya casi está hecha como ellas, y con ser de natural tan rica y poder tener su conversación no menos que con Dios, no hay remedio. si estas almas no procuran entender y remediar su gran miseria, quedarse han hechas estatuas de sal por no volver la cabeza hacia sí, así como lo quedó la mujer de Lot por volverla.” Teresa de Jesús, *Moradas Del Castillo Interior* in *Santa Teresa de Jesús: Obras Completas*, IC I, 1.6; I follow, Elena Carrera’s example in providing only chapter and section numbers for the Spanish edition “to facilitate consultation of other editions.” See Elena Carrera, *Teresa of Avila’s Autobiography: Authority, Power and the Self in Mid-Sixteenth-Century Spain* (London: Legenda, 2005), 15.
However, further examination suggests that for Teresa the use of the term “crippled” may connote an embodied and autobiographical connection. Teresa uses the word, “crippled” to describe herself in the *Life*, “Since I saw myself so crippled and still so young and how helpless the doctors of earth were, I resolved to go for aid to the doctors of heaven that they might cure me.”

Teresa seems to strive for a cure of her body and soul when she turns to the doctors of heaven. Teresa describes the power of turning to Saint Joseph as a master teacher of prayer, as she relates her devotion to the Saint back to the healing of her body:

> Because of my impressive experience of the goods this glorious saint obtains from God, I had the desire to persuade all to be devoted to him…. Those who cannot find a master to teach them prayer should take this glorious saint for their master, and they will not go astray. Please God I may not have erred in being so bold as to speak about him, for although publicly I am devoted to him, I have always been lacking in serving and imitating him. For he being who he is brought it about that I could rise and walk and not be crippled; and I being who I am used this favor badly.

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54 Teresa of Avila, *The Book of Her Life*, L 6.8, 80–81; “Si fuera persona que tuviera autoridad de escribir, de buena gana me alargara en decir muy por menudo las mercedes que ha hecho este glorioso Santo a mí y a otras personas; mas por no hacer más de lo que me mandaron, en muchas cosas seré corta más de lo que quisiera, en otras más larga que era menester; en fin, como quien en todo lo bueno tiene poca discreción. Sólo pido por amor de Dios que lo pruebe quien no me creyere, y verá por experiencia el gran bien que es encomendarse a este glorioso Patriarca y tenerle devoción. En especial, personas de oración siempre le habían de ser aficionadas; que no sé cómo se puede pensar en la Reina de los ángeles en el tiempo que tanto pasó con el Niño Jesús, que no den gracias a San José por lo bien que les ayudó en ellos. Quien no hallare maestro que le enseñe oración, tome este glorioso Santo por maestro y no errará en el camino. Plega al Señor no haya yo errado en atreverme a hablar en él; porque aunque publico serle devota, en los servicios y en imitarle siempre he faltado. Pues él hizo como quien es en hacer de manera que pudiese levantarme y andar y no estar tullida; y yo como quien soy, en usar mal de esta merced.” Teresa de Jesús, *Libro de La Vida* in *Santa Teresa de Jesús: Obras Completas*, L 6.8.
In the above passage, Teresa combines the importance of prayer with her embodied experience of healing. Teresa’s turn to the “doctors of heaven” implies that Teresa does something that the “crippled souls” on the outer courts are unable to do and that is to turn away from the worldly self in humility to ask God for help. In a sense, Teresa moves from having both a “crippled” body and soul in her life. Teresa’s emphasis on both the importance of prayer to St. Joseph and no longer being a “crippled” seems to suggest a possible autobiographical characteristic to the metaphorical use of the term “crippled souls.” For in using the term “crippled,” Teresa points to the necessary turn to God in prayer, and its connection for her in regaining her ability to walk. According to psychologists, to speak of the body is to call forth the use of metaphor. Teresa may in this text be metaphorically speaking of her own life and embodied impairment. Ruth Burrows argues that Teresa’s Interior Castle was a reflection of Teresa’s personal experience and conception of her own soul because by the time she wrote the classic book she had entered the seventh and final mansion. Carole Slade echoes a similar point when she suggests that, “God does appear to Teresa in the center of her soul, but rhetorically speaking, the castle, rather than a location from which God speaks, is principally a means of sketching some of the configurations of her soul.” This seems to suggest that there is an autobiographical component to The Interior Castle and that there


56 Burrows, Interior Castle Explored, 10–11.

may be a connection between Teresa’s experience of paralysis and the metaphorical use of the term “crippled souls,” but there is no way to confirm this contention.

The “crippled souls” may be making an even more significant statement than just the autobiographical use of metaphor, if we understand the particular historical context in which Teresa was writing. People with disabilities were subject to death at the time of the Inquisition. Historian Herbert C. Covey explains the derogatory stance toward people with disabilities, historically and during the Inquisition:

Some Christians also endorsed punishing or executing people who had disabilities or were physically deformed. For example, Christians sometimes encouraged the execution of children with deformities or disabilities when they viewed them as products of witchcraft. Likewise, Christians also condoned the punishment or execution of suspected witches when the assumption was they had caused deformities in infants. Some Christian authorities interpreted the birth of children with congenital deformities as a sign of demonic intervention. During the Inquisition, this belief resulted in the execution of people with disabilities and/or their parents. Protestant reformers and Catholics alike viewed mental retardation as a form of satanic influence and tortured, exorcised, or killed infants.58

In light of this fragment of historical information concerning people with disabilities during the Inquisition, we can offer one possible interpretation that Teresa’s use of the metaphor could be stating indirectly that no soul—no matter how broken, lost, or seemingly deserving of death—is beyond hope. Perhaps in Teresa’s eyes even the marginalized person who is culturally deserving of only to be put to death, may instead be worthy of a loving relationship with God through prayer. This proposal seems to fit

58Herbert C. Covey, “Western Christianity’s Two Historical Treatments of People with Disabilities or Mental Illness,” *The Social Science Journal* 42, no. 1 (January 2005): 110. Metzler and Striker point out that the association of disability and sin did not apply to all situations of disability, individual circumstances and the nature of the impairment influenced how disability was viewed.
into Teresa’s positive stance toward the marginalized among her. Thus, we cannot automatically infer that the crippled souls of the outer courts of her *Interior Castle* are intended to be a derogatory statement against people with disabilities. The reality is that we cannot know Teresa’s actual beliefs; instead, suggests David Tracy, we should pay attention to her “hints” and “guesses.” Thus, one possible explanation of what Teresa means by the crippled souls is to affirm that no one is beyond hope, and that instead all are welcomed by God, and all are worthy of being an intimate friend of Christ.

Elizabeth Psakis Armstrong, seems to support the idea of Teresa’s inclusive stance, when she writes, “Teresa, by exemplifying her ordinariness, fights for human, ordinary women. She can speak with God not because she is a saint, but because God makes himself accessible to all.”\(^59\) The point here is that if in Teresa’s view God is accessible to women, perhaps God is also available to those with disabilities.

Perhaps we can mine her *Interior Castle* for further clues. For example, what do the outer courts or the crippled souls have to do with embodiment? Slade points out, “The wall surrounding the castle offers an apt analogy for the body, not simply because it is exterior but also because it suggests that some physical barrier obstructs the entrance, and the image of the soul contaminating the outer rooms by the things it brings along, vanities and honors represented by wild beasts and snakes, conjures an effective image of a person walking on a carpet with muddy feet.”\(^60\) This does seem to suggest that Teresa is


\(^{60}\) Slade, *St. Teresa of Avila*, 98.
not at peace with her own embodiment and that it carries for her all kinds of “baggage” that she would like to be done with. Although Teresa says that she would endure bodily sickness for the Lord, she does mention a time when she found her bodily needs disturbing her companionship with Jesus in prayer. Teresa experienced the conflict between her bodily ailments and being in the deepest of prayer and the Lord appeared to Teresa and told her to take care of her body for the love of Him.  

Teresa writes:

> Sometimes I worry because I see I do so little in His service and that I must necessarily take time for a body as weak and wretched as mine, more than I would want. Once I was in prayer, and the hour for going to bed came; I was feeling many pains and had to induce the usual vomiting. Since I saw I was so bound to myself and that my spirit on the other hand wanted more time, I got so wearied I began to weep freely and grow distressed. (This has happened not only once but, as I say, often.) It seems to me I became angry with myself in such a way that I then truly hated myself. But usually I know I don't hold myself in abhorrence, nor do I fail to do what I see is necessary for myself. And may it please the Lord that I do not care for myself more than is necessary, as sometimes I'm afraid I do. This time of which I'm speaking, the Lord appeared to me and greatly comforted me and told me I should suffer and do these things for love of Him because they were now necessary for my life.

Teresa is comforted and encouraged by the Lord to take care of her bodily needs out of love of Him; he tells her that such self care is now necessary. Teresa’s nightly practice of using a feather to purge now became integrated into her life as a practice and the Lord seeks to comfort Teresa telling her to comply with her practice because these things

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62 Ibid.

63 Ibid., L 7.11, 87–88.
“were now necessary for” her life.\textsuperscript{64} Teresa’s narrative portrays God as wanting her to take care of her body. Furthermore, it is important to grasp that Teresa interacted during this intense time of prayer with God feeling as if she should not attend to her bodily needs, but God tells Teresa otherwise as the story is conveyed in the \textit{Life}. Teresa tells us that after this incident she was never afflicted afterward, “because I'm determined to serve this Lord and my comforter with all my strength; even though He allowed me to suffer a little, He consoled me in such a way that I don't do anything in desiring trials. So now it seems to me there is no other reason for living than to suffer trials, and this is what I most willingly beg of God.”\textsuperscript{65} In this statement Teresa appears to be willing to endure whatever the Lord hands to her. This shows that Teresa’s perspective on her own embodiment is unclear and hard to pin down. Teresa stands firm in her belief to be obedient to whatever she senses God is sending her way. In terms of what this means for Teresa’s perspective on the crippled souls and the outer courts of the \textit{Interior Castle}, two aspects become clear through analysis: First, some knowledge of the Inquisition shows us that those deemed to be “crippled” in sixteenth-century Spain were indeed considered not only lowly but perhaps worthless, and that Teresa’s use of the metaphor may suggest that no one is beyond hope and that everyone has worth. Second, Teresa could be including herself within this group of people relegated to the outer courts, and this would suggest

\textsuperscript{64} Of course there is no advocating for self-destructive practices. However in the 16th century with whatever ailments Teresa was dealing with her nightly practice of using a feather to vomit may somehow have been necessary for maintaining some measure of health or at least that was the belief behind the practice. Teresa speaks of being “bleed” (see Letters vol. 1, Letters 8 and 57) as a remedy for illnesses in her letters; this was a practice that also was thought to be helpful, whereas now in modern times we know bloodletting is not medically helpful.

\textsuperscript{65} Teresa of Avila, \textit{The Book of Her Life}, L 40.20, 361.
there is an autobiographical component to the term “cripple souls,” because Teresa does
describe herself as a cripple in the Life. Teresa writes, “Since I saw myself as so crippled
and still so young and how helpless the doctors on earth were, I resolved to go for aid to
the doctors of heaven that they might cure me.” The use of the metaphor may convey
that Teresa believed that she did not have “real” faith prior to her being healed of her
paralysis. This would coincide with the spirit and the timing of her conversion story, to
which we turn next.

**Teresa’s Conversion**

Spirituality scholar Mary Frohlich believes that Teresa found herself in a moment
of transformation after “she had been for some time caught in an unhappy impasse of
spiritual mediocrity.” The impetus for this transformation was a statue that depicted
Jesus as bloody and beaten. In the book of her Life Teresa conveys her experience during
this moving time:

*It happened to me that one day entering the oratory I saw a statue they had
borrowed for a certain feast to be celebrated in the house. It represented
the much wounded Christ and was very devotional so that beholding it I
was utterly distressed in seeing Him that way, for it well represented what
He suffered for us. I felt so keenly aware of how poorly I thanked Him for
those wounds that, it seems to me, my heart broke. Beseeching him to
strengthen me once and for all that I might not offend Him, I threw myself
down before Him with the greatest outpouring of tears.*

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66 Ibid., L 6.5, 79.

67 Mary Frohlich, “‘Set Me as a Seal upon Your Heart’: Image and Imagelessness in Teresian

Slade points out what is unusual about this experience is that “Teresa emphasizes that she had repeatedly taken the same postures: she used to think of the Magdalene's conversion; she often knelt before Christ; she frequently commended herself to Mary Magdalene. On previous occasions she had not been able fully to identify with Mary Magdalene, however, because the ‘hardness of her heart’ prevented her from weeping along with the Magdalene.” 69 Yet the conversion took place on the day the statue was put into the oratory and Jesus’ bloody beaten body was made visible to Teresa in a powerful way. Slade cites Concha to make the point that “reading of the *Confessions* provided an authentic revelation but that the contemplation of the wounded Christ’ moved her to conversion.” 70 Embodied and emotional experiences have a tendency to resonate in a person’s body and mind after the fact, so it makes sense that Teresa’s previous embodied impairment of paralysis and extreme bodily suffering may have laid the groundwork for the statue to have its profound effect on her, for it can be argued that by remembering the previous wounds of her own body and its suffering, and what Christ did to heal her, and then seeing the embodied wounded Christ via the statue, set the stage for its profound effect. According to Rowan Williams, Teresa comes to feel radically accepted and desired by Christ. He writes, “Conversion, for her, has meant simply the discovery of being desired in her entirety, as she is; being ‘needed’ by Christ.” 71

69 Slade, *St. Teresa of Avila*, 37.

70 Ibid., 35.

71 Williams, *Teresa of Avila*, 70.
But there are wider ramifications of this event too. Spirituality scholar Beverly Lanzetta believes that Teresa’s conversion upon seeing the bloodied body of the wounded Christ represented in the statue allows Teresa to establish within herself a sense of worthiness before God. Thus, according to Lanzetta, Teresa’s discernment of her self-worth before God allows her to understand the God-given worth of women and this originates from her life of prayer, and her encounter with the humanity of Jesus. Lanzetta argues that Teresa’s sense of dignity is established through her encounter with Christ, and this not only allows her to discern the patriarchal structure of her culture but it also empowers her to act to transform the culture’s misguided ways. Teresa’s encounter with the wounds and suffering of Christ at the time of her conversion forces her to banish worldly self-centeredness which in turn initiates a sense of responsibility for those in need, and a transformative encounter with the humanity of Jesus, mystical prayer, and social action.

Prayer and the Humanity of Jesus

Teresa began to experience the graces of mystical prayer after her conversion encounter at the statue of Christ. Teresa’s mystical prayer and how she felt about the humanity of Jesus in prayer are important for our exploration of Teresa’s relationship with physical disability because her mystical prayer is inseparable from her work as a

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73 Ibid., 6.
social reformer. Thus, we will briefly explore Teresa’s perspective on the humanity of Christ and its relationship to disability.

Sometimes mysticism and mystical prayer are seen as private experiences but this is not the case, as Elizabeth Newman rightly notes:

Christian mysticism is not a psychology or phenomenology of inner mystical states (though psychological transformation may well occur) but the embodiment of a Divine pattern in a whole way of life. This embodiment is not first about humans behaving in a certain way, though it involves this. It is rather the reception of a divine pattern as displayed most fully in the Word of God… From this perspective, the mystic is one who participates in God’s mysteries and illumines providential patterns in particularly vivid ways.74

Thus Teresa’s move toward mystical prayer should not be seen as an escape from the world or embodiment but as a deeper entry into the social world and embodiment. In analyzing Teresa’s mystical prayer it is important to note that Teresa wrote under the threat of what Williams calls “Inquisitional anxiety.”75 The anxiety focused on the problems caused by the alumbrados. The alumbrados were a group who Newman points out, “focused on a purely inward spirituality” and “believed the humanity of Christ was a hindrance to prayer and worship.”76 The alumbrados called for the abandonment of the humanity of Christ and this caused problems because it implied one should abandon fundamental religious practices. As Williams explains, “Inquisitorial anxiety was normally concentrated upon anything suggesting that the soul could make itself passive to


75 Williams, Teresa of Avila, 57.

76 Newman, Attending to the Wounds on Christ’s Body, 30.
God in such a way that the divine activity worked on and in the soul without any kind of mediation (historical, institutional and doctrinal).”\textsuperscript{77} In the \textit{Life} in which Teresa first expresses her transition to mystical prayer, Teresa is caught in a struggle to legitimize and authenticate her religious experiences to prove that her visions were not from the devil.\textsuperscript{78} Thus, Williams argues that the text of the \textit{Life} is a balancing act between seeking to authenticate her experience and to express what God reveals.\textsuperscript{79} Teresa’s writing about prayer is risky business for at the time many books on prayer were banned and on what was known as the Valdés Index of 1559, a list of banned literature.\textsuperscript{80} Teresa’s book of her \textit{Life} would end up on the Index and impounded by authorities of the Inquisition.

Teresa describes her relationship to the humanity of Christ in her description of mental prayer in the \textit{Life} and the \textit{Way of Perfection}. In chapter 8 of the \textit{Life}, Teresa writes, “For mental prayer in my opinion is nothing else than an intimate sharing between friends; it means taking time frequently to be alone with Him who we know loves us.”\textsuperscript{81}


\textsuperscript{78} Weber, \textit{Teresa of Avila and the Rhetoric of Femininity}, 44–45.

\textsuperscript{79} Williams, \textit{Teresa of Avila}, 55–60.

\textsuperscript{80} Elena Carrera, \textit{Teresa of Avila’s Autobiography: Authority, Power and the Self in Mid-Sixteenth-Century Spain} (London: Legenda, 2005), 80. Elena Carrera explains that the Valdés Index, “Intended to ban from circulation books containing any ideas that might have appeared Protestant, the Valdés Index contained a number of the earliest devotional writings to have been published in the vernacular. It also renewed the prohibition of Bibles in the vernacular. It drew a clear line between asceticism and mysticism, which it represented as incompatible methods. In an attempt to suppress the increasingly popular affective spirituality and reinforce the medieval ascetic practices of virtue and desarraigo de vicios’, the Index censors singled out any book with mystical overtones.”

\textsuperscript{81} Teresa of Avila, \textit{The Book of Her Life}, L 8.5, 96.
Teresa instructs her nuns to have a constant awareness of Christ through the prayer of recollection.\textsuperscript{82} For Teresa recollection occurs when the, “soul collects its faculties together and enters within itself to be with its God.”\textsuperscript{83} Upon collecting the faculties the task of recollected prayer according to Teresa is to, “just remain there in His presence with the intellect quiet. And if we are able we should occupy ourselves in looking at Christ who is looking at us.”\textsuperscript{84} This is intimate prayer, Teresa explains, “Represent the Lord Himself as close to you and behold how lovingly and humbly He is teaching you. Believe me, you should remain with so good a friend as long as you can.”\textsuperscript{85} Teresa calls her nuns to look at Him according to their emotional state, “If you are joyful, look at Him as risen. Just imagining how He rose from the tomb will bring you joy.”\textsuperscript{86} The point here is that Teresa’s prayer of recollection is an intimate exchange between friends that advocates for an encounter with the humanity of Christ.

Carmelite scholars commonly use the terms active and passive recollection to describe what Teresa calls merely the prayer of recollection.\textsuperscript{87} This conceptual split


\textsuperscript{83} Ibid., WP 28.4, 141.

\textsuperscript{84} Teresa of Avila, \textit{The Book of Her Life}, L 13.22, 133.

\textsuperscript{85} Teresa of Avila, \textit{Way of Perfection}, WP 26.1, 133.

\textsuperscript{86} Ibid., WP 28.4, 141.

among scholars is used to differentiate types of prayer that are in Teresa’s writings, but it is a differentiation that she does not herself make. The prayer of passive recollection has to do with prayer that is given to the soul in its passivity, whereas in active recollection the soul is actively representing Christ through thoughtful imagination and entering into biblical scenes with Christ as dramatic actors. In order to understand how active recollection works in Teresa’s writings one needs to understand that thoughtful imagination is distinct from prayer in Ignatian spirituality where biblical scenes are pictured.  

Teresa’s active prayer involves a much more embodied encounter; she enters into the scene in the sense that Christ is actively represented to her, and she knows the presence of God. What is important to grasp here is that Teresa after her conversion experienced what she calls, “the prayer of quiet” otherwise known as “infused contemplation.”

At the time that Teresa was experiencing deeper forms of quiet prayer, there was a controversy over whether a person should abandon all images in prayerful contemplation to obtain deeper mystical union with Christ.

Teresa argues in chapter 22 of the *Life* that the humanity of Christ cannot be abandoned. In the *Life* chapter 22 Teresa responds to those of her day who advocate for abandoning all images in prayer in order to reach higher forms of contemplative prayer. Kavanaugh and Carol Lisi point out that the idea of abandoning all images stems from

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neoplatonic ideas operating within the Christian tradition.\(^90\) Teresa writes that those who argue for the abandonment of all images usually quote the passage of Scripture which deals with the Ascension of Christ, where Scripture says that it is better for Christ to leave the world to bring the Holy Spirit.\(^91\) Teresa understands those who believe that in the advanced forms of contemplation all corporeal images must be set aside, which means that they proposed setting aside the humanity and images of Jesus because for them that is an impediment to the highest forms of contemplation. Teresa accepts this to a point but says that she “cannot endure” withdrawing from the images of Jesus.\(^92\) Barbara Mujica explains that for Teresa, “God leads souls down many paths and He has led her down one that requires images.”\(^93\)

In Teresa’s opinion the last thing we should do is to withdraw from the greatest help and blessing that is the humanity of our Lord Jesus Christ. Teresa settles the matter in chapter 22 of the \textit{Life}, concluding that in the higher forms of contemplation there may be a need to turn away from corporeal things but that the particular humanity of Christ “must not be counted in the balance of other corporeal things.”\(^94\) When she revisits the


\(^{91}\) Teresa of Avila, \textit{The Book of Her Life}, L 22.1, 191.

\(^{92}\) Ibid.


\(^{94}\) Teresa of Avila, \textit{The Book of Her Life}, L 22, 195.
matter in the later stages of the *Interior Castle*, Teresa revises her position, saying that she would not abandon “corporal things” and her concern is that a state of absorption which does not lead to delighting in the sacred humanity of Christ can be destructive.  

Teresa explains:

> How much more is it necessary not to withdraw through one’s own efforts from all our good and help which is the most sacred humanity of our Lord Jesus Christ. I cannot believe that these souls do so, but they just don’t understand; and they will do harm to themselves and to others. At least I assure them that they will not enter these last two dwelling places. For if they lose the guide, who is the good Jesus, they will not hit upon the right road.  

Teresa tells the members of her religious communities that they should always have the sacred humanity of Jesus before them, lest the devil be given an opportunity to divert their attention. Teresa’s concern is imageless prayer and getting caught up in a process of absorption that points nowhere and is experienced merely for the sake of its own enjoyment. For Teresa this is dangerous because it potentially cuts prayer off from Christ and from the central goal of the religious life, which for Teresa is loving His Majesty and loving one’s neighbor. Prayer without the image of the humanity of Jesus for Teresa presents a serious danger, so Teresa warns her nuns against the practice.

> Teresa firmly holds onto the humanity of Christ in her mystical prayer and this will be important in fully comprehending her as a social reformer and in turn gaining new

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96 Ibid., IC VI, 7.6, 399–400.
insights on how Teresa’s mystical prayer and social reforms relate to disability. Teresa explains that the humanity of Jesus is central to a life of prayer:

Whoever lives in the presence of so good a friend and excellent a leader, who went ahead of us to be the first to suffer, can endure all things. The Lord helps us, strengthens us, and never fails; He is a true friend. And I see clearly, and I saw afterward, that God desires that if we are going to please Him and receive His great favors, we must do so through the most sacred humanity of Christ, in whom He takes His delight. Many, many times have I perceived this truth through experience. The Lord has told it to me. I have definitely seen that we must enter by this gate if we desire His sovereign Majesty to show us great secrets.97

Teresa clings to her embodied Lord and calls us to do the same. This embrace of the humanity of Jesus for Frohlich has to do with, “God’s seal, God’s image, being impressed into the core of our humanity.”98 Frohlich explains that, “Actively, we are to engrave the mysteries of Christ’s life upon our memory; passively, we must await the action of God who will ‘impress’ Christ’s form upon our being.99 Frohlich’s point is that it is through active and passive prayer that Teresa experienced the presence of Christ and experienced the image of God impressed upon her soul.100 Furthermore, Frohlich suggests that this means of attaining the same imprint of God’s image is available to us too. She writes, “What Teresa seems to be saying is that the contemplative learns to let thoughts and images—including those that one conjures up through natural means—

97 Teresa of Avila, The Book of Her Life, L 22.6, 193.
98 Frohlich, “‘Set Me as a Seal upon Your Heart’: Image and Imagelessness in Teresian Prayer,” 35.
99 Ibid., 36.
100 Ibid., 37.
function in the way that icons do. The thought or image is held gently like an open door, inviting the presence of the one it represents.”

This all becomes very important when one considers the embodied presence of Christ companioning us in prayer. As discussed above, Teresa throughout her life had many embodied impairments; she carried these impairments as she engaged in and encouraged others to seek and hold onto the humanity of Christ. Teresa’s advancement in prayer (and, by, that of all persons) occurs in the midst of our imperfect and impaired bodies and in the context of our external trials and tribulations. What Teresa teaches concerning the humanity of Jesus and prayer becomes very powerful in light of Teresa’s embodied impairment and our own, given what Frohlich argues transpires in prayer:

Teresa teaches that when we actively conjure up images of Jesus in our mental world, this is a good and even necessary activity in so far as it helps to keep our memory of the presence of God alive. Yet vastly more substantive in their transforming effect are the occasions when the living presence of God is bodied forth at the very centre of our being. In these encounters a person is sculpted into the icon of God that the human being was created to be.

Thus, according to Frohlich’s conception of Teresa’s teaching on prayer, Christ’s embodied imprint is impressed upon our souls and we thereby know ourselves as sacredly made in His image. Now the difficulty with Frohlich’s conception of the presence of God being “bodied forth” is that it is spoken of in the context of Teresa having visions of Christ. The context of this is very important because Teresa did not

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101 Ibid.

102 Ibid., 38.
believe that everyone was called to experience the higher forms of mystical prayer. McGinn explains, “Teresa does not discuss the numbers who might be called to attain the “fourth water” of the Life, or the “Prayer of Quiet” of the Way of Perfection, though she admits in chapter 17 of that work that not all are called to contemplation because it is a gift of God.” The “Prayer of Quiet” and the “fourth water” is known as infused contemplation and it is similar to that which is discussed in the later mansions of the Interior Castle. Frohlich places this engraving of Christ’s image at the level of prayer in the sixth mansion of Teresa’s Interior Castle, thus closing off access to it for the everyday person. It is important to note here that Teresa agrees with Augustine that the place to find God is through searching within. This Teresa makes clear in the Life when she writes:

I think this vision is advantageous to recollected persons, in teaching them to consider the Lord as very deep within their souls; such a thought is much more alluring and fruitful than thinking of Him as outside oneself, as I mentioned at other times. And some books on prayer tell about where one must seek God. Particularly, the glorious St. Augustine speaks about this for neither in the market place nor in pleasures nor anywhere else that he sought God did he find Him as he did when he sought Him within himself. Within oneself, very clearly, is the best place to look; and it's not necessary to go to heaven, nor any further than our own selves; for to do so is to tire the spirit and distract the soul, without gaining as much fruit.

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104 Dubay, Fire within, 87.

105 Teresa of Avila, The Book of Her Life, 40.6, 356–357.
Frohlich addresses this issue through explaining the relationship she sees between us and Teresa’s form of prayer. Frohlich tells us that, “Probably few of us have visions with the extraordinary depth, intensity and fruitfulness of hers! Yet I think her teaching about how God does the work of engraving God’s own image on our heart and mind and soul does apply to all of us.” Frohlich believes that our powerful spiritual memories can function in our lives in much the same way as Teresa’s visions; while our memories may not be visions of the same kind as Teresa’s, the memories are nonetheless, Frohlich suggests, “the action of God impressing the knowledge of God into us in a way that transforms us in Christ’s image.” In light of Frohlich’s claim it can be argued that even for those of us who will not experience infused contemplation, the “bodied forth” image of Christ is nonetheless impressed upon our hearts. Teresa did experience this imprinting in her life of prayer and this is partly what propelled her to initiate social and religious reforms.

**Teresa as a Social Reformer**

Spirituality scholar Janet Ruffing points out the failure to see mystics as social reformers. Her book rectifies some of this lack through providing insightful essays on how mysticism and social reform operates within the lives of various well-known Christian figures, such as Francis and Clare, Ignatius, Eckhart, and Teresa of Avila.

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106 Frohlich, “‘Set Me as a Seal upon Your Heart’: Image and Imagelessness in Teresian Prayer,” 43.

107 Ibid.

Even though it is not often noticed or acknowledged, social movements often have mystical roots. The saints show us that social action requires contemplative prayer to sustain the discernment, resistance, and the courage to enact the vision embedded within the social reforms the mystic is working to carry out. Scholars tend to neglect Teresa’s work as a social reformer while there is a tendency to merely see her as the author of religious classics. Stephanie Paulsell reminds us that writing like all religious practice is a form of attention, a way of loving the world.\textsuperscript{109} Ahlgren believes that Teresa’s “vocation as a writer is tightly bound to her vocation as a reformer.”\textsuperscript{110} So the act of writing is a form of social justice that Teresa actively engaged. As well as her writing Teresa is a social reformer in the more traditional sense. Teresa’s reforms to the Discalced (“barefoot”) Carmelite order and the founding of twelve monasteries for women, and four convents for friars tells us otherwise. Why look at Teresa as a social reformer in the context of this study? Teresa’s work as a social reformer is important in discovering her response to marginalization, thereby empowering us to discern what Teresa’s response to the marginalization of people with disabilities might be for the mutually critical conversation that we will undertake in the next chapter.

Slade points out that when Teresa is considered as a reformer it is usually in her capacity of religious reform and the Discalced Carmelites.\textsuperscript{111} Slade explains that the


\textsuperscript{110} Ahlgren, \textit{Teresa of Avila and the Politics of Sanctity}, 39.

\textsuperscript{111} Slade, “St. Teresa of Avila as a Social Reformer,” 91.
development of the religious communities only conveys part of the story, the other part of the tale is the “rippling of social consequences…that Teresa also intended and indeed effected social reforms—specifically, increasing autonomy for women and integrating conversos (Jews who had converted to Christianity) into Spanish society.”

Converted Jews were largely not accepted into religious communities at the time. Teresa’s conviction to welcome marginalized converted Jews may have stemmed from her family lineage and the fact that her grandfather, Juan Sanchez, was a converted Jew. Slade believes that in response to her own secret blood lines, Teresa allows converted Jews or those with mixed blood (conversos) into her communities. The important point here is that Teresa has a conviction about the role of the conversos in society and translates it into action that assists the marginalized converted Jews of her time. Thus, the relationship between Teresa and addressing the marginalization of her day appears to occur on multiple levels through the inclusion of conversos, and of marginalized women.

Teresa not only welcomed the conversos into her communities but she also received marginalized women. Slade explains that women during Teresa’s day were prisoners of the domestic. A little investigation into Slade’s statement reveals that her claim is no mere exaggeration. In the introduction to Teresa’s book the Way of Perfection, Kavanaugh and Rodriguez explain, “More than mere jest was involved in a saying of the time that a woman should be allowed to leave the house on only three

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112 Ibid.
113 Ibid.
114 Ibid.
occasions: once for her baptism, another in order to go to the house of the man she
marries, and a third for her burial."\textsuperscript{115} Furthermore, nothing illustrates the extent of the
antifeminism of the day more than the passage Kavanaugh and Rodriguez cite from
Francisco de Osuna:

Since you see your wife going about visiting many churches, practicing
many devotions, and pretending to be a saint, lock the door; and if that
isn't sufficient, break her leg if she is young, for she can go to heaven lame
from her own house without going around in search of these suspect forms
of holiness. It is enough for a woman to hear a sermon and then put it into
practice. If she desires more, let a book be read to her while she spins,
seated at her husband’s side.\textsuperscript{116}

Teresa’s reforms and the accomplishments of her life are astounding when this extreme
climate of antifeminism is considered. Most of the information concerning Teresa’s
reforms is tucked away in her lesser known writings of the \textit{Foundations}, and fragments
gleaned from her \textit{Letters}, which illuminate some of her personal and physical challenges
as she worked to establish the new convents and monasteries. Slade explains that
Teresa’s work as a feminist reformer is most specifically depicted in six narratives in the
\textit{Foundations} that detail deplorable situations women were in because of the pervasive
antifeminism functioning in Spain.\textsuperscript{117} These narratives depict the biographical sketches of
women that Teresa rescued from oppression, marginality and lives of misery. Weber

\textsuperscript{115} Kieran Kavanaugh, introduction to \textit{The Way of Perfection} in \textit{The Collected Works of St. Teresa

\textsuperscript{116} Ibid.

\textsuperscript{117} Slade, \textit{St. Teresa of Avila}, 121.
points out that some accounts Teresa uses in the *Foundations* seem novelistic.\textsuperscript{118} In spite of the novelistic nature of some of the narratives, the narratives still serve as important illustrations of what Teresa’s reforms offered to the women of her day because the narratives tell the story of how Teresa provides a place of refuge for women who are oppressed and marginalized. Some of the women Teresa rescued were often exploited for their value in marriage. Women would often want to escape but would have no way out, an example of this is Beatriz de Chavez, as a young girl who resisted such an arranged marriage, and she was severely abused by her parents and nearly killed.\textsuperscript{119}

According to Slade’s reading of the *Foundations* chapter 20, Teresa takes an eternal view of reality and applies this to the plight of women of her day.\textsuperscript{120} To completely comprehend Teresa as a social reformer we must understand this new vision of reality that Teresa wished to convey to the world. Slade suggests that, “Like Dante in his *Divine Comedy*, Teresa measures the human reality of the world she knows against the divine order she has perceived in mystical vision. Like Dante also, although with deeds rather than words, Teresa undertakes to reform that human reality.”\textsuperscript{121} Teresa first mentions this new eternal order in the *Foundations* when referencing the story of Teresa

\textsuperscript{118} Weber, *Teresa of Avila and the Rhetoric of Femininity*, 150.


\textsuperscript{120} Slade, “St. Teresa of Avila as a Social Reformer,” 98.

\textsuperscript{121} Slade, *St. Teresa of Avila*, 112–113.
de Layz, who was the fifth child of a family that already had four daughters. Teresa points out that there is a failure on the part of Teresa de Layz parents to recognize the true ways of God and in this way they are ignorant. Teresa writes, “As people whose faith is asleep, they do not reflect or recall that it is God who thus ordains, and so they do not leave everything in His hands.” Teresa’s point here is that there is an ignorance here of a gift given by God that is born out of cultural prejudice that is completely unfounded in the eyes of God. Teresa’s point is that in the day when the truth of these matters is disclosed an entirely different reality is likely to reveal itself, “How differently will we understand these ignorances on the day when the truth about all things shall be understood. And how many fathers and mothers will be seen going to hell because they had sons and also how many will be seen in heaven because of their daughters.” Teresa explains that the time will come when we will understand our ignorances when the truth of these matters is revealed.

Teresa sees the misguided ordering of the role of women and the antifeminism of her time as contrary to God’s truth. Her conviction is ahead of her time. In an age with such antifeminism it is somewhat understandable for a family to be distressed not to be given a son; however Teresa is pointing out here that if the “world” would be willing to believe that daughters were a gift perhaps things would be more in line with the eternal

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124 Ibid.

125 Ibid.
order. Teresa’s vision of the eternal order of women should not be seen as unrelated to Christ’s imprint upon her soul. On the basis of the arguments of Lanzetta and Frohlich, it is contended that because of the imprint of Christ upon her soul, Teresa knows herself differently as a woman, in relationship to the antifeminism of her culture and thereby she is able to see the truth of the eternal order. Furthermore, it is this self-knowledge that empowers Teresa to take continual steps to orchestrate her social reforms. Robert Rudder also links Teresa’s social action with her mystical prayer. He explains, “Santa Teresa’s worldly actions are often based directly on her mystical experiences: her will conforms to that of God; God adds His strength to her own so that His will can be put to work on the worldly, practical level.”

The context of Teresa’s writing about the eternal order is important for discovering Teresa’s possible perspective on disability. The story of Teresa de Layz is that of an unwanted child because she is a daughter, and this story models those with disabilities because they are sometimes unwanted because of their embodied impairment. Teresa writes of the story in the book of her *Foundations*:

> [O]n the third day after her birth they left their baby girl alone and forgot about her for the entire day, from morning until night, as though she mattered little to them…When at night, a woman came who was taking care of the baby and knew what was going on, she hastened to see if the child was dead…..Weeping, the woman took the baby into her arms and complaining of the cruelty said: “How is it, my daughter, are you not a Christian?” The baby girl lifted her head and answered, “Yes, I am,” and

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spoke no more until reaching that age at which all children begin to speak.....

Teresa tells us that, Teresa de Layz’s mother made a commitment to love and cherish her child after that day and kept the child to a high moral standard. The interesting point of contact between this story and the lives of people with disabilities is that after the birth of a disabled child there is often dismay and a crisis that follows over the loss of normalcy. Just as Teresa discerned a heavenly order in which woman would no longer be marginalized, Teresa’s insights may open up new understanding into God’s way of conceiving disability. The discovery of the blessing of a person with a disability usually comes after the initial shock and trial of the event that precipitated the disability.

Teresa reveals through her Letters that she did not automatically accept all the displaced and marginalized women who crossed her path. Instead she was always on the lookout for a particular type of woman of faith who would indeed further the cause of the religious order or provide some measure of reasonable expectation that person was indeed called to be formed and could develop the capacity to live a holy life. In a letter to Madre María de San José in Seville from Teresa in Toledo on September 7th 1576 makes this point.

Teresa writes of accepting a postulant that she initially refused for having a scar. Teresa explains, “I began dealing with the Nicolao matter so that they will give you at the appropriate time the 400 ducats. I had refused that postulant because they told me she had

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128 Ibid.
I don't know what kind of scar.”

Regardless of this Teresa goes on to explain, “Nonetheless, I have not been insistent, because in our present need one could consider if it may not be fitting to give her a try. Perhaps she will turn out to be good. Speak of the matter with our padre if you think you need to and find out about her faults, for I spoke to him only a little about this. I see that your income is poor.”

Social attitudes toward personal injury in the sixteenth century sheds light upon the risks Teresa might be taking by accepting the woman with the scar.

The fear of personal injury through spirits, the reality of a personal devil, of evil demons and the acts of witches, formed a complex of belief held by high and low, ignorant and educated. Injury could be caused by evil demons acting on their own, by malicious human beings without spirit aid, or by demons and humans controlling or co-operating with each other, i.e. by witchcraft. Every known and unknown disease could be thus diagnosed.

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130 Ibid., LE 120, 314.

131 Ibid., LE 120, 314.

132 Sona Rosa Burstein, “Demonology and Medicine in the Sixteenth and Seventeenth Centuries,” *Folklore* 67, no. 1 (1956): 20. Burstein’s work is not specific to Spain in the sixteenth century but he does explain that, “The attitude to medicine, in these centuries of scientific discovery and achievement, was yet in the main permeated by primitive concepts of disease and healing still surviving from ancient times. Ancient beliefs in the causation of disease by spirits and evil eye were still held by common and learned people; magical remedies for headache, plague and a host of other ills are recorded by many contemporary writers.” Ibid., 20. There are limited historical resources that depict the social perceptions of disability. For this reason it is unclear what the exact social perceptions of the woman with the scar might be, Burstein’s texts provides the closest approximation at this time into the historical and social context.
Perhaps the social stigma of personal injury is part of what Teresa considers when deciding whether or not to accept the woman with the scar. In this letter there seems to be interplay between the needs of the religious community and whether this woman was indeed a fit for the community. What is telling about this letter is Teresa’s initial rejection of the woman and then reconsideration based upon the entirety of the situation. It is hard to tell from this letter what is at work in the overriding of the initial rejection because of the scar. What clearly can be gleaned from this letter is that acceptance and or rejection probably fit within the context of a complex web of individual, communal and spiritually derived concerns.

This story seems to support the idea that Teresa would have been initially hesitant to welcome people with disabilities into her communities, but if a person with a disability displayed the sort of character that would have supported the cause of her communities she likely would have reconsidered as expressed in the above letter. The woman with a “scar” could have been a hesitation of Teresa because of suspicions of those who had disabilities or defects in terms of the Inquisition. Teresa may not have wanted to attract “that kind” of attention to her order. It is difficult to determine Teresa’s perspective on disability with limited data and resources to do so. It is important here to reiterate that we cannot be sure of Teresa’s perspective; all we have are “hints” and “guesses” to what the truth of the matter might be.

One fact that we can be certain about is that if Teresa believed that it was the will of the Lord to accept a postulant with a disability she probably would have done so. As Teresa discerns God’s will in humility she takes social action in the name of obedience to
God. Rudder explains, “Santa Teresa is humble to God; He gives her His will so that she may use it in the world for His service...The Saint may be willful with all those she comes in contact with because she is humble before God and because she believes that she is performing His will on earth.”

Teresa’s vision for her religious communities and social reforms were directly connected to her intimacy with Christ as established in mystical prayer, in which she sees the misguided patriarchal social order of her day and subsequently uses wisdom obtained in prayer to establish necessary social reforms.

Summary of Teresa of Avila

This synthesis of Teresa of Avila in terms of disability reveals that Teresa suffered from many bodily illnesses and thereby she experienced embodied impairment. Given Teresa’s embodied impairment and ongoing illnesses, her use of the metaphorical “cripple souls” for the outer courts of her classic work the *Interior Castle* may seem out of place. While the metaphor of the cripple souls could be read as a derogatory remark concerning people with disabilities of her day, an alternate reading is possible. It may be a message of hope, that everyone no matter how culturally marginalized or lost has the opportunity to obtain intimacy with Christ. Because of her numerous illnesses Teresa is subjected to many harsh treatments and thus it seems plausible to argue that because of this Teresa held within herself a sense of her own embodiment, in terms of what was lost in her paralysis and what was thereby gained when she could move around again. It is argued that this sense of embodiment may be one of the forces that allowed the visual

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representation of the statue depicting the wounds of Christ to have such a profound impact on Teresa during her conversion. Although part of her firm grasp on the humanity of Christ may be born of Teresa’s Inquisitional anxiety, Teresa’s sense of embodiment born of her illnesses and conversion experience may be part of the reason why she clings to the humanity of Christ as part of her practice of prayer. Frohlich argues that as she clings to the humanity of Christ in prayer, the imprint of Christ is impressed upon Teresa’s soul. Although this strong impression occurs during mystical and infused prayer that is not available to everyone, Frohlich argues that such knowledge of the imprinting of the image of Christ upon our souls is available through our memories of spiritual experiences. It is argued that mystical prayer and the knowledge of the image of Christ upon the soul allows Teresa to discern an eternal order that critiques the patriarchal structures of her day and provides the impetus for her work as a social reformer.

In this analysis of Teresa in terms of disability several points stand out. In the *Life* chapter 40 Teresa becomes disturbed by her bodily needs while she is deep in prayer. In the same passage, Teresa writes that she is told by her Lord that she should attend to her bodily needs. What here is important to note is that Teresa’s embodied impairment did not impede her from entering into intimacy with Christ; furthermore, this did not prevent Teresa from attaining the imprint of Christ upon her soul. Teresa is a social reformer. Teresa establishes religious communities, increases the autonomy of women in a culture of antifeminism, and welcomes *conversos* into her communities. Teresa mentions that there is an eternal order of the nature of women before God, she explains that when we see the world in terms of the eternal order society will in turn value women and
daughters. Teresa points out that society fails to see the gift of women because of cultural prejudice. Teresa’s eternal order may be helpful in discovering the value of people with disabilities. Teresa’s vision of the eternal order of women also relates to Christ’s imprint upon her soul, because it is through the higher forms of prayer that Teresa discerns the heavenly order. The question for the next chapter becomes: what does obtaining this imprint upon the soul mean for people with disabilities? And lastly, Teresa’s discernment about the heavenly order brings up the question: what does it mean to look at that heavenly order from the vantage point of disability? These aspects will be considered in the next chapter in conversation with the interview data obtained from the people with disabilities in this study.
CHAPTER 5

A CONVERSATION WITH JULIAN, TERESA, AND PEOPLE WITH DISABILITIES

Introduction to the Conversation

The final chapter undertakes the constructive work of bringing the voices of people with disabilities into conversation with the themes of embodiment and marginalization in the theologies of Julian and Teresa, as developed in the two previous chapters. The integration of disability into practical theology allows the authentic voices of people with disabilities to speak and this invites human finitude, embodied difference and disability to influence practical theological discourse. This dissertation presents a new hermeneutical lens of disability, which one can expect to bring to light new and fruitful insights in practical theology.

In this chapter several methodological concerns will be considered in the “methodological notes” section below, before initiating the mutually critical conversation involving narratives of people with disabilities and Julian of Norwich and Teresa of Avila. After addressing the methodological issues, in order to assist the reader in the flow of the conversation I provide a brief summary of the contemporary situation of disability as developed in chapters 1 and 2. The next two sections present mutually critical conversations between Julian, Teresa, and four case study narratives. First, the theology of Julian of Norwich is put into conversation with a case study narrative on embodiment. Second is a conversation between a case study narrative on marginalization and Julian’s
theology. Third is a conversation between the work of Teresa of Avila and a case study narrative on embodiment. Fourth is a conversation between Teresa and a case study on marginalization. The chapter concludes with proposals for transformation in light of the mutually critical conversation with Julian of Norwich and Teresa of Avila. Specifically, these proposals include: a re-conception of the definition of disability, conception of disability as a practice, formulation of God’s relationship to disability based on mystical texts, and a theological construction that illumines and responds to the everyday experience of disability.

**Methodological Notes**

In *A Fundamental Practical Theology*, Browning proposes four questions that drive strategic practical theological thinking. The questions are:

First, How do we understand this concrete situation in which we must act...Second, strategic practical theology asks, What should be our praxis in this concrete situation?...The third question is this: How do we critically defend the norms of our praxis in this concrete situation?...The fourth question is: What means, strategies, and rhetorics should we use in this concrete situation?

Browning contends that, “Questions animate thinking. Questions are formed by the problems of life that impede our action.”

However, the focus of this study on the everyday lives of people with disabilities brings up methodological concerns about the utility of Browning’s questions that need  

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clarification. Browning primarily seeks to understand how religious communities exercise practical reason: “How can communities of memory and tradition also be communities of practical reason and practical wisdom?”\(^2\) This dissertation describes the everyday lives of people with disabilities not in the specific context of congregational life but negotiating everyday life in the context of various social situations that, unlike religious communities, do not operate as communities of explicit moral religious discourse and social action. Disability shifts the discussion of practical theology from communities of moral discourse, namely congregations, to everyday life; this prompts the reformulation of the strategic movement in this chapter.

Moreover, the practical theological method I employ accounts for marginalization in a way that Browning’s strategic movement does not. Graham critiques Browning’s book *A Fundamental Practical Theology* for privileging a particular form of rational and ethical action at the expense of other more symbolic or affective manifestations of Christian deeds.\(^3\) Graham contends that Browning relies upon a particular form of rational thinking that would helpfully be subjected to feminist critiques,\(^4\) for it does not take into account the plurality of human agency and reason that may vary according to context and culture, especially among the poor, oppressed, and marginalized. A practical theology of disability must address precisely the marginalization of people with

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\(^2\) Ibid., 2; Graham believes that Browning puts his focus on congregations because they are communities of moral discourse. See Elaine L. Graham, *Transforming Practice: Pastoral Theology in an Age of Uncertainty* (London: Mowbray, 1996), 89.

\(^3\) Graham, *Transforming Practice*, 89–92.

\(^4\) Ibid., 91.
disabilities, their struggle to maintain dignity and to secure the same social goods as their able-bodied counterparts in the forms of economic, social, and cultural capital. To address marginalization, practical theology must retrieve and analyze the unheard voices of persons with disabilities. This requires too expanding the scope of practical theological inquiry beyond philosophic rationality to encompass, as Graham asserts, a wider range of reflection and experience. Specifically, I draw upon spirituality to illuminate issues of embodiment and marginalization in the lives of persons with disabilities. Thus I build here on Browning’s strategic movement but integrate into my approach a focus on everyday life; attention to unheard voices and diverse forms of reasoning, and an ear for the “hints and guesses” that David Tracy attends to in his call for an aesthetic-ethical correlation in practical theology.

The move toward the aesthetic-ethical correlation assists in the development of mystical–prophetic theologies and therefore allows us to place the development of a practical theology of disability into a liberatory framework. Tracy explains: “All theology—especially all practical theologies designed for liberation in all forms (personal, social, economic, political, ecclesial)—should be mystical-prophetic or, in terms of correlation partners, ethical-aesthetic….An aesthetic-ethical correlation should, in turn, aid the further development of mystical–prophetic practical theologies.”

This leads to the addition of wisdom and mystical traditions of spiritualities into practical theology.

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theological work and constant engagement with the classics of theological discourse, a move that Tracy suggests leads to emphasis on, “justice—especially for the downtrodden, marginal and oppressed throughout the world and within every society.” Tracy explains the principal task of practical theology as being to carry out the aesthetic–ethical correlation in an integrated way:

The principal tasks—complementary to the correlation of practical theology correlated with ethics, politics and the social sciences—are the correlation of practical theology to art and to explicitly spiritual traditions: both prophetic traditions (akin to ethics and politics) and wisdom and mystical traditions (akin to aesthetics and metaphysics). Indeed, for the ancients as well as for such modern metaphysicians such as Alfred North Whitehead, aesthetics and ethics (i.e., the beautiful and the good) are intrinsically related.

Tracy believes that the beautiful and the good are present in our history but that “these realities need continual retrieval by unrelenting conversation with all the great classics.” Retrieval of the classics uncovers a call to integrate mystical theology into practical theological discourse, and this can heal the unfortunate split between theology and spirituality. In orchestrating the healing of this split, Wolfteich advocates for mystical-prophetic practical theologies while emphasizing that practical theology that is also

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6 Tracy, “A Correlational Model of Practical Theology Revisited,” 73.
7 Ibid., 72.
8 Ibid.
mystical theology needs to work toward being liberatory and socially transformative. Critical here is the work toward integrating spirituality studies, mystical theology, and practical theology in order to invite new modes of understanding so that we can construct proposals for transformation that will meet the needs of marginalized people with disabilities.

This study does precisely that. It engages the classics through the writings of Julian and Teresa. The resulting conversation with practical theology proposes ways in which the theological work of Julian of Norwich and Teresa of Avila offers theological insight into the everyday experience of disability. Thus this chapter takes the interpreted theory and praxis of the contemporary situation of physical disability developed in chapters 1 and 2 and places them into critical conversation with the interpreted theory and praxis of the Christian life, as represented by the mystical theologies of Julian in chapter 3 and Teresa in chapter 4. In order to assist the reader in the move toward the critical conversation between the case study narratives and Julian and Teresa, this chapter first summarizes the contemporary situation of people with disabilities.

**The Contemporary Situation of People with Disabilities**

The social model of disability seeks to end the oppression of people with disabilities by defining disability as entirely a social construction, thereby making

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everyone the “same” and moving people with disabilities out of the margins. Yet even if all the social structures that lead to the oppression of people with disabilities were removed, there would be nothing that could alleviate the harsh difficulties of living with embodied impairment and disability, because disability is both socially constructed and a biological reality.

The social construction model’s critique of the medical model of disability does not work, because it denies embodied difference and it does not express the true reality of the everyday lives of people with disabilities. As the narratives of Maria and Desiree attest, people with disabilities rely on specialized and individualized medical care to sustain their lives. It will always be better to be healthy than ill, and it will always be better or more advantageous to live without a disability than to have one. When the harsh reality of embodied difference is exposed, disability studies scholars become concerned, not least because the idea of inferior or lesser bodies was once used to exterminate people with disabilities during the Holocaust, and on various other occasions. This fear is ameliorated through a proper understanding of the value of every human being, regardless of ability or disability. As Francis Young notes in chapter 2, those with both cognitive and physical disabilities—namely, the weakest among us—have an epistemological advantage: they can offer us a critique about what it means to live without the drive for competition or success. ¹¹ This offsets the concern that defining people with disabilities as somehow lacking in their bodies will lead to a resurgence of

the eugenics movement and the extermination of people with disabilities. Regardless of whether disability is defined as a social construction or a biologically embodied difference, the goal of each perspective is to preserve the dignity of every human being, regardless of physical or mental status.

Practice is central to the discipline of practical theology and disability is a practice, as we see the embodied habitus of people with disabilities as they go about their everyday lives. What counts as capital in the field of everyday life for people with disabilities is adherence to standards of normalcy as defined by the able-bodied-centric position that operates in society. The drive to normalcy shows itself in the tradition of the American history of disability in our social expectation that people with disabilities should be hidden or locked away because they are deemed to be worthless. For years, the alternative to being invisible in American culture for people with disabilities has been to resist the biological physical limits of their bodies and “fit in” to society by being as normal as possible. So resistance among people with disabilities takes at least two forms: resistance to cultural expectations of being “worthless,” and resistance to physical limitations by overcoming constraints and appearing or living as “normal” as possible and finding ways to fit into society. The concepts of sick-role (Talcott Parsons) and the drive to order social situations (Harold Garfinkel) reveal a potential push to normalcy in social situations when disability shows itself in everyday life. Thus, the embodied habitus of disability as it situates itself in the American tradition with the thrust to normalcy unconsciously forces people with disabilities and able-bodied people alike to deny the biological differences of our bodies. The biological difference of disability drives
unconscious visceral reactions to disability, and this is what creates much of the social stigma and the oppression that people with disabilities have to endure. The reactions of able-bodied people are driven by the need to distance oneself from the negative connotations of embodied difference that are born from the American tradition of disability still operative in today’s society.

**Julian’s Theology, Embodiment, and a Case Study**

Having reviewed some of the major themes in the contemporary situation gleaned from this research thus far, we move now to the discussion of Julian of Norwich and the case studies. After this brief review of the findings of chapter 3 on embodiment and Julian, we examine a case study related to embodiment.

Julian’s bodily illness, mystical experiences, and revelations provide important information for the conversation with people with disabilities. Julian’s bodily illness is a form of embodied impairment, but though it is not considered to be a disability because Julian was not marginalized because of her illness, her case nonetheless speaks to the situation of disability. Julian seeks to embody a bodily illness as an act of devotion and this allows her to receive mystical revelations. Thus, Julian’s embodied impairment and illness did not prohibit contact with God. Julian then reconstructs in writing what it means to know that God’s goodness is in our humblest of needs, by which she means where the messy, embarrassing, and grotesque becomes a bodily space for God’s embrace of divine immanence and transformative power. Julian enters into a relationship
of shared embodied vulnerability with Christ and then subsequently uses the experience to reconstruct in writing what it means to be joined with God in a mutual embrace in the midst of suffering.

The first conversation is on Julian’s theology and embodiment, which is brought into dialogue here with the case study of Desiree on the topic of God’s presence in our humblest of needs.

**Case Study of Embodiment**

Desiree lives her life fully aware of its frailty and finality. The potential for sudden death is always knocking at her door because of her congenital heart condition: “I have a sleep doctor who says that I have lived with death for a very long time and I don’t know what to do with that because I think that it takes away from the enjoyment of life. I don’t know what to do with lingering on waiting for it to happen.” It is this living with imminent death that gives Desiree a deep appreciation for every day of her life. She explains, “I kinda wake up and in a way I think about God and thank God that I did wake up every day. You know I wake up and I’m happy… that I have another day. That’s connected to my disability because some days you don’t know whether you are gonna wake up. So I’m really happy [to wake up].” To go about her daily schedule Desiree must plan carefully. Otherwise she can overexert herself and end up bedridden for days. Because her heart condition means she has almost constant arrhythmias, and because her cardiac output is extremely low, a flight of stairs leaves her out of breath and at times
makes her skin turn blue. Desiree describes the ebb and flow of her experience of managing her heart condition in her everyday life:

A good day is [when] I wake up without a headache and without feeling too much pain. I have pain from all of the surgeries. I have arrhythmias, so on a good day I wake up with energy and I can do things. Waking up is interesting because I would ask my mother or my sister how they wake up and go to work every day. How do you get up?

What Desiree is wondering about here is how “normal” people feel when they get up out of bed and get going in the morning; her heart condition means that she rarely feels energetic and that no two days are alike. Desiree continues to describe her everyday life:

How do you do that? All my life I have wondered how people get up and just go and do things because my heart won’t let me. When I was little I didn’t understand how kids could get up and go to school every day when I had to lie on the couch. Because a bad day is [a day when] I don’t get up; I stay in bed all day. That’s [been] a bad day since I was a little girl. A good day is [when] I jump up and I go and: boom! And what happens sometimes, because of so many bad days, I burn out the good day. I drive everybody crazy by pushing everyone around saying we’ve got to get everything done because tomorrow might be a bad day. And if I have two good days in a row it’s like a miracle. So I wonder, how do you get up?

Like how do you do that? How do you get up and put one foot in front of the other and get dressed and go to work every day? I want to know how people [do that]? Is there some magic that they can do that? What’s in them that they can do that? And my sister would say they have a normal heart. That’s why they can do that. What I want to know [is] what that’s like that you can do that.

Desiree describes her experience of getting up in the following way:

I don’t feel weak, my heart feels good, and boom! I can go. I get dressed, I get in the shower, I make my bed because I like my bed made. I can go to work or go out. I am ready to go for the day. You need to watch out, hold on because if that’s a good day, you gonna have to keep up. But I say to my friend that I thought I was normal today because I did too much. That’s what I think: normal people feel that boom! rush and go.
This daily negotiation between taking part in everyday activities or having to rest because
of her physical limitations has been an aspect of Desiree’s life since childhood.

And yet despite those limitations, as a child Desiree’s friends would take her out
to play at a schoolyard near her house. While out of the sight of her mother, Desiree
would participate in all kinds of prohibited activities for someone with her heart
condition. As a result of stealing a few moments of more normal childhood living, she
might then be confined to bed for a few days or even land in the hospital. Desiree
recounts:

As a kid I wasn’t supposed to play hard, so I didn’t. I had a bike a
neighbor gave my mother but it was a heavy bike and we lived on the
second floor, so the bike was too heavy [to carry downstairs] every time I
wanted to play. So I couldn’t ride the bike because it was too heavy, but in
my family’s mind [the heaviness was good] to keep me from doing too
much. But I had great friends so I didn’t know this but my mom knew it. I
had my two girl friends who lived next door. I use to get on the back of
my friend’s bike and we used to go into the schoolyard. And I would ride
bikes and I would be on the roller skates and I would be running up and
down and running up and down. And these friends knew I had a bad heart
and they would watch to see how blue I got. Because I would get very,
very blue and so the more blue I got they would tell me wait catch your
breath. And then they would take me home and throw me in the bed so
nobody would know that I was out there doing all of those things. And
usually in a couple of hours midnight, 1 o’clock in the morning I would
end up in the hospital because I [had] played too hard. So the frustration
is not just work [and managing my activities] it is a buildup of a lifetime
trying to play, getting blue, recovering. Now as an adult, that [limitation]
is [still] part of the frustration.

Desiree confessed to me in our interview that her mother probably knew about these
excursions but pretended not to know and allowed it to happen, thinking, “She needs to
experience life even with that heart of hers.”
Desiree’s persistent frustration at managing her activities is understandable given that she now works as an accomplished tenured professor. In order to negotiate all of her work activities for a given day, she talks to her heart and tells it to comply with her demands to keep going. Desiree identifies this task of negotiating her daily life with spirituality. She explains:

Well, I used to tell my friend how I would talk to my heart when I was little to let me go run. I would talk to my heart all the time because I need to run. I still talk to my heart because I need to get up and go to work. I was saying the other day because I had to go to work and I didn’t sleep and I was talking to God and I said, “Okay God what do you have me doing now, okay we have got to get walking….It is like talking to my heart getting it to pump, getting it to function. My favorite poem is I guess the [one about the] footsteps [in the sand]. That supposedly they help you and I don’t know if it is a man or a woman. Well I have said to my mother, “You know how they say that God never gives you more than you can handle,” they gave mom too much. They gave her “way” too much [to handle] and sometimes I think He [God] gave me too much…

With her appreciation of everyday in spite of her heart condition, Desiree speaks to her heart to resist her embodied impairment, and when she can do no more she turns to the footsteps prayer.\[12\] In the prayer, which is often referred to as a poem, a Christian believer asks Christ why only one set of footprints is visible in the sand when the Lord promised the believer never to leave. Christ explains that he carries the believer during the troubled times. Desiree knows that God is with her in faith as she converses with her heart. She has faith that there are spiritual forces at work helping her manage her heart condition and thus enabling her to complete the tasks given to her by the demands of life.

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\[12\] John Marzulli, “3-Way Battle over Whose ‘Footprints’ Are in Poem,” *NY Daily News*, May 18, 2008. There is an ongoing court battle concerning who is the true author of this popular poem/prayer. Thus, because of potential permission problems, the intent of the poem is included here and not the actual words.
Her cardiologists and other health professionals have often told her that they are quite willing to sign a form declaring her to be completely disabled, which would allow her to collect full Social Security benefits, but Desiree flatly refuses to give in to her disability until her body clearly “tells” her that it is time to quit. Desiree’s plan is always to live life to the full. She explains:

I think one of the things that having a disability gives you is that you value every minute, every second, every breath, every sunshine, and every raindrop. You understand what life is about. I hear cancer survivors who say I wouldn’t really understand life if I didn’t have cancer and I think to myself, oh God give me a break [if] it took cancer for you to “get it.” I have always had it. Was it my disability that made me value life? Yes, but I think that it is also my personality. It came with who I was because there are people who have disabilities like mine who are just nasty and they don’t value life, they just see the hardship of it. I see there is another side. This is why on those good days I want to go everywhere and eat everything. I want to smell everything. I want to kiss everybody. I want to do it all. So there is life, life is beautiful and you have to take it.

Desiree is devoted to God but her God is not so much found in the organized church as in love, family, and being open to the fullness and the wonder of life. Desiree explains:

Well I would like to go to church but I don’t know where there is a church where I could trust, because the churchgoing people are the most judgmental and sometimes twofaced. I am surprised at that, I don’t understand. I think that if you go to church and you read the Scripture and you read the Bible, you are supposed to be saintly so I don’t understand.

Desiree lives on the edge of life and death every day. When Desiree arises in the morning, she thanks God that she has been given another day. Desiree’s faith is very strong even though she has difficulty with organized religion and the church. Her faith gets her up and going to work and living a full life in appreciation of each day. Desiree
describes how finding God within her heart helps her to contend with her disability and make the most of her daily life.

On Embodiment: Analyzing the Case Study

Desiree’s narrative reveals a theme of what it means to find God in the midst of our embodied vulnerability. In exploring this theme in relationship to Julian’s theology, we recall McGinn’s observation that Julian had, “an ongoing pursuit of an understanding of faithintellectus fides that was also meant to foster the intelligientia amoris, or loving knowledge of God, that was the goal of the medieval mystics.” Prayer leads to an understanding of faith and a loving knowledge of God. Prayer for Julian is not disembodied but rather is intimately connected to embodied life. Julian takes her concept of embodied prayer a step further when she includes embodied vulnerability. It takes faith to grasp that God is amid even the humblest of our needs and that the love of God is in even the most basic bodily vulnerabilities, but this is what Julian argues for in her passage about the man and his purse. What does it mean to find God in our humblest of needs? What does a conversation between Julian’s theology and Desiree’s case study convey about experiencing God in the midst of embodied impairment and the humblest of needs?

Julian and Desiree live in two very different times in history and have very distinct worldviews. In the Middle Ages, Julian’s desire for a bodily illness as an act of devotion fit squarely within the cultural norms of her day. In an era of “plagues and

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plunder,” people were devoted to the Passion of Christ because Christ’s suffering validated and made comprehensible their own. As mentioned in chapter 3, according to Caroline Bynum many medieval mystics viewed illness as a way to grow closer to God and obtain salvation.¹⁴ In short, the devotional practices of her day and the desire for intimacy with God drive Julian to ask for a bodily illness.

Julian’s request for an illness seems utterly misguided from a twenty-first century vantage point. Conventionally understood, illness and embodied impairment in our twenty-first century culture are either to be alleviated through medical intervention or hidden away. Most people today would not welcome illness, let alone desire it as Julian did as a form of devotion. One reason for this might be that as a culture we are afraid of our own embodied impairment, human frailty, and vulnerability. This fear could be a by-product of the American tradition of disability which promotes and encourages the desire to hide from the vulnerability of embodied impairment and disability. As mentioned in chapter 2, when confronted with disability, people in social situations typically seek to restore the situation to a state of “normalcy.” The fear of human vulnerability is in the background of this drive to normalcy, pushing away from view any signs of human frailty. In Julian’s day the everyday struggles of bodily illness and sickness could not be hidden from view because of their omnipresence in the “plagues and plunder” of the Middle Ages. Julian’s writing as a result of her illness situates God’s immanence at the center of human vulnerability. She explains in this context that God is in our humblest of

needs (LT 6 of her *Showings*). Though Desiree lives in a different era and with different challenges, perhaps this idea and assurance can help us make sense of Desiree’s narrative too.

Desiree converses with her heart in order to negotiate the challenges of her everyday life with a severe heart condition. Desiree prays simply, talking to her heart and asking it to comply with her requests to keep going. She illustrates this in her narrative as she says to God, “Okay God what do you have me doing now?” Yes, Desiree talks to her heart and God, but she also listens to her heart. This conversation illustrates a sacred discernment in negotiating her daily experiences. I am referring to every time Desiree considers whether to go to the store or rest, or deliberates whether or not to attend a meeting or she says politely, “I am sorry I can’t.” In this everyday push-pull of discerning what to do and what not to do to create a meaningful life with a severe heart condition, Desiree through her embodied wisdom illustrates the practice of disability.

Desiree probably does not recognize what she is doing as sacred discernment, yet her sacred conversation between God and her heart gives Desiree the wisdom to conduct her everyday life to the fullest extent possible. Julian notes that, “The highest form of prayer is the goodness of God and it comes down to our humblest of needs.” Julian illustrates in her writing what putting God’s goodness at the center of embodied life means because we are: “clad in the cloth, flesh in the skin, body in the bone, heart in the

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trunk, and so we are soul and body, clad and clothed in the goodness of God.\textsuperscript{16} Julian’s words and theology here are put into conversation with Desiree’s embodied wisdom. We see the immanence of God in Desiree speaking to her heart, telling it to please allow her to keep going, and we see it in the flesh and cells of that broken and congenitally deformed heart responding to her simple prayers to be able to get up and go about another day.

Julian’s notion that the goodness of God is in our humblest of needs seems to coincide with Desiree’s daily struggle to contend with her physical limitations. Desiree’s narrative illustrates embodied spiritual wisdom in the “practice” of her everyday life. Desiree’s case study also shows that knowing God as immanent in our vulnerabilities may be helpful to others with physical disabilities because Desiree’s sacred practice of listening to her heart is a form of resistance.

Desiree’s disability is not obvious to people. She looks like a normal person. Desiree hides her disability from her co-workers whenever she can and until recently she refused to use her handicapped parking card at work for fear of what others might think and the consequences it might have on her employment. Desiree explains how this hiding of her disability goes even further:

One of the things that I was going to talk with my good friend about is that, I am writing a book and I don’t know whether I should start off my introduction with introducing myself as having a disability because of the fear of what other people would think. But is it fair that I would write about people with disabilities [and] not identify myself? Is it fair for me to use their narratives and not talk about my own?

\textsuperscript{16} Ibid.
The marginalization of people with disabilities implicitly tells people with disabilities that they cannot be honest about their own embodiment. Furthermore, society implicitly rather than explicitly expects people like Desiree to keep their disability out of sight. As mentioned above, Desiree’s doctors are quite prepared to sign the form that would give her Social Security benefits. However, to Desiree this is saying, “Wouldn’t someone with your heart condition be better off on Social Security, rather than trying to work every day?” Desiree’s refusal to accede to the cultural pressure to take to her living room couch in response to her heart condition is an act of resistance. But it is an act of resistance Desiree that puts all the burden on Desiree; she alone must manage her limitations in order to function in able-bodied society. Society does not give her any help.

I suggest that embracing Julian’s theology and conception of the Trinity would allow Desiree and others with disabilities to live openly and with dignity, to put an end to this business of hiding and minimizing embodied difference. As Desiree’s life shows, embodied wisdom and simple prayer calls us to enter into our vulnerabilities with God in order to resist the able-bodied culture and live life to the fullest extent possible. The discussion now turns to Mary’s narrative in order to explore more deeply a conversation between Julian’s Showings and narratives of people with disabilities on the issue of marginalization.
Julian’s Theology, Marginalization, and a Case Study

The bodily pains that Julian perceives herself to share with Christ she considers to be an act of devotion. Julian takes this devotion a step further by writing about her experience of the revelations to address the inferiority of women. According to Baker, McEntire, and McAvoy, Julian seeks to dismantle the notion of the inferiority of women of her day through her nuanced conception of God as Trinity that is bidirectional and relational. Julian’s conception of the Trinity allows her to reconceive what it means to be made in the image of God. According to Julian, Christ continues to suffer with us in our sensuality (the lower part of the Trinity) and we are on the cross with Him. Furthermore, according to Julian, Christ is “oned” together with us in our suffering, and we likewise are united with him in his Passion. In Julian’s vision of reality, humanity becomes more holy and integrated into our true selves when our sensuality is integrated into our substance through the love of God. Julian’s response to the human suffering and pain in our lives is to assert that sometimes God leaves us to ourselves: “God wishes us to know that he keeps us safe all the time, in sorrow and in joy; and sometimes a man is left to himself for the profit of his soul, although his sin is not always the cause.” In short, though God leaves us to ourselves to experience suffering and the hardship of life, God wants us to know that we are always safe, and we are asked to endure because it is God’s will. In addition, we are left to ourselves in order to understand that we are completely dependent upon God. The truth that Christ dwells in our pain can be a comfort for those who physically suffer and those with physical disabilities.

17 Ibid., LT 15, 204.
In chapter 3 I argued that Julian’s conception of the bidirectional and relational attributes of the Trinity is helpful to people with disabilities because it makes the ongoing suffering of Christ central to the embodied sensual part of the Trinity. This in turn provides people with a conception of a God who suffers with them in their embodied impairments and physical limitations. I also showed in chapter 3 that scholars argue that Julian uses her reconceptualization of the sensual aspect of the Trinity to offset the cultural idea of female inferiority. Thus this conversation between a case study of someone with a disability and Julian concerning the topic of marginalization allows us to consider how Julian’s vision of the Trinity might address the embodied inferiority implied in disability. In chapter 1 I argued that disability does imply a body that is inferior, for it will always be better to be able-bodied than to have a disability; it will always be better to walk on two sturdy legs than two disabled ones. This is the difficult problem that arises when disability is a biological reality as well as a social construction. This complex problem reveals itself through the predominant cultural value of normalcy. Interviewees in this study did not articulate outright abuse in describing their experiences of marginalization. Rather, the interviewees articulated their fight to be accepted as whole human beings in spite of their physical limitations. Furthermore, physical disability seemed to set off an internal struggle to bolster a sense of self when biological limits within their own bodies seem to betray even the most well-intentioned actions. In other words, people with disabilities have bodies that work against them as they try to live within a society that is not always accommodating or helpful to the cause of successful living and the attainment of social, economic, and cultural forms of capital. It is difficult
to find a remedy for the physical limitations that “work against” people with disabilities. Interviewees in this study themselves seemed to deny the difficulty of their experience in order to keep that harsh judgment at bay.

The second conversation involves the case study of Mary, which is placed into dialogue with Julian’s theology on marginalization. This section proceeds with the case study and a discussion of Julian’s Trinitarian conception of God in relationship to disability and marginalization.

Case Study of Marginalization

The interviewee of our second case study is Mary. Mary’s muscle spasticity is the result of her severe cerebral palsy. She uses two crutches to help her walk. She moves slowly but methodically through her living quarters. Mary has a positive attitude toward life and God; she is a lifelong Episcopalian who enjoys singing in a large local church choir. Mary is a very bright, articulate woman who has a degree in business administration from a local university in her state of Rhode Island. She worked for many years as a bank teller and in bank administration. Mary describes how she got her first job:

The first job interview I went on was for banking and there was a branch that was near my high school and I went in after school one day. We were on double-sessions which meant that I could go to school until 1:00 [p.m.] and then I could go to a job. I went in, didn’t have a resume or anything, and I went in and asked to talk with the manager at the bank. I told him that I was looking for a part-time job. He [the bank manager] said, “You are,” and I said, “Yes I am.” After lots and lots of talking, he said, “Let’s go out and look at the teller line out here.” He said, “This is a new branch, and this might be a really good place for you, because we just started combining the teller line, which is all stand up jobs, with two customer
service seats.” [These customer service seats] were shorter desks attached
to the teller line. I could do teller work [while sitting] at these new lower
desks. I could also do account opening. And he said, “How soon can you
start?” And I said, “Tomorrow.” And I started.

When he encountered Mary’s tenacity to work at his bank, the bank manager
hired her on the spot. She worked at the bank and went on to college to obtain her degree
in business administration. Mary worked for nearly 35 years at various customer service
jobs before hitting a severe setback with her health; shoulder surgery (mentioned in
chapter 2) caused a severe blood clot to form in Mary’s leg and this clot caused very
severe lymphedema. Because she can no longer independently don the compression socks
to manage her lymphedema, she cannot work. Despite her strong desire to continue
working, Mary’s body betrays her. Mary explained in her interview that she is in the
process of applying for Social Security disability benefits because of the lymphedema.

Mary’s narrative shows that sometimes people with disabilities are marginalized
and oppressed by their own bodies. Mary’s body is no longer able to comply with the
demands of having a full-time job and a physical disability. In Mary’s case it is clear that
embodied difference makes a difference; the added complication of lymphedema finally
makes it impossible for Mary to work in the way that is expected of her, whereas if she
did not have her disability, working might not be out of the question. Mary’s body seems
to oppress her; because of her lymphedema she can no longer work and obtain social and
economic forms of capital. Thus the origin of the marginalization is not strictly social in
nature; it is also the result of her physical limitations.
On Marginalization: Analyzing the Case Study

The predominant theme of Mary’s case study is marginalization that originates from embodied impairment and disability, meaning that it is Mary’s lymphedema that prevents her from working, and not necessarily an overt discriminatory action. Although Julian and Mary share the experience of bodily illness, only Mary’s illness results in marginalization. Mary’s situation leaves her in a vulnerable place in society as a person who is unable to work. What does a conversation between Julian’s bodily illness and subsequent theology and Mary’s narrative tell us about responding to marginalization that originates in physical limitations?

Mary does not mention any enhanced experience of God as a result of her lymphedema. Instead, as mentioned in chapter 1, Mary conveys a sense of frustration at her bodily condition. By contrast, Julian willingly enters into the fullness of her bodily illness, and subsequently writes not only an initial account about the experience but spends nearly twenty years of her life making sense of the illness and her subsequent revelations. Julian suffers through her bodily illness and conflates her body with that of the suffering Christ as an act of devotion. Julian shares in the suffering of Christ, and thereby each mutually experiences embodied impairment. Furthermore, Julian’s embodied impairment through her bodily illness—or anyone else’s for that matter—does not prohibit or obstruct her contact with God but actually nurtured it, as we see in her experience of the sixteen revelations. All of these factors seem to indicate that there is nothing wrong with experiencing embodied impairment and physical limitations. Julian’s bodily illness shows that sickness does not inhibit the action of God but that it may
actually enhance it. If what the mystics believe is true, then bodily illness can enable a unique experience of God.

What does it mean for Mary and others with disabilities that bodily illness does not prohibit an experience of God and may even enhance it? God’s presence in the midst of illness is a critical point to grasp because the church at times perpetuates misguided notions of disability as sin and a hindrance to the ability to experience God. Nancy Eiesland writing in 1994 about those with physical disabilities identifies the conflation of sin with disability as just such an obstacle to inclusion into Christian community.\(^\text{18}\) The idea that those who are not healed are somehow harboring sin may seem far-fetched in the twenty-first century but Reynolds recounts a similar story that occurred just a few years ago of a paralyzed woman in a wheelchair who was talked into attending a Christian healing service:

She was called up to the front of a church during the service. The healing "failed." Not only did she remain paralyzed, she was publicly transformed into an embarrassing spectacle, and made the subject of awkward gazes and whispered questions. This diminished her sense of being welcomed as someone unique and loved by God with the same status as anyone else in the church community.\(^\text{19}\)

Reynolds notes that the woman in this story continues to harbor anger and resentment toward the Christian church and God.\(^\text{20}\) Extensive data do not exist to determine the predominant beliefs concerning disability and the conflation of sin. Yet what this story


\(^{20}\) Ibid.
does illustrate is that the church has held many assumptions concerning how and when God is present and working. Whether or not God is perceived to be working is considered to reveal something about the person with a disability and their character (not God’s faithfulness or character) and thus determines whether the person’s disability is perceived to be divinely inspired, demonic, or somewhere in between.

For Mary and others with disabilities Julian’s text and other mystics’ encounters with illness makes an important point: that embodied impairment does not imply God’s withdrawal, or failure to act. This means that Mary and others with disabilities should not harbor any hostile feelings toward themselves for their struggles with embodied impairment and illness. It is true that this does not address the social consequences of Mary’s unemployment. However, this point concerning God’s presence in the midst of bodily illness does provide a response to help prevent self-loathing and hatred as a result of one’s embodied impairment and bodily illness.

The biological aspect of Mary’s bodily oppression prompts the question: Does Julian’s re-conception of the Trinity help address the biological basis for marginalization that originates from embodied impairment and disability? The central issue to tackle in this discussion is the inferiority inferred by the biological basis of disability. Thus the discussion turns to Julian’s conception of the Trinity. Julian’s re-conception of the Trinity critiques the predominant view in Christian discourse during the Middle Ages that women were inferior based on their embodied difference. As mentioned in chapter 3, the Christian tradition ascribed gender to the higher and lower parts of the Trinity. Yet in her approach to the Trinity, Julian shifts the gendered aspects of the Trinity, in so doing
arguing against the common Christian position of her time that the male (thought to be superior) belonged with the higher part of the Trinity and the female went with the lower part (thought to be inferior). McEntire and Baker argue that Julian removes gender from persons of the Trinity and by doing so negates female inferiority. However, Julian adds the female gender back into her Trinitarian perspective, when she writes, “We have our substance in the Father, God almighty; and the second person of the Trinity is our Mother [Jesus] in nature in our substantial creation. Jesus is our Mother of mercy in taking our sensuality.”21 As mentioned in chapter 3, McAvoy believes it is through this notion of the embodied vulnerability of Christ as Mother that Julian offers the strongest critique of female inferiority.

The bidirectional and relational approach to the Trinity challenges the notion of the inferiority of women based on their embodiment because Julian as a woman shares in the suffering of Christ and Julian ascribes the role of divine Mother to Christ. Julian’s devoted sharing with the suffering of Christ along with her critique of the sensual part of the Trinity as inferior is an embrace of embodied vulnerability and marginality by Christ as Mother. Christ as Mother provides important insight into how Julian’s theology interacts with the inferiority of embodied impairment. A similar move is helpful in dealing with the negative connotations of physical disability and embodied impairment. Julian shares in the suffering of Christ, and in so doing each mutually experiences embodied impairment. The ongoing suffering in the midst of embodied vulnerability of Christ critiques the idea of the inherent inferiority of the body.

21 Julian of Norwich, Julian of Norwich: Showings, LT 58, 294.
Julian’s reconfiguration of gender in the Trinity allows her to address the assumed inferiority of women in her day. Physical disability impacts both men and women, so this shifting of gendered aspects by Julian may initially appear to be a moot point. However, adding the idea of Christ as Mother to her conception of the Trinity seems to imply an ascription of disability to God, much like Eiesland’s much later conception of “The Disabled God.” Yet Christ’s affliction and suffering on the cross cannot be classified as a disability, but is more accurately portrayed as embodied impairment, because Christ did not experience marginalization because of physical limitation. Therefore, the notion that Christ’s suffering is similar to a disability to my mind is not accurate.

In Julian’s theology, Julian is acceptable to Christ in her bodily illness and receives embodied revelations. Furthermore, Julian’s participating in embodied pain with Christ suggests Julian’s worthiness to be joined with Christ in this way. As people share with Christ their bodily pains, in the sensual part of the Trinity they also have this same worthiness ascribed to them and their embodied experience. Thus, according to Julian’s theology, Christ shares with us in our pain and in doing so ascribes dignity to living out the course of embodied impairments. Society may persecute Mary and limit her ability to work because of her embodied difference, but according to Julian’s theology, Christ would not. Here even in the midst of the harsh biological reality of disability, human dignity is upheld by affirming that the Divine exists in embodied impairment.

What does this sharing of bodily pain between Julian and Christ mean for Mary and others with physical disabilities? Specifically, what does Christ’s ongoing suffering mean for Mary’s lymphedema and the marginalization it creates in her life? Julian’s
Trinitarian theology implies a sense of dignity in embodied impairment. The relational and bidirectional aspects of Julian’s conception of the Trinity ameliorate the inferiority implied in the biological aspects of disability. The bidirectional and relational nature of sharing in relationship to Julian’s and Christ’s suffering locates dignity in the experience of embodied impairment.

Mystical theology grounds human dignity through spiritual experience. The mystical theologies of Julian and Teresa provide powerful theological grounding for human dignity that seems to assist in the inclusion of persons with disabilities. According to my interpretation of Julian’s theology, Christ is the liberating force and the one who empowers human dignity to take shape in the midst of embodied difference and human suffering. Thus Julian’s theology alleviates the marginalization that results from bodily illness and physical limitations, and this should be a great comfort for people with disabilities. As mentioned in chapter 1, disability studies use the social construction model of disability to make everyone the “same” in an attempt to ameliorate the marginalization of people with disabilities. Yet actually this well-intentioned move disembodies the discourse of disability studies because it cannot contend with the real embodied differences of disability. The move to deny the harsh realities of disability is not necessary when taking a theological approach, because according to Julian’s theology Christ is in the midst of the harsh biological reality of disability. Christ restores dignity to embodied difference and physical limitation.

Now the discussion will turn the conversation to Teresa’s embodiment and marginalization in order to shed more light on how each of the theologians interacts with
the case studies. We will first consider Teresa and embodiment and then turn our attention to Teresa and marginalization.

**Teresa’s Theology, Embodiment, and a Case Study**

Teresa endured numerous types of bodily illnesses as a result of which she experienced embodied impairment—but not disability, because she was not persecuted for her illnesses. Teresa uses the words “crippled souls” to describe those who are sinful and estranged from God and who live in the outer courts of Teresa’s metaphorical interior castle. At first glance this sounds as if Teresa is taking a derogatory stance toward people with disabilities of her day. Yet I suggest instead that Teresa’s use of the term “crippled souls” may be intended as a message of hope, one that says that no matter how lost or culturally marginalized a person might be, everyone has the hope of obtaining intimacy with Christ by entering the “castle” through the door of prayer. The crippled souls could be a product of Teresa’s memory of her own paralysis. It also seems plausible that Teresa remembered her own paralysis and being unable to move when she viewed the statue of the bloodied and wounded Christ during her conversion. This memory of paralysis could be a factor in what allowed her to be so emotionally moved by the statue representing the wounds of Christ during her conversion. This embodied remembrance also could be a factor in why Teresa in her practice of prayer refuses to give up her strong attachment to the embodied humanity of Christ.

In a similar way to Julian, Teresa’s ongoing illnesses did not prevent her from entering into the highest forms of mystical prayer and intimately knowing Christ. Teresa
and Julian both stand as examples of people who endured physical limitations and yet God works in their lives. Even in the midst of her bodily illnesses Teresa experienced the imprinting of Christ through deep mystical prayer. Thus the question becomes: “What does obtaining this imprint of Christ mean in relationship to embodying a disability? Frohlich suggests: “This is what Teresa refers to as having the knowledge of God ‘impressed’ upon her soul. It is a living, dynamic encounter that reconstitutes one’s very being as Christic.”22 As Frohlich notes in regard to such imprinting:

Obviously the Unseen does not hold before [a] person’s sensible and/or spiritual eye a picture-like representation, a figure, that allows one to gain an idea of God …. [Rather,] God’s form affects the human being as a whole. The person’s consciousness in its entirety is touched, and touched in the strong sense of the word: God strictly impresses his form into the conscious stuff of the body-heart-mind complex …. In brief, without presenting any figure, God represents himself in the human person who, far from looking at God’s image, feels his form.23

The reconstitution of one’s being comes about through Christ’s nature being imprinted upon one’s entire person. Frohlich suggests in chapter 4 that this imprinting does not require the highest forms of mystical prayer; it can also occur through powerful spiritual memories.

Case Study of Embodiment

The third case study is Lisa’s story. Lisa conveys the sort of spiritual memories that Frohlich describes above. She explains that when she provides the normal run down

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of her medical history, medical professionals note that there are multiple uncommon and unheard of surgeries on the list and they inevitably inquire about these uncommon procedures. Lisa explains:

It would end up with me being in the hospital for something…you know... and then I would be so upset on the day I was admitted. Every single time I would have a fever and my mother would say, “She’s not really sick, this happens every time [she has to be admitted]. She’s just upset” and then I would be really mad that she would tell them that…because I would always want her to say, “Yeah, you’re right, she’s sick, I can’t leave her here”…you know…it never happened…. So and also when I think back on it now, there’s one surgery in particular I’ve had that I’ve discussed with more than one physical therapist and their reaction to me was “I think they were experimenting on you,” because I had a soft tissue myotomy, you know, a lengthening on my hip flexors and they said they’d never heard of that and nobody ever has that…. And they said they thought… and my mother was meek and not assertive and if they said I needed surgery then I did…you know, and that was how she was…and when I think back on it now… you know… I wish she had been more assertive but that just wasn’t her make-up at all…you know… back then but, you know, if they were experimenting on me, I really wish they hadn’t…. because what they did to me was unethical…you know, and they knew my mother was the type that would be like “oh, okay.” You know and [she would easily agree thinking], “Well, if you think she needs that, well okay.”

Lisa bears the scars of this barbaric medical experimentation every day. She explained to me in the interview that part of the experience of having all those surgeries never goes away. It took years for Lisa to realize that she was angry about the uncommon surgeries that she endured because of the “well-meaning” doctors and her acquiescent mother.

Lisa’s story also shows that much about how being born and growing up with a disability is handled depends upon family attitudes, social class, and the attitudes of medical and educational professionals, and these responses can set the trajectory of a person’s life.
Lisa’s traumatic experiences make her angry about her situation as a woman with a disability. Lisa recounts how her outlook shifted from being very angry at her situation to finding self-acceptance.

In my 20s, 30s, and 40s I felt that way every day [that] I was frustrated I was in my body. So I tell people all the time I can understand transsexuals, totally, like they were born in the wrong body. I’ve always felt that way, you know, there’s really an abled-body person in this body but I got stuck in this crummy body. So, I can understand why people if they can have a sex-change would do. Having said that, [the] thought of having come far enough in my life, if I could be cured tomorrow I wouldn’t do it. This is who I am, it’s made me who I am, my disability has made me who I am, and it has shaped my personality. And plus, if I were cured tomorrow I wouldn’t be able to walk. I would fall down. I wouldn’t know what to do with myself… right, but also there are days when you know I’m like [thinking] “I don’t walk like everybody else, I walk like me” and I kind of like that sometimes… you know that I’m unique in that respect and each person with CP walks different you know.

Lisa credits obtaining her master’s degree with part of this transition from being angry and frustrated at her body to finding self-acceptance. She says, “I guess this kind of transition that I’ve gone through is kind of that but also a big moment of triumph for me was getting a master’s degree, it made me feel like I had triumphed in some way.” So how did Lisa go from being angry and frustrated about living every day in the wrong body to not wanting to be cured?

Well, honestly I do have to credit the things I learned in AA. Hearing the little things people would say, particularly practicing gratitude every day. In the beginning, I distinctly remember a moment that I’ve been going to AA for 2 years and I wasn’t completely sober and all I did was complain about my life when I went there and you know… So one day and granted this is really embarrassing… I feel embarrassed about it but I was working at a pediatric nursing home and I was a social worker there and the kids there were a hundred times more disabled than I ever was. They couldn’t walk. They couldn’t talk. They couldn’t see, or hear, and some couldn’t see or hear a lot of them. They were profoundly retarded and they couldn’t
do a thing for themselves and I felt sorry for myself, still? And this one
day, I was brushing my teeth and this is what would happen. I would wake
up and within 5 seconds I’d go to move and think “oh, I’m still stuck in
the same body, God dammit.” You know, and I’d be mad, and this one
morning I woke up as usual and I was standing brushing my teeth and I
looked at myself in the mirror and I said, “Well, at least I’m standing on
my own two feet.” And that was my first moment of gratitude ever… and
I remember it so distinctly because I was like “you idiot” you know… you
need to focus more on what’s right and what’s good… you know… and so
that was my first grateful thought and so from there it just went forward.

In discovering gratitude for her own body and its ability to stand, Lisa expresses deep
appreciation for her own unique embodiment. Lisa’s self-acceptance reached the point
that she did not desire to cure her disability even if it were possible to do so. Lisa
describes the vision of God that she has now after growing up Catholic and then moving
to the Unitarian Universalist church:

Well, I had a hard time with the higher power thing in AA but I finally
came to the conclusion that my higher power was the life force that’s in
everything including trees, and animals, [and] rocks. I think that rocks
being solid have a life force in them. I don’t know what this [life force]
thing is. I can’t see it with my eyes but I know it’s there and that’s what
keeps people going. That’s what keeps the world going right. So that’s my
higher power and so I see it everywhere. I see spirituality. I read a book by
Thomas More when I was in my 30s, *The Spirituality of Every Day Life*
and that [life force] was totally something like that [and] that’s what the
book was about—seeing the spiritual in everything, and that there really
was the spiritual in everything, and everything could be sacred.

Lisa herself does not directly link her version of spirituality as a life force to her
discovery of gratitude, but in her account of another experience in her life she clearly
does make the connection. For years Lisa believed that the doctors should not have
resuscitated her after the anoxia, which likely caused her cerebral palsy. Then, upon
working with a therapist and getting the insight of spirituality as a life force, she had the following experience on her thirty-eighth birthday:

So it was my birthday and I was up really early and I was standing in my bay window and I saw the sun come up and I said [to myself], “Wow, this is the first time I’ve ever seen the sun come up on my birthday” and it was so peaceful and I felt really peaceful and I said to myself, “I’m glad I’m here, I’m glad I’m here.” Instead of saying, “Damn, I wish that doctor had never saved my life. I’m glad, I’m here. I was meant to be here.” And that was a huge event for me.

On Embodiment: Analyzing the Case Study

Teresa of Avila may offer some insights into Lisa’s struggle, given her numerous illnesses and the trauma she experienced when her father took her to the faith healer. As narrated in chapter 4, although Teresa endured the treatments willingly, the treatments nearly caused her death. Consider for a moment that if Teresa of Avila’s father had not stepped in to stop her bizarre and unhelpful medical treatments, Teresa could have died, and we would have been left without this incredible saint. The actions of Teresa’s father in this situation seems to slip past us in our reading of the Life, but in the conversation with Lisa, the value of having this unique hermeneutical lens that focuses upon disability becomes apparent. The hermeneutical lens of disability reminds us of how just a few actions taken in one direction over another can have a tremendous impact on the entire direction of a person’s life.

Teresa’s experiences of being rubbed with scorpion oil, of being repeatedly bled, and of being subjected to countless other “cures,” must have had an influence upon the
rest of her life and theology. Lisa’s ongoing memory of her numerous surgeries reinforces the idea that Teresa could not easily have forgotten the trauma she faced at the faith healer’s hands. Thus, Lisa story appears to strengthen the conviction that Teresa’s crippled souls could be a description of her own life and experience, as I have contended in the previous chapter. This further bolsters the idea that the metaphorical crippled souls mentioned at the beginning of Teresa’s *Interior Castle* may not be a derogatory statement concerning people with disabilities.

At first the conversation between Teresa and Lisa in terms of the imprinting on the soul seems untenable because the two conversation partners do not share common religious perspectives. For Lisa, Christ is now a mythical figure and not associated with the Divine. Lisa’s perspective of Christ as mythical precludes her from making a strong concrete connection between the imprint of Christ upon her soul as the true source of her gratitude and the transformation of her mindset toward her disability. Teresa, on the other hand, holds on to the humanity of Christ, and for her he is far from being simply a mythical figure. However, the connection between the two conversation partners emerges if we examine what is happening in the imprinting of the soul and Lisa’s narrative. When

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24 Sabine C. Koch, ed., *Body Memory, Metaphor and Movement*, Advances in Consciousness Research 84 (Philadelphia: John Benjamins Publishing, 2012), 2. The argument among the authors of this volume is that memory is embodied. Koch explains, “The editors conceptualize memory as embodied; that means, memory is not a set of information stored somewhere in the brain, but the totality of the embodied subject’s dispositions, which allow the person to react to present situations and requirements on the basis of past experience.” Based on the concept of body memory, an entire study of Teresa’s *Book of Her Life* could be constructed. For the purposes of this study, body memory is mentioned to bolster the point that harsh bodily treatments such as those Teresa endured could not be easily forgotten by her brain or in her body.
Teresa receives the imprinting on her soul, Christ indelibly transforms her life so that she goes about her activities transformed.

Lisa experiences a spiritual transformation which changes her perspective of herself and her disability, and she too goes about her life in a different way. The life force she knows as spirituality and the gratitude Lisa feels are deeply inscribed and internalized spiritual memories and are a source of Lisa’s worldview. The transformation in Lisa’s life from wishing that doctors had not resuscitated her and not wanting to change her cerebral palsy is remarkable. Lisa’s move toward self-acceptance begins when she sees others who are less fortunate than her and she becomes grateful for her unique embodiment. In Lisa’s life an initial spiritual awareness allows her gratitude to take root and bring her to a point of realizing she will not be who she is unless she lives in her own body with cerebral palsy. Lisa’s story of transformation seems to indicate that for some there is spirituality and inner transformation involved in accepting one’s embodied life with a disability. This inner transformation leads to belief in one’s own worth and personal dignity.

It is true that the form of mystical prayer that Teresa experienced is not available to everyone. Frohlich’s contention that this imprinting of Christ is available to us through spiritual experiences and memories seems accurate but Lisa’s narrative only points to the value of a spiritual experience and not an encounter that indicates a meeting with the mystical Christ to make an indelible mark upon her soul. Apart from the imprinting of Christ, the important point to glean from this discussion is that there may be a relationship between the experience of spiritual transformation and self-acceptance and
love of one’s body. Future research will be necessary to begin to determine the complex relationships between spirituality and self-acceptance; for now, Lisa’s narrative shows that it is possible for someone to love and accept a physical disability.

**Teresa’s Theology, Marginalization, and a Case Study**

Teresa is a social reformer not only because she implemented religious reforms among the Discalced Carmelites, but because she increased the autonomy of women and welcomed conversos into her communities, thus giving them a less marginalized role in Spanish society. Carol Slade suggests that Teresa believes in a “divine order she has perceived in mystical vision… [and that] Teresa undertakes to reform that human reality.”25 Teresa mentions that there is an eternal order to how society sees women, and thus when we get a glimpse of the “heavenly order” ourselves we in turn see the value of women and daughters. Teresa sees the hierarchy that depicts women as inferior to men and the antifeminism of her time as contrary to the truth of God that women and daughters are a gift given by God. Teresa’s vision of the heavenly order of women relates to intimacy with Christ and Christ’s imprint upon her soul, which allows Teresa to know herself differently as a woman as regards the antifeminism of her culture, and because of her different outlook she is able to grasp the reality of the eternal order. Perhaps Teresa’s conception of the eternal order may be helpful in discovering a heavenly order in relationship to disability.

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Case Study of Marginalization

John’s story forms our fourth case study. John has Guillain-Barré Syndrome or GBS, a rare and debilitating neurological condition that causes temporary or permanent paralysis. The exact cause of GBS is medically unknown; however, the flu vaccine is believed sometimes to cause the sudden sickness that ultimately leads to paralysis. John attributes his case of GBS to a reaction to the flu vaccine. John describes himself as a born-again Christian but he did confess to me that he is far less devout now because of his disability. He cannot understand how God could allow the GBS to attack his body and offer him so little hope of healing. John endures permanent paralysis ever since contracting GBS sixteen years ago. John’s paralysis leaves him unable to feel anything below his waist and so he uses a motorized wheelchair for mobility. John experiences ongoing medical issues having to do with his condition and multiple admissions to various rehabilitation hospitals to build his strength after relapsing into deeper and more severe paralysis because of his GBS. John told me of one admission as a result of which he nearly got warehoused in the rehabilitation hospital:

The first day rolls around and you are there in the bed watching TV. Then the second day rolls around and you are watching TV. Then the third day and you are watching TV. And not much is happening. And finally after the third day I was like, “I am here for rehab right?” And they say, “Oh, yeah,” and I say, “I have been here for three days and I am still lying in the bed watching TV. I am not building my strength. I am not allowed to get in my wheelchair to go out into the flower garden and move around and get some fresh air. You are just stuck in the bed. If [I knew] that was the case I would have just stayed home.”

As a result of being stuck in the bed, John started complaining vociferously to the rehabilitation hospital’s administration.
So I was like, “You want me to rehab and gain my strength but I don’t see you helping me get to that point. I am lying here and I am doing nothing. I am not stretching. I am just lying here watching TV.” I said to them, “If this is going to be the case, [the extent of my rehab]. I am going to leave.” The administration said, “You can’t do that in this state.” I said, “I can do that. I have a copy of my rights, right here,” and I said, “I want to be discharged,” and then things started to change for me. I called friends and relatives and told them what I needed….It went from, “maybe this is the place you need to be for the rest of your life to, maybe in a couple of weeks you can go home.” I have the strength, I have the power. I have the mind. I know what I can do. I know what I can do and I am trying to tell them what I can do. It kinda worked out for me but I feel bad for some people who can’t verbalize what they need but they still are capable of doing stuff but they are [still] stuck there, and there is no one to advocate for them.

The culture of the rehabilitation hospital meant its nurses saw John only as an invalid and planned to “warehouse” him for the rest of his life. If he had not seen himself differently than the “rehabilitation” professionals, then he would still be locked away now. What a waste! This truly is a manifestation of oppression against people with disabilities and the failure of those with able bodies to see the value and worth of a human being regardless of physical capabilities.

*On Marginalization: Analyzing the Case Study*

Teresa discerns an eternal or heavenly order in which the value of women is properly understood. Given John’s story, one may reframe this understanding to ask: What does it mean to look at that heavenly order from the vantage point of disability? Central to Teresa’s religious reforms is her conversion and mystical prayer life. If Lanzetta is correct, this led to an inner transformation that established Teresa’s belief in
her dignity as a woman. In the midst of mystical prayer, Teresa experiences the imprint of Christ upon her soul as she orchestrates her reforms. John needed to know something different about himself before he could advocate to set himself free. Obviously John’s story of nearly being thrown away conjures up the similarities with Teresa de Layz as the unwanted daughter. Neither John nor Teresa orchestrated their liberation on their own. There was a cast of characters that intervened and pushed their situation in a more positive and loving direction. It takes a community of people that have a different vision for the futures of persons with disabilities to change things. For Teresa de Layz it was the woman who intervened and did not let her starve to death, thereby initiating her mother’s discovery of her worth. In John’s case it was his own advocacy that moved his oppressive situation into a new direction. John’s relatives and friends also played a critical role. If John’s family had ignored him, his protest to escape the rehabilitation hospital would have failed and he would have been lost to us forever. In a similar way we can ask, what would have happened to Teresa’s reform without Jerome Gratian? Gratian needed to have a vision of Teresa and her reform in order to play his critical role in it. It took many people working together to bring about Teresa’s vision. However, it is her conversion, the imprint of Christ upon her soul, and mystical prayer that together gave Teresa the self-knowledge about how to carry out the reform.

In terms of disability and the heavenly order, it is not just the individual with the disability that needs to know the reality of God operating and providing a revision of the

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cultural ideas of disability. It takes countless other able-bodied “believers” to support the person with a disability. Able-bodied supporters see the worth and potential in people with disabilities and do not succumb to the existential absurdity of the able-bodied culture. The resistance and knowledge of self-worth, though it may exist originally in a person with a disability, also needs other able-bodied “supporters.” The able-bodied supporters and people with disabilities together must grasp a glimpse of the “heavenly order” of disability in order to carry out social reform. For example, the health professionals initially only see John as able to live in the hospital because of his GBS, and do not view him as worthy or capable of living on his own and enjoying the best quality of life. It is up to other supporters to “see” other possibilities for John. The social reform in this case is not establishing new religious communities, as with Teresa of Avila, but rather promoting and advocating for opportunities for all people to reach their God-given potential by facilitating their attainment of Bourdieu’s forms of capital. In a sense, people with disabilities need to see themselves “differently” than those who in the culture adhere to the dominant able-bodied position. Teresa’s work points to the Christocentric imprinting as the impetus for change in persons with a disability who come to see themselves “differently” and in so doing obtain the power to resist the able-bodied position that labels them as “less-than” and in sometimes literally “worthless.”

The resistance to negative stereotypes of what it means to have a disability was common among my interviewees. It seems as if this resistance to the cultural ideas of who you are as a person with a disability means taking in or knowing a new vision of oneself that contradicts the false cultural perception of capability, personal value, and
worth. This discussion points out the relationship between self-perception and social action. In this way the stories of the interviewees echo Teresa. Although it is not possible to strongly establish the religious component operating in the revision of self-perception that is operative in the resistance, it is clear that there is a spiritual component that nurtures a sense of dignity which then enables a person to resist negative perceptions of disability.

**Proposals for Transformation**

The vocation of a theologian is to participate in “truth-telling.”

This dissertation is about “truth-telling” in terms of the everyday lives of people with disabilities. In this section I will make several proposals for transformation, which include: the re-conception of the definition of disability to include embodiment, conception of disability as a practice, re-examination of the American tradition of disability, formulation of God’s relationship to disability based on mystical texts, and a theological construction that illumines and responds to the everyday experience of disability.

This study seeks to tell the truth about inadequate conceptions of disability used to describe the experience of disability in the discipline of disability studies. Disability studies views the medical model as oppressive because it labels disability as a defect or imperfection in need of a cure. Some in disability studies call for the removal of the concept of “normality” in order to ameliorate the oppression of those with disabilities, but

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this is untenable because people with disabilities rely on conceptions of the normal in the form of scientific advancements that literally help to keep them alive and living independent lives. Furthermore, the critique of the medical model and the idea that disability is only a social construction does not accurately depict the lives of people with disabilities. The narratives of Maria and Desiree show that people with disabilities need individualized medical care to sustain their lives.

A central argument of this dissertation is that disability is not only a social construction but a biological reality. An examination of the biological reality of disability reveals that people with disabilities face specific challenges in daily life that others without disabilities do not. Examples are Mary’s inability to don her socks as a result of her lymphedema and Desiree’s heart condition that dictates her daily activities. In defining disability as only a social construction, disability studies fails to depict the true reality of the everyday lives of people with disabilities and in doing so does a disservice to the very people it wishes to serve. Part of the oppression that people with disabilities experience derives from their very own bodies’ inability to function normally, just like their able-bodied counterparts.

Scholars in the disability studies discipline fear that when the harsh biological reality of disability comes to light, those labeled inferior because of their disabilities will be in danger of experiencing the same atrocities of the eugenics movement and the Holocaust. Bonhoeffer speaks to the concern of the resurgence of mass killing in his book *Ethics* when he writes: “[L]ife, created and preserved by God, possesses an inherent right which is wholly independent of its social utility. The right to live is a matter of the
essence and not of any values. In the sight of God there is no life that is not worth living; for life itself is valued by God.”

This dissertation argues that disability studies scholars must turn attention to issues of embodiment and embodied vulnerability. This asks scholars to question the operative assumptions about embodiment in the disability studies discourse and begin to question what leads to the neglect of this critical work. Ultimately, if disability studies integrates embodiment and everyday life into its discourse ultimately it will develop more meaningful proposals for those it wishes to serve, because the discipline’s grasp on the actual challenges of the lives of those with disabilities will be more commensurate with reality.

Building a practical theology of disability is a first step to ending the neglect of embodied difference and disability in academic discourse. Practical theology brings to light the harsh everyday reality of disability through the integration of the social sciences, developing the concept of disability as a practice, and establishing that disability has an operative effective history. The contextual work of practical theology makes the discovery and analysis of the harsh reality of disability almost unavoidable. Looking at disability through the lens of practical theology brings to life the problems and issues of everyday life as experienced in the lives of people with disabilities, and this allows for a targeted and thoughtful theological response. With its call to the descriptive movement and the integration of the social sciences, practical theology opens up the conversation about people with disabilities to include actual narrative interviews rather than theoretical

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concepts of a “dummy” subject, who serves as a stand-in for the perspective of the researcher. Furthermore, practical theology opens up a lens on disability as a practice. Disability conceived as a practice in terms of Bourdieu’s work with habitus and the influence of social, cultural, and economic forms of capital shows that the cultural capital of education does not translate into social and economic capital in the lives of people with disabilities. A primary reason for this is that people with disabilities endure oppression from their physical limitations. In this dissertation I argue that there is an American tradition of disability that seeks to keep disability—and thereby human frailty and vulnerability—out of sight and locked away, and that it is time to “out” such destructive traditions. The contextual work of practical theology calls for a critique of the American tradition of disability.

The proposal for transformation here is not only to “out” the destructive traditions through describing the content and context of such traditions but also to initiate a response. First, this study calls for more research involving the everyday lives of people with disabilities from all kinds of ethnic backgrounds and forms of embodied diversity. The role of future theological research seems to be critical to coming to new knowledge of what it will take to emancipate people with disabilities from their marginal lives. This means undertaking more constructive work involving the mystics, practical theology, and people with disabilities in order to move the conversation forward. The broader call to all theologians is to end the neglect of embodiment in theological projects. This means taking thoughtful interest in embodiment when constructing theological projects, and it means asking, “What are the assumptions concerning embodiment and physical ability
that underlie the theological work?” To respond to the negative aspects of the American
tradition of disability that seeks to hide from disability and embodied difference,
theologians need to enter into their own embodied vulnerability. This better equips them
to understand and respond to the embodied vulnerability of the other. As this dissertation
shows, looking at theological texts through the hermeneutical lens of embodiment and
disability yields fruitful new insights. Even if such reflections on embodiment do not
become central to all our theological constructions, such reflections will nonetheless
strengthen and broaden theological work.

Disability is scary. Human vulnerability is threatening. Schillebeeckx is correct
that as humans we do not want to face what we cannot ameliorate by our human efforts.
It is true that disability does in fact position a person on the borders of finitude, a place
that is not ordinarily available to those who do not have to deal with physical limitations
on a daily basis. People with disabilities do indeed have the unique task of unveiling
interpretations that originate from the meaning of finitude and limitations. The people
with disabilities in this study ameliorate some of the neglect of embodied difference and
disability from academic discourse through offering their voices for this work.

This study provides an opportunity to pay attention to embodied difference and
embodied vulnerability by listening to the unheard voices of people with disabilities to
make their voices heard in the academy. Collectively, what do those voices say? By their
narratives, the interviewees offer us insight into their lives with disabilities and reveal the
true challenges of the existential absurdity they endure. Tom’s narrative shows that the
able-bodied culture does not support and nurture opportunities to work and translate the
cultural capital of education into economic capital. Mary’s case study reveals that at any
time embodied impairment can disturb a lifelong battle to negotiate life successfully in
able-bodied society. The story of John nearly becoming warehoused in a rehabilitation
hospital stands as an example of overt marginalization. Medical professionals push
people like Desiree to collect Social Security and stay home on the couch rather than
continue to work. How much easier it is to lock away our human vulnerability, out of
view. This mentality appears at times to still be operative, at least unconsciously in the
minds of some able-bodied people, or else John would not have had to protest repeatedly
to get himself out of the rehabilitation hospital. Culturally we only want to deal with
disability when it is convenient and it will not cost us too much trouble or anxiety
through confronting human vulnerability and frailty.

This study shows that for people with disabilities, resistance takes at least two
general forms. One form of resistance involves resisting one’s own limitations in order to
be as “normal” as possible in order to “fit in” to society. People with disabilities must
manage, hide, or minimize their embodied limitations in order to succeed, function and
obtain forms of capital in able-bodied society. The second form of resistance among
people with disabilities involves resisting the pressure to live as society conceives that
people with disabilities ought to live, for example, homebound, in rehab hospitals, and on
Social Security. Theological constructs of embodied spirituality seek to respond to the
difficulties people with disabilities face as they orchestrate resistance in their everyday
lives.
The theological constructs of embodied spirituality derive from the mutually critical conversation of practical theology and the discipline of spirituality studies. The mutually critical conversation brings to light potential responses to the everyday challenges of disability, and offers a starting point for building theological constructs of embodied spirituality. The embodied lives and spiritualities of both Teresa and Julian show that embodied impairment does not hinder God’s love and may even permit a unique experience of God. The presence of God in the midst of bodily illness is important for people with disabilities because it provides an answer to centuries’ old misperceptions that disability is synonymous with sin. The assurance of God’s presence prevents self-loathing and hatred as a result of one’s embodied impairment and bodily illness. The call here is for people with disabilities to practice the presence of God and engage in personal reflection in the midst of bodily illnesses and the challenges of disability.

Practical theological analysis of the everyday lives of people with disabilities yields numerous insights when integrated into a mutually critical conversation with mystical texts. The insights from the conversation disclose some measure of truth. David Tracy reminds us that, “there is never an authentic discloser of truth which is not also transformative.”29 The insights gleaned from Julian and Teresa in conversation with the everyday lives of people with disabilities suggest ways to ameliorate the daily challenges of living with a disability and our confrontation with existential absurdity.

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Julian’s theology situates God’s immanence at the center of human vulnerability. Desiree talks with her heart in order to discern sacred wisdom to negotiate the challenges of her everyday life. Desiree resists her physical limitations in order to experience a full life, while she must also listen to what her heart tells her and hold back. This is Desiree’s embodied wisdom. Julian finds God in our humblest of needs, so it follows that God is squarely in the midst of Desiree’s heart condition and embodied wisdom. More study will be necessary to show how this type of embodied wisdom develops and grows. The beautiful and remarkable help Julian offers here is that her theology places God in the midst of the most humble of our embarrassing and difficult needs. Julian’s theology tells us that, as humans, we need not be afraid of our human frailty or the vulnerability of others because God is immanent in what we do not want to face. This truth tells people with disabilities not to be afraid of the vulnerability disability gives to them. God immanently in the humblest of our human needs seems to say to people with disabilities: “You are not alone in your everyday struggle in living with a disability. I am with you in the harshness of your struggles with physical limitation.” Thus, the interviewees can find comfort that God is in all the falls, arrhythmias, the trials of lymphedema, the frustration in trying to do something physical and failing. Julian’s theology offers a simple word to everyone: God is in the midst of all our bad days. Knowing God is in the midst of trials provides a way to transform the suffering and challenges of everyday life with a disability.

Julian’s theology provides even more comfort to people with disabilities when she explains that Christ suffers with us in our pains. Julian’s reconstruction of the Trinity also
helps people with disabilities because this image helps alleviate the inferiority implied by the biological basis of disability. The physical limitations of disability work against people with disabilities as they try to live within a society that is not always accommodating or helpful to their successful living. Christ provides the remedy for the physical limitations that oppress people with disabilities.

Julian’s conception of the Trinity furthermore challenges the notion of the inferiority of women based on their embodiment. Her embodied sharing in the suffering of Christ is an embrace of embodied vulnerability. In suffering with Christ, Julian and Christ each mutually experiences embodied impairment. The ongoing suffering of Christ as an entrance into embodied vulnerability offers a critique to the inferiority of the impaired body. Christ does not turn Julian away because of her bodily illness. Instead, Julian shares embodied pain with Christ. This sharing implies worthiness and not inferiority because of her bodily illness. If Christ dwells with people with disabilities in their humblest of needs, this too implies embodied worthiness. Furthermore, if Christ suffers with all of humanity, even today, then it follows that Christ shares in the suffering of people with disabilities. As people with disabilities join with Christ in their bodily pains, they also have this same personal worth attributed to them and their embodied experience. The denial of the biological basis of disability is then not necessary because Christ upholds human dignity to those enduring embodied impairment and disability. The end of the denial and the establishment of dignity is transformative.

The conversation between Teresa of Avila and Lisa shows that the two do not share common religious perspectives. The mystical prayer of Teresa is not available to
everyone; however, Frohlich’s argument that similar transformation is available through spiritual memories seems plausible in light of Lisa’s narrative. Even though Lisa and Teresa have different perspectives of God, the two conversation partners share in the experience of spiritual transformation that influences how each person lives out her life. Lisa’s narrative reveals that a spiritual transformation is possible for someone with a disability. This spiritual transformation may be not only possible but necessary to find a self-acceptance and love of one’s body. As Lisa’s life shows, self-acceptance is transformative.

Unique forms of spirituality operate in the narratives of Lisa and Desiree to provide a source of comfort and support of daily life with a disability. Many more aspects of this phenomenon will need exploration in future research. In the case of these two narratives, spiritual experiences help Desiree and Lisa manage the harsh everyday reality of living with a disability. By talking with her heart, Desiree pushes her way through her daily activities, and she also draws strength from the idea of being carried by Jesus during the most difficult times, through the footsteps prayer. Lisa knows God in nature as a life force. Lisa concludes that she would not change a thing about her body, whereas Desiree desires the healing of her heart condition. Each appreciates her life and her body in a different way. Lisa appreciates her body as it is, while Desiree is grateful that she has life and that her body does in fact respond to her demands. Both Desiree and Lisa show healthy responses toward their embodied difference because they view their disabilities
as only one aspect of themselves. Not allowing themselves to make their disability their entire identity allows Desiree and Lisa to live with a decent quality of life while striving to reach their God-given potential. The two interviewees reveal the wonder of embodied wisdom that derives from the practice of disability born of unique spiritualities. Desiree and Lisa’s narratives attest that spiritual transformation and self-acceptance empowers the resistance to the existential absurdity of the able-bodied centric position that seeks to label people with disabilities as less than.

The internalized self-understanding born of spiritual transformation provides the impetus to live differently in the world. This is akin to Teresa’s life and conception of the heavenly order. Teresa’s social reforms derive from inner transformation and mystical prayer. John needed to know himself differently in order to orchestrate social reform related to his own life. Yet John did not carry out his reform on his own; various able-bodied people advocated for him. The same is the case in other interviewees discussed in this study; parents and loved ones carried out acts of kindness and love to help nurture the fullness of their lives. Desiree’s mother allowed her to play with her friends even though she knew it could be dangerous and even fatal. Lisa’s therapist helped her nurture her remarkable self-acceptance. Such able-bodied supporters see something different in their loved ones that oppressive able-bodied society does not recognize. Teresa believes that the people of her day will one day get a glimpse of the heavenly order and in so doing recognize the value of women and girls.

In short, in working toward the development of a practical theology of disability, the need is for able-bodied and disabled people alike to develop ways to nurture the belief in the true capabilities of people with disabilities, while also nurturing the inner transformation necessary to find self-acceptance and love in the midst of embodied impairment and disability.

In implementing Tracy’s aesthetic-ethical correlation through the integration of spirituality studies with the writings of Teresa of Avila and Julian of Norwich, this study shows that the two-way conversation between disability and the mystics offers a new hermeneutical lens through which to read mystical theology. The hermeneutical lens reveals the importance of embodiment in the lives of Teresa and Julian. In Julian, the importance of embodiment shows itself in the key insight that she enters into embodied vulnerability with Christ, receives her revelations, and reconceives of the Trinity to be welcoming to women. Furthermore, Julian’s conception of Christ as our Mother reveals Christ’s willingness to enter into embodied vulnerability. Julian enters into this embodied vulnerability with Christ as an act of devotion. This provides the basis to establish the dignity of people with disabilities. Sharing in embodied vulnerability with Christ allows Julian to understand the suffering of her day. From this I conclude that people with disabilities together with their able-bodied counterparts are also called to enter into their embodied vulnerability with Christ to experience embodied wisdom and self-understanding. Through embracing one’s own embodied vulnerability it will be easier to embrace and love the embodied impairment of the other.
The embrace of one’s embodied vulnerability opens up the way to see disability through the lens of Teresa’s heavenly order. In relationship to the heavenly order, this new hermeneutical lens offers an additional insight into the importance of those offering support to people with disabilities. The acts of Teresa’s father and a host of other characters supported Teresa in her efforts for reform. The vital role of these figures may be overlooked without the hermeneutical lens of disability. In the lives of people with disabilities, the small and perhaps seemingly insignificant actions of others can make a tremendous difference in the outcome of a person’s life. As people enter into embodied vulnerability, they need to see disability in terms of the heavenly order and to realize the true value and worth of all people before God. In seeing people with disabilities through the lens of the heavenly order, able-bodied supporters will assist in carrying out acts to nurture social change and reform. In this way people with disabilities will live out their lives not as people silenced and hidden away but as people with voices who are supported by others to live up to their full God-given potential.

**Conclusion**

This dissertation calls for a theological response to disability that integrates practical theology, spirituality, mystical theology, and embodied difference as reflected in the narratives of persons with disabilities. The mystical theologies of Julian and Teresa point toward a theology of disability that upholds the human dignity of people with disabilities in the midst of the biological reality of disability through acknowledging the power of God that is present regardless of our human efforts and abilities. In engaging
Julian and Teresa, I place Christ in the midst of the harsh experience of embodied impairment and physical disability. The conversation between the two mystics and the four interviewees’ offer us a new hermeneutical lens for reading the mystics, while providing us with new insights into practical theology, spirituality studies, and the lives of people with disabilities.

In terms of practical theology, this study shows that the method of a mutually critical conversation provides rich insight into both the contemporary situation of disability and the Christian tradition, as expressed in the writings of Teresa of Avila and Julian of Norwich. Practical theology’s emphasis on practice and effective history creates a deeply contextual vantage point from which to understand the everyday challenges of living with a disability. This deeply contextualized view of the operative and effective history of disability in relationship to disability as a practice would likely occur only through a practical theological analysis. The mutually critical conversation involving the mystics and spirituality studies reveals that the mystical voices of Julian and Teresa can speak to contemporary situations, such as disability. The challenge in orchestrating such a conversation is to allow the historical context of the conversation partner to speak being careful not to misappropriate mystical texts for contemporary purposes. Through the practical theological method of mutually critical correlation, this study reveals new insights concerning the lives of people with disabilities and the writings of Julian and Teresa.

The hermeneutical lens of disability offers important insights that are often missed through traditional reading of the mystics because of the influence of the
hegemony of the normal. First, it is easy to miss the influence of embodiment in the writings of both Teresa and Julian. It is only through delving deeply into the work of Julian and secondary literature that we find the true power behind the fact that Julian through her illness offers her body as an act of devotion. Second, it is not obvious without a detailed exploration of Julian in light of secondary literature that Julian’s Trinitarian conception had deep implications for women in her time. It is both the embodied aspects of Julian’s theology and her critique of the patriarchal structures of her day that Julian’s work finds relevance for the everyday lives of people with disabilities.

The hermeneutical lens of disability also reveals some significant new insights into Teresa of Avila. First, Teresa’s illnesses and paralysis are not insignificant events in her life that can be glossed over. Rather, Teresa’s embodied impairment must be considered as a critical factor in how we interpret her writings. The most obvious example of this is the interpretation of Teresa’s use of the metaphor of “crippled souls” not as derogatory toward people with disabilities but as more of an autobiographical statement. In the absence of an embodied approach to the text along with some historical analysis, this important insight is easily missed. Next, the hermeneutical lens of disability reveals the importance of the actions of other “believers.” Through this study, the critical role of able-bodied “believers” comes into full focus.

The fundamental call of this dissertation is to listen to embodied vulnerability and embodied difference. Hearing the voice of embodied vulnerability should prompt us to rethink our tendency to try to enforce normalcy and sameness, and instead to appreciate and nurture the God-given potential of each person. This is a critique of the American
tradition of disability that wants to keep embodied vulnerability hidden from view. It is in
listening and seeing embodied difference that we critique the American tradition. The
theologies of Julian and Teresa tell us that we do not need to hide or be ashamed of our
embodied vulnerability. God’s presence dignifies embodied difference; thus all
theologians should listen to the voice of embodied vulnerability and heed the call to
incorporate embodiment into their own theological work.
APPENDIX

Research Documents

BU IRB Approved Consent Form

*Note: This copy of the consent form reflects the content of the BU IRB approved consent form but not the document formatting. Some of the formatting needed to be removed to comply with dissertation document standards.

Informed Consent

<table>
<thead>
<tr>
<th>Study Title: The Unheard Voices of People with Disabilities in Conversation with Julian of</th>
<th>Teresa of Avila</th>
</tr>
</thead>
<tbody>
<tr>
<td>IRB Protocol Number: 3742E</td>
<td>Consent Form Valid Date: March 18, 2015</td>
</tr>
<tr>
<td>Study Expiration Date: March 17, 2016</td>
<td></td>
</tr>
</tbody>
</table>

Introduction

Please read this form carefully. The purpose of this consent form is to provide you with important information about taking part in a research study. If you have any questions about the research or any portion of this consent form, please ask us. Taking part in this research study is up to you. If you decide to take part in this research study we will ask you to sign this consent form. We will give you a copy of the signed form.

The person in charge of this study is Diana Ventura who is a Ph.D. student under the direction of her advisor, Dr. Claire Wolfteich, Associate Professor of Practical Theology and Spirituality Studies at Boston University. Diana Ventura can be reached at 617-XXX-XXXX or dventura@bu.edu, Dr. Claire Wolfteich can be reached at 617-353-6496 or cwolftei@bu.edu. We will refer to the Ph.D. student Diana Ventura as the “researcher” throughout this form.

Why is this study being done?

The point of this research is to get a better idea of what happens in the everyday lives of people with physical disabilities and to better understand how these everyday experiences relate to ideas about religion. We are asking you to take part in this study because you have express interest in the study and you have a physical disability. About 6 to 12 study participants will take part in this research study at Boston University. The entire study
will take approximately a year to complete.

**How long will I take part in this research study?**

We expect that you will be in this research study for one day, taking part in an interview about your everyday life and religion. The interview is expected to take 45 to 90 minutes to complete.

**What will happen if I take part in this research study?**

The interviews will be audio taped. If you do not wish to be audio taped you cannot participate in the study. The researcher will be the only person interviewing you. After the interview data is collected the researcher will compile the interview responses and write about how the interview data relates to thinking about religion, God and two Catholic saints Teresa of Avila and Julian of Norwich. Your only involvement in the research study will be providing the interview data.

You may be contacted up to three times by phone at a later date to verify portions of your interview responses. You may opt out of being contacted to verify your interview responses by telling the researcher at any time during the interview meeting. If you are called at a later date to verify your interview responses and do not wish to be contacted any further you can simply tell the researcher and the phone call will end, and you will not be contacted in the future. If at any other time you wish to let the researcher know that you do not wish to be contacted, simply call the researcher at: 617-XXX-XXXX and you will not be contacted again for the purposes of this study.

**Contact for the Interview Verification Purpose**

We may want to contact you in the future to verify interview themes. You can still participate in the study if you decide that you do not want to be contacted to verify interview themes.

Do you agree to let us contact you in the future to verify interview themes?

YES  NO  INITIALS

At the end of the study if you did not opt out of phone contact for interview verification purposes, the researcher will contact you to see if you would like to hear the study results (in person or over the phone). The conversation about the results will not revealing specific details of the interviews of others, it will only provide a general synopsis of the results of the study and general information that may be helpful. You will not be obligated to hear the results of the study, but this is an option if you wish.

If you agree to take part in this study, we will ask you to sign the consent form before we
begin activities related to the study.

**Contact for the Results of the Study**

We may want to contact you in the future to report the study results. You can still participate in the study if you decide that you do not want to be contacted in the future to hear the results.

Do you agree to let us contact you in the future to inform you of the results?

YES  NO  INITIALS

**Audio Recordings**

We would like to audio tape you during this study. If you are audio taped it will not be possible to identify you from the recordings. We will store these tapes in a locked cabinet and only approved study staff will be hear the recordings. We will code the recordings with a code instead of your name. The key to the code connects your name to your audio recording. The researcher will keep the key to the code in a password-protected computer/locked file. The audio recordings will be stored for seven years. If you do not agree to be audio recorded you cannot be in the study.

Do you agree to let us audio record you during this study?

YES  NO  INITIALS

**Storing Study Information for Future Use**

We would like to store your study information for future research related to disability, religion and spirituality. We will label all your study information with a code instead of your name. The key to the code connects your name to your study information. The researcher will keep the code in a password-protected computer/locked file.

Do you agree to let us store your study information for future research related to disability, religion and spirituality?

YES  NO  INITIALS

**Sending Study Information to Transcription Service Outside Boston University**

We will send your interview data to a transcription service that transcribes audio interview data into text files for analysis. We will label all your study information with a code instead of your name. The key to the code connects your name to the study
information. The researcher will keep the key to the code and will not share it with those outside Boston University. Nobody outside of Boston University will know which interview responses are yours.

**How Will You Keep My Study Records Confidential?**

We will keep the records of this study confidential by following procedures. Study participant contact information will be kept separate from all study data. You will not be identified in by name in any published reports or in the write up of the study results. A code will be used in place of your real name. The audio interviews will be transcribed into written text and the fake name or code will be assigned to your interview. The results of this research study may be published or used for teaching. We will not put your name or other identifiable information on data that are used for these purposes. The interview data will be used in writing a doctoral dissertation in partial fulfillment of a Boston University School of Theology Ph.D. in Practical Theology. The final dissertation will be read by a doctoral committee and publically defended. Direct quotes from your interview responses may be used in the dissertation, only the fake name will be associated with quotes and other identifying information will be anonymous.

We will make every effort to keep your records confidential. However, there are times when federal or state law requires the disclosure of your records.

The following people or groups may review your study records for purposes such as quality control or safety:

- The Researcher and any member of her research team
- The Institutional Review Board at Boston University.

The Institutional Review Board is a group of people who review human research studies for safety and protection of people who take part in the studies.

The study data will be stored on a password protected computer only accessible to the research staff or in a locked file cabinet.

**Study Participation and Early Withdrawal**

Taking part in this study is your choice. You are free not to take part or to withdraw at any time for any reason. No matter what you decide, there will be no penalty or loss of benefit to which you are entitled. If you decide to withdraw from this study, the information that you have already provided will be kept confidential.

Also, the researcher may take you out of this study without your permission. This may happen because:
The researcher thinks it is in your best interest
Other administrative reasons
What are the risks of taking part in this research study?

Interview Risks

You may feel emotional or upset when answering some of the interview questions. Tell the researcher at any time if you want to take a break or stop the interview. You may be uncomfortable with some of the questions and topics we will ask about. You do not have to answer any questions that make you feel uncomfortable.

Loss of Confidentiality

The main risk of allowing us to use and store your information for research is a potential loss of confidentiality. We will protect your confidentiality by labeling your information with a code or a fake name and keeping the key to the code in a password-protected computer.

Are there any benefits from being in this research study?

There are no direct benefits from participating in this research study. Others may benefit in the future from the information that is learned in this study.

What alternatives are available?

You may choose not to take part in this research study.

Will I get paid for taking part in this research study?

We will not pay you for taking part in this study.

What will it cost me to take part in this research study?

There are no costs to you for taking part in this research study.

If I have any questions or concerns about this research study, who can I talk to?

You can call us with any concerns or questions during normal business hours. Our telephone numbers are listed below:

- Diana Ventura (Ph.D. student) at 617-XXX-XXXX, or email dventura@bu.edu.
- Dr. Claire Wolfteich (faculty advisor) at 617-353-6496 or email cwolftei@bu.edu.
If you have questions about your rights as a research subject or want to speak with someone independent of the research team, you may contact the Boston University IRB directly at 617-358-6115.

Statement of Consent

I have read the information in this consent form including risks and possible benefits. I have been given the chance to ask questions. My questions have been answered to my satisfaction, and I agree to participate in the study.

SIGNATURE

I have explained the research to the subject and answered all his/her questions. I will give a copy of the signed consent form to the subject.

Name of Person Obtaining Consent

Signature of Person Obtaining Consent and Date
RESEARCH STUDY

People with Physical Disabilities are Needed

A Study on Everyday Life and Spirituality among Individuals Living with Physical Disabilities

The purpose of this study is to explore how everyday life and spirituality interact. Participation in this study involves an interview (up to an hour and a half in length) about everyday life with a disability and spirituality. People with physical disabilities are sought for participation in the study. Interviews will be scheduled to meet the needs of study participants.

For more information please contact:

Diana Ventura, M.Ed, M.Div.
call: 617-XXX-XXXX
email: dventura@bu.edu.

This study is being conducted as part of dissertation research at Boston University School of Theology.
Interview Guide

Interview Guide:

The Unheard Voices of People with Disabilities in Conversation

with Julian of Norwich and Teresa of Avila

by Diana Ventura

The following are examples of the types of questions that I propose to ask the research participants. The indented questions represent the information that I am seeking and potential probes for further details. I realize that as the interview progresses my questions may also shift to focus. I also expect that the preliminary questions will result in many different kinds of questions. These examples are therefore intended to guide me as I begin my interviews.

(Describe/review the study purpose with the participant)

Before the start of the interview the following demographic and general information will be collected. The data will be collected only to contextualize the interview data collected. No quantitative analysis will be conducted on the demographic data collected.

Demographics and General Information:

1. Demographic Data (completed by participant)

   1. Are you male or female? ______________

   2. In what year were you born?_____________

   3. What is your occupation (or what was it before you retired)?

   __________________________________________

   4. What is your highest level of formal education?

      [ ] less than high school [ ] high school diploma [ ] some post-high-school work

      [ ] technical certifications [ ] 4-year college degree [ ] post-college graduate work or degree

   5. What is your approximate total annual household income?

      [ ] under $20,000 [ ] $20,000 to $39,999 [ ] $40,000 to 59,999

      [ ] $60,000 to 79,999 [ ] $80,000 to 99,999 [ ] $100,000 or more [ ] Refused [ ] Unknown
8. Who lives with you in your current household? (check all that apply)

[ ] no one, I live alone
[ ] spouse [ ] partner (not married) [ ] other adult(s) [ ] family members

_____ # children under 6 years old _____ # children 6–18 years old

_____ # older children

9. What is your religious affiliation, if any? _________________

10. What is your disability? _________________

   a. What is the date or approximate date disability of onset: __________

Qualitative Interview Questions

Everyday Life Questions:

I’d like to start by asking you to tell me about a typical day—not everything, but think about the typical things that happen….

Can you tell me about a typical day? (Potential probes: work, school, social life)
   Can you tell me about your habits and routines or predominant activities that you make sure that you do nearly every day?
   Can you tell me what you would describe as a good day?
   Can you tell me what you would describe as a bad day?
   Can you tell me about what a typical weekday?
   Can you tell me about what a typical weekend?
   Can you tell me about your and work, school, leisure activities?
      Do you work outside the home?
      Can you tell me about the work you do?
      How did you come to do this particular work?
      Can you tell me about other activities you do besides work?

Disability Questions:

Can you tell me about your disability?

   Can you tell me about the onset of your disability?
   Who has helped you with what it means to be a person who lives with a disability?

Can you tell me about your experiences of disability in everyday life?

   Potential probes when adult onset allows:
How have your everyday activities changed since the onset of your disability?

Can you tell me about the things that are most helpful or unhelpful to you in relationship to your disability and everyday life activities?

What are the typical challenges?

- Can you tell me about a time when you found living with a disability particularly frustrating?
- Can you tell me about a time when you felt a personal moment of success or triumph related to your disability?

What are the interactions with others like in relation to your disability?

How does your disability influence your everyday activities (if at all)?

Are there times when you are encouraged or feel like giving up because of your disability?

Have you thought about why it is that your body has a disability?

**Religion/Spirituality Questions:**

Can you tell me about religion or spirituality in your life?

- How important is religion/spirituality to you personally?
- Do you think religion or spirituality makes you a different kind of person?
  - If so, how, what would other people notice that is different?
- How has your religion or spirituality changed overtime?
  - Was there ever a time when you found it hard to believe in your religion or God?

Where is it that you encounter the spiritual or sacred?

Where do you find the sacred in your life?

Where do you find God or spirituality?

- Where are the special places that were important to you?
- Are there sights or sounds that remind you of God or what is sacred?
- Have you ever felt like God or something sacred was really present?
  - Can you tell me about this?

Are you part of a religious or faith community, why or why not?

- Can you tell me how often you attended worship services in the last year?
  - Do you attend with other family members or friends?
  - Are you an official member? When did you membership begin?

Does participation in a faith community impact your religious or spiritual life?

Do you have any memorable religious experiences from your upbringing?

Was there ever a time when you were without a religious community?

Are there any other religious groups that are important to you?

Are spiritual practices involved in your spirituality?
Are there religious practices that you do frequently, every day or nearly every day? (such as, praying, reading etc.). How often do you pray, read etc.?

Have you ever considered everyday experiences, such as being in nature as spiritual? What experience have you had like this?

**Disability, Religion and Everyday Life:**

Have you ever experienced healing that you would describe as a religious experience?
Have you ever been angry or mad at God or the divine or what you name as sacred?

How does your spirituality, thoughts or experiences of the sacred interact with your everyday life with a disability?

Closing…Is there anything else you would like to add before we conclude?


Burns, Ken, *Cancer: the Emperor of All Maladies*, episode 1, (PBS Distribution. 2015), DVD.


Klages, Marisa. “Rhetorics of Pain and Desire: The Writings of the Middle English Mystics.” PhD diss., West Virginia University, 2008.


VITA

Diana Ventura is the author of *Our Fractured Wholeness: Making the Courageous Journey from Brokenness to Love*. Ms. Ventura frequently lectures and preaches on the topics of disability, religion, spirituality and theology. Ms. Ventura’s career also involves teaching and clinical research. Ms. Ventura’s primary teaching and research focuses upon spirituality, practical theology, disability studies, chronic disease and aging; qualitative research methods, Christian spirituality; spiritual autobiography; work and family life; contemplative prayer; and Christian mysticism. Her work integrates the academic disciplines of disability studies, practical theology, and spirituality studies in an effort to explore the current contextual and cultural situation of the everyday lives of people with disabilities. She serves as ethical reviewer for New England Institutional Review Board (NEIRB) and is Chief Data Administrator (CDA) at Harvard University’s Center for Biostatistics in AIDS Research (CBAR). Ms. Ventura earned her M.Div. at the University of Chicago. She also holds a M.Ed. degree from Temple University in Therapeutic Recreation. Contact information is available at www.dianaventura.com.