

Attending to Care:
A Pastoral Theological Response
to Families Facing Disabilities

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*For Edwin, Gabriel, and Lily,
who loved me and strengthened me,
all along the way.*

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CHAPTER 1

INTRODUCING THE PROJECT SUBJECT AND METHOD

Introduction

A few years ago, in a small town in North Carolina, a boy with cerebral palsy was escorted out of a church sanctuary during Easter worship, just after the opening prayer, when he voiced an “amen” that disturbed some worship leaders. What followed, precisely, is unclear. The boy’s mother said they were moved to the lobby; church officials said they were moved to the back of the sanctuary “where they watched the service in its entirety.” The mother said she was scheduled to meet with church officials to discuss the incident, but the officials canceled when they heard she had contacted a television news station. The mother said she called the pastor and suggested a ministry focusing on the needs of people with disabilities, but the idea was rejected. Later, when a reporter called the church, he was told that the church “focuses on worship, not ministry.” After a story aired on television about the incident, the church released a statement saying, “Everything we do is about ministry.” Finally, the church released another statement saying that its goal is “to offer a distraction-free environment for all our guests,” and indicating that the staff would be getting training from the local Arc, an organization that provides services and advocacy for and with people with disabilities.¹

There is much that is unfortunate in this story. For a church to set worship and ministry in dichotomous opposition is startling; for a child of God to be described,

¹ <http://www.wsocvtv.com/news/news/special-needs-boy-removed-from-church-service/nGR6S/>
Accessed June 19, 2012.

even implicitly, as a “distraction” is disturbing; and for one outburst at the beginning of worship to lead to an immediate removal is upsetting. But the back and forth breakdown in human relationship is also sobering. A potentially productive conversation between committed adults didn’t happen, leading the mother to call a reporter to talk about her experience. While this could be described as reactionary, it seems to have been born of deep frustration. One wonders how many times this mother has seen her child rejected. Ultimately, a potential relationship built on care broke down. This relationship might have fostered the development of a culture of intentional, meaningful welcome, but instead the experience led to antagonism, defensiveness, and hurt.

This dissertation attempts to consider what it might mean for congregations and denominations to care for and with families facing disabilities.² For reasons I will explore, I seek to more deeply understand care as an ethic that can offer

² Thoughts about terminology are appropriate at this point. Terminologies used for “disability” and “disabilities” are diverse, carry embedded normative values, and shift in connotation and resulting acceptability over time. For instance, the now generally unacceptable term “retarded,” at one point probably simply reflected unfortunate assumptions about an inherent and unchanging “lack” of intellect. The term may not ever have been “neutral,” but originally was likely meant to be a simple clinical definition for a person with a significant intellectual impairment, not a pejorative. Gradually, however, “retarded” acquired the stigmatizing shame most people associate with it today. Considering that history, my choice to use the term “disabilities” throughout most of this project cannot be seen as neutral. Language rarely is. Thus, I use “disabilities,” and use it in a way often described as “person-first,” for particular reasons. Person-first language uses the name of the disability as a noun, and places it *after* any other primary identity, which signifies the reality that one may have, but is never the sum of, a disability. For example, “a boy who has autism,” reminds us that this son also possesses many factors that make him who he is, besides his autism, in ways that the description of “an autistic son,” or, even worse, “an autistic,” cannot. “Disability,” meanwhile, is the most widely used term for an impairing condition at the moment. It encompasses conditions of many kinds – physical, intellectual, visual, hearing, emotional/behavioral, etc. -- and acknowledges the real challenges of impairments, a factor I find lacking in terms such as “differently abled.” I am also uncomfortable with the term “special needs” for two reasons. First, because it tends to be used primarily for children, it can infantilize its subject in ways that are utterly inappropriate for older individuals, and thus perpetuate human tendencies to relegate persons with disabilities to an eternal childhood. Additionally, and perhaps most simply, each of us has “special needs,” because of the rich diversity of God’s created world. “Special needs” assumes and/or connotes a dualistic human community in which some are “the same,” united in a shared state of relative independence and strength, while others are “needy.”

guidance in structuring human communities including the church for the furthering of justice, and a practice that is critical for the sustenance of life itself. All persons, both those who may seem especially vulnerable, and those who may seem more “typical,” need care to survive. Thus, this dissertation seeks to critically examine the concept of care for the purpose of strengthening the church’s response to some of the challenges and gifts experienced by families facing disabilities.

Why should we care? Why am I exploring care in response to challenges posed by disabilities? Care demands attention for many reasons. First, care sustains our world. *All* living creatures, communities, and the earth itself need care to survive, while *some* persons, animals, communities, and aspects of the earth exist in states of particular need or vulnerability that demand and deserve more care than others. Second, care for persons and for contexts is a primary role for the church. This conviction is grounded in the biblical witness of the early church, in which life was shared in common (Acts 2:44-45), in which diverse gifts and contributions were valued (1 Cor 12:4-7), and in which believers were called to be gentle and merciful with one another (Eph 4:1-2). Care, for those early Christians, was foundational for everything else they did. In addition, early practices of and teachings about care were responsive to the earliest understandings of the gospel message of life abundant, involving the lifting up of the vulnerable and downtrodden. (Luke 4:16-20)

Moreover, there is another reason to focus on care, a reason that perhaps comes closer to the contemporary experiences of families of children with disabilities. The project focuses on care because it is rarely used as a critically constructed

significant structuring force in church and society. This absence sharpens the challenges inherent to raising children with disabilities. Families of children with disabilities, despite tremendous social change in recent years, continue to live with challenges disproportionate to the experiences of families of typical children. Parents typically experience more stress,³ siblings often carry a burden of eventual – if not current – responsibility unlike that of many of their peers,⁴ and the whole family may struggle for full recognition and honoring of the unique needs and full personhood of the one among them who has a disability.⁵ In addition, the birth or diagnosis of a child with a disability often challenges embedded theological understandings about humanity, vulnerability, community, families, futures, hope, and God. For families that are economically disadvantaged, challenges are multiplied and intensified. These challenges are not unmitigated negatives – in some families, they may contribute to the development of strengths.⁶ But they are challenges, and their particular shape as challenges intersects with the fact that the world has not always been kind to people with disabilities.

³ See, for example, Naomi Ornstein Davis, Alice S. Carter, “Parenting Stress in Mothers and Fathers of Toddlers with Autism Spectrum Disorders: Associations with Child Characteristics,” *Journal of Autism and Developmental Disorders* 38, No. 7 (2008): 1278-1291; or C. Baxter, “Appraised Significance of Intellectual Disability for Parents of Children in 3 Age Cohorts – Exploring the Stress Process,” *Journal of Intellectual Disability Research* 36, No. 6 (1992): 519-529.

⁴ See, for example, VB Damiani, “Responsibility and Adjustment in Siblings of Children with Disabilities: Update and Review,” *Families in Society: The Journal of Contemporary Human Services* 80, No. 1 (1999): 34-40.

⁵ See, for example, Nancy B. Miller, Catherine C. Sammons, *Everybody’s Different: Understanding and Changing Our Reactions to Disabilities* (Baltimore: Paul H. Brookes, 1999), and Lise Fox, Bobbie J. Vaughn, Merili Llanes Wyatte, Glen Dunlap, “We Can’t Expect Other People to Understand: Family Perspectives on Problem Behavior,” *Exceptional Children* 68, No. 4 (2002): 437-450.

⁶ See, for example, Ronald Gallimore, Lucinda P. Bernheimer, and Thomas S. Weisner, “Family Life Is More Than Managing Crisis: Broadening the Agenda of Research on Families Adapting to Childhood Disability,” in *Developmental Perspectives on High Incidence Handicapping Conditions*, ed. Gallimore, Bernheimer, Donald L. MacMillan, Deborah L. Speece, and Sharon Vaughn (Mahwah, NJ: Erlbaum, 1999), 55-80; and Sarah Eleanor Green, “We’re Tired, Not Sad”: Benefits and Burdens of Mothering a Child with a Disability,” *Social Scientific Medicine* 64, No. 1 (2007): 150-163.

Historically and still today, the church has struggled to respond with care and openness to the gifts of people with disabilities and their families. Some congregations have developed thoughtful and sensitive disability ministries, and burgeoning multi-disciplinary fields of inquiry are working to examine the role of religion in family experiences with disabilities, and to critically consider inherited understandings of personhood, wholeness, community, and other themes that intersect with experiences of families facing disabilities. Yet, the longer history of the church's interactions with disabilities could be described, at best, as an example of "the fragility of care."⁷ Care is fragile because it is difficult to predict its results. Thus, some of the worst moments in the history of disabilities – mass institutionalization and involuntary sterilization, for instance – are linked historically to the church's misguided efforts to care.

Sadly, the church often still struggles with care related to persons with disabilities and their families. In part, this is due to burdens from the past that remain with us today. The burden of history,⁸ as well as traditional theologies that assign a high level of providential power to God, or that see difference as a sign of punishment or even demonic possession, continue to marginalize people with disabilities and their families. At the same time, to "include" people with disabilities and their families in congregational life – a common call from many sectors today – is much more complex than "include," or "inclusion," would seem to indicate. What

⁷ Guy A. M. Widdershoven and Marli Huijjer, "The Fragility of Care: An Encounter between Nussbaum's Aristotelian Ethics and Ethics of Care," *Bijdragen: International Journal in Philosophy and Theology* 62, No. 3 (2001): 308-312.

⁸ See, for example, Steven Noll and James W. Trent Jr., *Mental Retardation in America: A Historical Reader* (New York: New York University Press, 2004) and Christine Rosen, *Preaching Eugenics: Religious Leaders and the American Eugenics Movement* (New York: Oxford University Press, 2004).

does it mean to include someone with autism on a youth mission trip, for example? How can congregational leaders respond to complaints about behavior in worship? What can and should clergy say to questions about understanding of rituals and rites of passage? “Inclusion” brings with it practical and concrete challenges such as those alluded to in the questions above, and demands considerable, intentional thought. Opening the doors and saying everyone is welcome is not enough.

Finally, the church struggles to define itself in many ways, some of which have significant bearing on the lives of people with disabilities. Science, for example, which might help parishioners understand the etiologies and challenges of particular disabilities, remains suspect in some sectors of the church, as well as misunderstood, idolized, or avoided in others. Meanwhile, public life, where policy issues powerfully impact the lives of people with disabilities and their families, is an open question for many people of faith. What is the role of the church in public life? Does the church have a voice on such issues as adequate funding for assessments, therapies, and school-based services for children, for example, or insufficient supportive services for disabled adults? Should it?

These issues illustrate some of the most obvious struggles of the church to respond to families of children with disabilities. They are diverse, and yet they are united by an inadequately developed understanding of care. While the church talks about care, it has not dug deeply enough into the concept of care as a Christian practice, thinking about meaning, history, implications, limits, contextual distinctions, healthy and pathological forms of caring, ways in which care is related to human personhood, places where care impulses compete, and more. In this

inadequacy, the church frequently fails to support flourishing as it should for all people – including families of people with disabilities. And yet it is important to remember that care is a provocative concept for some people with disabilities. At times, care has meant control by well-meaning persons and institutions who denied autonomy and self-determination.⁹ Care must be addressed with attention to this ambiguous history and awareness that domination and paternalism are real dangers. At the same time, however, care is a critical topic for pastoral theology in a disability context, and in thinking about human life in general. As members of God’s creation, all persons need to give and receive care.

This dissertation seeks [to argue that a theological response to families facing disabilities must be shaped by a critically-understood concept of care that both clarifies disability experiences in families, church, and society, and is attentive to potential pitfalls in caring practices. It does this by](#) attending to several issues

related to disabilities, religion, and care. First, it offers a realistic picture of families living with persons with disabilities, considering how family members experience and practice care at home, in the church, and in society. Second, it develops a richer understanding of the often unspoken and even unconscious social and theological norms that guide everyday life with disabilities. Third, it asks how church and society, through more critical attention to understandings and practices of care, might better help these families to flourish. And finally, it seeks to contribute to deeper understanding about human beings as creatures of care and pastoral

⁹ See, for example, Bill Hughes, Linda McKie, Debra Hopkins and Nick Watson, “Love’s Labour’s Lost? Feminism, the Disabled People’s Movement and an Ethic of Care,” *Sociology* 39, No. 2 (April, 2005): 259-275.

theology as a practice of care. Thus, the project has a three-fold agenda: attention to disability practices that encourage flourishing; attention to human experiences of care as a Christian practice; and attention to the discipline of pastoral theology as itself a practice of care. This is a complex process that will be addressed in the back and forth of hermeneutic, interpretative thought.

Thinking about Care

The concept and practices of care are foundational to this project, so much so that while a later chapter explores care in greater depth, it is important to move forward into the first chapters with a basic definition of care in the context of disability. While other fields (including nursing, bioethics, political science and philosophy) have examined the concept of care on a theoretical level, my own “home” field – pastoral theology and care – has done surprisingly little of this work. This is a curious omission for a discipline that is committed to holding together theory and practice in the context of human pathos.¹⁰

This work must be done. All persons need to receive and give care. Seneca and other ancient philosophers pointed out that care is dual-natured; that is, while it is sometimes burdensome, it also possesses the power of transcendence. Care takes us outside of and beyond ourselves. And yet, people with disabilities and their families experience care in church and culture that is often inadequate, at best inconsistent, and inevitably worthy of reflection. Seneca said that in humans “the good is

¹⁰ See, e.g., Anton Boisen, *The Exploration of the Inner World* (Chicago: Willet, Clark, 1936), 10. Charles Gerkin’s *Introduction to Pastoral Care* may come closest to this theoretical-level thinking on the concept of care. His emphases on correlating the therapeutic, the theological, and the cultural aspects of care tends to lead away from a focus on just what care *is*, and what its implications may be, but the history of pastoral care in the first two chapters of the book is revealing. See Charles V. Gerkin, *An Introduction to Pastoral Care* (Nashville: Abingdon, 1997).

perfected by *cura*,” or care, and that this process brings us closer to God. I believe this can be true. Seneca also believed that care is the key to becoming fully human. I believe he was right. Care – good care – is a multi-faceted, multi-contextual practice with broad impact. As a practice it is value-laden; that is, its practice reflects the values we hold dear as human beings – for good, and, sadly, sometimes for ill. And while the work of care is essential for sustaining our world as a complex, interwoven, dynamic living body, care is more than labor, and it is more than personal or interpersonal effort. It is these things, most definitely, but it is also an attitude of giving that involves loving engagement with and investment in another, and it is an underlying virtue that sustains the attitude and the labor. Additionally, care occurs in contexts both public and private, bringing it closer, at times, to a political process than an interpersonal one.

While a later chapter will look more in-depth at the history and philosophy of care, for now it is important to understand care as a practice that involves labor for the sake of another, that is guided by a particular attitude, that is sustained by and that contributes to sustaining virtue in the giver of care, and that exists in the midst of a dialectical tension between personal and political.¹¹ Additionally, care as a

¹¹ Eva Feder Kittay and Joan Tronto are two care theorists whose perspectives have been utilized by nursing, bioethics, human services, and other fields. Eva Feder Kittay, *Love's Labor: Essays on Equality, Women and Dependency* (New York: Routledge, 1999) and “When Caring Is Just and Justice is Caring: Justice and Mental Retardation,” in Eva Feder Kittay, *The Subject of Care: Feminist Perspectives on Dependency* (Lanham, Maryland: Rowman and Littlefield, 2002), 257-276; and Joan Tronto, *Moral Boundaries: A Political Argument for an Ethic of Care* (New York: Routledge, 1993).

specifically *Christian* practice is part of a complex system that overlaps religious and secular worlds.¹²

The Belief/Practice Gap

This thinking on the practice of care is informed by recent theological writings on Christian practices, which in turn have been sustained by careful attention to late-twentieth-century theologies and other theories of practice,¹³ including attention to the sometimes frustrating, often revealing, and very common gaps between beliefs and practices.¹⁴ As human beings, we do not always live up to our beliefs. These gaps are evident as soon as we begin to look past examples of saints and heroes. For example, several Greco-Roman philosophers produced rich reflections on the importance of care – reflections that emerged from societies that practiced pederasty, infanticide by exposure, slavery, and other cruelties. How could

¹² Warren Thomas Reich, “History of the Notion of Care,” *Encyclopedia of Bioethics*, 3rd edition, Stephen G. Post, ed. (New York: MacMillan Reference, 2004) 349-359; Tronto, *Moral Boundaries*, 101-103, 109, 112, Chap. 6; Feder Kittay, “When Caring is Just and Justice is Caring,” 257-276.

¹³ See, for example, Miroslav Volf and Dorothy C. Bass, eds., *Practicing Theology: Beliefs and Practices in Everyday Life* (Grand Rapids, Michigan: Eerdmans, 2002); Edward Farley, *Theologia: The Fragmentation and Unity of Theological Education* (Eugene, Oregon: Wipf & Stock, 2001); Mary McClintock Fulkerson, *Places of Redemption: Theology for a Worldly Church* (New York: Oxford University Press, 2007); Elaine Graham, *Transforming Practice: Pastoral Theology in an Age of Uncertainty* (Eugene, Oregon: Wipf & Stock, 1996); Ted A. Smith, *The New Measures: A Theological History of Democratic Practice* (Cambridge: Cambridge University Press, 2007) and Ted A. Smith, “Theories of Practice,” in Bonnie Miller-McLemore, ed., *The Wiley-Blackwell Companion to Practical Theology* (Malden, Ma.: Blackwell Publishing, 2012), 244-254; and Kathryn Tanner, *Theories of Culture: A New Agenda for Theology* (Minneapolis: Fortress Press, 1997). All have drawn on one or more of the following theorists: Alasdair MacIntyre, who focuses on virtue achievable through excellence in practice; Pierre Bourdieu, who developed the concept of habitus to address the dialectic between freedom and control experienced by individuals; and Michel de Certeau, who wrestles with the question of agency necessary for real resistance. See Alasdair MacIntyre, *After Virtue: A Study in Moral Theory*, second edition (London: Duckworth: 1985); Pierre Bourdieu, *Outline of a Theory of Practice*, trans Richard Nice (Cambridge: Cambridge University Press, 1977); Michel de Certeau, *The Practice of Everyday Life*, trans. S. Rendall (Berkeley: University of California Press, 1984); and Smith, “Theories of Practice.”

¹⁴ Joyce Mercer, *Welcoming Children* (St. Louis, Missouri: Chalice Press, 2005). Mercer presents this gap as a critical part of her theological process. Amy Plantinga Pauw, “Attending to the Gaps between Beliefs and Practices,” in Volf and Bass, *Practicing Theology*, 33-48, also is attuned to this gap, but sees it more as evidence of human frailty and need for God’s abundant grace.

the Greeks have a myth of origin that celebrates caring, how could Seneca have insisted that in humans, “the good is perfected by care,” in the midst of societies that seem to us so harsh in their treatment of those who are weak and vulnerable?

The frequent distance between beliefs and practice (and the mechanisms by which they move toward and away from each other) brings to mind philosopher Pierre Bourdieu’s concept of *habitus*, a figurative environment in which persons are apprenticed to sets of beliefs and actions that are interwoven with institutions, social and cultural forces and norms, and underlying structures that may promote or constrain actions. These elements influence principles and practices in ways that may leave them, at times, inconsistent in their relationships between one another. By combining labor, virtue and attitude, and by reflecting commitments at once public, private, and political, practices of care create a habitus, or system “of durable, transposable *dispositions*, structured structures predisposed to function as structuring structures.”¹⁵ The habitus generates and structures practices and representations, often without conscious choice. Bourdieu’s understanding implies that human beings are continuously apprenticed to practices, structures and values related to various aspects of human existence. The habitus surrounds, informs, and often guides the choices related to internal and external aspects of the self. Bourdieu’s perspective is an important reminder that transformative practice does not emerge automatically from right ideas, such as the ancient, classical understanding of care, but demands awareness of, shaping and re-shaping the larger habitus, or system, in which ideas intersect with practice.

¹⁵ Bourdieu, 72.

A habitus, however, is not fully determinant. Those structuring structures do not structure us *completely*. Ted Smith writes about Bourdieu's work as an attempt to overcome the antinomy between "subjective" accounts of human activity, such as those by twentieth-century existentialists like Jean-Paul Sartre, who emphasized freedom in human actions; and "objective accounts," associated with structuralists such as Levi-Strauss, who saw human action as a result of historical, social, economic, and political forces. Instead, Bourdieu sought to create a dialectic in which the structures of the habitus do, indeed, present powerful forces that may limit or impact actions, but also provide bases for new actions, practices and ways of being. Essentially, the concept of habitus insists that we live in the midst of much more than we realize, but our actions still are not fully determined.¹⁶

This perspective has broad implications for this project. Because ideas and practices mutually influence each other, neither comes first. This means it is most helpful to think about the context in which they take place. This is what makes practical theology both "true and useful,"¹⁷ and allows it to offer "a valid and adequate account of the praxis of Christian faith in a particular context in which human beings strive to live lives in relation to God's reign."¹⁸ Praxis is not a sophisticated word for practice, but a particular term for the engagement of both theory and practice for the sake of human and world transformation, toward the reign of God. From a specifically Christian perspective, care is not just a value-laden practice. It is a practice that is laden with *particular* values of commitment to an

¹⁶ Smith, "Theories of Practice."

¹⁷ Mercer, 11.

¹⁸ Ibid.

eschatological vision of love and justice, and that seeks, through faithfulness to that vision, to draw closer to God's intention for humankind.

Disability Theology: A Common Commitment

This dissertation follows in the wake of a recent small wave of constructive theologies that seek to re-imagine aspects of Christian doctrine in response to disability experiences. Works like Nancy Eiesland's groundbreaking *The Disabled God* made it possible for a generation of Christians with disabilities to feel that they were, in fact, part of the Christian story, while the much more recent and very different *Theology and Down Syndrome*, by Amos Yong, gave families of people with Down Syndrome new ways of seeing loved ones in this life and in the life to come.

These works and more have helped the church to begin to address and respond to the ubiquity of disabilities. Unlike many centuries' worth of theological thinking, recent disability-focused theologies challenge long-held understandings of what it means to be human and to be created in the image of God. These theological works, in other words, help the church to understand disabilities on a new level, but they also help us to see ourselves differently. The ideas contained in work such as Deborah Creamer's *Disability and Christian Theology*, which insists on limits as part of the basic condition of being human, and Thomas Reynolds' *Vulnerable Communion*, which invites readers to a stance of hospitality as response to the deep vulnerability that all persons share, are significant as much for their descriptive statements about the general human condition, or "anthropology," as they are for their prescriptive imperatives about the work of the church.

Despite the significance of this work, however, it tends to focus on developing doctrine that is amenable to the human condition of disability, which does not necessarily enhance understanding of the complex, everyday existence of life with disabilities. For families facing disabilities, daily challenges are complex and frequent. Behavior and intellect may not conform to commonly assumed norms. Development sometimes is continuously scrutinized. Needs may be more numerous and more intense than those of “typical” children. Education often demands frequent negotiation with teachers and administrators. Social life may not happen as autonomously as that of “typical” children. Out-of-school time often is marked by tutoring, therapies, and other services. And yet life with disabilities offers unexpected joys as well as these real challenges. Thus, while re-examining inherited understandings of topics like what it means to be human, or how we understand the end of times in light of disability perspectives, or how God might or might not be involved in the manifestation of disability is important, disability theology can focus so heavily on “right ideas” that it seems somewhat disconnected from the daily challenges and joys of family life with disabilities.

Addressing a Gap

One of the earliest works in this genre, Eiesland’s *The Disabled God*,¹⁹ offers one idea. Although Eiesland did not describe herself as a practical theologian,²⁰ the work bears the reality of practical concerns. At its heart, her project is about ways that a

¹⁹ Nancy Eiesland, *The Disabled God: Toward a Liberatory Theology of Disability* (Nashville: Abingdon, 1994).

²⁰ Eiesland, who died in 2009, was a sociologist of religion by training.

God of enormous – but arbitrary – power did not make sense for one who had struggled with pain resulting from a physical disability as well as resulting social stigma. How was this God also “Love,” given what she had lived with? How could she find herself in the incarnation of God in Christ? And what did it mean for her to be made in the image of God? Rather than begin with doctrine and attempt to shoehorn her experience into a predetermined theological system, Eiesland drew on her own experiences as a person with physical disabilities, as well as the experiences of others. Ultimately, she argued that God in Christ actually had been *disabled* – not just wounded -- by the violence of the crucifixion. She turned to religious practice to suggest transformations in theology and practice informed by this renewed insight. Eiesland’s work entered a gap between traditional theology as she understood it and her own life experience, and addressed that gap by attending to a broad habitus of ideas, culture, structures, and practices.

This research also tries to address “a gap” – a gap in the literature between family experience and a methodological tendency within academic disability theology to emphasize theory over experience – *and* to address the broad habitus of care. Practical and pastoral theological approaches differ from much existing disability theology, and that difference has largely shaped the approach of this project.

Practical Theological Method Informs Understanding, Shifts Emphases

Briefly, most of the theologies described above come out of a systematic or constructive theological approach. Historically, systematic theology has been

concerned primarily with internal doctrinal coherence. Constructive theology, a more recent development, recognizes theology as a construct more than a positivistic ontological statement, and draws more heavily on human experience. Its emphasis, however, remains the development of theological ideas. This project represents a different approach. It employs elements of what has been described as the “critical correlational” method of practical theology, which alters the process of theological construction.²¹ Practical theology begins with an understanding that theology is most interesting in the ways in which it is embodied in the daily lives of people and communities, and engages “personal, ecclesial and social experience to discern the meaning of divine presence and to enable faithful human response.”²² It takes human experience as central, and insists that human practices evidence values that are worthy of investigation, interrogation, and, perhaps, thoughtful transformation.

Placing human experience at the center of theological analysis has led not only to new forms of practical theological thinking, but even to assertions that just about all theological thinking derives from practical concerns. In fact, Don Browning, a pioneer in the field of practical theology, argued that to avoid the complexity of

²¹ The critical correlational method, as well as practical theology more generally, often are associated with Don Browning, whose work has been highly influential in later work about practical theological method. See, for example Don S. Browning, *A Fundamental Practical Theology* (Minneapolis: Fortress, 1991), 6-7.

²² See, for example, Bonnie J. Miller-McLemore, “Also a Pastoral Theologian: In Pursuit of Dynamic Theology (Or: Meditations from a Recalcitrant Heart),” *Pastoral Psychology* 59, No. 6 (2010), 813-828; and Bonnie J. Miller-McLemore, “Practical Theology,” CQ Press Electronic Library, *Encyclopedia of Religion in America*, encyra_1.1. Originally published in *Encyclopedia of Religion in America*, edited by Charles H. Lippy and Peter W. Williams (Washington: CQ Press, 2010).

http://library.cqpress.com/era/document.php?id=encyra_1739.1&type=hitlist&num=0 (accessed June 21, 2010).

Quote from Bonnie J. Miller-McLemore, “Introduction: The Contributions of Practical Theology,” in *The Wiley-Blackwell Companion to Practical Theology*, ed. Bonnie J. Miller-McLemore (Oxford, UK: Wiley-Blackwell, 2011) doi: 10.1002/9781444345742.ch

human experience we must *deliberately* abstract doctrine from practice.²³ Practical theology, in this view, is merely an acknowledgment of the human reality that lies behind any quest for understanding. Browning also said his approach to practical theology “goes from practice to theory and back to practice. Or more accurately, it goes from present theory-laden practice to a retrieval of normative theory-laden practice to the creation of more critically held theory-laden practices.”²⁴ He argued that culture and theology can present problems and responses in mutually critical relationship, and that theology can both inform and be informed by other disciplines, including the physical and social sciences.²⁵ He called for descriptive, historical, systematic, and strategic “movements” in the process of [practical](#) theological reflection.

This four-stage process demands that the practical theologian first gain a rich, nuanced understanding of the current situation, often referred to as a “thick description.”²⁶ Next, the practical theologian must see the situation from a perspective informed by pertinent history, reflect upon the situation systematically,

²³ Browning, 6-7.

²⁴ Browning, 7.

²⁵ Don S. Browning, Bonnie J. Miller-McLemore, Pamela D. Couture, K. Brynolf Lyon, and Robert M. Franklin, *From Culture Wars to Common Ground: Religion and the American Family Debate*, second edition (Louisville, Ky.: Westminster John Knox, 2000) offers a helpful, concise summary.

²⁶ “Thick description,” a term often attributed to anthropologist Clifford Geertz, actually first appeared in work by metaphysical philosopher Gilbert Ryle, in which he emphasized the importance of discerning intentionality and context when studying and writing about persons and groups. See Gilbert Ryle, *Collected Papers: Volume II, 1929-1968* (London: Hutchinson, 1971), 474. Geertz adopted Ryle’s understanding and furthered it by applying it to ethnographic research practices, as well as emphasizing the importance of this work in helping readers to judge for themselves the researcher’s interpretations of others’ actions. See Clifford Geertz, *The Interpretation of Cultures* (New York: Basic Books, 1973), 6, 9. Finally, noted qualitative researcher and theorist Norman K. Denzin provides one of the most important understandings of “thick description” when he says: “A thick description does more than record what a person is doing. It goes beyond mere fact and surface appearances. It presents detail, context, emotion, and the webs of social relationships that join persons to one another. . . . It inserts history into experience. It establishes the significance of an experience . . . in thick description, the voices, feelings, actions, and meanings of interacting individuals are heard.” See Norman K. Denzin, *Interpretive Interactionism* (Newbury Park, CA: Sage, 1989), 83.

using relevant theological and other resources, and analyze *strategically*, developing a *telos* informed by theological commitment – the “critically-held theory-laden practice” described by Browning.²⁷

The practical theological process is an invitation for we who think and act in a faith context to see what is happening, to consider what may lie behind what is happening, to ask whether this is faithful to our self-understanding as disciples of Christ, and to develop a vision for practice that truly embodies the life of discipleship. This idea has been further developed by a number of persons in the practical and pastoral theological fields, scholars such as Bonnie Miller-McLemore, Pamela Couture, and Joyce Mercer, whose thoughts on the critical role played by practical theology in contemporary analysis crystallized my own understanding of what I needed to do in this work. Miller-McLemore points out that theology emerges out of experience, and that it is sustained by more than historical and philosophical work. Other sources of human knowing, including experiences of faith, experiences as members of cultures or communities, and formal knowledge through the social sciences and other disciplines *all* can inform theological thought, just as they inform people faced with the ordinary dramas of life.²⁸ Reflecting these approaches to practical theological process, this project seeks also to contribute to practical theology as an academic discipline that can help to inform practices and sustain faith.²⁹

²⁷ Browning, 7.

²⁸ Miller-McLemore "Practical Theology."

²⁹ See Miller-McLemore, "Practical Theology," for an exposition of practical theology as an academic discipline, as well as description of how practical theology is used in today's North American context. Miller-McLemore's description points to the complexity of practical theological work.

Pastoral Theology Emphasizes Human Pathos

While recent developments in practical theology represent a significant step in critical thought about the interrelationship of beliefs and actions on multiple levels, pastoral theology brings us even closer to the human person as a dynamic individual existing in dynamic contexts, including but not limited to the context of the faith community.³⁰ This is the true locus of this study. Pastoral theology is understood here as a subset of practical theology marked by focused attention on human pathos, or deep emotional experience, and on what this experience says to theology. Thus, this work attends to a wide range of emotional experiences associated with raising children with disabilities, including joy, pain, and many emotions in between. These are addressed in part via what has been called “the shepherding perspective,” a pastoral outlook that focuses on healing, sustaining, guiding, reconciling, liberating, nurturing, and empowering individuals within a congregation in the life of discipleship.³¹

Additionally, recent efforts unite pastoral theology with what has been called public theology, which seeks not only to analyze but also to influence the wider social order.³² As public theology, pastoral theology must name and respond to injustice and pain in ways that contribute to a greater good envisioned in the light of the kingdom of God. It is a way of bringing a Christian perspective to bear on the

³⁰ Miller-McLemore, “Also a Pastoral Theologian,” 813-828.

³¹ See, for example, Carroll A. Watkins-Ali, *Survival and Liberation: Pastoral Theology in an African American Context* (St. Louis, Mo.: Chalice Press, 1999).

³² Bonnie J. Miller-McLemore, “Pastoral Theology as Public Theology,” in *Christian Theology in Practice: Discovering a Discipline* (Grand Rapids, Mich.: Eerdmans, 2012), 74.

wider community. It questions norms of power and oppression that may further injure the most vulnerable, and names a social ethic that encourages flourishing for individuals and communities.³³

All of these inform this project. Pastoral theology is a work and a ministry for both the church and the world. Thus, while this project seeks to help congregations recognize the complexity of care for and with families of individuals with disabilities as both a practice and a theological and political construct, it does not intend to focus only on more effective care within congregations. People live within complex cultural and social contexts of which their congregational life is only one part. A public theological outlook, therefore, demands that we engage the broader context of structures, policies and practices within the world – not just the church. In this dissertation, pastoral theology is enacted as public theology in a way that reflects this description: “The pastoral task with regard to the world is twofold. First, in the manner of a good theology of culture, it involves discerning the quasi-religious norms and assumptions behind all acts of care, pastoral and secular alike. Second, it requires articulating alternative public norms derived from the Christian tradition.”³⁴ And so this is a work of practical, pastoral theology that seeks to move toward public theology by articulating a vision for a richer, more just life of care, informed by the Christian tradition’s vision of a kingdom of justice and mercy – a life that can contribute to the flourishing not only of families of children with disabilities, but to all.

³³ Robert H. Bonthius, “Pastoral Care for Structure – As Well As Persons,” *Pastoral Psychology* 18, No. 5 (1967): 10-19; Rodney J. Hunter, “Pastoral Theology: Historical Perspectives and Future Agendas,” *Journal of Pastoral Theology* 16, No. 1 (2008): 7-30.

³⁴ Miller-McLemore, “Pastoral Theology as Public Theology,” 87.

Qualitative Approach Offers “Thick” Understandings

The project is grounded in qualitative research, for the sake of facilitating a theological analysis of care in the context of disability that is deeply rooted in human experience. It [uses original case study research to show that disability-focused theological work needs to attend to concrete particularities of human life.](#) [To that end, the project](#) employs three case studies of three families that each includes a male youth with autism. The case study approach entailed interviews with parents, youths, pastors and lay people who had relationships with the families,³⁵ supplemented by quantitative and qualitative data drawn from an earlier study of youth and young adults with intellectual and developmental disabilities.³⁶ In terms of ideological orientation, the case studies begin with a conviction that families and faith communities exist within an overlapping, interactive, meaning-making relationship that is deeply embedded in and influenced by wider cultural ideals and concerns. Practically speaking, the case studies focus on practices, emotions, and theological commitments associated with the challenges of caring for and with persons with disabilities.

Data are used to construct a thick description of families living with disabilities, especially focusing on how they give and receive care. This thick description,

³⁵ I was not able to interview a layperson from House of Deliverance, the church of one of the families intended for interview and proposed in the IRB, because there was no layperson who had a relationship with James, their son with autism. Reasons for this will be explained more fully in Chapters 1 and 2.

³⁶ Strengths, Supports, Spirituality and Well-Being among Youth and Young Adults with Intellectual and Developmental Disabilities (SSSW). Study recently completed at the Vanderbilt University Kennedy Center. Principal Investigators: Professor Erik Carter and Courtney Taylor. Each of the families involved in the larger study and in this one gave significantly of their time and limited energy to make this work possible.

supported by content analysis of theological, biblical, historical, and philosophical sources, comprises the material that supports the pastoral theological labor of this work, helping the discipline to think more deeply about care – of its core concepts – and to do so in the context of families facing disabilities.

Structure of Project

The pages ahead examine the habitus of care experienced and practiced by these families, their faith communities, and others around them. Chapter One introduces the stories of families experiencing autism. It asks how families raising children with autism experience and make meaning in the midst of the challenges and joys of everyday life. Chapter Two moves [forward from the case studies into analysis of family experience to consider](#) how the experiences of families of children with autism reveal cultural understandings, ideals, and values related to the human person, the faith community, and God.

Chapter Three [steps behind contemporary experience to study](#) biblical and theological traditions related to disability, asking what lies behind the matrix of meanings uncovered in Chapter Two. This involves both historical Christian and social traditions and contemporary manifestations of and challenges to that tradition. As noted earlier, contemporary theological thinking related to disability has been primarily theoretical; in addition, scholarship historically has focused on physical disabilities. There is a need for practical, experientially informed pastoral theology related to developmental disabilities such as autism. [The chapter argues that the Christian tradition's relationship with disabilities has been at best ambiguous and sometimes even harmful. This reality makes a movement toward care as a](#)

[framework for understanding and responding to disability, which is the subject of the next chapter, critical.](#)

Thus, Chapter Four offers the most concentrated focus on care, introducing historical, ethical, and theological perspectives on care and considering how the care tradition intersects with family experience. The chapter is guided by critical questions about care, including meaning, history, implications, and relationship to theological understandings of divinity, person, and community. It presents important and serious challenges to the notion of care as an ethic and practice, and seeks to respond by considering why, given a painful history of often-misguided care associated with disabilities, the church should still lift up care as a guiding framework for its existence. [Theological perspectives drawn from the Christian tradition can support this approach, and some of these are explored in the following chapter.](#)

Chapter Five [argues that there are](#) theological resources [in the Christian tradition](#) that [can](#) deepen our understanding of disabilities and care, especially in terms of pastoral theology related to care for and with families facing disabilities. Resources include writings by Dietrich Bonhoeffer, the twentieth-century pastoral educator, theologian, and Nazi resister who was himself profoundly impacted by an experience in the 1930s at a community for people with disabilities and their care providers. Echoes of this experience ripple through his more widely-known work on resistance and discipleship. Bonhoeffer offers rich insight into the nature of the human person and what particularly vulnerable persons can teach human communities. Additionally, some of the practices of John Wesley, whose insistence

on the radically universal nature of the love of God and the inseparability of faith and love, have much to teach communities about welcome and the labor of care that welcome demands. These, amplified by late-twentieth century feminist thought, connect care with theological thought and practice, in ways that speak to disability experiences.

[And so finally](#), the concluding chapter returns to family experience, asking what the perspectives presented in the past five chapters might provide for pastoral and public theological thinking on disabilities. In particular, the project concludes by enumerating several key qualities of care and especially of care as *cura*, and inquiring what a deeper understanding of care might offer to pastoral and practical theology in contexts of disability (and beyond).

Attention to Disability Illumines Human Condition

In the preface to the second edition of *Childhood and Society*, Erik Erikson makes a simple point that he thought had received inadequate attention. He wrote that he wanted to help people to *see*. In that context, it is obvious that Erikson meant he wanted people to understand the complexity of human development. Less obvious, but perhaps more critical – Erikson sought to help readers understand that human growth and development incorporates the environment so that the developing self increasingly represents the structures and experiences that surround it. These structures and experiences included and continue to include (but are not limited to) family, school, faith communities, peers, and work. Erikson argued that the self incorporates these structures and experiences by an inherently conflictual process in which some inclinations and tendencies become solidified as traits and personal

qualities, while others are overshadowed. External structures, in other words, become internal structures, that then continue to structure the self in its relations with the wider world.

Similarly, this dissertation seeks to help people *see*. For example, I hope readers will see more clearly that many families of children with disabilities often struggle to flourish.³⁷ Individuals with disabilities are treated in ways that deny their full humanity. Congregations and pastors are unsure of how to respond. There is room to develop richer, more faithful understandings and practices related to disabilities. But also important is the fact that this “not-as-it-should-be” situation is not an unfortunate but inevitable circumstance; rather, it represents a modern habitus that frequently limits care to either an emotional response or a private, medical concern best attended by experts informed largely by assumptions derived from a modern American commitment to individual rights in a contractual society. The “structured structures” predisposed to act as “structuring structures,” as Bourdieu put it – the habitus of human response to disability, the structures and environments and responses that we incorporate into our own continually developing selves -- often have abandoned the families of people with disabilities to their own resources, and frequently have told them, explicitly or implicitly, *you are not welcome here, and you are on your own*.

By reading the narratives that follow, pastoral leaders can see and understand life experiences of families facing disabilities. Attention, accompanied by recognition

³⁷ Flourishing, in this context, involves positive engagement with others, with self, and with God.

that care is needed, is the beginning of care.³⁸ The human community, and especially the community of the church, needs to attend to the manifestations of care and lack of care experienced by families of people with disabilities because this complex habitus reveals much about how we understand what it means to be a human person created in the image of God. Moreover, this type of attention offers insight into how Christians understand God's call, especially in relationship with some of our most vulnerable brothers and sisters and those who live with and love them. By attending to this habitus it becomes clear that there is a significant gap between common practice, which has largely absented itself from the lives of those living and working with disabilities, and stated Christian commitments such as the goodness of all of God's creation, God's call to care for those in need, and oneness in the body of Christ. And while the gap is worth exploring, it also needs to be diminished.³⁹

Social Location in Contextual Theology

Theology that arises from experiences related to disability is a type of contextual theology. In any contextual theology, there is often an assumption that the theologian has some sort of very direct experience with the context under study. While this assumption can reflect a postmodern epistemological bias toward personal experience and the individual as the arbiter of understanding, it also reflects the tragic reality of power differentials in knowledge. The world often is not kind to nondominant groups – groups like women, people of color, people with differing abilities, people of nondominant sexual orientations – and this lack of kindness has included a universalizing attitude toward knowledge reflective of a

³⁸ Tronto, *Moral Boundaries*, 19, 104-108.

³⁹ Plantinga Pauw, 40-48.

white, male, heteronormative, abled perspective. Because of this, it is helpful to explain why I felt called to write a pastoral theology around family experience with disabilities. Briefly put, I do not “fit” the assumption.

Rather than having a disability myself or having a child with a disability, I have more peripheral but still close experiences. I have epilepsy, a chronic medical condition that, historically, before the era of anti-seizure medication, was often devastatingly disabling.⁴⁰ Because of my epilepsy and the medication I take to control it, my children were at greater risk for developing disabilities in utero, and I experienced early pregnancy as a sharpened mixture of blessing and concern. Additionally, I have a nephew with autism, a relative who has an intellectual disability due to a traumatic brain injury, and friends who have children with Down Syndrome. Finally, I am a former pastor who has worked with adults with a variety of disabilities, and families continuing to negotiate the complex contours of caring for adult children with disabilities. None of this is unusual. More than one in four families has a relative with a disability, and it is most likely that all people will experience disability at some point in their lives.

More interesting is the relative quiet from the church⁴¹ on the subject, over the centuries and still today. For while theologians have produced reams of writing taking up questions such as what it means to be human (anthropology), and how we understand the divine (theology), they have, until very recently, done little reflecting on how those developed understandings “work” in a context of intellectual disability, neurological diversity, or physical difference, for example. Moreover,

⁴⁰ Epilepsy is still extremely disabling to some people.

⁴¹ References to “the church” are meant to convey a sense of the broad, institutional, Christian tradition.

practices of church throughout history often have been more damaging than helpful. The church has, over the centuries, sometimes encouraged institutionalization, sometimes encouraged “weeding out” hereditary “lines” deemed damaging for the “fitness” of humanity, and more lately mostly stood by in the wake of the explosion of autism diagnoses, for example, or, farther back, the de-institutionalization of tens (or hundreds) of thousands of people with intellectual and developmental disabilities, leaving care mostly to families – when there were families available.

In considering disabilities and care, the church must learn from the past, listen to the present, and envision and move toward a richer future for all. This perspective reflects my own identity as a Wesleyan Christian. I am convinced that when we are faithful we work in responsive relationship with God for our own transformation and for the transformation of this world. This has driven me in the long work of this dissertation and in my ministry.

People of faith are called to deep and sustained attention to the practice – the habitus -- of care, including care with people with disabilities and their families. This habitus of care often fails to reflect Kingdom values of love, justice, and compassion. And we are fallible, always living somewhere between the ideal and the real. We cannot -- and will not – “master” care and then move on to the next practice, just as we will not “master” prayer, or discernment, or any other rich and meaningful practice. As practical theologians Craig Dykstra and Dorothy Bass so wisely said, “While the point of most human practices is the achievement of some form of mastery over a specific kind of conflict or chaos, Christian practitioners do not *master* death in the practice of dying well, or enmity in the practice of

forgiveness, or sound in the practice of singing our lives to God. Instead, in trying to engage in such practices faithfully and well, they seek to enter more fully into the receptivity and responsiveness, to others and to God, that characterize Christ and all who share in the new creation."⁴² By attending to the practice of care, Christians act in ways that are receptive to God's work for the coming kingdom.

⁴² Craig Dykstra and Dorothy C. Bass, "A Theological Understanding of Christian Practices," *Practicing Theology: Beliefs and Practices in Christian Life* (Grand Rapids, Mich.: Eerdmans, 2002), 28.

CHAPTER 2

BOYS, FAMILIES, FAITH COMMUNITIES, AND DISABILITIES

Introduction

Nolan, James, and Zeb⁴³ all have autism-spectrum disorders (ASDs). They are teenagers. They are active members of churches near their homes. They live in or near a mid-south city with a growing population, each in a two-parent family that defies the increased likelihood of divorce among parents of children with autism.⁴⁴ In these and several other characteristics, they are similar. But their particular experiences – as members of families, as students at schools, and as congregants at local churches -- are distinct.

Zeb, for instance, holds a prominent ministry and leadership role in his church. He is an acolyte. He carries the cross during worship, helps serve communion, and leads and guides younger acolytes. His pastor says his practice is to treat all children equally, including the several in his congregation with disabilities. This includes Zeb; one child with Down syndrome; several with fetal alcohol syndrome; a couple of children with diagnosed attention deficit hyperactivity disorder; and perhaps others with ASDs, as well. Zeb recently graduated from a well-regarded suburban high school after years of struggle to discern precisely his challenges and how to address them. At the time of our interviews he had just begun his freshman year at a nearby small private college.

⁴³ These are pseudonyms, as are the children's last names, the names of their parents, pastors, and adult friends, as well as their churches and schools. Other identifying details also have been modified to protect these individuals and their communities.

⁴⁴ See Sigan L. Hartley, Erin T. Barker, Marsha Mailick Selznick, Jan Greenberg, Frank Floyd, Gael Orsmond, and Daniel Bolt, "The Relative Risk and Timing of Divorce in Families of Children with an Autism Spectrum Disorder," *Journal of Family Psychology* 24, No. 4 (2010): 449-457.

James also has autism, though his autism is more severe than Zeb's. James's congregation admires his exuberance in worship. When he enters the sanctuary his face lights up. When he sits, his body leans toward the front, where the praise team and the preacher hold his attention throughout the two-hour service. He is quick to jump to his feet, shout and dance during worship, and to put his offering eagerly in the collection basket. He says he loves his pastor, the people at his church, and God. His pastor's wife did not know he had autism, and others in the church have expressed disbelief about this to his parents, and told them James "is fine."

His mother, however knows a different story. Ever since a frightening experience when, as a young child, James escaped a children's worship setting, ran outside, and was lost in the parking lot for several minutes, she does not let him out of her sight at church. James is a student at a small, private, Christian high school, a choice that meant "a financial sacrifice" for his family, according to his mother. The family decided to place James in that school after years of variable experiences in public schools. James was slated to attend a public high school with more than 2,500 students, where his mother feared he might feel lost and overwhelmed.

Like Zeb and James, Nolan lives with autism, but this does not mean he is not heavily involved in activities that matter to him. For example, Nolan was recently confirmed at his church. In preparation for this event, he joined the youth group and received a companion to help him stay focused during youth group events. This companion was a licensed clinical social worker who has experience working with youth with ASDs. She assisted Nolan in making choices about behavior, guided him when he felt overwhelmed, set limits for his participation when necessary, and

helped him understand the confirmation curricular material. Before she began her time with Nolan, she visited his home and asked his parents if she could read school files and any other information they had on Nolan, because, as she said, “he’s going to be mine.” During the confirmation preparation process, Nolan, like all participants, also received a mentor who was a spiritual mentor and guide -- and simply an adult friend. Nolan recently completed middle school and began high school, where he will continue to have a one-on-one aide to help him stay focused and learning in the large, busy setting.

Each Is Unique

Each of these youths, each of their families, and each of their faith communities is distinct. The families, and especially the faith communities, are whole systems, in which qualities and values reflect one another and influence practices. This chapter describes the youths, their families, and some of their experiences within and outside of their faith communities. The chapter focuses on who the boys are, what their lives are like, how their families experience caring for someone with an autism spectrum disorder, and how all of these components interact to create systems of care and relationships around these families and their sons. Special attention is paid to the role of the church in each of these boys’ lives. [This attention to concrete particularities is critical to the development of a sensitive response to disability that is attentive to the gifts and needs of each child and family.](#)

The Nelsons

Nolan's parents introduce him to anyone who will spend significant time with him via a four-page document called "Nolan notes." It starts like this: "Nolan is a friendly 14-year old who loves being with other kids, taking care of animals, and playing games on the iPad."

He is, indeed, all of these things, and this is important to remember. Leaders who work with people with disabilities call for "person-first" language because human communities often have failed to anticipate strengths and complexity among persons with disabilities. Even the most intentional among us can make this mistake. As a scholar who cares about justice and well-being for people with disabilities, I am embarrassed to admit that I did not anticipate how cognizant Nolan would be of conversations going on around him. This error readily emerges from unconscious assumptions about individuals with autism as well as the general insensitivity mentioned above. Autism is a "spectrum" disorder, comprising relatively mild to quite severe symptoms that may change over time, but it seems likely that the more severe manifestations are the most well known. In fact, when James' stepfather first met James, he wrongly assumed James would spend most of his life screaming and banging his head against the wall, unable to relate to those around him. It is common to assume that someone living with autism – someone like Nolan, or James, or Zeb -- would be so disconnected from his surroundings that one could have an in-depth conversation about him in his presence.

This is not true of Nolan or any of the boys involved with this project. They all are quite aware of what is being said around them; more importantly, there is no

reason to assume they – or anyone with a disability -- is not capable of this. So when I arrived at the Nelsons' house just before dinner on an early spring evening, and saw Nolan in the yard, by himself, independently preparing paints and poster-board to make a sign for an event at school, I realized my plans needed to change. This was not a youth who should hear a researcher ask his parents about what caring for him is like, about their struggles and joys, about how his autism has impacted their lives. These questions needed to be revised, and quickly. Not many 15-year-olds want to hear their parents talking about him in such ways. Few parents want their child to hear how his challenges have challenged them.

My erroneous assumption represented a remarkable insensitivity, an insensitivity that is not only unkind but also unaware that what we understand as a *disability* can carry with it fine gradients of many *abilities*. This lack of awareness can hurt, and Nolan and his parents already experience social rejection and isolation. A researcher's insensitivity could have amplified their suffering. Assuming uniform incapacity in persons with disabilities is an unfortunate reminder that despite idealistic commitments to care and human flourishing, human beings often fall short.

Adjusting the interview plan quickly was difficult and did not feel productive at the time. Despite sharing dinner, meeting a family friend, talking with everyone including Nolan, and joining in the weekday evening routine, I left convinced I had not gotten much of value out of the encounter. I was wrong.

Nolan can't be left alone, but, as mentioned, he understands what is going on around him. This can be a challenging combination. About five minutes into dinner

he got fidgety and was allowed to move to the kitchen counter where there is a small television for him to watch. "It's exactly what families should not do," says his mother, Nadine, "but it's how we get through dinner." Sometimes Nolan makes socially inappropriate or awkward comments, such as the time near the end of the dinner when he was using the bathroom (with the door open) and yelled "Dad, is 'piss' a bad word?" He is also kind and loving. An animal lover, he drew a picture of a fish with a blue marker, labeled it "Nemo" and gave it to me as I was getting ready to say goodbye. "You've just been adopted," his mother said, and smiled. The family friend – someone the Nelsons met when they were a part of a church they ultimately had to leave – treated Nolan as one might treat any 15-year-old youth, which he is, in many ways.

Keeping him safe: In other ways, however, Nolan is very different from a typical 15-year-old. It could arguably be said that for all parents, keeping a child safe is a primary responsibility. But for parents of children who are developing more typically, the responsibility shifts over time. Issues change; basic safety likely occupies less focused attention; and as children become youth and young adults, they begin to share this responsibility. For the Nelsons, however, keeping Nolan safe continues to be a primary aspect of care. The issues have indeed shifted over time, at least in part, but significant time and attention continue to be devoted to keeping Nolan safe. And for others who have significant relationships with Nolan, keeping him safe is sometimes a large aspect of that relationship.

Danielle, for instance, the church member who claimed Nolan as "hers," was not guided by a "gushy sentimentality" as she described it. "I'm not up for having to pet

disabled people,” she said. Instead, she shepherded him, “herding him back,” to help him focus in Sunday school and confirmation class so that he wouldn’t wander off and get into trouble (or head into the nursery and play obsessively with young children’s toys).⁴⁵ She also sets boundaries in planning his church involvement. For example, she gives him few opportunities to be around younger children – not only because of their toys, but because, as a middle-schooler, he exists in a world of surging hormones, crude language, and limit-pushing. And because, as a person with autism, he has less impulse control than a typical 15-year-old boy. His parents note that he is obsessed with women who have a particular look, especially women of color, and that he wants to – and has – come close to some and touched them on their arms. “That’s as far as it has gone, but it scares the crap out of us. Kids with autism often get in trouble for sexual stuff,” his mother says.

Danielle affirms this concern, noting that she has had clients who have gotten into trouble for inappropriate comments or touching, sometimes made with little or no intentionality but because peers who knew of their disabilities encouraged them to do so, usually even feeding them language or provoking actions. To protect Nolan and others, she has emphasized the importance of keeping him with age-peers.

Again, inappropriate words or actions made by youth with developmental disabilities rarely result from predatory tendencies, but may happen because they are curious teenagers with very low impulse control. Keeping Nolan safe, therefore,

⁴⁵ Like many children and adults with ASDs, Nolan sometimes fixates on particular toys, topics, or media, and, as is also not unusual, in his case these are items that are developmentally young. He is particularly interested in toys and television shows appropriate for preschool-age children, especially the Teletubbies. His parents strictly forbid access to these things, not only because it further alienates him from his peers, but also because once he gets involved with them, it is difficult to stop him – taking away the toy or turning off the show often results in temper tantrums and other challenging behaviors. They note, however, that he is very skilled at getting around their restrictions.

sometimes means keeping him safe from himself. “Caring means to be sophisticated, multi-dimensional, intellectual, non-naïve. I’m not going to care someone into a situation where they end up arrested,” Danielle emphasized.

Sometimes, of course, keeping Nolan safe is more basic. Because he can entertain himself safely for longer stretches of time than he used to be able to manage on his own, his mother occasionally forgets some of his challenges when they are at home, especially if they have been “on a roll,” as she says, really enjoying each other. But when they go to a store, or another public place, she knows she cannot give him as much freedom as other parents can give “typical” 15-year-olds.

They have had some frightening experiences when, despite her best efforts, Nolan got away from them. She described a recent incident when they went to a nearby grocery store, which was to be followed by a visit to the hardware store across the street. Because lists and schedules that plan and regularize the order of the day help Nolan to stay calm, they went with a plan, and he knew it. When they were in the grocery store parking lot, Nadine turned around to get the reusable shopping bags out of the car. When she looked again, Nolan was gone. She went in the store to look for him. As she walked the aisles, she began to panic. “I’m running up and down the aisles, calling his name, calling his name.” Finally, she thought he might have walked across the very busy street to a favorite hardware store. She went in, and he was there, at the counter, with the “old hippie guy that runs the place, and he looked down over his little hippie, round glasses, and said, ‘He was safe here. He will always be safe here.’”

Working on relationships: Nolan's voice carried across the café at Calvin Presbyterian Church as he walked sideways, backward, and forward, toward the counter where dozens of mugs sat waiting to be filled with coffee, tea or hot chocolate. He was focused on a peer, rather than on the pathway, and barely avoided colliding with chairs, tables, and people.

Like many children with disabilities, Nolan's circle of relationships is small, and, also like many children with disabilities, the circle has shrunk and the distance between him and his peers has grown over time.⁴⁶ "When the children he knew were riding tricycles, or even bikes with training wheels," Nolan generally could keep up with them, said his father, Matthew. Now, a confluence of factors separates Nolan from his age peers. He continues to want to see and play with developmentally immature media and toys. Besides the Teletubbies, he plays with his extensive supply of Playmobiles, and "most 15-year-olds would be horrified at that," Nadine said. He has little interest in common teen pastimes, like popular music. Matthew bought an MP3 player and stocked it with about 100 songs teens Nolan's age were listening to, but Nolan barely listened. And his social skills do not mesh with peers'. He recently asked if someone from school could "come over and play," and Nadine had to explain: "fifteen-year-olds don't play. They hang out. They don't play. But that doesn't really register with him."

Relationships – helping Nolan to build and maintain them -- is a labor of care for Nadine and Matthew. It's a labor that takes an emotional toll. Nolan wants friends.

⁴⁶ Benjamin T. Conner, *Amplifying Our Witness: Giving Voice to Adolescents with Developmental Disabilities* (Grand Rapids, Mich., Cambridge: Eerdmans, 2012) depicts the profound disconnection often experienced by youth with developmental disabilities. Conner, *Amplifying Our Witness*, 1-3, 21-33.

But usually, peers don't want to be friends with him. Nadine said he has no true "mutual" friendships, and the time that he does spend with peers happens because she and Matthew work to find opportunities for it – opportunities that depend on their willingness to take Nolan and others to places and activities. In fact, in the past several years, Nolan has only been invited anywhere by another teen or family once or twice. Sometimes this engenders counterproductive behaviors in Nolan, behaviors such as asking the same teen over and over for time and friendship. Sometimes it makes him sad, and Nadine and Matthew try to comfort him by saying that when they were children, they didn't have friends visit all the time. But this is difficult. Several boys he has known for years live a few blocks away. "And I see how tight their little friendship works," Nadine said. "They're always spending the night at each other's houses, and ... we're often feeling like we almost have to beg someone to spend time with our kid. It's demoralizing."

Nadine doesn't have to beg people to spend time with Nolan while they are at church. Nolan loves youth group and hanging out in the café, and has participated in confirmation and Sunday School. His pastor, Maryanne, said Nolan is "totally integrated" into the youth program of the church, and his peers accept him. The time and attention from Danielle have helped to make this possible. While she is less involved with him now that confirmation is over, her shepherding work not only kept him safe, it also freed the youth group to have an easier, more comfortable relationship with Nolan. Danielle emphasized that she did not ask the other teens to

be peer mentors.⁴⁷ She thought it could cause his behavior to regress, and perhaps impede the development of natural interaction with peers. Nolan also has relationships beyond the youth – with a college-age friend who is quite comfortable saying to him, when he starts talking about Teletubbies or another immature topic, “That’s not cool, Nolan.” And he continues to have a meaningful relationship with his confirmation mentor well after the actual confirmation ritual. Daniel, the mentor, gave Nolan a book about birds for confirmation, and continues to send Nolan postcards with pictures of animals weekly. Nolan takes the bird book with him when he and Nadine go “deer hunting” – looking for deer on warm evenings in the large park near their home. On one visit to Calvin Presbyterian I saw Nolan rush over to Daniel, book in hand, to show him pictures of birds he had seen recently. Daniel responded with questions about the birds as the two of them carefully examined the pictures.

Outside of church activities, however, it seems that Nolan is separated from peers, just as he is in the rest of his life. While Nolan participates fully in Sunday School, youth group, and, for one year, confirmation class, other church youth have never invited him to “hang out” or otherwise spend time together. Nadine and Matthew do have a friend from church who comes over for dinner and can have a comfortable conversation with Nolan, but this man -- a recent widower -- is not a peer.

⁴⁷ Peer mentors are generally typically developing youth about the same age as the youth with autism or another developmental disability, who help guide the youth with the disability in appropriate behavior, etc. See, for example, Amy J. Bohlander, Felice Orlich, Christopher K. Vorley, “Social Skills Training for Children with Autism,” *Pediatric Clinics of North America* 59, No.1 (2012): 165-174.

While Matthew and Nadine struggle to help Nolan build mutual peer friendships, Nolan does have what could be called “relationships of protection.” In Nadine’s terms, there are school peers “who have his back. He was getting blamed for doing some things wrong, like putting a lunch box in a toilet. And he didn’t know enough to defend himself.”⁴⁸ Nolan was too flustered to be able to respond truthfully to questions such as, “Were you in the bathroom?” “Did the lunchbox go in the toilet?” Under the pressure of questioning, Nadine said, Nolan “admitted” he had put the lunchbox in the toilet. But then, she said, three other boys went to the principal and told him Nolan did not do what he “admitted” he did, and that he should not be blamed for it. Matthew also mentioned a former friend, who has since moved to Pennsylvania, who used to be able to “roll with him just fine. He would take the most off-putting thing Nolan might say – we call ‘em ‘conversation killers’ – like ‘I think the Teletubbies is a good show, don’t you?’ And this kid would respond with, ‘Well, you know what I think is a good show?’ And it would just totally turn the conversation around,” Matthew said.

Community care and understanding: Calvin Presbyterian’s building is tall and white, offering an architectural grouping of rectangles with a steeple that points to the sky, and many clear windows that let in sunlight and encourage looking out upon the world. Its physical presence in the midst of an upper middle class neighborhood speaks of classical Reformed architecture, with spare spaces that

⁴⁸ Defending himself in this type of context would be exceedingly difficult for Nolan, who, besides autism, has a mild-to-moderate intellectual disability (as well as epilepsy and Tourette’s Syndrome), and needs a few extra seconds to process statements in a conversation, according to the “Nolan Notes” Nadine and Matthew give to people who spend time with him.

direct attention to God and God's call upon humankind. The style tends to look upward and outward more than inward and around.

The sanctuary, however, with its light, bright, nearly semicircular space, seems to envelop, even embrace, those who enter.⁴⁹ Many clear windows divide the walls, which are butter-yellow or pale green. On a sunny summer day the chancel is suffused with warm light. The only adornments are a large Celtic cross and long wall hangings that face the congregation, made of pale green gauze dotted sparingly by paper cranes in shades of yellow, blue and green. Echoing the hangings, several cranes also hang from the communion table. Beside the table a baptismal font made of art glass in swirling colors of blue, green and purple rests on a simple wooden pedestal.

The classic Reformation style seemed to be adapted in ways that emphasize warmth, a contemplative spirit, and artistry. The building creates what is at once a modern and a classic setting, a carefully designed architectural surprise that is puzzling until the history is explained. The church experienced a devastating fire in 2003 that destroyed the historic sanctuary as well as an almost-new, long-worked-for children's wing, and other important interior spaces. This was heartbreaking⁵⁰ for the congregation, but did offer an opportunity to create a new space while

⁴⁹ The difference between a third and a half of a circle is quite meaningful. The former evokes a sense of openness while allowing the pastor and congregation physical closeness not possible in a long, narrow sanctuary. The latter forces the worship leader, pulpit, and communion table into a position perpendicular to some of the community. It makes eye contact difficult, evoking distance, rather than proximity. Having pastored a church with such a sanctuary, I was particularly struck by the architecture of Calvin Presbyterian.

⁵⁰ It is important to acknowledge the heartbreak so common with the destruction of meaningful space. Not knowing the church's history, I expressed my enthusiasm and admiration for the design to a husband and wife, probably in their 60s, who said, with palpable sadness, that they were glad I liked it, but they deeply missed the sanctuary that was lost.

preserving heritage and meaning from the church's theological tradition. In the redesigned sections of the church, most rooms flow into one another, and views of the outdoors include a bank of windows, near the sanctuary, that look out on a small labyrinth. For Matthew, Nolan's father, the open style echoes the openness of the church and the love and care it offers all people. In this, the building and the messages it sends resonate with understandings of sacred space that note its practices of power and assumed proximity to divinity. Sacred space, in other words, signifies important values about relative roles in congregations.⁵¹ The architecture of Calvin Presbyterian, in which the pastor is simultaneously set apart from and enveloped by the worshiping congregation, and in which a feeling of openness can be said to convey welcome, carries its open spaces as an expression of its core identity.

The congregation is a "More Light" congregation, a denominational designation that signifies welcome to persons who are gay, lesbian, bisexual, transgender, or questioning their sexuality. It offers its space to community-based programs – one for seniors, and a court-sponsored one that allows parents who have struggled to care for their children to visit with them under supervision and guidance. And it simply possesses a spirit of welcome, according to Maryanne, the pastor who has been there for just over a year. Maryanne said she met with some parents of children with disabilities or other special needs just after she began her ministry at the church. She thought she would hear about a formalized program of hospitality

⁵¹ Jeanne Halgren Kilde, *Sacred Power, Sacred Space: An Introduction to Christian Architecture and Worship* (Oxford: Oxford University Press, 2008), 6-8.

and support. Instead, she said, “Katie (the youth and family minister) just made us feel welcome.”

For the Nelsons, that was enough. They came to Calvin Presbyterian after journeying through several congregations and denominations, due in part to their distinct religious histories and in part to Nolan’s needs. Most recently, they had been a part of Blessed Community Church, a new, non-denominational congregation near their home, that had grown rapidly from one service with a few dozen members to multiple services with hundreds of people. While they were there, the Christian education program grew rapidly and in ways that were not helpful for Nolan. All children were housed in one big room, which created a lot of noise and chaos that were sometimes problematic for Nolan.⁵² But the family was still attending regularly when two incidents pushed them out. First, Nolan, who loves cell phones and iPads and all things with screens, asked several people if he could look at their phones. Nadine and Matthew know that Nolan does this, and include a mention of it in their “Nolan Notes,” with explicit instructions to never let him have any phones. But the leaders at the church were not satisfied. They asked Nadine and Matthew if they could stop Nolan from asking. “I was like, ‘sure, if you can figure out autism,’” Nadine said.

Then, more troubling, Nolan made a remark about oral sex to a much younger child. Nadine and Matthew are convinced the words were fed to him by other kids, perhaps at school, because he wouldn’t have heard them at home and they are very careful with Internet use and television. Rather than speak to the Nelsons, the child’s

⁵² Many people with autism have sensory challenges, so that what typical people might experience as simply loud, for example, persons with autism can experience as literally painful.

parents contacted church leaders, who had several meetings in secret about the incident before finally alerting the Nelsons and asking if the family could attend a different service and remove Nolan from Sunday school.

Instead, Nadine and Matthew began to look for another church. Eventually, Nadine called the family minister at Calvin Presbyterian. “I gave her the whole story. ‘Here’s why we’ve left the church that we were attending.’ And she listened and then paused, and she said, and I get tearful every time I say this, she said, ‘At our church, we believe there’s room at the table for everyone. And what [you] described would never happen. We would have all parties come to a common table and talk it out.’”

The Nelsons visited Calvin and they stayed. And before Nolan began Sunday school, there was an organizational meeting for parents. After details like calendars and rules were addressed, Danielle, who would become Nolan’s shepherd, took the floor. “And she just talked about Nolan, and she’s not a forceful personality, but she was forceful in her quietness. And she said, ‘We’re gonna have an opportunity here to love a child who has a disability. We will not treat him any differently than anyone else.’” Matthew said, recounting the experience.

He paused. “Sorry, I can’t do this,” he said. Tears emerged in the corner of his eyes. He took a deep breath, and continued. “She said, ‘He could say something inappropriate.’ And she rattles off the words like, ‘blah, blah blah.’ And then she said, ‘If that comes up, we’re gonna have a meeting of you, the offended party, and the Nelsons, and we will talk it out. We will not talk behind anybody’s back. We will be direct with one another. Matthew, do you want to say anything?’ And I was floored. I got up and just gave a little ‘who’s Nolan’ kind of thing. And that was it.”

The Nelsons believe they can live their faith with a congregation that fully accepts the family and affirms what they do to respond to their challenges. Twice when I visited Calvin Presbyterian with the Nelsons, for example, their Sunday morning was cut short. One day they arrived late, after which Nolan and Matthew spent time in the hallway loading the iPad with video clips for Nolan to watch (wearing headphones) during worship. Another day Nadine worshiped alone, because a recent medication switch had disturbed Nolan's sleep. This meant he and Matthew went to Goodwill, a favorite place for Nolan, and Nadine left early to meet them. They are grateful for the affirming looks and hand squeezes they sometimes get when they have to leave during worship with a son who may have grown edgy, fidgety, or loud. And they know they are not alone. With several families facing disabilities in the congregation, they understand that they are a part of a community that must labor to make life – and a life of faith -- work.

Making it work: Making it work requires intentional effort and frequent compromise for Nadine and Matthew, at home, in the community and at church.

Matthew and Nadine have foregone higher salaries and greater professional status, for example, in favor of presence and flexibility for Nolan. Nadine works at a major research university but teaches just a couple of classes a semester and does a little consulting related to disabilities. She has two master's degrees, but has never tried to get a PhD, in part because of Nolan's needs. "I'm in a weird place vocationally, working in a climate in which the assumption is 'we sell degrees, but you don't seem to have one.' So the attitude is: 'don't you want to go on and get a PhD, or an Ed.D,' and it's like, again, I don't have any of that fire in the belly to do

that at this point in time, because I just can't see doing that for us." Matthew works at home as a freelance writer, which allows him to spend more time with Nolan and yet requires intentional planning and compromise due to Nolan's needs.

And then there are Nadine and Matthew's own needs – for restorative friendships of their own, time to themselves and together, and healthy practices. Both love to run, and even this demands strategizing. For example, they described a recent morning when Nolan woke up early, both parents wanted to fit in a run, and the dogs needed exercise. Nadine left, Matthew and Nolan played for an hour, and then Matthew took Nolan to the park. There, Nadine took over caring for Nolan, put the dogs in the car, and drove home, while Matthew used the trip home for his run. "And that sort of trapeze act is what we do all the time," Matthew said. The "trapeze act" is necessary, but it takes a toll on recreation and relationships. Matthew and Nadine have virtually no contact with a large group of close friends with whom they used to go on an annual camping trip and other social events, for example. They miss the closeness of that group, but as Nolan grew the closeness diminished.

"We went on one of those trips and it was really sad, because Nolan wasn't really connecting with the kids and the parents. And then [other parents said] 'oh, it's so good that they're older and we can just you know, sit and have a drink and they can all sort of just be running around.' And *I'd* be up and running around, or Matthew ... because of Nolan. And it was like, 'You know, I'm not experiencing that with you.'" That was their last camping trip with the group. Another tradition they have had to let go of is an annual New Year's morning brunch. "The deal was, roll out of bed and come over and it's a pot luck thing. And we had people showing up with hair in

curlers and night shirts.” Eventually, however, they realized that they couldn’t be hospitable and manage Nolan at the same time, so they ended the tradition.

Thus, the scale of their world has shrunk. Nadine said that when she can work at a local coffee shop for a few hours, “that’s like my trip to the mountains.” Matthew also reminded her what a treat it is when she can spend time with a good friend from church.⁵³ “Yeah, we went out [during] the university’s spring break, and it was happy hour and they brought two beers instead of one ... and we were like ‘whew, spring break, yeah!’ Because this is it, this is my spring break, you know?” Nadine said.

When Nadine and Matthew talk about challenges and meeting challenges with compromises and trade-offs, their stories often end on an upswing, especially when Matthew is speaking: “But we have different blessings.” “Every accomplishment is like a home run.” “There are times that are frustrating and then there are times that it’s like – ‘how sweet a moment was that?’” There is a lot of storying, or re-storying,⁵⁴ going on, almost as if they need to reframe⁵⁵ the experience of raising a child whose personhood impacts the family in ways many people can barely understand. Storying and framing – whether done by oneself, by another individual, or by a community or culture – can have a tremendous impact on emotional responses to an event or situation. Thus, it seems natural to wonder if the Nelsons are doing this for the listener, so that listeners can understand that their lives really are blessed with

⁵³ Nadine’s friend, Virginia, also has a child with significant disabilities. This friend has been instrumental in the development of Calvin’s caring practices related to persons with disabilities.

⁵⁴ Andrew Lester, *Hope in Pastoral Care and Counseling* (Louisville, Ky.: Westminster John Knox, 1995). Chapter Two, “Narrative Theory and Future Stories” presents story as an organizing principle for human life and behavior that helps persons to interpret and explain their own and others’ lives.

⁵⁵ Donald Capps, *Reframing: A New Method in Pastoral Care* (Philadelphia: Fortress, 1990), 9-13, explains reframing as a process of trying to help another (in Capps’ book, a pastoral care client) to see something differently so that he or she can respond differently.

beauty. It also seems natural to wonder if they do it for themselves, so that the meaning they make from their lives is redemptive. But redemption doesn't mean their challenges disappear. When Matthew says: "that's like care for everyone. That's like a circle of care," Nadine adds: "But it's not all sunshine and lollipops, you know."

"Feeding," in a figurative sense, seems to help. Both Nadine and Pastor Maryanne talked about "being fed." Nadine said she "gets fed" at the Bible study she participates in when Nolan is in Sunday school. Hearing others' stories, meeting people, and studying together are renewing for her. She said Matthew "gets fed" when he is able to participate in a group for fathers of children with disabilities and other challenges, which meets in the café at Calvin. She talked about the time when they often do not get fed – in worship, because of the challenges of helping Nolan to manage himself during an hour of sitting. "We've learned to take our little bits where we can get them," she said, "but that's not to say, wow, that was a wonderful, you know, worshipful experience and I feel restored and renewed afterwards. I'd be lying if I said that." Further, Maryanne said she is fed by the whole congregation, because "what they're doing has real rootedness and grace all over it." The rhetoric of feeding, which evokes images of primal care and nurture, and the experience of being *cared for* that it points to, provides a counterpoint to the significant care they offer to others – making it possible for them to "make it work."

Finally, at times "making it work" involves educating others about Nolan in particular and autism in general – the Nolan notes, for example, or Danielle's presentation to parents. These efforts help others learn about Nolan and offer strategies for responding to his challenges and gifts. Another practice that helps to

“make it work” is a T-shirt that Matthew wears when they travel. In big block letters it reads: “Yes, my son has autism. No, he’s not like Rain Man.”⁵⁶ “That shirt has bought us grace on many occasions,” Matthew said. “We almost have to say, ‘Read the label before you start interacting with him,’” he added, noting that some stereotypical behaviors associated with autism, such as hand-flapping and echolalia, can be off-putting to others. Disability activists often have a passionate resistance to labels, such as “a paralytic,” “a deaf-mute,” “a cripple,” etc. Parents of children with autism, meanwhile, sometimes say that “when you’ve met one person with autism, you’ve met one person with autism.” The point is that every person is an individual, complex and compelling, despite ability or disability. And yet, activists who have fought the use of labels tend to speak for themselves. Not all adults with developmental disabilities can do this; in this case, if only because of Nolan’s age, Matthew and Nadine speak for him. Matthew’s colloquial use of the term “read the label,” is spoken out of his care and his desire to help others to care for and with Nolan. It seems to be part of how he and Nadine are making life work, and making meaning out of blessings and challenges. For a person or a community to care in this relationship would mean to seek the grace of hearing and honoring the meaning they have made.

⁵⁶ Barry Morrow, Ronald Bass, *Rain Man*, major motion picture, directed by Barry Levinson, starring Tom Cruise, Dustin Hoffman (1988; Los Angeles; United Artists).

The Zanes

Geographically, the Zanes are quite close to the Nelsons. But factors as diverse as socioeconomic status, professions, religion, family structure, and the severity of their son's autism spectrum disorder put great distance between their experiences.

The Zanes live in a large, recently built home in a nearly complete suburban development that advertises houses at prices ranging from “the high \$800s to \$2 million.” Their house, brick with a curving walkway that runs past graceful plantings of shrubbery and perennial flowers, leads to a stone threshold and a heavy, dark wood door. Entering, I walk through a small hallway into a large room, topped by a cathedral ceiling sectioned with dark wood beams and partially ringed by a balcony. The house is very different from the Nelsons' small cottage home. Kerry is welcoming and warm as she seats me in a large brown leather couch near a fireplace, and begins to tell her story.

A long road to understanding: It is clear that years of misdiagnosis and partial diagnoses have been a part of life with an autism spectrum disorder for the entire family. Zeb's suffering [from how others respond to him](#)⁵⁷ and his family's struggles and worries were exacerbated by a long wait to learn what made Zeb so different from his siblings and peers. Zeb was “different” from an early age. When he was about two years old, Kerry realized he wasn't talking very much. He said words only occasionally, and instead pointed or made noises to indicate his needs. For a long time, the family accommodated him. When she realized what was happening, however, Kerry made a rule – no doing anything for Zeb “unless he used his words.”

⁵⁷ To refer to Zeb's “suffering” is not to say he “suffers from” Asperger's Syndrome. Instead, this statement refers to suffering that resulted primarily from others' responses to him.

It made little difference. By the end of preschool, Zeb's language skills lagged well behind his peers. People struggled to understand him, because he had trouble recalling words, often talked in circles around a subject, and linked multiple sentences into one. "We limped along," she said.

Then the bullying began. Zeb was isolated and teased. His peers called him "stupid," and "retarded." By second grade, when he was diagnosed with attention-deficit hyperactivity disorder, Zeb spent part of almost every day in the principal's office. Kerry spent hours at the elementary school and taught Sunday school at church, primarily for the opportunity to observe Zeb.

Zeb began to have almost daily panic attacks at school. He was sent to the nurse's office, frequently, and usually sat there convinced he was going to die. Kerry went to school nearly every day to try to calm him down enough so that he could go back to class. At home they had many sleepless nights filled with hours of panic attacks. Kerry saw Zeb "slipping away," she says. Kerry called a renowned teaching and research hospital nearby. After two full days of testing, they were told, again, that he had ADHD, but this time, anxiety as well. A doctor prescribed Xanax.

Kerry was working on Zeb's challenges "24/7," she said, an opportunity afforded by the fact that the family has significant financial resources. Although she owned a landscaping business early in their life as a family, her "career has been mostly raising kids," and she said she does not know how parents of children with significant challenges can manage full-time work. The schools were not much help, Kerry said, and the family paid for private speech therapy for four years, for math tutoring, and for therapy to help Zeb with his anxiety.

But they still did not know what was going on, and the years of searching were painful. “It rips your heart out,” she said, to see your child suffering and not understand what’s going on. Eventually, Kerry talked to Zeb’s therapist. She pointed out that Zeb’s speech was getting better and his anxiety was easing but he still had trouble relating to his peers. “It’s like he’s from a different planet,” she recalled saying. The therapist said, “Wait a minute. I’ve got something I want you to look at.” He produced a children’s book about autism, “and I thought, ‘Oh my God. That is so Zeb.’” Literalism, circuitous speech, running in circles, hand-flapping – traits that Zeb exhibited -- all can be indicators of ASDs. While Kerry was relieved to have answers, Zeb became depressed, and his father was bewildered. Zeb’s anxiety increased. “He thought he was ‘broken’ and he was embarrassed and felt very much ‘less-than.’ He wanted to keep it a secret.” While the family gained some understanding, Zeb’s peers did not.

The bullying continued and intensified when he entered middle school. Other children teased him, broke into his physical education locker and threw his clothes in the rafters, destroyed several calculators, threw a pair of shoes off of the bus on a band trip and even “pantsed” him on his first day of middle school, Kerry said, pulling his pants down so that “everything came with them.” Then, they *really* figured out how to upset him. Many people with ASD are sensitive to sensory experiences -- particular lights, noises, feelings or smells. Zeb hates the feel and smell of wet paper, so children threw spitwads at him. Eventually, a peer said he was going to come to the Zanes’ house and shoot Zeb. By the middle of the second quarter of eighth grade, Zeb was failing math. He could not concentrate in the midst

of the bullying. Kerry tried to talk to the school. “I said, ‘I don’t know what you’re going to do, but we cannot have this, he’s learning nothing, I’m not blaming the teacher, it’s the situation, but I need a solution.’” Rather than move Zeb to another class as Kerry requested, they moved him to the school library where he used a computer to study math by himself during the last class period of the day. Kerry added math tutoring to the emotional and speech therapy commitments.

While Kerry had hoped that knowledge would produce empathy among Zeb’s peers, Father Ronald, the family’s pastor, had a different perspective. Differences, he said, are rarely appreciated in what he calls “Perfectville.”⁵⁸ “This is a place where it’s all supposed to be great. All the colors of the brick are the right colors and there are enough trees and you hide your parking lot from the passing traffic. It looks like a garden, looks like a park.” But Father Ronald said the reality is more ordinary. “Even in there, there are addiction issues and there are special needs kids and there are husbands that murder their wives. There is a lot of pain and agony.”

For Father Ronald, struggle and suffering are part of the general spectrum of what he calls human brokenness – something we all share, he said. Clearly an important theological theme for him, Father Ronald mentioned “brokenness” at least four times in our conversations, including: “The church is a hospital for broken people,” “My vocation is the care of souls, the cure of souls. I can’t fix any of that brokenness; I have my own brokenness to deal with.” Brokenness, for Father Ronald, is not about disabilities, but is part of the general human condition.

⁵⁸ “Perfectville” was Father Ronald’s somewhat tongue-in-cheek name for the very well-off community around Canterbury. When he used the term it was clearly not meant to be disparaging but more expressive of pastoral concern for individuals and families living with the “brokenness” he also named, but feeling – correctly or incorrectly – that brokenness had no place in such an upscale environment.

Just as Father Ronald sees human brokenness as a universal quality, his perspective on practices related to disability reflect a commitment to the notion of sameness. He treats the several children in the congregation who have disabilities like everyone else, he claimed. He said he has expectations, but that they are not hard expectations, and he is willing to give everyone the same opportunities until they show that they can't or don't want to respond. This attitude probably facilitated Zeb's own ministry of sustaining ritual practice, a ministry that, quite literally, helps make it possible for Canterbury to "have church."

Having church: Canterbury Episcopal Church began as a new congregation about twenty years ago, and built its present sanctuary about ten years ago. There are no stone walls or red doors, as are often seen in Episcopal structures, but rather lots of steel beams, cement, and large expanses of glass. Flanked by parking lots, fronted with a driveway turnaround, and with secure doors to protect the children at the YMCA preschool the church houses, Canterbury's structure represents years of community building, planning, and financial giving. Inside, plain, light-colored wooden pews fill the simple sanctuary. At the front of the sanctuary there is a tall wall of dark gray brick, anchored by a large cross rising behind the altar and flanked by large windows that look out on grassy hills. The raised pulpit is off to one side to make space for the altar in the center. Communion is celebrated weekly here in accord with the Episcopal tradition. And down the center of the sanctuary there is a large aisle, so that the vergers and her assistants (the acolytes) can "bring in the church."

The vergers at CEC, Denise Canfield, works with Zeb and other children and youth, training them to perform the role of acolyte. She and her helpers, including Zeb, carry on an Anglican tradition. The role of vergers became popular in the middle ages when church space was also used for common areas and markets.⁵⁹ Because churches were sometimes bustling with human activity, the vergers needed to prepare the space for worship. She (originally he) shooed everyone to the sides. She brought the sacred articles – Bible, candlesticks, communion chalice and paten – in the voluminous pockets of a robe designed just for this purpose.⁶⁰ “They would literally sort of strap it all on, and pick up a big stick, an office stick, like you see when they go into Parliament, and bang the stick on the floor. That’s a verge. In our industry we carry a verge and that was used to clear the aisle so goats, people, whatever get out of the way so we can carry the stuff to the altar. ... Somebody had to go in there and say, ‘Okay, get out of the way, get back, make an aisle. We need to bring in and have church.’”

The acolytes follow the vergers. This is where Zeb comes in; he, too, is part of the vergers tradition – part of “making church happen.” These days, the vergers doesn’t carry the candlesticks in her pockets or shoo away merchants. But acolytes still carry in the light of Christ and light the candles on the altar. They carry in the cross, a role Zeb wanted for years, Denise said, well before he could have managed the heavy brass cross. Acolytes assist with communion. They help make worship happen.

⁵⁹ And as hospitals, hospices, and shelters for people with disabilities. See discussion in Chapter 3.

⁶⁰ Almost certainly, the vergers of the middle ages would have been a “he.” I am using “she” because Denise is the original referent in this discussion.

Each week, the verger communicates with acolytes, the altar guild, Eucharistic ministers, readers, ushers, people providing flowers, even the people who will make coffee after worship to make sure everybody knows their responsibilities. During worship, she keeps track of Eucharistic ministers, acolytes, and readers. It is a somewhat complicated administrative role, dependent for success on volunteer efforts and precise organization. It could be a role with little room for the sometimes unpredictable actions of children and youth who come with challenges related to disabilities. And yet Zeb has been able to serve as an acolyte for years and now is a team leader who trains younger acolytes, some of whom have challenges greater than Zeb's.

As Denise talked about this, her phone chimed, a 30-minute warning to remind her about an upcoming conference call. Being the verger is a ministry of love and passion – not a profession – at least for Denise. Professionally, she is a technology executive for a major international consulting firm. She squeezed in an hour conversation with me about her ministry – exactly one hour – between two conference calls on a weekday morning. Despite her intense schedule, it is important to her that she give her ministry and all of the children involved with it what they need to be successful.

“We come in all colors and flavors and so for me it's important to include everyone. I mean I could go to his mom and dad and say, ‘I don't want him on the altar any more. He can't sit still.’ But what does that tell them? That I don't care about him, that I'm more concerned about how people sit and what they do on an altar than him and his opportunity to participate. So for me it's much more important to love on

them and help them figure out how to be successful” by including anyone who wants to be involved.

Denise could not remember any major problems she found with Zeb or any of the others who also have disabilities or other special needs. Kerry does remember being embarrassed a couple of times when he laid down in the acolytes’ pew and perhaps even fell asleep. She remembers the time he walked down the center aisle barefoot, because his shoes hurt.

These are small, insignificant things to Denise and Father Ronald, who are proud of Zeb’s ministry. Denise and Kerry said Zeb clamored to be an acolyte (and was especially excited to carry the cross) from a young age. Zeb indicated that he took on the role only because his brother and sister had done so, and said that what he likes most about church is that it is “calm and relaxing; it makes you want to go to sleep.” The truth may be somewhere in between, but what matters most for this discussion is that Denise and the whole church have created a space in which children and youth who sometimes struggle to “perform” perfectly can carry in the sacred symbols so the congregation can have church.

Modeling ministry: Father Ronald seeks to model care, he said, and in so doing he models Christ who himself offered the ultimate model of care. He understands the work of a parish priest to be the embodied presentation of Jesus and values associated with him – who he was, how he lived, what he offers for humankind. Father Ronald mentioned the significance of his modeling of Jesus and of Jesus’ life and practices at least six times in a 90-minute conversation. For example, he talked about the fact that he baptized the child in the congregation who has Down

Syndrome even though baptism may not have been as “strictly necessary”⁶¹ for this child, as it is for everyone else, but that it served as a model of care for the congregation. “I’ve modeled care. I’ve modeled it in public, I’ve modeled it from the pulpit, I’ve modeled it from the lectern. And in the baptism, I gave the child permission to speak, to be himself, and that was a good model for the congregation.”

He said this modeling needs to be universal. “We cannot love only those who are easy to love.” This is clearly a core value for him. “I just see this model by Christ in so many places of caring for the broken, the person no one else cares about, caring for those who are beyond caring for themselves. Feeding the ones who couldn’t feed themselves. Touching the person that no one else will touch. And that’s what I believe I’m called to do and who I’m called to be. That’s the theology that undergirds my work. It’s the Gospel. And how dare I withhold something from someone that I want to receive myself. How dare I?” Again, Father Ronald said modeling is how he encourages care within the congregation, and that this is more effective than telling his parishioners to care for one another and others. “I’ve never had to go to anyone and tell them to accept a child – I just model it, and modeling without saying anything means they’re more likely to do it. I’m genuine about it. It’s not for show.”

Canterbury began as “an idea that emerged in my living room,” Father Ronald said, and the fact that many of its current parishioners authored the church’s founding narrative has had a broad impact on the life of the church. This reality has meant that as the congregation grew, members put significant effort into building community. It has meant that some people just weren’t interested in the new church, because not

⁶¹ This statement is worthy of reflection, and will be revisited in chapter two. Briefly, as kindly as it seemed to be intended, it also raises profound questions about identity and agency.

every “run of the mill Episcopalian,” as Father Ronald put it, wants to be a part of a congregation that depends upon commitments as mundane as setting up and taking down hundreds of folding chairs every Sunday. Finally, this has meant that Father Ronald has been the center of congregational life in ways that make a difference in how the church sees itself and enacts its identity. What has grown from Canterbury’s founding is a palpable atmosphere of acceptance. Kerry said this atmosphere is quite different from that in the church in which she was raised, where the confirmands, for example, were taught how to pray the “right way” so that they were breathing “at the right time,” where difference was not tolerated, and where family suffering often was ignored.

The same as everyone else? Father Ronald said he treats all the kids “the same,” including those with ADHD, those with autism spectrum disorders, and those who are simply working through the typical challenges of childhood and teen years. “We don’t try to normalize them. We treat your child like we treat everyone else, and that’s our normalization.” This philosophy has allowed Zeb and other children with disabilities to serve as acolytes, attend Sunday school, and participate in other activities. But Father Ronald himself pointed out a place where it did not work. Noting Zeb’s struggles to relate to his peers, he said Zeb has not been able to participate in the youth group because he is both “too brilliant” and “too eccentric” and it is difficult for him to make and keep relationships. Zeb’s mother does not quite see it like that. She, too, mentioned that Zeb was never able to “bond” with the youth group, but laid responsibility for this at the feet of the youth minister. “I tried to explain to her [the

youth minister] that Zeb probably needed some guidance, and that I was happy to help her, but she told me my help wasn't needed."

As Zeb struggled with peers at church and school, even after his diagnosis, Kerry tried to point out to him that while his Asperger's makes him distinct from "typical" people, he is also distinct in the color of his eyes, his interests and his hobbies. Zeb was weighed down with depression and anxiety after learning his diagnosis, Kerry said, until she brought home a movie about Temple Grandin.⁶² Kerry asked both Zeb and his father to watch the movie, which was transformative for their understanding. They realized that Zeb's traits were not a choice, but were part of "how he is wired," and that Zeb, too, could be amazing in his own particularity. Soon after this Zeb decided to tell his peers why he has always been "different." They finally understood, and the bullying stopped.

Kerry values Zeb's "differences," and reflected on the ways in which living with them has changed her. She said she has become more tolerant of others, more patient, and more able to accept multiple perspectives on an issue, simply because she has grown accustomed to the surprising insights Zeb sometimes offers. For example, she loves their good night ritual. Unlike many other teens, Zeb still likes to be tucked in, so Kerry sits with him and they talk. She said they have great discussions that often challenge her own assumptions. At the same time, she has been determined to help him develop so that he can function in the "real" world, which means being able to communicate and relate with others, so she pushes him a little bit.

⁶² Grandin is a woman with autism who is an animal/livestock scientist and writer/activist on behalf of people with Autism Spectrum Disorders. She is someone many people with ASDs and their families look up to as a prime example of some of the amazing things that people with ASDs can do, when they harness their gifts and strengths rather than fighting them.

The first time I met Zeb, he did not want to talk. He stood on the balcony above the leather couch, and looked down at us but would not join the conversation. Kerry encouraged him, saying: "Come on. It's not going to hurt you." Zeb rolled his eyes. He stood a while longer. Finally, he sighed and came downstairs. He told me to ask my questions, because he needed to "go back out." Kerry looked at him. He sighed again, and asked me what I wanted to know. Flustered by his obvious lack of interest, I just asked him to talk about himself.

"I like cats; I have two cats. Preferably like the gray cat, Jordan. He's nice, sleeps on my bed, purrs, doesn't hiss at me. Just wait for any second now that the cat will poke his head out over the balcony and just start meowing. But other than that I like to play videogames like any, you know, male would. And that's basically all I have to say. I mean I'm just average I guess you would say ... except I have more ideologies about different viewpoints than others."

He stopped, and began to pick at his toenails. Kerry looked at him, a little bemused. "What are you looking at?" he asked. "Nothing. Nothing." Kerry looked straight ahead, trying to ignore what he was doing. He began to talk about his "ideologies." While Christianity is his "main religion," he said he believes many things that come from outside of Christianity, and has lots of questions about some of the assumptions within Christianity. "So like for instance I guess you could say that I'm interested in how everything in the Bible at the beginning of time when it talks about the beginning and how man was made out of dirt, they take that idea and that ideal set and they've taken it from Hinduism, they've taken it from Greek, they've also taken it from Roman and they've all put that idea in there. Now I'm not saying that I believe

that we're made out of dirt cause I'm pretty sure we're not but other people might disagree with me and that's okay. Everybody's entitled to their own opinion. I'm not going to judge."

Zeb thinks deeply, which has contributed to a lively relationship between himself and Father Ronald. The priest said Zeb sometimes calls, says he needs to talk, and then comes to the office. (Kerry has to drive him, as Zeb is afraid to drive and has not yet gotten a driver's license.) Zeb comes full of questions, opinions, and excitement. And they are good questions, Father Ronald said – poignant questions that might be more advanced than those of other youth his age. When they have had conversations about the creation stories, for example, Father Ronald has told him about the commonly-held scholarly understanding that the Bible actually combines two creation stories in the first chapters of Genesis – "And he hasn't gone running from the room."

As Zeb continued to talk about his ideologies with me, he also continued to pick at his toes. Kerry, clearly uncomfortable, finally asked him to stop. "What? Why?" he asked. Then he asked if we were done. After I said we could be, he left quickly. Kerry expressed embarrassment at Zeb's behavior, but added that she has learned to choose carefully what to focus on and what to let go.

Knowing what to accept, what to push, and how to go about it is a significant part of care for Zeb. He is going to college but living at home because he is not ready for life in a dormitory. He cannot drive himself to school because of his fears about driving, so Kerry makes the 45-minute round trip twice a day. She and Stephen try to allow him to set the pace in this stage of his life, respecting his needs while also trying to

encourage more independence. Their intentional efforts to find the right balance between accepting and pushing are afforded in part by their family resources.

Zeb is lucky his family has such significant resources, Father Ronald pointed out, because they allow for time and options (some related to his Asperger's, some just general enrichment) that not all kids with ASDs have. The private therapies, the possibility of private school,⁶³ travel and family activities are expensive.⁶⁴ The time that Kerry can put into care for Zeb is time some parents might have to spend at work.

But of course, money is only one aspect of life. Two distinct themes emerged in conversations with the Zanes, both related to desires unmet or only partially met. Kerry said several times that Canterbury has been supportive in several ways. They prayed for her and the family when they were going through the years of struggle with diagnosis, and, more recently, when Zeb had surgery to address severe scoliosis. She has had offers of visits and meals during the surgery recovery period. And she said she has appreciated the informal support she felt during worship when a younger Zeb sometimes had sudden, noisy outbursts. But missing were the type of concrete supports many parents of kids with disabilities hope for in their faith communities, and which few faith communities actually provide. Kerry said she would have appreciated an extra support person in Sunday school, training in working with youth with disabilities for youth group leaders and others in ministry

⁶³ At one point, Kerry considered sending Zeb to a nearby private school that specializes in highly individualized instruction for children who learn and function differently from typical children. Some have relatively mild disabilities like Zeb's Asperger's Syndrome. The school has such a strong reputation that families move from other states to send their children to school there. Tuition and fees at the school are about \$35,000 per year. The Zanes decided not to send Zeb there, not because of the expense, but because of his commitment to marching band, which was not available at the private school.

⁶⁴ Zeb's graduation gift was a three-week European tour with Kerry and Stephen, and Kerry indicated that this was not unusual for their family. They like to ski, go to the opera, and see sporting events, all of which are out of reach or rare activities for many families.

roles, and, especially, a support group for herself and other parents.⁶⁵ Father Ronald is unaware of this desire. He said no one has ever asked for one. “You know I think about those things because every church has to have support for this, support for that. We’ve ... our best care is that we’re inclusive.”

Like the Nelsons,⁶⁶ Kerry wishes she experienced more care (stemming from deeper understanding) outside of the church. People make moral judgments about children’s behavior that often are unfair, she said. “When some kids are different, [but] they don’t look different, people jump to conclusions. They might think the kids are defiant when, in fact, they’re not. Maybe they just don’t get it ... or maybe they are so bored, they can’t see straight.” She linked this moralism to pressure to succeed, noting that when Zeb has not progressed in the same way and at the same speed as others, she has observed or felt a spoken or unspoken assumption that there is something “wrong” with him, and even that he is a “bad kid.” People need to be more accepting, she said.

The Talberts

Gail Talbert made similar comments during our interviews, but while Kerry emphasized that she has not felt others’ judgment of her and her child in church, Gail said she has. In her congregation the judgmentalism sometimes has taken on a spiritual quality, and some people have asserted that the proper response to sickness, disability, and troubles in life is prayer to “cast the devil out.”

⁶⁵ Kerry searched for a support group for years, including in the wider community, but never found one. Her desire for a support group is common – the Strengths, Supports, Spirituality and Wellbeing study found that more than 70% of parents said a support group would be helpful.

⁶⁶ This also will be part of the Talbert family’s experience, as well.

This troubles Gail. She said she is a mother who is proud of her son who happens to have autism; she does not see herself as a person caring for one who is possessed. She wishes others could see her family in this light, and also offer some support – just enough to make her feel known and cared for in all the complexity of raising a child with a developmental disability. The following section describes an early experience at her church that seems to have had a deep impact on Gail’s relationship with the church. It presents Gail’s desire that she, her son, and others with disabilities would be more fully known as whole people within the church. And it addresses what Gail is currently experiencing: the complexities of letting go and lingering questions about how to move forward in life and beyond the church’s response to disabilities.

Formative event shapes family’s experience of church: Gail has rarely felt known and loved by the human community at the House of Deliverance Church of God in Christ,⁶⁷ even after more than fifteen years in the congregation. Nevertheless, the church has been a significant part of her spiritual journey. She says it is where she became aware of God’s love for her, and where she came to truly know and love God. Her engagement there began when she was in college. As an international student from a former European colony off the coast of South America, Gail had grown up Catholic, but “it never meant anything” to her. While in college, she participated in a Bible study in her dormitory. The Bible study led her to know what she called “the real Christian ideas,” such as Bible study, a Pentecostal

⁶⁷ As will be explained in greater detail below, my understandings of House of Deliverance are limited by difficulties with the research process, including the pastor ignoring repeated phone calls requesting an interview, and the fact that there is no layperson in the church, according to the Talberts, who has a significant relationship with James.

understanding of salvation, and “knowing Christ.” She attended the Pentecostal church that was a precursor to House of Deliverance, and was baptized there during her junior year. At that time the church had a large population of international students (the current congregation is almost all African American). Except for a short time when she lived in Florida after graduating from college, she has been a member there ever since. She loves the praise and worship, and the sermons from the pastor. She takes notes during the sermon and the next day reflects on the notes, thinking about what they mean for her in her life. She prays for people, but emphasizes that she tries not to make a display of her faith, wanting it to shape how she lives rather than be spoken in words that might be perceived as an accusation or judgment. Her husband, Melvin, is a deacon at the church.⁶⁸

Worship at House of Deliverance is a celebration. The service, nearly two hours long, begins with 20 minutes of singing, dancing, clapping, and shouting praises to God, sometimes with eyes closed and faces tilted toward the heavens. A choir of about sixteen people leads the singing, accompanied by drums, keyboard and guitar. Several men sit on the chancel waiting for the pastor, Bishop Joel, to appear. Eventually, he and his wife, Renata, walk down the center aisle. Renata sits in a seat saved for her in the front center pew, near the church mothers.⁶⁹ The pastor joins

⁶⁸ Most leadership positions in the Church of God in Christ, as in other Pentecostal churches, are filled by men. For example, deacons like Melvin have significant power and authority within congregations. See, for example, C. Eric Lincoln and Lawrence Mamiya, *The Black Church in the African American Experience* (Durham: Duke University Press, 1990), 275.

⁶⁹ While “church mothers” in some African American denominations are primarily figureheads respected for their age and commitment to the church, church mothers in the Church of God in Christ historically developed significant leadership roles and deeply enriched the life of the church. Their work expanded leadership within the denomination by connecting the all male pastorate with a contingent of women. It helped maintain a healthy tension between the spiritual and the temporal by insisting that salvation be furthered by sanctification. Finally, it offered women (often assumed to be defined by homemaking) important opportunities to engage with civic challenges. Like many women’s organizations and movements

the men on the chancel, near a trompe l'oeil painting of a gate that borders a lush garden and is emblazoned with the words "maximize your potential." Church leaders repeat the theme in sermons, on the church's telephone message, and on the church web site.

The Church of God in Christ (COGIC) is a primarily African American⁷⁰ Pentecostal tradition that grew from nineteenth-century holiness movements and the twentieth-century Pentecostal movement. COGIC is by far the largest of the many African American churches and denominations that emerged from the Azusa Street (Los Angeles) revivals of 1906-1909 and 1911. Theologically it has been marked by intense attention to conversion, sanctification, and an emphasis on gifts conferred by the baptism of the Holy Spirit, as well as personal piety expressed by practices of prayer, singing, testimony, revivals, and more. Historically, though the early Pentecostal movement and many of its resulting denominations were interracial, COGIC (and others) soon became segregated into white and black communities. As it became a denomination deeply identified with African Americans, COGIC and other black Pentecostal communities developed schools and training institutes, publications, ecumenical and fraternal organizations. They fostered activist movements and organizations, including the National Council of

for autonomy and authority in many denominations, however, the COGIC Women's Department, overseen by church mothers, has experienced backlash from men with denominational power and internal corruptions of earlier ideals. See Anthea D. Butler, *Women in the Church of God in Christ: Making a Sanctified World* (Chapel Hill, N.C.: University of North Carolina Press, 2007), 2-3, 11-13, 43-45, 119, 133.

⁷⁰ While the approximately 800 members of House of Deliverance are primarily African American, there have been a few Caucasian members. Gail, who is a light-skinned biracial person from a Dutch colony island, sometimes has felt unsure of her place in the congregation.

Negro Women.⁷¹ The Pentecostal experience transformed Gail's spiritual life, and yet she struggles with ambiguous emotions about her congregation, triggered in part by an early traumatic experience.

Soon after her return to the congregation after living in Florida, Gail brought her son James, by that time diagnosed with autism, to what House of Deliverance calls Juvenile Church. When she dropped him off, she asked if the caregivers were equipped to care for a child with autism. She was assured that they were. But James escaped from the group that day and ran out to a parking lot. Gail has taken James to worship with her ever since then. He has almost never participated in activities for children or youth. The experience, she said, was too traumatic. "They apologized but I let everybody know what we were dealing with so I felt like if you didn't think you had enough staff, or you couldn't handle him, then just say, 'Sorry, I can't help you,' instead of saying, 'Okay, go ahead and sign him in.' I had signed him in, I was enjoying my service, and found out later he had run into the parking lot."

Not only has Gail taken James to worship every Sunday since the unfortunate incident fifteen years ago, she has almost never let him out of her sight. Indeed, the escape from Juvenile Church was so pivotal that she mentioned it each time I interviewed her, even during one of my visits to the church. For several years, she and James sat in a small, glassed in section at the back of the sanctuary during worship, so that they could leave easily if James grew difficult. Over several years, a couple of rows at a time, Gail and James (and, eventually, Melvin) worked their way forward toward

⁷¹ David D. Daniels III, "Pentecostals: African American," *Encyclopedia of Religion in America*, edited by Charles H. Lippy and Peter W. Williams (Washington, D.C.: CQ Press, 2010) http://library.cqpress.com/era/encyra_1633.1.

the front of the sanctuary. Now they are able to sit a few rows from the front with the other deacons. Like James, Gail's participation in the life of the church has been largely limited to worship. Gail and Melvin disagree in their assessments of the church and its care practices. When Gail mentioned that the church has never offered any specific supports to her or James, Melvin said she hadn't asked. While the parking lot incident convinced Gail that the church "was not equipped" to care for James, Melvin thought she should have given them another chance. At times, Gail talked about the church as if she was still "behind the glass," watching but not fully participating in the life of the congregation.

At our first meeting Gail said, with some trepidation, that she was not actually sure how the pastor would respond to the topic of the study, nor what he might be likely to say if he was willing to be interviewed. She was, however, quite interested in his comments because she wonders how well he knows the three of them, especially James, and what he might say about them. As noted previously, the meeting with the pastor never happened, even after weekly calls for almost five months. The church has a secretary and several other staff members besides the pastor, but my calls were never answered. Each call included a message left on the church voicemail, but no one ever called back. After the first couple of months, Melvin and Gail apologized profusely. Melvin discussed the study with the secretary and the pastor, who encouraged me to continue calling. After a couple more months of calling, Melvin brought the study up a second time with the pastor, and again he suggested leaving a message for the secretary. Finally, Melvin raised the issue with the pastor's wife, who said she was willing to be interviewed. Although the protocol for the study specified

interviews with pastors of the churches, I accepted the offer and let Melvin schedule a meeting with the pastor's wife. We met during a church visit.

Interviews with pastors were planned to be about an hour, but as we sat down, Renata said she had half an hour to talk.⁷² Quickly, I had to adjust the interview plan, and try to manage frustration over my entire experience with the church's leadership. During the interview, Renata spoke primarily about her experiences and philosophies as an educator.⁷³ She insisted that she and other leaders in the congregation do not and would not know if they have kids with disabilities, because of "all the services [they] offer," and because they "treat everyone the same." She talked about an inner-city ministry the church offers, which brings children and youth from subsidized housing to the church to engage in programs for Christian education, fellowship and enrichment. She emphasized that these children are treated like all of the other children in the congregation; they are loved and encouraged to lead a faithful, purposeful life, and to maximize their potential, she said, echoing the church's theme. At times, Renata's stories and lengthy explications of her experiences in education had little connection with questions asked about the church's response to disabilities, her relationship with James, his involvement at church, the congregation's relationship with him, or any theological understanding of disabilities.

In talking about parents of children with disabilities, for example, she said some parents do not face the reality of children's needs. "Oftentimes ... we find parents won't provide the support they need, because instead of them facing the dilemma,

⁷² Interviews with other pastors lasted about one and a half hours.

⁷³ Renata worked as a teacher, assistant principal, principal, and deputy superintendent at a school district in the southeast.

they feel that something is out of order.” In this statement, it was unclear if Renata was speaking of struggles at church, or in her school district, or about problems with all parents of children with disabilities or just parents in poverty. Because the interview was so brief, there was no opportunity to ask for clarification. She consistently called disabilities “learning difficulties,”⁷⁴ and emphasized the church’s youth ministries. She referred to James as “that little boy” (he is 17), and, while saying almost all children are gifted in some way, also described children with autism as “geeks:”

But they’re gifted. Only if they have a brain, you know, the brain damage, or brain injury, that’s about the only time they don’t have those gifts. So a child with even, you know, lots of little geeks, autistic children, and now, when I think about it, in my family I have, we have two or three geeks, and they, so they may be on that, you know, that continuum, just smart as they can be when it comes to technology and stuff, but the social skills are not what they should be.

The conversation was frustrating, but also seemed indicative of Gail’s experiences over time with the congregation – a disconnected “response” that was primarily a non-response to the lives and needs of persons with disabilities and their families. This experience, which has lasted for more than 15 years, has frustrated, hurt, and isolated Gail. She wishes she and James were more fully known in their community of faith.

Wanting to be known: James is known in one sense. His enthusiasm for worship has made him an example of powerful piety and religious fervor to those who sit near the Talberts. “I’m still being approached by people who say “I love the way

⁷⁴ Learning disabilities are one type of disability, and can include such conditions as dyslexia and attention deficit/hyperactivity disorder. Other types of disabilities include (but are not limited to): developmental disabilities, such as autism, and intellectual disabilities.

James worships. He encourages me. I can't sit still. If I see him stand up with his hands raised, I have to do something. I can't let a child outdo me. He inspires me." But Gail would like more than this. She would like the congregation to experience some sort of disability awareness program. She wishes people understood what autism is, how it manifests, and the challenges it can create for families. Instead, she has faced the insistence that James is "fine," and struggled to figure out how to respond to convictions that mental disorders are "a product of the devil." "He's not typical, our lives aren't typical, but no one's bothered to get to know us. It's like we've just been passing through, but for 15 years."

While no one has expressed convictions about the devil and mental differences in reference to James in particular, their presence in the mindset of the congregation still hurts and troubles Gail. She said she believes this understanding is wrong, and that it makes problematic statements about God and humanity.

There's goodness, that's God. There's evil, that's the devil, but we're created by the Creator, by God and things happen. Mutation, chemical imbalance, premature birth ... [these] can cause anything to go wrong in the brain. ... At times I've heard comments like, 'let's pray. Let's cast the devil out.' It may not be the devil. There's something else they're dealing with. A chemical imbalance, somebody on the spectrum, a child with attention deficit disorder who happens to be squealing and screaming because of the overstimulation. ... So [people] are not gonna talk about it ... so we say 'hush, hush, okay, I see it but I don't really see it. Let's move on. Maybe it'll go away.'

Gail acknowledged that some of her discomfort may stem from isolation and ambiguity she has felt as a mixed-race immigrant coming from a very difficult cultural context than that shared by many in the overwhelmingly African American congregation. And yet she and Melvin met and fell in love at House of Deliverance,

when she was a young, single mother with a two-year-old son with autism. At first, she said, Melvin (who has two older children from a previous marriage) was not sure he could manage to be a good father for James. All he could imagine about life with autism was “kids banging their heads against the walls,” and that scared him. Gail said she told him that their relationship was “a package deal,” and that if he could not foresee being a father for James, it might be time for them to end the relationship. Now, Gail said, Melvin says his relationship with James is “the best thing that happened to him.”

Gail said Melvin even became comfortable responding to some of James’ challenging behaviors. James used to spin on the carpet, for example, which frustrated her. “He would go, ‘Mom, Daddy, look what I’m doing.’ And then I’ll be, ‘No, stop. Please stop.’ But Melvin would say, ‘No, leave him alone. He needs that input.’ And so Melvin will get on the floor with him and they’ll do their spinning. I say, ‘Watch the furniture. Don’t knock yourself out.’ He’d do that a couple of times a week. He needed that.”

Melvin saw potential and helped to develop it. When James was three and still not speaking, Melvin thought he looked like he wanted to talk, but couldn’t figure out how. As a mechanical engineer, Melvin thought about this as a mechanical problem. “This kid is locked up,” he told Gail.⁷⁵ So Melvin sat James on his legs, and tried to teach the alphabet. For a long time, James just stared at Melvin. One day, Melvin was moving things in the house, and said the name of each thing he touched. James began to try to make the letter sound for “A.” Melvin had trouble at first convincing Gail that

⁷⁵ Gail, who is a speech pathologist, was particularly troubled by the speech issues.

James really was making the sound, but James quickly progressed to more sounds, words, counting, and even reading on his own.

Gail wishes more people saw potential in James. Like many people with autism, James has few peer relationships. Gail is convinced this reflects others' assumptions about autism. She wants him to be known as a human being, not just a teenager with autism. And she wishes others recognized that by engaging with him they could help him to develop, and enjoy his friendship themselves. This applies to experiences at school as well as at church.

While James did well in elementary school and the first couple of years of middle school (with some support), in eighth grade his teachers recommended he move to a school for students with severe disabilities. The new school was a terrible experience, Gail said. Teachers there did not think it was an appropriate setting for James, because his challenges were so much less severe than other students' disabilities, but the district would not allow him to move to another school. Then, the family was told that his high school assignment was to the largest school in the district. The prospect made Gail highly distraught. She was sure he would be overwhelmed and unable to perform up to his potential in such an environment. Because of this, she and Melvin decided to move James to the small private Christian school he now attends, and to provide tutoring in math.

Struggling to let go: Listening to Gail I was struck by an inconsistency in her understanding of God's role in her family's life. While she believes there are many natural causes for autism or other disabilities, she also has found peace in believing God is in control. Her spirituality developed around "trusting God all the way," as

she and Melvin have raised James. She also believes God trusts her. "There's a reason why I'm allowed to take care of James. God thought enough of me, thought that I'm fully equipped to care for this child and now he [God] is not going to abandon me," she said. When she prays, she thinks about her role and God's role as intertwined. She described it as a prayer that God would help her to help and love James, because James is a child of God. "I want to do right by him," she said. Renata, the pastor's wife, also said she believes God is in control, and cares for each child as a child of God, but there is a difference in the women's understandings. While Gail emphasized God's strength for the tasks she faces, Renata focused more on God's intention in placing challenges before people. Renata said God presents challenges in order to "strengthen" people.

Gail said she needs to trust God, James, and the rest of the world even more than she has in the past. Melvin insists that at 17, Gail still does too much for James. Gail explained that it is hard for her to let go, however, she believes she and James have made progress. While at one point Gail took care of almost all of James' personal needs including feeding him, cleaning up after him, making sure he showered and followed general hygiene practices, James now contributes to the maintenance of the household. He puts his clothes in the laundry, starts his own shower, turns on a crockpot to cook dinner, and makes his own bus reservations for his commute to school. Gail would like James to live on his own someday, and she thinks they are making progress toward that.

Gail continues to worry, however, about James' lack of peer relationships and subsequent dependence on her and Melvin for conversation and emotional support.

Recently, she and James went with the church youth group to Washington, D.C. Gail hoped the trip, which included visits to monuments, landmarks, and colleges, might help James make some social connections. Instead, it was awful, she recalled. James, who is always neat and often smartly dressed in dress pants, a perfectly ironed shirt, a blazer, bow tie and a fedora hat, was shocked by his peers' casual clothes. Their language made him uncomfortable. The noise and chaos of the bus were almost intolerable. And worst of all, both James and Gail thought the teenagers were rude to the people who guided their tours. "Never again," I said afterward," Gail declared. Several months later, the youth director encouraged her to let James try the youth group again, saying that the other kids were doing better. James, however, said he did not want to go again.

The experience was so uncomfortable that it seems to have made her and James wary of other social encounters. Gail would like to help James connect with other peers, but she is concerned about finding the *right* peers – she does not want anyone to hurt him. His small Christian school is beginning to be a place for these connections. She realized recently that he has been texting with another boy at the school – a first for James – and that he sometimes leads the morning prayer over the loudspeaker.

Moving forward is difficult for family and church: Gail is convinced the church needs to consider how it responds to people with disabilities and their families, not only for the sake of those who face the joys and challenges of life with a disability, but also for the sake of the church itself.

House of Deliverance reaches dozens of children and youth with tutoring, counseling, fellowship programs, and college scholarships. Renata emphasized that all of these programs are individualized. The church works to make the program fit the child, she said, but Gail hasn't seen that happen for James. Although she believes they are currently the only family in the congregation facing the challenges of autism or other developmental disabilities, she believes this will change over time, and other families facing similar challenges will appear.

She noted that the church wants to “get (more) people saved, so they will go out and reach more people,” and that if the congregation does not care for people facing disabilities, they will go elsewhere. “There will be more Jameses,” she says, and these Jameses and their families will not stay if they are ignored or treated as if the disability is the product of faulty parenting.⁷⁶ Many might face the same dilemma she faced – wanting to enjoy worship, but weary of managing a challenging child, fearing burdening others with her son's challenges and frightened when the care available cannot keep their child safe. They may decide the congregation is not worth the trouble, go somewhere else, or go nowhere at all.

Beyond her concerns that House of Deliverance is missing an important ministry by failing to respond to the reality of disabilities, Gail continues to be concerned for her son and his future. She's not sure when – or if – he will learn to drive, cook for himself, be able to get a job, or experience what Nadine Nelson referred to as

⁷⁶ The attribution of disability to flawed parenting – whether overtly or implicitly -- has a long history. A particularly damning term was coined in the 1950s to describe – and blame – mothers for their children's autism: “refrigerator mothers” which was meant to imply that these women were cold and emotionally distant. See Leo Kanner, “Problems of Nosology and Psychodynamics in Early Childhood Autism,” *American Journal of Orthopsychiatry* 19, No. 3, (1950): 416-426. Even contemporary emphases on the social construction of the self, however, can contribute to this tendency.

“mutual friendships.” She believes she cannot trust anyone else including Melvin’s adult children or other family members to care for James as she ages. Her own family is out of the country. And James’ birth father has no presence in his life.

Melvin continues to display confidence in James’ potential. He tries to set a good example for James (just as he says he has for his other sons) about what it means to “be a man, especially a Christian man.” He said, “You have to be a lot more patient with people, forgiving of people’s mistakes, and loving people even if they don’t love you and try to do your best to help everybody.” Melvin believes the opportunity to act as this role model is a blessing that gives him purpose in life. Although he disagrees at times with Gail’s assessments of the church’s response to James, he is supportive of her as a mother and they seem to embody the patience he names above.

Conclusion: Myth and Parable in Family Narratives

There seems to be a tendency, when talking about family experience with disabilities, to want to tie things up neatly by finding a positive aspect of a painful experience. Sometimes this is an important element of resistance to embedded cultural assumptions that life with a child who has a disability is unremitting struggle and sorrow. This resistance was evident in the narrative pattern frequently exhibited by all three families. Almost every story of challenge or suffering ended with or was followed by statements that brought out the grace that might be less evident to those without significant and intimate experience with persons with disabilities, but that seems to be a lifeline for families facing disabilities. In this, the families who participated in this project express their own unique experiences, but also a general human tendency. People need to find grace in situations that surprise, challenge, or

disappoint. The narrative practice of re-storying or re-framing, as earlier discussed, can be helpful in pastoral and other contexts, not only with families facing disabilities but with persons in many situations.

This re-framing expresses a grace that is real. When families, congregations, and the wider society care for and with persons with disabilities, they create openings for grace to be felt and seen. Enacting God's call to welcome, affirm, support, and sometimes challenge those who are most vulnerable among us, and providing care for one who is somehow atypical, who may challenge the time and talent resources in families, communities, and congregations, can be a blessing, and that blessing can make a profound difference in family life with disabilities – as it has, at times for the Nelson, Talbert, and Zane families. This experience was evident in their stories.

Yet, experiencing this grace can also lead to some narrative dishonesty. When our speech expresses what may be a subconscious desire to smooth out all of the rough edges of family and congregational life with autism or other disabilities, or any particularly challenging reality, this is unfaithful to the complexity and ambiguity of human experience. As Nadine Nelson says, life with autism is not all “sunshine and lollipops.” Some stories do not resolve themselves neatly and positively.

While each family expressed their own experience of grace, this chapter does not end with it, but instead poses a reflection about different types of stories that can move this project from description to interpretation. Myth and parable -- two polarities of narrative -- serve different functions.⁷⁷ Myths tie contradictions together. They take the messy parts of life and explain them neatly. They imply or even say that

⁷⁷ Herbert Anderson and Edward Foley, *Mighty Stories, Dangerous Rituals: Weaving Together the Human and the Divine* (San Francisco: Jossey Bass, 2001), xi-xii.

bad things happen to good people because God wants to make them stronger, that good people are rewarded, that the answer to uncertainty is trust. Although myths have little room for mystery, they serve an important function. They hold communities together by teaching communal ideals, and preserving personal and group identities. Parables, meanwhile, are messy and inherently full of tension -- like human life. Jesus spoke in parables, and he made no attempt to make them easy to understand or to “fit” prevailing understandings about strength and the importance of “winning.”⁷⁸

The desire to smooth out the rough edges of these stories so that they would be, ultimately, “good” stories was evident in some of the interviews for this project. Nadine, however, insists that it is not that easy, that parents of children with autism or other disabilities often have to live in a tense relationship with what they would like their lives to be, what they are, and where grace emerges in the midst of this. This more truly expresses the reality that care is work, often hard work, though it can reshape us and our lives in rich and rewarding ways. This will continue to be evident in this project as we explore more deeply the nature of care. For now, however, we shift to trying to understand theologies of person, God, and church, constructed by practices of care

⁷⁸ John Dominic Crossan, *The Dark Interval: Towards a Theology of Story* (Niles, Ill.: Argus Communications, 1975); Anderson and Foley, *Mighty Stories, Dangerous Rituals*.

CHAPTER 3

THEMATIC EXPRESSIONS IN FAMILY NARRATIVES

Introduction

Congregational practices reflect and construct theological understandings that have life-giving potential. Mentors and friends who provide time and guidance, for example, can help persons – disabled and temporarily able-bodied alike – to grow in their faith, develop skills and abilities, and contribute to the life of the church in meaningful ways. Supports for families can make a profound difference in family life, by affirming and strengthening efforts to help the family member with a disability to flourish, by relieving stress and fatigue, and, especially, by facilitating the very possibility of participation in a Christian community. These general approaches to care can manifest in numerous specific practices. Done well, such practices *respond* to the diverse challenges often presented by disabilities; *normalize* disability by reminding all persons of our universal human vulnerability; *provide channels* for human strengths to shine in ways that honor the goodness of all of God’s creation; and, most of all, *affirm the value of all people* by indicating that each person is important and irreplaceable.

Sadly, this potential often is not fully realized. Without careful attention to particular needs and strengths, practices may manifest insensitive attitudes that idealize human uniformity. Without general acknowledgment of the many ways in which life can challenge all persons, practices may subtly construct victim-oriented identities for those with the most visible needs. Without commitment to participatory ministry for all people, people with disabilities may be “used” in

ministry in ways that trivialize and patronize. Most critically, without basic attitudes of welcome, empathy, and gratitude, practices may imply, at best, mere tolerance for difference rather than loving relationship – or, at worst, may simply hurt.

Because practices of care (and their absence) have such profound potential both to support life and to deplete it, they must be analyzed critically, asking how they construct meanings and reflect unexamined beliefs, and how these constructed meanings and unexamined beliefs fare in conversation with understandings of God's desires for human persons and communities. Thus, this chapter critically interprets what the previous chapter presented: family and congregational experiences with disabilities and care. While Chapter One offered family stories -- thick descriptions of family and faith community practices, experiences, and feelings related to disabilities, this chapter synthesizes three major theological themes from the stories and looks for understandings of these themes manifested in congregational practice. It asks such questions as: What does one congregation's failure to respond to a traumatic event indicate about the congregation's understanding of what it means to be a human person, and what the congregation values within human persons? Or, what does one pastor's willingness to devote hours to theological conversations with a precocious young boy indicate about his understanding of human diversity?

Within the family stories presented in Chapter 1, there are many themes worthy of examination. This chapter, however focuses on theologies of the human person (anthropology), God (theology), and the church (ecclesiology), because they are basic to the experiences of the Zane, Talbert, and Nelson families, [and foundational to human existence in community](#). The chapter looks at anthropology through the

lenses of trauma, informed by the concept of “grievability,”⁷⁹ and desire, seeing desire in this case as a quality of human relationship expressive of persons’ urge for human relationship and valuing of one another. The chapter argues that liberative pastoral practice acknowledges the reality of trauma and its effects, and affirms that all persons, including persons with disabilities, are valued, or desired, simply because they are created beings. In considering theology, the chapter argues that common distinctions between God’s intimacy with the created world vs. God’s power and authority over the created world are less important than pastoral and congregational embodiment of and commitment to God’s universal and steadfast care for all human beings. Finally, in considering ecclesiology, the chapter argues that congregations that practice authentic care have the potential to create environments in which all persons can grow and develop, often in ways that are surprising and profoundly life-giving. This section also addresses a distinction between congregation-centered and pastor-centered churches, and argues that care practices may be more sustainable in a congregation-centered community.

Ultimately, these three themes and the analysis of them points to the need for compassionate, caring relationships that support and sustain growth and that affirm the value of all persons.

This analysis continues the practical theological process of describing, contextualizing, systematizing, and renewing theological practice. Additionally, the

⁷⁹ Judith Butler, “Violence, Mourning, Politics,” in Judith Butler, *Prekarious Life: The Powers of Mourning and Violence* (London, New York: Verso, 2004) xii. Butler is writing in the wake of heightened American nationalism following the tragedies of September 11, 2001. Her insights, however, seem highly appropriate for reflecting on understandings of what it means to be a human person in the context of disability. Her work addresses the value of life and lives in the wake of trauma, and the question of which lives are desired and valued.

analysis also draws on a pastoral theological commitment to the significance of human pathos. Finally, it uses these approaches to consider the stories of the three subject families for the sake of renewed, liberative pastoral practice. Unlike the previous chapter in which each family's and each church's stories were told individually to illustrate their distinctions and diversities, and in which themes were named but not critically examined for meanings and implications, this chapter uses the family stories to develop thematic expressions. In each major section, therefore, emphases found within families and faith communities are sometimes similar, sometimes vary, and sometimes even conflict. This thematic organization allows readers to see points of entry for the reconsideration of practice that are less bound to individual family stories, and more expressive of general understandings.

Anthropology

Pastoral theology regards the human person as a being of rich complexities, many challenges, messy internal contradictions, deep suffering and wonder-full joy. It sees the person implicated in other theological concepts, and thus insists that the person is worthy of extensive study. This is powerfully evident in the narratives presented in the previous chapter. In a theological context, therefore, anthropology raises many issues and questions, including the general nature of humanity, the function(s) of human creation, and the *telos*, or end, of human life.

While there are many anthropological themes that are worthy of study and that can feed the questions that help us to understand who we are and who we are called to be, this chapter focuses on trauma and desire. As themes, trauma and desire highlight what is valued in human life, who is valued, and what is the cost of a

general human tendency to devalue some lives. In this, they are deeply intertwined, as are many theological issues. Additionally, these themes represent some of the most powerful experiences and feelings cited by the families in the case studies from this project, and demand that we question the ways in which faith communities have – and have not -- offered care for and with families facing disabilities.

Trauma

The American Psychological Association defines trauma as personal experience “that involves actual or threatened death or serious injury ... or witnessing an event that involves death, injury, or a threat to the physical integrity of another person; or learning about ... threat of death or injury experienced by a family member or close associate. ... The person’s response to the event must involve intense fear, helplessness, or horror.”⁸⁰

Soldiers in wars experience trauma. Victims of sexual abuse experience trauma. Parents who feel powerless to protect their children, for one reason or another, also can experience trauma.⁸¹ Trauma can have long-lasting effects. It can cause symptoms such as hypervigilance, re-experiencing the traumatic incident in flashbacks, nightmares, or some other way, numbness, isolation or avoidance of other people, and more. These impacts often are exacerbated when opportunities to

⁸⁰ From DSM-IV-TR.

⁸¹ Understandings of trauma have evolved over time. Earlier, trauma was limited primarily to experiences of extreme violence or near-death. Sexual abuse, for example, was not considered traumatic. Presently, some people contest the emphasis on death or injury, saying many experiences that lead to long-lasting suffering can be considered traumatic.

process pain and fear are neglected. Conversely, reflecting on trauma and other forms of injury creates an opening to consider potential connections to other human beings through shared vulnerabilities, which can overcome the often-isolating effects of suffering. This can lead to deeper awareness of and greater empathy for others who are particularly vulnerable to trauma, those whose health and bodily well-being are easily damaged and those whose racial, sexual, physical, mental, or other traits often feel alienating to more typical majority populations. It also provides insight into the ways in which human life is valued and devalued.

Both the Talbert and the Nelson families had experiences in their faith communities that could be considered traumatic, but they experienced different outcomes. Gail Talbert experienced both trauma and long-term inattention to trauma, which compounded her suffering. The Nelsons were hurt during a traumatic experience at a previous faith community, but they found their way to a community in which shared vulnerabilities were highlighted and healing began. Both experiences point to the unfortunate reality that some lives are treated as more “grievable” than others.⁸²

A “grievable” life is one that is regarded as both human⁸³ and irreplaceable. While a person who is seen as less than a person cannot be fully (or even, at all) mourned if they or their gifts are lost,⁸⁴ grievability insists on the humanity of

⁸² Butler, 31.

⁸³ To see a person’s life as “human” may seem obvious, but the humanity of persons with disabilities actually has been questioned throughout history, as will be discussed in the following chapter.

⁸⁴ Butler, 32. In saying this, Butler points to an affinity between the question as considered by people who are sexual minorities, and those who are “physically challenged.” Unfortunately, she does not include people with developmental or intellectual or other types of disabilities in the statement, which I would argue reinforces what she is trying to avoid, and speaking against – the devaluing of persons who are not

another and argues that none of us is who we are apart from others. “If I lose you, under these conditions, then I not only mourn the loss, but I become inscrutable to myself. Who ‘am’ I, without you?”⁸⁵ Seeing and accepting persons with disabilities as grievable, therefore, demands a willingness to see “them” in “us;” to see that even people who have been regarded as less than human influence us in myriad ways that reverberate throughout our lives; to see and to accept that one has been changed by the presence of that person, *and* that one would be changed by their absence as well.⁸⁶ This is made difficult by cultural attachment to “able” bodies and minds, and antipathy to vulnerability. Unfortunately, those who fail to recognize the other in themselves deny that other’s humanity, often contribute to their suffering, and risk unacknowledged loss of their gifts.

For the Talbert family, trauma and inattention to trauma set a tone for 15 years in a church in which Gail has felt little known or understood. Her son’s escape from the nursery and into the parking lot was very traumatic for her. Moreover, the incident went virtually unaddressed. The church leadership never inquired about or responded to her trauma. There was no pastoral conversation, no invitation to reflect on her feelings about the incident, no collaborative effort to develop a prevention plan. The incident, in which a two-year-old child was endangered, seemed to have made little or no impression on those involved. Gail’s realization that she had inadvertently allowed James to walk into danger by placing him in “Juvenile Church” while she was “enjoying the service” continues to stir intense

“typical.” While this likely is inadvertent, it points to the persistence of images and understandings of what is required for one to be considered a human being that devalue persons with disabilities.

⁸⁵ Butler, 22.

⁸⁶ Butler, 23.

emotions in her. These emotions impact her participation in the church. Moreover, because the church has not engaged issues related to disabilities, Gail doubts that she would have an empathic community with which to discuss the traumatic experience or the challenges of parenting a child with autism.

Although the church leadership never acknowledged the incident, several weeks after it happened a worker approached Gail and asked her to give them another chance. Gail refused, and has kept James with her at church ever since. Gail said the church's non-response indicated that the event did not seem to matter to leaders. They were quickly ready to move on, to resolve within themselves any lingering concerns about care for particularly vulnerable children, and what the implications of this might be. These practices of non-response to trauma produce and maintain categories of valued and devalued human beings, and raise questions about "what counts as a livable life and a grievable death?"⁸⁷

While the Nelson family's experience of trauma did not involve the threat of imminent bodily harm as Gail's did and thus probably would not fit any official definition of trauma, it did involve a sense of powerlessness and the destruction of optimism about and attachment to their young congregation. Additionally, it seems to have heightened the family's awareness of how far they might need to go to protect their son. The trauma, in this case, involved a loss of trust.

The secret meetings about Nolan's sexual remark in Sunday school, followed by the sudden request months after the incident that the family attend a different service and take Nolan out of Sunday school, felt like a betrayal that they were

⁸⁷ Ibid.

powerless to prevent. It destroyed the strong relationship the Nelsons had developed this up-and-coming congregation, and it triggered their exodus from the church. While the Nelsons agree that Nolan's sexual remark was inappropriate and demanded a careful response, they also think his life, emotional well-being, and spiritual development are important enough that they should have been consulted after the incident. Instead, the church's actions implied that one child's well-being was more important than another's; that is, that the leadership of the church was more concerned for the children who overheard Nolan's remark than they were about Nolan. Not only did this indicate a lack of affirmation of their own child as a person and thus point to the devaluing of some lives, it precipitated such hurt and anger that it made it difficult for them to grieve the other child's experience. Instead, the Nelsons were left foundering in a sense of uncertainty about their role and place in the congregation, and their own grief at this was denied and discounted. They seem to have sensed that a place that could not trust them to work for the best for all children could not be a life-giving place for their own child and their family.

The Nelsons left the congregation and eventually landed at Calvin Presbyterian. There they were able to talk about their traumatic experience. Their feelings were affirmed, and they were promised that any conflicts or incidents at Calvin would be answered with collaborative conversation, negotiation, and planning for future challenges. That promise was later affirmed at the meeting described in the previous chapter in which congregants were reminded that Nolan might say or do something inappropriate. It was emphasized that this would not lead to private conversations and negotiations, but instead would initiate a process of care,

concern, and shared reflection about how to prevent similar incidents in the future. The church's response created a climate of welcome and care, and emerged from a conviction that each person, no matter what type of personal traits they may display, is fully human and irreplaceable.

These traumatic experiences and their effects represent ecclesiastical failures that precipitated pain and/or danger for the children and their families, as well as significant losses for the congregations involved. Moreover, they indicate a troubling theological anthropology, in which trauma is discounted and some lives are valued more than others. House of Deliverance scarred its relationship with Gail by encouraging her to believe her child would be safe in their care, by failing to ensure that he was safe, and, perhaps most significantly, by neglecting to hear and affirm Gail's suffering, the after-effect of her trauma. The incident and the church's lack of effective response to it cost the congregation any opportunity to engage James beyond worship. Meanwhile, Blessed Community Church offended Matthew and Nadine by working behind the Nelsons' backs to direct Nolan's involvement in the church after his inappropriate comment. This response led the Nelson family to leave that church. Both congregations might have been deeply enriched by James' and Nolan's gifts, and challenged to reassess their understandings of human persons – of “whose lives count as lives, and what makes for a grievable life.”⁸⁸ Through intentional affirmation of *all lives*, the congregations might have been inspired to attend more deeply to care for and with those society often deems less than valuable. Instead, by their actions and inactions these congregations made what is

⁸⁸ Butler, 20.

likely an unconscious but nevertheless egregious theological choice: They cast doubt upon the worth of some human lives – a position at odds with the love of One who has known and accepted each of us even while we were still “in (our) mothers’ wombs.”⁸⁹

Desire

As a theme, desire offers insight into the human condition. We desire that which we value; that which interests, intrigues, and excites us; that which – or those whom – we want to become “a part of” us, rather than “apart from” us. Desire has become an important theme and topic of study in many fields that draw from feminist perspectives, including feminist theology. In these contexts, examination of desire often has focused on human sexuality; general human development; or choosing between or against desires.⁹⁰ Using the language of desire in this project, therefore, is provocative, as the project does not focus on sexuality. Yet, it is an intentional choice. While a term such as “value” or “honor” does express the idea that someone is seen as having merit, “desire” more fully expresses the complexity of human relationship. In this case, desire points to priorities expressed by faith community practices and expressions of care (or their lack), *and* expresses the deep yearning described by families of children with disabilities that these children be seen as *desirable*. In other words: Value, interest, intrigue, and excitement come together for

⁸⁹ Psalm 139:13, Old Testament, New Oxford Annotated Bible, New Revised Standard Version (New York: Oxford University Press, 1991) 793.

⁹⁰ See, for example, Katherine M. Franke, “Theorizing Yes: An Essay on Feminism, Law, and Desire,” *Columbia Law Review* 101, No. 1 (2001): 181-208; Alisdair Macintyre, “Vulnerability, flourishing, goods and ‘good,’ in *Dependent Rational Animals: Why Human Beings Need the Virtues*, 63-79.

both communities and individuals in the concept of desire. We will not grieve that which – or those whom -- we do not desire.⁹¹

The three families involved in this project articulate, in multiple and diverse ways, desire as an aspect of personhood. No matter what language they use, individuals have desires, often for human connections as well as purpose and possibility in life. Parents, especially the parents in this project and in the wider quantitative and qualitative research of the “Strengths, Supports, Spirituality and Well-Being” study from which this project grew, yearn for others not only to befriend, recognize gifts in, and care for and with their children – but for others to *want to do so*. They know that many people are not interested in their children; in fact, are uncomfortable with or judgmental of them, and they grieve this, even as they are sometimes told, in subtle and less than subtle ways, that their children are not “grievable,” because they are not desired.

It should be said that none of the families involved with this project used the word “desire.” Yet, the families presented multiple desires, including: a desire to be known as whole persons; a desire for communities that accept and understand their challenges, and care for them in the midst of these challenges; and perhaps most of all, a desire that their children be seen as desirable.

Simultaneous with the experience and expression of desire are other emotions: Grief, as parents described experiences in which their children were seen as problems to be managed – or dominated – rather than individuals with desirable gifts that can enrich the world; and anger, as they described times when strangers

⁹¹ Butler, 20.

and acquaintances judged their parenting, or the parenting of others, rather than exhibiting kindness, a form of care that begins with the desire to know another and that other's story.

Grief and anger at the world's responses are a familiar experience for people with disabilities and people who love them. For generations people and cultures have indicated, through harmful practices and hurtful words, that they do not desire people with disabilities, a fact that has been reinforced through the vehicle of stigma.

The problem of stigma: The notion of stigma and its social functions⁹² comes originally from ancient Greece, where branding and cutting were used to mark those whose moral or social status was questionable or shameful. Slaves, criminals, and traitors, for example, were branded or cut to indicate that they should be avoided, punished, or abused.⁹³ More recently, stigma has been described as an attribute of a person or group that reduces that person or group's identity and value. This understanding is evident in common language such as "a failing, a shortcoming, a handicap."⁹⁴ Stigma can be related to body deformities, individual character, or assumptions about what reveals individual character, including mental illness and developmental disabilities, or race, ethnicity, or religion. Those who are stigmatized are seen as not quite human, and thus are subject to discrimination of many types. They are not desired as a part of human community, and their undesirable status

⁹² See Erving Goffman, *Stigma: Notes on the Management of Spoiled Identity* (New York: Simon and Schuster, 1967), the classic work on this concept.

⁹³ Goffman, 1.

⁹⁴ Goffman, 3.

contributes to factors that reduce the likelihood of flourishing.⁹⁵ There is a reciprocal relationship between stigmatizing beliefs and practices, as there is between theological beliefs and practices, so that stigma occurs because some persons engage in practices *and/or* hold beliefs that mark particular attributes of other persons as problematic, shameful, or discrediting.⁹⁶ Stigmatizing beliefs and practices build, reinforce, and amplify one another.

Moreover, stigma emerges from relationships. Persons with lighter skin, for example, have long engaged in practices that marginalize and sometimes terrorize persons with darker skin, despite the fact that there is no reason to assume that persons of color are inferior to persons of Caucasian origin and/or identity. Thus, the historic stigma associated with darker skin is not essential to any person, but is maintained by generations of self-reinforcing prejudice and discrimination. Similarly, persons with disabilities and those who love them have struggled for thousands of years against stigmatizing beliefs and practices that reflect cultural assumptions much more than they do any traits and of individuals.

Zeb's peers, for example bullied him to the point of threatening death. Their use of degrading violence and oppression exhibited discomfort with human difference – in this case, difference from the high-achieving context of apparently “typical” children and adults in Zeb's well-off suburban community. In many ways, Zeb did not “fit” his context, and thus his peers did not desire him as a friend or even, apparently, as a peer. Their actions, therefore, reinforced a stigma often seen around those who think and act in atypical ways. Additionally, these actions constructed an

⁹⁵ Ibid.

⁹⁶ Goffman, 2-4.

identity *for* Zeb that precluded development of his own self-identity. He saw himself as “weak, pathetic, weird” because he was treated as weak, pathetic, and weird. The school administration’s response, detailed in the previous chapter, was to sanction and further isolate Zeb rather than work to help those who bullied him to develop greater understanding about themselves, human difference, and the damaging effects of their actions, as well as deeper empathy, kindness, and care. This response may have protected Zeb from physical harm, but it did nothing to challenge the prejudice embodied in his classmates’ stigmatizing practices. Moreover, as is evident in Zeb’s story, stigma is self-reinforcing: When Zeb responded to bullying with angry outbursts that at times seemed nonsensical to those around him, they were further convinced that he was “different” in ways that made him inferior to others – and thus deserved further bullying.

Similarly, the Nelsons grieve Nolan’s friendlessness, born almost certainly of the stigma of difference. Nolan desires friends, but he speaks and behaves in ways that make him undesirable to his peers, and, thus, stigmatize him. The result is that his parents say they are demoralized by feeling as if they must beg people to spend time with their son. They felt this stigma and lack of desirability in their previous faith community, where Nolan’s inappropriate remark labeled him as a problem to be managed, and could have led to isolation that would have hurt him emotionally, thus limiting his opportunity to flourish. Their current faith community, where they feel desired as a whole family, is a bright spot in the midst of their challenges. Even there, however, Nolan lacks what his mother described as “mutual friendships,”

those friendships in which each person can contribute roughly equally and that can transcend the boundaries of church or school. Nolan is desirable, but only to a point.

For all three of the families in this project, mutual relationships have been a struggle, but this is most visible in James' family. James had a friend, but she moved away. For a long time, he had no friends, and insisted that he was happy that way, despite his parents' worries about him. Just recently, a nascent relationship seems to have arisen with a classmate. James' mother is considering how to respond. She is not sure how far to go in her involvement in the relationship. She wonders, for example, if she should offer to take them to movies or other activities. With no experience navigating a teenage child's friendships, she seems to worry that she will simply reinforce the stigma that has made James undesirable to so many for so long. She wonders how James and the new friend might each grow from the relationship, and if the potential for growth makes the risk of mistakes worthwhile.

This relationship emerged at school, but in church James is more anonymous. No one seeks a relationship with him. He is desirable only in his ability to function as an example of religious fervor. He "loves the Lord." He "encourages" people. He "inspires" people, because they "can't let a child outdo" them. The congregation desires James as they want James to be, not in the fullness of his being. James is clearly passionate about his faith. The congregation clearly has no ill will or evil intent. But members and leaders miss the fact that James is not *only* passionate about his faith. He also goes to school, loves cars and electronics, has a fantastic memory, and is learning how to be more self-sufficient. No one in the congregation

knows this, because they only know – and only desire to know – one small piece of who James is.

It could be said, in fact, that the members of the congregation have extracted what they want to see in James, what is useful for them, while ignoring or avoiding other details. This is not a relationship that honors the whole of who James is; it is one in which his person has been constructed as a type, and it implies that it is only in performing to that type that he is a “grievable”⁹⁷ human being, that is, one whose full humanity is fully recognized and who would be grieved if he were lost.

The goal of reciprocal grievability: This understanding of grievability and reciprocity in relationships is evident in the experiences of Daniel, a layperson at Calvin Presbyterian who mentored Nolan through confirmation. Daniel’s interview for this project occurred well after interviews with the family and visits to the church. This meant that I brought a significant amount of background knowledge and reflection time to our interview, more than for any other conversations. His words, therefore, were particularly poignant. Virtually everything he said implied or specified reciprocity in the relationship between himself and Nolan. He talked about thinking carefully about a confirmation gift, and realizing that a bird book would be perfect because of Nolan’s love for animals and the possibility of connecting that love with a general sense of wonder about God’s creation. He talked about the two of them developing a shared language in order to understand one another. He corrected himself when he began to say that Nolan struggles with transitions, and said instead that “he transitions a little slower than other people.” He talked about

⁹⁷ Butler, “Violence, Mourning, Politics,” 20.

the challenge of relating with someone who doesn't always relate back, or doesn't always relate in an expected way, and how this can make one question the value of this type of ministry. He also talked about his first hug from Nolan, saying it was the best thing that happened to him on what was already a great day. He went on: "I just feel blessed that God chose to talk with me in this way." That is, through Nolan.

As Daniel spoke it was clear that traces of Nolan have entered and transformed Daniel as a person, just as traces of Daniel have contributed to Nolan's own formation. They are who they are in part because of who each has been to the other. And they have developed an attachment important enough that each desires the other – desires to be both "with" and "a part of" the other. This type of desire shapes a grievable life, because it insists that we do not exist independently from one another.

This is also love. It is not love because it is warm, kind, "sweet," or any other sentimentality. This is a relationship of love – and, therefore, desire – because it is a relationship in which each is seen and desired in his individual complexity and particularity. Daniel sees Nolan as a person with the potential to change the world by sharing his own "language," and helping others to learn that difference is not necessarily a "lack." But Daniel also sees Nolan as someone who needs to be steered away from the Teletubbies in the nursery. And he loves all of this that is in him. Love is the expression of desire, the fulfillment of the desire to be desirable, and a "compassionate regard that draws near and attends to the beloved for its own sake

and with its good in mind.”⁹⁸ It requires that we adjust, that we are willing to receive another in his or her particularities, no matter how unfamiliar these particularities may feel. Love makes us move beyond any economy of equal exchange, and into an economy of grace.⁹⁹

This love animates the relationship between Nolan and Daniel, and others. We remember that when Father Ronald at Canterbury Episcopal Church shared his philosophy regarding Zeb and others in the congregation with disabilities he said he treats everyone “the same.” Danielle, too, the member of Calvin Presbyterian who guided Nolan through many of his youth activities, said something to this effect about Nolan. But while this represents their philosophies around the value they perceive in individual human beings, it clearly is not how they practice ministry in a diverse context. Both people – one a lay person, one a clergy person – responded to individual qualities, needs, and strengths in ways that are sensitive and affirming to child and parent.

Father Ronald listens to Zeb when Zeb needs to talk through his intense intellectual thoughts and feelings related to religion. He will spend an hour in the grocery store conversing with a young adult with autism. He allowed a girl with Asperger’s Syndrome -- a young girl who loves babies -- to work in the nursery, and convinced the congregation it would be not only safe, but a positive experience for children, parents and the girl herself. Danielle engineered a significant system of care for Nolan. In their respective ministries, Father Ronald and Danielle display the

⁹⁸ Thomas Reynolds, “Love without Boundaries: Theological Reflections on Parenting a Child with Disabilities,” *Theology Today* 62 (2009): 194.

⁹⁹ Reynolds, *ibid.*

distance between theory and practice that is evident in this project and often in historical understandings of and practices toward people with disabilities in general. While the church and society have not always lived out ideals of love and justice for the most vulnerable, Father Ronald and Danielle have acted in ways that bring the church's ministries well beyond "treating everyone the same." It is possible that reflection upon their actual practices of responding to people in ways that recognize and affirm their particularities may eventually inform Danielle's and Father Ronald's theologies.

This is a theology of human personhood, one that is embodied in various ways in faith communities, and that is present at Canterbury Episcopal and Calvin Presbyterian churches.¹⁰⁰ This theology insists that all persons are human, vulnerable and valuable; that trauma is painful and that the pain of trauma is compounded by inattention and disregard; that persons desire to be desirable in all of their rich complexity and particularity. And this theology insists that this desire, its fulfillment, and the recognition of the human person that makes that person's life grievable – is love.

Understandings of God and Their Implications

The theology of God focuses on consideration of who or what God is, how God interacts with the world, God's purposes in creating, what God desires from human beings, and how human persons come to know and understand (or if we can understand) God. Over time, these questions and others have been manifested in

¹⁰⁰ It is troubling to imply that this theology is not present at House of Deliverance. It may be in ways other than those that relate to this study, but within the context of considering care and disabilities, it was not evident.

beliefs and practices that reflect and construct a variety of understandings and emphases, focused generally on *content* and *method*. In the area of *content*, God has been understood, for example, as sovereign, continuing to exert power and control over history; transcendent, distant from the vicissitudes of everyday experience and relating to human beings and all of creation from afar; immanent, involved in creation in ways that emphasize closeness; intimate, desiring human relationship and movable by human will and desire; and more. In reflection upon *method*, meanwhile, some reflection processes prioritize historic teachings, especially within the Bible, seeing these as solely sufficient for theological thought and practice, while others include a strong emphasis on human experience and emotion.

These varying emphases in theological content and method continue to be constructed and reflected in practices, thoughts, and feelings related to disabilities. For example, they lie behind questions about the existence of disabilities (Why do they happen? How is God involved? How can we know?) and they shape reflections upon God's expectations for human response to disabilities. Because theological thinking both informs and is informed by practices with potential for significant impact upon the lives of persons facing disabilities, these varying emphases are important to consider within the context of this project.

God who transcends and makes change

Theological practices and traditions that represent and construct a transcendent, sovereign, providential God were evident in each of the case studies, though each manifested this emphasis in different ways.

At House of Deliverance, for example, the exuberant music that began worship was followed by a resounding set of questions and answers:

Can anyone honestly say God has not been kind to them?

No!

Can anyone honestly say God has not blessed them?

No!

The assumption in this church is that God is strong enough and active enough to bless, and the congregation seemed to know this at a very deep level, despite the historic and continuing racism perpetrated upon African Americans. The congregation's passionate commitment to a God who looks with love upon bodies that had been and often still are treated as less than human spoke volumes about the power of faith not only to support and strengthen, but to provide a discourse alternative to that of the majority white culture. While the western world's dominant discourse has insisted that the bodies of Africans and African Americans are little more than a scourge, created only to be used by the powerful, the discourse spoken in House of Deliverance said: "No. We are valuable. We are blessed. We have received and will receive grace that overflows our capacity to understand."

Other expressed beliefs also spoke to understandings of God as powerful, in control, distinct from and yet active in everyday life. For example, Renata's insistence that God places troubles before us "to strengthen us," implied a purposeful manipulation of the course of human events for reasons known only to God. This God of strength might choose to make people weak or strong, well or sick, able or differently-abled, and yet, judging from the discourse of gratitude at the beginning of worship, continues to bless. This is also a God whose distance affords a

certain freedom from creation, human or otherwise, but who may be persuaded – and is able – to alter circumstances at will.

This perspective is consonant with the Pentecostal tradition, which prioritizes the power of God expressed through the Holy Spirit and subsequently embodied within individual believers. The fact that Renata raised the idea of God strengthening through troubles may imply that she sees disabilities as a “trouble,” and believes God does, too, but that through these “troubles,” persons are or can be changed for the better – perhaps made holy. While Gail also voiced belief in the strong, transcendent God, her iteration of this did not assume disabilities were “trouble,” but focused on the privilege of being entrusted to care for a child with particular vulnerabilities. She agreed with the general tenor of her community, expressing belief that God is “in control,” but said nothing about suffering. Instead, Gail’s salvation-focused theology emphasizes God’s freedom to save or not to save, and points to challenges as a way in which God trusts persons to make a difference in human life.

At Canterbury, Father Ronald’s theological understanding of disabilities – what he actually called a “non-theological understanding” -- also spoke of a transcendent God, but one less sovereign and less providential. Exhibiting the faith in science probably more common than not in upper-middle class, predominantly white, Western communities, Father Ronald said he has “a scientific understanding” of some disabilities. In his understanding, Down Syndrome is caused by an extra chromosome. Autism has a genetic etiology that we do not yet fully understand, and

fetal alcohol syndrome is caused – seemingly simply enough – by the consumption of alcohol during pregnancy.

This understanding may contribute to a sense in his work and in congregational practices and understandings that God is unlikely – or unlikely to be able – to override chance or poor human decisions. Thus prayer is more likely to be focused on peace and comfort, rather than petition for change, healing, exorcism, etc. – but not exclusively. One practice that arose in my conversations with Kerry was the wearing of a cross, and prayers focused on Zeb’s depression and anxiety during the time when he was being bullied. Kerry asked Father Ronald to bless the cross, and Zeb wore it every day. “It really helped with the anxiety and depression,” she said. Belief in God’s ability to alter human experience guided her use of the cross and her own prayer. A sense that this “worked,” in turn, solidified her belief in God’s active presence in human existence.

At Calvin Presbyterian meanwhile, God generally seemed to be understood as more immanent and intimate, active within and through the congregation’s practices of care and hospitality. And yet there were moments when a more transcendent God-understanding was evident. A recent church bulletin, for example, included a petitionary prayer asking God to “remove the blindness from our eyes.” The language seemed to express trust in God’s power and potential to make revolutionary change in which the faithful are opened to a world only slightly antecedent to the Kingdom of God. And yet, this statement is a striking construction given the congregation’s general sensitivity to disability concerns. Even classic images of spiritual need and struggle can stigmatize and hurt when they employ

impairments as a vehicle to express spiritual or other inadequacies. This prayer's presentation of blindness as something that must be healed in order to achieve spiritual maturity, therefore, is worthy of consideration. While it might merely indicate a belief that human beings are powerless without God, to someone particularly sensitive to disability-based stereotyping, it could be a troubling statement. Whatever precise assumptions were carried within the statement, they indicated a powerful, providential (if not transcendent) God.

God Drawing Close

A theology of God that emphasizes immanence brings presence and involvement in the human life to the forefront. This is not generally a controlling presence, however. Instead, the theological focus is less on power and more on closeness. This understanding of God in intimate relationship with human beings creates an opening for a sense of mutuality in the God-human relationship, in which persons may act in concert with and on behalf of God to bring God's justice and mercy to humankind, and in which individuals and communities are strengthened to persevere through difficult times. This is God present, relational, attentive, and empathetic. This theology was evident in varying degrees in each family and at each church.

For Kerry Zane, for example, frequent practices of prayer engendered an absolute conviction of God's constant presence. She said these practices and the sense of trust that developed with them in the midst of very dark and difficult times allowed her to survive the rough years when Zeb was being tormented by bullying

and by his anxiety and depression. She said she did not know how she would have survived without trusting that God was walking with her. Although she said life with Zeb's autism has smoothed out significantly, her prayer practices and her understanding of an immanent God in intimate relationship with her and with other persons continues to provide comfort.

At House of Deliverance, meanwhile, the congregation and leaders seemed to be guided by their conviction that while God is powerfully providential, the Holy Spirit manifests intimacy with God, which is typical for Pentecostal/Holiness traditions. The Holy Spirit provides strength for life's journeys, and the conviction of the Spirit's presence includes a conviction that one who "loves the Lord," can and should be an example for others.

Renata does not lead the youth program, but she is active in it, engaging youth in classroom settings and offering informal encouragement in casual conversations.

She discussed one of her recent visits with the youth:

I asked [them] 'How many of you love the Lord?' They all raised their hand. There must've been about thirty of them in the room. I said, 'I know you believe you love the Lord, because I see some of you all celebrating Him. Some of you all even come up to the front of the church to celebrate, so I know you feel that you love the Lord.' I said, 'But at the same time, by the time church, the service is over, you get out in the corridor, some of you are being disrespectful to adults.' I said, 'That's not loving the Lord.' I said, 'If you love,' I said, 'How many of you have the highest grade point average in your class? How many?' I just asked questions about that. I said, 'If you truly love the Lord, then you should be able to demonstrate your love for God based on your behavior. You should be the top of your class. In terms of conduct, there should not be anyone whose conduct is any better than yours. You should be leading and showing the way.'

God's power and human beings' reciprocal love for God are invoked in this context. Together, they are believed to engender positive behavior, good grades, and

respect for adults – elements understood as markers of success. Children are not expected to succeed independently, however, even within the context of a loving relationship with God. Instead, Renata said adults must see children’s inherent gifts and capabilities, just as God does, and encourage children on behalf of God. Hence, the church has many supportive ministries for youth, some targeted at youth living in poverty. These ministries arise out of the church’s emphasis on the Holy Spirit animating the life and call of the congregation and its members, and from this immanent, intimate relationship the ministries reach children whose lives and abilities are often disregarded by society.

In a different context, when Daniel gave Nolan the book about birds for confirmation, he affirmed the possibility of God’s presence in the created world and in Nolan’s relationship with animals. The book, as mentioned in the previous section, was inspired not only by Nolan’s love for animals, but also by an experience Daniel had growing up, with his own confirmation mentor. His mentor was a woman he cared about and respected, and he appreciated their relationship. At his confirmation, she gave him a book of prayers. He appreciated the gift, but he also remembered that it mostly sat, dusty and unused, on a shelf in his bedroom. Daniel’s choice of gift, though, affirmed God’s intimacy with human beings and God’s immanence in the everyday world. By affirming this possibility -- that God could be present in ways that are deeply meaningful to people in their ordinary lives, and that God is reachable in ways other than those traditionally deemed “religious” – Daniel implied that God cares about who Nolan is and what he is about here and now.

Ecclesiologies and Their Implications for Practice

Ecclesiology focuses on understandings of the church. It invites reflection upon what it means to be a community united by faith. It asks about priorities, functions, characteristics, motivating forces, the exercise of gifts, authority, and more. Within the life of the church faith practices not only reflect but construct theological ideals, thus ecclesiology presents an opportunity to consider how a community can contribute to human flourishing in light of God's gifts and call. Whenever the community acts as a community, and whenever congregational practices are affirmed, the community further defines itself. Reflection on self-definition helps the community to develop deeper understanding of what it means to be a body inspired by the person and work of God in Christ. Moreover, ecclesial practices and understandings influence other aspects of theology, including understandings of God and the human person.

This section addresses two prominent emphases in ecclesial understandings constructed by faith community practices and stated theologies. These are: an emphasis on the congregation and an emphasis on the pastor. Among the pastor-centered churches, one focused more on the pastor's role in facilitating salvation, and one focused more on "shepherding" care. While each church had a dominant emphasis, however, that did not preclude some manifestation of the other potential emphasis named above. In fact, attention to the less dominant ecclesial understanding is important, because this can challenge the community to develop a broader understanding of what it means to be a people of God.

Pastor-centered community

Two of the three churches studied could be described as pastor centered, though this was manifested in different ways in each community. At Canterbury, Father Ronald is central to the work and identity of the church. His vocation is the cure of souls, he says, and he sees this vocation embodied in his work to walk with people and gently guide them in the midst of human brokenness. Bishop Joel of House of Deliverance, on the other hand is the bringer of the Word in a tradition that seems to see the Word itself as nearly transcendent, and has been chosen by God to fill this extremely important role. The congregation almost seems to worship him, as well as God, Gail said.

This section explores these related but distinct ecclesial understandings of the pastoral role in congregations that focus heavily on the person and work of the pastor. The roles are sustained by practices of leadership, worship, fellowship, and care and are important because they carry and manifest great power to influence the life and work of the congregation. They have the potential to make meaningful, positive differences in the lives of families facing disabilities, and even to contribute to the transformation of the wider culture in its treatment of persons with disabilities and those who love them.

A shepherd: The theology that emerges from Canterbury Episcopal Church's founding narrative and from understandings and practices of ministry and care in the congregation foregrounds the person and work of the priest. Father Ronald presented the church's founding narrative as a story of a reluctant priest who initially thought he had nothing to offer the community he described as "Perfectville,"

an “idea”¹⁰¹ that began in that priest’s living room, and years of building community while meeting in a school cafeteria where the “bringing in” so that they could “have church” *really* meant bringing in – everything. “We carried [the church]¹⁰² in and out for five years,” Father Ronald said. He said he invited and welcomed potential parishioners by offering them “a deal.”¹⁰³ “I’m going to offer you a chance to do something very few Christians ever get a chance to do and you’re going to get a chance to start a new church where no one can say ‘but we’ve always done it X and such.’”

The founding narrative was the first thing Father Ronald shared in his interview with me, and he spent a significant amount of time telling it – and then referred to it several more times later in the interview. This may be a natural focus for a priest in a sacramental tradition who planted the congregation he has served for 18 years. It clearly is an important part of the church’s identity, and was evident in congregational visits and conversations with Denise, Kerry, and Zeb.

While Father Ronald’s leadership places himself at the center of the church’s care efforts, this does not mean others do not practice care. Kerry discussed the prayer practices that happen in her women’s group and reading groups, saying these were important for her during the very difficult years earlier in Zeb’s life. Denise told a story about a parishioner’s car accident, and the congregation’s concrete practices – providing meals, transportation, hospital visits, and more – that

¹⁰¹ An “idea” was the term Father Ronald used to describe the nascent congregation, and in so doing seemed to emphasize not only the hope he and others supporting the establishment of a new church had for it, but also the creative process that goes into all beginnings.

¹⁰² “Carrying the church in” meant bringing in chairs, altar, paraments, communion vessels, and a sense of the holy – in other words, everything the congregation needed for worship and ecclesial community.

¹⁰³ Father Ronald is a former businessperson. He sometimes spoke in terms of “deals” and “selling.”

embodied congregational care and that contribute to the congregation's self-understanding as a caring congregation. But because of the congregation's history, and because Father Ronald's self-understanding includes a sense that he is modeling care for the rest of the congregation, he is central. This also means that Father Ronald has been the gatekeeper, rather than what he described as an old guard "that doesn't want their peace disturbed." He said there were certain things he would not tolerate, and people knew this.

In addition to the founding narrative and Father Ronald's self-understanding, some of Canterbury's leadership practices also evidence and construct a sense in which the priest is central. When Denise described the work of the verger, she mentioned that the person in this role can offer a major contribution in planning and leading worship, but said her work has been more limited at Canterbury. At Canterbury's worship services, there were few lay people involved in worship, with the exception of a scripture reader. Father Ronald said he wants to move lay people into more significant, authoritative ministry roles, because he is beginning to think about retirement, but that this is difficult. Finally, even Kerry's frustrated wish for a support group for parents of children with autism or other disabilities support group indicates Father Ronald's centrality in the life of the congregation. She wanted a support group, but one never was initiated. Father Ronald, meanwhile, said the congregation does not have any support groups because no one "ever asked" about it. While this may indicate that Kerry should have or could have asked for such a group, less obviously it points to a congregational dynamic in which practices begin

with the pastor, who actually may be less knowledgeable about individual and community needs than lay people.

Ecclesial practices and self-understandings that locate the pastoral leader at the center of the church's ministry seem a logical outgrowth of the church "planting" experience. A brand-new church requires a strong leader who can spearhead the congregation's organization. But it also resonates with a "priestly" understanding of ministry, which is shaped not only by the importance of the sacraments in historic Christianity, but earlier by the designated, hereditary role of the priest as the one who performed – and the only one allowed to perform -- the prescribed worship rituals of the early Hebrew cult. The Anglican tradition, with its emphasis on Eucharist and the lifetime identity of the priest "fits" this understanding.

There are strengths in this ecclesiology. As Father Ronald pointed out, because he cares (and probably, equally, because he began the church) people have adopted his model. This pattern may not be universally true, however. Even a priest who prioritizes and models care can be stymied by a congregation that has a long history of uncaring behaviors, because long-term habits can easily undermine efforts to develop new behaviors, especially in larger groups. Conversely, if the primary leader is not modeling care as a priority for the community, it seems unlikely that the congregation would naturally engage in significant care practices and subsequently develop this as a primary aspect of its identity. In the case of Canterbury Episcopal Church, both things happened. As a consequence, Kerry said she has felt deeply cared for in the family's time at Canterbury, which is almost as long as the church's history. Prayers, offers of meals, visits, and other concrete practices have helped her

to feel like she is “not alone” in the challenges related to Zeb’s autism. Meanwhile, Denise’s willingness to work with Zeb affirmed his gifts, which was deeply meaningful to Kerry.

At the same time, the priest-centered model presents significant challenges, especially in an era in which traditional authority roles and institutional teachings often are questioned. More immediately relevant for Canterbury, Father Ronald is close to retirement. If a stronger core of lay leadership (especially around ministries of care) does not develop before the priest’s retirement, the continuation of care practices for those who are disabled, sick, or experiencing other significant challenges is likely to depend on the priorities of incoming priest. Moreover, if the incoming priest does not focus on empowering lay leaders to care in ways that are truly transformative both within and beyond the congregation it seems unlikely that care understandings and practices would expand beyond kindness. Prayer groups and donations of time and money to service ministries that work to mitigate suffering caused by present injustices and vulnerabilities might continue under a priest who does not prioritize congregational care. System-changing, justice-oriented ministries that challenge common cultural practices that patronize and limit the lives of persons with disabilities, however, are unlikely to develop.

The bringer of the word: At House of Deliverance, as in other Pentecostal traditions, the Word and the pastor share a powerful role. The Word is highly important and anthropomorphized. It is dynamic, bringing about an encounter with

God, and expected to lead to salvation.¹⁰⁴ The pastor, meanwhile, “brings” this Word to the congregation. The Word is the vehicle for salvation, yet the Word is somewhat dependent on persons chosen to share it.¹⁰⁵ Thus, ultimately, and almost inevitably, the pastor is the epicenter of the church. This practice fits traditional understandings of Pentecostalism, in which the congregation’s self-identity is deeply bound to its feelings about the pastor. Also, congregational practices point to the importance of Bishop Joel at House of Deliverance. The pastor was close to a major anniversary during the interviews for this project, for example, and church deacons were planning a week-long celebration, including a major financial gift.¹⁰⁶ When Gail complained about this to Melvin, Gail said, he reminded her that the pastor deserves respect because he was chosen by God to lead.

While the pastor’s role at House of Deliverance certainly includes guidance or shepherding, he manifests his power and authority through the Word of God shared through scripture, expounded upon in preaching, and reflected upon in prayer. Preaching has the position of paramount importance in the mostly free-flowing worship style at House of Deliverance. While joyous singing, clapping, and dancing accompanied the music at the beginning of worship, once Bishop Joel began to preach the room was quiet and attentive. Everyone, it seemed, was watching and listening. Many people including Gail pulled out Bibles and pens and slips of paper to take notes on the sermon. Gail said she reads and reflects on her notes during the

¹⁰⁴Kimberly Ervin Alexander, “Pentecostals,” in *Encyclopedia of Religion in America*, ed. Charles H. Lippy and Peter W. Williams (Washington, D.C.: CQ Press, 2010), http://library.cqpress.com/era/encyra_1623.1.

¹⁰⁵ The Word, in Pentecostal traditions, is generally understood in a hermeneutic sense, historically true but also worthy of reflection and interpretation. It offers a participatory narrative that invites believers to live as actors in God’s ongoing holy story and experience. “More than ‘claiming promises,’ scripture becomes the word of God for an individual believer or a Pentecostal community.” See Alexander, “Pentecostals.”

¹⁰⁶ Each family was asked to give at least \$350 for this gift.

week, and she said that realizing that she had the ability to do this, for herself, was a critical part of the journey that brought her to House of Deliverance. Salvation is commuted through the Word, always delivered by the pastor.

Finally, the pastor also dictates giving practices in ways that reflect his understanding of scriptural mandate. Members are expected to give twice during worship: once in their tithe, or 10 percent of their income, which belongs to God and thus should be readily released back to God; and also in an offering, which is considered a freewill donation out of household surplus. Church leadership recently increased expectations for the offering, Gail said. Gail seemed eager to talk about financial practices at church, but her hushed voice indicated she was concerned that James might overhear her. She said she is frustrated by what she sees as an over-emphasis on money at the church and indicated that she was particularly troubled by the expectation for the pastor's gift. "Why would they do that? Did the bishop ask them to?" Gail's voice dropped to a whisper as we heard James moving from the living room toward the kitchen. "I don't do it. The tithe. I give, I'm a cheerful giver, but I give some to the Rescue Mission. They get a check from me every month. I know the church needs some, but they don't need that much. Melvin doesn't think I should do that, but I do."

Gail said she interprets financial expectations, especially the celebration of the pastor and expectations for cash gifts for him, as part of a general congregational attitude of "almost worshipping" the pastor. Thus, while Gail believes the pastor is an ordinary human being, Melvin and other members disagree, because Bishop Joel was "chosen by God" to preach the Word that leads to conversion, Spirit baptism,

sanctification, and ultimately salvation. Under this paradigm, the bishop is central to the whole work of the church. James agrees with this, as well. Church is “a place of salvation,” he said, which is the primary responsibility of the pastor.

When the pastor is central to the whole life of the church, therefore, both community practices and the perceived character of the church are shaped by the priorities of the pastor. Whether this is through shepherding guidance, sharing and preaching the Word, or another style, the pastor’s emphases are critical for the life of the congregation.

The Church as the Body of Christ: A Community-Centered Congregation

Unlike House of Deliverance and Canterbury, however, Calvin Presbyterian seems to find its focus in the community as the embodied Body of Christ. Practices and related theological emphases in this type of ecclesial community reflect understandings that highlight the whole community’s ministerial efforts. Salvation as a discrete event focused on a promise of eventual eternal life is less emphasized. Life in community becomes a source of individual and social transformation. The pastor leads with a style that draws others to lead with her, and helps the congregation develop practices that provide space for the body to define and live its vision. Calvin’s life as a congregation reflects this type of ecclesiology, consonant with the Reformation principal of the “priesthood of all believers,” but certainly not universal among Protestant churches.

Pastor Maryanne, who has been the pastor at Calvin for less than two years, said she sensed this “whole-people-of-God” spirit at Calvin as soon as she interviewed

there; that this was, in fact, part of what attracted her to the church. She said she learns from the congregation, and also said – in words that resonate with Nadine’s – she gets “fed” by the church as she witnesses its practices of hospitality and care, and that this guides her ministry. “What they’re doing [in their ministries] has real rootedness and grace all over it ... so I just keep wondering, what should I do? Should I, should we, do more? ... and I always think ‘no, just wait. Just watch it unfold and watch it be revealed, but be alert and make sure that things are working out.’”

Many ministry efforts to care for one another and the wider world have emerged in the past few years. Maryanne named several, including: the support group for parents of children with special needs described in Chapter 1; a proposal from the hospitality committee to install a new sound support system for people with hearing challenges; the development of relationships such as the one that has allowed Nolan to participate in youth group and Sunday School; prayer practices in worship that bring personal concerns before the whole body; and a recent effort by the hospitality committee that developed into a four-session adult Sunday school series on personal challenges that can hinder participation in a faith community and make life in general more difficult or painful – challenges such as depression/other mental illness, divorce or disabilities. All of these ministries were initiated by laypeople within the church.

Pastor Maryanne believes these community-initiated and led practices and priorities both reflect and teach that “there are a lot of things that can trip you up” in life. Nolan’s autism, therefore, does not stand out in this congregation as it might in

others because the congregation includes several other members (both children and adults) with disabilities, and because community leaders have been honest about their own struggles with mental illnesses, financial difficulties, and other challenges. There is an acceptance, Maryanne said, that these are the realities of life, and this acceptance challenges any assumption that this mostly white, mostly upper-middle-class congregation is overwhelmingly populated by “high achievers.” Instead, these are people with vulnerabilities, people who need each other.

Maryanne’s perspective resonates with Father Ronald’s perspective on human “brokenness” and his role as the caregiver of souls in response to that. Their thoughts also brought to mind Renata’s belief that autism and other disabilities would not be noticed at House of Deliverance because the services the church offers to people in need resolve or at least mitigate life’s many difficulties. This may be critical for some of the populations House of Deliverance serves, especially children living in poverty. Thus, while each leader presented similar ideas, each congregation presented diverse practices.

Developmental theory illumines congregational practices: Calvin’s identity as a congregation that emphasizes the work of the people is clarified by developmental theories that focus on human relationships. These theories offer insight into the character of a community that initiates ministries that focus on care within the congregation, and precipitates consideration of potential outcomes of these practices. These theories, in other words, deepen our understanding of the story of this congregation.

Calvin's emphasis on the community can be further explored using two similar yet distinct concepts from twentieth-century psychoanalytic thought: the holding environment, and the zone of proximal development. Both address similar questions about how human beings develop in relationship with one another, but they make different arguments that arise in part from different underlying assumptions about developmental processes. While both the holding environment and the zone of proximal development could be used to interpret ecclesial practices and understandings at all three churches involved in this study, they are particularly pertinent for reflection upon ecclesial practices and ideals at Calvin Presbyterian Church, probably because the high level of congregational involvement in ministry makes them very visible.

The holding environment: A community-centered ecclesiology such as that evident at Calvin can be understood as a holding environment. This concept, which emerged from mid-twentieth century object-relations thought, is particularly associated with pediatrician and psychoanalyst Donald W. Winnicott, though others presented similar theories. Winnicott applied the idea, which had been used primarily to describe the analyst/patient relationship, to the field of human development. Simply put, the holding environment is the time (infancy and early childhood) and space (a lap or another "safe" space) that allows an infant to develop healthfully. Empathetic caregivers provide physical safety, sensitive attention, literal physical "holding," and reliability. These characteristics, and sometimes more,

create an environment in which the child can develop through seemingly inherent processes.¹⁰⁷

The zone of proximal development: A similar concept comes from early-twentieth century educational psychologist Lev Vygotsky. His notion of the zone of proximal development continues to be used today to think about the ways children learn in peer contexts. The ZPD, as it is sometimes called, is the distance between one's actual capabilities when working or functioning independently, and one's level of potential development, which is indicated by working with a more capable peer or an adult.¹⁰⁸ At a time when development was understood primarily as an expression of individual accomplishment, Vygostky introduced the role that peers and mentoring adults can play in facilitating development. In so doing he anticipated much later understandings that emphasize the role of critical others in the shaping of the self.

A critical difference: The concept of the holding environment, therefore, presents development as a process of emergence. Inherent capacity is revealed by sensitive care. The theory of the ZPD, however, describes a more interactive and variable process. Development depends in part upon whether and how individuals who are more capable relate with those who are less capable. Optimal development occurs when the person with greater capacity assists the person with less capacity to reach a new capacity level. This perspective's emphasis on interaction also makes it useful

¹⁰⁷ D.W. Winnicott, "The Theory of the Parent-Infant Relationship," *International Journal of Psychoanalysis* 41 (1960): (585-595).

¹⁰⁸ L. S. Vygotsky, *Mind in Society: the Development of Higher Psychological Processes*, ed. Michael Cole, Vera John-Steiner, Sylvia Scribner, Ellen Souberman (Cambridge, Mass., London: Harvard University Press, 1978), 86.

for considering reciprocal processes – ie, how the experience of facilitating another’s development, intellectual or otherwise, impacts the one doing the facilitation, and, in turn, how this development constructs understandings of persons and the world.

Both perspectives are valuable for thinking about the work of the faith community in caring for and with families facing disabilities. At Calvin the congregation clearly has provided a *holding environment* for Nolan and his family. It has been a safe, reliable, empathetic space that has effectively responded to real needs for support and spiritual and social development.¹⁰⁹ The family has “been fed,” as Nadine might say, and in response, they have grown. But the ZPD is particularly useful in considering an ecclesiology constructed by practices of community care. A narrative about an event in the life of Calvin Presbyterian illustrates both the holding environment and the zone of proximal development, but also points to ways in which the ZPD is a more helpful framework for thinking about care in the context of a community-centered congregation, and recalls Bourdieu’s perspective on the habitus, or reciprocal processes between structures, persons, practices, and ideas.

When the qualitative research for this project was nearly complete, Maryanne saw me at a nearby seminary where she had a meeting. After saying she was glad to see me, she shared a story she had forgotten about during her interview. She then talked about a blog post written by a youth pastor at Calvin, reflecting on a youth-

¹⁰⁹It should be said that in this, Calvin is not unique. Canterbury’s openness to Zeb serving as an acolyte, which has given him the opportunity to lead and teach, also deserves this designation. House of Deliverance, though this type of care may not be evident in James’ experience there, offers a wide variety of services and supports to help other children, youth, and adults develop.

led worship service. Nolan became a focal point for the service, though unintentionally, and was the focal point for the youth pastor's writing.

Each youth had a prescribed role in the service, including preaching, carrying forward communion elements and food collected for donating, serving communion, and more. The youth pastor planned to have Nolan walk forward with a peer, but when the elements were parceled out, Nolan asked for a chalice. The youth pastor gave him an empty one. Then Nolan decided he wanted a plate – with bread on it. After the Great Thanksgiving was shared, Nolan came forward to serve. None of this was planned. The other youth responded by giving Nolan bread and quickly taught him to say, “This is the bread of heaven.” Then, they stood with him while he served. It was a holy experience for the youth pastor, who wrote:

Nolan stood ... and served communion to the congregation. He served his parents. He served one of his fellow youth group members who has severe physical and mental disabilities. ... And I saw the true face of God. My youth astound me. They are smart and funny and loving and wise and intelligent and reverent and perfect. They are children of God. They love the people Jesus loved. They speak their minds. They stand up for those who need a voice. I couldn't wait ... to witness their miracles. I couldn't wait to let the rest of the church witness their imperfect perfection. (And) I couldn't wait to see a young autistic man serve the Lord's Supper to the Lord's people. This past Sunday, I saw the face of God a thousand times...

Another person also told me about the blog post, so I asked Nolan's mother to send me a copy. I suspected it had deep meaning for the congregation, but I hadn't imagined how deep. Maryanne said several people have told her that they believe the incident offers a heartfelt depiction of the character of the congregation.

But beyond a holding environment, this is a contextual and reciprocal relationship. Notice in the story that the youth *taught Nolan* to say “the bread of

heaven” in the few moments they had on the chancel before serving communion. In that brief interaction Nolan progressed from what Vygotsky would consider his *actual* developmental level to his *potential* developmental level (at that moment). And he did this not only *with* but *because of* his more able peers. Additionally, witnessing and participating in the experience impacted the other youth. These more typical peers exhibited a desire to support Nolan and facilitate his expression of caring ministry, which resulted in a meaningful experience for the entire congregation and displayed a picture of human possibilities beyond what Western culture often assumes is feasible for persons with disabilities. Because this happened during the shared experience of Sunday worship, it provided an opportunity for the entire congregation to connect with the mutual care happening in their midst. The youth pastor said that in the moment of serving communion he “saw the face of God,” in all the youth (including in Nolan) whose vulnerabilities are commented upon with love in the article.

Additionally, others in the congregation saw the incident as a revelation in the church’s ecclesiological self-understanding. It was, Pastor Maryanne said, as if the experience suddenly made who they are much more clear. This ecclesiological self-understanding, therefore, seems to include: openness to difference; care as embodied love; trust in another’s ability, even when that other is one seen as “disabled;” and more. Most importantly, however, this is a church that has defined itself, through multiple and varied practices of welcome, as a congregation centered on community and willing to be shaped -- changed, even -- by the challenges and strengths of vulnerable people – all people, in other words.

Thus, while Calvin has touched lives and helped persons to develop through ministries characterized by “rootedness and grace,” as Pastor Maryanne said, the congregation as a whole has developed. The interactive processes of care practices, combined with the needs, gifts, and responses of people who are touched by them, provides energy for continued congregational self-definition via practices of care.

When Matthew discussed the care he, Nadine, and Nolan had felt at Calvin Presbyterian, he described it as “a circle of care.” Looked at through the interactive lens of the Zone of Proximal Development, it is clear that this circle is sustained by the community of the congregation, which continually contributes to care, and that it encompasses reciprocal processes in which care-receivers and care-givers exist in shifting, dynamic roles that are sensitive and responsive to particular needs rather than essential identities. The center of the circle, in other words, is the circle itself.

Conclusion: Disability Beliefs and Practices in Reciprocal Relationship

Religious practices and beliefs exist in reciprocal relationship with one another. In the context of families facing disabilities, beliefs and practices can support and reinforce long-held systems of discrimination and disregard that devalue persons with disabilities and fail to support their families. They also can challenge the wider world’s attachment to strength, power, and position.

The practices described here and in the previous chapter, and the anthropological, theological, and ecclesial understandings connected with them, construct and reinforce one another. A practice of openness and welcome such as working with a child with autism so that he can engage in acolyting and other ministries, for example, affirms the possibility of desire in relationship despite

disability. It indicates not only that the congregation and priest desire to share in the gifts that this child brings, but also that they embody God's desire for all human beings to flourish in human community. Thus, practices of openness and welcome construct understandings of anthropology, theology and ecclesiology. Conversely, a belief that all children are inherently gifted and that adults' consequent responsibility is to care for children in ways that bring out this giftedness can encourage practices that contribute to liberation and empowerment. Moreover, these practices can then deepen belief in children's giftedness. Again, this illustrates the reciprocal relationship between beliefs and practices.

An insistence that all children are and should be treated identically, however, not only belies the richness of God's diverse human creation, and denies the possibility that some children and some families may *need* different treatment, it can create an environment in which a practice of universal treatment feeds a belief in a universal, normative sameness, and ultimately denies the congregation the opportunity to engage in meaningful ministry that has the potential to be transformative for children with disabilities, their families, and the congregations themselves. What we *are* about determines at least in part what we *will be* about.¹¹⁰ In other words, what we practice now impacts the understandings that will drive who we are in the future.

Just as there is no simple, one-direction relationship between practices and beliefs, there is no universal rule about which beliefs and practices are "best" for families facing disabilities. Instead, congregations present a variety of faith

¹¹⁰ Bourdieu, 72.

understandings and practices in shifting reciprocal relationships, all of which have potential to impact persons with disabilities, their families, the church and wider community, for good or ill.

It is clear, however, that some practices and beliefs are more life-giving than others. First, ***acknowledging the reality of trauma*** affirms the internal reality of the person traumatized, and provides evidence that the life of one endangered or hurt, whether physically or emotionally, matters. Openness to the possibility of gifts that may not look “typical” and expression of desire to receive and honor those gifts, indicates that a life is “grievable,” that is, that if this person were lost in some fashion, others would experience it as a loss. Second, ***understandings of God that emphasize care*** are sustaining. The congregation that can say that God has been good to them, despite generations of brutal discrimination, is one that knows the supportive presence of the Holy Spirit. Members may not know or understand why the brutality happened, but they are convinced they were never alone in the midst of it. This clearly is evident at House of Deliverance. Moreover, in different contexts, others manage to maintain a conviction of God’s enduring and sustaining presence: in Kerry’s conviction that God was with her throughout the heart-wrenching years of Zeb’s earlier childhood; Nadine and Matthew’s insistence that they are fed spiritually through the care and love of their congregation; and Gail’s belief that she has been given James because God trusts her to care for him. All evidence the supportive presence of God. Finally, ***ecclesial practices matter deeply***. While pastor-centered ecclesiological beliefs and practices can provide care, they may not be as sustainable or as readily expanded and deepened as beliefs and practices that

emerge from the congregation. A congregation that believes care for others is a critical part of its identity is likely to find myriad ways of caring, and thus may more readily move beyond simpler, more immediate forms of care within the congregation to practices of justice that can impact the wider world. Thus beliefs and practices that honor the trauma sometimes experienced by families facing disabilities, that express desire for persons with disabilities as whole persons, that reflect and embody God's care for all humankind, and that emphasize the congregation's caring role are or can be life-giving for persons with disabilities, their families, and the congregations themselves.

Sadly, this has only rarely been the reality in the church and in the wider community. As we turn to investigation of the role and treatment of disabilities and persons with disabilities in the Christian tradition, it becomes clear that attitudes toward disabilities are ambiguous and continue to traumatize.

CHAPTER 4:

DISABILITIES IN THE CHRISTIAN TRADITION

Introduction

The Christian tradition has an ambiguous heritage related to disabilities. While churches and religious orders sometimes have provided significant care for people made especially vulnerable by causes of poverty, illness or disability, theological and biblical writings often have discounted the experiences of people with disabilities, or even defined people with disabilities as inhuman. Even in its attempt to provide care, the church has often diminished the full humanity of its members with disabilities and its practices exemplify this. Attempts to “protect” sometimes exclude; trying to “heal” implies sickness; and “care” can mask a desire for control and contribute to stigma. Values such as order, efficiency, and social priorities often have triumphed over care. Exploring the history of theological and social responses to disabilities can be disheartening.

And yet this exploration reminds us that historic teachings and practices live on in today’s unexamined habits, understandings, and assumptions. The past, at least in part, constitutes the present. To construct a thoughtful, intentional pastoral theology of care for persons living with disabilities demands that we explore the past to better understand the present and consider carefully the most faithful approach to the future. Thus, this chapter examines the witness of the Christian tradition related to disabilities, focusing on biblical texts and theological writings.

The Biblical Legacy

The Bible is foundational¹¹¹ for most faithful Christians. Today's readers are challenged, however, by worldviews distinct from those represented in the diverse texts of the Hebrew Bible and the New Testament.¹¹² Before describing a biblical legacy related to disability, therefore, it is important to acknowledge cultural differences between ancient and contemporary social understandings and practices.

Language is a challenge when we examine the Bible for its contributions to inherited understandings related to disabilities. Not surprisingly, there is no apparent biblical equivalent for the particular focus of this project – care, as experienced by teenagers with autism and their families.¹¹³ But the issue is larger than this. There is no term or concept in the Hebrew Bible, the New Testament, or other ancient writings equivalent to our broad category of “disability.”¹¹⁴ Instead, the Bible presents readers with a profusion of differences related to vision, hearing,

¹¹¹ What it means to say that the Bible is foundational for most faithful Christians is subject to interpretation, and what this looks like in practice will vary. However, the scriptures of the Hebrew Bible and the New Testament certainly function in critically important ways for people who identify themselves as Christians all over the world.

¹¹² Thomas Reynolds has noted that the Bible itself is polyphonic. Its readers/scholars/students are not merely trying to draw together the biblical horizon with that of the present world, but are trying to discern the contours of many horizons separated from by numerous gulfs in time and space. Thomas E. Reynolds, *Vulnerable Communion: A Theology of Disability and Hospitality* (Grand Rapids, Mich.: Brazos, 2008), 35.

¹¹³ Early biblical scholarship related to disabilities focused on medical diagnosis, seeking to label particular scriptural characters with diagnoses such as “cylossis” or “weakness of the astraguls and metatarsus bones of the foot,” or “Parkinson’s Disease.” Of course, there is little to say about a text once a diagnosis – which of course can never be proven – is made. More contemporary scholars tend to focus on how illnesses were experienced in the cultures of the ancient near east and what these experiences might signify. See, for example, Hector Avalos, Sarah J. Melcher and Jeremy Schipper, *This Abled Body: Rethinking Disabilities in Biblical Studies* (Leiden, Boston: Brill, 2007), 2-3.

¹¹⁴ See, for example, Amos Yong, *Theology and Down Syndrome: Reimagining Disability in Late Modernity* (Waco, Texas: Baylor University Press, 2007), 20-21; Amos Yong, *The Bible, Disability and the Church: A New Vision of the People of God* (Grand Rapids, Mich.: Eerdmans, 2011), 6.; Deborah Beth Creamer, *Disability and Christian Theology: Embodied Limits and Constructive Possibilities* (New York, Oxford: Oxford University Press, 2009), 36-37; Kristi Upson-Saia, “Resurrecting Deformity: Augustine on Wounded and Scarred Bodies in the Heavenly Realm,” *Disability in Judaism, Christianity and Islam: Sacred Texts, Historical Traditions, and Social Analysis*, ed. Darla Schumm and Michael Stoltzfus, (New York: Palgrave Macmillan, 2011), 94-95.

physical ability, and mental states. To understand the biblical witness, therefore – let alone to draw upon it for faithful contemporary Christian practice – demands constructive analysis. Even more critically, in this project and in other recent work related to disabilities, the social, economic, political, physical and structural forces that make impairments truly disabling are at least as important as the simple presence of impairments in biblical texts.¹¹⁵

Second, within the already-limited scholarship on biblical texts and disabilities, most focuses on what contemporary people would call physical disabilities, most often among adults. This project, however, also attends to the portrayal of “mental disabilities.”¹¹⁶ Looking for “mental disabilities” within the Bible reveals understandings of meanings and cultural roles of differences in how humans think, act, and interact with one another. Texts that portray parents and their children with apparent illnesses or disabilities are especially helpful for this project because they portray care in the family and raise questions about what care represents within the wider community.

Finally, although this chapter is primarily descriptive, it also calls for critical engagement with the tradition and a thoughtful epistemology related to the Bible’s role in the development and transmission of Christian understandings and practices.

¹¹⁵ This perspective resonates with a disability studies approach, which argues that disability is a socially constructed category comprised of the ontological reality of physical impairment (blindness, paralysis, Down syndrome, etc.) as well as the social norms and practices that make this impairment truly disabling (lack of Braille notifications for bathrooms, no curb cuts, poor accommodations for different learning styles and needs, for example). The “problem,” in other words, is not or at least not merely the ontological reality of specific impairment, but the social practices and assumptions occurring around it.

¹¹⁶ Olyan, *Disability in the Hebrew Bible*, 63. “Mental disabilities” is not a common contemporary descriptive term in the medical/psychological world of disability study. Olyan uses it as a broad and purposely ambiguous term because of the difficulty in applying contemporary categories and diagnoses to the Bible.

Pastoral theology is enriched by this engagement because it offers opportunities to respond constructively to damaging unexamined theologies and practices originating in the past, and to do so in ways that can be life-giving for the future.

General Themes

Several important themes in the Hebrew Bible and the New Testament are highlighted by texts involving what appear to be disabilities, including:

- God's sovereignty, which focuses on God's power to impact the created world;
- Difference, exclusion, and marginalization, which emphasize the ways in which human beings, seemingly authorized by God, have excluded and marginalized persons with disabilities from some experiences and privileges;
- Healing, which raises questions about the role and value of persons with disabilities in society;
- Discipleship, which sometimes portrays disabilities as a challenge that parallels the challenges of following Jesus;
- Understandings of mental disabilities, which may have been particularly frightening in the ancient world;
- Parents and children experiencing disabilities, which points to the challenges of interpersonal care in a world with highly limited resources.

Each of these themes will be expanded below, as their legacy continues to inform religious and social understandings and practices of care and misunderstandings about care related to disabilities.

God's sovereignty: God's sovereignty is perhaps the most prevalent theme associated with disability¹¹⁷ in both sections of the Bible, and continues to resonate in the church. Exodus 4:11-12, for example, presents blindness, deafness and muteness as evidence of the power of God. The text includes part of God's response to Moses, who is reluctant to appear before the Egyptian pharaoh on behalf of the

¹¹⁷ Creamer, 42.

Hebrew people. It portrays God as the originating source of the disabilities and any triumph over them.

¹¹Then the LORD said to him, “Who gives speech to mortals? Who makes them mute or deaf, seeing or blind? Is it not I, the LORD? ¹²Now go, and I will be with your mouth and teach you what you are to speak.”

Deuteronomy 32:39 not only attributes physical difference to God’s sovereignty, it also implies that this exercise of divine power serves as punishment or reward for human behavior. The text is located within the Song of Moses, which foreshadows the disobedience of the Hebrew people when they are settled in the land of Israel. It is preceded by a mocking accusation from God – that the gods to which people had turned will offer nothing when the people are in need. Then, in 32:39, God says (through Moses): “I kill and I make alive; I wound and I heal.” Meanwhile, in Numbers 12:1-16, Miriam speaks out against Moses and God and is struck with leprosy, which leads to her exclusion from the Hebrews’ settlement.¹¹⁸

The theme of God’s sovereignty is evident not only in texts that attribute disability and illness to punishment for transgression, but also in texts that associate social prosperity and well-being with faithfulness.¹¹⁹ This worldview implies that a healthy society that follows God’s desires will be blessed with healthy bodies.¹²⁰ Prophetic eschatological texts that foretell the coming of the reign of God as a time when (for example) “the eyes of the blind shall be opened and the ears of the deaf unstopped,” (Isa 35:4-10) amplify this perspective.

¹¹⁸ See, for example, Creamer, 42-43; Yong, *Theology and Down Syndrome*, 22-23;

¹¹⁹ See, for example, Exodus 15:26, which promises freedom from the diseases suffered by the Egyptians if the Hebrew people listen to God and follow God’s commandments.

¹²⁰ Creamer, 42.

Difference and exclusion: A particularly significant theme in the Hebrew Bible related to disabilities is the issue of exclusion due to physical differences or impairment, which often are connected to concerns about purity.¹²¹ This issue had serious implications for religious practice and daily living. Leviticus 21, for example, forbids people (assumed to be male) who have “any blemish” from offering sacrifices upon the altar. It identifies physical differences ranging from blindness to scurvy to crushed testicles, saying that one so impaired may not “offer the food of his God.” (v. 21) The person with “a blemish” may eat the bread of sacrifices¹²² but “shall not come near the curtain or approach the altar, because he has a blemish, that he may not profane my sanctuaries.” (v. 23)

This text, which makes plain that the exclusion of people with disabilities from cultic activity is not only acceptable but required, has deeply informed Christian beliefs and practices about disability throughout the history of the faith.¹²³ It should be seen, however, not as a rationale for continuing discrimination but as an artifact of a worldview that prioritized order and holiness through ritual, symbols, hygiene, and practices, and that associated holiness with physical perfection.¹²⁴ Included within

¹²¹ See, for example, Olyan, 27-33, 45-46; Sarah J. Melcher, “With Whom Do the Disabled Associate? Metaphorical Interplay in the Latter Prophets” in Avalos, Melcher and Schipper, 126-127; Brett Webb-Mitchell, *Unexpected Guests at God’s Banquet: Welcoming People with Disabilities into the Church* (New York: Crossroad Publishing Company, 1994), 54-55; Reynolds, *Vulnerable Communion*, 66-68; Yong, *The Bible, Disability and the Church*, 18-20, 24-29; and Yong, *Theology and Down Syndrome*, 23-24; Sarah J. Melcher, “Visualizing the Perfect Cult: The Priestly Rationale for Exclusion,” in Nancy L. Eiesland and Don E. Saliers, *Human Disability and the Service of God: Reassessing Religious Practice* (Nashville: Abingdon, 1998), 55-71.

¹²² Conversely, a priest who had a *temporary* impurity, such as a skin disease, could not eat the holy bread until the impurity was resolved.

¹²³ Melcher, “Visualizing the Perfect Cult,” 55-57, 68-70; Yong, *Theology and Down Syndrome*, 22-23.

¹²⁴ In this same ritual mindset, for example, not only did priests have to be physically perfect, so did the animals that they offered in sacrificial rites. See, for example, Yong, *Theology and Down Syndrome*, 22-23; Julia Watts Belser, “Reading Talmudic Bodies: Disability, Narrative, and the Gaze in Rabbinic Judaism,” Schumm and Stoltzfus, 6-7.

this orderly world are practices of high ethical standards – practices such as allowing the poor to bring smaller offerings if they cannot afford to give larger animals to the temple, gleaning the edges of the field for the poor, and requirements that people not “curse the deaf or put a stumbling block before the blind.” (Lev 19:14) But the logic that associates wholeness with holiness¹²⁵ also implies that disability represents the profanity of this world, and separates persons with disabilities from the holiness of God.

Marginalization: Deformity, disability, and illness are presented textually with categories of marginalization such as poverty and alien status, or with metaphors of infertility and fruitlessness, contributing to rhetorical marginalization of people with disabilities. This is evident in texts of various genres. Isa 35:4-10, for example, presents a utopian vision in which the desert becomes productive and “the eyes of the blind shall be opened” and “the lame” leap “like a gazelle.” Though this is meant to be a hopeful vision, it has been argued that it stigmatizes people with disabilities, first by associating disability with the arid, apparently unproductive desert, and second by implying that in an ideal world disability would be eliminated by the sovereign power of God.¹²⁶ Deut 28:28-30, meanwhile, promises “madness, blindness, and confusion of mind”¹²⁷ (v. 28) as part of a covenantal curse for disobedience, and goes on to associate these disabilities with weakness and

¹²⁵ Mary Douglas, *Purity and Danger: An Analysis of Concepts of Pollution and Taboo* (New York: Hammondsworth, 1970), 51-54, quoted in Melcher, “Visualizing the Perfect Cult,” 56-57. Melcher points out that the priestly writers who produced this section of Leviticus never describe a person as holy *just because* they are physically whole – only consecrated priests or Nazirites are holy. Holiness is, however, a goal, and physical wholeness is understood as the norm for embodiment. See also Yong, *Theology and Down Syndrome*, 23.

¹²⁶ Olyan, *Disability in the Hebrew Bible*, 86-87.

¹²⁷ Notice that the biblically rarer “mental disabilities” comes up in this text.

vulnerability (promising that “you shall be continually abused and robbed”) (v. 29) and even loss of male honor (“you shall become engaged to a woman, but another man shall lie with her”) (v. 30).¹²⁸ Even Psalm 146, in which God comes to the aid of those who are in need, associates “the blind” with those who are poor and oppressed, or with aliens, orphans, and widows. The biblical vision of people with what we understand as disabilities is clearly focused on vulnerability and need.

Jesus’ healing power: The gospel writers frequently draw upon disability as a vehicle to display Jesus’ power. Jesus heals those with physical disabilities, cleanses lepers, restores sight, delivers children from epileptic seizures, and brings peace to those whose behaviors were fearsome to themselves and those around them. In so doing, it might seem as though God through Jesus offers hope to people marginalized by illness or disability. And yet, biblical healings can be problematic from a disability perspective, for several reasons.

First, healings, especially as traditionally interpreted, often confirm stereotypes of people with disabilities – primarily that they are passive and destined to suffer until healed by Jesus (or later, through the church or at the end of time, in the coming of the kingdom of God).¹²⁹ Within some of the prominent healing texts, for example, persons with disabilities often are anonymous. Readers know nothing about them except the existence of their disabilities. These people live at the mercy of others, and

¹²⁸ Olyan, *Disability in the Hebrew Bible*, 77.

¹²⁹ Yong, *Theology and Down Syndrome*, 25.

their suffering and relief are utilized as narrative elements to point to the supernatural power of Jesus.¹³⁰

Second, healings often perpetuate traditional associations between disability and sin, impurity, or chaos.¹³¹ This is ambiguous. There are times, such as in the healing of the man born blind in John 9, when Jesus explicitly says that the disability in question is *not* due to sin. At the same time, God still appears to be involved in the existence of disabilities, and the disabilities – and, therefore, those who possess them -- are used to point to God’s power.¹³² Additionally, some texts *do* explicitly associate disability with sin. In John 5:14, for example, Jesus tells the man healed at the Pool of Bethzatha to “sin no more” lest something worse happen to him.

Finally, there is a growing association between disability and evil spirits within the gospels.¹³³ In Matt 4:24, for example, Jesus attends to “the sick, those who were afflicted with various diseases and pains, demoniacs, epileptics, and paralytics” – implicitly connecting what we understand as disabilities with demonology. Other texts are more explicit, and thus more damaging. Matt 12:22, for example, presents “a demoniac who was blind and mute” while Mark 9:14-29 describes a boy with epilepsy as possessed by a spirit. Given the overwhelming belief in and fear of

¹³⁰ See S. John Roth, *The Blind, the Lame, and the Poor: Character Types in Luke-Acts*, Journal for the Study of the New Testament Supplement Series 144 (Sheffield, England: Sheffield Academic, 1997), 141 ff. Roth points to such Lukan healing texts as: the paralytic carried to Jesus and lowered through the roof of the house (5:17-26), the raising of Jairus’ daughter from the dead (8:51-56), the healing of the boy with epilepsy (9:37-43) and many more. See also Colleen Grant, “Reinterpreting the Healing Narratives,” in Eiesland and Saliers, *Human Disability and the Service of God*, 72-87, 73; Yong, *Theology and Down Syndrome*, 25.

¹³¹ Grant, “Reinterpreting the Healing Narratives,” 75-77; Yong, *Theology and Down Syndrome*, 26.

¹³² Yong, *Theology and Down Syndrome*, 26; Jennifer L. Koosed and Darla Schumm, “Out of the Darkness: Examining the Rhetoric of Blindness in the Gospel of John,” in Schumm and Stoltzfus, *Disability in Judaism, Christianity and Islam*, 80-81.

¹³³ Yong, *Theology and Down Syndrome*, 26.

demons and spirits within the biblical context and stigma that surrounded spirits associated with persons, any connection between disability and demons – rhetorical and/or historical -- would be highly marginalizing.

Disability and faithful discipleship: The gospels and epistles also employ descriptions of disabilities to illuminate understandings of faithful discipleship. This theme arises in healing stories in which Jesus attributes healing to faith. In Matt 9:27-29, for example, two men who are blind call out to Jesus for mercy. He challenges them, saying “Do you believe that I am able to do this?” When they say “Yes, Lord,” he touches them saying “According to your faith let it be done to you.” They are able to see, apparently due to the strength of their faith. Again, we learn little about the men as people or even as characters in a narrative. They are presented as illustrations of patient waiting and trust. Eiesland addresses this in discussions of “virtuous” suffering and of the ritual practice of laying on hands, which in her experience as a person with disabilities was at times restorative and redemptive, and yet at other times marginalizing and stigmatizing. When the laying on of hands represented inclusion and care within the body of Christ, it was redemptive, Eiesland argues. When it was done with a focus on “healing” defined as the removal of her disability, and with an emphasis on Eiesland’s “faith” as the trigger for change, it led to suffering and alienation.¹³⁴

Paul, too, is an example of someone who appears to have lived with some sort of disability, suffered due to it in living out his faith, and has been valorized for

¹³⁴ Grant, 76; Eiesland, 72, 117.

“righteous submission to divine testing.”¹³⁵ It is difficult to know what Paul’s “thorn in the flesh” was, but his suffering remains a powerful legacy to face. It can present a dangerous theology for people with disabilities (and others), encouraging “adjustment” to injustice and “acceptance” of isolation, as well as resignation as a sign of God’s election that will lead to reward in the next life if one endures. “The theology of virtuous suffering has encouraged persons with disabilities to acquiesce to social barriers as a sign of obedience to God and to internalize second-class status inside and outside the church.”¹³⁶ This is a utilitarian theology that rewards those who are willing to “accept” their suffering, and that uses persons with disabilities as examples of faith for others.

Mental disability: The Bible offers fewer representations of mental disability than of physical disability, and an even more confusing vocabulary. There are, however, enough texts that present mental difference, especially involving apparent lack of self-control, to conclude that rhetorical practices of stigmatization marginalize people with mental disabilities in both the Hebrew Bible and the New Testament. Although mental disabilities are not addressed with the same discourses of pollution and impurity as some physical disabilities, mental disability appears as a covenantal curse in Deuteronomy, and people with mental disability are shown enduring contempt in 1 Samuel (21:14-16) and 2 Kings (9:11). In general, mental

¹³⁵ Eiesland, 72.

¹³⁶ Eiesland, 72-73.

disabilities are associated with such undesirable qualities as weakness, vulnerability, isolation, dependence, fear, and ignorance.¹³⁷

Several of these qualities are evident in the story of the man who lived among the tombs, also known as the Gerasene demoniac, in Mark 5:1-20.¹³⁸ This is the longest healing narrative in Mark, the gospel that generally moves at the swiftest pace. Its length alone, therefore, seems to indicate significance. The narrative is dominated by three main themes: the interplay of isolation and community; human response to mental disability; and Jesus' power to heal.

In this text, as in so many healing stories, healing is used as a vehicle to display the power of Jesus. But Jesus does more than heal illness in this narrative. He casts out demons so powerful that they have completely taken over the man's persona (when Jesus asks for a name, for example, he is talking to the demons) and so powerful that when they are cast out and enter the nearby herd of pigs, the pigs kill themselves immediately by jumping off of a cliff. Like medical models of disability, this emphasis on the power of Jesus' ability to cure raises discomfiting issues. What of those with severe mental illness who are not cured? Are they not trying? Are they not faithful enough? Sadly, mental illness continues to be connected to demons, in theology and in the life of the church, as was evident in Gail Talbert's description of some perspectives at House of Deliverance.¹³⁹

¹³⁷ Olyan, 62; Holly Joan Toensing, "'Living among the Tombs': Society, Mental Illness, and Self-Destruction in Mark 5:1-20," in Avalos et al, *This Abled Body*, 131-143.

¹³⁸ The description and analysis of this text is heavily influenced by the work of Holly Joan Toensing. Toensing's article, "'Living among the Tombs'" draws together biblical criticism from a disability perspective with personal experience and a practical theological telos in a way that is very helpful.

¹³⁹ See, e.g., Matthew S. Stanford, "Demon or Disorder: A Survey of Attitudes toward Mental Illness in the Christian Church," *Mental Health, Religion and Culture* 10, No. 5 (2007): 445-449.

Additionally, many details in the Markan account evidence common elements of human experience with mental illness. Fear, for example, a common instinctual human response to mental disability, is indicated in the fact that the man had been restrained. In addition, the story is grounded by an interplay of loneliness and community. The man lived and wandered among the tombs, a place of isolation and death. The community's role in his life, to this point, apparently had been limited to trying to restrain him. When the man is healed, however, Jesus sends him back to the community. He does not travel with Jesus, which would have continued his isolation from the community, but instead, he is called to live among others and to share his story. While this text certainly has aspects that are uncomfortable from a disability perspective, ultimately its drive toward community, connection, and care offers a message of hope for people with mental illness.

Parents, children and care: All three synoptic gospels place a story of Jesus healing an "epileptic" boy¹⁴⁰ between the presentation of the transfiguration and the call to care for some of the least in society – children. The placement itself seems meaningful. While the transfiguration focuses on the unearthly quality of Jesus' divinity as a source of awe and wonder; the call to care for the least answers the disciples' struggle to understand what it means to be followers of Jesus. In this call the disciples are told emphatically that following Jesus involves reversal of dominant social values. Thus, when Jesus insists that to be faithful is to become like children he is not offering a romanticized portrayal of innocence and sweetness (only understandable in a modern context), but the profound humility and lack of

¹⁴⁰ Matt 17:14-20; Mark 9:14-29; Luke 9:37-43.

status experienced by ancient children. Between these distinct poles of incarnational experience the story of the epileptic boy portrays parental care, mental disability, and divine healing, and in this portrayal brings the transfigurational experience back to earth while introducing the importance of care for those who are vulnerable and marginalized by disability.

Still, like so many biblical texts that include disabilities, this text is ambiguous. The boy with epilepsy is more like a foil to display the power of Jesus and the challenges of discipleship than he is a full character. Additionally, attributing epilepsy to demon possession – while not the fault of the Bible alone -- is a tragic misconception that certainly has contributed to fear and stigma associated with this neurological disorder.

Perhaps most promising are the details associated with care in this text: the father's persistence even when the disciples initially fail to heal the child; the father's willingness to recognize his own shortcomings if it will help his child (he asks for help with his flagging faith); and Jesus' commitment to care for a child on the margins, immediately following the transfiguration. While the text has shortcomings for an adequate pastoral theology of care, it portrays care – as well as a call to humility – in a way that offers critical elements of connection and community.

Considering the Context

It is not particularly surprising that biblical texts often stigmatize people with disabilities. The texts are products of subsistence cultures in which it may have seemed there was little room for those who needed extra care and were less able to

contribute materially to the larger society. Additionally, today's people with disabilities experience lives that – while far from ideal – are profoundly different from those of persons in the ancient world. Assistive technologies developed over the last 200 years as well as the late-twentieth century disability rights movement have brought profound changes to the lives of people with disabilities – changes that would have been virtually unimaginable to the ancient world. From the development of sign language and braille, to the ongoing and still developing mainstreaming of children with developmental disabilities into typical public schools, people with disabilities today live very different lives from those in the ancient world. Portrayals of disabilities in the biblical texts represent a culture that saw profound tragedy, suffering, and hopelessness in disability. Today, however, that fact means that texts must be used carefully.

The Bible is both formative and normative for Christians. Thus, people of Christian faith who seek to live into its call in the present day must approach the Bible -- including its portrayals of disability – thoughtfully. We must be aware that traditional readings of these texts may further stigmatize people with disabilities as well as inculcate attitudes of separation, blame, suspicion, and even fear among “the temporarily able-bodied.”¹⁴¹

The Theological Legacy of Disability

While the first half of this chapter focuses on biblical portrayals of disability, this section draws on historic theological perspectives in an attempt to discern the social/symbolic world behind the experiences of the Zane, Nelson, and Talbert

¹⁴¹ Eiesland, *The Disabled God*.

families. It must be acknowledged that disabilities – especially developmental disabilities -- have not been a major focus for Christian theology through the centuries; in fact, it has been argued that the concept of developmental disability as it is understood today simply did not exist until the modern era, when it appeared in the political writing of John Locke, who saw “idiots” as non-human.¹⁴² Thus, although the section ahead uses the word “disability” as it would be likely to be used today, this does not align precisely with the various terms – many of which we would now find offensive – employed by theologians in earlier eras.

Despite differences in language and understanding, however, many prominent theologians have, at times, raised challenging and important questions related to disabilities. They have considered God’s role in sickness and disability, for example. They have argued against accepted social practices related to infants born with obvious impairments. They have wondered about what persons with disabilities will be like in the final resurrection – and if the bodily resurrection will even be open to them. They have considered the possibility that some physical disabilities may be signs of devotion. They have wondered what the reality of persons with disabilities may indicate about the nature of humanity. They have called, occasionally, for compassion and care. Sadly, they also have stood silently in the face of oppression, an absence of theological consideration and development of practice that is itself telling. Ultimately, the Christian theological tradition and its approach to disabilities, like the Christian biblical witness, is diverse and ambiguous.

¹⁴² Tim Stainton and Patrick McDonagh, “Chasing Shadows: The Historical Construction of Developmental Disability,” *Journal on Developmental Disabilities* 8, No. 2 (2001): ix-xiii; C.F. Goodey, “What is Developmental Disability? The Origin and nature of Our Conceptual Models,” *Journal on Developmental Disabilities* 8, No. 2 (2001): 1-18.

To provide a comprehensive survey of the historic Christian theological tradition for this project would be impossible. Theologians have raised questions related to theology proper, ethical social practice, eschatology, anthropology, and ecclesiology. While these are too many categories to address with any depth and value in this section, the focus of this project – developing a pastoral theology of care related to families facing disabilities – helps define the task of the pages ahead. This dissertation is primarily concerned with the life and call of the church in relation with families facing disability, and so the theological resources presented will focus on understandings of humanity and ecclesial responsibility in a disability context, as well as places where care is emphasized in the Christian theological tradition.

Three kinds of discourses have shaped the church’s response to disabilities over the centuries, according to Brock.¹⁴³ These are: an activist discourse, which asks for whom we are called to care, and how we are called to provide that care; a definitional discourse, which asks what “disability” means, and how it is related to understandings of what it means to be a human person; and an existential discourse, which asks questions about ourselves – who do we need to be so that we might hear and act upon God’s call to love and care for everyone, even those who may make us uncomfortable? While this chapter and indeed the whole project focus on the activist discourse, other discourses are necessarily a part of any consideration of

¹⁴³ Brian Brock, “Introduction: Disability and, the Quest for the Human,” in *Disability in the Christian Tradition: A Reader*, ed. Brian Brock and John Swinton (Grand Rapids, Mich.: Eerdmans, 2012), 12-13.

how we understand disabilities. Moreover, how we understand ourselves surely influences what we think we should do in response.¹⁴⁴

This section, therefore, begins with a brief look at general theological themes and practices related to disabilities through the centuries, most of which have been addressed and critiqued in recent disability theology. I examine the contributions of four prominent theologians in the Christian tradition who have influenced contemporary theological thinking about disabilities: Augustine, arguably the father of traditional doctrine; the reformers Martin Luther and John Calvin; and Karl Barth, one of the modern era's most influential theologians. These were chosen because of their long-lasting and wide-ranging impact on the Christian tradition, and because they take up the subject of disability or related topics in ways that are useful for understanding care in the context of disability.

General Themes: An Unfortunate Legacy

There are few positive portrayals of or responses to disabilities within the Christian theological tradition. Most commonly theology and theological practices have interacted with disabilities in ways that are destructive and hurtful. Thus, recent disability theology critiques the tradition quite sharply for its insensitivity toward persons with disabilities.¹⁴⁵

¹⁴⁴ Brock, "Introduction," *Disability in the Christian Tradition*, 12-13.

¹⁴⁵ Others disagree. Brock's introduction, for example, talks about the "modern conceit" that earlier authors on disability (and other) issues are inherently primitive and backward. Brock, "Introduction," 4. This "modern conceit" may be operative at times, but Brock's argument separates the often surprisingly rich and promising theological perspectives described and excerpted in the book from the less promising perspectives that often coexisted with them, as well as from the sometimes depressing history of the church's interaction with people with disabilities. Again, this is a separation of theology and practice.

Eiesland's *The Disabled God*, for example, which set a course for later theological work related to disabilities, names three critical themes within Christian theological and practical history. First, sin and disability often have been conflated, as was evident in the biblical tradition. At times, fault was assigned to parents; at other times, the person with the disability was blamed. This biblical theology has survived in Christian history, Eiesland argues, in understandings that prevent people with disabilities from serving in religious leadership because of beliefs that the divine image has been "marred" in them. Second, the ideal of virtuous suffering, again beginning in the biblical era (especially with Job's and Paul's sufferings), at times has glorified suffering due to disability as a means of purification and at times has been used as a tool of oppression against people with disabilities. Finally, charity that segregates persons with disabilities from wider society has contributed to stigma around disability by creating and maintaining distinctions between able and disabled.¹⁴⁶

Unfortunately, Eiesland does not cite historic or contemporary theological writings in her critique.¹⁴⁷ She seems to write primarily out of general impressions born of personal experience. Others, however, have done more of this work. The results both support and challenge Eiesland's perspective. There is more in the tradition -- and more that is relatively positive -- than people today might assume. Yet some of Christianity's most prominent writers are known more for oppressive teachings related to disability than they are for those times when they resisted the

¹⁴⁶ Eiesland, 72-75.

¹⁴⁷ Eiesland does draw upon some biblical texts in her reflection.

dominant culture and worked toward liberation, justice, or care for people with disabilities.

St. Augustine: Augustine of Hippo (354-430), one of the great thinkers of the early church, wrestled with the meaning of disability. While his work was innovative in its context, ultimately Augustine left an unfortunate legacy for people with disabilities. To understand Augustine's legacy, one must remember that he lived and worked in a world that feared so-called "monstrous births," which were generally attributed to evil spirits; in which humanity as a whole was understood hierarchically based on rational ability, and in which individuals were valued primarily for their capacity to contribute to society. In this context, Augustine developed a theory of human perfection that is foundational for his later thinking on physical and mental differences. This theory combined ancient Greek understandings of harmony, a concept involving beauty and utility, with his own commonsense observations of norms – i.e., the idea that people generally have two arms, two legs, etc. The ability to use human reason was prominent in his theory, as was the idea that bodies would be perfected in the resurrection, which is based on the perfection of Christ's body. Given this understanding of the human ideal, therefore, Augustine makes two critical assertions: one, that bodily differences that deviate from norms are unfortunate and need to be "fixed;" and two, that to be human is to have full rational capacities.¹⁴⁸ While some scholars have pointed to Augustine's later insistence that the second of these assertions *did not* necessitate

¹⁴⁸ Tim Stainton, "Reason, Grace and Charity: Augustine and the Impact of Church Doctrine on the Construction of Intellectual Disability," *Disability and Society* 23, No. 5 (2008): 485-487.

its converse – that to lack rational ability was to be sub-human – the assertion is nonetheless exclusive in appearance and effect, if not in intent.¹⁴⁹

Even Augustine's attempts to include people with differences in his anthropological understandings are problematic from a contemporary perspective. For instance, although Augustine did argue against the common belief that disabilities were caused by evil spirits, he attributed them instead to *human* evil. Augustine argued that the existence of disabilities was due to humanity's fall from grace in the Garden of Eden, or as he put it: "humanity's condemned origin," implying that disabilities are "deserved" because humanity is so vile.¹⁵⁰ Augustine's argument in this statement is undergirded by a set of binary oppositions that divide the world into such opposites as "good" and "evil," "well" and "sick," "able" and "disabled." These binary oppositions contribute to a dichotomous understanding of the world that not only tends to associate sickness and disability with evil, but also fails to acknowledge that gifts and strengths can co-exist with sickness and disability. His perspective, therefore, is harmful on multiple levels.

Augustine's general attachment to this dichotomous understanding of the world set the stage for the long and continuing attachment to binaries in the Christian tradition. Unfortunately, this perspective has contributed to worldviews that occlude the possibility of flourishing with a disability.¹⁵¹ Within this dualistic

¹⁴⁹ Brian Brock, "Augustine's Hierarchies of Human Wholeness and Their Healing," in *Disability in the Christian Tradition: A Reader*, 68-72; Augustine of Hippo, *The City of God against the Pagans*, edited, trans. by R.W. Dyson (Cambridge: Cambridge University Press, 1998), 707-710.

¹⁵⁰ Augustine of Hippo, *Against Julian*, trans. Matthew A. Schumacher, in *The Fathers of The Church: A New Translation*, vol. 35, series ed. Hermigild Dressler (Washington, D.C.: Catholic University Press, 1957), 115, 118.

¹⁵¹ Sharon Betcher, *Spirit and the Politics of Disablement* (Minneapolis: Fortress, 2007), 5. For Betcher, Augustine's attachment to binaries means that the fall "came to assume the shorthand hermeneutic of

mindset, Augustine believed that disabled bodies and minds were lamentable, and that they caused sorrow for individuals and society.¹⁵² He noted, for example, the sorrow that would be experienced by a parent watching a son or daughter who was a “morione,” (the Latin translation of “moron”) being sold for amusement in the marketplace – but did not criticize the exploitative practice itself.¹⁵³

In fact, the only positive interest Augustine seemed to have in disabilities was to point out that a diversity of creatures, including human beings of diverse abilities, reflected the glory and wonder and wisdom of God.¹⁵⁴ From this perspective, disabled bodies function as “figural paradigms to show extremes to which spirit must go to reclaim wholeness,” thus displaying the power of God.¹⁵⁵ This perspective is displayed most vividly, perhaps, in his thinking on the “monstrous races,” the quasi-imaginary “races” of people with profound differences (from Augustine’s Greco-Roman context) who supposedly lived at the edges of the earth and needed to be converted to Christianity before the end of time could arrive. Here, racism merges with ableism. Augustine argues that if God is so incredible as to make such bizarre creatures, and if, in fact, such bizarre creatures can actually be converted, this is an indicator that God is at least powerful enough to resurrect normal, ordinary people.¹⁵⁶

brokenness versus wholeness,” which was subsequently, stigmatically, and inextricably linked with disfigurement and disability.” Betcher, vii.

¹⁵² Augustine, *City of God*, 918-924.

¹⁵³ Augustine, *A Treatise on the Merits and Forgiveness of Sins, and on the Baptism of Infants*. In *The Nicene and Post-Nicene Fathers*, vol. 5, ed. Philip Schaff (Grand Rapids: Eerdmans, 1978), quoted in Brock, “Augustine’s Hierarchies,” 67.

¹⁵⁴ Stainton, “Reason, Grace and Charity,” 489-491.

¹⁵⁵ Betcher, 45; Yong, *Theology and Down Syndrome*, 28-31.

¹⁵⁶ Betcher, 54-55; Augustine, *City of God*, 982-983.

Clearly, there is much to lament in Augustine's thinking on disabilities, especially as it relates to questions of anthropology. He does, however, offer a minor strand in his thinking that insists that individual perception of other human beings, when illuminated or sanctified by God, can shift its focus away from apparent deficits. This shift, he argues, can contribute to a deeper appreciation of God's generous work, and thus permit greater understanding of human worth. This approach, minor though it is in Augustine's work, resonates with contemporary critiques of disability as a social construction as it calls Christians to see beyond assumed standards for what counts as a good human life.¹⁵⁷

Two reformers: The most prominent among the reformers both focus on existential questions such as whether and how well persons with disabilities can "hear" the gospel, or who is capable of participating in the sacraments. They do this, however, in distinct ways that represent different contexts. And both left significant – and ambiguous -- legacies related to pastoral and social response to disabilities.

Theologian Martin Luther (1483-1546) is a paradox in regard to his attitudes and practices toward disability. Some of his perspectives related to disabilities reflect his historical context at the very end of the Middle Ages, while other perspectives and his practices are more reflective of a compassionate spirit and commitment to the possibility of salvation by grace for all persons.

Luther's context insisted that human life is short, messy, and uncomfortable if not painful; and that spirits -- including the devil -- are present and active in human life and misfortune. He was resigned to human struggle and most concerned about

¹⁵⁷ Brock, "Augustine's Hierarchies," 65-66, 74-76.

rescuing fallen humanity from the certain damnation that would befall it without the justifying grace of Christ.¹⁵⁸ Today, this resignation can seem to encourage passivity in the face of injustice, but this may not have been his intention.

Luther's legacy regarding disabilities is dominated by two images that appear to contradict one another but may in fact reflect a common foundation. First, Luther is perhaps best known for suggesting that a 12-year-old boy described as "misshapen," who perhaps may have had an intellectual disability, be suffocated. Luther wrote that the boy "devoured as much as four farmhands, and did nothing else than eat and excrete. ... I think he's simply a mass of flesh without a soul. Couldn't the devil have done this, inasmuch as he gives such shape to the body and mind even of those who have reason that in their obsession they hear, see and feel nothing? The devil himself is their soul."¹⁵⁹

While this statement marginalizes persons with disabilities, Luther was not primarily concerned about the boy's lack of rational ability. Instead, Luther's perspective represents the continuing development of biblical traditions (see section I in this chapter) related to demonological activity. Unlike earlier arguments from Augustine and, later, Enlightenment-era thinking inherited from John Locke, Luther is not distinguishing between normal and subnormal humanity, or even between human and non-human. Instead, he is distinguishing between human and

¹⁵⁸ Stefan Heuser, "Luther and Disability," in *Disability in the Christian Tradition Tradition: A Reader*, 184-188.

¹⁵⁹ Yong, *Theology and Down Syndrome*, 34-35; Martin Luther, *Luther's Works*, Vol. 54, *Table Talk*, ed., trans., Theodore G. Tappert (Philadelphia: Fortress, 1967), 396-397.

demon.¹⁶⁰ As sad as this statement is, its legacy is even more heartbreaking. Much later, Nazi Germany seized and used Luther's comments to justify the killing of people with disabilities during the 1930s and 1940s, saying they were merely a drain on the nation's strengths.¹⁶¹ Unfortunately, this legacy continues. We remember that Gail Talbert, mother of James, heard at least part of Luther's perspective in her church, when members said the devil needed to be "prayed out" of persons with disabilities and mental illnesses.

It might seem that Luther has little to contribute to a pastoral theology focused on disabilities and care. Further exploration, however, reveals practices and theological perspectives that are at least worthy of consideration. Luther is known for employing a personal assistant who appears to have been disabled, for insisting that people who are deaf hear the gospel because it is spoken to the heart as well as heard by the ears, and for comforting and encouraging the many people around him who would have faced sickness and disability in his era.¹⁶² He lived a sort of care that was profound, therefore, because it emphasized helping people facing illness, disability, and other life challenges to live as well as possible within their own limits and the limits of their context.

Luther's dual emphases – on the power of the cross and the helplessness of humanity – present significant implications for pastoral theology in a disability context. By emphasizing persons' inability to effect their own salvation without the

¹⁶⁰ Heuser, "Luther and Disability," 186-187; M. Miles, "Martin Luther and Childhood Disability in 16th-Century Germany: What Did He Write? What Did He Say?" *Journal of Religion, Disability and Health* 5, No. 4 (2001): 5-36.

¹⁶¹ Heuser, "Luther and Disability," 185.

¹⁶² Yong, 34-35; Heuser, 186.

cross of Christ, Luther insists that human dependency is universal. All persons are, in Luther's theological schema, universally vulnerable and universally dependent, and this provides a perspective that supports a pastoral ethic of care. Furthermore, he insists that God's will, God's motives, and the total narrative of human experience that God may see, all are inscrutable to members of the human community. This perspective is made visible in statements that evoke the paradoxical wisdom at the heart of the gospel, such as: "God has established a fixed rule: everything that is high and praised of men is disregarded and abominable in the sight of God. ... God turns all this upside down. Everything we call beautiful, jolly, rich, etc., he calls poor, sick, weak, impotent."¹⁶³ There is no focus on any one group labeled "disabled" or "broken," but instead a conviction that behind masks of individual strength and power human beings are united in a reality of shared vulnerability.

These aspects of Luther's theology often have been forgotten or ignored, not only by the Nazi movement in Germany, but by others throughout history who have insisted that human value resides in strength and ability, the "theology of glory," as Luther put it. Luther's insistence on a theological narrative that emphasizes social, theological, and personal reversal as God's vision for humanity, as well as his conviction that human beings often do not see what God sees, frequently have been affirmed by parents of children with disabilities. Parents often find, after initial shock and dismay, that they are stretched, enriched, and blessed in ways they never imagined before welcoming a child with a disability into their family. By honoring

¹⁶³ Luther, "Sermon on the Mount," from Martin Luther, *Luther's Works: American Edition*, ed. Jaroslav Pelikan and Helmut Lehmann (Philadelphia: Fortress Press, and Saint Louis: Concordia Publishing House, 1955-1986) vol. 51, 35-37, quoted in Heuser, 192.

human vulnerability and fallibility, Luther does offer something of value to the conversation on pastoral theology and disability.

Even so, Luther's emphasis on human helplessness can be problematic. It is important to remember that he wrote to address particular pastoral concerns, rather than to provide a structured ethical argument for a general response to disability. Yet, the emphasis on human helplessness can encourage a highly individualized, passive response of resignation to pain, suffering, and injustice. Moreover, his thought can seem to imply that what happens in this world is of little consequence because of the heavenly salvation that awaits those who are faithful.¹⁶⁴ Despite its strengths, therefore, Luther's work never developed into a general ethical framework that addressed oppressive structures and systems, nor developed a vision for a community of care.

Theologian John Calvin (1509-1564), however, does offer insights for considering care in an ecclesial context. Although Calvin, who represents the second generation of reformers, wrote relatively little about disabilities,¹⁶⁵ his perspectives on church structures and practices leave a significant legacy for theological practice related to disabilities, care, and the faith community. Additionally, his doctrinal work on anthropology and theodicy intersect in ways that relate to pastoral questions around disabilities.

Calvin's pastoral and theological work emphasized returning the church to the structures and practices of early Christianity, and demonstrates a greater concern

¹⁶⁴ Heuser, 189. Heuser points out that while Luther spoke on impairments and disabilities, his comments came in response to individual pastoral situations, and were made in the mode of pastoral care.

¹⁶⁵ Deborah Creamer, "John Calvin and Disability," *Disability in the Christian Tradition: A Reader*, 216-250.

for the community than with the rights or needs of particular individuals. Given this, it is not surprising that when his work did touch upon issues related to disability, it focused less on questions of definition and more on what has been described as “activist” or “existential” discourses. He was concerned with community care for those who were sick and access to the word and sacraments in the community of faith. In his “Draft Ecclesiastical Ordinances,” for example, Calvin assigned the care of those who were poor or sick (which at that time often included people with disabilities) to deacons. These deacons were not a secondary level of clergy, but were as highly regarded as pastors, and shared sacramental responsibilities with them. This seems to indicate that care for people in need – which presumably would have included people with disabilities – was regarded as an important role and function of the church.¹⁶⁶

Unfortunately, Calvin’s model tended to sharply divide healthy clergy and sick subjects. This model built relationships based on charity, in which the strong always gave to the weak. Rather than facilitating a culture in which limits and challenges were recognized as universal experiences of human life, Calvin continued to draw upon the binary assumptions seen earlier in Augustine. In fact, Calvin’s emphasis on care of those who were sick and disabled contributed to the growth in the numbers and sizes of hospitals, poorhouses, and other institutions, many of which actually

¹⁶⁶ Creamer, “John Calvin and Disability,” 220. It is important that support and assistance for people with disabilities likely would have been primarily due to poverty, which was highly common (as it continues to be today) for people with disabilities. See, e.g., Goodey, “What is Developmental Disability?” and Timothy Stainton, “Medieval Charitable Institutions and Intellectual Impairment c. 1066-1600,” *Journal on Developmental Disabilities* 8, No. 2 (2001): 19-29.

functioned to control people whose behavior made others uncomfortable.¹⁶⁷ While Calvin called for care practices such as visiting people in need and sharing the Word and sacraments, he did not question structures that contribute to suffering.

Moreover, because intellectual understanding of the Gospel and the Church were so important to Calvin, some ecclesial practices marginalized those with what we would now call intellectual or developmental disabilities. While service on behalf of those in need clearly was valued, and while Calvin insisted that the Word of God, the sacrament of communion, and catechism classes should be received by all people, limits arose based on intellectual ability. Children could not receive sacraments until they could recite the entire catechism from memory, a restriction that would, effectively, bar many individuals with cognitive differences from full participation in the faith community. In fact, not only were children excluded from the sacrament before they could recite the catechism, Calvin argued that "it is a very perilous thing to introduce them without ... adequate instruction."¹⁶⁸

This resonates with further thoughts on intellectual capacity in his *Institutes of the Christian Religion*, in which Calvin simultaneously appeared to value all people, and to regard them as equal in their fallen nature, and yet failed to recognize that people differ dramatically in terms of intellectual capacity, and made statements that dehumanized persons with lesser intellectual capacity.¹⁶⁹ When he wrote, for example that even "in man's perverted and degenerate nature some sparks still

¹⁶⁷ Wolf Wolfensberger, Lecture: "A History of Human Services," 1998; Yong, *Theology and Down Syndrome*, 34.

¹⁶⁸ John Calvin, "Draft Ecclesiastical Ordinances," in *Calvin: Theological Treatises*, translated, with introduction and notes by J.K.S. Reid (Philadelphia: Westminster Press, 1954), 68-69.

¹⁶⁹ Creamer, "John Calvin and Disability," 221.

gleam. These show him to be a rational being, differing from brute beasts, because he is endowed with understanding,"¹⁷⁰ he simultaneously celebrated humankind for its ability to reason, but excluded those without this ability from the general category of humanity, *and* implied that because these persons cannot reason they are more like "brute beasts" than human beings. Similarly, in his biblical commentaries, Calvin reflected on Matthew 11:25-26, which says the truth was hidden "from the wise ... and revealed unto babes." Here, Calvin added "ignoramuses and uncultivated men," again including people of lesser intellectual ability and lower classes, to a point, but not respecting them. This is problematic not only because the converse seems to imply that one without rational abilities is not a "man" (i.e. human), but also because within the context Calvin associates lack of rational ability with degeneracy and lack of spiritual gifts.

Ultimately, Calvin's contributions are ambiguous. His practices offer a general framework for care, and his understanding of God's role in human experience is helpful. Unlike many early Christian thinkers, Calvin did not ascribe disability to divine punishment, the devil, or evil spirits. Instead, he simply asserted God's presence in the midst of human life.¹⁷¹ Yet, Calvin offered little attention to real human struggle, experiences of impairment, or exclusion, and thus he failed to build a legacy that supports mutual, authentic care based in universal human vulnerability.¹⁷²

¹⁷⁰ John Calvin, *Institutes of the Christian Religion*, Book II, Chapter 2, ed. John T. McNeill, trans. Ford Lewis Battles (Westminster Press: Philadelphia, 1960), 270.

¹⁷¹ Calvin, *Institutes*, Book III, Chapter 9 "Gratitude for earthly life!" 712-715.

¹⁷² Creamer, "John Calvin and Disability," 222-223.

Theologian Karl Barth: Barth (1886-1968), has been compared to some of the most significant thinkers throughout the Christian tradition. Moreover, he left an important, if also ambiguous legacy for considering theology and the Christian tradition in a disability context. Briefly, while Barth's anthropology emphasizes human relationship, that relational orientation demands rational ability. His ecclesiology emphasizes care for the vulnerable, as well as respect and protection. But his method, which denies the value of human experience for theological construction, makes it difficult to determine what "respect" and "care" might look like in a disability context.¹⁷³

Barth insisted that the Word of God (Christ) is the sole and sufficient focus, and scripture the sole and sufficient source, for theology.¹⁷⁴ While this says little about disabilities as such, it raises foundational issues about theological perspectives that seek to correlate disability experiences with the promises and claims of the gospel. Barth's theological method does not value human experience or the human sciences as theological sources.¹⁷⁵ Barth insisted that any phenomenological understanding of human life is only partial and fallible, falling far short of the understanding offered in Jesus Christ. "In us the real creature is of course unknowable. In us it cannot express itself. Thus of ourselves we do not know what we really are. ... the incarnate Word of God, Jesus Christ, is really the true Word about man as well as

¹⁷³ Donald Wood, "Barth on the Concrete Freedom of Human Life," *Disability in the Christian Tradition: A Reader*, 391-426.

¹⁷⁴ Wood, 391.

¹⁷⁵ Wood, 391-392, 394-396.

God, and about the nature of man. ... It is either through him that we know what we truly are as men, or we do not know it at all.”¹⁷⁶

Barth’s low regard for human experience as a direct source for theology is at odds with recent theological work that tries to re-assess the Christian tradition from a disability perspective. Moreover, this perspective appears to have little in common with predominant contemporary approaches to pastoral/practical theology, which do affirm the value of human experience.¹⁷⁷ This makes his method and commitments ambiguous for anyone who does not “fit” the mold of typical humanity. I have included him in this analysis, however, because he has had a profound influence on theology, especially in a Western Protestant context.

Barth’s understanding of humanity – again, derived through the lens of Christ and the witness of scripture – is relational, which seems promising in the context of pastoral theological response to families facing disability. Moreover, Barth argues that the relational perspective arises from divine freedom, shared by humanity, which is a freedom-for: for relationship with God, persons, and other created beings.¹⁷⁸ Unfortunately, Barth attributes this relational existence to the ability to think rationally, saying, for instance, “As man is, he is endowed with reason to perceive God and responsibility to answer Him, he is capable of history and

¹⁷⁶ Karl Barth, *Church Dogmatics* III.2.52-53, ed. G.W. Bromiley and T.F. Torrance (New York: T&T Clark, 2009), 48.

¹⁷⁷ For exceptions, see Deborah Van Deusen Hunsinger, *Theology and Pastoral Counseling: A New Interdisciplinary Approach* (Grand Rapids, Mich.: Eerdmans, 1995) for a relatively recent pastoral theological work that relies heavily on Barthian theology, and Eduard Thurneysen, *A Theology of Pastoral Care* (Richmond, Va.: John Knox Press, 1962) for an older one. [OR in the realm of disabilities itself, what about John Swinton?](#)

¹⁷⁸ Barth, *Church Dogmatics* III.1.195; Hans S. Reinders, *Receiving the Gift of Friendship: Profound Disability, Theological Anthropology and Ethics* (Grand Rapids, Mich.: Eerdmans, 2008), 238ff; Yong, *Theology and Down Syndrome*, 173-174.

decision.”¹⁷⁹ This is problematic in a disability context because it disowns those who lack typical “reason,” “history,” or “decision” from human community.¹⁸⁰

In many ways Barth’s theology and method both are problematic in the context of thinking about disability, yet he also offers some helpful thoughts for considering care in communities. As indicated, he insisted that human experience, often drawn upon as a knowledge source in disability theology and other theologies arising from people on the margins, is fallible, insufficient, and tainted by sin. This perspective has significant implications, not only for theological method and pastoral reasoning, but also for contemporary understandings of disabilities, human community, and the Christian community’s response to a world in need. It is here, in fact, that some of Barth’s most valuable thinking for this project emerges.

For Barth, human vulnerability and limits are universal, divinely given, and paradoxically tempered. While these realities remind us of death, and perhaps judgment, they are actually a saving reality, because in accepting limits and vulnerability, one is reminded of one’s ultimate and complete dependence upon God.¹⁸¹ Furthermore, human understanding is fallible, and this imposes sharp limits on what we can presume to know about the value of human life, Barth argues. Barth’s thinking clearly was informed by the tragic eugenic practices against multiple populations, including people with disabilities, of the Third Reich and National Socialism. He wrote, using language no longer acceptable but typical for his

¹⁷⁹ Barth, *Church Dogmatics* III.2.202.

¹⁸⁰ Wood points out that Barth does not seem to have a heavy investment in this understanding, but that he also seems to have little concern with its implications. Certainly, his theology would have been enriched by sustained interaction with persons with disabilities and their families.

¹⁸¹ Barth, *Church Dogmatics* III.4, 372-373.

era, that society has no right to decide that certain people (i.e. "the incurably infirm, the insane, imbeciles, the deformed, persons who by nature or accident or war are completely immobilized and crippled and therefore 'useless' ") are unfit to live.

The value of this kind of life is God's secret. Those around and society as a whole may not find anything in it but this does not mean that they have a right to reject and liquidate it. Who can really see the true and inward reality of this type of life? Who can really know whether it may not be far more precious in the eyes of God, or reveal itself as far more glorious in eternity, than the lives of hundreds of healthy workers and peasants, technicians, scientists, artists and soldiers, which the state rates so highly?¹⁸²

Beyond "allowing" weaker, more vulnerable citizens to live, Barth argued for societies that care for those in need, saying no society that fails to care for those who are weaker or more vulnerable can be strong; that, in fact, this type of care strengthens societies by "knitting" them together and that any community that treats "weak members as a hindrance, and even proceeds to their extermination, is on the verge of collapse." Our human responsibility, according to Barth, is to respect, protect and care for life.¹⁸³

This is a valuable perspective to draw upon in a disability context, but it also raises a critical issue related to his method. Without honoring the insights of human experience, especially the experiences of marginalized persons, it is not clear what "respect" or "care" might mean for theological thought and practice that is life-giving, rather than paternalistic, controlling, degrading, or neglectful.

Barth's thoughts on care also appear in his understanding of the Christian community as one bound together by love, which allows people to serve a common

¹⁸² Barth, *Church Dogmatics* III.4, 423-424.

¹⁸³ Barth, *Church Dogmatics* III.4, 397.

vocation. This, too, may be a valuable resource for a pastoral theological response to disability. Barth argued that Christians must unite with one another and serve one another so that each is free to live life in service to God and the world, in a way that both imitates and represents God's love for the world.¹⁸⁴

Barth's insistence on the mystery of life and subsequent understandings of human ethical response challenge a utilitarian mindset in which individuals are valued only for what they are able to offer to society, and permitted to receive the benefits of life in human community only because of what they have contributed.¹⁸⁵ This is a valuable reminder that welcome and care for and with persons with disabilities is a call and claim upon all people not because communities will gain (compassion, understanding, broader appreciation for diversity, etc.) from their presence – though, most likely, they will gain this. However, to make that welcome and care contingent in any way upon what the community might receive in return is dangerous. This attitude treats our most vulnerable brothers and sisters as a commodity for self or community improvement, and continues to put them at risk of neglect and marginalization. Instead, each person deserves welcome and care simply because each person is a part of God's creation.

Thus, Barth's legacy is, indeed, ambiguous, especially for the purposes of this project. In pastoral theological work that seeks to honor authentic human experience and to connect theological thought and practice with a long-disregarded population, Barth's valuable insights into the human person and human communities are somewhat overshadowed by his rigid method, which devalues

¹⁸⁴ Barth, *Church Dogmatics* III.4, 500, 502.

¹⁸⁵ Barth, *Church Dogmatics* III.4, 424.

human experience, as well as his strong emphasis on reason as the distinctive foundation of the human person.

Conclusion

Clearly, the Christian tradition has responded to the reality of disability in a variety of ways, and this heritage is ambiguous in the truest sense of that word – it offers both positive insights and damaging declarations. Moreover, while the Christian tradition is highly textual, texts associated with it are not complete iterations of practices and attitudes in response to disabilities. The church has both offered care and exercised control in its relationships with people with disabilities. At times, however, the church's response to disabilities most resembled an attitude of less-than-benign neglect.

Three points are critical to this broad historical survey. First, the tradition is ambiguous. While some teachings urge care and justice for those with disabilities, others are harsh and dehumanizing. In practice, the church has responded to people with disabilities in a multitude of ways – offering critical care, yet also participating in state-run efforts that primarily functioned to control. Second, the ambiguity within the tradition continues as denominations and congregations seek to discern what it means to care for and with persons with disabilities, as today's faithful disciples of an ancient religion. Finally, this brief survey of a few leaders in the Christian theological tradition reminds us that there are powerful -- if imperfect -- resources within the tradition to support a pastoral response to families facing disability. Those who prioritize care as an ethical imperative have much to offer

contemporary discussions about disability, even when their understandings of care may be more representative of their own era than they are of current conceptions.

The Christian tradition, therefore, ultimately presents both assets and liabilities in the continuing quest to develop appropriate pastoral response to the particular strengths and challenges of disabilities. In its ambiguity, it invites a look outward, beyond the Bible, beyond doctrinal heritage, to other sources that may offer other wisdom for this journey. The chapter ahead, therefore, turns to history, theory, ethic, practice, and critique of care as possible resources for this project.

CHAPTER 5

CARE THAT CREATES, SUSTAINS, AND PERFECTS

Introduction

Human beings are creatures created to care.

We care by laboring in ways¹⁸⁶ that sustain and nurture, allowing persons not only to survive, but also to develop potential gifts and strengths. Thus, while children need food and a safe environment, for example, they also need intellectual and physical challenges, and, sometimes, supports that can help them to meet those challenges. They need opportunities for spiritual engagement and, sometimes, supports that can make that engagement possible. They need opportunities to develop empathy, self-control, and other emotional strengths and, often, responsive relationships that can foster the development of these strengths. This type of care, oriented toward development as well as basic survival, enriches human lives and human communities.

In addition to enhancing community, the practice of care structures the self. Care can liberate care receivers from neglect, discrimination, and cruelty, and caregivers from unexamined assumptions about power, strength, and vulnerability. When care is healthy, these roles overlap and shift dynamically. The one who is at one time a care receiver, becomes at another time a caregiver. Always, all persons

¹⁸⁶ The argument that care is labor has been developed by several scholars including Joan Tronto (*Moral Boundaries*) in contrast to earlier work by Nel Noddings and Sara Ruddick, both particularly known for emphasizing the emotional qualities of care. See: Nel Noddings, *Caring: A Feminine Approach to Ethics and Moral Education* (Berkeley: University of California Press, 1986), esp. 14-19; and Sara Ruddick, "Maternal Thinking," *Feminist Studies* 6, No. 2 (1980): 342-367.

are respected.¹⁸⁷ Both roles are essential to human life and personhood. Thus caregivers and care receivers who practice healthy care are empowered to live authentically, cognizant of their own gifts, passions, and challenges.

Finally, the practice of healthy care fosters human and divine relationship. Human beings engage with one another in the experience of care. As tasks from the mundane to the magnificent are accomplished, human beings can come to know one another and to respect one another's personal qualities. Moreover, through that engagement, persons can taste just a bit of the life of God, whose care for humankind is foundational to all the care that persons can give and receive to and from one another. Care allows persons to live, even to flourish, in relationships both human and divine that support, sustain, and empower so that we might experience fullness of life in the light of God.

We care by *adopting an ethic* that shapes the way we see and respond to our world. As a normative framework, care insists that all persons deserve sustenance, nurture, and rich opportunities to develop their fullest selves, even if this means that all persons *are not* treated equally. Thus, [thoughtfully developed](#) care ethics [and practices](#) emerge from critical attention to the particularities of individuals and the purposes of human communities. A care ethic assumes that human beings are constituted by and through human relationship. This means that these relationships are worthy of attention and reflection, that moral understandings develop within human relationship, and that power dynamics are part of the context of care

¹⁸⁷ Martin Heidegger, *Being and Time*, trans. John Macquarrie and Edward Robinson (London: SCM Press, 1962), 235-244; Reich, 353-354.

practices and are, themselves, worthy of attention.¹⁸⁸ This viewpoint contrasts with rationalist understandings that argue that the best moral rules are universally applicable and developed far from particular relationships and practices. In this way, an ethic of care values relationships as well as the emotions that arise within them. Importantly, especially for this project, an ethic of care (like the practice of care)¹⁸⁹ argues that care is an important area of public concern that not only challenges public/private boundaries,¹⁹⁰ but that also incorporates issues of power “from the household to the global political economy.”¹⁹¹

Clearly, care is at once mundane, complex, and provocative. Practiced well, it not only addresses the most basic human needs, it empowers persons to more deeply engage with the world and the self. Moreover, it challenges longstanding cultural assumptions about ethics related to vulnerability, equal treatment, and independence. Care carries the weight of generations of cultural discourse, sometimes contemporary efforts to develop it as an ethical framework, and, sadly, tragic history associated with control, coercion, and even abuse in relationships with people with disabilities. Thus care as a concept and as a set of practices is worthy of examination. Scholars and other writers from a variety of perspectives have done this, wrestling with questions related to care such as definition,

¹⁸⁸ Definitional understandings of the ethic of care in this paragraph are drawn from a variety of thinkers, but especially Fiona Robinson, *The Ethics of Care: A Feminist Approach to Human Security* (Philadelphia: Temple University Press, 2011); Virginia Held, *The Ethics of Care: Personal, Political and Global* (Oxford: Oxford University Press, 2006); Kittay, *Love's Labor*; Heflinger and VanHooser-Suiter, “When Caring Is Just and Justice Is Caring;” and Tronto, *Moral Boundaries*.

¹⁸⁹ This is more true of later ethic of care work, including that of such scholars as: Virginia Held, Marilyn Friedman, Eva Feder Kittay, and Joan Tronto, than it is of earlier thinkers such as Nel Noddings, Carol Gilligan, and Sara Ruddick.

¹⁹⁰ Tronto, *Moral Boundaries*, chap. 5, “An Ethic of Care,” and chap. 6, “Care and Political Theory.” It is important to note that Tronto argues that care is generally *not* appropriately valued in public life.

¹⁹¹ Fiona Robinson, 5.

significance, role, process, and more. Care has been addressed in a variety of genres, including myth, essay, scripture, and academic work (often from feminist perspectives) such as philosophy, political science, bioethics, and nursing.¹⁹² Yet care [as a construct](#) has been strangely under-addressed in pastoral care or pastoral theology, despite its many connections to theological and pastoral questions. [While the field uses the term “care” there has been little historical or philosophical exploration of its meaning, influences, and implications.](#) As the introduction to this dissertation noted, what does it mean to care for and with a family facing disability? How does a care perspective guide pastoral practice? Where and how might theological identity intersect with and shape that care perspective? These are critical questions for persons who seek to lead, sustain, guide, reconcile, liberate and empower individuals and communities in the light of Christ.

Therefore, this chapter examines care in two ways. First, it presents contemporary and historic discourse regarding care in non-theological terms. Additionally, it presents recent critiques of care that call into question its use as a structuring perspective for thinking about disabilities and families facing disabilities. The chapter begins with a critical examination of the “Different Voice” – the voice of care as an ethical framework – popularized by Carol Gilligan in the 1980s. Gilligan is highlighted because she was one of the earliest scholars to connect morality and care. This move began to shift care from an exclusively private concern

¹⁹² See, for example, Kittay, *Love’s Labor*; Craig-Anne Heflinger and Sarah VanHooser-Suiter, “Issues of Care Are Issues of Justice: Reframing the Experiences of Families of Children with Mental Illness,” *Families in Society* 92, No. 2 (2011): 191-198; Tronto, *Moral Boundaries*; Reich, “History of the Notion of Care,” “Historical Dimensions of an Ethic of Care in Health Care,” “Contemporary Ethics of Care,” all in *Encyclopedia of Bioethics*, second edition; Virginia Held, ed., *Justice and Care: Essential Readings in Feminist Ethics* (Boulder, Colo.: Westview Press, 1995).

to one more present in the public sphere. To explore care more fully and to begin to develop a perspective¹⁹³ that examines the world through the lens of care, the chapter will move backward in time and will present historic cultural discourse about care that has contributed to western social understandings and practices. This investigation illumines some of the distinctive contributions of care as a social and theological framework. The chapter also presents recent critiques of care perspectives and practices, especially critiques that come from disability communities. Care has become a provocative word in some disability communities, and any work on care involving disabilities needs to hear these critiques and respond to them.

Drawing from contemporary and historical voices, the chapter concludes by arguing that despite its potential pitfalls, the language of care is an important element to include in conversations about family experience with disabilities, especially when its richness and complexity – the product of thousands of years of discourse – are appreciated. This argument describes the care perspective that seems most appropriate to bring to the task at hand: description, analysis, and pastoral theological construction drawing from qualitative research with families of teenagers with autism.

¹⁹³ While it is important at times to distinguish between the practice and the ethic of care, it will become apparent in this chapter that the distinction is not always sharp. In keeping with a philosophical and theological orientation that sees practices as generally value-laden, practice and ethic overlap. When the overlap is particularly operative, I will describe this as a, or the, care perspective.

A Case for Care as Orientation and Practice

As a practice, care often happens without reflection. Persons care out of instinct, out of love, out of habit. As a concept, however, care has a long history of reflection. One of the most prominent recent thinkers in lifting up the significance of care as a factor impacting human behavior has been Carol Gilligan. Gilligan's groundbreaking work, *In a Different Voice*, argued that women generally are driven by moral understandings based primarily in relationship and responsibility – understandings that can support a focus on care. Men, meanwhile, are driven by an urge for independence, and tend to prize abstract understandings of rights and fairness, Gilligan argued. This difference has meant that theories of human development, which tend to prize the tendencies more often exhibited by men, often have devalued women, Gilligan argued. Gilligan used empirical research and critical examination of existing developmental theory to argue that while female development was distinct from male development, this did not mean it was inferior. She also insisted that the stronger sense of obligation to relationships evident in girls' interpersonal interactions (vs. the stronger tie to abstract principles of justice evident in boys' decision-making processes) was not a sign of "poorer" development, but instead a sign of a different strength. This strength, she argued, is derived from an epistemological approach that sees moral decision making as a process of understanding and responding to specific situations that are rich with emotion and contextual particularities.¹⁹⁴ Gilligan called this strength an "ethic of

¹⁹⁴ Carol Gilligan, *In a Different Voice: Psychological Theory and Women's Development* (Cambridge, Mass.: Harvard University Press, 1982), 100. Though Gilligan is the most prominent thinker in early ethic of care work, she was not the first. Sara Ruddick, whose groundbreaking 1980 essay "Maternal Thinking"

care,” understood as relationally-based, compassionate efforts at seeing and responding to need, “taking care of the world by sustaining the web of connection so that no one is left alone.”¹⁹⁵

Gilligan’s work introduced the ethic of care to the late-twentieth century intellectual lexicon as an important, though disregarded, element in human society, by pointing to it as a centering value that can guide decisions, actions, and practices with integrity. In 1982, this perspective was revolutionary. It legitimized patterns of interaction that had been disparaged by generations of psychological thinking. And it represented some of the first feminist efforts to argue that care was more than a private practice, and more than “natural instinct” for woman – that it could, in fact, offer something to society.¹⁹⁶

This contribution cannot be minimized. In the end, however, Gilligan’s contribution is limited by a gender-based, essentializing focus in her method and its resulting ethic of care. Briefly, her argument depends upon gender-stereotypical understandings of men and women. Gilligan was not alone in this reasoning among early thinkers on the ethic of care – Sara Ruddick, for example, located care’s origin

raised the possibility that the attentive love generally characteristic of maternal practice and thought had value outside of the privatized sphere of the home, has been accorded this honor.

¹⁹⁵ Gilligan, 62-63.

¹⁹⁶ See, for example: Noddings, *Caring*, which begins from an attempt to distinguish between “natural” or instinctive caring, and the character of the obligation assumed in an ethic of care; Marilyn Friedman, “Beyond Caring: The De-Moralization of Gender,” *Science, Morality and Feminist Theory*, Marsha Hanen and Kai Nielsen, eds., Supplementary Vol. 13 *Canadian Journal of Philosophy*, (Calgary, Alberta: University of Calgary Press, 1987) 87-110; and Sara Ruddick, “Injustice in Families: Assault and Domination,” in *Justice and Care: Essential Readings in Feminist Ethics*, Virginia Held, ed. (Boulder, Colo.: Westview Press, 1995). Friedman’s work wrestles with questions of gender-normative behavior and attitudes and addresses distinctions between universal and particular moral systems, while Ruddick looks at the public/private split inadvertently reinforced by most feminist ethics of care, and asks how an ethic of justice can operate alongside care in the intimate and private space of the family.

in “maternal thinking.”¹⁹⁷ Unfortunately, this simply reified a gender-based division of moral labor.¹⁹⁸

The problematic nature of this approach is perhaps more obvious now than in the early days of ethic of care work. While Gilligan sought to prove that the interdependent, concerned, “women’s morality” is equally as valid as a more distant moral framework based in abstract understandings of fairness, her impact was limited by a simple reality: The values Gilligan associated with women also are associated with private life and personal relationships, while the values she associated with men also are associated with the public sphere, and thus are understood to be more “powerful.” Ultimately, while Gilligan’s work did advance somewhat the notion of an ethic of care in contemporary scholarly discourse, it also reinforced reigning understandings about gender roles, authority, and responsibility. Moreover, it continued to hold ethics of justice and care in dichotomous opposition to one another.¹⁹⁹ Instead, for care to contribute more significantly to ethical and theological reflection, it needs to be appreciated as a significant perspective that deepens understandings of justice beyond simple fairness.

Thus, voices other than Gilligan’s are critical for developing a theory of care that will be useful for a more robust pastoral theology of care for families living with disabilities. Some of these voices emerged very early in western civilization, some much later. By connecting care with the social and political economy, this later work

¹⁹⁷ Ruddick, *Maternal Thinking*.

¹⁹⁸ Friedman, “Beyond Caring.”

¹⁹⁹ Tronto, 96; Kittay, “When Caring is Just and Justice Is Caring,” 257-276.

makes the practice and ethic of care more than “women’s work,” and thinking about care more than a “woman’s voice.” Additionally, some are – even if inadvertently – more amenable to theological analysis, as well.²⁰⁰

The Cultural Weight of Care Discourse

The history of care as a concept carries a cultural weight that is rich and useful in pastoral theological thinking, including in reflecting on family experiences with disabilities. Throughout many centuries, thinkers including philosophers, playwrights, writers of myths, and others have wrestled with the meaning and impact of care, as well as the implications of prioritizing care in human relationships and human experience. This rich heritage can illuminate contemporary human experiences of care – both ethic and practice – and thus contribute to families’ attempts to understand the challenges and gifts of their lives with disabilities, many of which involve both giving and receiving care. These historic contributions, then, are of significant contemporary interest. They offer valuable insights to aid in developing a pastoral theological response to families facing disabilities.

From the ancient world: care is ambiguous, but critical

Early writing about care offers valuable contributions for contemporary pastoral theological thinking related to disabilities. The contemporary word “care,” for example, comes from a Latin term, *cura*, which had a dual meaning. On the one hand, *cura* implied anxious effort, worries or troubles that burden an individual or group.

²⁰⁰ Despite an abundance of feminist work on the ethic of care, critiques of care from disability studies perspectives, and some philosophical work on nursing that attends to care as a concept, the only apparent source addressing the history of care is Warren Thomas Reich’s, “Care I: History of the Notion of Care.”

At the same time, *cura* pointed to solicitous, tender efforts on behalf of another, accomplished with conscientious devotion.²⁰¹ The ancient philosopher Seneca, who favored the second understanding, insisted that in humans “the good is perfected by care,”²⁰² and thus pointed to the idea that care effected positive internal personality change. One of the earliest recorded statements about the meaning and significance of care comes from Greco-Roman mythology. The myth, known simply as “Care,” unites a statement about origins with ethical and philosophical analysis, and its insights have contributed to thinking about care throughout history.

As Care (Cura) was crossing a river, she thoughtfully picked up some mud and began to fashion a human being. While she was pondering what she had done, Jupiter came along. (Jupiter was the founder of Olympian society, a society of the major gods and goddesses who inhabited Mount Olympus after most of the gods had already appeared.) Care asked him to give the spirit of life to the human being, and Jupiter readily granted this. Care wanted to name the human after herself, but Jupiter insisted that his name should be given to the human instead. While Care and Jupiter were arguing, Terra arose and said that the human being should be named after her, since she had given her own body. (Terra, or Earth, the original life force of the earth, guided Jupiter's rise to power.) Finally, all three disputants accepted Saturn as judge. (Known for his devotion to fairness and equality, Saturn was the son of Terra and the father of Jupiter.) Saturn decided that Jupiter, who gave spirit to the human, would take back its soul after death; and since Terra had offered her body to the human, she should receive it back after death. But, said Saturn, "Since Care first fashioned the human being, let her have and hold it as long as it lives." Finally, Jupiter said, "Let it be called *homo* (Latin for human being), since it seems to be made from *humus* (Latin for earth)."²⁰³

Myths of origin help a people to understand themselves. In addition to clarifying where communities have come from, myths of origin incorporate ethical statements

²⁰¹ Hyginus, “Care,” *The Myths of Hyginus*, Mary Grant, trans. (Lawrence, Kan.: University of Kansas Publications, 1960), 18-19, 157-158.

²⁰² Reich, “History of the Notion of Care,” 350.

²⁰³ Hyginus, “Care.”

about the values those communities find most fundamental to human life, statements that help people to discern where they should be going.²⁰⁴ Accordingly, the myth of Care presents a rather obvious allegorical statement about *how* humanity came to be, and to whom human beings must assign the creating force (and, therefore, appropriate respect and gratitude). In this, it is similar to one of the biblical stories of origin (Genesis 2, in which God creates “man” from the dust of the ground)²⁰⁵ although the multiplicity of gods, the arguing over taking credit, and the complex judgment, which assigns not only credit, but also responsibility, is distinct. At the same time, however, the myth also offers a more subtle ethical argument. In this myth, power is used to create, tenderly, rather than to dominate or oppress, and care accompanies the human before life, into creation, throughout life, and beyond, into death. Thus, both the channeling of power into care, and the critical social role of care, imply that “care is the glue of society,”²⁰⁶ that which holds us together as a human people and that which can carry us forward.

The ancients were not blind to the complexity of care. They recognized that care can be burdensome, restricting and painful. And yet, in both myth and philosophical discourse, they insisted that we are, ultimately, people of care.

²⁰⁴ Carol A. Newsom, “Genesis 2-3 and 1 Enoch 6-16: Two Myths of Origin and Their Ethical Implications,” in Christine Roy Yoder, Kathleen M. O’Connor, E. Elizabeth Johnson and Stanley P. Saunders, eds., *Shaking Heaven and Earth: Essays in Honor of Walter Brueggemann and Charles B. Cousar* (Louisville, Ky.: Westminster John Knox, 2005), 7.

²⁰⁵ In comparison, in the Hebrew scripture it is the man, or *adam* in Hebrew, who is linguistically related to the ground, or *adamah*, while in the Greco-Roman myth it is a god, *terra*, whose name arises from the stuff of creation. The literal ubiquity of gods in the Greco-Roman understanding creates an atmosphere different from that of the Genesis story, where God seems to enter and to create, but to create out of something separate from godself. Later in Genesis, when the man and woman have disappointed God, the land is cursed, and the labor that it will take for the man and woman to produce food from it is called toil, not care. By this point, there is a separation not only between God and land, but between humanity and land. When God says “you are dust, and to dust you shall return,” the implication is that the broken nature of the relationship separates humanity, land, and care.

²⁰⁶ Reich, *Encyclopedia of Bioethics*, 350.

German Romanticism: care is relational, but also political

Like ancient philosophers, more recent authors have wrestled with the meaning and role of care. One of the most important arguments for an expansive, political, role for care in human society comes from the German Romantic poet Johann Wolfgang von Goethe's dramatic poem *Faust*.²⁰⁷ In the poem, Dr. Faust is a scientist who cares for little but the pursuit of pure knowledge. He wants to be unencumbered, so that he might commit his life to science and reason. So he makes a deal with the devil. He will gain pure knowledge and power, but he may eventually lose his soul. By the end of the play, Faust has become ruler of a land reclaimed from the sea by the development of a technologically complex system of dikes. Again, so that he might be unencumbered, he agrees with the devil that the last remaining home on the island must be destroyed. It is only after the home is destroyed that Faust learns that an elderly couple were killed as well. Faust breaks down and decides he must break his pact with the devil.

It is at this point that the figure Care (*Sorge*, in German) appears. Care describes herself as the "eternally anxious companion," who embodies qualities of attention and responsibility. She denounces Faust for his hard-hearted selfishness that has led to such destruction and blinds him because he will not acknowledge her fully. Finally, he begins to understand that though care can be burdensome, it also can be tender and uplifting, and is necessary for the well-being of the world. As a ruler, he

²⁰⁷ Analysis of *Faust* is drawn from Reich, *Encyclopedia of Bioethics*, 352.

begins to offer solicitude and kindness to his people, and is transformed by the experience. Reich argues that:

Goethe's Faustian narrative demonstrates that striving for one's own life goals while shutting out a sometimes worrisome and painful concern for people and institutions results in terrible external and internal harm. In the pursuit of one's destiny, a human cannot avoid care. ... In contrast to today's tendency to associate care exclusively with interpersonal devotion, Goethe works out the meaning of care in a political setting...

Faust's presentation of care as a political concept anticipates the much more recent notion that care can and should challenge the advantages of the powerful by bridging splits between public and private, and morality and politics.²⁰⁸ Moreover, Faust presents a political and ethical framework, undergirded by a focus on care, that demands attention to the needs of the most vulnerable and contributes to the flourishing of all. This blurring of political, personal, and moral boundaries is a valuable resource for reflection on relationships with those who are particularly vulnerable and their families, including persons with disabilities. Moreover, the experiences of families in this study make clear that this reflection is necessary. They have experienced care inconsistently in the church and in the wider community, and care at home has challenged their stamina. Only rarely have they been supported in caring for and with their children with disabilities, and none described experiences of public advocacy for justice in solidarity with others.²⁰⁹

²⁰⁸ Tronto, 77-97, 111-122.

²⁰⁹ For some thinkers, it is the specificity of the relational/personal sphere that signifies care. See, for example, Patricia Benner and Judith Wrubel, writing from a nursing perspective, who insist on the specific, relational context of care and thus object to the idea of ethical theories of care. Patricia Benner and Judith Wrubel, *The Primacy of Caring* (Menlo Park, CA: Addison-Wesley, 1989).

Twentieth-century philosopher emphasizes attention

Simone Weil wrote in the midst of the Holocaust, when many people sought to ignore the genocidal violence around them. In this context, Weil elevated the concept of attention as a critical moral quality and a foundational component of care. In Weil's work, attention refers to one's relationship with the world outside oneself, to the person who seems to be in need of care, and to oneself as a person attempting to care. She described attention as the effort to offer patient, loving regard to another by "suspending our thought, leaving it detached, empty, and ready to be penetrated by the object."²¹⁰ She encouraged would-be carers to attend to the fullness of human persons as they are, not as we might want them to be,²¹¹ and argued that this is foundational to all fully human relationship and to ethical thought.²¹²

The quality of attention is not uniform, however. Weil distinguished between voluntary and involuntary attention. In her view, involuntary attention arises spontaneously from emotion – we are horrified or frightened by something we see or hear, for example, and thus are involuntarily pulled into an attentive relationship with the object of our emotional response. This type of attention, Weil argued, is not a moral accomplishment, but rather a reactive response in which one cannot choose anything but attention.²¹³ In terms of care, it seems that involuntary attention *could* lead to care, but this is far from certain. In fact, it could be at least as likely to

²¹⁰ Iris Murdoch, *The Sovereignty of Good* (London: Routledge & Kegan Paul, 1970), 40.

²¹¹ Simone Weil, "Reflections on the Right Use of School Studies with a View to the Love of God," in George A. Panichas, ed., *The Simone Weil Reader* (New York: David McKay Company, 1977), 49, 51.

²¹² Tronto, 127-128. Tronto's analysis of attention draws heavily from Simone Weil.

²¹³ Simone Weil, *Lectures on Philosophy*, Hugh Price, trans. (Cambridge: Cambridge University Press, 1978), 205-206.

precipitate the all-too-human response of shutting out that which horrifies or saddens us, a response that is disheartening in part because it is, indeed, all too human. In this process, involuntary attention has not led to care, but has provoked a deliberate attempt to avoid *both* voluntary attention *and* care.

Care as a form of moral practice, on the other hand, is attention not for the sake of the self, but for the sake of another, even when there are obvious negative consequences. This is voluntary attention. Voluntary attention is marked by a feeling of deliberation – one has chosen to attend to a subject, and, consequently, one makes subsequent decisions about avoiding thinking of other subjects, avoiding being swayed from the attentive task at hand by emotion, and avoiding acting in ways that violate one’s own best ideals. In fact, Weil argued that the mind “shuts out the thoughts it wants to shut out,” and wrote that attention “prevents sin.”²¹⁴

Succeeding in the effort to suppress certain thoughts seems extremely difficult, and perhaps not helpful psychologically. Noting and *seeking* to set aside unwanted thoughts, however, is significant. This is how Weil believed attention distinguished “people from animals,” presumably because she believed animals were unlikely to achieve this type of deliberation. While her assessment of non-human animal capacities may be contestable, her point reflects a commitment to the importance of attention for meaningful and just human life, and this continues to be valuable. In short, Weil insisted that attention matters. It is necessary for ethical behavior; it frees human beings to draw close to God; it creates opportunity for the object of attention to be true to him or herself; it is essential for the development of justice

²¹⁴ Weil, “Reflections on the Right Use of School Studies,” *Simone Weil Reader*, 49.

and equality; and it entails – and demands strength for – facing mystery in human life.

The simple call to *pay attention* not only to suffering but to God's call in the midst of suffering is critical in any historical moment, but especially in the market culture of contemporary Western society. In this culture, the market often seems to be entrusted with responding to human needs traditionally addressed via human relationship. While at one time neighbors and family helped with childcare, farm work, and housing construction, for example, today we are more likely to hire and pay people with whom we have no relationship other than that of employer/employee to accomplish these and other tasks. It is important to avoid romanticizing earlier practices as we consider those that are more current. The practice of addressing human need in relational ways continues to be valuable, however. Relationally-based attention to suffering or need can deepen and strengthen relationships, so that people grow closer together and thus are more likely to see and respond to future needs. Care receivers are more likely to be supported as they grow into their own capabilities, caregivers experience the joy of giving, and the widespread practice of care can communicate the idea that vulnerability and need are normal, expected aspects of human life.

A market-based society impedes all of this. Contemporary western society tends to assume that the market is a (sometimes *the*) solution to all problems and concerns. This relieves people from the challenges of interdependent relationships that demand attention, and frees (those with resources) to engage with others in ways primarily shaped by the ability to buy and sell labor and products. With

enough money, there is little need for ongoing relationships of unpaid interdependence, and thus little incentive to truly attend to others with care.²¹⁵ Thus, habitual inattention is at least in part a product of a market society, and likely even more of a temptation today previously.

Deep attention as a continual, contextual, narrative task has important epistemological implications. It makes visible the unique qualities of individuals, groups, and cultures, which challenges moral philosophy's traditional desire to develop universal principles for response to human need and ethical challenge. Instead, deep attention of the type described by Weil insists that the moral response to human limits and suffering is the development of "perceptive, imaginative, appreciative, and expressive skills and capacities which put and keep us in unimpeded contact with the realities of ourselves and specific others."²¹⁶ This is a relational, narrative epistemology, a form of learning and knowing that is thoroughly dependent on who people are for and with one another. Those who are willing to hear, respect, and learn from the complexities of one another's experiences develop distinct and authentic forms of care that have the potential to effectively address particular needs. This care does not engender a set of universal principals that will define care for all persons and families, but repeated practice of it teaches the importance of beginning by understanding. In seeking to care for and

²¹⁵ Tronto, *Moral Boundaries*, 129-130. The observation is particularly pertinent to pastoral care, which is increasingly dominated by a market ideology that often forces separation from ecclesial identity and movement to the alternative "sacred canopies" of medical technology and economic orthodoxy. See Pamela D. Couture and Richard Hester, "The Future of Pastoral Care and Counseling and the God of the Market," in *Pastoral Care and Social Conflict*, Pamela D. Couture and Rodney Hunter, eds. (Nashville, Abingdon: 1995), 44-54.

²¹⁶ Margaret Urban Walker, "Moral Understandings: Alternative 'Epistemology' for a Feminist Ethics," in *Justice and Care*, 145.

with families with teens with autism, the importance of attention – especially Weil’s insistence on setting aside selfish and simplistic desires and assumptions so that we might *fully* attend to another -- is obvious.

Weil’s work on the subject of attention has left an important legacy. She teaches the importance of resisting any temptation to avoid or ignore the concerns of others, and calls all persons to hear, witness, and respond to others’ suffering and challenges. This legacy must be tempered, however. Those who seek to give care must learn healthy care practices from those receiving care. Care offered in ways that patronize, isolate, or control is not care.

Moreover, cultures in which some (usually women and persons of color) have been assumed to be the caregivers for the whole society must engage in self-examination and encourage broader attention to care. Attention to others can and at times has degraded necessary attention to self, and a completely other-directed existence is dangerous. This point is particularly pertinent in thinking about women, who have long been socialized to put themselves last in relationships. The glorification of the caregiving role often has served to reinforce traditional family and social structures that oppress and marginalize women, especially women of color. Constant self-sacrifice can lead to frustration and resentment that prevent caregivers from living into the fullness of their being – even as they try to facilitate this among care receivers. This is nonsensical. To fully attend to others in their needs, one must recognize and accept one’s own need for care.²¹⁷ Recent writings in

²¹⁷ Tronto, *Moral Boundaries*, 131; Tronto, “Women and Caring: What Can Feminists Learn about Morality from Caring?” in *Justice and Care*, 106-107.

the fields of pastoral care and pastoral theology, especially work written from a feminist perspective, often has sought to address this issue.²¹⁸

Contextual care in the care of souls tradition

While pastoral theology has not contributed significantly to the contemporary discussion that seeks to analyze care as a concept, practice, or ethic, many centuries of pastoral reflection offer rich resources for a conversation on care. In particular, the *cura* tradition of the early church, the emergence of “modern” pastoral care in the late nineteenth and early twentieth centuries, and contemporary feminist pastoral care perspectives are especially pertinent to considering care as an ethic and practice.

Care is described as “helping acts”: A classic definition of the care of souls, or pastoral care, includes reference to “helping acts” done by “representative Christian persons” in the context of “ultimate meanings and concerns.”²¹⁹ Aspects of this definition can contribute to broader understandings of care. Most basically, the ancient care of souls tradition contributed the idea that care is *responsive* to persons and situations in need, a quality that follows well from Weil’s analysis of attention. For example, monastic leaders who lived lives of ascetic spirituality helped their disciples to gain self-knowledge so that they might speak honestly of passions and temptations. Attending to human experience allowed leaders to tailor advice on mastering temptations to individuals’ personal life histories. These spiritual guides

²¹⁸ See, for example, Chapter 10, “Tending Yourself,” pp. 281-306, in *Cultivating Wholeness: A Guide to Care and Counseling in Faith Communities*, Margaret Kornfeld (New York: Continuum, 2000).

²¹⁹ William A. Clebsch and Charles R. Jaekle, *Pastoral Care in Historical Perspective: An Essay with Exhibits* (Englewood Cliffs: Prentice-Hall, 1964), 4.

recognized that what might help one person could seriously hurt another. Finally, they encouraged disciples to share all of their thoughts, no matter how embarrassing or seemingly trivial they might be, because they recognized that speaking temptations diminished their power.²²⁰

Care is informed by the particularities of those in need: The emphasis on careful attention to individual qualities and needs continued into the middle ages as pastoral care became grounded in one of the Christian tradition's most widely read descriptions of pastoral practice in – the book, *Pastoral Care*, written by Benedictine monk Gregory the Great, who became pope in 590. Gregory the Great called upon pastors to attend to the particularities of individual situations.²²¹ Using what Thomas Oden has described as a “dipolar method of pastoral case studies,”²²² that sets different “types” of persons in opposition to one another (the humble and the haughty, the obstinate and the fickle, etc.) Gregory urged pastoral care providers to tailor care (described as “admonishing”) to the precise nature of persons. This development in pastoral care practice is important. Gregory's approach indicates a growing understanding that care that helps one person might be ineffective or even hurt another. None of us is exactly alike in our perspectives, life experiences (past or present), hopes or fears. Yet Gregory's recommendations are not perfect. The dipolar method is inherently dichotomous, and implies value judgments about where individuals lie in Gregory's various categories. Moreover, Gregory's work

²²⁰ Roberta C. Bondi, “The Abba and Amma in Early Monasticism: The First Pastoral Counselors?” *Journal of Pastoral Care* 40, No. 4 (1986): 311-320; see also Roberta C. Bondi, *To Love as God Loves* (Philadelphia: Fortress, 1987).

²²¹ Gerkin, 38-39.

²²² Thomas C. Oden, *Care of Souls in the Classic Tradition*, Theology and Pastoral Care Series, Don S. Browning, ed. (Philadelphia, Fortress: 1984), 97; 76-96.

raises at least two critical questions: First, how successful are pastors likely to be in their assessment of persons; and, moreover, assuming the categories are “correct,” or at least accepted by individual careseekers and pastors, does that mean persons are permanently bound to one category or another? Ultimately, the reader is left wondering: Is this really how human beings are? Thus, to better understand human persons, their experiences, natures, and responses, pastoral care needs resources beyond theology.

Multiple perspectives and resources influence care practice: Perhaps for this reason, the modern field of psychology, which emerged in the late nineteenth and early twentieth centuries, had significant appeal for pastoral care. The invitation of Anton Boisen, who developed the clinical method of pastoral education, for pastors to attend to “living human documents,” as well as books,²²³ sometimes is seen as a marker for this movement. Yet Boisen’s interest in the “living human document” was about much more than the adoption of modern psychologies, with their metaphors of conflict and turbulence as tools for pastoral counseling. He saw, instead, conflicts and yearnings of troubled persons as windows into the self and sources for theology, a way of anchoring theology in the “concrete data of human experience.”²²⁴

While Boisen’s heirs in twentieth-century pastoral care have been critiqued for relying heavily on psychological perspectives, often at the expense of theological

²²³ Anton Boisen, cited in Charles V. Gerkin, *The Living Human Document: Re-Visioning Pastoral Counseling in a Hermeneutical Mode* (Nashville: Abingdon, 1984), 37.

²²⁴ Gerkin, *Living Human Document*, 37-38.

depth,²²⁵ the field and the church have benefitted from a conviction that human beings are helped by knowledge stemming from many disciplines, and that human experience is a valuable source of knowledge within multiple disciplines. This is an epistemological perspective evident in some recent work on care, in which human experience becomes a source for political and social thinking. Similarly, this project insists that care experienced by families raising teenagers with autism illuminates social and ecclesial life, which resonates with recent thinking on virtue, learning, and practice.²²⁶

Care attends to both individuals and communities: Attention to particulars continues in today's feminist and womanist discourse about the current shape and future orientation of pastoral care and pastoral theology, especially in what is known as the *communal-contextual paradigm* for pastoral care.²²⁷ This paradigm carries with it at least three implications that are especially pertinent for this discussion of care. First, the paradigm insists that individuals live in reciprocal, transactional relationship with contexts, and that individuals cannot be fully understood without attention to contexts, meaning that context and person mutually influence and shape one another, and that healing and growth emerge in

²²⁵ See, for example, Oden, *Care of Souls in the Classic Tradition*; and Thurneysen, *A Theology of Pastoral Care*.

²²⁶ See, for example, MacIntyre, *After Virtue*; Kittay, "When Caring Is Just and Justice Is Caring;" Patricia Benner, *From Novice to Expert: Excellence and Power in Clinical Nursing Practice* (Upper Saddle River, N.J.: Prentice Hall Health, 2001); Tanner, "Theological Reflection and Christian Practices," in *Practicing Theology*, 2002; de Certeau, *The Practice of Everyday Life*; Bourdieu, *Outline of a Theory of Practice*.

²²⁷ See, for example, Bonnie J. Miller-McLemore, "The Living Human Web: Pastoral Theology at the Turn of the Century;" Pamela D. Couture, "Weaving the Web: Pastoral Care in an Individualistic Society," and Teresa E. Snorton, "The Legacy of the African American Matriarch: New Perspectives for Pastoral Care," in *Through the Eyes of Women*, ed. Jeanne Stevenson Moessner (Minneapolis: Fortress Press, 1996). Contextual attention is evident in work that is not explicitly feminist or womanist, as well. See, for example, Graham, *Care of Persons, Care of Worlds*, which draws on process theology to develop an empowering pastoral care approach that incorporates both person and context.

relationship to context. Second, the paradigm assumes that the context must not only be understood, but that the context itself also needs care, and that part of the role of the caregiver may be to help to empower those within the context to define and speak for themselves. And, finally, the communal-contextual paradigm argues that part of pastoral theological work is the development of systems and networks of care that broaden the dyadic partnership of pastor/counselor and counselee into a more holistic vision of communities existing in interdependent care for and with one another.²²⁸

The language that has been used to describe this approach is that of: resisting, by confronting evil; empowering, through “advocacy and tenderness on behalf of the vulnerable;” nurturing, of a type that offers “fierce, dedicated proclamation of love that makes a space for difficult changes and fosters solidarity among the vulnerable;” and liberating, which involves helping particularly vulnerable others to “escape from unjust, unwarranted affliction” so that they might experience wholeness as “created, redeemed and loved people of God.” This perspective represents a profound shift from earlier understandings of pastoral care as a much

²²⁸ Miller-McLemore, “The Living Human Web;” Couture “Weaving the Web;” Snorton, “The Legacy of the African American Matriarch;” Bonnie J. Miller-McLemore, “Shaping the Future of Religion and Psychology: Feminist Transformations in Pastoral Theology,” in *Religion and Psychology: Mapping the Terrain: Contemporary Dialogues, Future Prospects*, Diane Jonte-Pace and William B. Parsons, eds. (London, New York: Routledge, 2001), 189-192; and Bonnie J. Miller-McLemore, “Feminist Theory and Pastoral Theology,” in Bonnie J. Miller-McLemore, *Christian Theology in Practice: Discovering a Discipline* (Grand Rapids, Mich.: Eerdmans, 2012); Barbara J. McClure, *Moving beyond Individualism in Pastoral Care and Counseling: Reflections on Theory, Theology and Practice* (Eugene, Ore.: Cascade Books, 2010).

more individualistic and psychologically-centered effort of healing, sustaining, guiding, and (sometimes) reconciling.²²⁹

Contemporary analysis, therefore, indicates that pastoral theology and care focus on flourishing in a way that is contextually responsive and communally oriented, especially for those who have been marginalized and oppressed. This perspective has much to offer to a discussion on care in the context of families facing disabilities. Evil, understood simply as alienating or immoral behavior that damages, destroys, or prevents human relationships, has hurt and continues to hurt people with disabilities and their families. This makes them highly vulnerable to continued suffering. Yet, like all people, individuals with disabilities and their families can grow and flourish. Like all people, they often desire and seek solidarity. And, also like all people they deserve to be liberated from structural injustice and societal neglect, both of which hinder flourishing and fullness of life in community and church. Pastoral theology is well-positioned to respond to these conditions, especially when as it develops a more intentional focus on and deeper understanding of the concept and practice of care.

Care as central to the self

Twentieth-century phenomenological philosopher Martin Heidegger, whose challenging work offers a final historical contribution to the critical conversation on care, focused particularly on what it means to be human. This work offers important

²²⁹ Miller-McLemore, "Feminist Theory and Pastoral Theology," 217-218; Seward Hiltner, *Preface to Pastoral Theology* (Nashville: Abingdon, 1958); Clebsch and Jaekle, *Pastoral Care in Historical Perspective*.

insights for a theologically grounded conversation about care.²³⁰ Heidegger recognized the primal importance of care in structuring the self, while also recognizing care's complexity. He drew on the care myth cited early in this chapter, as well as other ancient sources, and his work is readily connected with some of the contemporary challenges to care ethics that demand attention in thinking about care in the context of disability.

For Heidegger, care structures the self. Care is fundamental to what it means to be human, care holds the self together, care allows the self to be authentic, and care animates the self's participation in the world.²³¹ In the self, which he called *dasein* (which also means *being*) Heidegger saw a continual movement between authentic existence, which involved attending to and acting upon one's true interests, concerns, etc. – a form of caring – and inauthentic existence, which he called fallenness, and which entailed accommodation to the expectations of the crowd. Fallenness can be seen as a flight from caring or even as a form of caring in itself -- caring via involvement in others.²³² In either case, care forms a sort of sub-strata; that which allows the self to be. In a section that has puzzled a number of interpreters, Heidegger's book *Being and Time* even drew upon the Myth of Care discussed earlier in this chapter. While Heidegger's intent in quoting from the myth is not entirely clear, he seems to use it to support his assertion of the primordial importance of care – not by arguing that the myth is factually *true*, but by seeing its

²³⁰ And has been seen as such by others from outside of the philosophical, theological or even simply humanistic fields. See, for example, Anne H. Bishop and John R. Scudder, *Nursing: The Practice of Caring* (New York: National League for Nursing Press, 1991), quoted in Reich, 354-355.

²³¹ Heidegger, *Being and Time*, 235-244; Reich, 353-354.

²³² Heidegger, *Being and Time*, 235-237; Reich, 354; Michael Gelven, *A Commentary on Heidegger's Being and Time*, rev. ed. (DeKalb, Ill.: Northern Illinois University Press, 1989), 106, 119-120.

very existence as evidence of just how significant care has been in human life, thought and discourse, from very early in history.²³³

Heidegger also recognized some of the complexities of care that are particularly pertinent to the effort to develop a care-based framework for understanding family experience with disabilities. He affirmed Seneca's ancient observation about the dual nature of care, the possibility that care might imply and be experienced as anxious exertion *or* devoted solicitude – or both.²³⁴ Moreover, he distinguished between concern, or caring *about* (*besorgen*), which is the stance of care given toward objects: I care about things that I can use for my own wellbeing; and solicitude, or caring *for* (*fursorge*): I care for other people, for their sake, not for my own. This distinction, which resembles Weil's distinction between involuntary and voluntary attention, anticipates later feminist work that is careful to distinguish between caring about (understood as an emotional quality) and caring for (understood as critical, sustaining human labor). All of these distinctions will be useful as we develop a pastoral theology of care that describes healthy care and reflects an attitude of respect and appreciation for all people.

Ambiguities in Histories of Care

Clearly, care carries with it a richness of meaning that has developed over thousands of years of discourse and practice. And yet care as a concept and practice can be problematic, so problematic that some contemporary thinkers argue for discarding it as a framework for thinking about disabilities and services related to

²³³ Gelven, 122.

²³⁴ Heidegger, *Being and Time*, 243.

disabilities.²³⁵ These thinkers present significant critiques that must be heard. For the purposes of this project, three critiques are particularly pertinent.²³⁶ First, human practices of care have at times oppressed persons with disabilities more than they have helped them. This oppressive legacy indicates that care has the potential to devolve into paternalism and control, while disability activists name a desire for agency and self-determination in their lives. Second, an insidious instrumentalism often underlies contemporary work on care, compassion, or related topics. I will attend to each of these critiques in turn.

Care as paternalistic practice

The horrific conditions of some massive institutions that emerged beginning in the 1960s and 1970s were only a recent manifestation of the dark side of care for people with disabilities.²³⁷ The various state schools, hospitals, asylums, and colonies generally ignored individual differences and placed people with various disabilities together with little or no regard for what might help them to develop and flourish. Residents became part of an institution whose goal was to prevent

²³⁵ Critiques of care have come especially from scholars in the field of Disability Studies. See, for example, Christine Kelly, "Making 'Care' Accessible: Personal Assistance for Disabled People and the Politics of Language," *Critical Social Policy* 31, No. 4, (2011): 562-582.

²³⁶ See, for example, Nick Watson, Linda McKie, Bill Hughes, Debra Hopkins and Sue Gregory, "(Inter)Dependence, Needs and Care: The Potential for Disability and Feminist Theorists to Develop an Emancipatory Model," *Sociology* 38 (2004): 331-350; Tom Shakespeare, *Help* (Birmingham: British Association of Social Workers, 2000); Kelly, "Making 'Care' Accessible," 564-567, 569, 572.

²³⁷ See, for example, Burton Blatt and Fred Kaplan, *Christmas in Purgatory: A Photographic Essay on Mental Retardation* (Syracuse, N.Y.: Human Policy Press, 1976), and the film *Unforgotten: Twenty-Five Years after Willowbrook* (New York: City Lights Home Entertainment, 2008). The photos from *Christmas in Purgatory* are also available at the online Disability History Museum, <http://www.disabilitymuseum.org/dhm/lib/catcard.html?id=1782> *Unforgotten* contains the original Geraldo Rivera expose that contributed to the closing of Willowbrook, as well as stories of people who were "cared for" in the institution, looking at their lives since its closure.

“feble-mindedness” through segregation and separation from the outside world,²³⁸ rather than seeking to support personal development and possibly prepare people with disabilities to return to families and communities better equipped to live in the ordinary world. Remarkably, this devolution of institutional care was an outgrowth of human services that emerged from three convictions held by the very early church related to care: first, that no one within the community should suffer; second, that a “hidden Christ” rested within those in need; and third, that in serving others, those who provided care were working out their own salvation.²³⁹ Institutional and custodial care for persons with disabilities, therefore, represents a perversion of earlier ideals.

This perversion of care is visible in care practices that changed over time, often to accommodate increasing needs. These changes include: moving what were originally called hospices meant for temporary assistance, protection, and treatment away from churches and into ever-enlarging institutions; eliminating regular celebration of the sacraments (the earliest hospices were built around an altar where communion was celebrated at least daily) from sites for care; and what has been called the “menacization of the afflicted,” or development of a public discourse around people with disabilities and people in poverty as a threat to society. Given this history, it is little wonder that by the mid-twentieth century vast numbers of people with disabilities were “contained” within institutions that took little regard

²³⁸ James W. Trent, *Inventing the Feeble Mind: A History of Mental Retardation in the United States* (Berkeley, Calif.: University of California Press, 1994), 128-129, 142.

²³⁹ See Wolfensberger, “*A History of Human Services*,” <http://www.mnddc.org/wolfensberger/index.html>

of them as whole persons, sometimes with disastrous results.²⁴⁰ Care, in other words, had become a form of control exerted by external sources in such a way that it diminished or even eliminated possibilities for self-determination for persons with disabilities.

Care as control

This devolution of care into paternalism and control is one of the most common problems with care raised by disability activists and scholars. The Independent Living Movement that began in the 1960s among adults with physical disabilities, for example, has emphasized the idea that people are disabled by society, rather than by their bodies, that disabled people have a right to participate fully in society, and that all people are capable of exerting choices.²⁴¹ These arguments raise questions about the wisdom of emphasizing care for persons with disabilities. Anita Wood, for instance argues:

Disabled people have never demanded or asked for care! We have sought independent living, which means being able to achieve maximum independence and control over our own lives. The concept of care seems to many disabled people a tool through which others are able to dominate and manage our lives.²⁴²

Disability scholars and activists have argued, therefore, that any assumption of difference and vulnerability is demeaning and ultimately controlling. They often emphasize individual rights such as those described in legislation like the Americans

²⁴⁰ Disease, early death, sexual and physical abuse, misdiagnosis, and other problems were the norm at most institutions. See Trent, *Inventing the Feeble Mind*; Wolfensberger, *A History of Human Services*; and Noll and Trent, *Mental Retardation in America*.

²⁴¹ Jenny Morris, "Feminism and Disability," *Feminist Review* 43 (1993): 57-70.

²⁴² Anita? R. Wood, "Care of Disabled People," in *Disability and Social Policy*, G. Daley, ed. (London: Policy Studies Institute, 1991), 199-200.

with Disabilities Act as a solution to challenges faced by the wider world's response to disabilities. Moreover, they often call for systems of consumer-directed personal assistance that allow the person with the disability to retain control of her or his own life.²⁴³ Thus, disability critiques often consider care a form of oppression, due in part to its sad history, but also as an expression of more philosophical arguments about the nature of difference, human relations, and the value of independence in human life. Some argue for abandoning care as an organizing category for thinking about human response to disability.²⁴⁴

Care as instrumental engagement

Additionally, care related to disabilities has been construed as a virtue because it demands that one (the caregiver) shift focus from self to other (the care receiver) and thus reflects and furthers personal ethical/moral development of the caregiver.²⁴⁵ This perspective is problematic. It assumes an inherently asymmetrical relationship between caregiver and care-receiver, and thus diminishes the humanity

²⁴³ Anita Silvers, "Equality or Difference: Caring (f)or Justice for People with Disabilities," *Hypatia* 10, No. 1 (1995), 30-55. See also: B. Hughes, "Medicine and the Aesthetic Invalidation of Disabled People," *Disability and Society* 15, No. 4 (2000): 155-172; R. Hurst, "Rethinking Care from a Rights Perspective" in *Rethinking Care from Different Perspectives*, 2001, ed. WHO Disability and Rehabilitation Team, <http://www.leeds.ac.uk/disability-studies/archiveuk/WHO/rcpapers.pdf> and M. Priestley, *Disability Politics and Community Care* (London: Jessica Kingsley, 1999).

Priestley argues that the focus on care perpetuates an image of caregivers "as brave self-sacrificing martyrs." This reflects an additional challengeable assumption – that care is an unremitting burden. See, for example, G. Grant, P. Ramcharan, M. McGrath, M. Nolan, J. Keady, "Rewards and Gratifications among Family Caregivers: Towards a Refined Model of Caring and Coping" *Journal of Intellectual Disability Research* 42, No. 1 (1998): 58-71; and Trent, *Inventing the Feeble Mind*, which argues that the story of intellectual disability in the United States is a story of the merging of care and control.

²⁴⁴ See, for example, Vic Finkelstein, "Rethinking Care in a Society Providing Equal Opportunities for All," discussion paper prepared for the World Health Organization. Milton Keynes: Open University, 1998, who argues for support to replace care and Priestley, *Disability Politics and Community Care*.

²⁴⁵ Kittay, "When Caring is Just and Justice is Caring," 260. Kittay draws from nursing theorists Gastmans, Dierckx de Casterle, and Schotsmans, who seek to ground nursing in an ethical perspective. See Chris Gastmans, Bernadette Dierckx de Casterlé, and Paul Schotsmans, "Nursing Considered as Moral Practice: A Philosophical-Ethical Interpretation of Nursing," *Kennedy Institute of Ethics Journal* 8 (1998): 43–69.

of the person with a disability for the sake of the caregiver.²⁴⁶ Because this asymmetrical relationship is based on “essential” differences (disabled/non-disabled; responsible/dependent), a virtue-oriented care relationship invites oppressive paternalism that defeats equality, demeans relationships, and betters the caregiver more than the care receiver. Moreover, a care-based approach to disability demands that the disabled person “deserve” care – which means he or she must be sick, incompetent, dependent, submissive etc. – even when this is not strictly true. Sometimes this simply reflects the dynamic nature of human life. We all, at various times, are more or less dependent and vulnerable. Yet this points to an uncomfortable reality: Because “caring-for” often is the way persons with temporarily-able bodies relate to those with disabilities, “it becomes socially incumbent upon the latter to profess incompetence even where they are [not]. ... It was not too long ago, recall, when women were expected to dissemble this way to men.”²⁴⁷

There is a paradoxical quality to this relationship that is evident in this critique, in which the sort of “no-win” situation suffered by some people with disabilities is evident. The virtue orientation that grants elevated moral status to care, including assumptions that care somehow makes the caregiver better, stronger, more moral, even more happy/satisfied with life, etc., and therefore implies that the caregiver has the opportunity to benefit from providing care, generally says little about the place of the care receiver in this exchange. The ethic of care perspective is

²⁴⁶ See Maureen Sander-Staudt, “The Unhappy Marriage of Care Ethics and Virtue Ethics,” *Hypatia* 21, No. 4 (2006): 21-39, or Held, *The Ethics of Care*, 19-22, for critical explorations of the conflation of care and virtue ethics.

²⁴⁷ Silvers, “Equality or Difference,” 40.

structured on the assumption that some be disadvantaged (poor, sick, weak, etc.) so that others might have opportunities to be strong and virtuous. “In a framework of moral relations in which some must make themselves vulnerable so that others can be worthy of their trust, the disabled are typecast as subordinate.”²⁴⁸ Additionally, the virtue orientation in ethic of care work has two equally dangerous tendencies: Individual experience and psychology are readily elevated at the expense of relationship; and excessive focus on individual, internal “betterment,” overshadows the real, often hard, labor of caring.²⁴⁹

While each of these critiques is important, the final one is perhaps the most serious of all for an adequate pastoral theology of care. Care and the ethic of care, from this perspective, may contribute to a form of symbiotic altruism in which some people (those who are more vulnerable) function as instruments to serve the self-development of other people (those who are stronger). This more contemporary intellectual tendency diminishes the humanity of persons with disabilities (and their families) as surely as the historical physical abandonment of persons with disabilities to warehouses of indifferent “care” and control.

Contributions of Care Orientation and Practices:

What Is Lost without Them?

Given the gravity of these critiques, some disability scholars have recommended eschewing the concept of care in favor of alternative emphases such as the individual rights and consumer-driven approaches named earlier in this chapter. However, the subject of care has a long history and much to recommend it,

²⁴⁸ Silvers, “Equality or Difference,” 23-48, 33.

²⁴⁹ Held, *The Ethics of Care*, 34-35.

especially within the field of pastoral theology. Care should not be abandoned lightly. Instead, guided by awareness of universal human vulnerability, pastoral theology should develop an approach to care for and with persons with disabilities and their families that acknowledges care's oppressive legacy, is intentional about avoiding any tendency to devolve into control, and ensures that some do not profit at the expense of others. Authentic, effective, healthy care demands, engenders, and sustains human relationships and deeper understanding of the human condition. To abandon care is to risk losing these valuable contributions to understandings and practices associated with human life in relationship with self, others, and God. Below, I will examine more closely several aspects of the care orientation we should want to retain, and associated significant potential "losses" when understandings and practices of care are de-emphasized.

A relational understanding of human life

By prioritizing care in analysis of the labor involved in sustaining human beings or in ethical frameworks developed for understanding human society and addressing moral decision making, we indicate a commitment to the idea that human persons are ontologically relational, because authentic care demands relationship.

Alternatives to care as a practice and as an ethical framework have been proposed, but they have inherent problems. When addressing the daily needs of people with disabilities, the dominant alternative to care is the consumer-driven

model of “personal assistance” described earlier in this chapter.²⁵⁰ This model intends to empower people with disabilities to make their own decisions about hiring, training, and directing individuals who will assist them with daily tasks. It is specifically described as *not* being care, yet, this may not be realistic. The intimate nature of the work often leads to complex relationships; moreover, to insist that the person providing personal assistance is not providing care can diminish his or her work and personhood, making the assistant effectively “invisible.”²⁵¹

Additionally, the Independent Living movement and personal assistance models are more appropriate in cases of physical disability, rather than intellectual or developmental disability, and may even contribute to tensions between these communities. Finally, foregrounding the market as a substitute for care based in relationships raises significant concerns. The market operates by values that include, most prominently, the expansion of profit. One danger, of course, is that quality of assistance and relationships may suffer when profit expansion is the guiding value,²⁵² but this move also contributes to a dehumanizing commodification that can seriously damage human relationship.

Meanwhile, the dominant alternative perspective²⁵³ to the ethic of care as a means for understanding and structuring human society is a contractual model.²⁵⁴ This model assumes that individuals are independent and autonomous, little affected by the needs, gifts, joys, and sorrows of those who surround them, and able

²⁵⁰ Kelly, Williams, Watson et al.

²⁵¹ Kelly, “Making ‘Care’ Accessible,” 566-569; Kittay, “When Caring is Just and Justice is Caring,” 260-261, 268-270..

²⁵² Held, “Care and the Extension of Markets,” *The Ethics of Care*, 107-124.

²⁵³ Historically, just the dominant perspective.

²⁵⁴ Held, *The Ethics of Care*, 46-47.

to enter into relations relevant for moral decision making freely, unencumbered by self and other. This perspective has been widely criticized by feminists who argue that it is distant from the reality lived by most people, especially women.²⁵⁵

By shifting away from perspectives that emphasize care, therefore, both in terms of ethical thought and in discussing labor that sustains human beings, we risk a loss of focus on human beings as relational creatures.

Epistemology of human experience

The care perspective argues that care is an under-appreciated, under-analyzed form of labor that, in both giving and receiving, can reflexively inspire the normative thinking that gives rise to ethical thought, as well as simply reveal human needs of great significance. Care, carefully examined, is illuminating in its complexity. This fact is evident in one of the earliest understandings of care – the dual nature highlighted by ancient thinkers who saw in it both the upward lift of joy and fulfillment and the downward drag of obligation and burden. The experiences of providing, receiving, witnessing and reflecting upon care offer opportunities for meaning making, as we saw in our earlier examination of the work of historic philosophers, theologians, mythmakers and contemporary ethical thinkers.

This epistemological commitment to human experience is put at risk when we substitute “rationalist approaches” that seek to divorce moral thinking from experience and its attendant emotions, and assume that the only route to a moral

²⁵⁵ Held, Kittay, Tronto, Noddings, Lynch et al., Bubeck, and many others address this issue.

framework with broad appeal is via abstraction.²⁵⁶ The epistemological loss in the abandonment of the care perspective, therefore, involves attention to and appreciation of contextual specificities and human practice that may challenge attempts to develop universal understandings and moral theory.²⁵⁷

Justice that emerges in vulnerability

Third, the care perspective assumes a fundamentally vulnerable human ontology. Unlike principles of justice based in pure “fairness” (equal rights, equal resources, equal opportunities, with little or no regard for situational particulars such as disabilities), care concepts recognize what all religions affirm: that human beings are fragile, necessarily interdependent, and diverse. This alternative to fairness-oriented justice more effectively illuminates the labor of care, those who labor, the complexities of their work and their contexts, resource allocation, the impact of care work on caregivers and care receivers, and more. Normative, ethical thought that arises from this analysis offers an important voice in considering issues of fundamental human significance,²⁵⁸ and can lead to a principle of justice based on what has been described as “unequal vulnerability in dependency.” This principle reflects the reality of individual life and human communities much more accurately than principles based in “equal rights.” Moreover, it expands conversations about human ontology, human needs, and care beyond interpersonal relations into public

²⁵⁶ Held, 10-11.

²⁵⁷ Urban Walker, “Moral Understandings,” 15-28; Held, 11.

²⁵⁸ Held, *The Ethics of Care*, 11, 29-36. Whether this perspectival voice is truly an alternative to a “justice” orientation (as originally argued by Gilligan) is a subject of discussion and sometimes contention in ethic of care work today. See, for example, Held, 29-36; Tronto; Fiona Robinson, *The Ethics of Care* 31, 62; Kittay, “When Caring Is Just and Justice Is Caring,” 262-263.

life, community relations, and public policy,²⁵⁹ which is critical for the challenges faced by persons with disabilities and their families in modern, liberal, Western society.

Because “rights” and “equal rights” are an inadequate framework for ensuring a society that offers justice and the possibility of well-being for all people, therefore, the care perspective is critical to public life. This principal of justice is endangered when care conversations are discarded, making it less likely that that each person’s care needs will be answered by those with the capacity to give, including individuals and social institutions. Ultimately, supportive, sustaining relationships that contribute to justice and flourishing are put at grave risk when care perspectives are abandoned.

Theological understanding of dependence

Finally, the care perspective is particularly significant for the life of faith communities, especially the Christian church. Care assumes dependency,²⁶⁰ which is inevitable in human existence. None of us is completely independent. This reality, however, can contribute to profound inequalities in any situation of competition for resources. It is, thus, the precondition that must be accounted for before any practical experience of *interdependence* can happen. “Dependencies may be alleviated or aggravated by cultural practices and prejudices, but given the

²⁵⁹ Robinson, *The Ethics of Care*, 24-26; also see, for example, Tronto, *Moral Boundaries*; Kittay, *Love’s Labor*; Eva Feder Kittay, “Dependency, Difference, and the Global Ethic of Longterm Care,” *Journal of Political Philosophy* 13, No. 4 (2005): 443-469; Held, *The Ethics of Care*; and Michael D. Fine, *A Caring Society? Care and the Dilemmas of Human Service in the Twenty-First Century* (Houndmills, Basingstoke, Hampshire: Palgrave MacMillan, 2007).

²⁶⁰ While much of Kittay’s work addresses the issue of dependency, and some makes a subtle distinction between dependency work and care work, *Love’s Labor* draws out the theme most extensively.

immutable facts of human development, disease, and decline, no culture that endures beyond one generation can be secure against the claims of human dependency.”²⁶¹ Assuming dependency of various types and degrees, asking what is needed for well-being in various dependencies, and then modifying those demands and responses as we encounter greater independence and ability to live reciprocally,²⁶² can structure the self²⁶³ so that it can live authentically in human relationship.

Most mainline theologies support the basic assumptions of an ethic of care as outlined above. Any understanding of humans as inevitably, inescapably dependent resonates with a long tradition of understanding God in relational terms, human beings as created for community, and humanity as dependent upon God and one another for life and being. It is certainly more amenable to a Christian theological perspective to acknowledge dependency, and to call for willingness and ability to receive, as well as to give, than it is to insist upon human independence and autonomy.

Toward an Adequate Pastoral Theology of Care

The critiques of care as an ethic and practice are serious and justified and should not be dismissed or ignored. Yet the care perspective also emphasizes important insights into what it means to be human, including ambiguity in life, relationships, vulnerability and dependency, as well as a human need for attention and contextual commitment. These factors can contribute to deeper understanding of the gifts and

²⁶¹ Kittay, *Love's Labor*, 1.

²⁶² Kittay, *Love's Labor*, xiii.

²⁶³ Heidegger, *Being and Time*, 235-244; Reich, 353-354.

challenges of life with disabilities, and they resonate with theological perspectives that prioritize justice and flourishing for all of God's creation. The challenge is to use care so that it can lead to deeper and richer understanding, rather than contributing to stereotypes and oppression. Below, I outline some ways in which this can happen.

Care should be intentional

First, care must be used care-fully, seeing it as an "unstable,"²⁶⁴ contradictory category that demands awareness of both its devastating legacy and its current challenges. In particular, those who seek to offer care must be particularly attentive to challenges arising from the dynamic swirl of complex relationships, especially those of power and authority, that are inherent in "care" interactions. Care is complex and ambiguous, but that is part of its strength. When it is used as an organizing category, it offers the opportunity of deeply attending to the ways in which one individual's personhood intersects with the personhood of others, and how this intersection might be life-giving, rather than life-depleting. By intentionally attending to care, therefore, human beings are challenged to live conscientiously, attendant to relationships and dependencies. This intentional approach to care can become a transformative practice that accepts and carefully responds to persons, families, and groups as individuals, not as representatives of a type,²⁶⁵ and by

²⁶⁴ Kelly, 575.

²⁶⁵ Weil, "Reflections on the Right Use of School Studies," *Simone Weil Reader*, 49.

remaining aware of the danger, well-documented in historical work, of devolving into control.²⁶⁶

Aware of the dangers of an emphasis on care, intentional care can, instead, constantly adapt to the particular conditions of individual persons and thus contribute to “the building of dynamic interrelated communities of well-being.”²⁶⁷

Care should be treated as an epistemological practice

Some thinkers, especially in early feminist ethic of care work, have presented the practice of care as an unmitigated good.²⁶⁸ This is unrealistic, unwise, and, in fact, potentially abusive. Some care, especially care offered thoughtlessly to people with disabilities, may be unneeded, unwanted, and destructive. Sometimes, for example, people may simply need supports (systems, technology, adaptive construction) so that they can care for themselves. Also, the ethic of care may offer its most illuminating work when it is employed as a methodology, or an epistemology, rather than an ideal. As an epistemology, the ethic of care encourages attention to the dynamics of care and lack of care, power relationships, and the effects of these. For this project, looking at how families provide and experience care and lack of care in multiple settings, the epistemological approach is more illuminating than a simple argument for more care.

²⁶⁶ See description of care that functions to control, which draws from the historical work of Wolfensberger, “*A History of Human Services*,” <http://www.mnddc.org/wolfensberger/index.html> and Trent, *Inventing the Feeble Mind*, among others; and the philosophical/disability studies work of Wood, “Care of Disabled People,” and Silvers “Equality or Difference: Caring (f)or Justice for People with Disabilities.”

²⁶⁷ Marjorie Suchocki, “Christian Perfection: A Methodist Perspective on Ecclesiology,” in *Our Calling to Fulfill*, ed. M. Douglas Meeks (Nashville: Abingdon/Kingswood, 2009), 96.

²⁶⁸ See Robinson, *The Ethics of Care*, 3-6 for a discussion of this quality of some ethic of care work.

This approach does not preclude a normative perspective. But beginning with an epistemological approach means beginning by assuming that care, its composition, and its effects, aids in *understanding* human experience – not simply *judging* it. As an epistemological practice for faith communities, therefore, intentional care²⁶⁹ can reveal much about the lives of families facing disabilities, and thus continually inform and re-inform the faith community about how it can be most helpful for these families, and most faithful to the community’s own tradition. Epistemological care, then, produces a dynamic that is similar to the work of pastoral theology, in which action and reflection contribute to constant refinement of pastoral and theological practice.

Care should be relational

The care perspective assumes that human beings flourish in relationship, that relationships involve inevitable, sometimes varying dependencies, and that this web of interdependence is simply an expression of humanity. Intentionally employing a care epistemology involves attending to relationships, dependencies, and the dynamic nature of both. This entails looking, for example, not only at what churches can or should do for families with children with disabilities, but at what children with disabilities can bring to their churches; looking, for example, not only at the burden of caregiving that families bear, but also at how the “good” in those families is “perfected by care,” as Seneca would say. Additionally, this work entails asking

²⁶⁹ Intentional care as described in the previous subsection demands attending to both the ever-present potential of abuse in the midst of care, and to the particular needs, challenges, joys, and personal/familial qualities of those we are caring for or with.

how care relationships ripple outward into the public, political realm, or how they might, and what that outward rippling might represent theologically.

Finally, this project and the perspective from which it arises regards the dependency of care relationships as something far from problematic; in fact, attended to carefully, these relationships can foster a human parallel to the life of God and God's relationship with humankind. Dependency relationships present the possibility of flourishing not only because one human can care for another; but because both individuals (and communities) can understand what it means to give and to be given, in a dynamic dance of relationship that ultimately becomes *interdependency*, which acknowledges that all of us are both dependent on others and capable of supporting others. Interdependence posits care, then, as a condition of social relations rather than an expression of power and control.²⁷⁰

Conclusion: Care Perspective Continues to Be Valuable

Contemporary perspectives on care, which have been informed by thousands of years of reflection, offer a valuable resource for considering family experience and social and ecclesial responsibility in a disability context. The perspective offers an approach to human relations and human culture that is more just and more reflective of the reality of human experience than any model emphasizing social contracts shaped by notions of equality, independence, and freedom. Moreover, from a pastoral outlook, the care perspective offers a way of thinking about human relationships that is deeply faithful to theological commitments to dependency on God and one another.

²⁷⁰ Fiona Williams, "In and Beyond New Labour: Towards a New Political Ethic of Care," *Critical Social Policy* 21, No. 4 (November, 2001): 467-493.

Despite these strengths, however, the care perspective is imperfect. It can and has disregarded the strengths of those who are particularly vulnerable; it can and has devolved into control; and it can and has served to divide caregiver and care-receiver in ways that effectively dichotomize humanity and put the ostensible care-receiver in the limiting position of “disassembling,” for the sake of maintaining *some* relationship. Given the tragic history of societal and ecclesial treatment of persons with disabilities, as well as the reality of continued suffering, these critiques are important to hear. They serve as a reminder of the importance of drawing on care intentionally, relationally, and epistemologically, seeking always to sustain the full humanity and potential for flourishing of all persons.

Moreover, these critiques can and should offer a valuable caution to any theological outlook that emphasizes shared vulnerability, commitment to community, and willingness to participate in an economy of grace marked by dynamic engagement in receiving and giving. The chapter ahead, therefore, explores theological perspectives that can contribute to this outlook and provide resources for faith communities that seek to care authentically for and with persons facing disabilities – persons like the Talbert, Zane, and Nelson families. Though these families’ experiences are diverse, they present a common need for care that not only can free each person to live into fullness of being, but that can challenge society to respond more justly and more compassionately to the challenges -- and gifts -- of life with disabilities.

CHAPTER 6

THEOLOGICAL RESOURCES FOR A PASTORAL THEOLOGY OF CARE

“ ... when we try to pick out anything by itself we find that it is bound fast by a thousand invisible cords that cannot be broken, to everything in the universe.”
John Muir²⁷¹

Introduction

Human culture is dependent on care as an orientation and as practices that sustain life. The urge to care arises from deep within the self; care ethics emerge from awareness of both human suffering and human potential; and care practices can facilitate human flourishing in individuals and communities. To excise care from human existence, therefore, even in situations of disability in which an authentic and sadly often neglected desire for independence must be respected, is virtually impossible. Just as the twentieth-century naturalist John Muir recognized the interwoven nature of the created world, we who seek to respond to individuals and families facing disability must recognize that care simply *is*. It is present, it is needed, and it is practiced.

Muir’s perspective, therefore, bears particular consideration within pastoral theological contexts, especially in considering the place, foundations, and significance of care within the Christian tradition. For, despite the litany of problematic biblical and theological texts and interpretations that often represent the Christian tradition’s response to disabilities, despite insensitive historic and contemporary practices that have fostered suffering, and, especially, despite the

²⁷¹ John Muir, journal entry July 27, 1869 in John Muir papers, Ronald H. Limbaugh and Kirsten E. Lewis, editors, *The John Muir Papers*, 1858-1957 MICROFORM, (Stockton, CA: University of the Pacific, 1980). With accompanying Guide (Alexandria, Virginia: Chadwyk Healey, 1986).

serious concerns raised by persons with disabilities, care can be an alternative embodied discourse embedded in individuals, social organizations and structures, values, and relations of power.²⁷² Though our understandings of care have been imperfect, care orientations and practices are critical. They have the potential to create communities bound by relationships of love and labor as they prioritize attending to human suffering and furthering human flourishing. Care – enacted with sensitivity and thoughtfulness – can and has created worlds in which human existence, human vulnerability, human community, and the human capacity to draw close to the glory of God matter deeply.

The concerns about emphasizing care in relationship with people with disabilities must be taken seriously, however – attended to, just as this project calls for attention to care itself. Care can be neglected or misunderstood, and its practices can be perverted. And yet just as abandoning care in a secular context for a market-oriented model of personal assistance seems unwise, within the church such a move seems quite simply impossible. The tradition has arisen from divine and human relationships of care, which are a surprisingly enduring, if always imperfect, presence in the life of the church. For people of Christian faith, healthy care offers an opportunity to embody God's loving, creative work in the world by resisting and challenging oppression, fostering solidarity and wellbeing among those who are

²⁷² Susan Dunlap, "Discourse Theory and Pastoral Theology," in *Feminist and Womanist Pastoral Theology*, 134-135, 144. Dunlap argues for the power of language to create worlds and express understandings and relationships. Her argument is helpful for thinking about care's potential for shaping communities, and yet it should be challenged for failing to attend significantly to embodied discourse and/or language that does not involve spoken words. Non-verbal language and discourse can be meaningful in many contexts, but is especially important to consider in a context involving disabilities, where some individuals may understand but not speak, or may hear but not understand, or may understand but not hear.

isolated and suffering, and bringing individuals and communities into relationships of mutual vulnerability that can lead to flourishing.

This chapter draws upon historical and contemporary resources to argue for the theological value of attending to care as an organizing concept for pastoral theology focused on families facing disabilities. It does this for several reasons. First, care recognizes human vulnerability as a source of strength, which is a critical reality in a theological context. Second, care embodies a conviction that all creation has inherent value. Third, care answers a call to live with and for one another, within secular human communities and in the body of Christ that is the church. Finally, care can transform persons and societies. As Seneca said, “the best in humans is perfected by care.” While human beings live “caught” between suffering and glory, healthy care “tips the balance” toward glory²⁷³ by deepening individuals’ sense of themselves and others, by strengthening communities, and by challenging oppressive structures.

The chapter uses several resources to make these points. John Wesley and Dietrich Bonhoeffer, neither of whom is typically thought of as a theologian focused on disability, offer surprisingly illuminating wisdom for pastoral theology related to care. Both faced distinctively challenging contexts that demanded thoughtful care; moreover, their pastoral orientations afforded opportunities to imagine, practice, facilitate, and reflect upon care. Both seem to have understood care as a form of wisdom that acknowledges and addresses the reality of vulnerability as an expected

²⁷³ This image and understanding comes from Suchocki, whose work draws together Wesleyan and process theologies in ways that are deeply meaningful within a disability context. Suchocki, “Christian Perfection: A Methodist Perspective on Ecclesiology,” in *Our Calling to Fulfill*, 91-107.

aspect of the human condition. Wesley's and Bonhoeffer's theological perspectives are clearly intertwined with and informed by their historical environments and ministry practices that are responsive to these contexts. Because context and practice are so important in their thoughts, and can be so important for this project's attempt to develop a pastoral theology of care, Bonhoeffer and Wesley will be presented narratively. This, then, will be followed by further reflection upon some experiences of the Talbert, Nelson, and Zane families. Theology and experience then will further inform the argument that care must be relational, epistemological, and intentional.

Vulnerability: An Ontological Reality

Nancy Eiesland (physically disabled herself) famously wrote that each of us is "temporarily able-bodied." In this she articulated the perspectives of other theologians including Wesley and Bonhoeffer, who also noted, lived with, and reflected upon the reality of universal vulnerability. Their experiences continue to be instructive in pastoral contexts today, and their writings remind us of the reality of human vulnerability; the notion that strength arises from vulnerability itself; and the folly of ignoring this reality.

Practicing mercy as a means of grace

John Wesley's (1703-1791) teachings and practices related to care for those who were sick and poor illustrate this concept of shared, universal vulnerability, and were derived directly from his historical context. Many members of the early Methodist movement were among England's early industrial underclass. Trying to

adjust to a shifting economy, both children and adults worked long hours in dangerous settings where they were frequently sickened and disabled. Many were unable to afford even basic medical care. Yet Wesley, the founder of the church renewal movement that evolved into early Methodism, encouraged these often poor, often sick persons to visit and care for others who also were sick and poor. This was a hallmark of early Methodism and part of Wesley's wider sense that works of mercy (including such disparate types of care as providing clothing, healthcare, food, or education) were as much a means of grace as the more traditionally emphasized works of piety such as prayer and fasting. Wesley, who often used sermons to instruct his generally poorly-educated lay ministers in Christian understandings, highlights this conviction in the sermon "On Visiting the Sick."²⁷⁴

In the sermon Wesley argues that all Christians are called to visit – not just to send help or money, but to visit. He cites the call of Jesus in Matthew 25 ("I was sick, and you visited me"), and asserts that in visiting, the visitor grows in thankfulness to God and connection with others. Wesley offers specific instructions that convey values relevant to our discussion of care.²⁷⁵ Visitors were told to attend to persons' particular needs rather than assuming a standard approach would work for all; to address material needs (such as food, medicines, coal for heating, etc.) before offering any spiritual counsel, and to advocate on behalf of the sick to those who

²⁷⁴ Melanie Dobson-Hughes, "The Holistic Way: John Wesley's Practical Piety as a Resource for Integrated Healthcare," *Journal of Religion and Health* 42, No. 2 (2008): 237-252; Randy L. Maddox, *Responsible Grace: John Wesley's Practical Theology* (Nashville: Abingdon/Kingswood, 1994), 215-216; Richard P. Heitzenrater, *Wesley and the People Called Methodists* (Nashville: Abingdon, 2013), second edition, 84, 140, 200.

²⁷⁵ E. Brooks Holifield, *Health and Medicine in the Methodist Tradition* (New York: Crossroad, 1986) chap. 7, "Caring and Well-Being," 160-180.

might be able to help. Only after having done all this could they proceed to spiritual care.

Importantly, visitors were urged to remember their own insufficiency for the task of care, and to turn to God in humble prayer for strength, wisdom, and understanding. More than simple piety, this advice cautioned early Methodists against pride and self-superiority.²⁷⁶ Care providers were reminded that they themselves were vulnerable, like all people, that on their own they were not strong enough to face the reality of human suffering in challenging conditions, and that only God's sustaining presence allowed them to offer meaningful assistance.

Thus, though Wesley rarely wrote about disabilities in particular, the early Methodist movement was marked by a commitment to care for and with those who suffered in early industrial England. This care was epistemological and relational, in that followers were urged to *learn from* those they visited, and it was intentional, in that these followers also were urged to adhere to a specific order of care that Wesley believed to be just, sensitive, and effective, and that was inherently founded upon particular needs of particular persons. Moreover, it evidences and argues for an understanding of shared, mutual vulnerability. For Wesley, care for and with others functioned as a social ethic motivated by the combination of deplorable conditions wrought by massive, often unjust social change, as well as the gospel's command to care for those who suffer.

²⁷⁶ Wesley, "On Visiting the Sick," in *The Works of John Wesley*, vol. 9, Albert Outler, ed. (Nashville: Abingdon, 1985).

Caring for whole persons

The conviction that all of creation is valuable and worthy of care is illustrated by practices designed to empower those marginalized by social forces to care for themselves, their families, and others, such as the poor and sick. In addition to the visitation and material care discussed in the previous section, Wesley and the early Methodists developed a practice that is particularly helpful for reflection in this context. *Primitive Physic*, a collection of holistic advice for health as well as basic treatments for illness and injury, was meant to empower people living in poverty and those who lived far from medical resources to take charge of their own health.²⁷⁷ Though the book was scoffed at in Wesley's lifetime and later downplayed as a bit of an embarrassment within the Methodist tradition, it was one of the most widely distributed of Wesley's many writings, went through 23 printings in his lifetime and remained in use until the late 1800s. Additionally, scholars have begun to reassess *Primitive Physic*, arguing that although it certainly is not an exemplary medical text, it does represent both an important "moment" in the development of healthcare *and* a profound ethical commitment to care that challenged established structures of power.²⁷⁸

²⁷⁷ Wesley was not completely ignorant of medical practice. Though many "Primitive Physic" remedies seem absurd today, they were based on the basic medical education that Wesley, like many men preparing for the Anglican priesthood, received, as well as later experiments and observations. See Maddox, "John Wesley on Holistic Health and Healing," in *Methodist History* 46, No. 1 (2007): 4-5.

²⁷⁸ See, for example, Deborah Madden, 'A Cheap, Safe and Natural Medicine': *Religion, Medicine and Culture in John Wesley's Primitive Physic* (Amsterdam, New York: Rodopi, 2007); Deborah Madden, "Wesley as Adviser on Health and Healing," in *The Cambridge Companion to John Wesley* (Cambridge, New York: Cambridge University Press, 2010) 176-189; and Randy Maddox, "Reclaiming the Eccentric Parent: Methodist Reception of John Wesley's Interest in Medicine," in Deborah Madden, ed., *Inward and Outward Health': John Wesley's Holistic Concept of Medical Science, the Environment and Holy Living* (London: Epworth, 2008) 15-50.

Visitors to those who were sick were instructed to leave *Primitive Physic* at every house, along with Thomas a Kempis' *The Imitation of Christ*.²⁷⁹ This became a "value-laden" practice that points to a theology of creation and salvation in which the body is a good part of a good creation, not a temporary, worthless shell for an eternal, valuable soul, as it has sometimes been understood. Moreover, while sin, disease, and mortality are a part of this world, they neither define it, nor make the body evil, nor separate the unity of body and soul. Salvation is a process of healing, at least as much as it is a process of forgiveness. Healing frees people to share the image of God with others and to work for the healing of the world. *Primitive Physic*, therefore, represents a passionate commitment to salvation as a present-day experience that includes body and soul and that renews the image of God in each person.²⁸⁰ Critically, the community has an ethical responsibility to participate in this process,²⁸¹ which is why it became so important to share this book of simple remedies.²⁸²

Others' vulnerability can clarify our own

Bonhoeffer too, was profoundly influenced by an experience in which it became clear that the line between well and sick, or able and disabled, was rarely clear and sharp. In fact, it has been argued that this experience was critical in his theological

²⁷⁹ Maddox, "John Wesley on Holistic Health and Healing," 8.

²⁸⁰ Melanie Dobson Hughes, "The Holistic Way" 237-252. The theology of creation, the human person, and salvation shows a distinction between Wesley's perspectives and those of most Western Protestants.

²⁸¹ Maddox, "John Wesley on Holistic Health and Healing," 7.

²⁸² Maddox, "John Wesley on Holistic Health and Healing," 8.

development and that it clarified for him how imperative it was that the church resist emerging Nazi ideology.²⁸³

Bonhoeffer was awakened to theological questions and insights related to disabilities following a 1933 visit to Bethel, a small German town where a religious community cared for people with significant disabilities. He was particularly moved by observing residents with epilepsy, who swiftly and frequently moved between wellness and impairment.²⁸⁴ The powerful impact of this experience led him to write to his grandmother about how defenseless human life really is. “Their situation of being truly defenseless perhaps gives these people a much clearer insight into certain realities of human existence, the fact that we are indeed basically defenseless, than can be possible for healthy persons.”²⁸⁵ Bonhoeffer became convinced that true humanity is found in those who are sick, disabled, or weak, not in the idealized visions of strength and power that decorated Nazi propaganda and

²⁸³ Bernd Wannewetsch, “‘My Strength Is Made Perfect in Weakness’: Bonhoeffer and the War over Disabled Life,” in *Disability in the Christian Tradition*, ed. Brian Brock and John Swinton (Grand Rapids, Mich: Eerdmans, 2012) 353-390.

²⁸⁴ While epilepsy still is sometimes disabling, the emergence of effective, widely used anti-seizure medications later in the twentieth century has made a profound difference in the lives of many living with epilepsy.

²⁸⁵ Dietrich Bonhoeffer, Letter to Julie Bonhoeffer, Aug. 20, 1933, in *Dietrich Bonhoeffer: Works* vol. 12, ed. Clifford J. Green, (Minneapolis: Fortress, 2009), 157-158. Wannewetsch argues that the Bethel experience is fundamental to everything else in Bonhoeffer’s theology, including not only his resistance to genocide of all kinds, but also his deep disappointment with and separation from the mainstream of German Christianity as the church grew closer to the Third Reich. See Wannewetsch, “‘My Strength Is Made Perfect in Weakness’: Bonhoeffer and the War over Disabled Life,” 360-362. Interestingly, Eberhard Bethge, author of what is considered the standard academic biography of Bonhoeffer, offers virtually no mention of this experience, nor Bonhoeffer’s letter to his grandmother describing it. Bethel comes up as a site for the development of an alternative confession, and because its leader was at one point elected bishop in a contentious election, but other than a very brief mention of the euthanasia that took place there later in the 1930s, it is hardly addressed at all in Bethge’s massive work. See Eberhard Bethge, *Dietrich Bonhoeffer: A Biography*, rev. ed. (Minneapolis: Fortress Press, 2000).

that found ready audiences in a European society struggling to recover from the devastation of World War I.²⁸⁶

This represented a revelation for Bonhoeffer, and led him to invert traditional anthropological understandings, such as the binaries associated with Augustine. Rather than trying to define or understand weakness while assuming a normative context of strength and ability, Bonhoeffer understood weakness, dependence, and defenselessness as the norm. He tried not to define disabilities, but to explain human life, assuming universal vulnerability. As a foundational stance for a pastoral theology of care this intentional inversion of human understanding facilitates avoiding the weak/strong binaries that can contribute to patronizing treatment of care receivers. It begins with an assumption that all human beings share a need to give and receive care.

By 1934, Bonhoeffer had moved to London to serve a German-speaking congregation that he encouraged to help support the Bethel community. While at the London congregation, he preached a sermon based on 2 Corinthians 12:9 “My Strength Is Made Perfect in Weakness.” The sermon encapsulated many of Bonhoeffer’s theological values related to disabilities. In it, he presented the question of the meaning of “weakness” in a world that valorizes and idolizes strength, and argued that weakness is actually holy and that respect for weakness is vital in a Christian context.

²⁸⁶ See Robert Vosloo, “Body and Health in the Light of the Theology of Dietrich Bonhoeffer,” *Religion and Theology* 13, No. 1 (2006): 23-37, for a discussion of how this resistance to both the idealization of the perfect body and the assumption that individual bodies are valued primarily for how they can contribute to the body politic relates to Bonhoeffer’s understanding of the Body of Christ.

What is the meaning of weakness in this world? ... Have we ever realized that ultimately our whole attitude toward life, toward man and God depends on the answer to this problem? ... We are all dealing with the problem of weakness every day, but we feel it somewhat dangerous to give account of our fundamental attitude.²⁸⁷

Bonhoeffer began with a basic point: that the “mystery” of weakness is ubiquitous. Human beings live life consciously or subconsciously trying to understand the relationship between strength and weakness, he argued. The reality of weakness presents an uncomfortable truth, Bonhoeffer wrote, and yet we cannot become happy in this life as long as we hide from it. Next, Bonhoeffer acknowledged that Christianity has been mocked since its earliest days for the fact that it found its identity with the “weak” of this world, such as slaves, children, and those who are sick.²⁸⁸

Presenting the history and theology of Christianity as an epic conflict between strength and weakness, Bonhoeffer argued that “Christianity stands or falls with its revolutionary protest against violence, arbitrariness, and pride of power, and with its apologia for the weak.” Moreover, making a point particularly pertinent for considering disabilities and care, he argued that the church is called not only to *do* more for those who are weak, but to *be* more *identified with* weakness itself.²⁸⁹ Here, Bonhoeffer depicted the perspectives of “the strong” as a tantalizing but ultimately corrupting force that is actually foreign to Christianity and ultimately dangerous for

²⁸⁷ Dietrich Bonhoeffer, “My Strength is Made Perfect in Weakness,” Sermon preached in London, 1934; Dietrich Bonhoeffer, *London: 1933-1935, Dietrich Bonhoeffer Works* vol. 13, ed. Keith W. Clements, (Minneapolis: Fortress, 2007), 401-402

²⁸⁸ Bonhoeffer, “My Strength Is Made Perfect in Weakness,” 402.

²⁸⁹ Bonhoeffer, “My Strength Is Made Perfect in Weakness,” 402-403. In this call, Bonhoeffer seems to have anticipated some of the liberating emphases of later theologians who called for solidarity *with* the poor, rather than simply providing for them.

the world, convenient for those who would like to hide from, eliminate, or suppress the reality of weakness, but an existential falsehood with frightening implications.

Finally, Bonhoeffer criticizes attitudes of benevolence, saying they condescend toward certain groups rather than embody Christian love for the world. He calls instead for the “strong” to look up to the “weak” by seeking to suffer for their sake and for the sake of God, and to serve them “not by benevolence, but by care and reverence.”²⁹⁰ In so doing, he wrote, we glorify God and share in God’s life and grace. “Suffering conforms man to God. ... ‘My strength is made perfect in weakness,’ says God. ... God glorifies himself in the weak as he glorified himself in the cross.”²⁹¹

This challenge may be hard to hear for well-meaning people of faith who are seeking to show love and care, but often are unsure how to do so. It is an important caution, however. Bonhoeffer indicates that benevolence sees difference and wants to fix it, to improve the “weak” by making them more like the “strong.” This is a dangerous position from a disability perspective, because it assumes inferiority in the one with the disability. It is also an unfortunate position in terms of social life, because its ethical imperative is generally limited to charity rather than justice – and the entire notion of charity tends to maintain a mindset in which the strong are “aiding” the weak, out of an inherent goodness that is easy to withdraw, rather than recognizing solidarity in vulnerability, which creates a stronger bond.

Additionally, Bonhoeffer’s strong reaction against benevolence is easier to understand within his own context. While injustice and discrimination toward people with disabilities is still widespread, in our contemporary world it is often

²⁹⁰ Bonhoeffer, “My Strength Is Made Perfect in Weakness,” 403.

²⁹¹ Bonhoeffer, “My Strength Is Made Perfect in Weakness,” 404.

more hidden in civic structures and systems. In Bonhoeffer's context, the danger was blatant. Bonhoeffer knew that difference meant danger under the Nazis. In this sermon he called Christians to truly suffer for the sake of people who were in real danger of being exterminated. In this suffering, he wrote, they would share in the life of God.

As a corollary to his understanding of vulnerability, Bonhoeffer named a false god that not only drove some of the madness of the Nazi era, but that remains a present danger – the false god of health. In his August, 1933 letter to his grandmother, he wrote that it was “madness” to believe that the sick can and should be eliminated. Moreover, he insisted that this effort would lead to disaster.²⁹² In a world of ubiquitous human vulnerability, therefore, care facilitates human life and flourishing as it functions as an embodied discourse that reminds us of relationships between human and divine.

Pointing to danger in a utilitarian society

While Wesley's ministry drew upon simple practices of care to embody the conviction that all creation – including earthly life itself -- has inherent value, Bonhoeffer's work offered further explication of a theological understanding that ties the value of creation to God's work in creating.²⁹³ Bonhoeffer was faced with the terrifying, zero-sum logic of the Nazis, whose commitment to creation was limited to what they saw as “healthy” creation – persons who could contribute in material

²⁹² Bonhoeffer, Letter to Julie Bonhoeffer, 157-158. See also Dietrich Bonhoeffer, *Ethics*, Dietrich Bonhoeffer Works, vol. 6, ed. Clifford J. Green (Minneapolis: Fortress, 1995), 196.

²⁹³ Bonhoeffer also engaged in practices of care, but his theological explication is helpful alongside Wesley's ministry practices.

ways to the wider society, and whose genetic makeup did not threaten what they understood as the “Aryan race.” In reality, this was a commitment to utility, *nutzwert*, in German – to what the Republic could get out of its people. People with severe disabilities were seen as merely a “drain” on resources and costly to the vitality of creation, leading the National Socialist government to develop measures beginning in the 1930s to remove such persons from the nation – first with forced sterilization of those seen as “genetically ill” and ending with killing alongside other victims of the Holocaust.²⁹⁴

In response, Bonhoeffer insisted that *all* creation, all life – including life that is fully dependent – is valuable, because the value of human beings comes not from what we can give, make, or do, but merely from our creation by God.²⁹⁵ “ ... There is no worthless life before God, because God holds life itself to be valuable. Because God is the Creator, Preserver, and Redeemer of life, even the poorest life before God becomes a valuable life.”²⁹⁶ By providing care for and with someone who is weaker, Bonhoeffer argued, the strong are made stronger and more capable of continued care. “They will be ready to risk their own lives for those whom society values less -- the strong for the weak, the healthy for the sick The strong will see in the weak not a lessening of their strength, but an incentive to higher deeds.”²⁹⁷ Moreover, Bonhoeffer pointed out, we cannot trust the community to determine which lives are valuable, because, influenced by the mood of the moment, it would likely be

²⁹⁴ Wannenwetsch offers a helpful perspective on the place of actions against those with disabilities within the total Nazi schema; as well as on the place of disabilities in Bonhoeffer’s broader theology. Wannenwetsch, 353-354; 357-360.

²⁹⁵ Bonhoeffer, *Ethics*, 192. Bonhoeffer deplored the dehumanizing Nazi concept of the superhuman, or *ubermensch*, which illustrated the Nazi fetish for strength, power, independence, and invulnerability.

²⁹⁶ Bonhoeffer, *Ethics*, 193.

²⁹⁷ Bonhoeffer, *Ethics*, 193.

arbitrary in its judgments, allowing presently undesirable groups to be persecuted or destroyed.²⁹⁸

Theologies and practices that emphasize vulnerability

Clearly, both Bonhoeffer and Wesley were shaped as persons by their historical contexts. Bonhoeffer lived and learned and served during a reign of terror that destroyed human life by perverting basic understandings of God's creative work. Wesley considered what it meant to be a person of faith in a new industrial age in which the most vulnerable frequently were further victimized by systems and structures that had no concern for human life.

Both Wesley and Bonhoeffer, therefore, responded to their contexts and experiences with theologies and practices that emphasized vulnerability as a universal aspect of the human condition, and that demanded care that was intentional, relational, and epistemological. For example, both Wesley's insistence that those visiting the sick first must remember to inquire about and seek to meet physical and practical needs, before addressing spiritual concerns; and Bonhoeffer's demand that theological understandings of anthropology and care begin by assuming weakness as the norm, and seek solidarity between caregivers and care-receivers, rather than "fixing" the "weak" so that they might be "strong," indicate relational approaches that assume the care "receiver" knows best what he or she needs. Moreover, both looked at contexts and individual needs as a source for social understandings, that, in Wesley's case, then led to more public action and advocacy,

²⁹⁸ Bonhoeffer, *Ethics*, 194.

even when it violated social norms. Both were intentional in their work, considering situations and persons carefully, before acting on their behalf. Ultimately, both theologians developed theologies that assume weakness is a source of strength when it is acknowledged and accepted and that see care as a source of grace as it expresses commitment to the goodness of creation.

All Creation Has Inherent Value

An adequate understanding of care assumes that all of God's creation is worthy – worthy of love, worthy of work, worthy of relationship. No one is insignificant in a theology that focuses on care, and the lives that people live here and now are seen as an integral part of God's total desire for human flourishing.

Moving toward "fullness"

This assumption of creation's inherent value continues to resonate in more contemporary theological thinking, including process theology's understanding of human life as striving toward fullness and an expression of love that represents the glory of God. In a disability context "fullness" may look very different from fullness in a "typical" world, but this does not mean the concept is necessarily alien to this discussion. As previously discussed, impairments and challenges are a part of all human life,²⁹⁹ and we all live hedged in by circumstances. "Fullness," therefore, that which we grow toward and into, is personally specific, and is guided by the love of God and our call to participate in that love, for the good of all creation. Love -- human love, for one another and for God -- is the telos of creation, and this love

²⁹⁹ Suchocki, 92, 95-96.

mirrors God's own love and represents the image of God. Thus, creation is meant to move toward its own fullness, in a communal process that encompasses care for the other, and to do so for the glory of God. The process is part of how we are called to the body, the community, the whole.³⁰⁰

Just as it may be common to assume that impairments and disabilities deny the possibility of fullness, it also seems easy to assume one's own understanding of fullness and value in a human person, rather than to take the epistemological stance that allows persons to define for themselves the meaning of fullness in their context. Such attitudes and practices foreshorten possibilities for self-definition, and are likely to offer simplistic understandings of families and individuals. This is problematic within any context, but especially so in relationship with persons with disabilities, who are particularly subject to marginalization due to social understandings of fullness. The opportunity for self-definition, especially for those who are most vulnerable, must be preserved in any community of care.

Called to the Body of Christ: Communities of Care

People of faith are called to the body. We live not for ourselves alone, but for who and what we might be together. Individuals and communities, therefore, are called to facilitate one another's growth in faithfulness. By developing pastoral theological understandings of care for and with families facing disabilities, communities can learn from the dynamic interplay between ethic and practice, which urges attention to contexts, structures, and systems, for the sake of the common good.

³⁰⁰ Suchocki, 92, 95-96.

Intentional care can sustain spiritual growth

Wesley and the early Methodists, for example, developed a formalized system of community care initially as a means of organization and funding, but found that it contributed much more than this. The group expressed early Methodism's commitment to care based in human relationship and represented an important contribution to the development of congregationally-based care.³⁰¹ People involved in the Methodist movement were expected to be a part of a "class," a group of about twelve people who covenanted to meet at least weekly to support one another in living out their spiritual commitments, which included works of piety and works of mercy. They prayed, shared spiritual challenges and experiences, and held one another accountable for faithful living. Members were called to attend to a dialectic "of limit and possibility," in which sin was admonished, spirits were comforted, and prayers were offered for healing. Additionally, while the groups focused on spiritual growth, they also provided material and emotional support for one another in times of need. The congregational care provided within the groups grew outward, contributing to the development of multiple ministries³⁰².

³⁰¹ These groups arose from a practical need – the need to organize and fund a movement growing exponentially and led, often, by inexperienced, under-educated, little-trained individuals. Groups and the structures that supported them were a way of maintaining connections and clarifying focus and teachings. Yet they rapidly evolved to take their place as cornerstones of the movement itself. Care, formalized in these small groups, facilitated the growth of a discipleship movement.

³⁰² Heitzenrater, 200-202, 240; Manfred Marquardt, *John Wesley's Social Ethics: Praxis and Principles*, trans. John E. Steely and W. Stephen Gunter (Nashville: Abingdon, 1992), 15, 23, 28, 33-34.

Responsibility and interdependence strengthen persons and communities

This call “toward the body” as an expression of care is important; however, without thoughtful, intentional application, it can actually contribute to the devaluing of certain individuals, especially those who are or seem less able to contribute to the body as a whole. This was particularly apparent under National Socialism in Nazi Germany, where life was “mechanized” and individual lives were valuable only to the degree that they were useful for the social machine that was society as a whole.³⁰³ The tragic consequences of such a viewpoint make it clear that a productive tension between the individual and the community is critical for human life and flourishing. As human beings, we are called to lives of responsibility and interdependence, in which the bonds we share with one another and with God exist in productive tension with human freedom. Within the church, this perspective expresses a theological conviction that the body that is the church community is the continuation of the bodily presence of Jesus as experienced by the disciples, through which they – and we – suffered and are called to suffer, if necessary, with Christ.³⁰⁴

Care, then, as a set of practices emerging from relationship and proximity, functions as a sort of recapitulation of the life of Christ emerging from the church. Importantly, this occurs at all times and in all places of the church, not at an undefined future eschatological point. “It is this bond of life to human beings and to God that constitutes the freedom of our own life,” Bonhoeffer argued, suggesting

³⁰³ Robert Vosloo, “Body and Health,” 24-25.

³⁰⁴ Dietrich Bonhoeffer, *Discipleship*. Dietrich Bonhoeffer Works, vol. 4, ed. Jeffrey B. Kelley and John B. Godsey, (Minneapolis: Fortress, 2003) 215, 217. See also Vosloo, who draws upon Bonhoeffer’s thinking on the body to call upon the church for deeper engagement with the AIDS pandemic in Sub-Saharan Africa, pointing out that Bonhoeffer provides resources for a theology of “vulnerable, interdependent bodies.”

that only in the productive bondage of responsibility can there really be freedom. And, he added, it is out of this position of freedom and bondage that the church is called to witness, as a community, in word and deed, to God's love in Jesus Christ.³⁰⁵

While witness to God's love surely happens in many types of care, ultimately those who care are called to look outward, beyond individual suffering, toward larger structural and systemic issues that create and exacerbate this suffering. In short, care is called to move toward justice. Truly attending to care demands asking *why* suffering occurs, and *how* those with more power might facilitate the empowerment of those with less. It demands, for example, asking why families facing disabilities frequently struggle to access needed services for their loved ones, and working with families to help remedy their situations. This is a part of the epistemological approach to care recommended in Chapter Four. Movement in this direction has been particularly evident in recent pastoral theology, especially that written from feminist and womanist perspectives, which offers a liberative telos that has broadened the scope of pastoral care beyond immediate individual concerns toward the human context around individuals and families. As discussed earlier, feminist/womanist approaches to pastoral care demand that would-be caregivers analyze structures and ideologies, reclaim marginalized voices, and encourage prophetic challenge to systems of domination.³⁰⁶ This movement toward

³⁰⁵ Bonhoeffer, *Ethics*, 357.

³⁰⁶ See, for example, Miller-McLemore, "The Living Human Web: Pastoral Theology at the Turn of the Century;" Couture, "Weaving the Web: Pastoral Care in an Individualistic Society," and Snorton, "The Legacy of the African American Matriarch: New Perspectives for Pastoral Care," all in *Through the Eyes of Women*.

an approach to care that attends to contexts as well as individuals, continues to deepen the church's response as it answers the call "to the body" – the call to care.

Movement toward others can mean movement toward God

To give and receive care, then, is to move outside oneself for the sake of another, and to do so in ways that challenge pain and suffering. This movement toward the body of the whole is also a movement toward God, because it is as we care for and with others that we participate in God's love. Wesley insisted that one of the principal rules of religion was to serve God, but, that, because God is invisible to our eyes, we serve God in our neighbor, and that, then, God receives that care as if it was given directly to God.³⁰⁷ Participating in God's love, then, demands that we care deeply about the physical, emotional, spiritual, and intellectual well-being of all creation and the things that contribute to well-being – "for God does."³⁰⁸ To love is, in short, to care.

Care Engenders Transformation

Attending to care clearly has precedent in the Christian tradition. Mutual vulnerability, created worth, and the call to community all are values at home in the tradition, and these values are foundational for a focus on care, as well. But care also has a telos that expresses historic and contemporary theological commitments. Both care and the Christian life move toward personal and social transformation. This statement risks insensitivity in a disability context. As disability activists have

³⁰⁷ John Wesley, *A Plain Account of Christian Perfection* (London: Epworth Press, 1952), 102, quoted in Suchocki, "Christian Perfection," 98.

³⁰⁸ Suchocki, 98.

pointed out,³⁰⁹ to say that care transforms the care receiver may imply that he or she needs transformation; to say care transforms the caregiver may imply that his or her gain is worth any loss of independence or dignity the care receiver may experience.

Yet the disability context – while it is critical to this study – does not completely define its parameters. This work seeks to be a faithful expression of pastoral theology from within the Christian tradition, and within the context of that tradition it is entirely reasonable to insist that each of us does indeed need transformation, that such transformation is possible, and that none of us is truly independent. This is a perspective that is both humble and hopeful, and one that is sorely needed in a world that often seems to have forgotten our most vulnerable brothers and sisters, and the vulnerability we all share. Yes, care must be approached relationally and intentionally, with mutuality and humility. Within a theological context, however, care is not optional. It is fundamental to our being.

Personal and social transformation through the ethic and practice of care is a perspective fully at home in the Christian tradition, though always worthy of approaching with caution. Attending to care expresses Christianity's long-standing commitment to the need for and the possibility of personal and social transformation. Care has the potential to nurture, empower, and liberate persons with disabilities, their families, and the communities that surround them by resisting oppressive assumptions and structures that diminish the human person.³¹⁰

³⁰⁹ See chapter 4.

³¹⁰ See Bonnie Miller-McLemore's feminist reformulation of the aims of pastoral theology and care. Miller-McLemore, "Feminist Theory in Pastoral Theology," 80.

By enabling participation in divine love, care makes us human, and in so doing creates new worlds based on the divine will for wholeness and wellbeing.

Care's potential for transformation is evident in the lives of each of the churches involved in this study. At Good Shepherd, the priest "models care" in his vocation of the "care of souls." He sees the congregation reciprocate in care for one another. At House of Deliverance, where personal salvation is the center of church life, the pastor's dynamic "bringing of the Word," offers what the congregation most likely sees as the ultimate form of care. And at Calvin, care and the transformation it can offer is so dynamic that at times, Pastor Maryanne almost struggled to name it precisely. This is probably why she hesitates to quickly engage in a more active role in community care – and why she is watching and waiting to see what will "be revealed" as God works transformation out of intentional, relational, epistemological community care.

Case Studies Reveal Pastoral Priorities for Care

Effective care in community supports the ideas that: Human vulnerability is one source of strength; Care for one another affirms the universal value of all creation; Care is a practice that creates and sustains human community and thus challenges individualism; and, care, despite its "unstable" nature, always has the potential to transform human persons and society for good. Below, I will draw upon family experiences to explore where and how these perspectives operate in faith community life.

Vulnerability can divide and unite

The reality of vulnerability and an important role for care in the midst of vulnerability are easy to forget and avoid, as was evident in the bullying that Zeb experienced. Clearly, the bullies saw Zeb's vulnerability and acted to deepen it and to use it as a tool to make him suffer further. He was having trouble learning, so they called him "retarded" and "stupid." He was uncomfortable with wet paper, so they threw it at him, even spitting on it to add the shame and stigma of being violated with a product of another's body. He was anxious, and so they threatened to kill him. In each of these actions and more, those who bullied Zeb used what they had learned about him to exploit his vulnerability and in so doing to deny their own. Moreover, while there is obviously an individual toll in this – emotional pain, fear, and shame – there is also a communal toll. The process of bullying feeds a sense of division within the community, and makes care for and with one another ever less likely to occur.

The desire to deny one's own vulnerability is not surprising. Vulnerability is a common source of insecurity. Conversely, however, individuals and communities that acknowledge their shared vulnerability can strengthen personal emotional resources and communal ties. At Calvin Presbyterian, the congregation has been working on this reality since before the current pastor, but the recent four-week adult program described earlier encapsulated this community tendency. We all face things that can "trip us up," the pastor said – things like disability, divorce, substance abuse, and more. In response to this human reality, the church's hospitality committee created an opportunity to explore and discuss challenging

experiences in a community setting. By bringing people together to consider experiences that often can isolate individuals in their pain, the church not only reminded members and friends that vulnerability is ubiquitous, but also that shared vulnerability actually can hold a community together by witnessing and caring in the midst of one another's challenges and pain.

Creation Can Be Valued or Marginalized

The Nelsons left a young, vibrant church that they loved because it acted in ways that called the value of their own child into question. When church leadership effectively pitted the well-being of one child (the younger child to whom Nolan had made the sexual remark) against another (Nolan himself) by insisting that Nolan leave Sunday school and that the family attend another service, they suggested that one child of God was more important than another and that they would not honor their call to care for all. Moreover, as indicated earlier, this approach essentially denied the Nelsons the opportunity to live in caring relationship with the family who complained about Nolan.

At House of Deliverance, meanwhile, some practices of care for children and youth do indicate a theological perspective that sees value in all creation, especially in terms of children. We remember that Renata said one of the most critical responsibilities for adults is to help children to develop to their fullest potential. By seeing and acting upon a communal sense of responsibility for those who are often the most vulnerable among us, House of Deliverance offers intentional care that can be life-changing for some children.

Sadly, this was not evident in the church's failure to pay attention to James and to exhibit a culture of welcome and care for all persons with disabilities. Not only was the pastoral leadership entirely unaware of James' autism, the church as a whole knew him simply as an exuberant worshiper. Members defined him as the embodiment of what the congregation sees as exemplary worship behavior, rather than trying to know him as a complex person. By limiting James' role in the congregation to that of unwitting performer of community ideals, the church has deprived itself of James' other gifts. Moreover, while it is impossible to know if or how this impacts James himself, it is logical to think that constructing an idealized vision of who the congregation expects/wants him to be could function to define for James his own personhood, rather than freeing him to do so.

When, however, individuals and communities honor persons' self-definition, they affirm the value of all creation. For example, David's gift of a book about a subject he knew that Nolan loved – animals – illustrates a relational type of care that honors Nolan's whole personhood as a created child of God. David did not assume that his role as a confirmation mentor required him to give Nolan a "religious" book; instead, he acted with epistemological and intentional care that was based in understanding and appreciating another human person, even one who is "not typical."

Care answers a theological call to live with and for one another

Essential to the Christian tradition is a call from God to live with and for others, rather than for ourselves alone. Authentic care is a response to this call. Within the

experiences of the families and faith communities involved in this study, this is most evident at those times when care is *reciprocal*; that is, when the lines between caregiver and care receiver blur, even if only slightly. At these times, one person's intentional, relational attention to another facilitates the exercise of gifts and service for both persons.

For example, Zeb's experience as an acolyte would have been impossible if there had not been a verger willing to work with him and with other youth with significant, particular challenges. As Kelley Canfield pointed out, what's important in her role, is that she "love on them and help them figure out how to be successful." Because she has been willing to work with the challenges Zeb and some of his peers have brought to the ministry that Kerry leads, she has allowed him to serve and lead and thus contribute to the whole life of the church.

Similarly, Father Ronald said he is grateful for the many long conversations he has had with Zeb in response to Zeb's urgent theological questions. The priest said Zeb's challenges to more typical pious assumptions about the Christian tradition not only make him think, but also have provided an opportunity for him to discuss biblical scholarship that he said might have sent some people "running out of the office." Moreover, when a teenage girl with autism wanted to work in the nursery, Father Ronald acted on her desire. In so doing – against the advice of some in the congregation – he provided her a space for a ministry of her own, which was needed by the congregation. The girl's ministry eventually expanded from just holding babies on Sunday mornings to working with children in other settings at the church and in the community. In the process, it became clear to the congregation that this

teen was capable of doing much more than many had assumed. Because the church cared for her, she was able to care within the church and beyond.

Care can be transformative for individuals and communities

The call to live with and for one another, realized in the reciprocal nature of authentic care, can so energize the care experience that it can contribute to profound transformation for individuals and communities. Nolan's experiences with Danielle at Calvin Presbyterian, for example, have allowed him to engage with other youth and adults in multiple contexts.

Part of his experience has been receiving and accepting limits, and that alone has been transformative for Nolan and the congregation. Because Danielle is not inclined to "gushy sentimentality" and was not willing to just "pet disabled people," as she puts it, she set limits on his activities. These limits included shepherding him back to the group when he was inclined to wander down the hall, and recommending to his parents that he forego certain activities. By limiting Nolan's physical wandering and his involvement with younger children, Danielle managed to keep him more connected with his age peers than he might otherwise have been, and thus offered him increased opportunity to make friends, and the congregation – especially the youth – the opportunity to have a meaningful relationship with Nolan, to focus less on his challenges and more on the gifts he brings to situations.

This in itself could be and in some ways was transformative to the congregation, but there are other ways in which the care exercised in this faith community has been transformative. For instance, the relationship Daniel shared with Nolan around

confirmation continues, and as it deepens, Daniel said he is more and more convinced that one day the world will realize that Nolan, and others like him, really are the ones with earth-shaking abilities we simply have been unable to recognize. As Bonhoeffer reflected, Daniel's experience with Nolan has helped him to recognize the universal reality of human finitude, and the surprising truth that those who may seem "sick" to the typical actually may be the most authentically human among us.

Calvin Presbyterian's experiences with the Nelson family and with others facing disabilities and things in life that can simply "trip us up," as the pastor said, have clearly been transformative for individuals and the congregation as a whole. When we pay attention to these rich experiences, the lack of attention to James' challenges – and gifts – at House of Deliverance is particularly poignant. If the pastoral staff had ever pursued a deeper relationship with James' family, they might have come to understand him and his parents' experiences with him more fully. If this were the case, they would likely have even deeper understanding of and appreciation for James' spiritual gifts.

Conclusion

This chapter has sought to present theological resources for renewed pastoral and congregational practice related to disabilities. The chapter has argued that value-laden practices and theological convictions indicate that: Vulnerability is a fundamental part of being human; All creation has inherent value; Each of us is called to live "toward the body" of the community of Christ; (and) Care possesses an inherent possibility for profound personal and communal transformation.

Moreover, these resources from the Christian theological and ecclesial tradition reaffirm the notion that effective, healthy care must be intentional, epistemological, and relational. Thus, despite practices and theologies of marginalization and neglect, in both historical and contemporary society and church, the tradition does offer an alternative discourse focused on theologically-grounded care that “makes room” for welcome, affirmation and support of persons with disabilities and their families.

The call to care rests not merely on an objectively attained understanding of any particular human lack, nor on a philosophical outlook that persuades one of the logical value of care for the betterment of human communities. Instead, the call to care arises from deep understandings of what it means to be a human being, caught up simultaneously in *both* systemic, intergenerational suffering and evil, *and* God’s will for well-being for the world, convinced of the significance of relationship of all persons, experiences, and God (and importance thereof) and committed to a human telos of “active and intentional” caring for the sake of the glory of God.³¹¹

We care, in other words, because we must, if we are to be fully human, not because we “should” because of some “problem” (although we should), and not because it makes more sense than the other options (sometimes it does, sometimes it most definitely does not). Moreover, as we care intentionally, we realize that we are participating in God’s creative work in the world and that the fullness of our flowering as human beings reveals a glimpse of the goodness of God.

This intentional, relational, epistemological care arises from a conviction of the inter-relatedness of all beings and all aspects of the world, and a desire to care

³¹¹ See, e.g., Marjorie Suchocki, *The Fall to Violence: Original Sin in Relational Theology* (New York: Continuum, 1994); Suchocki, “Christian Perfection,” 92.

toward the fullness of all things, within the circumstances that always limit our fullness. And it occurs with a relational desire to learn and know the other, such that the other is teaching us of his or her care needs, and in so doing, caring for us, as well. This care, then, constructs a web of relationship that permits some release from the oppressive effects of evil and suffering.³¹²

Communities of faith that create “interwoven webs of care for one another’s well-being,” webs that express love of God and love of God’s creatures and creation, help to liberate and empower by the grace of God who is with us.³¹³ The possibility of such transformation grows from a conviction that the world can be shaped and re-shaped by human participation in divine love, expressed through care. As a framework for response to disabilities, therefore, care offers the possibility of *reflection* upon individual and group strengths, needs, and contexts; *attention* to ways in which the community of faith might help to support efforts for justice; and value-laden *action*, or practices, that discipline persons and communities into living lives that reflect God’s love. These lives of love witness to theological and social ethics sharply at odds with any emphasis on strength, power, and contractually-based social structures that understand personal worth to be determined by capacity to contribute.

Bonhoeffer offers a vision of the transformation that can be created by care, shaped by his experience of “what the church could be about,” in the fluid community of well and sick, stable and unstable, at Bethel. As he wrote to his grandmother:

³¹² Suchocki, “Christian Perfection,” 92-96.

³¹³ Suchocki, 92.

I have just come back from the worship service. It is an extraordinary sight, the whole church filled with crowds of epileptics and other ill persons, interspersed with the deaconesses and deacons who are there to help in case one of them falls; then there are elderly tramps who come in off the country roads, the theological students, the children from the lab school, doctors and pastors But the sick people dominate, and they are keen listeners and participants.

Clearly, there is precedent within the Christian tradition for a focus on care. Care invites the Christian community to honest reflection about individual and communal vulnerability; care calls the community to tender nurture and “fierce, dedicated”³¹⁴ labor on behalf of the oppressed; and care reminds each person of the universal need for transformation that arises from basic humanity. All of these are values and practices reflective of basic Christian commitments.

³¹⁴ Miller-McLemore, “Feminist Theory,” 80.

CHAPTER 7

CONCLUSION: THE GRACE OF CARE

Introduction

Christians understand the human community as existing within the long historical moment between the gift of God incarnate and the promise of history's fulfillment. This moment presents an essential tension: the tension between the ideal and the real. The real, that which already is, tugs at our bodies, minds, and spirits. It can disguise the distance between the here and now and God's desire for human life. It can muffle the sounds of wounded people. It can imprison individuals and communities, and convince us that liberating change is so difficult as to be impossible. And yet, the telos-directed existence of the ideal – that time when those who are hungry are fed; when those who are sick are comforted; when those who are lonely are befriended; and when those who are disabled are enabled to live life to their fullest -- is ever before us. Living life toward this ideal could be described as living with both "rootedness and grace," as Rev. Maryanne described what she has found in Calvin Presbyterian's care work, indicating an existence grounded by identity found in the complete love of God incarnate, and lifted by practices that share that love whole-heartedly. This telos-directed existence creates communities in which all persons are recognized and valued as whole but vulnerable human beings, both deserving and capable of great love. It creates communities in which persons live for one another and the wellbeing of the whole and are transformed by this other-directed existence. It creates, in other words, communities of care.

Learning to Attend

This project has been grounded in a hope that individuals and Christian communities might recognize people who frequently have been ignored or who have experienced less-than-helpful “help,” often based in lack of understanding and fear. The project, in particular, has sought and seeks to help Christian communities and leaders to hear and receive persons with disabilities and their families, as well as to ask several critical questions: What does it mean to truly care? Why should communities care? What does care have to do with disabilities?

The project focused on three topics: family experience with disabilities; disability representation in the historic Christian tradition; and care, with a pastoral theological telos. It sought to make more visible the challenges and beauty of life with disabilities, the richness of healthy care, the pain of inadequate care, the subtle, nuanced imperfections that attend virtually every effort that we make, as vulnerable persons, to love and care for other vulnerable persons, and to see possibilities for rootedness and grace that might move us just a little bit closer to the ideal.

Along the way, it has become clear that none of us is immune to the blind spots that can engender poor care practices. Blind spots related to disabilities, assumptions about faith communities and public society, or biases related to religion, race, and culture, all need to be addressed. All persons are called to seek to see more clearly, so that individuals and communities might consider what the “visual evidence” of this project indicates about the possibilities for renewed practice that are the critical telos of practical and pastoral theology.³¹⁵

³¹⁵ Miller-McLemore, “Practical Theology,” *Encyclopedia of Religion in America*.

Attending to family experience

Persons living with disabilities want to be seen and understood. Whether it was Nadine telling a former pastor that, yes, she could stop her son from asking to look at other parishioners' phones if he could explain autism to her, or Gail trying to help the church staff to fully appreciate the challenges of a two-year-old with autism, or the larger percentage of participants in the Strengths, Supports, Spirituality and Well-Being study who wished for disability awareness efforts to be offered by their congregations, families facing disabilities want the wider world to understand their life experiences.

We should see that families facing disabilities want to be honored for the gifts they bear. They want others to recognize that their lives are not experiences of unremitting suffering, and that their children's challenges do not mean that they do not have gifts. Sometimes, as Nadine said, they get "on a roll" at home, laughing and playing and having fun, appreciating one another, and it is not until they go out into public that they are reminded that they live with significant difference. Sometimes they feel privileged, as Gail says, that God trusted them to care for a child who truly needs "extra" care. Sometimes, when they engage deeply with their child, they are reminded that this child possesses wisdom and insight that others do not.

Persons living with disabilities want to be seen as human, meaning that they, too, crave grace-filled relationships, for themselves and for their children. Because they sometimes face the demoralizing task of "begging" people to spend time with their children with disabilities, as Nadine put it, they deeply desire to be loved and appreciated in their faith communities. They want to know that their presence

matters, that they have something to offer, whether it is through support and care for and with other families facing challenges, as at Calvin, through ministries offered by their children with disabilities, as at Canterbury, or simply because their presence reminds their communities that all people are vulnerable and challenged. And in the midst of this desire to be valued, they wish that churches were more likely to offer concrete supports that might facilitate experiences of grace in their lives, such as resource centers, companions for worship or Sunday school, transportation to youth activities, occasional financial assistance, and more.³¹⁶

Attending to care

This project's focus on care sought to make visible the rich complexity of a seemingly simple concept. When the field of pastoral care has taken an ontological stance on its self-understanding, it has tended to focus more on the substance of "pastoral," and much less on the substance of "care." After all, developing pastoral identity and competency takes time and deep reflection. It is not generally seen as a common pursuit, but one limited to a particular ministry community. Care, on the other hand seems to be something that people can just "do." It can seem beyond examination, beyond reduction. It can even seem ... easy. And yet care is far from simple.

Authentic, appropriate care is a perspectival orientation to life in community. As such, it is curious about the experiences and feelings of others and about

³¹⁶ Carter, Boehm, Annandale, Taylor, Liu, McCormick, Kinney, and Bullion-Medlin, "Parent Perspectives on Congregational Supports for and Inclusion of Young People with Intellectual Disability or Autism and Their Families" (2013). Manuscript in preparation.

appropriate responses to suffering and joy. It is filled with interest in human experience, desirous of knowing individuals at levels that are rich and complex, and committed to healing attention in the midst of pain. It is *epistemological*, in other words, and it is strengthened by theological perspectives that emphasize vulnerability as a ubiquitous, shared human experience, and that recognize the inherent value of all creation. When the church leadership at House of Deliverance offered no response to Gail's trauma over James' escape from Juvenile Church, for example, she was denied the comforting experience of simple interest in her emotions, and the affirmation of her personhood and of James' personhood that might have emerged had somebody expressed regret, given her a non-anxious space in which she could feel and express her emotions, and presented a constructive opportunity to be a part of making the church safer for particularly vulnerable persons.

Authentic, appropriate care is more than an emotion that signifies like or love of some person or some thing. It is committed to the wellbeing of others and willing to do what is needed to reach relative wellbeing. It is labor, therefore, that is *relational*, and it is or should be guided by a theological telos that recognizes the transformative potential in practices of care, the possibilities for growth into human fullness of all persons, and the ever-present call within the community of faith to live with and for the body of the church that is the Body of Christ in this world. When Denise pointed out that it would be much easier for her to make church happen at Canterbury if she avoided the kids with special challenges, she named the tension inherent in relational labor. Denise noted that she *could* simply tell the

parents of the acolytes who spin on the altar or walk down the center aisle barefoot that they just can't handle an important public ministry. And then she asked, rhetorically but with deep sincerity: "But what would that tell [them]? That I don't care about [them], that I'm more concerned about how people sit and what they do on an altar than [them] ... For me, it's much more important to love on them and help them figure out how to be successful." In the careful consideration of what it means to do the work of caring in community, Denise practices relational care.

Finally, it is important to understand that authentic, appropriate care is attentive to the ever-present danger of substituting control for care. This is why care must be *intentional*, cognizant of its own essential pitfalls yet committed to its strengths, and, again, undergirded by practices and theologies that recognize the goodness inherent in each person as an embodiment of God's goodness in creation. Danielle walks this tension when she helps Nolan to manage himself and at the same time sets limits to keep him and others safe and to facilitate his long-term development and ability to relate and function in more "typical" contexts. At the same time, she must recognize the ethical danger involved in limiting one less able to resist limits. As disability rights advocates have indicated, care can be a dangerous concept in disability contexts, and there are good reasons (institutions, forced sterilizations, invasive surgical procedures, and many, many more violations) to resist care.

Attending to theologies, theological practices and implications for care

Theologies that reflect the reality of human vulnerability create environments in which care for one another can flourish. This type of anthropology is authentic to

the gift of the incarnation, the moment in which God became human and shared our fragile state. At Calvin, this theological anthropology emerges from practices of care, such as a support group for parents of children with special needs; a guide to help Nolan and others negotiate the challenges of youth activities; even the simple touch of an understanding friend when families leave worship because their child is having trouble controlling his or her behavior. At House of Deliverance, although disabilities remain a growing edge, services of support for children and families in material, spiritual, academic, and emotional need have the potential to remind the congregation of the vulnerability they share. And at Canterbury, Father Ronald's modeling of the Christ of vulnerable care and love builds a theological understanding in which parishioners can find themselves.

And yet, it is important to recognize that practices and statements offered with the best of intentions can inadvertently create problematic understandings. The notion of "brokenness" for instance, while it can unite humanity in struggle also can seem to essentialize and make permanent human failure and inability to grow. Conversely, a congregational "theme" like "Maximize your potential," could, without careful nuance and accompanying practices of care and support for *all* people, imply a universal human power to overcome impediments that serves to shut out those who do not fit a typical mold. Even at Calvin, where care and support that honor human vulnerability seem most well-developed, there are questions about what the church is trying to accomplish when it includes persons with severe disabilities in programs that they may not understand. Does this honor the reality of human vulnerability? Or does it, as Danielle wondered, simply make the rest of the church

feel good? And, importantly, recognition of vulnerability cannot be an end. “In a fallen world, recognition of the importance of vulnerability may be required to be accompanied by moral outrage, lament, protest and social action.”³¹⁷

We should see that understandings of God that honor the mystery of *not knowing* – not knowing *why* disabilities happen, not knowing *why* God has presented persons with disabilities to particular families, churches, and communities; and not knowing *how* God understands disabilities and the place of disabilities in God’s reign, offers space for families to honor grief and hang on to hope, faith, and purpose. From Father Ronald’s conviction that it is science, not divinity, that causes disability, to Gail’s wonder that God would trust *her* to care for her son in his particular needs, to Kerry’s heartfelt conviction that God walks with her every day, the notion of God as mystery seems to speak to people who face the challenge of disabilities, whether as a parent or a faith leader.

This perspective, which can be known as an apophatic understanding of God, is one in which humanity’s very inability to understand God is primary. This makes the liberatory emphases of disability studies and some disability theologies temporary measures as we seek to live more fully into the kingdom of God (where they will not be needed.). “What we can know of God is that God is love and that God loves us; that love is self-sacrificing and open to all, and that love and justice are related.”³¹⁸ This understanding of God seems to imply an ecclesiology of openness to others and rich participation in the life of the church as a way of participating in the

³¹⁷ John Swinton, “Who Is the God We Worship? Theologies of Disability, Challenges and New Possibilities,” *International Journal of Practical Theology* 14, No. 2 (2011): 299.

³¹⁸ Swinton, “Who Is the God We Worship?” 302-303.

life of God, as well as a willingness to recognize that our communal life in this age is only a partial representation of what is to come in the fullness of time. This is a relational ecclesiology in which power is dispersed and each person's contribution is critical.

Seeing Possibilities: Persons Held by Care

This relational ecclesiology reflects practices of care that have and that continue to help youth with disabilities and their families to feel secure, to grow and to develop – and that, in turn, deepen practices and understandings within the wider congregation, as well. The care practice of working with acolytes who present special challenges, for instance, not only helps the youth to develop skills and competencies, but reminds the congregation that challenges and vulnerabilities are a core part of what it means to be human – and that they can be faced constructively in the context of authentic relationships.

And yet, there is a tension here. Challenges that are or seem to be “overcome” can seem to support a belief that God presents challenges to make us stronger – a perspective that has potential to trivialize something as momentous as learning that a child has a disability, or as significant as living with a disability, in an often unaccommodating world, from day to day. Pastoral leaders and congregational care practitioners must attend to the messages they send about God's person and work in the world if they are to avoid hurting families. To create an environment in which challenges exist to be simply “overcome” denies the reality of universal vulnerability and asserts knowledge of God that is, in fact, unknowable.

Moreover, the particular environment of the church demands *care*, not simply programs to facilitate overcoming challenges. This has several implications. First, as we saw earlier, care is *labor, emotion, and virtue*. Thus, the promise that in a particular community there is “room at the table for everyone,” conveys a feeling of care that is born of a theological conviction, that energizes particular practices, and that, in turn, continues to shape and re-shape theological beliefs. But it is not only a feeling. Instead, welcome or care demand practices that may not always be easy, that may, in fact, be burdensome, as the ancient thinkers on care pointed out. Not only is it work to be a guide or a mentor for *any* child, including for children with disabilities, it is work to find and support those who provide this labor. Recognition that care is actual work, not simply a warm feeling toward those facing particular challenges, is critical for long-term commitment. Finally, care is a virtue, and as such it contributes to the internal development of persons and communities that perform it. As communities engage in care, they become aware of their strengths and challenges and face a holy challenge: to re-shape their practices and identity so that they are more faithful to the values of love, justice, and liberation that are promised in the reign of God.

This identity as people of faith also provides an inherent response to some critiques of care. While it is important to attend to the worthy historical and contemporary observation that care can slip easily into control, as we discussed in Chapter 4, the solution suggested by some disability activists – an autonomous consumer model -- is antithetical to life on the way to the reign of God. Communities of Christian faith are called to live with and for one another. While no one should be

“used” for the satisfaction or even moral development of another (one of the dangers noted not only by disability activists but also by some of the sources for the qualitative work in this project) as Christians we are called to live with and for one another.

Christ stands in need of care, hidden in the suffering of present life – yet, there is no “us” who are well to care for “those” who are sick, but instead, in vulnerability and intentional relationships we live a dynamic existence between suffering and glory. Bonhoeffer credited the Bethel epilepsy patients for making this visible, for reminding him that in this life all people live ever between able and disabled, well and sick, whole and broken.³¹⁹ “Holding” others, as Winnicott described it, allows others to hold us.³²⁰

The Importance of Paying Attention

Reflecting on the experience of entering and serving a congregation that has developed deep awareness of the human challenges of disabilities and the reality of universal vulnerability, as well as a willingness to respond to the many things that can “trip us up,” Pastor Maryanne noted that she sometimes wonders if she is doing enough to guide the congregation in its efforts. She generally believes, however, that her primary role at this moment is to be aware of the grace unfolding in response to human need – to watch, to affirm, and to learn. Her thoughts evoke the words of Jesus as he promises his eschatological return in the fullness of history.

Therefore stay awake—for you do not know when the master of the house will come, in the evening, or at midnight, or when the rooster

³¹⁹ Suchocki, “Christian Perfection,” 98; Bonhoeffer “Letter to Julie Bonhoeffer,” 157-158 in *Bonhoeffer: Works*, vol. 12.

³²⁰ Winnicott, “Theory of Parent-Infant Relationship,” 585-595.

crows, or in the morning— lest he come suddenly and find you asleep.
And what I say to you I say to all: “Stay awake!”

-- *Mark 13:35-36*

Though it is filled with imagery that can create a sense of foreboding, this text and the verses that precede it in Mark 13 also can be read as a promise of reversal – a promise of a kingdom world in which those who are powerless and downtrodden are lifted up, and in which places of fear and suffering are gifted with grace. This resonates with the experiences of the families in this study.

Within their stories there are visible moments of grace in surprising places, moments that human persons living in this in-between historical moment must sometimes work to see. To keep awake is to allow oneself to witness wonder and joy. This is evident in the words and experiences of Gail and Melvin, who are so proud of James’ accomplishments; of Daniel, who is convinced that one day the world will learn from Nolan; of Father Ronald, who learns from Zeb’s insightful questions – and more. These and others like them are people “keeping awake” to witness grace embodied in those whom the world often discounts. The church – in all of its representations -- is called to this wakefulness. In caring relationship with persons with disabilities and with all people, the church is called to trust that the mythic possibility of being surprised by grace is as real as the parabolic challenge of living challenged toward a horizon of eschatological goodness and love, love that is nothing less than life lived in care. Care that is intentional, cognizant of its inherent dangers but committed to its importance; care that is epistemological, desirous of knowing, understanding, and responding to another; and care that is relational, in the best sense of the word – feeding and being fed by one another in one another’s mutual vulnerability – this is the care that loves, that embodies God’s love, and that

brings eschatological goodness to the present moment. It is this care that is, can, and should be the telos of the church's relationships with persons with disabilities and their families. May it be so.

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