

The Disabled Church

Human Difference and the
Art of Communal Worship

Rebecca F. Spurrier



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A Sacred Family congregant participates in liturgy with bulletin, hymnals, prayer book, and hat. (Photo credit: Cindy M. Brown)

INTRODUCTION

Disabling Liturgy, Desiring Human Difference

The beauty is there, all over the church, on the inside,
right there on the inside of the church. . . . That's us,
that's the beauty, the attitude and the love and respect,
and showing respect and love and happiness.

—ROSE WILLIAMS, congregant at Sacred Family Church

A priest I know once described Episcopal liturgy as a dance. Processing, sitting, standing, setting the table for communion, and moving around the altar—all of these movements were a way of being caught up in something greater than herself, a mode of prayer and praise that was not solely about the words she was professing but also about an embodied unity with others in love to God. Over the years, I have come to know what she means. Although I initially felt awkward and inept, juggling prayer books and learning to sit, stand, and kneel at the appropriate moments, I grew used to the rhythms and became able to keep worship time with the rest of a community. I came to understand this priest's description of liturgy to extend to many kinds of worshipping communities, where a unity of movements, songs, cries, shouts, and silences becomes a dance whose rhythms guide each member to take their part.

Yet since 2006, I have become a regular visitor at an unusual church community in Atlanta, Georgia, whose worship calls into question these understandings of a well-choreographed dance of prayer. Sacred Family¹ is a church in which more than half the congregants live with diagnoses of mental illness; many of them come to the church from personal care homes

or independent living facilities. Here the dance of the Sunday Eucharist often seems dissonant or disjointed. Some people stand for the hymns and the gospel reading as the prayer book instructs. Some people sit with their bodies folded over into their laps for most of the service. Some wear dresses and suits, and some wear sweatpants and never take off their coats. Some people sing all of the hymns, and some do not sing at all. During the prayers of the people, a congregant inserts his own needs and concerns before he is called upon to do so. A woman reads her own poetry softly to herself. One congregant flips through a travel magazine during the eucharistic prayer. Another negotiates with his neighbor for a cigarette. People walk in and out, disappearing from a pew for a time only to reappear in the same seat or in another. Even in the long amen after the eucharistic prayer, someone's voice bursts forth with an "Aaaa" before the rest of us begin to sing. Whenever one worships God at Sacred Family Church, there is someone who is doing it differently.

"What do you need in order to have *church*?" liturgical theologian Gordon Lathrop asks to begin his study of the holy people called to worship God.² He describes how holy people in all their diversity gather weekly around central symbols of Christian liturgy—a day set apart for the reading, praying, and preaching of Scripture and the meal of Christ.³ The people gather to share food and stories and to remember the poor.⁴ He suggests that these symbols invite difference by means of "a strong center and an open door" through which all are welcome. The open door is a symbol of access by which the holy people come, bringing their own needs and gifts to the transforming work of the assembly in order to participate "side by side, in the concrete gifts of the mercy of God."⁵ Sacred Family opens wide the church doors, and yet the central elements and the participation in the symbols of Christian worship raise questions rather than supplying clear markers of unity. Not everyone is awake for the Scripture reading. Not everyone pays attention to the sermon. Not everyone goes forward for the meal. Even the collection highlights the differences between poor and wealthy, as some congregants dig coins from their pockets and others lay folded checks and envelopes on the offering plate as it is passed.

Thus my question: What do you need in order to have a church that assumes difference at its heart? Sacred Family is not a communion of different people with similar capacities to read, pray, think, move, and love, but a gathering of people with and without mental disabilities who challenge assumptions about the bodies we call church. Sacred Family congregants embody the struggle of a church imagining people with disabilities as

essential to its life and faith. They point to the gathering of difference itself as an act of faith: the belief that human beings in all their variety can enter through an open door to be held together through love rather than coercion or conformity to particular practices or beliefs. If, as disability theologian and sociologist Nancy Eiesland argues, a body is that which is being held together and enabled to act out,⁶ how are the bodies at Sacred Family held together and guided into the rhythms of acting out this life together? What does divine love, spoken and embodied through the liturgical symbols of the Christian tradition, have to do with this holding and acting?

The central argument of this book is that Christian liturgy embodies consensual, nonviolent relationships that rehearse a Christian response to an encounter with the creative beauty of divine love, which makes possible belonging to a community through and across difference. It is not first or primarily the ability to grasp or articulate a set of ideas about God nor to conform to a set of normative practices. Rather, the liturgy of Sacred Family, choreographed with and through disability, reveals both the fragility of human connection that is requisite for any worship of God and the persistent beauty of this connection as the gathered ones find, create, and improvise access to one another and the divine. The unconventional arts of becoming church are key to a liturgical theology with and through disability. By artistry, I include the forms of interaction between people that highlight the ordinary works and pleasures of a disabled church.⁷ Naming and recognizing these arts illumines both the beauty and the struggle that incorporating difference into the church as the body of Christ entails.

Exploring Sacred Family Church as a community of difference, I analyze the significance of embodiment in shaping a sacramental community. My research methodology was primarily ethnographic participant observation, with its attention to thick description and listening to a multiplicity of voices within a community. Here, I had in mind anthropologist João Biehl's "The Right to a Nonprojected Future," in which he argues that:

Attending to life as it is lived and adjudicated by people on the ground produces a multiplicity of approaches, theoretical moves and counter-moves, an array of interpretive angles as various as the individuals drawn to practice ethnography. At stake is finding creative ways of not letting the ethnographic die in our accounts of actuality. We must attend to the ways people's own struggles and visions of themselves and others—their life stories—create holes in dominant theories and interventions and unleash a vital plurality: being in motion, ambiguous and

contradictory, not reducible to a single narrative, projected into the future, transformed by recognition, and thus the very fabric of alternative world-making.⁸

I also investigated this community through a threefold approach to theological aesthetics: an emphasis on the role of sensory participation in relationships with God and others, attention to the role of art in theological interpretation, and a focus on beauty as a theological category.⁹

But that is not all. For this work is a conversation not only among the community at Sacred Family with the theological categories it performs and creates, but also with disability studies and disability theology with their critiques of cultural and theological presuppositions about well-being and embodiment, and with liturgical theology with its emphasis on the gathering of Christians to worship God as a primary mode of knowing and loving God.¹⁰

Sacred Family as a Community of Difference

Sacred Family, founded in the late 1800s as a mission church, moved to its current location in Atlanta in the 1950s.¹¹ The racial integration of schools that took place throughout Atlanta's neighborhoods in the 1960s, as well as the effects of post-war white flight to the suburbs challenged Sacred Family, then a small and struggling white parish, as it did many other churches and communities. According to one story told around the church, it was in the early 1980s, after a series of changes in the neighborhood and conflicts over church leadership, when membership at Sacred Family had dwindled once again, that the parish faced imminent closure by the bishop.¹² The vicar at that time began inviting people he met in the neighborhood, many of whom lived in group homes. The church not only shared a weekly meal with those who visited but also welcomed them into the worship life of the community.

During the planning for the 1996 Olympics held in Atlanta, some advocates for people with mental illness became concerned about the increased vulnerability of those who spent time on the streets.¹³ As part of an initiative by the Georgia Department of Human Resources to create safe spaces during the Olympic Games for local people with mental illness, Sacred Family began its day programs.¹⁴ What started as a temporary response to possible stress and displacement during the Olympics has evolved into a set of programs known as the Circle of Friends, which

involves both congregants who attend Sunday and Wednesday services and those who do not. Many of the Circle participants have been diagnosed with various forms of mental illness—such as schizophrenia, bipolar disorder, anxiety disorder, or cognitive illnesses due to aging. Some live with other kinds of disabilities. Many describe themselves as people whose lives have been affected by addictions and homelessness. Some of them have been incarcerated.

Most of those who come to the Circle have been affected by government and state policies that took effect in the 1970s and '80s when persons were released from psychiatric institutions with the anticipation that community-based supports would provide necessary resources for their well-being.¹⁵ In place of government institutions, there emerged for-profit group homes, many of which cannot or do not provide adequate support systems for the people who live there, as I discuss further in Chapter 5. Church staff and lay leaders at Sacred Family speak of group homes as enmeshed in systems that frequently exploit the vulnerabilities of people who have few viable options about where or with whom to live. Those who work at Sacred Family understand part of their mission as ongoing advocacy to secure essential resources for good meals, safe housing, adequate medical care, and, above all, the right to belong to a religious community of mutual care and support. They believe that Sacred Family itself is one of these resources, a place for relationships that are life-giving and transformative. They also acknowledge the limits of what Sacred Family can do and be for those it gathers.

Relationships at Sacred Family are constituted through a wide variety of interactions and contexts. Different kinds of church services take place throughout the week: Tuesday and Thursday morning and noonday prayer; Sunday morning and Wednesday evening Eucharist; and the monthly music event known as Worship Live, which features both dancing and solo performances by community members. In addition to attending services, some members gather twice a week for the Circle (located at the church) to do woodwork and weaving, to paint, and to play bingo and do yoga.¹⁶ Some sell plants from the greenhouse on second Saturdays of the warmer months of the year. Tuesday and Thursday mornings begin with breakfast, and all mid-week services are followed by a shared meal, which is supplied either by Sacred Family or by other churches. After lunch, some members choose to stay for support groups for those with mental illness. Many Circle participants also share a life together outside the church, returning by van to the eight or nine group homes where they spend most of their time.¹⁷

*Ethnographic Methods and Assembling
the Pieces of a Theological Puzzle*

During one of my first interviews, Tanya, a young woman with mental illness, volunteers to speak to me about experiences at Sacred Family. She appears nervous, and as soon as we enter the interview space, she confirms that she feels anxious about taking part in the conversation. In line with my research protocols,¹⁸ I assure her that she does not need to participate in this recorded discussion if she feels uncomfortable. I also give her the option to meet with me at another time when she feels more at ease.¹⁹ Tanya insists that she wants to continue our conversation and that she likes being able to contribute in this way, even if she feels anxious. She thinks she might be the “missing piece of the puzzle” I need to understand this community.

Like Tanya, I imagine that all people at Sacred Family are missing pieces of a puzzle about the church as a beloved community that witnesses to divine beauty and justice in the world. I also investigate Sacred Family Church as one missing piece in a larger puzzle about how the broader Christian church not only feels obligation to include those with disabilities but also how it comes to desire the beauty as well as the struggle that human variation brings. Assembling these pieces of the puzzle requires that my readers imagine what it would feel like to be part of a community like this: the excitement, the confusion, the boredom, the laughter, the distress, the tenderness, and the exhaustion. As Eiesland writes, “An accessible theological method necessitates that the body be represented as flesh and blood, bones and braces, and not simply the rationalized realm of activity.”²⁰ Ethnographic methodologies keep me grounded within my field of inquiry to record in field notes and to evoke for my readers what it feels like to be part of Sacred Family’s everyday liturgy. In order to draw readers into the flesh and blood—the hope and the struggle—of lived experience at Sacred Family, I have chosen to convey my research in the present tense so that the reader might feel the immediacy of events and relationships.

As a participant-observer, I investigate the stated goals, descriptions, and explanations offered to me by different kinds of participants about the purpose and identity of the parish, but I also investigate the sounds, gestures, silences, and relationships that are as much a part of Sacred Family as that which is explicitly claimed for the church’s identity. I include in my study the kinds of participation and non-participation that confirm or contradict this church’s own explicit theological claims about what Sacred

Family is and does. Ethnographic methods encourage me to pay theological attention not only to the places most obviously associated with religious or theological identity but also to a range of relationships that happen across space and time when people gather at the church.

Ethnographic methods as well as ethnographic writing ground my theological interpretations in a close description of ecclesial life and of the social dimensions of Christian worship. Such descriptions bring to my theological writing an openness to multiple and, at times, disparate and diffuse interpretations of who God is and how God is working among those who identify as Sacred Family. By grounding my methodology and my writing in close and careful descriptions of particular times and spaces at Sacred Family, I offer a multi-dimensional, theological portrait that illustrates both the beauty as well as the ambiguity of this church's struggle to keep the doors open to all who seek a place at Sacred Family—and by extension in the broader Christian church.

Sacred Family's doors were opened to me long before my formal research and writing began. Sacred Family is unusual not only as a church that welcomes people with mental illnesses, but also as a site of education and training. The parish welcomes many students from medicine, theology, and other disciplines for experiential learning opportunities that last from a few weeks to a couple of years. A supervised internship program during my master of divinity degree introduced me to this parish six years prior to my formal study of it. Even after I completed the internship, I found it difficult to leave Sacred Family and often returned to visit. Whenever I encountered a theological or humanistic claim about proper virtue or worship, the faces of Sacred Family parishioners appeared in my mind, gently interrogating its premise.

How and why has Sacred Family inscribed itself so deeply on my theological imagination and the imagination of so many others who spend time there? As one woman, a volunteer for over thirty years, declared to me, "There's no other church like Sacred Family. . . . I don't think there's any place in the world you can say is as nice as Sacred Family; what do you think?"²¹ There are many members of the parish and former interns who would confirm her sentiment. Through a research period of careful participant observation, I have sought to understand better both what makes Sacred Family unique and what it holds in common with other Christian churches and communities.

To understand and describe divine and human love manifest through difference at Sacred Family, as well as to study the forms which constrain or obscure such configurations of difference, I have spent three years of

research at Sacred Family (one full-time and two part-time years). I have attended Sunday morning and Wednesday evening communion services and eaten meals with the community. I have also participated in Circle activities: gardening, art, games, socializing, yoga, and Bible studies. I have attended occasional events such as plant sales, Worship Live services, social outings, and visits to other church communities. I have visited personal care homes and independent living facilities, so that I have a sense of life at Sacred Family in relation to these other primary communities that affect relationships within the church. I have also conducted interviews with congregants, interns, and volunteers in order to hear stories shared less frequently in the day-to-day activities of the church. I have tested my own theories and assumptions about the community by inviting others to reflect on the categories I employ. As an ethnographer and a theologian, I both trust and evoke divine agency in calling and shaping the church, an assumption shared by many who gather as part of this community. I also listen to voices and observe behaviors that would counter these beliefs and assumptions, seeking both confirmation for and doubt about the approach I have used to describe and identify “Christian liturgy” at Sacred Family. I take seriously the woman who says she can feel the presence of God at Sacred Family and the man who sits at the entrance, refusing to go in for noonday prayer, because he “never saw Jesus in a church.”

Like anthropologist Karen McCarthy Brown, I understand ethnography to communicate a particular, subjective truth that occurs in between a participant-observer and the people she is studying and, as such, to rely on the process of ethnographic research as a “social art form, open to both aesthetic and moral judgment.”²² Such an art form acknowledges that ethnographic methods rely on the creation and maintenance of human relationships that affect both researcher and those from whom and with whom she seeks to learn; thus, there is no clear boundary separating the ethnographer from those she studies. Even as I seek a truthful and accurate representation of the community and individuals with whom I spend time, I also help to create this representation through my interactions with others and through the history, knowledge, and experience I bring to this place.

Aware of the part I have played in Sacred Family, I describe my interactions within the narrative of this book so that readers can observe my participation in community life. I often use a first-person narrative both in field notes and in this chapter to remind myself and my readers of my active part in discovering, eliciting, selecting, and interpreting particular elements of Sacred Family’s life together. Ethnographic research and theological inquiry are inherently subjective tasks, shaped by the stories, relationships,

cultures, and resources of the writer, who captures partial memories from a particular time within an ever-changing place. Thus, ethnographic and theological narratives always include some characters and exclude others. By focusing on some parts of a story, they obscure others. Thus, we might think of this book as one brief chapter in the yet unfolding story of Sacred Family.

Parts of my story are animated by my identity as a Christian who has been going to church all her life. Although I am currently a member of a Mennonite church, I have worshipped with and deeply engaged churches of many different denominations throughout the forty-five years of my lifetime. I am also a temporarily abled, white, straight, cisgender, married, childless woman, who has not yet been diagnosed with a mental illness and who has never lived in poverty. I have spent time with communities advocating for people with disabilities and mental illness prior to coming to Sacred Family. I have also had friends and family members who have been diagnosed with psychiatric disabilities.

Occupying both insider and outsider positions, I follow ethnographically and theologically this church's movements and struggles. I do not offer Sacred Family as a model that should be replicated by other churches and faith communities, but as a window into the kinds of aesthetic frames and questions that a disabled church inspires. As I do so, I take my cue from the philosopher and theologian Jean Vanier, founder of a worldwide movement of intentional communities focused on core members with intellectual disabilities. When Vanier was asked to give a formula for the organization called L'Arche, he suggested that L'Arche is a sign not a solution, a movement to transmit a vision and a counterculture rather than an institution that is about successful replication.²³ Following Vanier's suggestion, I do not view Sacred Family as the ideal form a church or community should take. Rather, I maintain the vital significance of that to which Sacred Family points, for its desires and limitations tell us something about the presence and absence of God in community through disability. Sacred Family offers wisdom about the liturgical formation of faith communities that manifest divine and human beauty as a response to social violence.

I gathered information so as to represent accurately the encounters in which I took part, as well as to maintain the research forms that felt least intrusive to the community. I took psychiatric disability into account not only as a critical lens through which to interpret church community but also as an experience that might affect a process of informed consent. I built into my research protocols an awareness of possible mental distress or change. Because some congregants struggle to remember certain kinds of

information, as often as possible I reminded those with whom I was speaking about my role in the community; this included not only congregants but also staff who sometimes asked me to take on volunteer roles. I made sure congregants were always aware that they did not need to respond to my questions and could choose to end, to put on hold, or to continue our conversation at a different time if they were feeling uncomfortable. Some congregants asked to speak with me but then changed their minds when I offered them the option not to speak. I tried to build in a flexible and sensitive approach to interactions that did not contribute to any anxiety that congregants might be experiencing and that also took into account dramatic fluctuations in the ways that people expressed themselves to me. I used a process of oral consent to help protect the confidentiality of those with whom I met individually in formal interviews, made sure they knew that what they shared would have no impact on their participation in the church or its programs, and made clear that those with whom I had formal interviews knew that they could come back to me prior to the completion of my research and ask me not to use any information they had shared.

I carried a digital voice recorder with me, taped all formal gatherings and interviews, and recorded some informal interactions. Some congregants were more comfortable with taking written notes than audio recording our interactions. Thus, there are numerous events and conversations that I recorded in a small notebook and then reconstructed through field notes. I give you, my readers, indications to these different forms of gathering information through the punctuation I use in the dialogues I recreate here. Quotation marks denote conversations where a recording or the pace of a conversation allowed me to capture the conversation verbatim. When I do not use quotation marks, I have reconstructed conversations from notes I have taken when I was not able to capture every single word. For these reasons, some conversations are written with the use of quotation marks and some are not.

Mental Illness through the Lens of Disability Studies

I come to the study of this community as a liturgical theologian who uses ethnographic methods and as a disability scholar. I am not trained as a mental health practitioner or as a psychiatrist. Thus, I attempt to describe behaviors and interactions within the parish as I observe them or as I hear them described rather than analyzing them through a medical or psychiatric lens.²⁴ For example, I describe genres of touch and what this touching evokes

within community, rather than asking what mind-body processes lead a certain group to use touch rather than speech or how certain kinds of medications affect the embodied interactions of the community. In doing so, I assume the legitimacy of such forms of interaction and behavior. By drawing on my own experiences and the experiences of others who participate in or otherwise engage with this community, my primary interest lies in investigating communal experiences of church with and through disability. I seek to keep disabled and non-disabled people together as theological subjects within my field of inquiry rather than to turn to the disabled body or mind as an object of inquiry. At times, I explain both conventional and non-conventional forms of interaction when people in the community choose to explain behaviors for me, and I want to highlight their interpretations of themselves or one another.

I use disability criticism to consider the activities of persons with diagnoses that explicitly label them as mentally ill or as people with mental health challenges. Psychiatric disability is not a term that is deployed at Sacred Family, where mental illness or mental health challenge/disorder is more commonly used to refer to the experiences of many congregants. While some scholars might desire a clear distinction between disability and mental illness, much disability criticism emphasizes different forms of embodiment on a continuum rather than making hard distinctions between embodied experiences.²⁵ Three approaches of disability criticism are particularly helpful in thinking through the relationships that Sacred Family explicitly seeks to nurture and transform.²⁶

First, disability studies and disability theology tend to emphasize the capacities and limitations of embodied minds as manifest through relationships with other people and places and through political, religious, and social assumptions about what it means to be human. That is, if I come to identify as mentally ill, I know this through cultures, environments, and discourses that give me that designation and that construct some behaviors as sane and others as crazy. Real suffering exists, and people desire that their bodies be transformed in light of this suffering. However, these desires and experiences of pain are inextricably enmeshed in social relationships and cultural representations through which people negotiate their own meaning and worth and receive care from others. Through these relationships and representations, we learn to identify the meaning of sickness and health, capacity and incapacity; we learn to name and understand our conditions, as well as to envision alternatives. Using the language of psychiatric disability, I identify two systems (psychiatry and law) through which persons at Sacred Family come to know themselves and others as

normal or abnormal. To describe human life in these ways is both useful and limited.

Second, disability studies as a form of critical discourse emphasizes that in order to talk about a particular category of embodiment (woman, black, gay, poor, disabled, sick, mad) we must also think carefully about both the construction and the invisibility of its opposite. What kinds of behavior come to be designated as abnormal and through what relations to the normal? What sorts of descriptors, capacities, and aesthetics set apart the able bodied from the disabled, the mentally healthy from the mentally ill, the sane from the insane, the ordered mind from the disordered one? In particular, disability discourse highlights the normal as an exclusive and elusive category—one that often remains uninterrogated and, therefore, works against an affirmation of human difference. Given that every year one in five American adults experiences a diagnosable mental illness and over forty-five million Americans live with mental illness in a given year, disability studies raises vital questions about what constitutes a “normal” human life and whose lives are considered good lives.²⁷ Thus, disability studies provides a critical framework for understanding how mental illness, a common human experience, occupies an aberrational and stigmatized position.

Third, disability scholarship also tends to emphasize vulnerability, interdependence, accommodation, and bodily variation and change as part of what it means to be human. This emphasis stands in opposition to certain ideals of ability, health, wholeness, independence, progress, and normalcy that are unattainable or unsustainable over the course of a human life. While there are different forms and degrees of joy and suffering, all of us face radical changes in our embodied minds and relations with the world and with others throughout the course of our lives. Some disability theorists emphasize that if we live long enough, most of us will experience disability. Thus, mental illness is not an extraordinary fate that affects only a small number of abnormal people, but a condition that is shared among many or indeed most families and communities. Disability must be reckoned with as part of human life; it is not something from which we can isolate ourselves.²⁸

I use the terms psychiatric disability, mental illness, and mental difference.²⁹ Mental illness is the terminology that the people I encounter at Sacred Family use most often; I use it as a description indigenous to the community and to the surrounding culture. Psychiatric disability places this community within a larger conversation about what disability means and provokes as it encounters the assumptions of normalcy and ableism.

The language of mental difference emphasizes the fact that a range of body-minds is present within any human community, even if particular mental differences come to characterize Sacred Family. By using a diversity of terms, I intend “to recognize the complex interactions among individuals, their illnesses, and the larger social contexts in which these are all embedded.”³⁰ Thus, I work to keep multiple frames for identifying and understanding human persons and interactions in play.³¹

Disability and the Christian Church

In *The Disabled God*, Eiesland describes significant ways that the Christian church has harmed people with disabilities through inadequate theological models of disability. The church has done so in part by regarding disabled persons as props and instruments of theological inquiry rather than as “historical actors and theological subjects.” Unjust theological interpretations have prevented the church from accessing the lives of persons with disabilities, as well as barring disabled persons from the symbols of the church. Such “carnal sins” of the institutional church reveal not only the fragility of human bodies but also the fragility of the church that claims to be a witness to God’s love in the world.³²

Eiesland identifies three such “carnal sins” that have prevented churches from accessing the lives and insights of people with disabilities. First, she argues that the church has tended to practice segregationist charity.³³ While congregations desire to help people with disabilities, they often maintain a safe distance between church members and those whose forms of embodiment might challenge their theologies and body practices. Charitable practices that focus on helping and healing individuals—those deemed dependent or needy—often obscure the broader questions of “political engagement and social inclusion.” Second, the church has used persons with disabilities as examples of “virtuous suffering.”³⁴ By highlighting their suffering as a means of divine work in the world, the church symbolizes disability as a temporary test to be endured for a spiritual reward. In such a theological framework, disabled lives provide others with inspirational examples of suffering and overcoming. Such theologies have been used to isolate people with disabilities and to encourage them to adjust to unjust circumstances. Third, the church has participated in what Eiesland calls the “sin-disability conflation,” where a causal relationship between sin and impairment is implicitly or explicitly evoked.³⁵ Disabilities are associated with evil; they are not part of God’s good intentions for the world, and thus persons with disabilities become evidence of the

sinfulness of the created order that God seeks to heal and transform. Through these three critiques, Eiesland identifies what she sees as a persistent thread in Christian theology: persons with disabilities are “either divinely blessed or damned: the defiled evildoer or the spiritual superhero.”³⁶ Such theologies fail to represent “the ordinary lives and lived realities of most people with disabilities.”³⁷

Sacred Family is a community that seeks to transform these carnal sins of the church into new relations with persons who are often excluded from ecclesial practices and theologies. Although the church explicitly promotes its Circle activities as part of its mission, it intentionally distances itself from a communal ethos that views persons with mental illness as recipients, rather than full participants, in community. In an older pamphlet written about Sacred Family entitled “WHO we are! WHY we are! WHAT we are!” I read this assertion:

It seems so difficult for many to accept the fact that Sacred Family is not a Church with a program for the mentally ill. Just as we are not a church with a program for women or persons of differing races, cultures, or lifestyle preferences; we are likewise not a church with a program for the poor, the ill and/or the oppressed. **They are us.** We are one body. We are a church. They run for church office, serve on parish boards and committees and help lead our congregation in worship. We at Sacred Family do not differentiate between persons or types of persons. Together we respect the dignity of every human being as all are welcome and included in our community.³⁸

In addition, a newsletter reporting on activities in the Circle describes the community this way: “We are not a community of staff and clients, or even staff and participants. We are a community in the tradition of mutuality. We are all participants, we all benefit from [the Circle] and we are all supporters and friends of one another.”³⁹ Sacred Family does not speak of its parishioners as singled out for divine blessing, nor does it connect mental illness to discourses of evil and sin. Rather, congregants, interns, and volunteers explicitly and implicitly challenge other churches and communities to consider how they might become more welcoming to persons with mental illness and participate in the creation of communities of mutual support.

At the same time, like any community of difference that embodies a shape of communal interaction rarely found in the wider church or society, Sacred Family struggles to become a group that is not easily divided: into “us and them”; into people who have mental illness and people who do not;

into people who have money and people who do not; into residents of group homes (a greater percentage of whom are black) and leaders, church visitors and volunteers, and donors (most of whom are white). Church structures, liturgical practices, and patterns of administration regularly perform and perpetuate such divisions, for Sunday congregants who work during the week rarely attend the Circle activities or experience the relationships created there. Few people from group homes participate in the primary decision-making positions and committees of the church.⁴⁰ At the same time, these power structures affect the shape, the rhythms, and the meanings of community life together as well as performing what is considered the primary work of the church. A smaller group of persons who do not live in group homes is often asked to bear numerous responsibilities for the everyday running of buildings, meetings, congregational care, and fundraising efforts. Many of the home-owning, wage-earning congregants must find money to provide for the inclusion of persons from group homes and for sustaining community programs and meals.⁴¹ Such asymmetries in care and responsibility for Sacred Family provide potential places of fragility and explicit divisions within the community. They raise questions about who and what is central to the work of the people that Christian liturgy assumes.

Eiesland argues that the church's ongoing conversion to a more truthful understanding of God involves "two-way access,"⁴² so that persons who historically have been marginalized find themselves at the "speaking center" of their own lives in a community of grace and struggle and the community itself comes to understand God differently in light of the experiences of people with disabilities. She argues that it is not enough to make a physical space within a church building for persons with disabilities, but that the actual "body practices" of the church must be transformed.⁴³

As a participant-observer at Sacred Family, I look for evidence of two-way access and I study forms that facilitate such bridges across difference. How do the community's body practices incorporate and make space for the differences of congregants? What kinds of relationships shape the possibility of shifting not only the speaking center but also the moving, dancing, sitting, walking, and reading centers of the liturgy? What forms of interaction resist the asymmetries of power that so easily divide faith communities, where hierarchies threaten and sometimes obscure the work and witness of Love? Conversely, what are the obstacles that prevent such a community from being held together and acting together as a communal body able to bear witness to divine love?

These questions are not only about justice for persons excluded from the church; they are also about the possibility that Christian communities

will cut themselves off from experience of the infinite differences that illumine divine love and justice. When congregations fail to recognize persons with disabilities, they also fail to name God adequately. People with disabilities surface new truths about what it means to be in relationship with God and others, uncovering hidden histories of the Christian tradition.⁴⁴ Such embodied truths participate in an “insurrection of subjugated knowledges” that Eiesland describes as “the corporate enactment of the resurrection of God.”⁴⁵ In other words, Christian churches need the wisdom and struggle of disabled lives to help them interpret anew their holy texts and body practices, their traditions of gathering, their symbols and sacraments, in order to grasp the latent truths suppressed through segregation and stigma. Thus, the title of this book is offered not so much as a particular name for Sacred Family Church as it is for the broader Christian church, an evocation of how the symbol of church would be transformed if the myriad and manifold lived experiences of disabled people were invited to transform the practices and theologies of the people of God.

The One and the Many in Christian Liturgy

To attend to the wisdom of disability within Christian community is to question what disability theorist Tobin Siebers calls “the ideology of ability”⁴⁶ or what theologian Thomas Reynolds describes as “the cult of normalcy.”⁴⁷ It is to query assumptions about abled human capacities as prescriptive for gathering as church. It is to mine the implicit prerequisites for experiencing and manifesting love and knowledge of God and neighbor through prayer, praise, contemplation, and reflection. It is to ask about the subtle forms through which we isolate and elevate individual persons or devalue and obscure their differences through assuming their similarity with others in community.

Descriptions of Christian worship often assume an ideal worshipper, who is also an able-bodied, able-minded congregant capable of demonstrating that he is being shaped by God through the sacraments and Christian practices in a particular way.⁴⁸ If, as a liturgical theologian, I focus only on ideal individual capacities to perform and grasp Christian practices of prayer, interpretation of Scripture, and participation in communion, then I imply that certain people with disabilities lack the ability to be in relationship with God. Graver still, I imply that they lack the preferred abilities to participate in Christian worship in a way that reflects the depth of liturgy’s symbolic meaning. For example, when a congregant from Sacred Family goes forward to take communion, grabs the wafer from the priest,

dunks it in the wine, refuses to say “Amen,” and rather than consuming it, brings it back to stick it in his pocket or in the prayer book, he becomes an unlikely exemplar of Christian community. While loving exceptions might be made for such a congregant who is unable to show the reverence or intentionality expected of him, such a person would not be conferred the implied status of ideal Christian practitioner. At the same time, other congregants might experience the presence of this congregant as central to their worship at Sacred Family. His presence might serve as an icon of the cherished differences that are essential to the worship of God at Sacred Family, even if he is not an ideal practitioner.

Focusing on an idealized, synchronized communal body often obscures the diversity of individuals, the forms by which the many congregants access a common liturgy, and the varied tones and textures throughout a gathered assembly. To describe a parish as an assembly capable of doing and being one thing is to obscure the full range of responses and experiences occurring throughout the liturgy and liturgies of the community. For example, when I note that the congregation at Sacred Family offers prayers of intercession together by responding in unison, “Hear our prayer,” such language fails to conjure the group in the back right whose members appear to be sleeping. It also fails the two individuals in the front right who eagerly desire to insert the names of their beloved family and friends into the formal prayers we are reciting. Worship at Sacred Family is different depending on where and with whom I sit and stand. Such differences matter not only to the prayers that are offered but also to a theological understanding of a beautiful liturgy as pleasing to God. Those with whom I worship contribute to a theological aesthetic of a communal body even if they seem to be utterly disengaged or disruptive to others.

Theologian Min-Ah Cho writes of the urgency of attending to the divergent responses of those who are present:

The weakness of the believers at the margin, their “flaws” and “crooks” are precisely the nudge that their power lodges, as they reveal the illusion of the homogenous institution. Even though these individuals seem passive and guided by established norms, each of them is an agent that brings divergent plurality to the institution and alters its conventional determinations. Without the individual bodies, the body of Christ remains dormant and fails to incarnate.⁴⁹

Cho emphasizes what may be lost when we elevate the communal response over the individualistic one. The many may obscure the one; but the one is always affected by the ones around her. Her worship is informed by the

bodies that open or obstruct her way into the church, the individuals who border and nudge her thanksgiving or petition or lament. Thus, the quest for a liturgical theology that captures the “divergent plurality”⁵⁰ of Sacred Family includes a frame that holds the individual difference and communal action in dialogue, interanimation, and tension.

Theological Aesthetics through Embodiment, Art, and Beauty

Theological aesthetics affords a nuanced yet dynamic way to attend to dimensions of difference and interdependence present within a communal body through individual bodies. Attending to bodies, to sensory experiences, and to the performance arts evoked by clusters of individuals within the church helps me to recognize the possibilities of difference. At the same time, it refuses to elevate individual capacities as the ideal for those who come in through the open door of the church.

Likewise, when I contemplate communal interactions at Sacred Family, in all their ambiguity, the word *beauty* comes to mind; the way that beauty, in all its culturally constructed and often very conventional forms, calls forth attention and invites some shared word or comment of appreciation or curiosity. I consider this word *beauty* not only in relationship to the ostensible pleasures of an ecclesial gathering but also to all of the sensory experiences that evoke disgust or confusion in this community: body odors and disheveled clothing; the way some people eat their food; some people standing very close to others and staring; someone’s condescending words to another; and someone else’s expressionless face. Are these beautiful too, or ugly, or neither? What makes someone or something beautiful, and for whom? Why do some people or parts of a liturgy seem beautiful to me and others do not?

According to theologian Edward Farley, Christian theological language has often neglected beauty as a lens through which to consider a relationship with the divine as well as to trace the process of redemption. Fearful of idolatry and concerned that beauty is a superficial distraction from the ethical dimensions of faith, Christians have paid insufficient attention to beauty as a way to describe the Christian life.⁵¹ Reflecting on the absence of an aesthetic dimension in his own theological writing, Farley observes, “It was as if the most concrete way in which human beings experience their world—namely, their emotional participation in surprising, interesting and attractive events—had no place in the world of faith.”⁵² What might it mean, he asks, to take seriously this dimension of faith and beauty.

Farley distinguishes the “aesthetic” as an immediate relation to beauty mediated through embodied experience from “aesthetics” as a theological consideration of the arts.⁵³ Thus, he articulates two approaches to the relationship between Christian faith and human embodiment: theological aesthetics attends to the relationship between religion and the arts, and a theological aesthetic reflects on beauty’s role in the life of faith. Both require discernment of embodied practice and response. Both involve attention to the sensory experiences of faith, to the way it feels to be faithful.

Farley argues that discerning a theological aesthetic begins with the beauty in “redemptive transformation,” which he describes as a life moving from unfreedom to new freedom through transcending oneself toward another in need. Made in the image of God, humans are freed by God for a transcending turn in which freedom and compassion are non-competitive. Beauty is found in the faith of one who is called to respond to another: a theological aesthetic tracks the shape of this faith, its desires and hopes for “ethical self-transcendence” in a relationship with another through divine grace. It looks for the beauty inherent in such a relationship and tracks the sensations that a life of such hopeful turning to another arouses in them.⁵⁴

For Farley, beauty, as a theological term, marks the lived experience of one’s outward turn to another, a turn both passionate for another and restrained by the needs of the other. As we turn to the ones who call to us, through their need for us to turn, we become beautiful, and the turning arouses our interest and desire in the beauty of another. A theological aesthetic thus implies an inherent sweetness, an eroticism to asceticism: a faith in the pleasures of the disciplines of loving God and another. Beauty in this sense “means the inevitable grace of a living body as it movingly negotiates the world of space, place, time and gravity.”⁵⁵

In an alternate analysis of the aesthetics of Christian doctrine, theologian Serene Jones also articulates two approaches to theology: one analyzing the category of beauty (a theological aesthetic, using Farley’s definition) and another offering a more detailed analysis of “what particular features of something—an idea, an object, a person—make it appealing (or not) to us” (a theological aesthetics). This second level of analysis should focus on “the qualities of a given topic or object—its form, shape, texture, proportions, feel, sound, color, and so forth.” Giving an example of the aesthetics of a Christian understanding of creation, Jones asks: “What does creation look like when we see it in our mind’s eye: what does it taste like, what colors appear when we hear the term; what memories do we associate with it; what kind of music does it play?”⁵⁶ This kind of theological analysis

connects with the affective connotations of Christian discourses. To explore the meaning of a Christian doctrine, we begin by asking: Does it make one fearful or indifferent, or does it elicit passion or desire?⁵⁷ Jones, like Farley, suggests a different approach to evaluating faithfulness to Christian belief, one that traces the subtle patterns of embodied relationships within and among human persons.

I begin by using theological aesthetics as an analytic tool, with attention to both sensory descriptions of bodies in space and time and to the artistries of relationships that constitute the parish of Sacred Family. I remain as close as possible to the affective responses and embodied interactions that constitute the space, time, form, and names of Sacred Family—the qualities of the given congregation and the associations to which they give rise. I hope to turn my readers from fear or indifference to desire for the kind of community that Sacred Family hopes for and imagines. In doing so, I also propose an understanding of art forms, broadly conceived, as a helpful frame for describing the unities and coherence of Sacred Family's practices with attention to the nonconformity of human differences. I illustrate how an expansive weeklong liturgy is created with and through configurations of individuals in ongoing, flexible, imaginative, and collaborative forms that exist alongside assumed rituals of Christian worship (offering spoken and sung prayers, listening to God through scripture and a sermon, reciting the creed, participating in communion, silence).

At the same time, I also use a theological aesthetic as I evaluate these forms and the relationships they help to create through the lens of beauty as a theological and ethical category. I want to argue for a theological criterion of beauty as a means of assessing the communal life of Sacred Family: its hopes and fragilities, its strange humor and its suffering, its cohesion and incoherence, its consent to difference and its powerful hierarchies of ability, wealth, and race. Beauty, as a theological trace of consent to a shared liturgy, matters to an unconventional, disabled church community struggling to incorporate human difference into the heart of its gathering.

In choosing aesthetic/s as an analytic framework, I join a company of disability scholars and theologians concerned with how senses of the good and beautiful exclude many bodies from the desires of others. In the contrasts they establish, some definitions of goodness and beauty thwart desire and, instead, conjure up disgust, revulsion, or fear in the wake of strange difference. At the same time, disability scholars and theologians emphasize the potential of the arts as catalysts for altered experiences of difference and for the transformation of human perception to new understandings of what it means to be beautiful. They maintain the hope that “rare beauty”

might be allowed to do the works of justice in the world.⁵⁸ Aesthetic concerns can be said to serve justice insofar as they probe the heart of stigma. Philosopher and theologian Sharon Betcher asks: “What ‘rites of passage’ make sharing of this everyday world and our urban neighborhoods possible among bodies with whom we do not always share taste, smell, or cultural resonance?”⁵⁹ She goes on, “To find a place of equanimity, of deep love and insight about the world, humanity, and our urban situation will require the navigation of disgust, fear, and pain otherwise than by encultured avoidance.”⁶⁰ Betcher describes the vocation of Christians who seek to transform the aesthetics of public life through intentionally navigating and occupying the streets of a city.⁶¹ In turn, I pursue the aesthetic encounters offered by a church’s liturgy: through the places it creates and sustains and through the persons who navigate and occupy it.

A turn to theological aesthetic/s also marks the work of scholars who consider the subtle ways that oppression moves through the guise of the well-intentioned and charitable congregation. For these theologians, an emphasis on aesthetics invites witness and reflection on power, stigma, and violence without proclaiming solutions that further obscure the structures through which certain bodies, minds, and lives are idolized over others.⁶²

I find a particularly helpful example in scholar of religion and humanist Anthony Pinn’s reflection on the significance of arts for theologies that take human bodies seriously. In *Embodiment and the New Shape of Black Theological Thought*, Pinn argues that black theologies, in their quests for liberation from unjust systems, often exit certain normative hierarchies only to reinscribe harmful constraints through other exclusive definitions of a good human life. Thus, he argues that when black religious communities seek freedom from the pervasively racist ideologies and institutions of North American cultures, they often force worshippers to identify themselves through other rigid and reductive categories that fail to account for the complexity of human beings: certain definitions of black and white, cults of domesticity and notions of masculinity, descriptions of good and evil, and even distinctions between human and non-human. Pinn argues that the task of theology is not to fix and confine bodies but to move with them, finding new ways to keep embodied lives visible in relation to the social and religious definitions that identify them. Theologians must engage in this task without pretending to escape the discourses within which we all live and move.⁶³

Pinn broadens the discourses in which theology moves by turning toward the public arts. He analyzes resources for black theology in photography

and hip-hop, in the blues, and in abstract expressionism. He regards these art forms as an interrogative rather than prescriptive mode of struggle. Interrogative art both keeps individual particularity perceptible and troubles the rigid categories through which embodied lives seek expression. In doing so, some art communicates a genre of “creative disregard” that respects religious forms and institutional norms while also calling them into question, sometimes playfully, sometimes angrily, sometimes mournfully.⁶⁴ Pinn’s work raises provocative questions for a community like Sacred Family, which not only seeks to exit the practices of charity, segregation, and stigma, but also desires justice for congregants who live without adequate resources and community support.

At the same time, there is a danger that Sacred Family as a liturgical community exits certain harmful relations only to reify other stigmatizing identities. For example, on Sunday mornings, those who can read and participate fully in the explicit liturgy of the community and those who cannot read and participate in such ways are set apart from each other. Every Sunday I watch some members refuse to engage the two to three books we use to worship, and I watch others who at first engage with the texts but then stop somewhere in the middle of the service, apparently giving up or growing disinterested. Still others keep the books open without singing or reading. While Sacred Family is intentional in offering forms of community life in which everyone can take part, there are also occasions on which some people are invited again and again to do what they seemingly cannot or will not. The refusal to comply with expected forms of full and active liturgical participation implies and creates alternate forms of engagement. Still the explicit request to comply persists. Disability scholars Sharon Snyder and David Mitchell critique a rehabilitation approach to persons with disabilities that reinforces a “persistent historical attention to formulations of disability as excessive functional deficit.” They ask, “What is the psychic toll of repetitiously attempting to perform activities beyond one’s ability?”⁶⁵

While Pinn turns to public art forms outside the institutional church to address this question, my intention is to extend a definition of artistic forms and to think them from within the community. How does a church keep mental difference visible, audible, and palpable without dismissing it as distraction or deviation from the common good? What I find most surprising and arresting at Sacred Family are the artistries of interpersonal connections that make community life not only possible but also joyful. There is a performance art in the creativity of interactions that enable a frame for difference to emerge from Sacred Family’s liturgical choreography. I choose

the phrase art form rather than the word practice to highlight the differences that arise within the congregation rather than to evoke regular actions or responses of worshippers. Such art forms seem to complicate categories of exclusion and practices of condescension, and these in turn obscure the lively and perplexing differences of people in the church. These forms also illumine how congregants creatively regard and disregard expectations or anticipations, turning them into something new. For example, where worship leaders often assume what liturgical theologian Siobhan Garrigan calls “the myth of the single acting agent”⁶⁶ (e.g., “Will everyone please turn to page 121 in the hymnbook?”), there are ways in which people at Sacred Family question these ideals of uniform liturgical ability.

One man, who is almost blind, walks and plays bingo with the help of another woman who leads him around. I observe the two of them walking one in front of the other, her large frame followed by his slender one with his hand resting on her shoulder. They have learned the rhythms and postures by which walking in tandem is possible, and they serve as a perceptible reminder that when everyone is invited to do something, some people might only respond as others move with them. These sorts of interdependent art forms do not dispel the normative habits through which Sacred Family orchestrates community life. However, they do keep visible, audible, and palpable the differences within community while at the same time transforming the possibilities for participation and access. Watching two people walk together or play bingo through the other’s presence suggests an alternate response to a liturgy that assumes capacities either on the level of individuals or on the level of the whole community. To mark this as an art form, rather than as a reciprocal gift between two people or the relationship between a dependent person and an independent one, is to emphasize what is created through relationships in the community. Identifying artistries of social interaction draws attention to who is beside whom and what hope or harm might occur among them through their presence. Such new creations become possible within configurations of relationships that would be difficult to prescribe ahead of time, but that emerge over time from this community’s life together. Such art forms have theological significance for a community that often claims God’s presence and transforming love through sermon, song, and in conversation.

Dichotomies such as disability/ability, mentally ill/normal, leader/recipient of help, high-functioning/low-functioning, wealthy/poor, arrive by van/arrive by car powerfully affect Sacred Family’s desire to be an inclusive community. These divisions obscure the complexities of a diverse group of people who, living out their faith, struggle with love and loss together.

Like other churches, Sacred Family participates in what theologian Mary McClintock Fulkerson calls obliviousness, “a form of not-seeing that is not primarily intentional but reflexive . . . [that] occurs on an experiential continuum ranging from benign to a subconscious or repressed protection of power.”⁶⁷ For Fulkerson, the theological response to wounds of obliviousness involves accessing the embodied practices through which transformation occurs: “What is needed to counter the diminishment and harm associated with obliviousness is a *place to appear*, a place to be seen, to be recognized and to recognize the other.” She sees this as “essential to a community of faith as an honoring of the shared image of God.”⁶⁸ If embodied responses to ourselves and other people obscure their particularity and beauty from us, how is it that the church might become a “place to appear” to one another?⁶⁹ In light of my experiences at Sacred Family, I argue that such artistries of interpersonal relationships—performed through touch, through jokes, through gestures, through music, through stories, through paintings and tiny plants, through sitting together, through silence, through the struggle to name one’s relationship to another—are key to answering this question. People appear to one another at Sacred Family insofar as these artistries bridge the socially and theologically inscribed categories through which disability and human differences are obscured. People create and manifest access to one another in their ways of inhabiting sacred space and time and in their patterns of naming their losses and desires together.

Furthermore, such artistries of social interaction are intimately involved with a theological understanding of beauty. In claiming beauty as theological, I intend the qualities of joy and pleasure that mark the possibility of non-violent transformation. Certain forms of oppression challenge Sacred Family’s ability to name its life together as one of love through God. Certain mysteries of human pain and difference may also make it difficult to envision a communal transformation in which oppressive practices no longer operate. Such possibilities render necessary these artistries of difference as signs of love and hope for a community with psychiatric disability at its heart. To hold together a community like Sacred Family as a common relation is costly and requires hard work from many of its members, but where the Spirit of God breathes and animates, beauty ensures that such a journey is possible and even pleasurable. Thus, discerning beauty’s presences and/or its absence is an important and even urgent theological task, one that Pinn describes as moving with bodies, noting their fluidity, and noting places where such movement is constrained or obscured.

*A Liturgy in Five Movements: Gathering, Weaving,
Disrupting, Naming, and Sending*

To describe Sacred Family as a community of difference, I follow a liturgy through five movements. Describing worship through these five movements draws attention to the dynamic margins as well as the shifting centers of Christian worship. While each chapter explicitly focuses on one movement, a single chapter also highlights multiple movements. For example, the chapter on weaving also includes movements of disrupting and the chapter on sending turns a reader back to choreographies of gathering and arts of weaving. Thus, each chapter is, itself, woven of threads that run throughout the book, much as are the movements of the liturgy at Sacred Family.

Chapter 1 describes how those who gather understand their access to this church and community. Mapping different centers of interaction at Sacred Family, I explore their relationships to one another and make the case for a decentered liturgy that manifests activities and relationships outside the boundaries of the sanctuary and the prayer book. Decentering a liturgy emphasizes the central works of persons who might otherwise be deemed peripheral to its movements. It also requires a definition of a weeklong liturgy that does not confine common prayer to ritual actions within a church building but understands liturgy as communal work of/for the people of God. Such work involves the multiple actions and relationships that a community might offer to God both within and outside the walls of a church building. Thus, Sacred Family offers clues to the significance of a consensual and non-coercive unfolding of sacred space.

In Chapter 2, I examine the arts of interdependence through which congregants weave one another into community, with a particular focus on three art forms: arts of gesture and touch, arts of silence and imagination, and arts of jokes and laughter. I consider the role of these unconventional arts both in inviting people with very different abilities to be present with and through one another and in keeping the doors of the church open. Encountering barriers to a common liturgy, congregants improvise access to one another through their artistries of social interaction. In doing so, they reveal such art forms to be essential to communal belonging premised on consent rather than on coercion.

In Chapter 3, by focusing on disruption as a common experience of liturgical time at Sacred Family I consider how this community makes time for these artistries of interpersonal connection. Arguing that disruption is a fluid category across difference, I examine how different senses of time, work, and pleasure disrupt anticipations about what it means to come to

church. People whose lives are often disrupted by poverty and by loss of families, jobs, and homes navigate communal time differently than those who do not. I argue that consenting to share time together requires an experience of time as pleasure rather than as measured by obligation. Thus, pleasure disrupts an approach to “the work of the church” as efficiently accomplishing a set of objectives or worship practices for God.

In Chapter 4, I return to the arts of community by exploring a fourth art form, the arts of naming. I consider how this church as a “communion of struggle”⁷⁰ uses multiple ways of naming what it means to be human, Christian, and mentally ill, and how the church searches for adequate names to account for the differences and desires of community members. Finding a Christian theological method for understanding the church’s struggle to name adequately the losses and recoveries congregants experience becomes important. The ongoing struggle for good names for consensual relationships at Sacred Family reveals the desire for such relationships. This struggle for good human names is, moreover, essential to a communal pursuit of the love and knowledge of God.

In Chapter 5, I explore the limitations the church faces in sending congregants to do the work it gives them to do—to love and to serve—within a segregated and increasingly gentrifying city. Given that, outside of the church, some of the congregants have lives deemed of little public worth, these limitations raise questions about the church’s mission. Examining Sacred Family’s past and imagining its future, I consider how structures of ableism, as they intersect with racism and poverty, challenge this church’s abilities to imagine a common good for all of its members. Coercive relationships outside the time and space of Sacred Family trouble the consent to a shared liturgy and point to the importance of other shared spaces and times across a segregated city.

In the Conclusion, I return to beauty as a theological lens through which to understand the liturgy of Sacred Family and the mysteries of divine work in its midst. Indeed, Sacred Family’s creative patterns of consent to shared time, space, and form, as well as the struggles to belong to one another that Sacred Family embodies, manifest a theology of beauty. Such beauty is revealed through the creation of space, time, and social forms for both human difference and manifold belonging.

Being Human, Becoming the Disabled Church

Ginny tells me a story about how she first became a part of Sacred Family. She came because she and her friends could no longer carry her disabled

friend Belinda, for whom she provides care, up the seventeen steps and through the doors of another church they had lovingly attended for over ten years. Ginny came tearfully at first, grieving the loss of access to a church they could no longer attend together. She came alone the first time and then, the second time, accompanied by Belinda in her wheelchair. She became certain in just one Sunday that “the Spirit of God was there” and that they could find a home at Sacred Family. What happened that day is a story she repeats to me on several occasions:

A guy who introduced himself as Orange Juice brought up bulletins and gave me a bulletin and handed one, *tried* to hand one to Belinda, and I said something like “Oh, thank you, she can’t read.” And he just looked at me with these beautiful eyes and said “Lady, you don’t got to know how to read to need a bulletin.” And I thought “Wow!” (She laughs.) He wasn’t scolding me but he had *told* me. (Again laughter.) And then I notice that people are singing out of the wrong books, and the books are upside down, and it was quite all right. Then I began to hear the rhythm of Roy’s voice always praying and somebody else who is no longer here always praying, and I began to see the rhythms.

Seven years later, she does not know what happened to Orange Juice, who no longer comes to the church. She still recalls him as a sign of the open door at Sacred Family, a gentle challenge and reminder about what she and her loved ones needed in order to worship God.

Thus, a third question: *Whom* do you need in order to have a church that assumes difference at its heart? Liturgical theologian Don Saliers declares that in worshipping assemblies “to meet God is to meet our own human lives in unexpected form, and to ‘pray without ceasing’ is the stretch of a whole lifetime—in season and out of season, in joy and pain, in fear and hope, in great gratitude and sorrow, in cries for justice and healing and in sheer ecstatic delight in the beauty of God.”⁷¹ The arts of becoming church, then, have to do with the possibility of meeting human lives in an unexpected form, so as to understand the ways these lives stretch our understandings of what it means to be holy, human, community, disabled, and mad. It is my hope that as you read this text you will meet your own human life in unexpected form in the strange rhythms of liturgy, lament, love, and struggle that is Sacred Family.

NOTES

PREFACE

1. João Biehl, "The Right to a Nonprojected Future," *Practical Matters*, no. 6 (2013), <http://practicalmattersjournal.org/2013/03/01/nonprojected-future> (accessed May/06/2019).

INTRODUCTION: DISABLING LITURGY, DESIRING HUMAN DIFFERENCE

1. The name of the church and all names of persons have been changed to protect confidentiality.

2. Gordon W. Lathrop, *Holy People: A Liturgical Ecclesiology* (Minneapolis: Fortress Press, 2006), 1.

3. *Ibid.*, 8.

4. *Ibid.*, 13.

5. *Ibid.*, 93–94.

6. Nancy L. Eiesland, *The Disabled God: Toward a Liberatory Theology of Disability* (Nashville: Abingdon Press, 1994), 94–95.

7. Identifying Sacred Family as a disabled church, I extend Eiesland's argument about naming Jesus Christ as the disabled God. I call for the use of the disabled church as a term to identify and interpret the meanings and significance of disability in and for the broader Christian church. As Eiesland argues for a contextualized Christology, so I argue for a contextualized ecclesiology that responds to "the particular situation in which people with disabilities and others who care find themselves as they try to live out their faith and to fulfill their calling to live ordinary lives of worth and dignity."

Eiesland, *The Disabled God*, 98–100.

8. João Biehl, "The Right to a Nonprojected Future," *Practical Matters*, no. 6 (2013), <http://practicalmattersjournal.org/2013/03/01/nonprojected-future> (accessed May/06/2019).

9. Edward Farley, *Faith and Beauty: A Theological Aesthetic* (Aldershot, UK: Ashgate, 2001), 117. Farley summarizes these three different approaches to theological aesthetic/s. He focuses on the third approach.

10. Throughout this book, I also engage theologians who wrestle with what Mary McClintock Fulkerson calls "a worldly church": a church that is

participant in forces of oppression and injustice, as well as a people that embody the love and justice of God. Mary McClintock Fulkerson, *Places of Redemption: Theology for a Worldly Church* (New York: Oxford University Press, 2010), 6.

11. The church first met in a saloon and then in private homes for some time when the saloon burned down. It moved into its first church building in 1899. Later it would be forced to move again, to its current location, due to the City of Atlanta's plans to build an expressway through the neighborhood where it was located. Sources are on file with the author but not cited in order to maintain confidentiality.

12. I encountered different narratives about how demographic changes in Atlanta affected this particular neighborhood, but it seems clear that practices of racial segregation and integration were important factors in the parish's current identity.

13. For an account of the debates surrounding the City of Atlanta's treatment of homeless people and people on the streets in preparation for the 1996 Olympics, see Ronald Smothers, "As Olympics Approach, Homeless Are Not Feeling at Home in Atlanta," *The New York Times*, July 1, 1996, sec. U.S., <http://www.nytimes.com/1996/07/01/us/as-olympics-approach-homeless-are-not-feeling-at-home-in-atlanta.html> (accessed by author May/06/2019).

14. Staff Writer, "Atlanta Preview '96: The Olympic Games Begin in 2 Weeks," *Fort Oglethorpe Press*, July 3, 1996.

15. For a discussion of patterns, practices, and policies of de/institutionalization in North America, see Chris Chapman, Allison C. Carey, and Liat Ben-Moshe, "Reconsidering Confinement: Interlocking Locations and Logics of Incarceration," in *Disability Incarcerated: Imprisonment and Disability in the United States and Canada*, ed. Liat Ben-Moshe, Chris Chapman, and Allison C. Carey (New York: Palgrave Macmillan, 2014), 10–15.

16. During the period of my research, the church worked to establish the Circle as its own 501(c)(3) organization in order to secure funding and support that is not available for churches.

17. While a significant number of group homes were located near the church when its ministry to persons with disabilities first began, gentrification has increased property values, and many of these homes are now located in other parts of the city. Many congregants now travel into the neighborhood rather than being a part of it. The number of group homes fluctuated during my time at Sacred Family.

18. My research was approved by Emory University's Institutional Review Board on October 16, 2013. The Institutional Review Board aided me in establishing research and informed consent protocols that accounted for the mental differences that are present at Sacred Family.

19. Taking into account the differences of people with mental illness meant that I was always careful to make such options clear and to take note of any signs of discomfort during my interactions at Sacred Family, so as to do no harm through my research.

20. Eiesland, *The Disabled God*, 22.

21. Ellipses in material from field notes and recordings indicate omission, as well as incomplete thoughts expressed by the speaker.

22. Karen McCarthy Brown, *Mama Lola: A Vodou Priestess in Brooklyn* (Berkeley: University of California Press, 2001), 12.

23. Jean Vanier, “The Wisdom of Tenderness,” interview with Krista Tippett, *On Being*, podcast audio, December 20, 2007, <https://onbeing.org/programs/jean-vanier-the-wisdom-of-tenderness/>.

24. For a discussion of the individual/medical model of disability, see Alison Kafer, *Feminist, Queer, Crip* (Bloomington: Indiana University Press, 2013), 5–7.

25. *Ibid.*, 4–10.

26. For a brief introduction to the term “disability” from a disability studies perspective, see Rachel Adams, Benjamin Reiss, and David Serlin, “Disability,” in *Keywords for Disability Studies*, ed. Rachel Adams, Benjamin Reiss, and David Serlin (New York: New York University Press, 2015), 5–11.

27. National Alliance on Mental Illness, *Mental Health by the Numbers*, <https://www.nami.org/Learn-More/Mental-Health-By-the-Numbers>, accessed May 6, 2019. According to NAMI’s figures, one in twenty-five adults will be diagnosed with a serious mental illness, such as schizophrenia, bipolar disorder, or major depression.

28. Recent North American discourses about gun violence and public shootings illustrate this desire to distance and distinguish between normal and abnormal persons. As discussions focus on how to keep guns away from the mentally ill, persons with mental illness quickly become associated with a potential violence from which those who do not live with mental illness are automatically exempt. When I ask my students what they think of when they hear the words “mental illness,” they respond with notions of instability and violence.

29. For an insightful reflection on the liabilities and benefits of different kinds of language used for mental disability, see Margaret Price, “Defining Mental Disability,” in *The Disability Studies Reader*, ed. Lennard J. Davis, 4th edition (New York: Routledge, 2013), 298–307.

30. Karen Nakamura, *A Disability of the Soul: An Ethnography of Schizophrenia and Mental Illness in Contemporary Japan* (Ithaca, NY: Cornell University Press, 2013), 25.

31. For helpful introductions to mental illness from a disability studies perspective, see Nakamura, *A Disability of the Soul*, 35–69; Margaret Price,

Mad at School: Rhetorics of Mental Disability and Academic Life (Ann Arbor: University of Michigan Press, 2011), 1–24; Margaret Price, “The Bodymind Problem and the Possibilities of Pain,” *Hypatia* 30, no. 1 (2015): 268–284. For a theological perspective on mental illness, particularly schizophrenia, from a practical theologian and former mental health professional, see John Swinton, *Resurrecting the Person: Friendship and the Care of People with Mental Health Problems* (Nashville: Abingdon Press, 2000).

32. Eiesland, *The Disabled God*, 67–70.

33. *Ibid.*, 73–74.

34. *Ibid.*, 72.

35. *Ibid.*, 71–72.

36. *Ibid.*, 70.

37. *Ibid.*, 70–71, 75.

38. The author and date of the pamphlet are unknown but it was written some years prior to my introduction to Sacred Family. The terminology of “lifestyle preferences” does not reflect the congregation’s current language regarding gender identity and sexual orientation.

39. The newsletter, which provides regular updates on the Circle at Sacred Family Church, was written by a staff member and circulated by email to the parish listserv, April 2014.

40. Potential divisions in the church are not primarily identified as occurring between those with mental illness and those without mental illness, but rather between persons from group homes and those who are able to live in their own homes and maintain full-time work. Some of the staff and committee members identify themselves as persons with mental illness but also identify their choice to “pass” as normal or to “come out” as a person with mental illness. Persons from group homes, who embody the intersections of disability and poverty, are often immediately identifiable as those unable to perform the activities, work, or social interactions of an abled person.

41. Sacred Family receives significant support from the denomination, which pays the salary of its priest in addition to other forms of monetary and institutional support. At the same time, Sacred Family must raise additional funds to support its Circle staff and programs. During my time at Sacred Family, raising such funds was a significant source of concern and stress for leadership at Sacred Family, most of whom were not people from group homes.

42. Eiesland, *The Disabled God*, 20–21.

43. *Ibid.*, 112.

44. *Ibid.*, 98.

45. *Ibid.*, 105.

46. Tobin Siebers, “Disability and the Theory of Complex Embodiment—For Identity Politics in a New Register,” in *The Disability Studies Reader*, ed. Lennard J. Davis, 4th edition (New York: Routledge, 2013), 279.

Siebers writes, “The ideology of ability is at its simplest the preference for able-bodiedness. At its most radical, it defines the baseline by which humanness is determined, setting the measure of body and mind that gives or denies human status to individual persons.”

47. Thomas E. Reynolds, *Vulnerable Communion: A Theology of Disability and Hospitality* (Grand Rapids, MI: Brazos Press, 2008), 59–63.

48. Molly Haslam argues that theological anthropologies often describe what it means to be human in a way that occludes the intellectually disabled. I would argue that liturgical anthropologies also often assume capacities that do not attend to mental disabilities in their descriptions of and prescriptions for individual and communal responses to God and one another. Molly C. Haslam, *A Constructive Theology of Intellectual Disability: Human Being as Mutuality and Response* (New York: Fordham University Press, 2011), 1–18.

49. Min-Ah Cho, “The Body, To Be Eaten, To Be Written: A Theological Reflection on the Act of Writing in Theresa Hak Kyung Cha’s *Dictée*,” in *Women, Writing, Theology: Transforming a Tradition of Exclusion*, ed. Emily A. Holmes and Wendy Farley (Waco, TX: Baylor University Press, 2011), 205.

50. Ibid.

51. Farley, *Faith and Beauty*, 6–12.

52. Ibid., vii.

53. Ibid., 117.

54. Ibid., 83–99.

55. Ibid., 98.

56. Serene Jones, “Glorious Creation, Beautiful Law,” in *Feminist and Womanist Essays in Reformed Dogmatics* (Louisville, KY: Westminster John Knox Press, 2006), 22–23.

57. Ibid., 23–24.

58. I borrow this phrase from Rosemarie Garland-Thomson’s description of disability activists who use their bodies to help us understand beauty in a new way. See Rosemarie Garland-Thomson, *Staring: How We Look* (New York: Oxford University Press, 2009), 188–193.

59. Sharon V. Betcher, *Spirit and the Obligation of Social Flesh: A Secular Theology for the Global City* (New York: Fordham University Press, 2013), 16.

60. Ibid., 17.

61. Ibid., 22–23.

62. See, for example, a theological interpretation of the arts and of beauty in James H. Cone, *The Spirituals and the Blues: An Interpretation*, 2nd rev. ed. (Maryknoll, NY: Orbis Books, 1992); James H. Cone, *The Cross and the Lynching Tree*, reprint edition (Maryknoll, NY: Orbis Books, 2013), 93–119. See also M. Shawn Copeland’s focus on human beauty in theological anthropology in M. Shawn Copeland, *Enfleshing Freedom: Body, Race, and Being* (Minneapolis, MN: Fortress Press, 2009), 7–22.

63. Anthony B. Pinn, *Embodiment and the New Shape of Black Theological Thought* (New York: New York University Press, 2010), 38–52.
64. *Ibid.*, 24–33, 123–41.
65. Sharon L. Snyder and David T. Mitchell, *Cultural Locations of Disability* (Chicago: University of Chicago Press, 2006), 8.
66. Siobhan Garrigan, “The Spirituality of Presiding,” *Liturgy* 22, no. 2 (2007): 5.
67. Fulkerson, *Places of Redemption*, 19.
68. *Ibid.*, 21.
69. *Ibid.*, 17–21.
70. Eiesland, *The Disabled God*, 108.
71. Don E. Saliers, *Worship as Theology: Foretaste of Glory Divine* (Nashville: Abingdon Press, 1994), 22.

I. GATHERING: UNFOLDING A LITURGY OF DIFFERENCE

1. Teresa Berger, *Fragments of Real Presence: Liturgical Traditions in the Hands of Women* (New York: Crossroad, 2005), 6.
2. Gordon W. Lathrop, *Holy People: A Liturgical Ecclesiology* (Minneapolis: Fortress Press, 2006), 21.
3. Williamson notes the history and significance of the term: “The noun form of the word ‘access’—meaning ‘the power, opportunity, permission, or right to come near or into contact with someone or something’—first appears in published texts in English as early as the 1300s. It has been used to characterize the relationship between the disabled body and the physical environment since the middle to late twentieth century.” She then describes the ways a broader set of meanings around inclusion and integration have become attached to this word in the history of disability rights. Bess Williamson, “Access,” in *Keywords for Disability Studies*, ed. Rachel Adams, Benjamin Reiss, and David Serlin (New York: New York University Press, 2015), 14–16.
4. Nancy L. Eiesland, *The Disabled God: Toward a Liberatory Theology of Disability* (Nashville: Abingdon Press, 1994), 23.
5. Aisha was nervous about disclosing these beliefs, so I did not name them here.
6. While Fiona imagines that she could end up in a position like those Sacred Family congregants with mental illness who live in poverty, she does not speak about the intersections of whiteness and wealth that make it much less likely for her to experience the precarity that many people at Sacred Family experience.
7. Teresa Berger, *Gender Differences and the Making of Liturgical History: Lifting a Veil on Liturgy’s Past* (Burlington, VT: Ashgate, 2011), 30.
8. *Ibid.*, 40.
9. *Ibid.*