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WELCOMING ALL: A COMPARISON OF CHURCH
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Welcoming All: A Comparison of Church and Familial Expectations in Disability Ministry
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Abstract

This project compares the expectations of churches providing intentional disability ministries with the expectations of members affected by disability. Questionnaires were developed for churches with disability ministries and for members or families affected by disability. The comparison of these questionnaires provides a glimpse into the expectations held by families and churches that provide disability ministry. According to the results of this survey, families tend to seek a faith community where their entire family is included and supported. They also believe that the church benefits by welcoming individuals with disabilities. Churches, in general, strive to provide a place that is welcoming to all but with little attention given to issues of assimilation, and churches tend to see little or no benefit to the congregation through including families affected by disability other than in ways that trivialize disability as charitable acts to those in need. Although these churches seek to meet the needs of families affected by disability, issues of assimilation to cultural norms and trivialization of disability continue to impact the practice of disability ministry.

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Introduction

In January 1995, my first child, Mia, was born. At the age of four weeks, she slept through the night for the first time. I remember thinking that this would be the first of many important milestones. At the age of six weeks, my beautiful little girl was hospitalized for what her doctor thought was a respiratory infection. After several tests and consultations with pediatric specialists, Mia was diagnosed with a neurological condition called Aicardi Syndrome. Little did I know at that point that the milestones I had dreamed of—a first smile, a first step, a first word—would turn instead into a first feeding tube, a first wheelchair, and a lifelong concern with inclusiveness both inside and outside the church.

At the time of my daughter's diagnosis, my family attended a small church that, like many churches, believed itself to be accessible. I remember the first time I had to wheel my daughter's wheelchair up the ramp at the back of the church, entering through the sacristy, and wondering why it had never occurred to me—or anyone else in the congregation—that maybe it isn't acceptable for someone with disabilities to have to enter the sanctuary through the "back door" so to speak.

Over the years since that first personal encounter with accessibility issues, I have continued to question what is generally accepted as accessible concerning the church. Beyond the issues of physical accessibility, what assumptions do churches make with respect to individuals and families affected by disability? Do attitudinal barriers prevent those with disabilities from participating fully in the life of the church? Are churches that offer intentional disability ministries meeting the spiritual needs of families affected by disability or are they even aware of what those needs are?

These questions led me to this research project. In the next chapter, I will look at the theological basis for disability ministry. Why should the church provide ministry to those affected by disability? Is there a scriptural basis for such ministry?

In chapters two and three, I present the results of my research: information compiled from questionnaires sent out to churches with intentional disability ministries and members who participate in those ministries. My aim was to compare the theological assumptions and goals of intentional disability ministries with the expressed needs and expectations of families involved in those ministries.

The final chapter will revisit my original theological arguments in light of the information compiled from the questionnaires. Are the theological assumptions that I have made regarding disability ministry the same theological assumptions that influence churches and members involved in disability ministry? Are the assumptions the same for those who develop and staff disability ministry programs as they are for those whose families are affected by disability and who participate in such programs, or does having a child with disabilities somehow shape and change your theology in ways that those not affected by disability may not consider or embrace?

Some of these questions are difficult for me to answer although I am involved in the ministry of a local church. The congregation with which I minister does not have an “intentional” disability ministry. That is not to say that we do not have members who are affected by disability; rather, we have not been intentional in reaching out to this population or in trying to determine what it is that those who have been affected by disability are seeking in a Christian community.

I also find these questions difficult to answer because they no longer confront me daily. When my daughter was four, my family made the difficult decision to place her in a

long-term care facility. Because of her level of care and medical involvement, we cannot have her at home for visits, including attending worship services with her family. My interest in disability ministry stems from my experience as a parent of a child with disabilities, but in many ways I feel like an outsider to intentional disability ministry.

When my daughter began school at the age of three, I remember speaking with other parents of children with disabilities about schooling options. Some parents voiced concern and even indignation at our decision not to mainstream Mia in a regular classroom within our public school system. I support the right of all parents to determine what is best concerning the education of their children, and it had never occurred to me that others might think I was somehow cheating my daughter because I was choosing to place her in a school for children with moderate to severe disabilities where she would receive instruction, not in reading and math, but in physical and occupational therapy.

Similar objections were voiced when we decided that, because of the level of care Mia required, she would be placed in a long-term care nursing facility. Responses from loved ones and strangers alike ranged from relief that we would finally be free of the day-to-day care of my daughter to something close to horror that we could even consider shirking our parental duties by committing our daughter to life in an institution. Where understanding and compassion would have been helpful, we instead felt judged.

Given the wide range of disabilities, diverse services for education and care are available to, and required by, individuals and families affected by disability. These two experiences opened my eyes to the sometimes subtle, sometimes obvious, opinions and views that individuals hold with respect to disabilities and how best to address disability in our daily lives. In the course of this research, I came to realize that this holds true with

respect to ministry as well. Very early in my research, I began to hear conflicting opinions about whether “intentional disability ministry” is something a church should even offer.

Initially, I contacted churches that did not offer intentional disability ministry to determine why such ministry was not offered. The answers that I received pointed at times to resentment that I would even ask. I remember one response in particular from a pastor of a church who had heard of my project and offered her assistance. When I explained the nature of my research, she replied that she did not think her church could help after all because they welcome everyone, regardless of ability, and do not see the need to offer special or separate ministries for those affected by disability.

At first this comment made me question the purpose of my project. After all, isn't that what the church should do? Shouldn't everyone be welcome? Upon reflection, I realized that the assumption that all are welcome, without ministries to back up that assumption, can perpetuate some forms of discrimination and assimilation to which many social organizations, including churches, fall prey.

At the same time, I was receiving feedback from churches that had thriving intentional disability ministry programs. The individuals involved in these ministry programs believed that these ministries were an answer to God's call to reach out to all of God's children. If there were individuals who required separate worship services and activities to feel a part of a community of faith, these churches felt called to offer such ministries.

I chose to limit my research to churches that provide intentional disability ministry so I could focus on what these churches consider intentional disability ministry to be and what they seek to provide to the families that participate in these intentional ministries.

Many of the families completing the questionnaires simply wanted their family member to be included. The ways in which their congregations went about meeting that concern varied. Some churches have found the best way to meet the needs of those with disabilities is to offer separate ministries to individuals affected by disability such as separate Sunday school classes or worship services. Other congregations believe strongly that all people should feel comfortable and welcome within the congregation, so they offer services such as sign language interpretation or one-to-one buddies for those affected by disability within existing ministry frameworks.

In the end I came to realize, as I had years ago when it came to my daughter's care, we are all different, and we have different needs. With respect to ministry, although there may be common theological foundations for the kinds of ministry we do, the ways we choose to carry out those ministries are quite different. Those ministries are, and should be, as varied as the many forms of disability by which we have all been touched.

My hope in completing this research project is that churches will better understand the families they minister with who have been affected by disability. These families are impacted in a wide range of ways, and, just as there is no one right way to do ministry, there is no one right way to do disability ministry.

Chapter One
Theological Assumptions

“No real dialogue is possible between somebody and a nobody.”
Henri Nouwen

Definitions

It may be helpful to clarify some of the terminology used in this paper. When discussing disability, it is important to distinguish between the terms physical impairment, disability, and handicap.

Impairment is used to describe a physical abnormality or loss of function. Disability refers to the effect of impairment or the inability to perform socially necessary activities. If an impairment or disability causes social disadvantage, a handicap occurs. According to this understanding, impairment does not automatically cause disability, and disability does not automatically cause handicap (Eiesland, quoting S. Z. Nagi and Hahn, 27).

Those whose social roles or tasks are affected by an abnormality are most frequently referred to as persons with disabilities (Eiesland 27). So, when we speak of persons with disabilities, we are speaking of individuals who have lost physical form or function that then limits the individual's social performance. According to this definition impairment does not necessitate disability, and disability does not necessitate handicap. These are socially determined categories.

As Swinton explains, it is not the impairment that is disabling but the "negative social reactions to such impairments and inflexible social structures which assume a norm that excludes particular impairments which causes a person to become disabled" (278-9). It is building design and not the wheelchair that leads to disability. It is the assumption of sight and hearing and not the blindness or deafness that is disabling.

Reynolds builds on this definition, arguing that the criteria able-bodied persons generally use to measure another's ability are societal assumptions based on how a normal or healthy person functions within society. Reynolds views disability as the intersection of

involuntary bodily impairment, socially acceptable roles, and external obstructions that converge in such a way that expected community participation is impossible (27).

Given such definitions of disability, we might begin to question who the disabled are. As Eiesland states, “The difference among persons with disabilities are often so profound that few areas of commonality exist” (23). We cannot speak of “The Disabled” as if there were a homogenous group of people who happened to have some form of impairment and who all felt, believed, and acted in the same way. That would be like speaking about “The Brunettes” as if hair color determined a person’s belief system.

Eiesland goes on to say that, although these differences can be profound, persons with disabilities are still often thought of as a group that shares common characteristics “not because of [their] shared physical, psychological, or emotional traits, but because ‘temporarily able-bodied’ persons single [them] out for differential treatment” (24).

By using the words “temporarily able-bodied” Eiesland touches on a very important truth. Those of us who believe that it is only others who experience disability, those of us who have not yet been personally affected by disability, are only temporarily in that condition. As Bruce Epperly, my seminary advisor, once said, “Each one of us is only an accident away from being in a wheel chair.”

Although we may try to make distinctions between us and them, the able and the disabled, the whole and the broken, such distinctions are illusions. Still, many of us don’t appreciate just how fragile and fleeting that condition of being able-bodied is until disability affects us personally.

Because our society values those who are able-bodied (for more information on the value of able-bodied individuals and the “cult of normalcy” see Reynolds, p 56-59), and because, as Eiesland argues, those who are able-bodied tend to single out persons with

disabilities for differential treatment, the ways that we traditionally have approached disability have been from what is known as the medical model of disability which is “based on what non-disabled people think is best for persons with disabilities.... Hence, disability represents an inability, abnormality, or disadvantage calling for management and correction in order to restore proper functioning” (Reynolds 25).

Medical Model of Disability

The medical model of disability has the tendency to view disability as a problem in need of correction. One of the most obvious problems with this model is the reduction of persons with disabilities to a function of their disabilities (Reynolds 25).

In this model, disability becomes what a person is: a person’s worth and usefulness is inversely related to the extent of disability. “This is the substance of the oppression faced by persons with disabilities. [This model] relies on a notion of disability that is absolute and totalizing rather than the consequence of an impairment that a person happens to have, which impedes getting along in ways set down by non-disabled persons” (Reynolds 27).

Going back to our definitions of disability, we are reminded that disability is not simply a medical problem for impaired individuals in need of a cure, it is a social problem that comes out of communally held beliefs about personal worth and ability.

Because the medical model emphasizes rehabilitation and cure, it “inadvertently perpetuates processes of disempowerment, exclusion, and isolation, concealing deeper attitudinal, employment-related, education, and architectural obstacles to genuine inclusion” (Reynolds 26). Reynolds instead sees disability as the ongoing interactions between people and the institutions where these interactions take place (26).

The reliance on treatment and cure of disability makes the primary objective of society's interaction with persons with disabilities assimilation into society as normally functioning members of community. In cases of extreme differences that prevent integration into what is generally accepted as normal life, persons with disabilities may be excluded, depersonalized, and rendered almost invisible to society (Reynolds 47).

Even within faith communities, the medical model greatly determines attitudes toward disability, and disability continues to be seen as a deficiency, a cause for pity, or a source of inspiration for others. When "Christians take for granted assumptions about normalcy that stem from their sociocultural environment and that reflect certain interpretations of the scriptures, they inadvertently give theological sanction to principalities and powers that are disabling" (Reynolds 28).

The acceptance of the medical model of disability by faith communities leads to the oppression and alienation of persons with disabilities and prevents these individuals from full participation in communities of faith, possibly as much as physical barriers do:

Negative attitudes toward people with disabilities create less visible but equally daunting barriers. If members of a small congregation see no one with an obvious disability, they may think there is no need to take action—not realizing who may have been left at home by the family in the next pew, or in a nearby group home, wanting to come if only they were made welcome...[Those with disabilities] have won the legal battle for inclusion, but by the time they land in the pew at church, they may be too exhausted to fight for something more precious than their rights (Pinsky, par. 10).

Although the focus in the medical model is on healing, Reynolds argues that a different type of healing is needed when addressing disability where genuine healing is less about those affected by disability adjusting to a societal norm and more about society's acceptance of diversity (26).

Forced assimilation and conformity to a norm determined by the temporarily able-bodied is not true healing according to Reynolds. True healing for persons with disabilities only occurs when society can accept and value the presence of difference and diversity.

Reynolds's definition of healing does not, at first glance, seem to be supported by scripture. Because I am researching disability ministry in the Christian church, it is likely that some of the existing theological assumptions and beliefs held by individuals involved in offering disability ministries, as well as those held by individuals and families affected by disability, would be influenced by Christian scripture. In the next section, I will look at some Biblical passages and themes related to disability ministry and healing.

Scriptures Related to Disability

Many stereotypes, points of view, and theological implications are found in biblical passages relating to disability and healing including questions about sin and disability, how disability affects an individual's relationship with God, and how disability affects our relationships with one another.

The way scripture is interpreted and the scriptures that influence a church's disability ministry will influence the ministries offered. For example, a community of faith that sees impairment and subsequent disability as God's punishment for sin will probably reinforce this belief with ministries aimed at repentance and healing.

Reynolds gives an unfortunate example of this kind of disability ministry in the first chapter of his book. He tells the story of a woman who was pressured into attending a healing service, was called up front during the service, and was turned into a spectacle after physical healing didn't occur and she remained paralyzed (23).

By taking a closer look at the Biblical passages and interpretations that influence our attitudes toward disability in general, we can begin to understand why churches offer disability ministries and what families see as the scriptural basis for such ministries.

It will probably come as no surprise to the reader to find passages in the Bible that are ambivalent or disparaging toward disability. Many passages, especially within the gospels, reveal ambivalence toward those marginalized by disability. In Luke 5:18-26, Jesus heals a paralyzed man and tells him his sins are forgiven. The implication is clear: when the man is healed he is also made free from sin, so, at least in this case, sin was a factor in his disability. In fact it is only after his sins are forgiven that the man is instructed by Jesus to get up and walk (Jesus Heals a Paralytic).

Conversely, in the ninth chapter of John's gospel, the disciples ask Jesus concerning a man born blind: who sinned, a man or his parents? In this case Jesus does not blame the man's impairment on anyone's actions. Instead, "Jesus answered, 'Neither this man nor his parents sinned; he was born blind so that God's works might be revealed in him'" (NRSV). This answer implies that the man's blindness is not a result of sin but instead serves a purpose in God's work in the world. It would appear from these two examples that a causal relationship between sin and disability is affirmed and contradicted by Jesus in scripture (Eiesland 71).

Passages in both the Old and the New Testament portray God as one who punishes disobedience with plagues and pestilence (see, for example, Exodus 9:14-16, Leviticus 26:14-18, and Deuteronomy 28:15.) It is not difficult to imagine from such passages that the result of God's actions would be disability: plagues, pestilence, curses, consumption and fever that waste the eyes and cause life to pine away, would all cause impairment that could result in disability for those affected.

If we refer to the definition of disability as the social consequences of a physical or mental impairment, we are reminded that disability is a failure of relationship between those considered able-bodied and those considered differently-abled with respect to the socially accepted norm. Therefore, by definition, these disabilities (that have been sent by God) would affect an individual's relationship with other people, but would such a disability affect one's relationship with God?

According to Eiesland, the view of disability in Christianity "has run the gamut from symbolizing sin to representing an occasion for supererogation." Either of these extremes "denotes an unusual relationship with God and that the person with disabilities is either divinely blessed or damned: the defiled evildoer or the spiritual superhero" (70).

If we assume, as would appear to be the case in many scripture passages, that disability is the result of sin, and if we assume that sin is the separation of an individual from the presence of God, or more to the point, as a weakening or failure in the relationship between an individual and God, it would be impossible for disability not to affect an individual's relationship with God (see Avolos, 93).

This point is Biblically supported as well:

Leviticus 21:17-23 ¹⁷ Speak to Aaron and say: No one of your offspring throughout their generations who has a blemish may approach to offer the food of his God. ¹⁸ For no one who has a blemish shall draw near, one who is blind or lame, or one who has a mutilated face or a limb too long, ¹⁹ or one who has a broken foot or a broken hand, ²⁰ or a hunchback, or a dwarf, or a man with a blemish in his eyes or an itching disease or scabs or crushed testicles. ²¹ No descendant of Aaron the priest who has a blemish shall come near to offer the LORD's offerings by fire; since he has a blemish, he shall not come near to offer the food of his God. ²² He may eat the food of his God, of the most holy as well as of the holy. ²³ But he shall not come near the curtain or approach the altar, because he has a blemish, that he may not profane my sanctuaries; for I am the LORD; I sanctify them (NRSV, emphasis added).

This passage gives Biblical support to the belief that persons with disabilities are somehow incomplete or lacking some aspect that makes a person acceptable to God. Those considered blemished in any way will not be allowed to profane God's sanctuaries. Such beliefs have prevented those with disabilities from becoming fully functioning members of the body of Christ including exclusion from leadership roles or roles that might put them in the forefront of worship services.

When seeking guidance from scripture in the study of disability ministry, although many passages are at best ambivalent toward disability, some passages promote a sense of concern for those who are marginalized. In fact some passages reveal God's purpose being worked out through those who might otherwise be considered outside the realm of normal or acceptable behavior – such as the blind man mentioned above, Moses with his stutter, or Paul's thorn in the flesh (Reynolds 178).

William Gaventa adds that we should not base our identity on what we don't have, nor should we judge others in that way. He uses Luke 18:9-14 as an example. In these verses, Jesus tells us we should not "claim our identity and worth by thanking the Lord we are not like those others" (105).

Because the majority of scriptural passages directly related to disability are negative or ambivalent, it often becomes necessary for churches, and families affected by disability, to look to a broader scope of scriptures to guide decisions related to disability ministry.

Avalos identifies three common ways that scripture is interpreted with respect to disability ministry. One method, a historicist approach, "undertakes historical examinations of disabilities in the Bible and its subsequent interpretation, sometimes in comparison with neighboring ancient cultures, without any overt interest in the

consequences of the conclusions for today” (92) The other two methods are more helpful in looking at how scripture influences disability ministry because they seek to determine what our modern use of scripture should be. The first, a redemptionist approach, “seeks to redeem the biblical text, despite any negative stance on disabilities, by recontextualizing it for modern application...Alternatively phrased, a redemptionist approach seeks to ‘rescue’ the Bible from itself or from any modern misperception” Finally, a rejectionist approach argues “that the Bible has negative portrayals of disability that should be rejected in modern society” (Avalos, 91-2). Avalos considers himself a rejectionist, but he does acknowledge that a redemptionist approach is helpful for those who “still have an interest in applying the Bible’s understanding of life to their own lives” (99-100).

Although Avalos does not seem to allow for the use of scriptures not specifically related to disability in explaining disability ministry, McNair makes note of the fact that scriptures specifically related to disability and healing “have not been appropriated in determining the types of interactions we might have with persons with disabilities” (66). Even where scripture supports positive interaction with those affected by disability (see Matthew 12), those passages are generally not used to bring about changes in church behavior (McNair, 66).

When positive interactions do take place, it is often scripture passages related to hospitality and welcoming those on the fringes, and not passages that specifically relate to disability, that prove most helpful in determining particular congregational, familial, or individual beliefs about disability ministry. Passages such as Hebrews 13:2, which serves as a reminder to offer hospitality to strangers, or Luke 14:12-24, that tells of a man giving a dinner and inviting the poor, the blind, and the lame, are often used to justify the disability ministry offered by a community of faith whether or not such passages specifically mention

those affected by disability. The relationship between scripture and disability ministry will be discussed in further detail in subsequent chapters.

Disability and Theology

Reynolds points to two ways that disability is viewed negatively in Hebrew and Christian scripture: theological denigration and theological trivialization. These are ways that disability is consistently characterized throughout scripture and are passed down through Christian traditions, but, “which are inadequate representations of disability... because they are superficial, either (1) denigrating disability as a human flaw or deficiency or (2) trivializing it as something serving a beneficial or positive end” (Reynolds 34).

As noted above, disability is often presented in scripture as a symbol of “divine punishment or forsakenness” (Reynolds 36). God is viewed as whole and perfect, and those affected by disability are incomplete or lacking in some way. This view of those with disabilities as less than whole “adopts widely held beliefs in ancient Babylon and Egypt that disability was an evil omen or the product of evil spirits” like the unclean spirits mentioned in Mark 5 and Luke 9:38-42 (Reynolds, 36).

“The notion that dependence and limitation are per se marks of imperfection can and does suggest that disabled people... are farther from the divine perfection than are those who are not disabled” (Cooper, 175).

Denigration of disability also can be used to imply a lack of faith based on healing stories in the gospel. Reynolds points out that there are occasions in the gospel narratives where “Jesus heals afflicted people and exclaims, ‘Your faith has made you well’” (Reynolds 36). If the reader or interpreter of such healing passages is not careful, the result can be a

belief that if one's faith is strong enough healing will occur, as was the case in the story mentioned earlier of the woman invited to the healing service.

One of the ways disability has been trivialized is by viewing disability as an opportunity for able-bodied persons to perform charitable acts or as a way to learn "virtuous suffering," but Reynolds argues that those affected by disability do not need pity but empowerment based upon the belief "that persons with disabilities are self-defining agents – like non-disabled persons – who are capable of contributing to society and Christian communities in ways not necessarily defined by their disabilities" (Reynolds 37-39).

Eiesland compares the theology of virtuous suffering that "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" with that of the practice of encouraging self-sacrifice in women (73).

Similar to the denigration of women, the denigration of the disabled is presented as God-ordained rather than socially derived, but "[m]ost human suffering serves as neither an expression nor a reminder of Christ's suffering for us. Most human suffering arises out of human selfishness or ignorance or indifference or the fragile finitude of the human body and psyche" (Cooper, 176).

In both denigration and trivialization of disability, the medical model of disability forms the underlying framework. Both blur the lines between illness and disability, viewing disability as something to be removed or cured. Although illness can lead to disability, people affected by disability are not sick. Social restrictions stemming from impairment, not illnesses, cause disability (Reynolds 37).

One topic that becomes unavoidable in this discussion is theodicy. Can we reconcile our faith in God's goodness and power with the presence of disability in the world? The

issue of theodicy becomes important for two reasons: first, because the presence of disability in the world forces able-bodied persons to consider their own “fragility and contingency”; and, second, because those who find themselves within the limits of what society considers normal often feel as if disability must be removed or hidden (Reynolds 29).

If disability can be blamed on personal behavior, or sin, and God’s punishment of that sin, disability becomes much easier for those not affected by disability to explain theologically.

Our “normal” constructions mean that disability can only be perceived as an abnormality which, it is assumed, cannot reflect the true image of God. If disabled lives are presumed not to represent God’s image, clearly they “must” be a product of sin or some other distortion of the natural order. In other words, those defined not to adhere to God’s image need to be explained. The precise nature of that explanation will determine how individuals and communities respond (Swinton, 277).

In other words, those explanations will determine whether and what disability ministries will be provided, but such explanations do not take into account the complexities of disability or the fragile nature of human existence. Questions of theodicy tend to paint the issues of ability and disability in only black and white, but “[t]here is a kind of continuum on which all human abilities can be located, where shadings of grey eliminate dualistic distinctions between ability and disability” (Reynolds 41). As I mentioned earlier, we are all one accident away from being in a wheelchair, and that realization makes it difficult to reduce disability to an act of God as either punishment or virtuous suffering.

If faith communities are to move past seeing disability as only punishment or virtuous suffering, they must first begin to understand that each of us falls somewhere along that continuum and can even move along it because of injury, age, and even advancements in treatment. When members of the church begin to understand disability in

this way, they are better able to appreciate the diversity of human life and welcome all into a faith community.

The Church's Relationship with the Disabled

Given the varied ways that disability and theology have interacted in the past, the relationship between the church and those affected by disability has been ambiguous at best. Rather than being a place of empowerment, the church has tended to support the “societal structures and attitudes that have treated people with disabilities as objects of pity and paternalism. For many disabled persons the church has been a ‘city on a hill’ – physically inaccessible and socially inhospitable” (Eiesland 20).

Eiesland has come to believe that there is “no single story about the relationship between persons with disabilities and the Christian church [that] can express our diverse, complex, and enigmatic connection ... Clearly, disability has never been religiously neutral, but shot through with theological significance” (69).

Because disability is generally viewed by those who are able-bodied as something that affects them and not us, the theological implications of disability ministry are often relegated to the periphery which “can be disastrous not only for people with disabilities, but also for institutional integrity and justice” (Eiesland 75). Sometimes even an attempt to create access can lead to discrimination.

Eiesland gives as an example a resolution adopted by the American Lutheran Church (ALC) in 1980 in preparation of the observance in 1981 of the United Nations International Year of the Disabled. As a result of this resolution, the “General Convention of the ALC wholeheartedly embraced the concerns of persons with disabilities and encouraged systemic change;” but only five years later the ALC announced at its General

Convention that “people with ‘significant’ physical or mental handicaps would be barred from ordained ministry in the denomination” (76). This inconsistency is attributed, in part, to the failure of the ALC to consider the history of the disability rights movement and to their exclusion of those affected by disability from what Eiesland calls the speaking center.

Eiesland argues that symbols are vital to any marginalized group, and that only when symbols are revisioned and linked to the dominant culture will practices, ideas, and our relationships with God be thoroughly transformed (91). The dominant cultural and religious symbols must be deconstructed and reconstituted to make “them both liberatory for the marginalized group and unsettling for the dominant group” (Eiesland 98). Eiesland calls this the method of two-way access where those affected by disability “are empowered to participate more fully in the social and symbolic life of the church and wider society” while able-bodied individuals gain “access to the social-symbolic world of persons with disabilities, such that the disabling framework of the ‘normal’ becomes questionable” (Reynolds 15).

This deconstruction and reconstruction is also at the center of Cooper’s proposition that God be imagined as disabled. Cooper has come to believe through his interaction with those affected by disability that by viewing God as disabled we can “deepen our understanding of the nature of God’s creative and redemptive love” (Cooper 173).

Cooper believes that we tend to see God’s power as similar to our power only unlimited, so our ability is the basis for God’s ability. Within this framework, thinking of God as disabled “jars us out of our tendency to conceive God as ‘unlimitedly’ able. It reminds us to think of God’s power christologically—God’s being with us, suffering with us, broken for us” (Cooper, 180)

In thinking of God as disabled, we are forced to reexamine our common beliefs about God, God's power, human ability, and disability. Our symbols are deconstructed and reconstructed to question what is normal.

As Henri Nouwen wrote, Jesus, as the central symbol of Christianity, makes "his own broken body the way to health, to liberation and new life" (The Wounded Healer, 82). Eiesland also begins this reconstitution of symbols with the central symbol of Jesus Christ as the disabled God: "The theological lenses through which we have traditionally viewed our own and others' bodies distort the physical presence not only of people with disabilities but also of the incarnate God" (Eiesland 99). Our traditional symbols have not addressed adequately the broken body of Jesus Christ as God incarnate affected by disability and a symbol of the fragility of human life in general. A new understanding of God as disabled allows us, both able-bodied and disabled, to see that disability does not diminish a person but instead is central to our Christian faith (see Eiesland 100).

This view of Jesus Christ as the disabled God rejects disability as the result of sin. Eiesland sees injustice against those with disabilities as sin, but not the disability. We reveal the image of God through our disabilities, not despite them. Eiesland reaffirms disability as a social construction, but she also goes a step further and calls that socially constructed injustice sin. Disability is not the consequence of an individual's sin, but the social stigma imposed by able-bodied individuals is (Eiesland 101).

If the able-bodied can begin to reconceptualize their view of disability and those affected with disability in this way, communities of faith can begin to see disability and those affected by disability in new ways. Hospitality is the goal, but this means more than simply removing barriers to entrance. True hospitality means welcoming those with

disabilities as people “with inherent value, loved into being by God, created in the image of God, and thus having unique gifts to offer as a human being” (Reynolds 15).

Stanley Hauerwas recognizes the difficulty of such a radical form of hospitality: “There should be no mistake about it, a community of diversity that enhances differences is indeed a hard enterprise to sustain” (40). Fulkerson also recognizes that “the belief that the church should welcome those who were different was not sufficient to sustain [a church’s] identity” (81). It takes more than the recognition that we are called to be inclusive to make a faith community welcoming and accepting of differences.

This kind of hospitality is possible only when we realize that all life is a gift from God so the distinctions between ability and disability start to fade (Reynolds 14).

Theologian Juergen Moltmann seems to make no differentiation between those affected by disability and those not affected by disability, believing that “every human life has its limitations, vulnerabilities, and weaknesses” (110).

Although Christians testify to strength in weakness and power in vulnerability, faith communities still tend to ignore those who, as a result of disability, fail to comply with generally accepted standards (Reynolds 19). Reynolds argues that “a vigorous inclusion of differences remains one of the more important tasks of Christian communities today (46),” but he does recommend proceeding with caution because too often inclusion is done in the interest of maintaining the status quo and not with enough attention to the uniqueness of an individual. “And because the focus is on preserving group identity, tolerance can easily slip into assimilation. In an effort to maintain social control, assimilation is a community’s way of imposing conformity on differences, remaking them in its own image” (Reynolds 46).

With assimilation, the differences and uniqueness of an individual are not appreciated in and of themselves, but are valued only in the way that those differences are

overcome to allow an individual to become a functioning part of the status quo or acceptable norm. As Nouwen reminds us, “[h]ospitality is the ability to pay attention to the guest” (The Wounded Healer, 89). This means we put our own preoccupations, needs, and worries aside and give others “a friendly space, where they may feel free to come and go, to be close and distant, to rest and to play, to talk and to be silent, to eat and to fast,” basically, to allow them to be themselves and not simply meet our expectations of them (Nouwen, The Wounded Healer, 92).

To genuinely practice hospitality to persons with disabilities, the church must look beyond tolerance and assimilation. This means seeing disability as something that affects “us” as well as “them.” (Reynolds 47). It also means that we must recognize the presence of the image of God in all people and recognize the benefits to truly welcoming another.

Families who have been affected by disability have learned “that the extra work it takes to accommodate those with obvious disabilities is the price of experiencing the kind of deep love and fulfillment that only comes with self-sacrifice” (Pinsky, par. 16).

Samuel George goes a step further to argue that inclusion of those with disabilities is not merely desirable or beneficial but crucial to the church’s relationship with God. “God is not incompatible with disability and God is for and on the side of people with disabilities. The Exodus God is the God who is on the side of the marginalized” (103) George sees Disability Ministry as an issue of justice. Exclusion of those affected by disability “is not only a truncated mission endeavour, but is also impossible, because God is not a partner to such an endeavour” (103).

Summary

Theological understandings of disability and disability ministry are probably as varied as the range of impairments faced by those affected by disability. Going back to our definitions, disability is not simply a medical problem for impaired individuals in need of a cure, it is a social problem stemming from communally held beliefs about personal worth and ability.

The medical model of disability, which relies heavily on treatment and cure of disability, has greatly impacted societal views of impairment and disability -including views of disability within the church. Because disability has often been viewed as a weakness or fault either caused by God or pointing to a separation from God, disability is seen as something to be removed. Under this model, society's primary objective becomes assimilation into society. If the differences caused by impairment are too extreme to allow assimilation, exclusion is the typical solution.

When considering disability and ministry, we must also give consideration to scriptural influence and tradition with respect to disability. Some of the issues that arise from a study of scripture and disability include questions of whether sin leads to impairment or disability, how disability affects an individual's relationship with God, and how disability affects our relationships with one another. The way scripture is interpreted, and the scriptures that influence a church's disability ministry will influence the ministries offered.

Scriptural interpretations can then become the basis of theological traditions within faith communities. Disability is often portrayed scripturally and traditionally in one of two ways: either denigrating disability as a weakness or flaw or trivializing disability as a means to a positive end.

Looking carefully at issues of disability also requires those who are able-bodied to consider their own contingency and the exclusionary practices many faith communities have in place despite a professed belief that we are all children of God and are all made in the image of God. Until the church looks carefully at accepted practices of tolerance and assimilation, ministry with those affected by disability will not genuinely include persons with disabilities in the life of the faith community.

Expectations to Be Tested

In response to the theological assumptions presented in this chapter, I will examine whether those affected by disability seek a faith community:

- that understands true healing is not what we have been led to believe under the medical model of disability: a removal or cure of a physical impairment
- where they are accepted as individuals bearing the image of God just as any other individual bears the image of God
- where they are not expected to conform or assimilate to maintain the status quo
- that allows for theological explanations of disability other than as a punishment for sin, denigration, or trivialization

Chapter Two
The Ministries Churches Are Providing

“You cannot take seriously the spiritual practice of hospitality and remain as you are. If you are serious about it, nothing will ever be the same again.”
Father Daniel Homan

I ended the last chapter with a list of things those affected by disability might tend to look for when choosing a faith community: a place that understands true healing is not what we have been led to believe under the medical model of disability, a place where they are accepted as individuals bearing the image of God just as any other individual bears the image of God, a place where they are not expected to conform or assimilate to maintain the status quo, and a place that allows for theological explanations of disability other than as a punishment for sin, denigration, or trivialization.

If I am correct in my assumptions, it would make sense that churches providing intentional disability ministries would seek to meet these needs. To examine whether and how these needs are being met, I developed a brief questionnaire for clergy and lay leaders involved in the disabilities ministries of their congregations to complete (see Appendix A).

The questionnaires were distributed to churches in New Jersey and Pennsylvania through a network of individuals involved in disability ministry. I received information from five churches that provide disability ministry services directly to families and one response from a coordinator of special needs religious education for a Catholic Diocese in New Jersey. The churches that provided information ranged from Catholic, to non-denominational, to Lutheran, to Mennonite. These congregations ranged in size from 20 members to 5,000 families. Three of the questionnaires were completed by pastors who provide services aimed specifically at those affected by disability. One is located in a residential community for individuals with disabilities; the two others provide special services for those affected by disability within an existing congregation.

In this chapter, I will highlight some of the answers provided by those seeking to develop and lead intentional disabilities ministries. In chapter four, I will compare this information with the information received from questionnaires completed by individuals

and families affected by disability that participate in intentional disability ministries within these churches.

What do you see as the purpose of intentional disability ministries?

The first question for church staff gets at the heart of why a particular congregation offers the kind of intentional disability ministry it does. An individual's answer to this question also provides some insight into either their own beliefs about theology and disability or the congregational attitude toward disability. These answers begin to touch on the issues discussed in the first chapter in that the generally accepted view of disability and disability ministry will influence the kind of ministries offered by a particular congregation and the ways those ministries are offered or explained.

As already mentioned, a community of faith that sees impairment and the subsequent disability as God's punishment for sin will probably reinforce this belief with ministries aimed at repentance and healing. However, a community of faith that seeks to include all people as valuable children of God will focus on the individual worth of all people regardless of ability.

None of those providing information for this project stated that they saw the purpose of disability ministry as a means of providing healing or mentioned a correlation between disability and sin. Instead, the answers mentioned that the purpose of disability ministry was "to support the individual with a disability... when a need arises" and "to create a safe environment where anyone, regardless [sic] of behavior and cognitive level, can come to worship and know Jesus in his or her own way."

Some seemed to see disability ministry not as a separate ministry only for those considered by "normal" members to be disabled, but as a ministry to and an opportunity for

all members to be integrated “as fully possible in our worship, education and ministry efforts.” This was reinforced by other answers that sought to “include those with disabilities in the life of the church as we would with any person.”

One congregation took this a step further seeing disability ministry not only as a way to “include these individuals in the life of the church so that they can use their God given gifts in service to the Lord”: but also “to serve as a witness to the community as [they] attempt to meet the spiritual, physical, social and emotional needs of the individual with a disability.” For this congregation, it is not enough to meet the needs of those with disabilities within the community of faith; their ministry should also serve to show the larger community just what this faith community believes as a Christian church.

There is a fine line between revealing God’s love to others through ministry with and trivializing disability through ministry to those perceived as needing “our” help. This view of disability ministry as a witness to the larger community may fall into trivialization of disability as acts of charity by a “normal” congregation to those in need of such charity.

Disability ministry for this church is also seen as a way of “working together to reach people with [sic] who have a disability with the Gospel so that they can know Christ in a personal way.” Although there is a focus on the larger community and witness to it, that focus does not come at the expense of the individual’s relationship with Christ.

These answers express the belief that all people should be accepted into a faith community regardless of real or perceived need. They also seem to point to a deeper understanding that we all have needs, that some might just be more visible, and that those needs might change for any of us at any time. In short, in some of these answers, there is a subtle acknowledgement of the contingency of life and “normalcy.”

Why did this church begin a disability ministry?

Closely related to what a congregation sees as the purpose of disability ministry is the reason a congregation began a disability ministry. Often a specific need is seen, and a ministry is formed to meet that need: “Because those with disabilities were born into, or began attending our congregation.”

These occurrences may be viewed as a way for God to use the people of a particular congregation to meet the needs of those with disabilities: “Twenty-five years ago a little girl was born into our congregation with multiple physical disabilities. God used this to open the eyes and hearts of our congregation to the needs of families facing the challenges of disability. A few years later a man with quadriplegia joined our congregation and helped spur the effort to continue to meet the needs of these families.”

This particular answer touches on another issue that was mentioned a few times: the struggle to support a disability ministry program long-term. This was also mentioned under the question related to the biggest challenge to establishing or maintaining a disability ministry and on questionnaires completed by families affected by disability. Both sides (staff and members) seem to recognize the level of commitment needed to keep this type of ministry going.

In another congregation, members saw a need and felt called to address that need: “The ministry here actually began after some of the members of the congregation noticed that the parents of a daughter with severe disabilities were never able to attend church together because one of them had to stay home to care for their daughter. This was the catalyst for our Sunday morning class that is designed for adults with intellectual disabilities.”

Sometimes a faith community is encouraged to begin a disability ministry by a clergy member who believes strongly that such ministries should be provided: “Our intern began the Rejoicing Spirits worship service as an intern project this year. Other efforts have been driven by pastoral care.”

In another instance, the individual leading the worship services “saw a need for it at... a residential home for adults with intellectual and developmental disabilities. We had too many folks who could not go to a traditional church service [because] of lack of staffing on a Sunday, or inappropriate behaviors, or lack of attention span, but who clearly wanted to participate in a faith community, so I started a weekly church service right on campus that folks could walk to. We started with about 10 people, and now we have close to 50 who attend each week.”

In many of these cases, disability ministries began as a response to a need within a faith community: a child with disabilities was born into a church, or a family affected by disability began to attend. Members within the church saw a need and responded by providing services. Occasionally, a clergy person encouraged a congregation to provide such ministry because he or she believed it was an important form of ministry.

How do individuals with disabilities participate in your disability ministry program? How do they participate in the life of this congregation?

Because of the wide range of disabilities found within the congregations completing the questionnaire, and because of the various forms of ministry offered, the answers to this question were also diverse. In some faith communities, those affected by disability are included in worship and activities just as any other member would be, sometimes with special services to accommodate disability such as providing a sign language interpreter,

while in other congregations those with disabilities are invited to become involved in services and worship opportunities aimed exclusively at those affected by disability.

One faith community, located in a residential community for those with disabilities and primarily serving people with disabilities, also offered additional opportunities within the services: “We have special music each week where folks can come up and sing a song. I usually offer at least three spots. We also have an usher who handles the greeting and sign in, and I normally invite at least one person to help lead in prayer.”

Some faith communities offer both separate opportunities for learning and worship for those with disabilities as well as providing times for these individuals to “participate in worship, social and service ministries with family members.”

This approach to providing disability ministries appears to be a middle of the road approach, perhaps in an attempt to limit polarization around issues of inclusion similar to issues around mainstreaming in the education system in this country.

One respondent realized that involvement and participation in aspects of the congregation beyond ministries offered specifically for the disabled is a challenge for them. Their members with disabilities attend classes for individuals with disabilities and participate in worship, but the church leadership continues to try to find ways for these members to be more involved in the life of the church:

As far as taking part in the life of our congregation, we make sure to invite them to most church programs and activities. Some of them participate in our worship service by taking the offering. A few have even used their musical talent by performing as the special music in a church service. Several of our students come once a month to help “stuff” our bulletins with inserts.

We know that there is much room for improvement in the area of inclusion of those with disabilities in our church. We continue to discuss this at our meetings, and have set this area as a goal to work on.

The fact that this congregation recognizes the need for more inclusion and has set this as a goal for the congregation to work on is interesting for two reasons. First, although they already offer several forms of ministry to those with disability, they continue to seek additional and better ways to reach this population. Additionally, it brings up questions related to what is behind this recognition. Is greater inclusion a societal trend that has finally reached the church, or is this a grass-roots effort by family members beginning to realize “separate but equal” just isn’t an option?

This particular questionnaire was also interesting because those individuals involved in disability ministry were never called members. They were always referred to as students. It is unlikely that the staff of this congregation refer to any individual involved in the ministries of the church in this way, so one might question whether these individuals can become members.

The use of the word “intentional” may have caused some confusion in answering this question. I was trying to get those completing the questionnaire to think about how their congregation “intentionally” reaches out and ministers to those with disabilities. For some of these congregations, attitudes and assumptions about Christianity and disability make this form of ministry so central to who they are they are not aware that other faith communities do not believe the same things or offer the same kinds of ministry.

This may be true of the following answer:

Maybe I am misinterpreting what you mean by ‘disability ministry program.’ We have a boy, now 14, who was born deaf into a family attending our congregation. We now provide ASL interpretation for him most Sundays, On Sundays when we do not have an interpreter someone types the service for him on a laptop. This coming Sunday he will be signing Scripture as part of our Pentecost service.

We have two boys with autism. We continue to try to find ways to welcome them into our congregational life, allowing them the space they need. We offer respite care to their parents. We have become more involved with [a]...

local non-profit working with those with disabilities, our youth volunteer with them most months.

One church provides for the spiritual and religious needs of individuals and families affected by disability through programs such as one-to-one buddies on Sunday mornings, worship and learning opportunities, and an annual Disability Awareness Sunday. The members also seek to address other challenges faced by families affected by disability through programs such as monthly respite, work projects for families, a Day of Pampering for women whose children or husbands are affected by disability, and a monthly outreach to single adults affected by disability. This group is planning a prom and has formed teams for teens with special needs.

Offering services such as these to families affected by disability goes beyond participation in intentional disability ministry and the life of the congregation to address non-spiritual, and often-overlooked, needs of these families.

Participation in disability ministries within these congregations ranged from involvement in worship services and education opportunities established specifically for individuals with disabilities to participation in worship and education opportunities much like any other member would participate but with some services, such as sign language interpretation, to accommodate special needs. One of the churches, in addition to providing for the religious needs of families affected by disabilities, also sought to provide opportunities for respite, mission, and fellowship for those affected by disability.

How does this congregation specifically welcome individuals/families affected by disabilities?

If a church is being intentional in their attempts to minister to those with disabilities, there should be ways that the congregation is specifically reaching out to or welcoming these individuals. The answers to this question give some insight into the ways that congregations are being intentional in this form of ministry. For the one congregation that ministers almost exclusively to those with disabilities, there didn't appear to be much thought given to specifically welcoming individuals or families affected by disability because that is the purpose of their entire ministry.

For congregations seeking to provide services for those with disabilities either within an existing framework of worship and education or alongside the existing framework, there is a wide range of attempts made to be more intentionally inclusive of those affected by disability from putting announcements in the bulletin about upcoming disability events to offering assistance during worship and religious education. One congregation relies on "[w]ord of mouth and paying attention to their needs when [those with disabilities] are with us." This community has also established support groups of three to four people to respond to expressed needs.

The two parts of this answer are in tension with one another. On one hand, it is great that this church has set up support groups for those families who have expressed a need; on the other hand, it is somewhat concerning that the congregation relies on word of mouth and paying attention to those with disabilities when they are present. Is there any concern for these individuals and families when they aren't present? Is there any continuity of the disability ministry or at least a continual recognition of the congregation's view of welcoming those with disabilities?

One respondent mentioned that members were “very warm and welcoming to the individuals and families touched by disability just as they are to others who attend.” Many of these members were also “involved in transporting them to and from church and other special programs. Some invite them to their homes for a meal or take them out to eat from time to time.” The individual providing this answer was also the only individual to mention that many of her members pray for those affected by disability.

Some congregations did not go into detail about how they specifically welcome those with disabilities, but instead mentioned striving to create “a congregation-wide environment that is open and hospitable.” One respondent believed that, in her particular congregation, “[t]here is a wonderful openness to do ‘whatever it takes’ to include all.

Such an openness and striving to be welcoming to all is admirable as long as there is intention behind that openness. If a church is not specifically and intentionally welcoming those with disabilities and trying to meet their needs, it runs the risk, as mentioned above, of losing continuity and providing sporadic services to those with a continual need.

What has been the biggest challenge to the establishment or continuation of the disability ministry of this church?

The challenges faced by congregations looking to begin an intentional disability ministry—such as attitudinal barriers, financial concerns, and issues of sustainability—continue, and may increase, as a church strives to maintain or expand disabilities ministries. Although this question was asked only on the staff questionnaire, challenges were mentioned by both the clergy and lay leaders of the disabilities ministries as well as the families that participate in the ministries.

Some of the challenges mentioned by the staff members who completed the questionnaire were the difficulties associated with physical barriers. Although those

completing the questionnaire provide various disabilities ministries within their church buildings, it should not be assumed that all of the buildings are without physical barriers. One individual mentioned that her “parish is over 125 years old and not totally handicapped accessible.” Sometimes those involved with disability ministry must get by with what they have to work with and work around.

Other answers mentioned difficulties in “[g]etting individuals with special needs and their families to tell us their needs.” This answer gets to the heart of this research project. I am attempting to compare the ministries offered by faith communities with the needs and desires of those affected by disability. One of the biggest challenges, not only for churches offering disability ministry, but also for any kind of ministry, is the challenge of getting members, potential members, and members of the community outside the church to be open and honest about their needs and the church’s role in meeting those needs. This answer makes it clear that this challenge is one faced specifically by congregations that are trying to be more inclusive of those with disabilities. It is only when a church decides to be more intentional in reaching out to persons with disabilities that the needs of those individuals become important.

Another challenge mentioned more than once is the need for more help. Often disabilities ministries are established in response to a specific need: a particular member needs additional services, or a lay leader or clergy person feels called to offer disabilities ministries. This specific focus of the ministry offered can lead to a small pool of supportive members. A few people take on the responsibility for seeing to the needs of the member or family affected by disability: “When long-term care is needed, e.g. a child with learning/social disabilities, it has been challenging to keep a support group active over the

years.” If support for the ministry does not grow within the congregation, it can lead to resentment, burnout, and even the demise of the ministry.

Sometimes it isn’t possible to get any additional support from the community, as was the case for one respondent: “I need help! It’s pretty much just me doing set up, break down, worship and teaching.” It takes dedication and a firm belief in the importance of disability ministry to continue such a ministry on your own.

Finances can also have an impact on the provision and continuation of a particular disability ministry: “It is challenging to find an ASL interpreter on a Sunday morning, and this is fairly expensive for a small congregation.”

Other answers indicated an understanding that disability ministry was not solely the responsibility of the faith community, but that some of the responsibility for continuing such ministries rested with the families and members who participated and relied on such ministries saying what was needed was “[c]onsistent attention and sensitivity on our part. Consistent participation on the part of our families [sic].”

In addition to the difficulties involved with finding support for disability ministry, the challenge of providing age or ability appropriate ministry was also mentioned: “It’s also quite difficult to teach a message at a level that my folks can understand.”

The task of teaching at an appropriate level becomes more difficult as the range in ability becomes greater. This dilemma is reminiscent of what Eiesland had to say about “normal” society grouping all those affected by disability together without consideration for the range of disabilities. This tendency may also point to an underlying financial dilemma: it can be financially daunting for a church to provide separate curricula and resources for varying levels of disability and understanding.

Only one respondent mentioned that it was a challenge for her to come up with an answer to this question, stating that “God has always blessed the ministry with faithful volunteers and a staff and congregation who support the ministry.” She went on to give as an example a lack of space as the number of people involved in their disability ministry continued to grow. The congregation was soon “blessed with a 2000 square foot suite for our use each Sunday morning, and other times during the week.” The implication in this answer is if this disability ministry is God’s will, God will provide for the church’s needs.

Challenges to providing ongoing disability are many and were acknowledged by both staff members providing the services and by family members who participate in the ministries. Although each of these congregations does provide some form of disability ministry, physical barriers still exist within some of these churches. Other challenges include issues with communication between staff and family members, a lack of help or support for the ministry, and financial concerns.

Why do the members of this congregation think it is important for individuals with disabilities to attend church?

This question attempts to delve deeper into the challenges faced by some congregations with respect to maintaining disability ministries. The dedication of a few members, lay leaders, or clergy is often not enough to sustain a demanding ministry like this. The support of the congregation must be garnered to continue or grow a disability ministry program. One way to determine whether the congregation is supportive of the disability ministry is to ask why the members of the faith community think it is important that individuals affected by disability attend church.

The answers to this question reveal some of the underlying reasons that a particular congregation believes disability ministries are important to their faith as a Christian

community. The answers ranged from a clinical determination “that activity [sic] participation in a faith community has a positive outcome for that individuals [sic] quality of life” to indications that a congregation strives “to be an inclusive and hospitable house of faith” and that those with disabilities “are also part of our faith community and we want to be together.”

In one case, scripture was used to help explain why a congregation believes disability ministry is important: “I believe this can be answered with scripture. In 1 Corinthians 12: 18-26, the scriptures tell us the importance of all parts of the body. All parts, weak or strong, should have equal concern for each other.” This use of scripture to answer this question segues nicely into the next question on the questionnaire.

What scripture passages, if any, inform your disability ministry or your decision to establish an intentional disability ministry?

As discussed in chapter one, the way scripture is interpreted and the specific scriptures that influence a church’s disability ministry will also influence the ministries offered. By taking a closer look at the scriptures that inform a congregation’s disability ministry, we might begin to understand the specific types of ministries offered to individuals affected by disability. In hindsight, it would have been helpful to ask not simply for passages but also some reasoning or explanation as to why a certain passage was helpful or meaningful to a particular individual.

The passages cited fall into several categories. A few of the scriptures speak of God’s will or God’s power in creation. For example, Exodus 4:11: “Then 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?” or Psalm 139:13-16:

¹³ For it was you who formed my inward parts; you knit me together in my mother's womb. ¹⁴ I praise you, for I am fearfully and wonderfully made. Wonderful are your works; that I know very well. ¹⁵ My frame was not hidden from you, when I was being made in secret, intricately woven in the depths of the earth. ¹⁶ Your eyes beheld my unformed substance. In your book were written all the days that were formed for me, when none of them as yet existed (NRSV).

Others point to the way we are called as Christians to include or interact with those in need or on the margins:

Matthew 25:31-40 (Scriptural passages/translations not included on questionnaire)
³¹ "When the Son of Man comes in his glory, and all the angels with him, then he will sit on the throne of his glory. ³² All the nations will be gathered before him, and he will separate people one from another as a shepherd separates the sheep from the goats, ³³ and he will put the sheep at his right hand and the goats at the left. ³⁴ Then the king will say to those at his right hand, 'Come, you that are blessed by my Father, inherit the kingdom prepared for you from the foundation of the world; ³⁵ for I was hungry and you gave me food, I was thirsty and you gave me something to drink, I was a stranger and you welcomed me, ³⁶ I was naked and you gave me clothing, I was sick and you took care of me, I was in prison and you visited me.' ³⁷ Then the righteous will answer him, 'Lord, when was it that we saw you hungry and gave you food, or thirsty and gave you something to drink? ³⁸ And when was it that we saw you a stranger and welcomed you, or naked and gave you clothing? ³⁹ And when was it that we saw you sick or in prison and visited you?' ⁴⁰ And the king will answer them, 'Truly I tell you, just as you did it to one of the least of these who are members of my family, you did it to me' (NRSV).

Luke 10:25-37 ²⁵ Just then a lawyer stood up to test Jesus. "Teacher," he said, "what must I do to inherit eternal life?" ²⁶ He said to him, "What is written in the law? What do you read there?" ²⁷ He answered, "You shall love the Lord your God with all your heart, and with all your soul, and with all your strength, and with all your mind; and your neighbor as yourself." ²⁸ And he said to him, "You have given the right answer; do this, and you will live." ²⁹ But wanting to justify himself, he asked Jesus, "And who is my neighbor?" ³⁰ Jesus replied, "A man was going down from Jerusalem to Jericho, and fell into the hands of robbers, who stripped him, beat him, and went away, leaving him half dead. ³¹ Now by chance a priest was going down that road; and when he saw him, he passed by on the other side. ³² So likewise a Levite, when he came to the place and saw him, passed by on the other side. ³³ But a Samaritan while traveling came near him; and when he saw him, he was moved with pity. ³⁴ He went to him and bandaged his wounds, having poured oil and wine on them. Then he put him on his own animal, brought him to an inn, and took care of him. ³⁵ The next day he took out two denarii, gave them to the innkeeper, and said, 'Take care of him; and when I come back, I will repay you whatever more you spend.' ³⁶ Which of these three, do you think, was a neighbor to the man who fell into the hands of the robbers?" ³⁷ He said,

“The one who showed him mercy.” Jesus said to him, “Go and do likewise” (NRSV).

The use of such passages when discussing disability ministry probably stems from the medical model of disability where disability is seen as something to be fixed or cured. Other scriptures are centered in Christian hospitality and the equality of all God’s children as in Hebrews 13:2: “Do not neglect to show hospitality to strangers, for by doing that some have entertained angels without knowing it”; or in Matthew 19:14-15 where “Jesus said, ‘Let the children come to me, and do not hinder them; for to such belongs the kingdom of heaven.’ And he laid his hands on them”; or in Luke 14:16-24 (Scriptural passages/translations not included on questionnaire):

¹⁶ Then Jesus said to him, “Someone gave a great dinner and invited many. ¹⁷ At the time for the dinner he sent his slave to say to those who had been invited, ‘Come; for everything is ready now.’ ¹⁸ But they all alike began to make excuses. The first said to him, ‘I have bought a piece of land, and I must go out and see it; please accept my regrets.’ ¹⁹ Another said, ‘I have bought five yoke of oxen, and I am going to try them out; please accept my regrets.’ ²⁰ Another said, ‘I have just been married, and therefore I cannot come.’ ²¹ So the slave returned and reported this to his master. Then the owner of the house became angry and said to his slave, ‘Go out at once into the streets and lanes of the town and bring in the poor, the crippled, the blind, and the lame.’ ²² And the slave said, ‘Sir, what you ordered has been done, and there is still room.’ ²³ Then the master said to the slave, ‘Go out into the roads and lanes, and compel people to come in, so that my house may be filled. ²⁴ For I tell you, none of those who were invited will taste my dinner (NRSV).”

and in Paul’s writing about the parts of the body in I Corinthians 12:18-26 (Scriptural passages/translations not included on questionnaire):

¹⁸ But as it is, God arranged the members in the body, each one of them, as he chose. ¹⁹ If all were a single member, where would the body be? ²⁰ As it is, there are many members, yet one body. ²¹ The eye cannot say to the hand, “I have no need of you,” nor again the head to the feet, “I have no need of you.” ²² On the contrary, the members of the body that seem to be weaker are indispensable, ²³ and those members of the body that we think less honorable we clothe with greater honor, and our less respectable members are treated with greater respect; ²⁴ whereas our more respectable members do not need this. But God has so arranged the body, giving the greater honor to the inferior member, ²⁵ that there may be no dissension within the body, but the

members may have the same care for one another. ²⁶ If one member suffers, all suffer together with it; if one member is honored, all rejoice together with it (NRSV).

Only one person included a specific translation associated with the scriptures listed, and that translation was Eugene Peterson's The Message for Ephesians 3:4-6:

⁴⁻⁶As you read over what I have written to you, you'll be able to see for yourselves into the mystery of Christ. None of our ancestors understood this. Only in our time has it been made clear by God's Spirit through his holy apostles and prophets of this new order. The mystery is that people who have never heard of God and those who have heard of him all their lives (what I've been calling outsiders and insiders) stand on the same ground before God. They get the same offer, same help, same promises in Christ Jesus. The Message is accessible and welcoming to everyone, across the board.

This passage, by stating that outsiders and insiders stand on the same ground, reveals that all of God's children are equal before God, regardless of how they might be viewed by others. This "equality of all people" was also found in this passage from Matthew 28:18-20 on evangelism:

And Jesus came and said to them, "All authority in heaven and on earth has been given to me. ¹⁹ Go therefore and make disciples of all nations, baptizing them in the name of the Father and of the Son and of the Holy Spirit, ²⁰ and teaching them to obey everything that I have commanded you. And remember, I am with you always, to the end of the age."

One respondent offered her "primary bible passage" as the story of the well at Bethesda in John 5, saying, "I believe God has spiritual healing available to those with Intellectual and Developmental disabilities, and can use our service as a tool to help our individuals connect to the healing power of Jesus Christ." Although this is a scriptural reference to physical healing, she chooses to focus instead on spiritual healing available to those with disabilities.

Some who answered this question mentioned general themes in scripture such as "Jesus was continually drawn to those on the fringes (and they to him!). We want to do the

same” and “all of the references in the New Testament of Jesus compassionate interactions with countless individuals affected by disability.”

One person included a non-scriptural quote from St. Gregory the Great: “When we attend to the needs of those in want, we give them what is theirs, not ours. More than performing works of mercy, we are paying a debt of justice.” (The individual who gave this answer is the parent of a child with disabilities as well as a lay leader involved in the disability ministry in her congregation. Her answer to this question was the same for both questionnaires and was included in this chapter and chapter three.)

As discussed in chapter one, the scriptural passages that inform the ministries offered rarely mention disability. Because many biblical passages related to disability are negative or ambivalent, those who offer services to individuals affected by disability must look elsewhere in scripture for a scriptural foundation for such ministry. The scriptures cited mention God’s will or God’s power, as in Psalm 139; point to expected behavior of those considered “normal” toward those on the fringes, as in the parable of the Good Samaritan, or in Matthew 25, or hospitality as in Mathew 19:14-15 or Luke 14:16-24.

While these passages encourage certain behavior by those considered normal toward those considered outsiders, several questionnaires did mention scriptures that see all of God’s children as equal before God if not one another. In these cases, offering disability ministry appears to be a means to allow all of God’s children access to a God who loves and cares for each of them in the same way.

Summary

The staff members completing the questionnaire most commonly expressed the purpose of the ministries they provide as a way to support individuals with a disability and

to create a worship environment where anyone can worship and can come to know God. In some of these answers, there was an assumption that intentional disability ministries are something required only when an individual with disabilities is present, but such an attitude toward this kind of ministry can lead to inconsistencies in services provided and, over time, to a decline in support for the disability ministry program. If a church does not consistently and intentionally welcome those with disabilities, it runs the risk of providing sporadic services to those with ongoing needs. Churches may not initially recognize that the challenges faced when beginning an intentional disability ministry will continue, and may even increase, as a church strives to maintain or expand disabilities ministries.

The answers provided also touched on the fine line between ministry to those with disabilities and ministry with those affected by disability. When a church provides ministry with those affected by disability, they reveal an understanding that we all have needs and that all people should be accepted into a faith community regardless of those needs.

One of the ways to determine how welcoming a church is to those affected by disability is to look at the ways these individuals are involved in the life of the congregation. Participation in these churches ranged from attendance at services and other activities aimed specifically at those with special needs to full participation in all aspects of the life of the faith community. One congregation also sought to provide opportunities for service and fellowship outside the strictly spiritual or religious realm.

The information provided regarding scripture affirmed the discussion in chapter one that scriptural passages that inform disability ministries rarely mention disability. Instead, staff members looked to passages related to God's will and power, passages that reveal expected behavior to those affected by disability or those on the fringes, or passages related

to issues of hospitality. In a few cases, passages that show all of God's children as equal were cited, revealing a belief in God's concern for all persons regardless of disability.

Chapter Three

The Experiences of Families Affected by Disability

“For it was you who formed my inward parts; you knit me together in my mother’s womb. I praise you, for I am fearfully and wonderfully made. Wonderful are your works; that I know very well.”

Psalm 139:13-14

This chapter will look at information that was collected from families whose lives have been affected by disability in some way. A second questionnaire was developed and distributed to members of churches that provide intentional disability ministry in Pennsylvania and New Jersey through the same networks as the questionnaire for churches (see Appendix B).

I received responses from members of three of the churches that completed questionnaires and had information included in chapter two. I also received additional responses from four families who attended churches that did not respond to the staff questionnaire.

The group of individuals who responded to the questionnaires is made up entirely of parents of children affected by disability. Their children range in age from four to fifty-five, and the disabilities with which they are affected include deafness, Down's syndrome, mental retardation, autism, and cerebral palsy. The answers to this questionnaire point to different aspects of disability and different experiences of families affected by disability within the church.

Please provide the age, diagnosis, and age at diagnosis of the family member affected by disability:

Age in Years	Diagnosis	Age at Diagnosis		Age in Years	Diagnosis	Age at Diagnosis
4	Cerebral Palsy; Diagnosed with Brain Injury at Birth Due to Prematurity	Birth		18	Asperger's and Anxiety and Food Allergies	4 Yrs
4	Autism, Premature Birth	2 ½ Yrs		18	Autism	3 Yrs
6	Hydrocephalus and Static Encephalopathy at Birth; Autism Intellectual Disability (MR)	Birth 20 Months 5 Yrs		19	Autism	NA
8	Cerebral Palsy	NA		23	Epilepsy, Developmentally Delayed, Started Talking; Uncontrolled Seizures And MR; Behavior Problems; Seizure Free for 19 Years	2 Yrs 3 Yrs 5 Yrs
9	Bipolar, ODD, ADHD, Reactive Attachment Disorder, Anxiety	Na		35	NA	NA
14	Asperger's Syndrome, Reactive Attachment Disorder	9 Yrs		38	Moderate MR	2 Yrs
14	Profoundly Deaf	1 Yr (Born Deaf)		55	Down's Syndrome	6 Months
17	Profound MR Seizure Disorder	1 Month		NA	Seizure Disorder; MR/Developmental Delays; Movement Disorder	7 Months 15-16 Months 2 Yrs

Parents were asked to provide basic information about their children: current age, diagnosis, and age of diagnosis for their family member with disabilities. The children ranged in age from a set of twin boys, age four, to a fifty-five-year-old man, with an average age of nineteen. The disabilities varied greatly, from profound deafness, which the boy's father conceded is not considered a disability by some, to profound mental retardation, cerebral palsy, and seizure disorders. For the children whose parent provided information about the age of diagnosis, many were diagnosed within two years of birth. One child was diagnosed at age four and another was diagnosed at age nine.

What do you see as the purpose of intentional disability ministries?

The purpose of this project is to get at the heart of intentional disability ministry: why do those affected by disability choose to attend a church that offers ministry developed for and aimed specifically at them? What do these families see as the purpose of such intentional ministries?

The most common answer to this question was "inclusion." Most answers used the word included while some used accepted-but at the center of these answers was a desire to be part of a community, and specifically a faith community. This desire was not only a desire for the individual affected by disability to be included, but also for the entire family to be included when so often, in their day-to-day lives, they are not: "I like the word intentional – to be intentional to include, honor, care for the person affected by disability and their family members."

From their answers, these families seemed to be seeking a place where everyone is welcome and everyone has something to contribute:

“These ministries allow the individual and the families affected with disabilities to feel included, important, loved, and of worth, special, valued and have something to offer.”

“Inclusion of all of God’s people, disability or no disability; to be able to worship and gain strength, hope and support among other believers.”

“Intentional” I assume you mean a church being summons [sic] to have such a ministry for ‘our people.’ However, my purpose has always been ‘please just include’ my daughter.”

Some respondents went beyond inclusion and acceptance to seeing these ministries as a way for the church to celebrate the gifts that those with disability bring to a faith community. One person viewed the purpose of disability ministry as “[h]elping the church identify GIFTS of those with disability so they can minister.”

Others who expressed the primary purpose of disability ministry as inclusion also believed that there is a secondary benefit to the congregation in offering such ministries: “The purpose is that all people in the church family or wanting to join it can be included. God doesn’t exclude people based on disability, nor should the church. That’s primary but secondary is that the church learns too about life with a disability, its pluses and minuses, it opens our eyes to the many ways people live in the world.” Disability ministry not only helps those affected by disability but also helps those who have not been affected by disability to broaden their view of “the many ways people live in the world.”

The answers that mention those with disabilities having something to offer or having gifts for ministry are unique to the questionnaires completed by parents. The staff questionnaires focused on providing a place where everyone was welcomed but didn’t mention any benefit received by the congregation through offering such ministries. This seems to point to a belief by the staff members who completed the

questionnaire that these disability ministries are ministries to those with a particular need and not ministry with these individuals just as a congregation would minister with any other individuals but with certain necessary accommodations.

These ministries are also viewed by families as a way for members of a congregation to support those facing disability, and as a way for those affected by disability to receive support that might not be found outside the church or in churches without intentional disability ministry:

“To come along side of a family with more difficulties than normal family, to encourage and show God’s love in a special way. To allow a family to worship. To encourage family in ways others can’t or don’t know how.”

“The church reaching out to their members and the community as a whole to support families dealing with a disability... To come alongside families affected by disabilities, learning more about the challenges they face and ways to minister to them.”

These two answers, from members of the same congregation, mention “coming alongside” families affected by disability. In the first answer, disability is seen as causing more difficulties for a family than those a “normal” family would face. The answer then implies that such a family needs to be shown God’s love in a special way. If this answer reveals a true and honest recognition of the difficulties faced by those affected by disability and a willingness to embrace those challenged and accept that family as is, it would support my argument that families are looking for a community of faith that does not demand assimilation. However, if this answer assumes a special relationship with God for those affected by disability, it may point to trivialization of disability.

One respondent, who is involved in the intentional disability ministry within her congregation and who also has a son with disabilities, saw the purpose of the disability

ministry in her church as a means “to provide a place for Christian Education and a mechanism for service for those with mental retardation who are affiliated [sic] somehow with our congregation or wish to learn more and grow in their faith.”

For one individual, the purpose of these intentional ministries is “[t]o help the disabled to foster their relationship with God.” Although several answers mentioned showing God’s love to those affected by disability or including all of God’s people, only this answer spoke specifically of fostering an individual’s relationship with God.

Why did you choose to attend this church?

Many of those answering this question stated that they attend their current church specifically because of the disability ministries provided by that congregation. For example, one person answered that he attends the church he does “[b]ecause they have the best disability ministry of any church in [this] county.”

Some mentioned the fact that the church had a disability ministry and went on to give an additional reason: “[We attend b]ecause of the disability ministry and because they encourage members to be the hands and feet of God. We are being helped but we want to help others too.” This answer shows that, at least on the part of the family if not the individual affected by disability, there is a benefit to the congregation.

Some began attending a certain congregation because they already knew members of the church through other disability ministries such as Joni and friends.

A few of the respondents had already attended their current church when the diagnosis of disability was made and continued to attend that church even after the diagnosis of disability. One father of a deaf son admitted that he and his family had considered joining a church with an intentional deaf ministry but decided to stay with their

current congregation due to “[d]istance, history with the church family,” and the fact that the other church “had mostly deaf adults and hearing children, if it had had more deaf kids [they] might have gone that route.”

This is an interesting comment that could point to issues of assimilation in churches with ministries aimed at specific disabilities. Would it have been just as difficult for these parents to feel welcome at a church for the deaf as it is for those with disabilities to feel welcome at a church for those considered normal? Is there a level of assimilation expected in such a setting?

Some attended a particular church because of family connections or loved ones who already attended that congregation. One respondent indicated that they originally attended the church because it was “closer to home” but stayed “because of the love [they] felt and because of the disability ministry. (Both boys felt like they fit in more.)” Another parent noted that her son chose the church for the youth group.

One survey mentioned “the acceptance and love and kindness everyone shows to individuals and families affected with disability.” The only person who mentioned an action by clergy answered that her “Priest was willing to welcome [her son] into the parish and was open to seeing to our family needs.” This answer indicates that clergy openness and responsiveness to the needs of those with disabilities can be an important foundation for disability ministry. If clergy and lay leaders are not able or willing to consider and address the needs of those affected by disability, it is unlikely that an intentional disability ministry will grow and thrive within a congregation.

If this church did not have an intentional disability ministry program would you continue to attend?

This question attempts to determine how important the intentional disability ministry of a church is to those who participate in that ministry. Because most of the answers in the previous question indicated that these families attended their current church specifically because of the disability ministry, it would seem to follow that if the church did not have an intentional disability ministry, they would no longer continue to attend that church, but the answers to this question were much more varied than expected.

Several respondents did indicate that they would no longer attend their current church if there weren't a disability ministry. The most common explanation for this was that these families wanted to be in a congregation where their loved one would be included. The father of the deaf son mentioned above wrote that if his church "had not been willing to provide ASL [American Sign Language] interpreters and alternate keyboard typists for [his son he] would have had to find other options. It was not an option for him to be excluded." This answer echoes an answer in chapter two that those with disabilities are part of the community too and all members want to be together (see p. 41).

One person indicated her involvement in disability ministry has led to her being the most involved and connected she has been in a church, so she was uncertain whether she would continue to attend if that ministry did not exist.

Another mother explained the difficulties involved in attending church if no disability ministry were offered: "My husband and I would have to alternate weeks so one of us would always have to stay home with our son. There would be no other way for us to attend as a family." She also mentioned that they may not be attending church at all if it weren't for her son: "It was because of our son's disabilities that we began attending [this

church]. Without him, we may not be attending [this church] or even attending a church at all.”

A third parent admitted that, although she would continue to attend this church, without this type of ministry “[s]ome Sundays it would be easier to stay at home.”

All of these answers give some insight into the day-to-day difficulties families affected by disability face. For families who have the added stress of disability and who have to make the extra effort to deal with disability daily, the existence of an intentional disability ministry may be seen as an issue of Christian hospitality. These ministries are meeting families where they are and allowing them the opportunity to worship together. They also point to a deeper need: families, when faced with the challenge of disability, desire to be part of a faith community that is willing to support the entire family in that challenge.

For those who answered that they would continue to worship at their current church despite the absence of an intentional disability ministry, the reasons given ranged from a sense that their child had already been accepted by the wider congregation to a need to continue to try to change the church “by making them aware of ‘disability issues.’”

Did you attend this church prior to the diagnosis of a disability?

This question was included as a way to begin to look more closely at how disability changes an individual or family church affiliation. If all churches were equally willing and able to meet the needs of those with disabilities, it would be expected that most of the individuals completing the questionnaire would still be attending the same church that they attended when a diagnosis of disability was made, allowing for changes from relocation, marriage, or other common reasons for transfer of church membership.

However, approximately 80% of the respondents indicated that they had not attended this congregation prior to a diagnosis of disability. Only one respondent indicated that a change was made due to a move.

Given the answers to the previous question and to this question, it seems clear that for families affected by disability, the inclusion of their family member is a priority in choosing or staying in a congregation. If a family does not feel welcome or does not believe that the needs of their family member affected by disability are being met, they will seek another congregation where they believe those needs will be met.

Some of the answers to this question and the previous question beg another important question related to disability ministry: does the diagnosis of disability draw families back to church or to church for the first time? In that case, the church in general may be missing out on a valuable form of ministry if it continues to ignore ministry to those affected by disability. In light of this it would have been helpful to know whether these individuals and families attended any church at the time of diagnosis or whether a diagnosis of disability led these families to become involved in a church either for the first time or to return to church after an absence from regular attendance.

How does your family member participate in the disability ministry program of this church? How does your family member participate in the life of the congregation?

From the answers given, it is clear that congregations offer a wide array of disabilities ministries. This question examines how individuals with disabilities are involved not only in ministries aimed at reaching those with disabilities but also how they are involved in the life of the congregation.

A few of the answers given explained ways that parents participated in or helped with the ministries of their congregation rather than ways that the family member affected by disability participated in disability ministries offered or in the life of the congregation.

For those who gave information about their family member with disabilities, the most common answers to the question of involvement in disability ministry were involvement in respite programs offered by the congregation and involvement in Sunday school classes. Some indicated that their child attended special needs education classes, while others indicated that their child was involved in a one-to-one buddy program that allowed their child to attend a Sunday school class with their non-disabled peers.

Only one respondent indicated that, by choice, her daughter was not involved in the church: “She doesn’t really participate, because she chooses not to. But everyone at church greets her and even our [sic] new pastor acknowledged her birthday when she attended church service on her birthday.” Another father indicated that his deaf son “participates in the life of the church pretty much like other kids his age, with certain minimal limitations. He is part of the appropriate age Sunday school, he pays attention to the sermon and other aspects of worship as much or as little as other children his age (14).” These answers remind us that individuals affected by disability are individuals, with individual desires just like any other person. The father of this fourteen-year-old boy reinforces this fact by pointing out that his son is more like other kids his age than not concerning involvement in the life of the church.

Several parents indicated that their child with disabilities not only participated in the ministries provided for those with disabilities, they also helped serve on these ministries. One daughter serves as an aide to her church’s respite program. Another individual indicated that her daughter has been “asked to speak about disability to

different groups of people at the church.” This example seems to be the exact opposite of the case used in chapter one relating to the American Lutheran Church and to the exclusion of those affected by disability from what Eiesland referred to as the “speaking center.”

Another parent mentioned that his son has “served as a 1:1 buddy for a younger child with autism and as an intentional friend of a teen with autism” These answers support the view of these family members that their sons and daughters have something to offer the church, although that belief was not shared in the questionnaires provided by staff members.

The other common area of involvement for those responding to this question was involvement in Christian education or Sunday school. Some of the respondents mentioned involvement in education classes aimed specifically at those with disabilities: “Our son... attends our Sunday School class... that was created for members of our congregation who have mental retardation.”

Others indicated that their family member attends inclusive classes with a one-to-one buddy. One father admitted that while the current situation may not be ideal, he and possibly others involved in the ministry are looking to increase his son’s involvement in the life of the church: “[My son] is not with his typical peers but we are working on finding ways to teach him about the Bible and eventually, include him more.”

This hope, that a child would become more involved in the life of the congregation, was echoed by another father: “Our [church’s] approach to communion (eucharist) is that anyone age 12 and older who wants to follow Jesus is welcome to partake, and [my son] has done that since age 12. I hope that some time in the next several years he will choose to go through catechism class, be baptized, and join the church.”

Again, these answers show a parent's concern for the spiritual well-being of a child and reinforce the fact that these are parents and children just like any other parents and children struggling with issues of faith, church involvement, and church membership.

Another parent whose child is involved in a one-to-one buddy program wrote that "as parents, knowing they have a buddy, we can serve in other areas like nursery or being a greeter. We would love to do more." The buddy program allowed not only their child with a disability to be more involved in the life of the church but also allows them, as parents of a child with disabilities, to become more involved in the life of the church.

Some of the answers indicated that family members affected by disability served as greeters or ushers for worship services. One parent responded that her son is "an unappointed greeter! (Ha!) He's very social and greets everyone he sees. Each greeting varies from a verbal 'hi', 'I see you' 'E-I-E-I-O' or 'yeah baby' or a high 5. He's well known for his inability to remain still and is in constant motion. More people in the church know him than us!"

A few parents indicated that their children serve the church in addition to participating in the disability ministry programs. One young man "volunteers twice a week to ready the sanctuary for service, shred paper for the office, and do light janitorial work." This service to the church meets needs in addition to spiritual and religious needs for these individuals. This additional involvement in the church also meets social needs and can promote feelings of worth and a sense of accomplishment.

Participation by these individuals ranged from intentionally choosing not to be involved in the disability ministries offered, to being as involved or not involved as other children the same age, to serving the ministry in some capacity. These answers remind us that these are individuals just like any other members of the church, and that they can and

should make decisions about levels of involvement that are appropriate for them and their families.

How has your family member with disabilities been welcomed in this church?

For this question, I was looking for specific ways that family members with disabilities have been welcomed into a congregation. On several questionnaires, it seems this question was misread to ask whether the family member has been welcomed and not how, so several answers were simply, “yes.” For those who answered in more detail, the common answers were that their family member was “warmly” or “well” received or welcomed with “open arms.” Consistency in welcoming those with disabilities also seemed to be a common thread among these answers. One person indicated that her family had been “[w]elcomed by open arms from [their] first Sunday there. Everyone is very friendly and interactive with [our son]. The 1-to-1 buddies/volunteers paired with him are energetic and know how to work with him. The ministry tries to pair people who might work well with our son. He’s a big handful and can be very difficult. They’ve matched buddies who are good with his personality.” Another parent echoed the importance of that consistent welcome “[My son] is welcomed with love and affections, routinely...every Sunday and every time we set foot in this church.”

One answer also reaffirmed the belief that individuals affected by disability are not loved any less than anyone else. For this individual, being valued and accepted are important parts of being welcomed. For some families, the ministries provided make the church welcoming: “[Our] Church has provided 1 to 1 Buddies for both our boys during the church service, respite at church once a month and a pampering day.” In another case it

was the willingness of the congregation to try to meet the needs of the person with disabilities that was seen as welcoming, although there were some difficulties at first:

Ideally church leadership should take initiative to find services as needed for disabled attenders, to ask parents or adults with disabilities what their needs are and be proactive. This is harder for a small church than a larger I am sure.

From a parent's perspective, one is overwhelmed at first having a child with a disability, and may continue to be maxed out with time considerations and stresses for a long time. So if the church takes the initiative and doesn't leave it to the parents it is hugely helpful. Parenting a child with disabilities can be very stressful over long periods and involve stressful decisions, church at best can be a place of respite. (Deafness is an "easier" disability in my opinion, in fact many culturally Deaf people don't regard it as a disability at all but as a defining feature of their language and culture. Nonetheless for hearing parents it doesn't look that way, and there are many hard choices. For us a short list was choice of language (ASL or spoken English), hearing aids or not, later cochlear implant or not, mainstreamed education or not. We did choose cochlear implant surgery at age 3, which was a very hard decision and stress of major elective surgery. In deafness all these choices are politically polarized, with very different opinions out there, very overwhelming to a parent.)

When my late wife, [my son's] mother, died of cancer in 2006, [our church] was very supportive of my 2 boys and me. They provided an interpreter at the funeral service, which was absolutely essential. Many attenders told me also they found the interpretation very moving. I don't think [my son's] experience of the church through that experience was any different than mine or that of his hearing brother.

The same parent who gave the above answer also made an interesting point about the church providing sign language interpreters for his son: "Early on several adults took ASL classes, and [the church] sponsored a several-week basic vocabulary evening for the children of the church. Unfortunately as with most languages, if you don't use it regularly it doesn't stick, so there is minimal fluency in ASL among members." This comment serves as a reminder that disability ministry is an ongoing ministry, and that there are challenges to maintaining such a ministry. Disabilities do not generally go away – they are usually lifelong aspects

of the person affected, and so churches seeking to provide disability ministries must take this fact into account.

One person indicated that it was not so much the welcome of her family, but the congregation's support of her, personally, during difficult times that made her feel welcomed:

I would be lost without my church family... I'm the one that needed prayers when we were going thru the agonizing time of getting seizure-free; and now being the sole caregiver of my 83 yr. old mom who has been dealing cancer, you betcha [sic] I needed that prayer shawl to wrap around myself during these past 3 yrs. without my dad.

Why do you think it is important for your family member to attend church? Why is it important that you attend a church with an intentional disability ministry?

The answers to this question fell mostly into two categories with some overlap between the two. The first reason that people gave was the importance of a relationship with God. The second reason given was the importance of developing relationships either with other Christians or with other families affected by disability.

For those who answered that attending church is important in establishing or building a relationship with God, their specific reasons ranged from attending church "because life is found in Jesus and we need to connect with that life! The DM [Disability Ministry] helps with the connection process" to believing that their family member with disabilities "has the right to practice his faith" with the implication that he has the right just like any non-disabled person has the right to practice his or her faith.

In some cases, the importance of a relationship with God was expressed not only for the individual affected by disability but also for other family members. For one family, the existence of a disability ministry is what allows them to attend church and strengthen their faith:

As it is for any member, to strengthen your faith in God, to serve Him, to encourage and love others. With a disability ministry, our boys feel a part of the body of Christ. They can be taught God's word, how to love others, in their own way. Attending a church with a disability ministry allows us to have uninterrupted time to worship and connect with others.

Another parent indicated that worship is just as important to her and her marriage as it is to her child with disabilities: "We want to always continue to grow spiritually closer to God and to each other in our marriage. To do that, we need Buddies so we can attend church together."

Some answers indicated that there is a benefit to those not affected by disability when a church provides a disability ministry: "People need to be able to learn to enter into the lives of those affected with disability because it is gift to see how the suffering of those with disability leads them to worship and praise God. It is a challenge to us 'typical' Christians. I need my daughter to be included because she is important and has much to offer to the church." Another answer suggested that God uses those affected by disability, not to reveal punishment as discussed earlier with respect to scriptural passages related to disability, but to show the love and character of God: "She has a heart for worship and loves God so much. She has a beautiful spirit of God within her that He uses to reveal his love and character."

Other answers indicated that they had received benefits by being part of the disability ministry but also believed it was their Christian duty to minister to others in need: "1. To feel he's no less important to God; 2. For support, but also offer support to other families that are affected by disability."

One parent touched on many of the theological assumptions I am examining through these questionnaires:

I want my sons to follow Jesus. My whole life is about trying to live ethically and follow Jesus' teachings, to me it is the core thing despite often-confusing

theological questions. If my sons chose not to follow Jesus and reject the church I would be more than disappointed, I would feel I had failed as a parent. But it has to be their own choice. The fact that [our church] has welcomed [my son] with the same open arms with which they welcome all our church children is very important to me. On the practical level they recognize his deafness and that he needs certain accommodations, but on the personal level there is no division between him and the other kids, he is “one of us.” To me attending church isn’t about getting services for [my son], it is about him being part of the church on the same footing as everyone else. Here I guess I think we are mistaken if we think too hard about the phrase “disability ministry.” If it means inclusion, that is wonderful, if it indicates “we” the non-disabled are reaching out to “them” the disabled, then it is a kind of misunderstanding. On a certain level there ain’t any disabled or non, ugly or beautiful, damaged or non-damaged. Everyone has damage in their life some way, some are more visible than others. Everyone has strengths and limitations. If a church isn’t automatically including people with disabilities, people with any kind of problems in fact, then it had better examine its heart because it isn’t following Jesus.

This father begins his answer to this question by emphasizing the importance of his son’s relationship with Jesus and the church. Although this answer was not a common answer for family members when discussing the purpose of disability ministry, as it was for staff members, the importance of their loved one’s relationship with God was expressed throughout the family questionnaires as it was in this instance.

This father goes on to mention that the church welcomes and accepts his son the way he is, just as they welcome and accept any other child of the congregation. His son is accepted “on the same footing as everyone else” and “with the same open arms with which they welcome all our church children,” implying that his son does not have a relationship with God that is any different from another person’s relationship with God – he is not being punished by God with disability or being held up as an example because of his disability (there is no denigration or trivialization of disability).

Assimilation is not expected either. The disability is recognized and accommodations are made for it, but the disability does not lead to a differentiation between this young man

and other children. The congregation seeks to meet his particular needs, but welcomes him into the life of the congregation in the same way other children his age are welcomed.

This father, like Nouwen, Eiesland and Reynolds, also realizes that we are all “damaged” in some way and that any distinctions we make based on outwardly recognized disabilities are purely arbitrary. In his own words, he recognizes the existence of a cult of normalcy and the contingency of “normal” life.

The second category of answers to this question involved those parents who believed an important aspect of attending church was the opportunity, for the family member affected by disability as well as other family members, to build relationships with other people: “He needs the social aspect and being around people. He needs to have somewhere safe to go when not at home... change of scenery” or with other families who share the experience of having a family member affected by disability: “For the love, acceptance, support and connection with others who truly understand what you are going through.”

This connection with others going through or who have gone through similar experiences may relate to issues of assimilation. If there are other families within a faith community whose lives have been touched by disability, it may be assumed that assimilation would not be an issue. After all, in a diverse congregation to what would people be expected to assimilate? In such a setting can a culturally defined norm be assumed?

Another mother felt that it wasn't that important that her church community knew exactly what she was going through as long as they were supportive: “I don't think its [sic] important to attend a church w/ an intentional disability... if it doesn't have one, then create one. If you have to pick your battles, then leave it in God's hands, and He will surround you with the community of people that will be there for you... even if they don't

know exactly what you're going thru, but they are rooting for you." She was just wanted her daughter to know "she has a church family; she even has a 'Christian brother' who she refers to and he has special needs but not as severe as my daughter."

Another parent provided an article that she had written about her son's experience at their church and gave me permission to include it in this paper. This article relates not only the ways that her son, Matthew, is involved in the life of the congregation but also just how important that involvement has been for Matthew and for her.

My View
By Ellen Herman Campbell

Matthew, our son, provides the soundtrack for our Sunday drive to church:
"Jesus takes care of us. We should believe in Jesus, right, Mom? Right, Dad?"

"Everyone will be glad to see me."

Then, he adds gestures, emulating our Pastor and paraphrasing the liturgy,
"God says, you may drink the cup in re-remembrance of me."

He repeats these words and phrases to prepare his heart and mind for worship. Simple sentences...childlike understanding, but Matthew at age 34 is far from being a child. Our son, diagnosed with mental retardation at age two, is a grown man who lives, works, and worships in his community. And Sundays are clearly the highlight of his week.

We arrive at church, and even before we enter, Matthew is greeted by name repeatedly. He stands taller. He easily follows the path to the sanctuary, nodding and smiling his own welcome with a raised wave or a shy hello. The first Sunday of the month, we arrive early to begin our ushering duties by passing out bulletins. He enjoys wearing a coat and tie on those days.

Matthew participates fully in worship, having memorized the liturgy because of its oral nature. From the predictable flow of our service, he has learned to kneel, share a greeting, pray, and make his offering. At communion, he rises, intuitively understanding the difference between rail communion and intinction. He receives the bread and comforting words from Pastor Steve, "The body of Christ given for you, Matthew."

Sundays are not the only days Matthew finds solace in the sanctuary. As part of his day program, Matthew, along with his job coach, volunteers his time to ready the pews, empty waste baskets, or fold bulletins. He is proud of his contribution and basks in the praise of those who notice.

Even though society has evolved to be more welcoming to those with handicaps, Matthew's journey is not an easy one. For my son, our church, the building and its people, serve as a refuge from a challenging and complex world. Because of his participation in the life of our congregation, Matthew knows a lot; he understands the importance of fellowship, the role of worship, the responsibility of service, the nature of Christian love, and the basic tenet of God's good and omnipresent grace. For all these things given my son, I remain most humbled and grateful.

For this young man, church is a refuge from a world that, although more accepting of individuals like him, is still a challenging place for him. Through his involvement in the congregation, his mother believes he has come to understand "the importance of fellowship" and "the nature of Christian love." These are valuable and meaningful for both Matthew and his mother, but what has the congregation learned or received from having Matthew in its presence? This is a question that was overlooked by the staff who completed the questionnaires as well, and it would seem from this that disability ministry is still, to a large degree, ministry to and not ministry with those affected by disability.

What scripture passages, if any, inform your view of the church and disability ministry?

The answers to this question fell into several categories. The first category is made up of answers that seem to give scriptural reasons for providing disability ministry. The scriptures cited include the banquet for the poor, crippled and lame in Luke 14; bringing good news to the oppressed in Isaiah 61:1-4; and the admonition to let the children come to Jesus in Matthew 19:14-15.

All of these verses speak to the inclusion of those perceived as weak, powerless, or affected by disability such as blindness or a crippling disorder or disease. Although the respondents did not give the reasons that these scriptures are important to them, it would seem that in these passages they find Biblical support for the disability ministries that are

important to them and their family members. As noted in previous chapters, these scriptures are not specifically related to disability per se. Instead, they reveal a divine concern for those who fall outside the realm of acceptable or normal.

Many of the families who provided information see inclusion as central to disability ministries and to their attendance at a particular church. The scriptural passages referenced deal with inclusion, but inclusion is usually an afterthought or the result of a refusal by “normal” individuals. Are these families so accustomed to being excluded or having their family members excluded that they don’t care at what point their family member is accepted as long as they eventually are? Do they accept this “second-class citizen” treatment because it is so prevalent in our society and the church? Just as I thought about the implications of taking my daughter in the back door of the church but did nothing about it, these parents may just not be up to fighting the status quo (see Pinsky). The churches they attend are far from perfect, but they are still better at accepting their family members with disabilities than other churches are or have been (see the section on how their view of church has changed).

A second category of answer included non-specific quote or generalizations of themes within scripture, usually the life and teachings of Jesus:

Here as with other issues for me it is Jesus and his life and teachings, his healing, his ministry. It seems to me he was a terror to the complacent, to the mainstream, to those who “knew the rules,” to those who look at how things appear but close their heart. He was a healer, he touched lepers, he interacted with Samaritans and “unclean” women, he apparently loved children. He had harsh words for some but he was always gentle and healing with those who were damaged or outside.

One answer mentioned “God’s multiple promises to the poor, broken, needy, lonely, etc.,” and another simply stated “Love one another.”

The third category includes scriptures that speak of God’s plan for us such as:

Psalm 139:13-14: “For it was you who formed my inward parts; you knit me together in my mother’s womb. I praise you, for I am fearfully and wonderfully made. Wonderful are your works; that I know very well.”

Jeremiah 29:11: “For surely I know the plans I have for you, says the LORD, plans for your welfare and not for harm, to give you a future with hope.”

Romans 8:28: “We know that all things work together for good for those who love God, who are called according to his purpose.”

A related category includes scriptures related to God’s power as in Mark 10:27: “Jesus looked at them and said, ‘For mortals it is impossible, but not for God; for God all things are possible.’ More than one respondent mentioned Philippians 4:13: “I can do all things through him who strengthens me.”

A few answers revealed an uncertainty about scripture and Biblical knowledge, sometimes even in spite of growing up in the church: “I’m not very proficient (yet!) at knowing where certain scriptures are in the Bible. I was not raised reading the Bible even though I went to church every Sunday growing up.” One person answered that he did not know of any scriptures but wanted to hear some suggestions. Another parent, in addition to a scripture verse, included a non-scriptural quote in answer to this question (also included in chapter two): “When we attend to the needs of those in want, we give them what is theirs, not ours. More than performing works of mercy, we are paying a debt of justice. – St. Gregory the Great.”

Speaking of attending to the needs of others as a debt of justice reflects back to George’s comment that “churches... should attend to this issue as an issue of justice, that people with disability, too, are part and parcel of the church” (103). Disability ministry, as seen in this light, is not charity, it is what should be done in a Christian community.

There was surprising overlap between the answers given in chapter two by staff members and the answers given here by parents. Again, most of the scriptures cited do not

relate specifically to disability, but instead to issues of inclusion and hospitality, and occasionally to God's power or plan for our lives.

How has your view of the church changed since having a family member with a disability?

Perhaps the answer that best sums up the responses to this question is: "It is mixed, I hear a mix of uplifting stories and horror stories." The answers to this question were also mixed. Some answers spoke of previous church experiences in comparison to their family's experience within their current congregation: "The church for many years of my daughter's life did not recognize our needs or help [her]. We were left out. [Our current] church has done much more for [her] in the past 3 years of any church in her 55 years!"

Some answers implied negative experiences at other churches:

The "Church" as [this church], I feel is accepting and loving towards people with disabilities. The "Church" as a whole (many churches and Christians) don't know what to do. They stay away because they don't feel comfortable or it comes across of "bad parenting" or "bad kids". At [this church] we feel like coming to church.

One respondent spoke of their reluctance to even attend their current church based on the type of church they had grown up in:

Before attending [this church], I always thought it was too big of a church for us to feel comfortable attending, let alone feel welcome. (We're from small-town churches.) We wanted a church that wasn't so big that we felt intimidated to try to get to know people. We also like a church where we're known by a small group of people. Our view of [this church] as a whole was way off base from what we initially thought (before attending). The disabilities ministry has meant (and still does) the world to us. The two of us can attend the service while knowing our son is safe and is having fun. We can attend as a family.

The desire to attend as a family reveals the importance of disability ministry and acceptance or inclusion not only for the individual affected by disability but also for the entire family.

Several answers mentioned that the person answering thinks of the church as “the hands and feet of Jesus Christ” and that the congregation in which they are currently involved has done “more than just talk about it with the loving actions.” Another stated that “[s]ince coming to this church I have seen a church family who are (demonstrate) the hands, feet, voice of Jesus like I have not seen before.” It is interesting to me that so many people talk about being the “hands and feet” or even “voice of Jesus” when discussing the issue of disabilities and disability ministry. These comments begin to touch on the subject of disability and embodiment, and remind us how easily we slip into language and practices considered “normal” but which can be disempowering even when discussing disability ministry.

A few of the answers also touched on “the cult of normalcy” in their own words: “We see that prosperity and “comfortableness” with normal lives in the church affects how people see families with disabilities. This church is unique in their heart for these families.”

This is the only time that the issue of prosperity was mentioned in any of the questionnaires (although some of the scriptures provided did touch on concern for the poor). This raises questions about an association, real or perceived, between disability and poverty. This association may be a reality for some of these families due to costs associated with care for a family member with disabilities, an inability of that individual to provide for himself or herself, or an inability of a parent to work full time or at all.

One parent indicated that, although he was certainly aware of his own child’s disability, he has become more aware of issues of inclusion on a broader scale:

I think it has emphasized what I already thought, that the church should pay less attention to looking nice and being a nice social club, which sometimes happens. People’s lives are messy and damaged and the church needs to get in there and maybe look messy and sound noisy if necessary. If Jesus transforms people then they have a warm heart for others who have needs, disability or otherwise, and they will form churches that reach out and include. I think I

understand the “we” of the church to be bigger now, I see how people’s inclusion of [my son], and more recently of our autistic children, helps change all of us in good ways. I understand a little about autism now that I didn’t before, my sons regard these kids with autism as interesting but not scary, the older boy is increasingly part of the youth group and he is one of them, not an “add-on” to be nice. He is not other, [my son] is not other, because of their different disabilities, now that we know them and include them they are part of the body like anyone else.

This answer is reminiscent of Nouwen’s definition of hospitality being “the ability to pay attention to the guest” (The Wounded Healer, 89). When we are open to the guest and accept them for who they are, the church will be messy and noisy because people’s lives are noisy and messy. One thing that I have come to realize, and that many of these parents have come to realize as well, is that having a child with disabilities tends to make one much more accepting of people in general. When you have a child who makes noises at inopportune times, or who as an adolescent still wears diapers, or who can’t clearly communicate with others, you tend to be much more forgiving of what the world sees as shortcomings in others.

One parent answered that his view had changed “because I was raised Catholic and now I’m at a Brethren in Christ church and loving it!” Although the answer did not indicate that this change was directly related to the disability ministry or the fact they were affected by disability, that could probably be assumed through the wording of the question.

Only one respondent mentioned anger as an initial response. This anger was transformed into a desire to change the way things were and, finally, recognition that ministry related to disability can be a difficult ministry for a church to sustain:

At first I was mad, but then, I wanted to change the world. So I started w/ the coalition to be “trained” before I would present to the Council of Ministries Ginny Thornburgh’s Accessibility Plan years ago. They listened, they formed a committee, they tried. They had a “buddy” for my daughter throughout Sunday

School; and a very loving pastor at the time actually “confirmed” my daughter – that is all I wanted. I wanted her to be confirmed!

The one thing that the answers to this question had in common was that they were not neutral. The experiences that these families have had within the church have influenced their views of the church in clearly positive or negative ways. Some mention experiences so negative that families leave the church. Other experiences, usually those where families found inclusion for the entire family, were described in a very positive light.

Summary

Most of the parents answering this questionnaire saw the purpose of disability ministry as the inclusion or acceptance of their child by a faith community. The consistency of this inclusion was a common concern. A few answers went beyond just inclusion to see these ministries as a way for the church to celebrate the gifts that those with disability bring to a faith community and revealed the belief that, in addition to the primary purpose of inclusion, there is a secondary benefit to the congregation in offering such ministries. Such references to congregational benefits received through intentional disability ministry were exclusive to the parent questionnaires. This further supports a ministry to approach by staff but a ministry with approach by parents.

Many of the families attend their current church specifically for the disability ministries offered, and several stated that they would no longer attend if those ministries were not provided. The reasons given revealed a fear that the individual with disabilities would no longer be included or accepted, and the acknowledgement that the difficulties of attending with a child affected by disability would be too great without the help and support of an intentional disability ministry. For those parents who would continue to

attend a particular church despite a lack of disability ministries, the continued inclusion of the family member was central to that decision.

Similar to the amount of participation reported by staff members, there was a wide range of participation by the individuals affected by disability and by their families as well. Some of these individuals attend only special needs education classes and worship services while others not only attend but also actively participate in the life of the church including during worship.

Regardless of the level of participation, most of the parents believed it was important for their child to attend church. In general, two reasons were given: it was important for their child to develop a relationship with God, and it was important for their child, or for the whole family, to develop relationships with other Christians or with other families affected by disability. It may also be the case that when several families affected by disability worship together, the expectation of assimilation is greatly diminished.

The scriptures that parents found helpful in explaining disability ministry were quite similar to those mentioned by staff members. The answers fell into similar categories: passages that show inclusion of those perceived as weak, passages that show hospitality, and passages that speak of God's power or plan for our lives. As in chapter two, most of these passages do not touch specifically on disability, but instead show a concern for all of God's children.

The experiences that these individuals and families have had in the church are generally viewed in a very positive light or a very negative light, and more than one parent reported having first had a negative experience in another church before finding their current church home. Their view of church has changed because of their experiences in the church. The families completing this questionnaire continue to attend a church despite

having to sometimes overcome negative experiences. It makes one wonder about the many families who did not continue to search for a church home after a negative experience and underscores the importance of consistent welcome and inclusion of families affected by disability.

Chapter Four
Comparisons and Reflections

“Rather than seeing society as two separate groups, the disabled and the nondisabled, we need to understand that we are all, in fact, one combined group. And disability is what we have in common.”

Rosemarie van der Jagt

The information gathered from staff members and families could be compiled into a few fundamental categories for consideration: issues related to inclusion of the individual with disabilities and that person's family members, expectations of assimilation within a congregation, issues related to the cult of normalcy, trivialization of disability, benefits to the congregation and to those affected by disability, and issues of consistency in providing services and communication between staff and family members.

Issues of Inclusion

Based on the information provided in the questionnaires, the primary concern for both staff members and families affected by disability is inclusion, and this concern was revealed in many ways. Staff answers related to inclusion tended to focus on providing an environment that was welcoming to all, but there was little explanation of just what that meant. Many family members also mentioned that persons with disabilities should be included just as any other person would be included. If we look more closely at the answers provided by staff members and family members, inclusion may mean two different things to these two groups.

For the churches, inclusion means providing a place where all are welcome, which, on the surface, is what the families were seeking from inclusion as well, but many staff questionnaires went on to give additional insights that might reveal an assumption of assimilation or might be viewed as trivializing disability.

As mentioned above, many of the staff answers explained disability ministry as a means to welcoming all. Families would agree with this view of disability ministry to the extent that it means their family members are included in the life of the church with accommodations that make church life accessible to them in the same way it is accessible to

any other person; however, family members seem to be much more aware of issues of assimilation discussed in chapter one. If welcoming all means a true acceptance of difference, families and staff are in agreement. If welcoming all requires some level of assimilation to congregational norms, then families do not see this as inclusion.

Comments that might be seen as trivializing included viewing disability ministry as “a witness to the community” as the congregation seeks to meet the needs of those affected by disability. The congregation may see this as serving as an example to the larger community of just how a Christian church should act, but it could also be seen as a way of showing just how charitable a congregation is to those in need. Some of the scriptures mentioned by staff members also touch on trivialization such as Matthew 19:14-15: “Jesus said, ‘Let the children come to me, and do not hinder them; for to such belongs the kingdom of heaven.’ And he laid his hands on them” If this passage is used to support ministry to all children, including those with disabilities, it points to Christian hospitality; on the other hand, if it is instead used to compare those with disabilities to children, it falls into trivialization of disability.

An awareness of these issues related to inclusion is important for churches because many of the families completing the questionnaire indicated that they attend their current church because the church has a disability ministry, and several family questionnaires mentioned feeling excluded in other church settings in contrast to feeling included in their current church.

If we also take into account that the most common challenge for these churches is sustaining a disability ministry, we realize how central the issue of inclusion is. Families expect to be included in the life of the church from the first time they set foot inside the building; churches find it difficult to sustain ongoing disability ministries even when those

affected by disability are present on a regular basis. At some point each of these churches decided to begin offering ministries aimed specifically at those affected by disability.

Several churches began a disability ministry as the result of a specific and personal experience. The church recognized a need, provided appropriate ministries, and included the family affected by disability in the life of the church. The churches that have learned to do it well have drawn in other families affected by disability. As one family member indicated when asked why he attended his current church, he attends because “they have the best disability ministry of any church in [the] county.” In each of these churches, someone had to be first, and for that first family affected by disability the most important factor is inclusion. If a family feels loved, welcomed, and included, they will stay in a congregation, sometimes regardless of the specific disability ministries offered for their family member with disabilities.

The result of feelings of exclusion becomes even clearer when we consider that 80% of these families did not attend their current church when their family member was diagnosed with a disability, but many would stay in their current church even if there were no disability ministry. The most frequent explanation for remaining in the church was the belief that their family member had already been accepted and included by the members of the congregation. Additionally, some who indicated that they would leave the church if it did not offer disability ministry said it was “not an option” for their family member to be excluded. In these answers we see that the very thing that drew these families to a particular church – disability ministries – may be a means to what these families are really seeking – inclusion.

Expectations of Assimilation

While churches are attempting to provide a setting welcoming to all, families are looking for support in their specific needs. They are looking for members who will “come alongside families affected by disabilities, learning more about the challenges they face.” They do not simply want to be comfortable; they want to be part of a community that understands and supports them, and often that meant attending a church with other families affected by disability. The implication is that such a community will be more accepting of differences so there will be no expectation of assimilation.

These findings support my original assumption that families affected by disability are seeking a faith community where they are not expected to conform or assimilate to maintain the status quo. When families are not expected to conform to cultural norms within the church, genuine healing can take place. This was seen in answers that view disability ministry as a way to support not only those individuals affected by disability but also the entire family.

Two answers, both from members of the same church, mentioned that the purpose of disability ministry is “to come along side” families affected by disability. These answers imply a concern by the church not only for the spiritual and religious needs of the family, but also a genuine concern for the entire family. This church is also the congregation that mentioned providing respite, support groups, and days of pampering for families affected by disability. The staff person providing information about the congregation added that “there is a wonderful openness to do ‘whatever it takes’ to include all.”

One must wonder whether the congregation really is willing to do whatever it takes. Is there a point beyond which the congregation would be unwilling to include an individual

or family? What might that point be: lack of time or manpower or money, severity of disability, or disruption to the congregation?

A few answers from parents mentioned financial concerns when providing disability ministry, such as the expense involved in providing American Sign Language interpretation. In contrast, one staff answer mentioned that God always has blessed the disability ministry of her church, implying that this ministry is God's will, but if disability ministry becomes too expensive, or if it no longer seems to be blessed by God, is that the point at which a congregation will refuse to include all through disability ministry? If expectations of assimilation still exist in the church, and a disability is too extreme to allow for any assimilation into a congregation, will exclusion of that individual occur?

Another issue that was raised in the family questionnaires is whether there is such a thing as "reverse assimilation" with respect to disability ministries. One father shared that he and his wife decided not to attend a church for the deaf because the congregation was made up mostly of hearing children with deaf parents (the opposite of their situation). Although this father didn't specifically mention issues of assimilation for him or his wife, that may have been an issue that prevented them from joining such a church.

Because inclusion is central to the purpose of disability ministry for families and for staff members, several of the scriptures referenced deal with inclusion but often inclusion as an afterthought or as the result of a prior refusal by "normal" individuals. Two exceptions, included by staff persons, were the Corinthians passage that mentioned the importance of all parts of the body, and the passage from Ephesians 3 that states all, both insiders and outsiders, stand on the same ground before God (Peterson).

The Cult of Normalcy

It may be that these families are so accustomed to being excluded or having their family members excluded that a “second-class status” has been internalized to the point that they don’t recognize the contingency of their inclusion in such scriptures. Such an inability by these family members to see how “normal” thought processes influence beliefs and practices reveals how deep-seated the “cult of normalcy” is in society and the church.

There was a subtle acknowledgement of Reynolds’ “cult of normalcy” and the contingency of normal life in the answers provided by staff, and even more in the answers provided by family members which touched on issues of prosperity, normalcy, and how cultural norms affect families dealing with disability. Some family members revealed a deep understanding of the cult of normalcy and the contingency of life: “On a certain level there ain’t any disabled or non, ugly or beautiful, damaged or non-damaged. Everyone has damage in their life some way, some are more visible than others. Everyone has strengths and limitations.” Others seemed unaware of how cultural norms continue to affect our beliefs and even the language we use: “[We attend b]ecause... they encourage members to be the hands and feet of God” and “[s]ince coming to this church I have seen a church family who are (demonstrate) the hands, feet, voice of Jesus like I have not seen before.”

This acceptance of societal norms was also seen in the particular scriptures chosen by staff members and family members. Psalm 139:13-16, which speaks of being fearfully and wonderfully made by God, was included in the staff answers as was Exodus 4:11: “Then 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?” This verse sounds very similar to the scriptures mentioned in chapter one which showed God punishing those who don’t obey with some form of disability: God gives and God takes away.

What is surprising is that the answers from family members referenced similar scriptures including Psalm 139, Jeremiah 29:11, Mark 10:27, and Romans 8:29 which all speak of God's power and purpose and verge on divine responsibility for disability. Psalm 139 speaks of being formed by God. If we are all formed by God and knit together by God, then disability must be formed by God as well. The verse from Jeremiah says "surely I know the plans I have for you. If God knows the plans for each one of us, an individual's disability must be part of that plan. This verse goes on to say that God will give a future with hope, and the verse from Mark tells us for God all things are possible. Does this mean that these parents are hopeful about their child's prognosis? Does the verse from Matthew begin to touch on hopes of healing and conformity according to the medical model? Or does this verse instead point to a strength found in God to handle the struggles of having a child with disability? Individual interpretation of these passages is vital to understanding why these particular verses are important; unfortunately, this information was not provided on the questionnaires.

Trivialization of Disability

Also surprising were the ways that family answers tended to slip into denigration or trivialization of disability. One individual who mentioned coming alongside a family affected by disability also believed it was the role of the congregation to "show God's love in a special way." As mentioned in chapter one, if this answer presumes a special relationship with God, not only for the individual affected by disability but also for the family members, it might lead to trivialization of disability as something that serves a positive end for those providing the ministry.

When disability is trivialized, churches and possibly even families, tend to see the purpose of disability ministry as ministry to which means they see little or no benefit to the congregation through the provision of disability ministries. The only staff answer to even hint at a congregational benefit to offering disability ministry was an answer that mentioned those with disabilities using “their God given gifts in service to the Lord.”

Families tend to view disability ministry as ministry with – children do ministry, family members do ministry – and so see benefits to the church family including increased involvement and opportunities to learn more about disability and how families are affected by disability. As one parent put it, “the church learns too about life with a disability, its pluses and minuses, it opens our eyes to the many ways people live in the world.”

One father summed up the difference between ministry to and ministry with like this: “Here I guess I think we are mistaken if we think too hard about the phrase ‘disability ministry.’ If it means inclusion, that is wonderful, if it indicates ‘we’ the non-disabled are reaching out to ‘them’ the disabled, then it is a kind of misunderstanding.”

Even while recognizing a benefit to the congregation, some comments continued to trivialize disability: “People need to be able to learn to enter into the lives of those affected with disability because it is gift to see how the suffering of those with disability leads them to worship and praise God. It is a challenge to us ‘typical’ Christians.”

Benefits to the Congregation, to the Individual, and to the Family

In addition to providing insight into life with a disability, individuals affected by disability are often not only recipients of these ministries but also serve these ministries as well, for example as a one-to-one buddy for another member with disabilities. In a few instances, the person with disabilities also volunteered in other areas of church life by

helping to stuff bulletins or by doing janitorial work. Many family members other than the individual affected by disability also become involved in the ministry of the church. These families acknowledge that they do receive benefits from the disability ministry, but many feel it is their Christian duty to give back as well.

From the point of view of the families, one of the most important benefits provided through disability ministry was the opportunity for their family member to grow in his or her relationship with God. Only one of the staff questionnaires specifically mentioned disability ministry as a way to encourage those affected by disability to “know Christ in a personal way.” Although only a few of the parents mentioned a relationship with Jesus or God when asked about the purpose of disability ministry, this reason for providing disability ministry was mentioned in other places on the family questionnaires.

One father saw developing a relationship with God as central to his role as a father to both his disabled and his non-disabled son: “If my sons chose not to follow Jesus and reject the church I would be more than disappointed, I would feel I had failed as a parent.” This same father acknowledged that his son was involved, or not involved, in the church much like other kids his age, and his was not the only answer that attempted to explain a child’s involvement or lack of involvement in the church.

Issues of Consistency and Communication

Answers related to involvement in the church remind us that these are families, children, and adults just like other families, children, and adults; and they choose to be involved or not involved just as anyone else would. There was no indication that a lack of involvement was due to a lack of inclusion, caring, or appropriate ministries by the churches. If we contrast this answer to one provided by a staff member when sharing his

biggest challenge, there may be some tensions related to expectations with consistency of ministry and consistency of involvement.

The particular staff person believed that some responsibility for disability ministries rests with the families and that to continue such ministries required “[c]onsistent attention and sensitivity on our part. Consistent participation on the part of our families [sic].” Other staff member answers provide additional insight into this discrepancy mentioning supporting an “individual with disabilities... when a need arises” or “paying attention to... needs when they are with us,” but it is unclear whether such an “as needed” approach can provide the level of attention and consistency parents expect from disability ministries.

Parents, when asked how their family member has been welcomed in their church, mentioned consistency in the welcome - “every Sunday and every time we set foot in this church” - from their very first visit. One father expressed the view that it should be the church’s responsibility to take the initiative in providing appropriate ministries: “Ideally church leadership should take initiative to find services as needed for disabled attenders, to ask parents or adults with disabilities what their needs are and be proactive.”

Another staff member expressed some frustration in trying to get family members to express their needs so the church could try to meet them. All of these answers show the importance of communication between staff persons and families in this process of providing disability ministries. Developing methods of communication is vital because disability ministry is generally a long-term endeavor, and one of the greatest challenges faced by churches is maintaining such a ministry over long periods. In fact, this was the most common challenge faced by congregations.

Another issue related to communication and disabilities in general, and so disability ministry as well, is the polarization that can occur. This polarization was mentioned

indirectly in staff answers. Some churches offer only separate ministries for those affected by disability, but almost apologetically go on to say that greater inclusion in the life of the congregation is an important goal. Some churches provide both, separate services for those with disabilities as well as services within “normal” ministries, in an attempt to accommodate families and minimize polarization. One parent even called this polarization “political” and explained that differing opinions can be overwhelming to a parent trying to cope with disability.

Conclusion

The information obtained from these questionnaires begins to reveal some of the issues involved in providing disability ministry: the expectations of inclusion by families and the attempt to be welcoming by church staff; the trivialization of disability that still exists in the church and the cultural norms that we often don’t even realize exist; the hope for genuine healing of not only an individual affected by disability but also an entire family affected by disability; the belief that everyone has something to offer and that churches can benefit by welcoming families affected by disability, and the view by many churches that they are providing ministry to someone in need but not necessarily receiving anything in return. All of these issues are tied up in the lives of these individuals, those affected by disability and those seeking the best way to provide disability ministry.

Perhaps the best example of what disability ministry should be was written by a father about his wife’s funeral:

When my late wife... died of cancer in 2006, [our church] was very supportive of my 2 boys and me. They provided an interpreter at the funeral service, which was absolutely essential. Many attenders told me also they found the interpretation very moving. I don’t think [my son’s] experience of the church through that experience was any different than mine or that of his hearing brother.

This is disability ministry: providing the necessary services for an individual affected by disability so that the experience of God, worship and community is no different for that individual than it is for anyone else.

Appendix A

Questionnaire for Staff Members of Churches with Intentional Disabilities Ministries

Name (Optional): _____

Involvement with Disability Ministry: _____

Church Name/Denomination: _____

Church Location: _____

Number of Members: _____

What do you see as the purpose of intentional disability ministries?

Why did this church begin a disability ministry?

How do individuals with disabilities participate in your disability ministry program? How do they participate in the life of this congregation?

How does this congregation specifically welcome individuals/families affected by disabilities?

What has been the biggest challenge to the establishment or continuation of the disability ministry of this church?

Why do the members of this congregation think it is important for individuals with disabilities to attend church?

What scripture passages, if any, inform your disability ministry or your decision to establish an intentional disability ministry?

Appendix B

Questionnaire for Parents or Families Affected by Disability

Name (Optional): _____

Church Name: _____

Involvement with Disability Ministry: _____

Please provide the age, diagnosis, and age at diagnosis of the family member affected by disability:

What do you see as the purpose of intentional disability ministries?

Why did you choose to attend this church?

If this church did not have an intentional disability ministry program would you continue to attend?

Did you attend this church prior to the diagnosis of a disability?

How does your family member participate in the disability ministry program of this church?
How does your family member participate in the life of the congregation?

How has your family member with disabilities been welcomed in this church?

Why do you think it is important for your family member to attend church? Why is it important that you attend a church with an intentional disability ministry?

What scripture passages, if any, inform your view of the church and disability ministry?

How has your view of the church changed since having a family member with a disability?

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