

Faith Formation for Children with Disabilities

by

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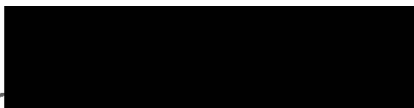
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Chapter 1

Disability: A Foundational Understanding

“God creates us in His image. We are created whole. Not in parts judged by those who believe their lives are full. God utilizes the humble to educate the great, or in this case, the whole. Until we understand that none are whole, we will continue to question God’s purpose for bringing children with special needs into the world...”¹

At age ten, I began working with a therapeutic riding program. This program was and still is dedicated to teaching children with disabilities how to ride and take care of horses. The disabilities this program accommodated ranged from various forms of ADHD, to autism, to spina bifida, and everything in between. Fourteen years later, my sister’s oldest child was diagnosed with severe ADHD. My sister found out that her son needed additional living and learning accommodation to better assist him in everyday life. My nephew has opened my eyes as to what it can be like to need additional living and learning accommodations. As stated in the opening quote, “God utilizes the humble, to educate the great, or in this case, the whole.” Every person with a disability deserves every accommodation possible because we are all created in the image of God. I am inspired to write on this topic because of my experience working with children with disabilities and because of my nephew’s condition.

Through my own experience and participation in the Episcopal Church, I have seen few examples of the active participation and incorporation of children with disabilities. I do not have a disability, and do not know what it is like to have a child with a disability, but through my own gifts and passion, I hope to inspire churches to create

¹ Julie M. Lane and Quentin P. Kinnison, *Welcoming Children with Special Needs: Empowering Christian Special Education through Purpose, Policies, and Procedures*, (Bloomington: West Bow Press, 2014), pg. 116.

room for, minister to, and fully welcome children with disabilities and their families. My goal is to provide a foundational understanding of disability for all who feel called to work with this precious part of God's community. To begin this vital discussion on disability, it is important to explore various disability terminology.

The Importance of Language

The terminology we use when describing those with a disability is important and requires intentionality. Popular terms like "special needs" and "disabilities" are often used interchangeably to describe this group of God's people. In her article, "The Difference Between Special Needs and Disabilities," Mariah Nichols, a mother of a child affected by Down Syndrome, explains that the words "disability" and "special needs" are not interchangeable and that the context in which the two words are used is equally important to be aware of.² Nichol says, "Special needs" is about education "disability" is about your body, your brain, your senses being wired and tapped in a unique way."³

Kathy Snow, a Jewish woman with cerebral palsy, admits that there is no one overarching word to describe the disability community, but says, "the word 'special need' has disturbed me and many others with disabilities for years."⁴ Kathy believes that by using the term "special need" instead of "disability," we hide the person's disability behind the "special need," placing shame on those who embody a disability.⁵ With these

² Meriah Nichols, "The Difference Between "Special Needs" and "Disability"", *Meriah Nichols*, accessed December 15, 2018, <https://www.meriahnichols.com/difference-special-needs-disability/>.

³ Nichols, "The Difference Between," 2014.

⁴ Kathie Snow, "Disability and Special Needs", written by Sharon Shapiro-Lacks, *The New York Jewish Week*, April 11, 2013, accessed December 15, 2018, <https://jewishweek.timesofisrael.com/disability-vs-special-needs/>.

⁵ Snow, "Disability", 2013.

two stories in mind, it is important to identify and define three words related to this significant discussion on disability: ableism, disability and special need(s).

Ableism is the judgment and discrimination against and towards people affected by disabilities.⁶ Ableism can also be described as favoritism towards certain ideals, attributes or abilities, thereby diminishing the value of human beings without them.⁷ Ableism is complex because it can be both a conscious and unconscious form of favoritism.⁸ Ableism exists even in the people we might trust the most, in this particular context, I am referring to some doctors.

An example of ableism, found in an article from Christianity Today, is about a mother who received a diagnosis from her doctor that her unborn child has Down Syndrome. The doctor said, “society is not ready for this child. Your other children will be burdened with the care of this child.”⁹ The doctor’s dismissal of the future ability this child will embody is an accurate representation of ableism. Despite where the doctor clearly stood, the mother chose to keep her child. Today, this child has friends at school and brought the family closer together.¹⁰

In addition to understanding ableism, defining and identifying the difference between “disability” and “special need(s),” is of equal importance in this foundational discussion on disability. According to the American Psychological Association,

⁶ Carli Friedman and Aleska L. Owen, “Defining Disability: Understanding of and Attitudes Towards Ableism and Disability, *Disability Studies Quarterly*, Vol. 37, No. 1, 2017, accessed December 15, 2018, <http://dsq-sds.org/article/view/5061/4545>.

⁷ Friedman and Owen, “Defining Disability”, 37.

⁸ Friedman and Owen, “Defining Disability”, 37.

⁹ Amy Julia Becker, “Prenatal Diagnosis of Down Syndrome: What Would You Choose?”, *Christianity Today*, Vol. 59, No. 1, February 15, 2013, accessed December 15, 2018, <https://www.christianitytoday.com/amvjuliabecker/2015/february/prenatal-diagnosis-of-down-syndrome-what-would-you-choose.html>.

¹⁰ Becker, “Prenatal Diagnosis”, 59.

“disability” is defined as, “a condition linked to a particular person—present when every day activities are somehow restricted.”¹¹ A disability can be classified as anything that restricts someone physically, emotionally, or mentally. Examples of disabilities include but are not limited to—autism, a chronic illness, deaf or blindness, or a developmental delay.¹² In the Americans with Disabilities Act (ADA), 1990, the term disability refers to anyone who, “has a physical or mental impairment that substantially limits one or more major life activities of such individual; has a record of such an impairment; or is being regarded as having such an impairment.”¹³

The term “special need,” has often been used interchangeably when describing people affected by a disability, however, this is not an accurate or appropriate use of the word. “Special needs” are additional requirements, enhancements, or adjustments made to an environment to better accommodate those with physical, emotional, learning, or mental disabilities.¹⁴ In other words, a special need(s) is the “extra something” a person needs to succeed or better participate in the classroom, workplace, a church ministry or other activities in life. As stated by Mariah Nichols, context and the way in which “disability” or “special need” is used, is crucial to articulate and understand.

There is no one right word to use. When in doubt, it is wise to ask the person with a disability what term they prefer or how they would like to identify. Disability language is dependent on the person embodying the disability and how they choose to identify and

¹¹ “Choosing Words for Talking about Disability”, *American Psychological Association*, 2019, accessed March 9, 2019, <https://www.apa.org/pi/disability/resources/choosing-words>.

¹² “The difference between Special Educational Needs and Disabilities”, *Southend’s Children and Families Information Point*, accessed December 15, 2018, <http://www.southendinfopoint.org/kb5/southendonsea/fsd/site.page?id=zm03Sn1Pb-4>.

¹³ Snow, “Disability”, 2013.

¹⁴ “The difference between”, 1.

define their individual being. This research has led me to the conclusion that the term “disability” is the most accurate word to use when discussing this group of God’s good creation.¹⁵

Disability: The Episcopal Church’s Response

It is important for the Church to listen to stories of the disabled and choose its language carefully when grappling with the complexity of human disability. According to the Episcopal Disability Network (EDN) “The Episcopal Church is committed to welcoming all people, spiritually, and physically, which includes becoming more hospitable and accessible to those who are living with disabilities.”¹⁶ The EDN seeks to equip the church with resources to accomplish that vision. It highlights disability advocacy and strives for the full inclusion of all people.¹⁷ There are Episcopal Churches that ensure their building is accessible for all people. For example, St. Mark’s Episcopal Church in Manhattan’s East Village, New York City, spent five years planning and installing an outdoor ramp, increasing accessibility to parishioners with disabilities.¹⁸

While accessible buildings are important, it is only the beginning. Of course, we want all to feel welcomed, but what happens within the walls of the church is equally as important as a ramp outside. There is a clear emphasis on advocacy and inclusion of all affected by disabilities in the Episcopal Church, but how do we ensure that people living

¹⁵ Examples of three people living with or with someone who has a disability, share why they prefer the term “disability” over “special need,” https://www.washingtonpost.com/news/parenting/wp/2017/09/28/my-daughter-doesnt-have-special-needs-she-is-disabled/?utm_term=.e44f68c1858a.

¹⁶ “Ministry by and with persons with disabilities”, Episcopal Disability Network, 2019, accessed December 15, 2018, <http://www.episcability.org>.

¹⁷ Episcopal Disability Network, “Ministry by and with”, 2019.

¹⁸ Amy Sowder, “How Episcopal churches embrace ‘radical welcome’”, *Episcopal News Service*, January 18, 2018, accessed December 15, 2018, <https://www.episcopalnewsservice.org/2018/01/19/how-episcopal-churches-embrace-radical-welcome/>.

with disabilities are included and given the space to both grow and share their gifts?¹⁹

While the Episcopal Church identifies and recognizes the lived reality of those with disabilities, there are very few formal resources that the Episcopal Church has produced regarding disability.²⁰

Sarah Burton, a Doctor of Theology candidate at Duke Divinity School says, “this lack of resources is part of the reason I am doing the work that I do. My work centers on re-enlivening baptismal identity and multi-sensory practices of baptismal remembrance and catechesis as central for doing work around disability inclusion and belonging particularly for people with intellectual and developmental disabilities.”²¹ In a Vestry Paper publication through the Episcopal Church Foundation, Burton emphasized the importance of living into our Baptismal Covenant. Burton spent several months visiting and researching churches where adults with disabilities were active members.²² Through this research, Burton explains that ways in which we can better live into our Baptismal Covenant is by embracing our call to help all of God’s people flourish and to greet all who are affected by disabilities with an honest, radical welcome.²³ Burton encourages the church to visit disability group homes, to invite people with disabilities to participate in

¹⁹ Wendy Johnson, “Welcoming All Children, part 1”, *The Episcopal Church*, December 12, 2012, accessed December 15, 2018, <https://www.episcopalchurch.org/posts/lifelongformation/welcoming-all-children-part-1>.

²⁰ Sarah Burton, e-mail message to author, February 15, 2019.

²¹ Sarah Burton, e-mail message to author, February 15, 2019.

²² Sarah Burton, “Welcoming Adults with Intellectual and Developmental Disabilities”, Episcopal Church Foundation Vital Practices, November 2018, accessed February 15, 2019, <https://www.ecfvp.org/vestry-papers/article/719/welcoming-adults-with-intellectual-and-developmental-disabilities>.

Burton, “Welcoming Adults”, 2018.

church events, and to incorporate members of churches with disabilities into liturgy and worship.²⁴

Overview

This project aims to be a foundation in understanding the importance of faith formation for children with disabilities. These ideas will be appropriate for all church denominations to use but are ultimately aimed at and influenced by the Episcopal Church perspective. Areas of focus include theology, pastoral care, practical accommodations, and envisioning a future for the disability community in the Episcopal Church. Practical accommodations are various tools and adjustments made in ministry to better include all people, so that they might better use their gifts in serving, learning about and engaging in relationship with God. The language of “practical accommodations” places the emphasis on what is being done towards full inclusion of a person with disabilities by contrast with the term “special need(s),” which labels the person.

In Chapter 2, *Disability: A Theological Understanding*, insight into a theology of disability will be provided. Specifically, how society defines disability, God’s creation, and the *imago Dei*. The overall goal in Chapter 2 is to successfully build a thoughtful, theological foundation for the ways in which we view our brothers and sisters with disabilities, while remembering our own human brokenness, the redemption we find in Christ’s saving acts on the cross, and the vows we, as Episcopalians, made in our Baptismal Covenant.

²⁴ Burton, “Welcoming Adults”, 2018.

In Chapter 3, *Disability and the Church's Response*, the focus will be on the nature of pastoral care and what it means to be present and provide pastoral care to children disabilities and their families. I will also demonstrate ways churches can aim to be more inclusive of children with disabilities in their formation and education programs by creating practical accommodations specific to the child's needs. In addition, foundational steps to begin a Disability Ministry in a church will be examined and provided.

Finally, in Chapter 4, *Disability and the Episcopal Church: Creating a Vision for the Future*, I look towards the future of the disability community in the Episcopal Church. Specifically, what additional work the Episcopal Church can seek to do to better accommodate and include children with disabilities and their families. In addition, I will highlight several existing organizations and programs dedicated to supporting the disability community in the Episcopal/Anglican Church.

Chapter 2

Disability: A Theological Understanding

The theology of disability is complex, and worthy of continual questioning. God works in mysterious ways and our human nature plays a part in the way in which the universe works and has its being. We are all created in the image and likeness of God. God lives in each of us and that Divine connection can never be broken. This chapter will begin to examine the theology of disability. What does it mean to have a disability and how can we better understand our brothers and sisters who fall under this scope?

I will begin by exploring God's active hand in creation, the *imago Dei* and its relation to disability, and will then turn to Anglican Thought as demonstrated in an Outline of Faith. Following this exploration will be a discussion on Human Nature, specifically the importance of welcoming all people, science and its effect on human judgment, and finally an examination on society's perception of disability.

Disabled and Created in the Image of God

The direct connection and correlation between God's will and creation can never be disturbed because God is actively around us. As Christians, we look for signs of God's love and work in creation every day, ultimately recognizing God's active hand and all-encompassing power. In his book *Vulnerable Communion*, Thomas Reynolds challenges this idea, that God is not an imposing power, but rather that the world has its own integrity and momentum.²⁵ Then, what are the sources of this integrity and momentum? This integrity is found in the majesty and wonder of the universe. God's power is not

²⁵ Thomas E. Reynolds, *Vulnerable Communion: A Theology of Disability and Hospitality*, (Grand Rapids: Brazos Press, 2008) 154.

imposing because God is love and that love has put into motion our freedom of choice to exercise love in God's image.

Since humankind is created in the image of God, we have a natural invitation to seek God's image in others.²⁶ Our relationship with God comes before any earthly relationships.²⁷ This first relationship is a connection to God that cannot be broken, it is deeper than any of us can describe. We have all been touched and loved on by God, including the vulnerable and weak. Our human intuition is to focus on others' pain, labeling them as weak and perhaps not worthy. T.E. Reynolds reminds us of what Jesus said to his disciples as to who will enter the Kingdom of Heaven, "not the first, but the last; not the privileged, but the underprivileged."²⁸ Jesus underscores this idea that God works through and for those who might be viewed as vulnerable and weak. So, if we are all images of God and God lives in each of us, how might we practice seeking and serving Christ in all persons?

In our Baptismal Covenant, we vow to respect the dignity of every human being.²⁹ Each person is worthy of respect because they are created by God. The former Archbishop of Canterbury, the Most Reverend Rowan Williams, tells us that we all have meaning in one another's existence.³⁰ Each person was created for a reason, and we all come to the table with unique and beautiful differences. Our gifts were given to us by the same loving and creating God, and we are called to find this gift in one another because humankind needs each other and God. God lives in each of us and when we depend and

²⁶ Reynolds, *Vulnerable Communion*, 186.

²⁷ Rowan Williams, *Being Human: Bodies, Minds, Persons* (Grand Rapids: William B. Eerdmans Publishing, 2018), 36.

²⁸ Reynolds, *Vulnerable Communion*, 221.

²⁹ *Book of Common Prayer*, 1979, 305.

³⁰ Williams, *Being Human*, 33.

lean on one another, we are indeed, depending and leaning on part of God. We are not perfect, nor can we do everything, therefore, we must be interdependent on one another because we do not contain all capacities of what it means to be human.³¹ This interdependence is a way in which all of creation is connected, has integrity, and makes us whole.³²

Through our gifts and differences, we learn to support, treat, and help others. T.E. Reynolds says, “God’s love values the differences of what is other, remains faithful to it, and shows compassionate regard for its well-being.”³³ Since humankind is created in the image and likeness of God, we have the potential to live into the same love that God sheds on God’s perfect creation. If it is the totality of God’s creation that is perfect, then people with disabilities are not less than whole. God does not purposely create disability; it is possible for us to discover different aspects of God’s love through their experiences. To model God’s likeness and to find Christ in each person, I urge others to show love and compassion, not judge or label those who might appear different from us—loving, caring and respecting our neighbors as ourselves.

The range of human disability is wide, allowing for an equally diverse glimpse of God in each person. The lived experience of people living with diverse disabilities allows able-bodied persons to experience God anew. During my time as a volunteer with a therapeutic riding program I distinctly remember a six-year-old girl, who had a stroke when she was born, which caused her severe physical and cognitive disabilities. This young girl was so weak, she was not able to sit up on her own, but after being in the

³¹ Quentin P. Kinnison and Julie M. Lane, *Welcoming Children with Special Needs: Empowering Christian Special Education through Purpose, Policies and Procedures*, (Bloomington: West Bow Press, 2014), 16.

³² Kinnison and Lane, *Welcoming Children with Special Needs*, 18.

³³ Reynolds, *Vulnerable Communion*, 166.

program for over two years, she was able to get on a horse and sit up all by herself. This is one of the first moments in my life that I was witnessing the power of God working through and present in this little girl's resilience and growth.

I am inspired by the wisdom from a young woman with Down's syndrome, "I was born with a hole in my heart. When I was little it needed a patch and I was very ill. It might be because of this that I have always felt special...God is my best friend. God made me special because I am special to him."³⁴ Our society, specifically ableism, imposes the assumption that to be less than whole is to somehow be less than human, and therefore, disability is viewed as a form of suffering. Suffering and pain as it relates to disability will be discussed later in this chapter. When humankind's vulnerability and brokenness are visible, our dependence on the loving, creating God is known. Reynolds encourages humankind to recognize, accept and welcome these gifts as valuable assets to the rest of the world.³⁵ Identifying God's image in another person is essential to prevent humankind from distorting the humanity of another.

An Outline of Faith in the 1979 Book of Common Prayer tackles questions of Human Nature and God as Father. Under the category "the Catechism on Human Nature," humankind is defined as, "part of God's creation, made in the image of God."³⁶ Following this, we are asked what it means to be created in the image of God, "it means we are free to make choices: to love, to create, to reason and to live in harmony with

³⁴ Brian Brock and John Swinton, eds. *Theology, Disability and New Genetics: Why Science Needs the Church* (London: T&T Clark, 2007), 4-5.

³⁵ Reynolds, *Vulnerable Communion*, 139.

³⁶ *Book of Common Prayer*, 1979, 845.

creation and God.”³⁷ However, what if we are born with a condition in which this harmony is disrupted, or we are not able to make our own choices?

Redeeming Brokenness through Christ

The Catechism on Human Nature gives us an answer to the question of what it means to be out of harmony with creation and apart from God. We learn that, “from the beginning, human beings have misused their freedom and made wrong choices.”³⁸ Does this explain why someone might be born with a disability? If so, it would imply that experiencing tragedy or pain, is a form of punishment. This conclusion is not congruent with our understanding of God as a compassionate, loving creator. When people who believe in a just world experience tragedy or feel pain, we struggle to search for an answer.³⁹

The Catechism on Human Nature gives us a brief, yet meaningful answer to this question, “our help is in God.”⁴⁰ As Christians, the times when we doubt, or fear are often times we turn to God for help, guidance and strength. But what if we call upon God for help and we do not hear God? What if we pray to God to heal a child with a disability, but the prayer does not work as we intended it to? In “the Catechism on God the Father,” God is the Almighty Creator and defines the universe as “good,” which underscores the idea that all of humankind, regardless of ability, is worthy of respect and honor because God touched and created all people.⁴¹

³⁷ *Book of Common Prayer*, 1979, 845.

³⁸ *Book of Common Prayer*, 1979, 845.

³⁹ Harold S. Kushner, *When Bad Things Happen to Good People* (New York: Schocken Books, Inc., 1981), 11.

⁴⁰ *Book of Common Prayer*, 1979, 845.

⁴¹ *Book of Common Prayer*, 1979, 846.

By recognizing Christ's full humanity, including imperfections, our perception of what it means to "lack" something or to not have a certain ability is challenged because Christ bore our human imperfections, brokenness, and sins while nailed to a cross. Someone with a disability might be viewed as broken, or imperfect, but no one is perfect, expect Jesus. Jesus Christ knew and experienced pain while on earth but was raised by God so that future humanity might know new life, regardless of our bodily conditions, brokenness, or imperfections.⁴² But, how can those living with a disability simply accept this idea that "we all have limits?"

God loves us all the same and Christ's brokenness on the cross is the prime symbol of what it means to be human and broken, but still be made in the image and likeness of God. Nancy Eiesland's "disabled Christ" is defined as, "the one who understands by embodying disability even in his transformed, resurrected body."⁴³ Eiesland's disabled Christ is powerful and creates an image of what Christ felt and took to the cross to save future humanity. While this might not fully comfort the mother whose child will never talk or walk, the Bible tells us in 2 Corinthians 12: 9-10 that, "God is made manifest and perfect in weakness and lack of ability."⁴⁴ We can look to Christ on the cross as an image of what it means to be broken and disabled. We find true healing in accordance with God's will through the power of the cross.⁴⁵

The underlining meaning of our redemption in Christ is through the power, safety, and welcome to all that is found at the cross. At the cross the pain, alienation, and impoverishment humankind experiences are redeemed and taken up into the life-giving

⁴² Reynolds, *Vulnerable Communion*, 162.

⁴³ Reynolds, *Vulnerable Communion*, 177.

⁴⁴ Reynolds, *Vulnerable Communion*, 177.

⁴⁵ Reynolds, *Vulnerable Communion*, 228.

core of God's being.⁴⁶ Regardless of our abilities, we all need redemption, just as much as we need each other's gifts. God created us to bring certain attributes to the world, through the saving acts of Jesus Christ. Redemption is the key to freeing all of humanity from pain and sin.⁴⁷ If Jesus's death on the cross was a saving act, and if we are redeemed by this act because Jesus bore all aspects of humanity, including vulnerability, brokenness, and weakness, can those with a disability look to Christ for strength and comfort? I believe so. However, often the natural integrity and momentum found in this world distorts our judgment and the way in which we view others.

Called to be a Neighbor: Called to Community

As human beings, we long to feel welcomed, loved, and part of a community. The very essence of our being is this desire to feel a sense of belonging and purpose.⁴⁸ Our God did not create and call us to diminish and exclude others, but rather, called us to welcome all as mirrored images of God.⁴⁹ As a society, we are called by God to welcome, support, and love all persons, regardless of abilities or differences. All people have the ability and potential to show love and compassion towards others because God is an active part of our being. T.E. Reynolds states that, "love always exists as a possibility within human relations."⁵⁰ The importance of welcoming all into society is an affirmation to God that we recognize the Divine in the other.⁵¹ In our Baptismal Covenant, we are called to love our neighbors as ourselves, and in order to live into this

⁴⁶ Reynolds, *Vulnerable Communion*, 229.

⁴⁷ Reynolds, *Vulnerable Communion*, 151.

⁴⁸ Reynolds, *Vulnerable Communion*, 51.

⁴⁹ Kinnison and Lane, *Welcoming Children with Special Needs*, 11.

⁵⁰ Reynolds, *Vulnerable Communion*, 137.

⁵¹ Reynolds, *Vulnerable Communion*, 143.

vow, it is important we understand how to be a neighbor. So, how do we, as part of humankind, show our neighborly love towards those with a disability?

As a neighbor, we are called to help those in need, to love those who are in pain, and to comfort the sick. Humankind has a natural desire to feel, give, and receive love, despite differences.⁵² Our differences are ways in which we live and thrive in relationships. These differences remind us of our own humanity.⁵³ Our differences speak to ways in which God is present in all our lives, the many “faces” of God and ways we live into our human potential. When we learn to appreciate and respect our natural human differences, only then can we reach our full human potential of loving our neighbors as ourselves.⁵⁴ However, too often our human nature causes us to quickly judge a person because of how they look or act, but we often do not think about why we reacted in this way. If someone looks, acts, or thinks differently, we judge, but why? Does science affect and mold ways in which we perceive and judge what full human potential looks like?

God does not purposefully place suffering or pain into our lives, but rather society and science tends to point out physical or visible flaws others embody. Reynolds tells us that God does not want creation to suffer, but rather creation has its own being because of the energy and integrity of natural law God originally bestowed onto creation.⁵⁵ Part of this energy and integrity is found in technological advancements made by humankind.

In John Swinton and Brian Brock’s book, *Theology, Disability and New Genetics*, they examine the writing of Dr. Linda Ward, former professor at Bristol University, and

⁵² Reynolds, *Vulnerable Communion*, 183.

⁵³ Reynolds, *Vulnerable Communion*, 186.

⁵⁴ Brock and Swinton, eds. *Theology, Disability and New Genetics*, 242.

⁵⁵ Reynolds, *Vulnerable Communion*, 163.

her question on whether prenatal tests are good knowledge to have because they show and determine defects of the unborn child.⁵⁶ While, this is a good thing to know, so parents and doctors can be better prepared, I also see the concern Ward shares. A woman who discovers her child's life will never be society's "normal," might experience societal pressure to terminate the pregnancy. It is important to consider what we are saying to people with disabilities whenever we explicitly or implicitly communicate children who will not have a "normal" life should not be born.⁵⁷ We need to consider how our perspectives are shaped by our conscious and unconscious assumptions.

Rowan Williams describes our consciousness as a machine and its job is to think and formulate thoughts.⁵⁸ The ways in which our brains are wired, and our personal background affect ways in which we view the other.⁵⁹ The left brain can influence and persuade our way of thinking into ignoring the complexity of human nature.⁶⁰ When we see a person with a disability, our left brain (might) persuade(s) us into thinking that the person is flawed or is lacking something. This flaw might be seen as an "abnormal" human condition, putting limits on how this person can participate in society.⁶¹ Eugenics plays a vital role in understanding why humankind focuses on what is "normal" verses "abnormal." Specifically, on the brokenness, vulnerability, and suffering others experience.

⁵⁶ Brock and Swinton, *Theology, Disability and New Genetics*, 2.

⁵⁷ Brock and Swinton, *Theology, Disability and New Genetics*, 2.

⁵⁸ Williams, *Being Human*, 3.

⁵⁹ Williams, *Being Human*, 15.

⁶⁰ Williams, *Being Human*, 5, 32, 51.

⁶¹ Reynolds, *Vulnerable Communion*, 25.

Eugenics is, “a form of social theory that advocates the improvement of human hereditary traits through the use of various forms of intervention.”⁶² Eugenics categorizes human characteristics as positive or negative. First, the positive category of eugenics is seen as a set of traits that are “desirable.”⁶³ Second, the negative category of eugenics is described as a “lack” or “elimination” of certain genetic traits that are desirable, yielding “undesirable” characteristics.⁶⁴ According to the Rev. Dr. Christopher Newell (1964-2008), genetic technology can yield to oppressive attitudes, which by nature, becomes part of our own characteristics and genetic traits.⁶⁵ Thus, suggesting that disability is a form of brokenness, or is a negative characteristic.

Societal Influences on Our Perceptions of Disability

According to T. E. Reynolds, “the perception of inability by ‘able-bodied’ persons functions to define a person’s whole being. Disabled, then, becomes something one is—this is powerless and useless, incapable of participating adequately in social exchanges.”⁶⁶ What have we, as humans, created as part of our societal culture and perception? Why do we focus on pain? C.S. Lewis describes pain as, “any experience, whether physical or mental, which the patient dislikes.”⁶⁷ In other words, pain is anything that might be uncomfortable or something that limits our way of thinking and/or living.

Technology and science, not mediated by faith, can play a detrimental, yet significant role in influencing society’s critical views of disability. It is imperative to

⁶² Brock and Swinton, *Theology, Disability and New Genetics*, 3.

⁶³ Brock and Swinton, *Theology, Disability and New Genetics*, 3.

⁶⁴ Brock and Swinton, *Theology, Disability and New Genetics*, 3.

⁶⁵ thus suggesting that disability is a form of brokenness, or is a negative characteristic.

Brock and Swinton, *Theology, Disability and New Genetics*, 4.

⁶⁶ Reynolds, *Vulnerable Communion*, 27.

⁶⁷ C.S. Lewis, *The Problem of Pain* (New York: Macmillan, 1944), 78.

point out that our understanding of God's loving and powerful hand is not present in creation to create punishment or tragedy. In the Biblical book of Job, Job challenges this idea of reward/punishment because his faith and relationship with God surpasses everything.⁶⁸ Job continues to be a loving and faithful servant, despite the tragedy, pain and suffering he experiences, and despite not understanding the full nature of God. Much like Job, C.S. Lewis encourages humankind to surrender its will to God, accepting that God's work in creation is God's will.⁶⁹ Lewis' idea is aligned with the book of Job; however, it is a hard concept to grasp and even more-so, a difficult explanation to why disability is lived reality in this world. So, why do we, God's perfect and good creation, experience suffering?

In his book, *When Bad Things Happen to Good People*, Harold Kushner provides two critical responses in attempts to make sense of human suffering. First, we try to make sense of our suffering by thinking, "we get what we deserve" or "maybe if I wait long enough and let this pain subside, God's righteousness will emerge."⁷⁰ The second explanation offered is that creation has its own specific pattern and our own, individual lives, help create this pattern.⁷¹ I believe we cannot ignore this specific and perhaps natural pattern creation has. These are eternal questions, but it is important to focus on the idea that humankind has the potential to show and give love because a piece of the Divine lives in everyone.

⁶⁸ Sarah Melcher, Mikeal A. Parsons and Amos Yong, *The Bible and Disability: A Commentary* (Waco, TX: Baylor University Press, 2017), 15.

⁶⁹ Lewis, *The Problem of Pain*, 88.

⁷⁰ Kushner, *When Bad Things Happen to Good People*, 14.

⁷¹ Kushner for Thornton Wilder, *When Bad Things Happen to Good People*, 26.

The morals of our society are not accidental, they are choices, something we have chosen to build our communities around, something humankind labeled as “the norm.”⁷² In the book, *Bible and Disability: A Commentary*, editors Sarah J. Melcher, Mikeal A. Parsons, and Amos Yong, present multiple authors and their explorations of disability in the Hebrew Bible. Mentioned is Jeremy Schipper, who studied and reflected on the “suffering servant” in Isaiah 53. Schipper argues that the servant in Isaiah 53 is depicted as having a disability and experiences both social and political mistreatment because of the disability.⁷³ Essentially showing that the servant in Isaiah 53 was labeled in accordance with the dominant ways of societal construct, which view those with a disability as a marginal “other.”

As humankind, created in the image and likeness of God, are we are called to love and welcome all people, regardless of ability. Science and technological advancements have influenced societal opinion on what is “normal” and “abnormal”, ultimately placing those who look or act different into boxes or categories. Understanding theology as it relates to the realm of disability is foundational for formulating ways in which we can welcome, minister to, and accommodate families and children with disabilities.

⁷² Brock and Swinton, *Theology, Disability and New Genetics*, 5-6.

⁷³ Melcher, Parsons and Yong, *The Bible & Disability*, 8.

Chapter 3

Disability and the Church's Response

Whether we are aware, or not, our theology influences our responses to the ways in which we minister to and accommodate children with disabilities. By affirming our own worth, only then can we begin to respect and identify the worth of others. Affirming God's active presence in those affected by a disability, will better inform the church in ministering to this community of God's people. In this chapter I will seek to articulate the meaning of providing pastoral care to children with disabilities and their families. In addition, it is important to explore the differences between inclusion and integration, and how these differences can shepherd the church in beginning a Disability Ministry. The goal is to encourage both clergy and lay leaders to see how including children with disabilities in their churches will transform their ministries.

The aim of a Disability Ministry is to articulate and formulate ways in which the child's disabilities are accommodated in conjunction with that child's gifts. Therefore, a Disability Ministry seeks to accommodate any child's ability even when that includes such diagnoses as ADHD, cerebral palsy, hearing impairments, or autism. In addition to ministering to and accommodating the child, a Disability Ministry provides support and comfort to the family because they know their child is seen and included.⁷⁴ It is foundational to identify who a Disability Ministry is intended for as it will guide our call to minister and provide pastoral care to those who need it.

⁷⁴ Verbaľ, *Special Needs Ministry for Children*, 15 & 17.

Disability and Defining Pastoral Care

Before a church can build a Disability Ministry, it is important to define what it means to be pastoral and to provide pastoral care. Pastoral care is a calling of all baptized Christians, lay and ordained.⁷⁵ In this section, I explore the meaning of pastoral care and suggest ways of supporting families affected by disabilities through the power of prayer. As a lay person and an Episcopalian, I want to stress the importance of my Baptismal Covenant, “seeking and serving Christ in all persons.”⁷⁶ Pastoral care is not only for clergy. The call to serve as partners in ministry extends to all baptized Christians. Providing pastoral care to those who are suffering is a way in which we, as baptized Christians, can seek and serve Christ in all persons.

As a clergy or lay person in ministry, providing pastoral care is deeply rooted in understanding ways in which another person hungers for meaning, or thirsts to rebuild their lives after a crisis, and actively creating a compassionate, culturally-appropriate space for them to heal.⁷⁷ Hearing personal testimonies of others experiences with the nature of pastoral care can better enhance our understanding of what it means to provide this kind of care. When I asked two of my classmates at Virginia Theological Seminary how they define pastoral care, here were their responses:

⁷⁵ The Book of Common Prayer describes the orders of ministry for lay and clergy, found on pages 855-856.

⁷⁶ The Episcopal Church, *Book of Common Prayer and Administration of the Sacraments and Other Rites and Ceremonies of the Church, together with the Psalter or Psalms of David*, (New York: Church Publishing, 1979), 305.

⁷⁷ Bridget Clare McKeever, editor, *Basic Types of Pastoral Care & Counseling: Resources for the Ministry of Healing and Growth*, (Nashville: Abingdon Press, 2011), 1, 2 & 65.

“the act of holding space for others to feel safe, loved, heard, seen and always witnessing God in that midst and in their circumstance.”⁷⁸

“supporting God’s people emotionally, spiritually and mentally. Meeting people where they are at, actively listening to them and being present with them through tough times.”⁷⁹

In her book, “Leading a Special Needs Ministry”, Amy Fenton Lee defines pastoral care as, “when friends, group leaders, clergy and staff members rush to the aid of families experiencing a major life crisis.”⁸⁰ When a family or person is experiencing a crisis, creating a safe space, being physically present and listening to them is essential. For example, when parents have just received news that their child has a disability, listening to them and getting a sense of where they are in processing the news is important.⁸¹ Pastoral care requires understanding that people, children and adults, cope with things differently and it is imperative that the church meets them where they are. One of the primary ways in which we can provide pastoral care is through and by the space created. The desired space to be created is filled with a true, honest connection between the family, the one who is providing the care, and to God.

Pastoral care is about providing that safe space for the family to open-up about their struggles.⁸² The emotional space for processing is equally as important as the physical space itself. Often the person providing pastoral care might feel the need to “fix” the issue. Rather than trying to “fix” the issue, focus on creating space for healing,

⁷⁸ Josh Barrett, Postulant for Holy Orders at the Episcopal Diocese of Rochester, interviewed by author, Virginia Theological Seminary, Alexandria VA, 11 December 2018.

⁷⁹ Melina Dezhbod, Postulant for Holy Orders at the Episcopal Diocese of Connecticut, interviewed by author, Virginia Theological Seminary, Alexandria VA, 11 December 2018.

⁸⁰ Amy Fenton Lee, *Leading a Special Needs Ministry*, (Nashville: B & H Publishing Group, 2016), 5.

⁸¹ Lee, *Leading a Special Needs Ministry*, 10.

⁸² Lee, *Leading a Special Needs Ministry*, 18 & 26.

yielding a space where the person or family can truly grieve.⁸³ If the emphasis of “fixing” the issue is at large, the person or family might get overwhelmed and not feel emotional or spiritual support. The sole aim of pastoral care is to find this balance of emotional and spiritual support, by listening and responding to the needs of the person being served.⁸⁴

Supporting the Family

People go to church for spiritual nourishment and when they are not satisfied, seeking pastoral care is often an avenue people will follow to find that nourishment.⁸⁵ Understanding and recognizing these burdens will better our approach in providing spiritual nourishment to those seeking pastoral care. In this context, it is wise to discern, with other leadership or clergy how a family is coping with a recent disability diagnosis.⁸⁶ It is also important to try and comprehend what everyday life is like with a child who has a disability. If a child has a disability, it is important to note that the child is not the only one affected—everyone living in that home feels the same sense of pressure to provide for that child. Laying a foundation of what it means to be pastoral and provide pastoral care will better the way in which we, as pastoral care providers, support the family.

Pastoral care involves supporting the entire family. A foundational principle in pastoral care is listening to others to better understand the best way to support their situation. A part of understanding a family’s situation involves asking appropriate questions and showing support. There are a few key phrases to avoid when asking

⁸³ Lee, *Leading a Special Needs Ministry*, 11.

⁸⁴ Erik W. Carter, *Including People with Disabilities in Faith Communities: A Guide for Service Providers, Families and Congregations*, (Baltimore: Paul H. Brookes Publishing Co., 2010), 137.

⁸⁵ Carter, *Including People with Disabilities*, 27 & 29.

⁸⁶ Verbal, *Special Needs Ministry*, 26.

questions or showing support, including, but not limited to the following: “God doesn’t give us more than we can handle...”, “Special needs children are blessings...”, or “everything happens for a reason...”⁸⁷ While these statements may include some truth, they risk reducing the message to sound clichés that are superficial and, in that moment, can also cause pain and alienate people. Families often long for something deeper—something that will get them through more than just that moment.

As previously stated, providing a safe space for families to talk about their struggles is a key component in providing pastoral care. Every member of the home is affected by a disability diagnosis and often these family members will find comfort in someone providing pastoral care.⁸⁸ The family wants to be seen and to feel welcomed in their home and church communities.⁸⁹ For example, if a child has a disability, his older sister might not receive as much attention from her parents as her younger brother does. The older sister might need someone to talk through her feelings with—someone to listen to her, when her parents might not be able. Supporting the family involves more than “checking-in” on Sunday mornings. Offering time and space for pastoral care during the week is of equal importance.

Clergy and lay leaders might reach out to families affected by disabilities during the week to see how they can be supported.⁹⁰ I imagine that each family faces a steady set of challenges, but also new challenges arise as time passes. Let the family know that no matter how much time has passed since their child’s diagnosis, that pastoral care and

⁸⁷ Lee, *Leading a Special Needs Ministry*, 13.

⁸⁸ Verbal, *Special Needs Ministry*, 27.

⁸⁹ Lee, *Leading a Special Needs Ministry*, 8.

⁹⁰ Carter, *Including People with Disabilities*, 124.

support will always be available.⁹¹ Some families might feel that it is time to move beyond the guidance of the pastoral care provider. In this case, other forms of guidance, such as support groups, might be the next step for the family to take.

These support groups could be for individual members of the family, or something the entire family attends. Some families or parents might find that a group of others experiencing similar situations is a helpful tactic in coping with their child's disability diagnosis. However, it is important that we, as pastoral care providers, listen to these families and assess if they are ready for this step. Parents might still be in the "processing stage" of their child's diagnosis and listening to other parents tell their stories, might not be helpful in this process.⁹² If the family or individual family member is not ready for this step or does not want to go, they do not have to. However, if they feel ready or are interested in a support group, they would be immersed in and surrounded by people in similar situations. This group would become a place for companionship, support, and encouragement.⁹³

Another essential part in providing pastoral care involves advocating for the true inclusion of a child with a disability.⁹⁴ I will discuss advocating for the true inclusion of children with disabilities into church communities later in this chapter, but for now, it is important to note that advocating for the child is a part of supporting the family. When showing your support towards the family, a close and meaningful relationship can be created, and it becomes natural to hold those for whom we care in prayer.

⁹¹ Carter, *Including People with Disabilities*, 145.

⁹² Lee, *Leading a Special Needs Ministry*, 14-15.

⁹³ Carter, *Including People with Disabilities*, 142-143.

⁹⁴ Andrew D. Lester, *Pastoral Care with Children in Crisis*, (Philadelphia: Westminster Press, 1985), 59.

The Power of Prayer

As the pastoral care provider, our constant prayer and communication with God informs and allows us to seek God's wisdom and guidance. When we prayerfully listen to God our understanding of which direction to take when helping a family becomes clearer. In addition, the job of a pastoral care provider is to lead and surround everything by prayer.⁹⁵ Carefully listening to the family and pray for their concerns, needs and unanswered questions.⁹⁶ Let the family know you are praying for them and encourage them to continue their prayers and conversations with God. Encourage them to see the presence of God in their lives through prayer, helping to shape, form and enhance their spiritual nourishment.⁹⁷ Individual or familial prayer

Some churches have prayer groups or "shepherds on call." These are groups of people that are available for immediate prayer. This is a powerful resource for a church to provide and for a family to use. Families are reminded that someone is always ready to think, talk and pray for and with them.⁹⁸ Understanding how to pastor and minister to families and their children with disabilities will better guide the church in how to be more inclusive. The ways in which pastoral care providers hold and guide these families and their children, will intentionally immerse the provider in a situation where they better understand the needs of the child and the family. In addition, it will provide better insight into identifying if the child is experiencing integration, verses inclusion.

⁹⁵ Carter, *Including People with Disabilities*, 68.

⁹⁶ Lester, *Pastoral Care*, 47.

⁹⁷ Lester, *Pastoral Care*, 47.

⁹⁸ Carter, *Including People with Disabilities*, 127.

understand the needs of the child and the family. In addition, it will provide better insight into identifying if the child is experiencing integration, versus inclusion.

Inclusion, Integration, and Practical Accommodations

Now, I will demonstrate the difference between inclusion and integration, and will examine steps for a church to follow if they feel called to begin a Disability Ministry. All disabilities are different and it is important to emphasize that there is no “one-solution” or “one-size-fits-all” A healthy response always depends on the child.⁹⁹ I encourage the church to develop a plan best suited for each child, it will take work, but it is not impossible. My goal for this section is to examine possible ways to include children and their families affected by disabilities, but also, how the church might build its own Disability Ministry. Identifying the difference between inclusion and integration will inform how and where practical accommodations are provided and found.

At first glance, the words inclusion and integration might seem to be referencing the same idea, however, after deeper examination there is a small, but mighty difference between the two. According to an article written by Bryan Harman, “Inclusion/Integration: Is There a Difference,” integration in a school setting assumes there is a problem with the child that must be fixed or adjusted to fit the classroom setting.¹⁰⁰ On the other hand, inclusion focuses on how the classroom can be fixed or

⁹⁹ Lee, *Leading a Special Needs Ministry*, 17.

¹⁰⁰ Bryan Harman, “Inclusion/Integration: Is There a Difference?”, Canadian Down Syndrome Society, Accessed December 11, 2018, <https://cdss.ca/wp-content/uploads/2016/06/CDSS-integration-vs-inclusion.pdf>.

adjusted to suit and accommodate the child.¹⁰¹ In other words, there is nothing about the child that needs “fixing”, but rather the classroom is adjusted in such a way that it supports the child’s success, because each child learns differently.¹⁰² Success, for reasons of this topic, will be defined as the quality of formation and spiritual nourishment that each child will receive and that the church aims to provide.

Preparing and planning for children with disabilities within the walls of a church involves forming accommodation plans to better include these children. Accommodation is the “tools given to a student so that they have access to the curriculum.”¹⁰³ In this case, the “student”, is the child and “curriculum” can mean anything from Sunday School curriculum to various ways of learning, completing, or partaking in worship and/or ministry. Since each disability is different and the “one-size-fits-all” model is irrelevant, there are several ways to accommodate and include children with disabilities in the church. One of the most important signs of aiming towards full inclusion is by talking to and creating a relationship with that child’s parents.

Talking to and creating these relationships will open a window of opportunity for parents to explain ways in which their child might be able to get involved in congregational activities.¹⁰⁴ In return, this relationship with the parents will help formulate ways in which churches can properly accommodate children with disabilities. Talking to and asking parents for accommodation advice will give them a voice and

¹⁰¹ Harman, *Inclusion/Integration*.

¹⁰² Harman, *Inclusion/Integration*.

¹⁰³ Julie M. Lane and Quentin P. Kinnison, *Welcoming Children with Special Needs: Empowering Christian Education through Purpose, Policies, and Procedures*, (Bloomington: West Bow Press, 2014), 95.

¹⁰⁴ Carter, *Including People with Disabilities*, 54.

Examples of Formation Inclusion

The main goal in any Disability Ministry should be the act of actively including the children in everything, especially the Sunday School classroom. However, part of accommodating a child with a disability is to ensure they have tools for formation, while continuing to enhance the formation of other children. The primary goal is making the Gospel of Jesus Christ accessible to everyone.¹⁰⁵

The first way in which a church can strive towards full inclusion is by adapting materials or curriculum in a Sunday School setting. Ministry with children affected by a disability does not require new programs, but rather adjustments for weaving these children into existing programs. In her book, *Special Needs Ministry for Children*, Pat Verbal describes four types of disabilities and ways in which a child affected by that disability can be accommodated for in the classroom. Keep in mind that including children with disabilities in worship would require equally specific accommodation ideas. See chart below:¹⁰⁶

Disability	Accommodation Idea
1- Visual Impairments	1- Print Sunday School lesson plan in Braille; custom Braille Documents (Bible Verses, Activities, etc.) can be ordered at read.brailleworks.com or at brailleit.com .
2- Partial Vision	2- Print a Sunday School lesson plan in larger print, paying attention to color and contrast.
3- Learning Disabilities	3- Color-code important parts of the lesson plans, being aware of limitations some children may have from color blindness
4- Intellectual or Developmental Disabilities	4- use the buddy system or provide the child with lesson plan materials ahead of time; please note that this accommodation idea

¹⁰⁵ Lee, *Leading a Special Needs Ministry*, 65.

¹⁰⁶ Verbal, *Special Needs Ministry*, 69.

	contrast.
3- Learning Disabilities	3- Color-code important parts of the lesson plans, being aware of limitations some children may have from color blindness
4- Intellectual or Developmental Disabilities	4- use the buddy system or provide the child with lesson plan materials ahead of time; please note that this accommodation idea will not fit for all intellectual or developmental disabilities

Another approach towards full inclusion is by providing and offering a dedicated classroom space for children with disabilities, an optional place for them to go and experience Jesus, perhaps in a language only understandable to them.¹⁰⁷ I am not suggesting that all children with a disability should be in this specific room, but rather the space should be created as an option. If a dedicated space is an issue, try to find a space that can be transformed specifically for Sunday School hour. This, again, is where the “one-size-fits-all” model is inadequate—and providing parents with options is important.

A third approach is the “buddy system.” This option of accommodation and inclusion is the most ideal, common and inclusive.¹⁰⁸ The buddy system’s goal is to provide each child with a disability the option and access to an adult or peer buddy to help them engage in a ministry or assist them in a Sunday School setting. Theologically speaking, the buddy system is a glimpse of how Jesus desires to be in a personal relationship with us and a model of how Jesus loved and cared for his disciples.¹⁰⁹ The buddy system also displays another way in which we, as Baptized Christians, live into our Baptismal Covenant of “seeking and serving Christ in all persons.”

The final option or approach towards full inclusion is a combination of the separate classroom and the buddy system. It is important to note that these approaches

¹⁰⁷ Lee, *Leading a Special Needs Ministry*, 65.

¹⁰⁸ Lee, *Leading a Special Needs Ministry*, 63.

¹⁰⁹ Lee, *Leading a Special Needs Ministry*, 63.

might need to be adjusted or not work for every child. If a certain tactic does not foster healthy engagement, include the child's parents in coming up with a new accommodation plan best aligned with the child's gifts.

Ways of inclusion extend outside a Sunday School setting, into spaces of worship, outreach opportunities and volunteering. During worship, using visual aids, providing quiet objects or toys, and walking through the service with the child are a few ways in which the child might be able to participate in worship.¹¹⁰ In addition, many children with disabilities can read scripture, sing in the choir or acolyte during a worship service.¹¹¹ As always, it is important to align the child's gifts with tasks or ministries that are available in a church, both in worship and in Sunday School. Should a church feel called to include and accommodate children and families affected by disabilities, it is important to know what full inclusion is, looks like, and how to strive towards full inclusion.

Steps to Begin a Disability Ministry

It is important to be committed to the full inclusion of all people before a church can form and sustain a Disability Ministry. In this section, five key steps to beginning a church Disability Ministry will be examined. These steps presuppose that at least one person with a calling to this ministry will be identified. Then, the first step as in any ministry, but especially for a Disability Ministry, is to assess the church's culture. It is crucial to assess a church's culture to gauge what the community thinks about welcoming and putting time into creating a Disability Ministry.

¹¹⁰ Carter, *Including People with Disabilities*, 80-82.

¹¹¹ Carter, *Including People with Disabilities*, 83.

Step One: Assess Your Church's Culture¹¹²

To begin a Disability Ministry, it is imperative to discern if a congregation is ready to welcome families affected by disabilities. This ministry is not for every church and the answer might be “no.” However, true discernment and assessment of the church's culture will guide the community to a place where God is calling them. This step is for the clergy person, lay leader, or parishioner who feels called to begin this ministry. The first question that should be considered is, “what does my church think about people with disabilities?”¹¹³ Do research within the church—ask other parishioners and leadership what they think about beginning this ministry.

Once a church has established that they feel called to begin a Disability Ministry, a committee or core team of individuals will be assembled by clergy or lay leadership. Before a church would be able to establish this committee or team, there should be approval from the governing church body, for the Episcopal Church that would be a vestry. If others believe this ministry aligns with and enhances the mission of the church, clergy or lay leadership will invite and identify possible parishioners who might be interested in helping to lead this ministry.¹¹⁴ Step two is to establish a committee or a core team that will discern the future of this ministry.

Step Two: Establish a Committee and Formulate Goals

Understanding where the church is in these areas is a difficult task. Ideally, a clergyperson or lay leader will gather a committee of 5-7 individuals—other clergy,

¹¹² Verbal, *Special Needs Ministry*, 37-43.

¹¹³ Verbal, *Special Needs Ministry*, 38.

¹¹⁴ Verbal, *Special Needs Ministry*, 40.

formation/education leaders and volunteers, parents, and possible experts in this field.¹¹⁵

If a committee of that size is not possible, consider inviting 2-3 individuals, be sure at least one is in a leadership or clerical position, and a parent. The size of this committee might depend on the church's size. As interested parishioners are identified, culture will continue to be assessed, and a vision will need to take shape. Consider if your leadership will need professional training, how children with disabilities will be served in the church, and what policies/procedures need to be in place.¹¹⁶

The goal(s) of this committee or team will vary depending on the goal of the ministry.¹¹⁷ First and foremost, connect the church's mission to that of the Disability Ministry's.¹¹⁸ Having a Disability Ministry mission statement will remind volunteers, leadership, families and other parishioners of the goal and reason for investing in this ministry. When establishing the Disability Ministry's vision, consider the following: what classrooms and worship space will look like, what types of accommodations are realistic, and discern if a professional should be involved."¹¹⁹ It is important to be realistic about motives and what the church can and cannot do. Equally as important as the mission of the Disability Ministry, are the limitations to this ministry. If parents understand expectations and limitations of the ministry, the less likely they are to feel disappointed.¹²⁰ One of the ways in which you can ensure the Disability Ministry stays on track is by establishing a vision for each child with a disability.

¹¹⁵ Lane and Kinnison, *Welcoming Children with Special Needs*, 79.

¹¹⁶ Lane and Kinnison, *Welcoming Children with Special Needs*, 78.

¹¹⁷ Lane and Kinnison, *Welcoming Children with Special Needs*, 79.

¹¹⁸ Verbal, *Special Needs Ministry*, 44.

¹¹⁹ Lane and Kinnison, *Welcoming Children with Special Needs*, 82.

¹²⁰ Lee, *Leading a Special Needs Ministry*, 58.

Casting a vision and goals for each child is equally as important as the goals the church sets for itself. Create a portfolio for each child, so that all who work with and minister to that child know how to properly support him/her.¹²¹ Creating these portfolios will ensure that your church can make appropriate accommodations and goals for each individual child. In return, these goals will ensure that the child is receiving proper accommodations and tools needed for success. Once goals are established, be sure to explain and publicize these ideas to the rest of the congregation, and especially to parents.¹²² It is important to include parents in this process, so they can express concerns and provide feedback. These goals should be surrounded by deep, loving discernment, and prayer. It is also important to keep all files in a secure location and to honor the confidentiality of families to the extent they request it. See Appendix A for additional information on the creating a vision and goals.

Step Three: Establish a Timeline

Keeping a timeline and establishing how to support those involved in this ministry will help form various goals and visions for the future. The committee is encouraged to establish a timeline and assign responsibilities to reach specific goals, as identified in step two.¹²³ Assigning certain tasks and creating a timeline will keep the Disability Ministry on schedule in order to reach its goal. The timeline should include times when this committee/team will meet and when responsibilities should be completed. All committee/team gatherings should be surrounded by true, honest, and loving prayer.

Step Four: Recruiting and Educating Volunteers

¹²¹ Carter, *Including People with Disabilities*, 103.

¹²² Carter, *Including People with Disabilities*, 91.

¹²³ Lane and Kinnison, *Welcoming Children with Special Needs*, 80.

Having a strong group of volunteers in a Disability Ministry is vital to its success. However, some supporters of this ministry might not understand or know what volunteer opportunities are available. Before the committee can successfully identify volunteers, it is important to lay out possible volunteer roles and descriptions. In general, it is helpful to identify expectations, skills a volunteer should already possess, and skills the volunteer can learn.¹²⁴ After laying out general expectations and skill requirements, begin to formulate volunteer positions, accompanied by a description of that position. See the chat below for examples of Sunday School volunteer positions and their descriptions.¹²⁵ Keep in mind that these positions and descriptions can be adjusted depending on what works best for the church's children, and that to include children in worship would require equally specific roles.

Volunteer Role	Description
1- Lead Teachers	Lead Teachers are encouraged to adjust lesson plans to include various teaching methods/in conjunction with the way special needs children in their class learn the best; be yourself—you know more than you think, and you will learn so much by welcoming these children and parents into your classroom; always ask the parents for guidance, if needed
2- Assistant Teachers	Will help the Lead Teacher come up with creative ways of learning and including the child in the classroom; they will encourage the special needs child to interact with the other children (and vis-versa)
3- Buddies	A “buddy” will be paired with a child who needs minimal assistance in the classroom; this buddy will be a fellow peer, who will guide and assist the special needs child with classroom activities and assignments
4- Substitute Lead & Assistant Teachers	Will take the place of the Lead or Assistant

¹²⁴ Carter, *Including People with Disabilities*, 107-108.

¹²⁵ Carter, *Including People with Disabilities*, 105-107.

Teachers in case of their absence and are encouraged to follow what they do; consider visiting the class a few times to observe

Once roles and descriptions are outlined, consider the way in which your teachers and leaders will continue to be educated. Continue to provide volunteers with resources for handling behavior, including suggestions specific for certain disabilities.

Educating teachers and leaders volunteering with a Disability Ministry is equally as important as outlining their roles and descriptions. Encourage the Disability Committee members to stay in contact with teachers and leaders, so they can get a sense of how often and what kind of continuing education or help is needed.¹²⁶ This is where a professional in the disability field might be called upon for help and guidance. Bringing in a professional to lead seminars or workshops, and encouraging volunteers to attend, is a way in which the church can provide continuing education.¹²⁷ In addition, encourage parents, whose children have disabilities, to share their advice and knowledge with the church community.

In conjunction with information the parents provide, consider brainstorming accommodation ideas that will help volunteers with behavioral issues. While the topic of a child's behavior might be an uncomfortable conversation to have, keeping lines of communication open with the parents on ways to help their child is essential to ensure proper accommodations are provided.¹²⁸ Ask the child's parents to help identify jobs/tasks that might upset the child and try to avoid asking the child to do them.¹²⁹ In

¹²⁶ Verbal, *Special Needs Ministry*, 70.

¹²⁷ Carter, *Including People with Disabilities*, 109.

¹²⁸ Verbal, *Special Needs Ministry*, 71.

¹²⁹ Verbal, *Special Needs Ministry*, 73.

addition, if behavior continues to be an issue, consider visiting other churches in the area to see ways in which they accommodate behavior.¹³⁰ Behavior is not always a major issue but understanding proper ways to accommodate and help the child will ensure all participants can experience God.

Learning about the most common types of disabilities might help the teacher or leader in preparing and accommodating children affected by a range of disabilities. The chart below explains five common types of disability.¹³¹

Type of Disability	Description of the Disability	Accommodation Idea(s)
1- Physical Disabilities	Capable children affected by disabilities, including but not limited to: cerebral palsy, spina bifida and muscular dystrophy	Come up with or adjust games/activities, so they can fully participate
2- Autism	There are different levels to Autism; mainly it is a complex disorder in which the brain is affected	Keep things simple and calm- use as few words as possible and break things down. Meet with natural light whenever possible.
3- Hearing or Visual Impairment	These children might take longer to grasp lessons and will often struggle with pronouncing words	Use sign language; make sure to have the child's attention before speaking; these children might have devices to help them see or hear
4- Learning Disability	These children might have behavior issues due to their brain processing; there are typically no physical indicators that this child has a disability; types include but not limited to, ADD, ADHD and dyslexia	Keep things simple and calm; give them a single task, at a time; try to keep things as consistent as possible- no added surprises!

¹³⁰ Verbal, *Special Needs Ministry*, 109.

¹³¹ Verbal, *Special Needs Ministry*, 105-108.

5- Developmental Disabilities	Varies depending on the disability itself; types include, but are not limited to: Down syndrome, alcohol syndrome and Fetal X syndrome	Will typically need an extra set of hands/guidance to be pointed in the right direction
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Providing educational opportunities and accommodation ideas for leaders and teachers will ensure your Disability Ministry maintains an appropriate level of good health and sustenance.

Step Five: Sustaining Your Church's Disability Ministry

Continuing to educate your teachers, leaders and committee members is just one way to enhance and sustain a church's Disability Ministry. As this ministry progresses and grows in the church community, communicate with the church's clergy, vestry, family members and other parishioners so they feel connected to this new adventure in ministry. Encourage members of the church community to spread word of this ministry to the wider community.¹³² The church might make flyers or create a page on the church website describing the Disability Ministry.¹³³ When appropriate share stories that illustrate the inclusion of people with special needs. Make sure parishioners and clergy know about these resources so they can share with others.

Another way to can educate the wider community on what the church is doing is by creating relationships and partnerships with local organizations that support disability accommodations.¹³⁴ Educating the church community and the wider community will help a Disability Ministry be fruitful and thrive. As always, encourage parishioners to pray for

¹³² Verbal, *Special Needs Ministry*, 79.

¹³³ Verbal, *Special Needs Ministry*, 92.

¹³⁴ Verbal, *Special Needs Ministry*, 92.

this ministry and encourage teachers and leaders to honor their passion for this vital, often under-appreciated work in the church.

A Disability Ministry is not easy and will require work and continual education. Grasping with what it means to be pastoral and to provide pastoral care to others, lays a solid foundation for those who feel called to work with children and families affected by disabilities. This solid foundation is a guiding principle when discerning your church's call to a Disability Ministry and what that ministry might look like. Providing pastoral care is primarily about meeting people where they are and practically speaking, so are the beginning steps of a church's Disability Ministry. Keeping lines of communication open and available to parents, will better educate a committee, leaders and teachers on ways to help accommodate children.

As always, the work is not done and will never be done. There is so much more to learn and do with and for children with disabilities, and their families. In Chapter 4, *Disability and the Episcopal Church: Creating a Vision for the Future*, a brief vision for the future of disability in the Episcopal Church is articulated and described.

Chapter 4

Disability and the Episcopal Church: Creating a Vision for the Future

In recent decades, the Episcopal Church has demonstrated increased thoughtfulness in providing both radical hospitality and an inclusive environment to all people. In 1985, the Most Rev. Edmond L. Browning, the newly elected Presiding Bishop said, “there will be no outcasts.”¹³⁵ This statement became a defining character of his tenure. Despite tremendous progress in many areas of inclusion, there are always things the church can strive to do better. My focus on the theology of disability, the importance of pastoral care, and practical ways of accommodation for children with disabilities has led me to articulate the importance and need for better, more concrete ways to serve and welcome this community of God’s people.

The first part of my vision for disability in the Episcopal Church is by fully living into our Baptismal Covenant, the foundation and very essence of our faith. The second part includes supporting, advocating, and creating resources for the disability community on a diocesan level.¹³⁶ Individual churches are capable of all these things, but guidance from an experienced individual will help churches on their journey towards providing a more inclusive church experience for people with disabilities. The goal in this chapter is to articulate a new vision to better serve the disability community in the Episcopal Church.

¹³⁵ The Episcopal Diocese of Oregon, *Rest in Peace: The Rt. Rev. Edmond L. Browning*, July 11, 2016, accessed March 11, 2019, <https://www.diocese-oregon.org/rest-in-peace-the-rt-rev-edmund-l-browning/>.

¹³⁶ The Episcopal Church, *A-Z Glossary: Diocese*, <https://www.episcopalchurch.org/library/glossary/diocese>, accessed April 19, 2019.

Living into our Baptismal Covenant

The beginning of our Christian journey is marked by the sacrament of Holy Baptism. As Episcopalians, we make a vow in our Baptismal Covenant to “seek and serve Christ in all persons, loving our neighbors as ourselves.”¹³⁷ This vow in the Baptismal Covenant is the very essence and foundation of what it means to minister to all of God’s people, regardless of ability. If we remind ourselves to first seek, identify, and recognize Christ in the other, only then are we able to serve the essence of Christ that lives in that person. Serving Christ in a person who embodies a disability involves identifying ways to allow their gifts to shine, and to create a space in which they can experience God in a language best understood by them.

Visibility, Advocacy, and Resources

When we as Christians, and specifically as Episcopalians, hear the call to live into our Baptismal Covenant we begin to understand the priority God places on our honoring all dimensions of the human experience. Part of my vision for the future inclusion of people living with disabilities in the Episcopal Church is to respond on a diocesan level.¹³⁸ A way to better advocate for and support the disability community in Episcopal churches and affiliated schools or organizations is through the creation of a ‘Disability Accommodations Officer.’ This kind of role would be beneficial to individual churches because it would provide them with an experienced person to help support and guide

¹³⁷ The Episcopal Church, *Book of Common Prayer and Administration of Sacraments and Other Rites and Ceremonies of the Church, together with the Psalter or Psalms of David*, (New York: Church Publishing, 1979), 305.

¹³⁸ A diocese is, “the territorial jurisdiction of a bishop”, <http://www.dictionary.net/define/diocese>.

them in establishing a plan for including people with disabilities into their church communities.

A Disability Accommodations Officer would represent the theology of disability and would advocate for the full inclusion of people living with disabilities throughout the church, inspiring Episcopalians to live into our Baptismal Covenant. This person would be the one to better support and serve those with disabilities, ultimately ensuring that their gifts are visible to the wider church community, so that they might serve Christ in the best way. Providing this kind of officer on a diocesan level would be the best way to ensure that the disability community is both heard and seen in the immediate community.

It is important that our dioceses do their best in supporting and supplying resources that include all people for all aspects of ministry. Examples of the kind of support a Disability Accommodations Officer could provide can be found in work already being done in the Anglican Diocese of Liverpool and the Episcopal Diocese of Michigan. These two dioceses are leaders in disability advocacy and inclusion. The Diocese of Liverpool has two staff members dedicated to pastoral care for people with disabilities, and disability awareness. In addition, the Diocese of Michigan has emphasized the importance of visibility in the disability community through an affiliated disability awareness organization.

The Diocese of Liverpool has written the Equalities Act which requires churches in the diocese to, “make reasonable adaptations with regard to physical access and the way church services are conducted.”¹³⁹ The Diocese of Liverpool has two team members

¹³⁹ The Diocese of Liverpool, “Disability”, 2019, accessed February 15, 2019, <http://www.liverpool.anglican.org/Disability>.

that minister to people with disabilities. The Rev. Dr. Hannah Lewis is the Pastoral Team Leader Among Deaf People, and Sr. Ruth Reed is the Diocesan Disability Awareness and Vulnerable Adults Coordinator.¹⁴⁰ They both ensure that the disability community in Liverpool is visible and advocated for. In addition, they also help establish a framework for ways to ensure people with disabilities are included in both churches and church schools.

The Episcopal Diocese of Michigan has also taken steps to ensure inclusion and visibility of the disability community in their common life. The mission statement goal of ‘Disability Awareness in the Episcopal Diocese of Michigan’ ambitiously claims all churches in the diocese will be accessible to all.¹⁴¹ In addition to creating this mission statement goal, the diocese has articulated a clear vision for the future of disability in their diocese and church communities. This vision sets foundational expectations on disability inclusion and accommodations for churches.¹⁴² Some of these expectations include but are not limited to: materials needed for worship will be adjusted in accordance with the person’s disability, and various tools will be given to those who need might have a hearing-impairment.¹⁴³ When dioceses commit resources to the full inclusion of people with disabilities, I believe churches feel more confident and compelled to address the issues locally.

Another benefit of the Disability Accommodations Officer is the ability to create and provide trainings and workshop opportunities to train lay professionals and

¹⁴⁰ Diocese of Liverpool, “Disability”, 2019.

¹⁴¹ Chuck Swinehart, “Disability Awareness,” Episcopal Diocese of Michigan, 2019, accessed February 15, 2019, <http://www.da-edomi.org>.

¹⁴² Swinehart, “Disability Awareness,” 2019.

¹⁴³ Swinehart, “Disability Awareness,” 2019.

volunteers, and clergy. In addition, it would be appropriate to thoughtfully create resources on how to support and care for families affected by disabilities. In the Church of England, St. Martin's-in-the-Field, London, partners with the Inclusive Church Network (ICN) to create an Annual Disability Conference.¹⁴⁴ This conference is an open invitation for all to learn about disabilities and the inclusion of people living with them in the church. All workshops and reports given at this conference are published for the wider church community to see and use.¹⁴⁵ This Annual Disability Conference is an opportunity to learn and discuss new ideas and developments within the church and disability community.

Episcopal based organizations or conventions such as The Network for Christian Formation (FORMA), General Convention, Diocesan Conventions, and/or the Global Episcopal Mission Network (GEMN) are areas in which the Annual Disability Conference can be adopted. For example, FORMA, has an annual conference that provides workshops, ideas, and networking opportunities for Christian Educators from across the United States. This could be an opportunity to hold workshops to provide educators or formation leaders with foundational tools and ideas to better support and accommodate anyone with a disability that might attend their church. In addition, it would lay the foundation for beginning conversations towards disability advocacy and awareness in more churches, dioceses, and beyond.

Conclusion

¹⁴⁴Inclusive Church, "Disability," 2019, accessed February 15, 2019, <https://www.inclusive-church.org/disability>.

¹⁴⁵Inclusive Church, "Disability," 2019.

In conclusion, a foundational understanding of various realms of disability as it relates to the study of theology, pastoral care, and practical accommodations are essential aspects for the Episcopal Church to remember. The theology of disability is complex, but by remembering that we are all created in the image of God only then can we better serve those affected by disabilities in a pastoral way. Pastoral Care is an intentional act of meeting families affected by disabilities where they are. As pastoral care providers, we are called to show these people love and support, to pray with them, and to listen to them. These practices and habits of pastoral care will lead us to better understand the way in which we can better accommodate our brothers and sisters with disabilities. New curriculum is not needed, and the child does not need to be “fixed,” but rather the classroom, worship space and/or curriculum should be adjusted, in conjunction with each child’s gifts and abilities.

Disability inclusion and advocacy is more than simply saying, “The Episcopal Church Welcomes Everyone,” or publicizing this on your church’s website, or putting a ramp outside your church’s building. These things are important, but what is equally important is discerning a true and honest understanding of what this kind of radical hospitality and welcome looks like for real people with real differences, and fully living into our Baptismal Covenant of “seeking and serving Christ in all persons.” Since this conversation on disability is important to continue, I invite everyone to continue to ask themselves, “how am I living into my Baptismal Covenant, and how am I encouraging others to live into theirs?” Ministering to those affected by a disability will forever change and transform our hearts, souls, and minds, because our acts are outward, visible signs of God’s loving embrace.

APPENDIX A:
Supplemental Resources on Disability

Creating a Special Needs Ministry in the Church: Julie Lane, E.D. and Quentin Kinnison, Ph.D., pose eight questions for a Disability Committee to consider as they discern the future goals and vision of their Disability Ministry. These sample questions are provided below and found on page 82 of their book, *Welcoming Children with Special Needs*.

- 1) Do we want to serve children formally identified with a disability?
- 2) Will we serve our students in an inclusive classroom setting, a resource setting, and/or special day class setting?
- 3) What types of disabilities do we want to serve?
- 4) Will we need to hire a special education teacher, or do we have someone who has training or willing to get trained?
- 5) How many students are identified with special needs or are struggling?
- 6) Should we consider team teaching with a special education teacher?
- 7) What types of services can we provide?
- 8) Will we use specialized curriculum? Differentiated instruction? Intervention strategies?

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