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INTRODUCTION

I can do all things through Christ who strengthens me.

PHILIPPIANS 4:13

I have never been more optimistic than I am today about the real opportunities for persons with disabilities to participate in the life of the church, and for faith families to flourish with this full and profound participation. With societal improvements in physical accommodation and accessibility to medical and other progress that enable persons with disabilities to be more active in the world around them, this is a very exciting time for those with all manner of physical, emotional, and psychological challenges. And, with ongoing and increasing commitment of persons in the church to fully welcome all members, including those with disabilities, to every aspect of church life, the possibilities are endless.

Of course, there is still much to be done. But on a personal level, as someone who has since birth lived with often-disabling health conditions, and as a Catholic journalist and author who has lived, studied, written, and spoken for nearly twenty years about the places where church, disability, faith, and suffering meet and intertwine, I have never seen such good potential for persons with disabilities to be present and completely engaged in church life.

WHAT PROGRESS?

Developments in medicine have fostered tremendous potential for persons with disabilities. I have experienced this personally: Twenty years ago, I was diagnosed with systemic lupus erythematosus, “lupus,” a chronic autoimmune condition that has no cure and can sometimes be life-threat-

ening. At that time, most of my doctors were sketchy about my prognosis: lupus patients usually did not live as long as people who did not have the disease. Now, my doctors have modified their opinions: I can expect to live a normal lifespan—but with “difficulty.”

It is a subtle, yet significant difference, one that fuels forward thinking, dreaming, and action like never before. And, with other such developments over the past several decades, it speaks to a marked shift in the positive ability and outlook for persons with disabilities of all kinds.

Besides medical advances, the passage into law in 1990 of the Americans with Disabilities Act (ADA)¹ has spurred tremendous innovations in mobility and other aspects of accessibility. These have opened up the world of work, leisure, entertainment, and church, among other avenues, to and for persons with disabilities at all ages and stages of their conditions.

Advances in education have empowered persons with learning impairments to receive information in creative, effective ways, increasing their ability and capacity to move ahead in fields that previously were closed to them. Technological breakthroughs, especially in our means of communication, have brought persons with disabilities closer to each other and the world at large in novel and profoundly exciting ways.

Alongside these societal developments, church leaders have repeated their commitment to educating all Catholics, that ours is a universal church, one that should and must welcome all members, including those with disabilities and the Deaf. This has been accompanied by ministerial efforts that have brought great comfort and encouragement to persons who have, in many ways, been on the outskirts of society.

There is nothing new in such a commitment; the catalyst for it can be traced all the way back to Jesus Christ, who paid particular care to the poor, sick, infirm, and other marginalized individuals and called them to fully follow him. But as a better understanding of the effects and potential of disability within the church has emerged, a significant linguistic shift has occurred: the emphasis in documents and focus for efforts to fully welcome has moved away from ministering “to” persons with disabilities to ministering “with” them.

This might seem too subtle to be of importance; however, in practice, it reflects an imperative that is the essence of full welcome: Persons with disabilities are “created in God’s image and likeness.”² By their baptism, they are equal members of the body of Christ, and are to be fully welcomed to participate in all aspects of the life of the church. And we are, each of us, *all* of us, involved in this ongoing process.

A very exciting distinction, a wonderful opportunity!

And, a mission much more easily articulated than carried out.

CHURCH LEADERSHIP AND THE (EARLY) PARISH RESPONSE TO FULL WELCOME

In November 16, 1978, twelve years before the Americans with Disabilities Act was enacted, the United States Conference on Catholic Bishops issued their *Pastoral Statement of U.S. Catholic Bishops on People with Disabilities*. This comprehensive document put forth the “Church’s Response to the Person with a Disability,” framing it with Scriptural examples, church teaching, and an active understanding of who persons with disabilities are and what they seek in faith. Among these: “Persons with disabilities are not looking for pity. They seek to serve the community and to enjoy their full baptismal rights as members of the Church.”³ These include the right to dignity, respect, life, and full participation in all aspects of the church.

To help with the tangible aspects of implementing “full participation,” the USCCB established the National Catholic Office for Persons with Disabilities. Now the National Catholic Partnership for Disability (NCPD, www.ncpd.org), the office offers resources and training for clergy, lay ministers, and others who work toward full welcome of persons with disabilities and who are Deaf. Also, many dioceses have established ministries for persons with disabilities and the Deaf, and some parishes are formally active in this work too.

But in those early days, without a history of “best practices” and with many moving parts to the subject as a whole, practical progress at the parish level was slower than many would have hoped, and it was peppered with twists, turns, and detours.

Physical and structural changes to church buildings, education of the faith community, and pastoral preparation posed significant budgetary and logistical challenges, often complicated because of the age and historic significance of some churches or misunderstandings among members of church congregations.

Those involved in the Deaf community were undergoing their own development as a culture while also trying to find their place in the Catholic church. (An excellent book, *In Silent Prayer: A History of Ministry of the Deaf Community in the Archdiocese of Philadelphia*, by Anthony Russo, CSSR, gives an enlightened telling of one archdiocese's experience building an effective, profound Deaf ministry.) And welcome, for them, was complicated by their distinctive language, whose syntax is unlike more common linguistic constructions.

But perhaps the most daunting challenge faced by those who would implement the guidance from the USCCB *Pastoral Statement* was (and still is) catechesis, particularly preparation for the sacraments.

Disability is not uniform, and persons who have disabilities often have unique learning needs. These have nothing to do with the ability to understand the fundamentals of faith but do impact how persons with learning difficulties process language and are taught. For many catechists, the feasibility of providing religious education to church members with special needs posed confusing, daunting problems. How were they to do this? Where could they do this? Who had training to do this? Could it possibly be done credibly? Validly?

In 1995, five years after the Americans with Disabilities Act, the USCCB issued the first edition of the *Guidelines for the Celebration of the Sacraments with Persons with Disabilities*. It clarified, sacrament by sacrament, that persons with disabilities are to be prepared for and welcomed to the full table of the Body of Christ under the same conditions (but not necessarily by the same teaching method) as all other members. This was followed three years later by *Welcome and Justice for Persons with Disabilities: A Framework of Access and Inclusion, A Statement of the U.S. Bishops*, which reaffirmed consideration of disability to include issues of respect for life and the dignity

of all persons, moral values increasingly under siege by society's increasing acceptance of abortion, and other trends counter to Christian beliefs.

Persons with disabilities within the church community, thus understood, are not only equal members of the body of Christ, but an essential presence within the church community that reflects the reality of our ongoing commitment to dignity for all, respect for life, and welcome of a truly universal church.

The USCCB was not alone in this affirmation. Other church leaders were also articulating the same position, providing much welcome and needed support for grassroots activity.

POPE AND PERSONS WITH DISABILITIES

Over the past several decades, three popes have built upon their predecessors' calls to fully welcome persons with disabilities into the life of the church.

In October 1992, Saint John Paul II inaugurated the "World Day of the Sick." Unlike many other "commemorative" days that seek to statically mark a particular event or cause, from the start, the Holy Father intended the day to spur forward-moving action.

In his message for the first World Day of the Sick, Saint John Paul II writes, "This day, which, beginning in February 1993, will be celebrated every year on the commemoration of Our Lady of Lourdes, for all believers seeks to be a special time of prayer and sharing, of offering one's suffering for the good of the Church and of reminding everyone to see in his sick brother or sister the face of Christ who, by suffering, dying and rising, achieved the salvation of mankind" (*Letter Instituting the World Day of the Sick*, 13 May 1992, n. 3).

And, he writes, "The World Day of the Sick—in its preparation, realization, and objectives—is not meant to be reduced to a mere external display centering on certain initiatives, however praiseworthy they may be, but is intended to reach consciences to make them aware of the valuable contribution which human and Christian service to those suffering makes to better understanding among people and, consequently, to building real peace."⁴

In subsequent messages on the World Day of the Sick and elsewhere, Pope Emeritus Benedict XVI and the current pope, Pope Francis, continued what Saint John Paul II began. Their messages on The World Day of the Sick, and at other times, reemphasize the necessity of welcome and state that persons with disabilities need to be treated, and act, as full members of the body of Christ.

Most recently, Pope Francis reiterated the church's commitment to persons with disabilities, and the expectations for their full participation, in an October 2017 address to participants in the Conference on Catechesis and Persons with Disabilities: A Necessary Engagement in the Daily Life of the Church.

"The Church cannot be voiceless or out of tune in the defense and promotion of people with disabilities..." Pope Francis said. "This applies even more so due to her responsibility with regard to *generating and forming the Christian life*. The community must not lack the words and above all the gestures for encountering and welcoming people with disabilities. The Sunday Liturgy, especially must be able to include them, so that the encounter with the Risen Lord and with the community itself may be a source of hope and courage in the difficult journey of life."

"Lastly," he said, "I hope that in the community, more and more, people with disabilities may be their own catechists, by their witness, too, so as to pass on the faith in a more effective way."⁵

ORDINARY CHURCH

In early 2017, the United States Conference of Catholic Bishops (USCCB) issued their *Guidelines for the Celebration of the Sacraments with Persons with Disabilities, Revised Edition*. In keeping with the progression of earlier documents, when ministry "to" became ministry "with," full welcome of persons with disabilities is not meant to be a rare or out-of-the-ordinary occurrence; rather, it is meant to be "ordinary"—a regular part of the life of a church community. They write: "Catholics with disabilities have a right to participate in the sacraments as fully as other members of the local ecclesial community."⁶ And, "Parish sacramental celebrations should be accessi-

ble to persons with disabilities and open to their full, active, and conscious participation, according to their capacity... Full accessibility should be the goal for every parish, and these adaptations are to be an ordinary part of the liturgical life of the parish.”⁷

Through ministries for persons with special needs and the Deaf community, more dioceses are equipping themselves to help parishes reach this goal. Publishers and diocesan religious education departments have fashioned training and in-the-classroom programs that can be used to teach children and adults with a wide range of learning disabilities. At the local levels, persons with and without disabilities are involved in efforts of full welcome, including catechesis, liturgy, and ministry through volunteer and paid positions. Academic institutions are ramping up coursework focused on issues related to disability, and many pastoral training programs also include modules on disability understanding and ministry.

All of this work and the wonderful people involved in it give me great optimism for the future, a future that sees parishes completely reflecting the universality of our church. But, there is still work to be done. People with disabilities are still missing from our pews and the life of our parishes.

Although there are few studies that focus on persons with disabilities and church attendance, as I interviewed experts for this book I kept hearing, anecdotally, that an estimated eighty-five percent of persons with disabilities do not regularly attend church. When families where one or more members (often, a child) has a disability are included in this percentage, the number of people absent skyrockets. I also heard more than one story about people leaving Catholic churches for other denominations or to explore spiritual practices on their own, many after having had negative experiences in one or more parishes.

One study issued in July 2010, “The ADA 20 Years Later,”⁸ looked at the impact of the ADA on several different aspects of daily life, including attendance at church. According to its findings, in 1986, four years before the ADA went into effect, fifty-five percent of persons with disabilities who were surveyed said that they went to “church, synagogue, or any other place of worship at least once a month.”⁹ In 1994, four years after the ADA

went into effect, the number fell to 48 percent. And in 2010, the last year included in the survey, the number had only risen to 50 percent—better than the anecdotal perceptions, but still not a robust or complete figure.

Could it be that, despite making physical accommodations, establishing pastoral programs, and deploying volunteer and paid staff, we're missing something?

I think we are. I think we're missing something very significant. And, much like the "elephant in the room," until this necessary ingredient is understood and completely mixed in with everything else we have and do, we'll still come short of our full potential for full welcome.

What is the "necessary ingredient"? *The right attitude.*

THE HEART OF WELCOME

In their *Guidelines for the Celebration of the Sacraments with Persons with Disabilities, Revised Edition*, the USCCB writes, "The creation of a fully accessible parish reaches beyond mere physical accommodation to encompass the attitudes of all parishioners toward persons with disabilities. . . . Pastoral ministers are encouraged to foster attitudes and a parish culture, and to develop informational materials, aimed at forming a community of believers known for its joyful inclusion of all of God's people around the table of the Lord."¹⁰

This passage is insightful: Although the phrase, "attitude is everything" might sound like a cliché, it is absolutely spot-on when it comes to productively and constructively living with a disability, working with those who have disabilities, and developing and supporting a community commitment to full participation in the life of the church.

Saint Paul writes, "If I speak in the tongues of mortals and of angels, but do not have love, I am a noisy gong or a clanging cymbal" (1 Corinthians 13:1, NRSV).

The right attitude is founded on and exudes love. It is a positive attribute to cultivate within ourselves and one that flows outward, into tangible words and deeds. It becomes compassion, care, service, willingness to listen, desire to accompany. And it is necessary in everyone involved with

full welcome, from the person with disability to clergy and other church leaders to every person in the pews.

To paraphrase St. Paul, I, as someone with disabilities, could have all the accommodative supports in the world, but if I do not have a positive attitude toward using them, I will not make the most of them. If I adopt an “all about me” attitude, I will fail in faith and fellowship.

As someone who wants to live out her Catholic faith, if I expect accommodation within the Christian family, I need to also desire and have a willingness to serve *within* it. This includes working hard to help others understand disability and to be understanding toward them too. It requires that I strive to be my best, to continually develop spiritual insight and virtues, to make the commitment (have the attitude) to constantly learn and grow—to discern where others’ needs are, what it is I am called to do, and then to make the necessary sacrifices to do it. Christlike service is not about “look at me,” but rather “look at you” and, especially, “look at God.”

Likewise, someone who is in ministry can have all the training possible, have worked through the most demanding spiritual formation, and know chapter and verse about the church, faith, and sickness, but if he or she does not have the compassion and willingness (attitude to love) to walk with someone who is disabled and take time to listen, understand, and respond personally and charitably to that individual, he or she will fail the people they seek to serve.

For someone formed and trained to serve, this means taking training to heart as well as head, thinking outside the “boxes” of schedules and pressures of other responsibilities to make time for and pay attention to persons who might be quite challenging to get to know, communicate with, or, even sometimes, like, let alone love as Christ did. It requires going after the “one lost lamb” and having the courage to face down opposition (“Why do we need to do that here? They do it over at St. [fill in the blank]”), spending time with people who often do not have financial resources to offer back, and extending an ever-present hand *out* to that individual and all the others, too—not a hand *off*.

The right attitude is also crucial to success in our faith communities.

A faith community that relies on formal ministries to address hospitality, accommodation, and support for persons with disabilities is doing good work, but only partially fulfilling its purpose. *Each* member, *all* the time is hospitality, accommodation, and support. And if the members of a faith community do not embrace this, the community will fail to be a universal, loving reflection of Christ. Perhaps it will continue to physically exist, but its heart will be hollow.

To achieve the right attitude in a faith community takes group effort and individual work. The community as a whole needs to be committed to treating each person with a disability as a respected, full brother or sister in Christ and to reflect that commitment in how they communicate information about the parish and its activities. And each member needs to be aware of his or her individual biases, misconceptions, or prejudices. He or she needs to continue that soul-searching in order to be able to truly and lovingly respond to persons with disabilities.

Members of the community need to understand, accept, and respond to the fact that persons with disabilities have distinctly different life experience through, and by, their suffering, needs, and abilities—no “one-size-fits-all.” Yet it is that life experience that enhances understanding of the Christian journey and, thus, is a blessing to all. So when it comes to the presence of disability, we need to move away from the vision of the beatific, silently suffering worshiper; there is no more hiding in the corner; there is a need for visibility—acknowledged and accepted belonging—woven directly into the tapestry of the whole body.

Without the right attitude, the most high-tech, architecturally stunning ramp will ultimately be of absolutely zero benefit for achieving full welcome. With the right attitude, everything else we do and everything else we are that is good will take root, grow, and flourish. This is because not only does the right attitude, the true heart for this work, put us all in a good position with one another—it opens us up fully to God’s guidance, strength, and help.

IT'S PERSONAL AND PUBLIC—NOT POLITICAL

Attitudes can be sticky subjects. No one likes to be told theirs is “bad.” But we are human, after all, and we’ve each had those moments, those days, when we’ve said or done something toward someone else (personally or even at a distance, in our heart) that did not reflect an attitude Christ would approve of. Becoming acquainted with and accepting persons with disabilities can help us view ourselves and our attitudes (unhelpful ones, especially) through a different lens and work on our unhelpful biases, perhaps expressed through hasty, ill-used words (“retarded,” instead of “developmentally impaired,” for example) or actions, as in the tacit but profoundly unkind gesture of walking very quickly by someone who is walking more slowly, and not even taking a moment to say hello.

It is good that we do this kind of soul-searching. The most unhelpful attitudes can have long-ranging, long-term consequences for our church communities and ourselves. Parents who experience one negative attitude from a parishioner toward their child who has a disability could be so hurt or angry that they uproot the whole family and go to another church. Someone who wants to serve in the parish but is told, “We don’t have anything for you to do here,” or “We can’t work with your kind of disability,” will probably leave too. And someone who has not yet set foot in your church might not come in if there is no sign that all, including persons with disabilities, are truly welcome.

The right attitudes, however, can move mountains of prejudice, misunderstanding, and fear. In my own experience as someone with profound, but “invisible” disability, when I’ve responded to someone’s unkind remarks with anger (a very negative attitude), I usually only receive unpleasantness. But when I take a deep breath and respond with patience, the result is much more positive. And when I’ve been met with compassion (“We’ll figure this out”) instead of “No,” I have felt my heart fill ever increasingly with gratitude and love—and a willingness to be even more involved!

Our attitudes toward disability and persons who live with it spring from a combination of influences—personal (our fears, biases, life experience, education and upbringing, for example), and societal (trends and ideas of

how things “should” be). They can be molded by external stresses—economic, professional, political, and spiritual. And our attitudes can warp if they are not well shaped by experience that helps us see the common ground we all have in faith and the love that God has for each of us.

What is that experience, and how do we get it?

Experiences that draw us toward forming attitudes of full welcome are decidedly personal, not political, which is sometimes misunderstood by well-meaning parishes that run programs aimed at some aspect of disability or health (such as a “health and wellness ministry” or a monthly blood drive) but do not pay as close attention to the individual, regular reality of persons with disabilities in their midst.

True, issues related to persons with disabilities often do have a social justice component. Right-to-life efforts, for example, touch persons with disabilities in profound ways, and efforts to push against the rising acceptance of “right to die” do too.

But the reality of bringing all of us brothers and sisters in Christ together as one community has little to do with a particular cause or program, or taking a political tack (one party or group against another). It is also not about one group (persons with disabilities) “taking over” a parish, or “making a statement” for this or that cause, nor is it about the parish or individuals within it “allowing” persons with disabilities to practice their faith and satisfying some more self-serving need.

Rather, full welcome is about leaving behind those differences that might cause animosity, power struggles, or isolation—problems of politics. It is about coming *together* as one body each Sunday, each day, and building our individual relationships with God, our parishes, and our world from a position of love and faith.

So, then, the more experience we get in personal spiritual development and growth, relationship with others, and common worship, the more we build the attitudes that foster the very love we seek to reflect. As we do so, our willingness to worship, work, pray, and serve together increases. We look for possibilities and potential in one another and nurture them—*together* and in a spirit of faith. We find ways to reflect welcome so that

those searching will find and join us. And, as loving, light-filled attitudes reflect in our parishes, we spark “firsts” that break down barriers to full welcome and experience growth in joy and numbers.

“FIRSTS”?

Years ago, I worked in the early days of recruiting “underrepresented” persons (particularly persons of color and women) into the business for which I worked. It was fascinating to hear that one of the reasons we were not seeing applications from the people we were interested in hiring was because the potential applicants did not see anyone who looked like them working in our company.

And so it is with full welcome in a parish—absence of visibility for persons with disabilities will create an attitude of unwelcome and continue to deprive our church communities of the full presence of everyone belonging to the body of Christ.

But the active participation and visibility of persons with disabilities will do just the opposite—open doors and hearts to unlimited blessings as the community grows in size, understanding, and love.

It begins with us as we...

... sit beside a person with disabilities at Mass and say, “Welcome.”

... take catechetical training and say, “Yes. I will teach your child about God.”

... welcome to the liturgical team an adult with Down syndrome who desires to serve at the altar during Mass.

... show others how to communicate in American Sign Language so all can share in the richness of a Deaf Mass.

... preach and talk about the grace and blessing of suffering, letting others know we care and we desire to walk with those who live with heavy personal burdens.

... provide spiritual support so that a man or woman with disabilities and filled with the fire of the Holy Spirit can grow in faith and find his or her true purpose, perhaps a vocation to religious life born from our own parish family!

THIS BOOK

When I first thought about writing this book, I almost decided I couldn't do it. I'm not a certified catechist, nor am I a structural engineer. I have no degree in theology or years in seminary. I'm not a medical professional, either. So the technical aspects of full welcome, including specs for ramps and intricate theological citations just are not in my "wheelhouse."

But I have lived in and through the world of disability nearly all of my life; I have written extensively about it, and in doing so have acquired an excellent, albeit informal, education in the areas of faith, health, church, and "disability issues" through study and practice. With this experience and knowledge, I hope I can shed a practical and personal light on subjects that might seem, to some, too daunting, conflict-ridden, or hard to articulate.

So, far from being an architectural plan for building ramps, this book is about building bridges: how we can identify, understand, and cultivate the right attitudes as we individuals and church communities move toward full, wonderful welcome of persons with disabilities.

The subject is both tangible and intangible. Here, you will find facts and figures about disability and other important factors that impact full welcome, and references to key documents in various areas of church life, history, and disability issues. You will find discussions of terminology and language, etiquette, and other aspects of welcome of persons with disabilities and persons who are Deaf. And there are practical suggestions, too; ways that attitude can be formed and supported by us individually and throughout the church community.

There are very few surveys, research papers, books, or other sources on the subject of church and disability, but I have benefited from some and include these as resources for your further review. Many of the suggestions, ideas, and experiences here are gleaned from interviews that I have conducted with persons heading up special needs and Deaf ministries, Catholics and others living with disabilities, and their caregivers. I thank these individuals from the bottom of my heart for their generosity of time and willingness to suffer my questions! I was also honored to attend the

recent Vatican Conference on Catechesis and Persons with Disabilities: A Necessary Engagement in the Daily Life of the Church, and information from that Conference is included here too.

Welcome is an active, ongoing process. So, this is a participatory book. You will find a question at the beginning of each chapter. These are not “loaded,” or meant to point out deficits of understanding. But, I hope they will help you articulate what you and/or your brothers and sisters in Christ are doing, feeling, and reflecting about disability and your faith community now. Perhaps, when you frame your current actions or attitudes by these questions, you’ll find that you are in good shape—well on your way to fully welcoming everyone. But, perhaps, these questions will spark ideas of how you can improve, or subjects you had never considered. No right or wrong, here—any deep thought on the subject is important and for the better!

At the end of each chapter, there is “Food for Thought,” a phrase to consider in light of the attitudes prompted by the questions posted at each chapter’s beginning. Then, completing each chapter is, most important of all, a prayer.

We cannot do any of this work, or anything else worthwhile, without God’s grace, support, and guidance, and these are best discerned through careful, mindful prayer. Each moment spent in quiet with God is valuable, and as you and your faith family work for greater welcome, expanding prayer to a regular time and place can increase this crucial connection with Our Lord. I offer these focused prayers as a start and as touchstones as you journey onward.

The book is loosely divided into two parts. The first three chapters explore disability, welcome, and who welcomes within the context of the life of the church. Chapters 4–8 focus on the practical areas of church and parish life where we engage in prayer, volunteerism, spiritual development, worship, and other activities, and how we can adopt helpful attitudes toward each other. Vocations and discernment, physical considerations and accommodation, matters of privacy, humor and the social life of the church, catechesis and participation, and reaching out to those not cur-

rently coming to church (at least, not to your parish) are also covered, as are candid discussions of unhelpful attitudes we might not be aware of but that certainly impact the quality of the welcome we extend to our brothers and sisters in Christ. Chapter 9 explains why “salt” and why “light,” and how those two descriptions can motivate and inspire us for years to come.

Chapter 10 contains further resources that can be helpful to you and your faith community as you develop a universal approach to full welcome.

I pray that, however flawed, this book will promote understanding, encouragement for individual and community faith journeys and, especially, help clarify attitudes and actions that promote courage, grace, and heart for truly universal, welcoming fellowship in Christ.

Food for Thought

*Welcome is much more about attitude
than it is about programs or procedure.*

Prayer

*Dear Lord, settle my heart from all its cares
and keep me focused on serving you.
Let me be open to your wisdom that teaches me,
grace that steadies me, and
courage that enables me to overcome any
impediment that might work against fully welcoming
all to the table you have prepared. Amen.*

What Is Disability?

*So God created humankind in his image,
in the image of God he created them;
Male and female he created them.*

GENESIS 1:27

What does
“disability”
mean to
you?

Our attitudes toward disability are as individual as everything else about us. Some persons who do not have disabilities, for example, might be afraid of the subject (and the people who live with these challenges) or unsure how to relate to it (often because they were not taught adequately about suffering and pain as children). Others might be utterly compassionate, caring, and not bothered by disability of any kind.

Persons with disabilities also have distinct attitudes toward their conditions. Some might view their suffering as a blessing, and others might become depressed or angry because of the disability or the challenges it presents. Each of us encounters situations that can bring up uncomfortable or negative emotions, but we deal with them differently, depending on many factors, including our pain level at the time of the incident and

our attitude toward the event (is it an isolated occurrence or yet another “thing” in a long string of “things”?).

Misunderstandings about disability do seem to occur with some frequency, including in our church communities. In my own life in and outside of church, I’ve heard some express disbelief that anyone except someone in a wheelchair could “qualify” to be disabled. Other times, I have also heard someone ask, “How can they do that [athletic endeavor, work] if they’re disabled?” or say, “She’s disabled, so she must be stupid,” and “You’re not cured because you’re not faithful enough.”

I could write an entire book about these misunderstandings alone!

But in this one, I will provide a very simple working definition of “disability” that will be the framework for this chapter and those that follow, and offer suggestions for how to approach, communicate about, and understand key aspects of this very complex subject. I hope that this will take away some of the fear and misunderstanding and provide common ground as we explore what disability is, how it affects those who have it, and how those who do not have it might communicate better with people who do.

Here is a working definition of “disability”: *A disability is a physical, emotional, or psychological impairment that limits or prevents someone from doing one or more necessary life activities.*

From this general definition, a disability...

- is a difference; it makes the person who has it different in some way from others who do not.
- may require some reasonable kind or degree of assistance (accommodation) for the person with the disability or who is Deaf to be able to fully participate in church life. This is not “playing favorites” or doing a favor for someone but an action integral to welcoming all.
- can be visible (for example, someone who is missing one leg and is mobility impaired) or invisible (someone with end-stage kidney failure, or who has heart or lung disease).
- may be total (complete deafness or blindness) or partial (some hearing, some sight with or without a need for accommodation).

- can be static (will always be the same) or variable (may flare and subside, or get progressively worse).
- usually affects the person who has it at least somewhat differently from someone else who has the same disability; no two people will have the very same disability, even given the same diagnosis.
- complicates life for the person who has it and his or her caregivers.
- has usually not been caused by the person who has it (we cannot blame ourselves for having a disability).
- is not punishment from God (we cannot blame God for our disability, either).
- does not reflect the state of someone's soul: The soul has no disability.

Many areas of the subject of disability are constantly evolving. Developments in medicine continue to bring us greater understanding of the origins and treatments of certain conditions, and in light of these we can have a less judgmental and more compassionate attitude toward them. For example, until fairly recently, substance abuse was often considered a mark of poor character, but now, related conditions such as alcoholism are recognized as diseases and can be classified as disabilities and treated medically.

Not long ago, mental illnesses could be thought of as “craziness,” and persons who suffered from them were often isolated from society. Now, science understands much more about the chemical and neurological workings of our bodies and is able to distinguish, diagnose, and treat many mental disorders—and help us understand, too, that these are not manifestations of a broken soul, but rather a broken body (or body chemistry) that can be treated.

Invisible illnesses can be understood in this context too. If someone doesn't “look” sick, it is difficult for someone unaffected to believe that the other person can possibly have a disability and a need for accommodation. I know this first hand; lupus is “invisible” on most days, but even so can be utterly debilitating. Other conditions, such as hemophilia, fibromyal-

gia, cardiovascular disease, lung disease, epilepsy, acute migraines, or some other neurological disorders don't usually manifest outwardly but can be very painful and, yes, disabling.

Besides these aspects of disability, misunderstandings still exist regarding persons who are Deaf. Over the past several decades, Deaf culture has developed its own language (American Sign Language, ASL) and a distinct identity that is not reflective of disability but is a sociological and linguistic culture, quite separate from other disability identifications. As one person in Deaf ministry tells me, in church life, for example, this means that having a signed Mass, while very welcome, does not constitute full participation for persons who are Deaf. Other aspects of church life, such as catechesis and support for families, must be considered too.

With today's sophisticated technology, persons who are blind can navigate the world more effectively than ever before and be involved more widely in church life too.

"Disability" does not, except in very rare cases, mean that someone is entirely incapacitated. Everyone, through their gift of life, can contribute. Besides driving, working (in their own or another's business), and belonging to family and society in tangible ways, persons with disabilities can actively participate in many areas of church life, including ministry, catechesis, and volunteer efforts. Even someone who cannot speak and needs to be wheeled in to church contributes to the community through his or her presence at the table of Christ. And someone who is comatose in bed, waiting for God to call him or her home? That individual is contributing too; up until the very end, he or she is teaching us to care.

WHAT DO YOU SAY?

Full welcome thrives on friendly, open communication. However, some people hesitate to speak with persons who have a disability for fear that they will sound stupid, say the "wrong" thing, or offend. They might also think (incorrectly) that someone with a profound disability is not capable of communicating and so direct their conversation to caregivers and not to the individual with the impairments. Or, they might have an aver-