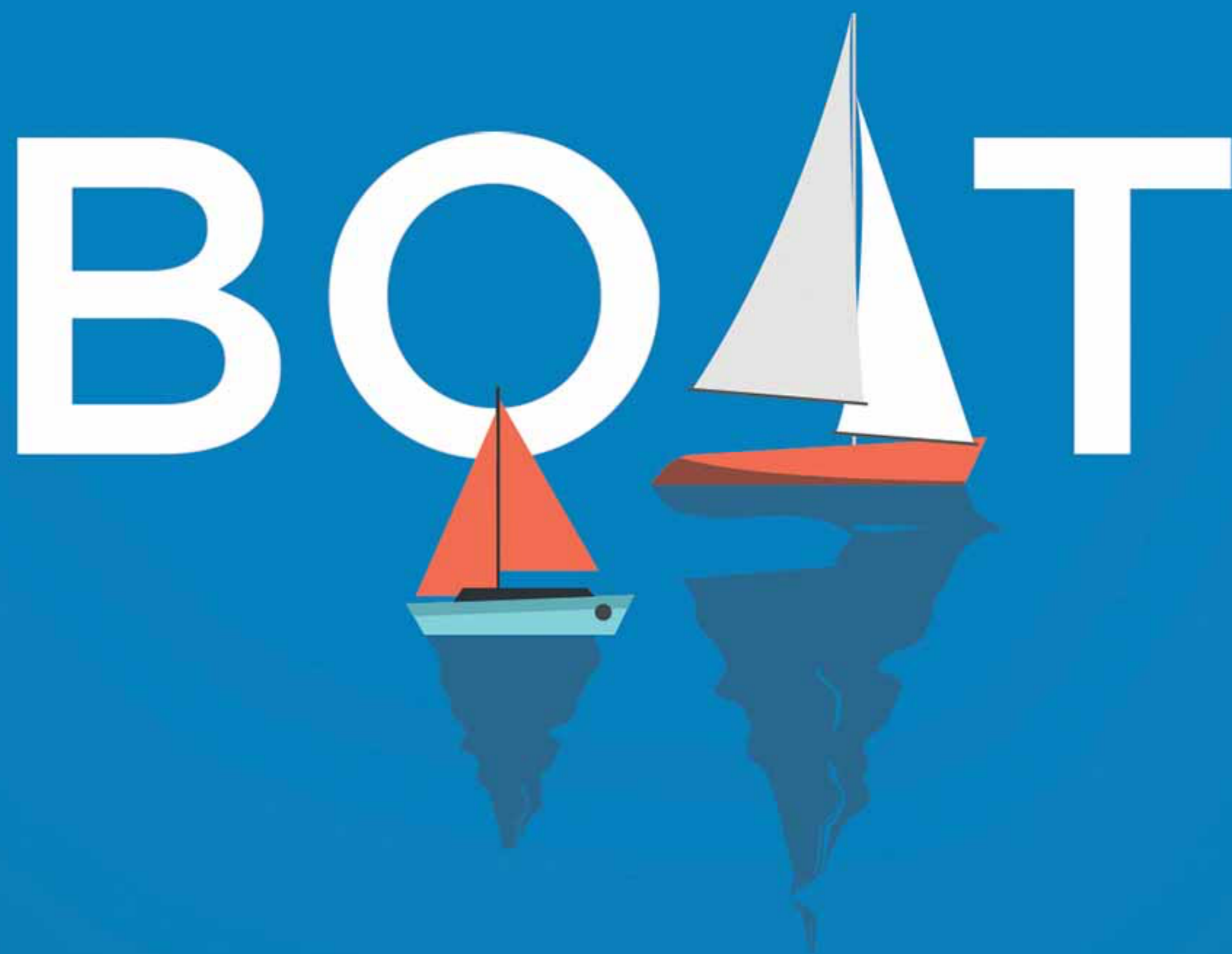


Foreword by Joni Eareckson Tada

Stephanie O. Hubach

same lake
different



Coming Alongside *People*
Touched by *Disability*

REVISED AND EXPANDED

This is a beautiful book. I loved reading the first edition, and I believe the two new chapters are worth the price of the book. Stephanie Hubach's cultural understanding, theological depth, and biblical insight are profound and unusual in reflection on issues of disability. She faces squarely the brokenness of the world and so is thoroughly realistic about the challenges of dealing with disability in one's family, church, and circle of friends. Steph sees the pain and faces it with clear eyes and a passionate commitment to serve.

Fundamental is Steph's recognition that all of us are marred reflections of God's glory, so that there is no qualitative difference between me and any other person. At the same time, Steph always affirms the glory of the person with disabilities and their dignity as one made in God's image, and therefore she insists that each person is given to bless others, to give as well as to receive. Her exposition of John 9 and the way Jesus related to the man born blind is masterful and wonderful. I am sure that every church needs to have this book so that people with any kind of disability are welcomed to serve and to be served. Thank you, Steph, for writing such a lovely and such a needed book.

—**Jerram Barrs**, Professor of Christian Studies and Contemporary Culture, Covenant Theological Seminary; Senior Scholar-in-Residence, Francis Schaeffer Institute

This book is exceptional. It is required reading for my students. Chapter 1 presents a biblical view of disability and is worth the price of the entire book. But information alone is insufficient for transformation. Chapters 2 through 13 bring you into virtual relationship with one family impacted by disability to help the informational become transformational. The new chapters, 14 and 15, are treasure troves of contemporary reflections carrying deep biblical wisdom. I wholeheartedly recommend this book to anyone who desires to think more biblically about disability, to relate more lovingly to individuals impacted by disability, or just to fuel their pursuit of God and his purposes for their lives more wholeheartedly.

—**Thomas L. Boehm**, Ann Haskins Assistant Professor of Special Education, Director of Ann Haskins Special Education Program, Director of Wheaton Center for Faith and Disability, Wheaton College

Same Lake, Different Boat is a disability ministry classic! My highlighters came out before I finished the introduction and were used heavily throughout the book. Stephanie Hubach tells her story, shares her unique and useful philosophy of ministry, skillfully exegetes Scripture passages related to disability, builds a bridge between church and disability cultures, and gives a plan for how to minister to and with the families with disabilities that you know. And she does so in a very relatable, readable style with plenty of humor. This book is for pastors, church leaders, disability advocates, students, people in the pew, and people with disabilities and their families.

—**Jerry Borton**, Cofounder, Luke 14 Exchange, Inc.

Believing and belonging—these two themes run rich throughout Stephanie Hubach’s compelling book. She reminds us of God’s clear call to become communities of belonging for individuals with disabilities and their families. And she equips us with the perspectives and practices needed to move in this direction.

—**Erik Carter**, Cornelius Vanderbilt Professor of Special Education, Vanderbilt Kennedy Center

This book encourages, inspires, and teaches us how to be so much more welcoming to all, especially those with disabilities. Stephanie’s humor, delightful storytelling, and theological insights combine to correct us and to strengthen us to action. She does not make light of the great challenges and pain for families caring for those with special needs but gives us a path to provide real help and hope. This update includes important discussion of popular disability advocacy culture and how we can respond with both affirmations of grace and firm biblical challenges, while caring for the very real pain and injustice in both the social and functional aspects of having a disability.

—**Tasha Chapman**, Professor of Educational Ministries, Covenant Theological Seminary

Same Lake, Different Boat has become a classic in disability ministry literature. It is one of the core textbooks in the disability ministry courses I teach at Moody Bible Institute. In this new edition, Hubach

makes key distinctions between inclusion and belonging and brings fresh insights to the neurodiversity conversation. She clarifies her understanding of the functional and social aspects of disability and articulates a model of belonging in the church that is gospel-centered and leads to the flourishing of all people. This book will transform your church and equip you to welcome people with disabilities and their families into the life and mission of the church.

—**Dawn Clark**, Instructor in Disability Ministry, Moody Bible Institute

Delightfully engaging. Personal and poignant. *Same Lake, Different Boat* is a must-read for anyone who wants to make the church as God has designed it to be . . . beautiful.

—**Emily Colson**, Author, *Dancing with Max*

In *Same Lake, Different Boat*, Stephanie Hubach integrates the most current concepts about neurodiversity with the timeless truth of Scripture in presenting God’s vision for doing life together. Stephanie Hubach does a masterful job of integrating the “how” of disability ministry with the “why.” She inspires fellow Christians to recognize and embrace the gifts Christ has given to persons with disabilities for the benefit of the church.

—**Stephen Grcevich**, MD, President and Founder, Key Ministry

Whether you are someone who is navigating the challenges of dealing with disability in your own family or someone who can’t imagine—and perhaps doesn’t want to have to imagine—the difficulties faced by families touched by disability, this book is for you. Steph Hubach comes alongside readers, disarming us with personal stories that range from hilarious to heartbreaking, and then gently challenging us to live graciously and generously as members of a body that includes those with disabilities.

—**Nancy Guthrie**, Author, *Hearing Jesus Speak into Your Sorrow*

Hubach has both lived and studied the experience of disability. The challenges she describes are real and hard. The successes are real and

beautiful. Deep reflections on these experiences are informed by a vibrant understanding of the Bible. This book has become a classic for families and ministries. As a starting point, I would endeavor to put it into the hands of parents, family members, and pastors. As you understand what she shares, you understand a great deal about God's plan for the church and people, particularly those affected by disability.

—**Jeff McNair**, Professor of Education, Director of Masters in Disability Studies, Director of Education Specialist Studies (Moderate/Severe Disabilities), California Baptist University; Senior Editor, *Journal of the Christian Institute on Disability*

The new chapters in Steph Hubach's updated *Same Lake, Different Boat* are worth the price of the book. She combines a deep understanding of the world of disabilities and disability thinking with a rich biblical perspective that brings fresh insights to the church's (and our) struggle to include people with disabilities. And the stories of her son Tim are always delightful.

—**Paul Miller**, Author, *A Praying Life*

As the father of a son on what is now known as the autism spectrum, I share the otherworldly experience of hearing "through a funnel in another place" when my wife told me that our son failed every developmental test with flying colors. This book captures the pain of the experience, but it sets the experience in biblical realism and does so over against current cultural attitudes and ideologies. It lifts the eyes of both parent and child above the despair to see the true dignity of their personhood reflected in the image of God. It makes plain that people with disabilities have a place and purpose in an abnormal world rather than being victims and/or burdens in a normal world. They are like us but at a different place on the continuum of human life.

I particularly appreciate how the author engages the ideas of the disability industry that ultimately paint children and adults with special needs into the corner of victimhood or else give false hope that every child with disabilities can become the exceptional person ("Rain Man"). She demonstrates their inherent dignity without

pretending that the burden of disability isn't there or can be erased. Finally, she treats justice issues comprehensively with compassion and truth without creating the unhelpful identity categories characteristic of postmodern analysis. This book is not only a gift to the church, it is also a gift to the world. Thank you, Steph!

—**C. Stanley Morton**, Senior Pastor, Crown & Joy Presbyterian Church (PCA), Richmond, Virginia

Stephanie Hubach has created a new gift for the Christian community as we think about forming and maintaining relationships with people of all abilities. This gift, the second edition of her book *Same Lake, Different Boat*, shines the light of biblical truth on many of the disability-related conversations and current words and trends to give us a well-articulated place where Christians can plant their feet. This book will be an excellent resource for study in Christian communities eager to be a living, breathing picture of 1 Corinthians 12.

—**Barbara J. Newman**, Director of Church Services, All Belong; Author, *Autism and Your Church*

Imparting encouragement, the apostle Paul stated that “for now we see through a glass, darkly; but then face to face.” Sometimes, through suffering and/or disability, God allows greater clarity to those struggling to see through that dark glass. In this wonderful book, God uses Stephanie Hubach’s journey—and even her tears—to provide a clearer view of his grace, mercy, and provision.

—**Peter W. Rosenberger**, Radio Host, *Hope for the Caregiver*; Author, *7 Caregiver Landmines and How You Can Avoid Them*

Just like its author, this revised and updated edition of *Same Lake, Different Boat* is a gift to the church at large. Recognizing that understanding is necessary for compassion and presence is the prerequisite for meaningful response, Stephanie Hubach graciously opens up her own experience and, in so doing, equips us to come alongside others touched by disability. Readers familiar with the first edition will be gladdened by the minor revisions and especially by the inclusion of additional chapters. New readers will find the author to be equal

parts gentle guide and firm advocate and her content to be simultaneously rooted in biblical wisdom and judiciously informed by her work in disability studies. While not the last book that any of us should read on this important topic, *Same Lake, Different Boat* is a great first book, and I am delighted to be able to recommend such a valuable yet accessible resource to all who desire the church to be a welcoming place for people with disabilities and their families.

—**Mark P. Ryan**, Director of the Francis A. Schaeffer Institute, Adjunct Professor of Religion and Culture, Covenant Theological Seminary

Steph Hubach is an exceptional Christian leader whose honest, wise, and hope-filled book has helped Christians worldwide to enable people with disabilities to find places to belong. *Same Lake, Different Boat* is a required text at Wheaton College and many other schools and churches committed to serving all God's children. Now revised and expanded to address certain issues with greater biblical and practical depth, it remains the first resource I recommend to anyone who wishes to demonstrate the love of Christ in response to human disability.

—**Philip Graham Ryken**, President, Wheaton College

As an adult living with autism who regularly advocates for others on the spectrum, I'm often asked about resources that will increase understanding about disability in general and help to promote disability ministry in particular. At the top of my recommended reading list is *Same Lake, Different Boat*. Stephanie Hubach has given us a work of inestimable value—one that contains a beautiful balance of theology and practice. This book is poignant in its description of how the fall has made disability a heart-wrenching reality in our world; powerful in the way it continually points us to Jesus; and practical in the nuts and bolts it provides to help God's people to step into the stories of those enduring the unrelenting challenges of disability. Stephanie practices what she preaches, and as one who has experienced the authentic amalgamation of her words and works firsthand, I endorse this second edition with great enthusiasm. May it be used mightily to make us better instruments of Christ's mercy.

—**Lori Sealy**, Autism Advocate; Singer-Songwriter

**same lake
different
BOAT**

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Coming Alongside *People*
Touched by *Disability*

REVISED AND UPDATED

Stephanie O. Hubach


P U B L I S H I N G
P.O. BOX 817 • PHILLIPSBURG • NEW JERSEY 08865-0817

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In honor of my parents,
Darah and Everett Opdahl,
who have so faithfully modeled for me
the love of God, love for neighbor, and a loving family

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Foreword

Back in the 1980s when I served on the National Council on Disability, words such as *inclusion* and *mainstreaming* had specific meanings. These words and their carefully constructed definitions guided us in our early efforts to make life more accessible for Americans with disabilities. I was convinced of their import. So, it was no surprise that those words often peppered my messages when I would speak to the church about disability ministry.

“It’s all about church inclusion,” I would say. Then I’d cite the words of Jesus from Luke 14:12–14 (NIV):

When you give a luncheon or dinner, do not invite your friends, your brothers or sisters, your relatives, or your rich neighbors. . . . Invite the poor, the crippled, the lame, the blind, and you will be blessed. Although they cannot repay you, you will be repaid at the resurrection of the righteous.

I’d expound on this: “There aren’t many passages where Jesus gets this specific about who he wants invited into the kingdom. But of all the people you might overlook; of all your rich neighbors, friends, and relatives—people with whom you easily identify—do *not* forget people with disabilities.” I particularly emphasized verse 14 and its incentive of rich rewards awaiting those who followed Jesus’s mainstreaming mandate.

Although it is correct that the larger theological point behind Luke 14 is about God’s grace being lavished upon the

undeserving, the principles of compassionate inclusion are inherent in the text. Simply put, God tells us not to overlook the lame and the blind. We are to reach people we do *not* easily relate to, those with whom we do *not* typically rub shoulders. To name just a few, it includes people on the autism spectrum, people with brain injuries, visual impairments, those with Tourette syndrome and intellectual disabilities—all these *and* their families.

No doubt about it. If you had attended one of my workshops in the 1980s, you clearly understood the importance of including kids and adults with disabilities, as well as their families. Put out the welcome mat. Make your sanctuary fully accessible, and don't forget church programs, restrooms, and the parking lot. Inclusion and mainstreaming pave the way for fulfilling God's Luke 14 mandate.

This was disability-talk nearly forty years ago. But words and their concepts evolve.

I became aware of that evolution many years ago while talking to Jeff and his friend Brad, who has Down syndrome. Jeff had brought his young friend with the winning grin to a disability conference where I was speaking, and when I prodded Brad to expound on his friendship with Jeff, he said with a matter-of-fact smile, "Jeff isn't paid to be my friend. He likes me without being paid to like me." He then gave Jeff a good-natured elbow in the ribs.

Brad resides in a residential facility where staff people are "paid to like him." Spend time with him. Play games with him. But Brad is aware that Jeff is different. Jeff invites him out to movies, to baseball games, and to chow down pepperoni pizzas at Papa John's. He also invites Brad to spend weekends at his house with Jeff's family. They hang out together at Jeff's church. Jeff *likes* Brad. They are friends. *Good* friends.

Listening to Jeff and Brad? It altered my view on the church and disability ministry. *Inclusion* and *mainstreaming* may well

be the “welcome mats,” demonstrating to the community that “this church has prepared a place for people with disabilities and their families.” But it’s much more than that.

It’s about relationships. More to the point, friendships. It’s about family and belonging. If Brad is not able to make it to church for an event, he wants to know that *he will be missed*. That he *belongs*. That things will be *incomplete* if he’s not there. And that his church family will *seek him* out. Belonging is what it means to *be* the gospel of Jesus Christ to one another.

My friend Stephanie Hubach knows this well. Yes, she is a studied scholar—in my opinion, this woman of sharp intellect is the brightest mind in disability ministry studies. She has long campaigned for the expansion of disability ministry in my denomination, the Presbyterian Church in America (PCA). She has served as research fellow in disability ministries at Covenant Theological Seminary. As a research scholar, Steph understands that words and concepts *will* evolve. But the Word of God does not. And so, what has most influenced her thinking may not be her academic studies, but her family . . . her church . . . and her son Tim, who has Down syndrome. Tim has had the greatest influence on this woman’s development of thought.

It’s one reason she decided to revise and update her remarkable book, *Same Lake, Different Boat*. Stephanie knows a lot has changed since her book was published in 2006. My friend admits that some of her concepts need updating and clarification. In fact, I love what she says about the kind of relationship Jeff and Brad enjoy. In one of her new chapters, “On Clarification: Growth in Grace,” Stephanie wrote, “This type of embracing community does not come naturally to wounded-but-redeemed sinners. It is learned throughout a process of lifelong transformation and by the regular reminders of God’s grace toward us when we gather together to hear the preaching of the Word and to receive the sacraments. These practices are not done in isolation, but in community, as the body of Christ. In worship,

we not only praise God and receive encouragement from the Scriptures, we do so in a way that we also receive each other.” She goes on to say, “We are not born to live in isolation or self-protection—we are born for so much more, and all for the glory of God. . . . [Belonging] conveys that each party is required to enter the life of the other in a way that brings blessing to everyone—in other words, it brings collective flourishing.”

To borrow a word from this book, Jeff’s and Brad’s church is *flourishing*. It is because these followers of Jesus keep advancing Christ’s kingdom in their community from a point of grace. Brad’s presence in the church reminds the body of Christ of something it has forgotten: that we are *all* frail, vulnerable, and in desperate need of God’s transforming mercy. The highly organic disability ministry in Brad’s church restrains those who might convey the gospel from a position of power or influence.

This new and expanded edition of *Same Lake, Different Boat* shows that a flourishing church is one that recognizes its members as belonging to the community of the broken . . . yet blessed through Jesus Christ!

The book you hold in your hands considers the countless avenues where *all* broken people can grow together in grace—especially among those whose brokenness might just be a bit more noticeable, like Brad and Stephanie’s son Tim. Stephanie Hubach shows how we can *be* the gospel to one another. My friend takes great pains in helping us think through our world-views, while grappling with the reality that the impairment itself *and* the ways in which we mistreat others *both* contribute to disability.

If you want your church to be a place of belonging, then turn the page. You’ve landed on the right book.

Joni Eareckson Tada
Joni and Friends International Disability Center
Agoura Hills, California

Preface to the Second Edition

In 2006, I ended my preface to *Same Lake, Different Boat*, “This book is intended as a gift to the church. May it be received in the same generous spirit with which it is offered. And most of all, by God’s grace, may it make a positive difference.” That prayer has been answered in mighty ways—and it continues to be my heartfelt prayer for this new edition.

As William Cowper (a hymn writer who struggled mightily with psychiatric disability) once wrote, “God works in a mysterious way, his wonders to perform.” In the thirteen years since the first copies of *Same Lake, Different Boat* hit the shelves, I’ve been amazed at how the hand of Providence has opened avenues for this book to be widely accessed in disability ministry circles and translated into Spanish, French, Mandarin, and Bulgarian. In addition, it has been required reading for courses at Christian colleges and seminaries including Wheaton College, Covenant College, California Baptist University, Moody Bible Institute, Lancaster Bible College, Covenant Theological Seminary, and Dallas Theological Seminary. Described once as “defying genre,” *Same Lake, Different Boat* has been widely used as both a casual conversation starter and a vehicle for deep reflection across a very broad spectrum of readers. This audience includes people in the pews, people with disabilities and their family members, pastors and their local church leadership teams, professors and those studying for Christian ministry.

Keeping this wide spectrum in mind impacted how I chose to approach this new edition. In order to keep the book as

accessible as possible, I chose to make only minor revisions to the original thirteen chapters. Instead, the text is updated by adding two new chapters in part 4. These chapters take several of the original concepts in the book and drill more deeply into them.

This approach accomplishes several objectives. First, the new chapters provide additional challenge to the layperson who wants to dig into God's Word or is willing to engage some of the challenging social issues that can arise in disability ministry contexts. At the same time, they provide colleges and seminaries with the opportunity to propel their students into reflection on and application of the core principles of the book at a more robust level.

While stories about my family, and my sons Freddy and Timmy (who has Down syndrome) in particular, regularly introduce material in the text, none of us are the focus of any chapter—Jesus is. With that important distinction in mind, I do receive many requests from people asking about my family. When the book was first published, Freddy was sixteen and entering his junior year of high school, while Timmy was fourteen and entering eighth grade.

By the time this edition is released, Freddy—who now goes by Fred—will be thirty, and Timmy—who now prefers to be called Tim—will be twenty-eight. Fred has been married for six years to his wonderful and delightful wife, Cecelia. She has been an amazing gift to him and to our whole family. Cecelia and Fred met at Wheaton College and graduated in 2012. Several weeks ago, their first child was born—our granddaughter—Caroline June. Needless to say, we adore her! Fred and his family live in Washington, DC, and we are thankful to be close enough to visit easily. As a couple, Fred and Cecelia continue to provide valuable insights and practical encouragement to Tim, and to my husband Fred and me, as Tim's parents.

Tim graduated from Ephrata High School in 2011 after

enjoying a rewarding and inclusive high school experience. While continuing to navigate the transition into adulthood and increased appropriate independence, he lives in his own apartment on the lower floor of our home. Tim has worked for seven years (one morning per week) at a local doctor's office and for six years (five evenings a week) at our local grocery store where he is affectionately known as "Cart Man." He continues to bring lots of joy and humor to his customers, his family, and his church community. Tim plays the drums regularly in the praise band at Reformed Presbyterian Church where he inspires all of us to worship more wholeheartedly.

As for my husband, Fred, he recently retired from thirty-one years of dedicated employment as an engineer with CNH Industrial. It is great to have him at home with us! Since 2017, I've continued to work from home as a research fellow in disability ministries, in affiliation with Covenant Theological Seminary. Prior to that, from 2007 to 2016, I had the privilege of serving as the founding director of Mission to North America (MNA) Special Needs Ministries—the disability ministry of the Presbyterian Church in America (which still continues under the new name Engaging Disability).

I have been blessed—beyond measure—not just by my family, but by the opportunity to learn from, work alongside, and minister with so many different people across the country and around the globe. Frankly, I can't wait to see what God has in store next, as he "works in a mysterious way, his wonders to perform."

For Christ and his kingdom,

Stephanie O. Hubach
Summer 2019

Preface to the First Edition

Those who are closest to me know that one of my greatest desires in life is to understand and to be understood. While, in my best moments, that can be a wonderful gift, in my worst moments that same passion can be excessive. I like to understand life, I like to understand others, I like to understand myself—and when all is said and done, I love being able to explain what I have come to realize. Agreeing to write a book, therefore, has caused me at times to tremble in fear. While permanently printing one's thoughts onto paper surely affords the potential opportunity to be understood by a large audience, at the same time it poses tremendous risks of being seriously misinterpreted. However, I have decided—that when it comes to identifying with and ministering alongside people touched by disability—it is worth the risk.

Why write another book on disability, you may ask? Aren't there enough books out there already? Yes and no. For the most part, the available Christian literature on disability could be divided into several categories. The first group consists of the experiential books. These are the stories that attempt to help the reader identify with the challenges that the writer has experienced. The second set includes motivational texts. These are the books that attempt to convince the reader of all the reasons *why* disability ministry is important in the life of the church. Finally, there are publications that are programmatic in nature. These are the practical manuals on *how* to establish programmatic ministries on behalf of individuals who are disabled.

Each of these types of books has made a wonderful contribution to the collection of available resources. What I hope to offer, however, is an innovative alternative. And a different outcome requires a different approach. As a result, this book is not an inspirational book *per se*, or an A-B-C how-to volume. Neither is it a bird's-eye view into the unprocessed, raw emotions of my family's experience with disability—even though much of the manuscript was written through tears. Instead, it is the compilation of what we have come to understand is *true* as a result of actively engaging in the struggle. Our intentional wrestling with God and his Word, with the realities of family life, and with the all too frequent inadequacies of the broader Christian community's response have brought us to a place of resolution and understanding that is positively portrayed in the text as a vision for a better way:

- A better way to understand disability biblically.
- A better way to understand the challenges that face individuals and families touched by disability.
- A better way to understand the role of the church in the lives of people with differing abilities.

That does not in any way diminish the reality of the struggle that my family has engaged in to arrive at such a place. It simply means that the focus of this book is on a vision for the future, not the pain of the past.

One of the unique gifts that God has given my family is the ability to laugh at ourselves. God has used the entrance of disability into my world as a refining fire that has profoundly changed how I view and value others and myself. It has caused me to be deeply convicted of my need for grace, and at the same time it has encouraged me to embrace God's grace and "lighten up." Throughout the book you will meet my family. They are the delight of my life. My older son, Freddy (now age sixteen),

is academically gifted, relatively serious, philosophically reflective, and immensely caring. Timmy (now age fourteen)—my younger son who has Down syndrome—is bright in his own unique way, has a hilarious sense of humor, is occasionally very impulsive, and is quite the encourager. Fred, my patient and loving husband, is a deeply warm and practical man in both faith and practice. He is truly my best friend, gently bringing balance to my passion, intensity, and vision in our shared life. The relational dynamics of our family that occur around our dinner table, at the grocery store, and in the church parking lot are enough to—at times—send me into simultaneous gales of laughter and rivers of tears.

In the context of this book, the stories I tell about my children are simply used as bridges to the world of truth that I hope you will come to understand. Such tales are not intended to be universally representative of *every* individual's or family's experience of living with disability—not even representative of most—for that is quite literally impossible. Disability covers a huge spectrum, and both individual temperaments and family personalities are diverse. But the specific realities to which the stories about Freddy and Timmy point are, I believe, universal truths. It is my hope that you will embrace these truths, either better than before or, perhaps, for the first time.

This book is intended as a gift to the church. May it be received in the same generous spirit with which it is offered. And most of all, by God's grace, may it make a positive difference.

To God be the glory,

Stephanie O. Hubach
Spring 2006

Part 1

foundations

1

On Truth

The Four Missing Words

Truth and the morning become light with time.
—South African Proverb

April 30, 1983, was truly the quintessential spring day in Timonium, Maryland. A gentle rain shower had passed through in the morning and now warm sunshine bathed the sanctuary of Timonium Presbyterian Church. Resonating from the voice of the tenor soloist came this beautiful prayer:

O Lord most holy,
O Lord most mighty,
O Loving Father,
Thee would we be praising always.
Help us to know Thee, know Thee and love Thee,
Father, Father, grant us Thy truth and grace;
Father, Father, guide and defend us.

Rule Thou our wilful hearts,
Keep Thine our wand'ring thoughts;
In all our sorrows, let us find our rest in Thee;
And in temptation's hour,
Save through Thy mighty pow'r,
Thine aid O send us;
Hear us in mercy.

Show us Thy favor,
 So shall we live,
 And sing praise to Thee.¹

Then we pledged our vows—“I, Stephanie Darrah, take thee, Frederick Robert . . . in joy and in sorrow . . . in plenty and in want . . . in sickness and in health”—never imagining how deeply those vows would be tested, nor how fully our wedding prayer would be answered.

SURPRISED BY DISABILITY

Timothy Robert Hubach was born on January 5, 1992. Unlike the birth of our first son just two years earlier, this delivery was rapid and intense. As I gazed at Timmy immediately after his speedy arrival, I was stunned by his appearance. Everything about him seemed different from our elder son, Freddy—*really* different. His stocky, round figure was a marked departure from the defined features of his older brother. *But then again, we have had some rather rotund relatives on both sides of the family*, I reasoned to myself. When I first held him and noticed his slanted little eyes, my own eyes darted around the delivery room to see if anyone else saw what I saw. But noticing the hospital staff going about their postdelivery tasks as usual, I dismissed my concerns as irrational. Quite uncharacteristically, I never even voiced my thoughts to my husband, Fred.

My next clue might have been the remark made by a nurse early that afternoon. Timmy was sleeping soundly in the bassinet next to my bed. Having experienced an all-night labor and knowing that I was going home the next day to our extremely energetic firstborn, I was resting for the few precious hours I had left. The nurse entered my room and in a patronizing

1. Arthur H. Ryder, “O Lord Most Holy (Panis Angelicus),” 1908.

voice said, “It’s OK to *hold them*, you know.” I felt irritated and annoyed by her mysterious comment but chose to dismiss it.

Soon after, a doctor from our family practice group arrived on the scene. Without indicating anything specific, he came in and spoke to me in a very serious tone. His words assured me that there was probably nothing to be concerned about, but his face told the truth. He had requested the town pediatrician to come in and evaluate Timmy.

At this point, it seemed as if everyone was talking *at me*, but no one was actually communicating *with me*. A sense of inexplicable sadness and solemnity hovered over the proceedings of the afternoon. Alone at the hospital while Fred cared for Freddy at home, I felt a tad confused and lonely but attributed it to fatigue.

That evening, all the events of the day finally came into focus even as the room around me began to swirl out of focus. The pediatrician entered my room and, after brief introductions, announced, “We believe that Timothy has a chromosomal abnormality.” I remember feeling dizzy and disoriented, as if the physician’s words were being spoken through a funnel in another place. As he began to talk to me about Down syndrome, hot tears streamed down my face. *How could this be? I’m only thirty-one years old.* Somehow, I stumbled through a series of questions and answers with him. Then he turned and left. Sobbing alone in the darkness, I entertained the bizarre thought, *I wonder if I should tell Fred. Maybe I’ll call him tomorrow.* Mind, body, and soul—I was already in a state of shock. Eight simple words had been spoken by the pediatrician, yet I knew instinctively that our lives would never be the same.

Why didn’t my husband and I anticipate the possibility? Very close friends of ours had recently become the parents of not one, but two sons with significant disabilities. What made us assume that we were exempt from a similar occurrence? We aren’t the only ones who have been surprised by disability. In

fact, surprise appears to be a nearly universal response to disability. Why is that?

Many years ago, there was a television show called *To Tell the Truth*. The object of the show was to present three contestants to a panel of questioners. Each of the contestants claimed to be telling the truth about their identity. The job of the panel was to discern who indeed was being honest. There is a game of *To Tell the Truth* going on with regard to disability today. In this case, there are three different views of the nature of disability and the nature of our world at large. Let's explore these three views and determine which is consistent with reality.

THE MODERNIST VIEW

Throughout the ages, people with disabilities have typically been—and continue to be—seen as aberrations. They are viewed as an *abnormal* part of life in a *normal* world. This is why we are often surprised by disability: it is viewed as outside the expected. You've heard the questions; if we're honest, we can admit that we've all asked these questions (or ones similar to these):

“Psssst! Mommy—what's *wrong* with her?”

“What's his *problem*?”

“What is that child's birth *defect*?”

What is the underlying assumption in these questions? It is the modernist view that the routine of the world in which we live is the baseline—and, therefore, “normal.” Differences from the norm are thus something *other*—something *abnormal*. This does not have a positive connotation.

It does not take much imagination to understand why people with disabilities resent being seen as abnormal. No one wants to be defined exclusively by their limitations. No one wants to be considered unacceptable to the rest of the human

community. Worse than that, the “abnormal part of a normal world” perspective has been the basis and even the justification for countless abuses against people with disabilities. One well-known disability advocate writes, “Throughout history, people with physical and mental disabilities have been abandoned at birth, banished from society, used as court jesters, drowned and burned during The Inquisition, gassed in Nazi Germany, and still continue to be segregated, institutionalized, tortured in the name of behaviour management, abused, raped, euthanized, and murdered.”² Tragically, this is an accurate accounting.

How people are viewed affects how they are treated. The modernist perspective of disability has focused almost exclusively on the distinctive, negative characteristics of the diagnosis and very little on the reality of the shared, valuable personhood of the individual. A reaction to this imbalance has given rise to the next view: the postmodern view of disability.

THE POSTMODERN VIEW

For some time now, disability advocates have been thoroughly annoyed by the “abnormal” label slapped on those with disabling conditions. As we’ve just seen, there is good reason for this frustration. Determined to improve the lives of people affected by disability, activists are attempting to reframe the debate. In predictable postmodern fashion, they are accomplishing this by changing the language of disability. Disability is presented as a *normal* part of life in a *normal* world.

This alteration cannot be overemphasized. Ponder this statement from a nationally known speaker, Carol Tashdie: “Having a disability is a difference like any other human characteristic.

2. Norman Kunc and Emma Van der Klift, “A Credo for Support,” 1995. Available at <https://www2.gnb.ca/content/dam/gnb/Departments/pcsdpcpmcph/pdf/docs/CredoforSupport.pdf>.

It is not a deficiency. It is by no means a tragedy and does not deserve pity or benevolence or charity. Now is the time to recognize and celebrate disability rather than ignore, devalue or use it as a justification for lower expectations.”³ Can you feel the huge shift? The new language confuses everything and solves nothing. Does Tashdie really mean that disability requires no greater acknowledgment than something like hair color? No one wants to be an object of pity, but are people affected by disability begging to be released from the compassion of those around them? If disability is something to be celebrated, why don't more people attempt to acquire traumatic brain injuries? In response to an appropriate desire to celebrate the *individual*, the postmodern view ends up celebrating the *diagnosis*.

Imagine the ramifications of this postmodern view. Suppose you had walked into my hospital room just after the town pediatrician had left. What if you had stood by my bed and greeted me with, “Hey! Isn't this great? So glad to hear of your son's diagnosis. It couldn't have happened to a nicer family! I just wish it was me!” How long do you think you would have been allowed to stay before the nurse called for the hospital security guard? Would you have walked away bewildered, thinking, *What did I say that upset her?* Or would you inherently have known that the things you said were cruel?

This example may seem absurd, but that is because the “normal part of a normal world” perspective is absurd. Those who promote this new philosophy fail to, or refuse to, recognize that the deeper issue lies in our worldview—our view of the world itself. Such a perspective directly impacts how we see ourselves and others. The postmodern approach does nothing to remedy that.

3. Carol Tashdie and Zach Rosetti, “Facilitating Friendship: Barriers and Strategies” (unpublished paper, National Down Syndrome Conference, Philadelphia, August 2003), 2.

THE BIBLICAL VIEW

Those with a postmodern perspective capture partial truths in an inaccurate context. Disability is indeed a normal part of life as we know it. It is unpredictable but occurs with a degree of regularity. You will find people with an endless variety of disabilities in cultures of every kind across the world. This has occurred across the centuries. But does that make disability itself something celebratory?

The key to understanding this is the context, and the context is these four missing words: *in an abnormal world*. When we recognize that disability is a *normal* part of life in an *abnormal* world, we can begin to make sense of it—and ourselves. In his book, *The God Who Is There*, Francis Schaeffer put it this way: “It is not that philosophy and Christianity deal with completely different questions, but . . . differ in their answers—including the important point as to whether man and history are now normal or abnormal.”⁴

When we begin with the biblical account of creation, we realize that everything God created was good, and humankind was deemed *very* good:

So God created man in his own image,
in the image of God he created him;
male and female he created them.

God blessed them and said to them, “Be fruitful and increase in number; fill the earth and subdue it. Rule over the fish of the sea and the birds of the air and over every living creature that moves on the ground.” (Gen. 1:27–28)

4. Francis A. Schaeffer, *The God Who Is There* (1968; repr., Downers Grove, IL: InterVarsity Press, 1998), 132.

Human beings were God's crowning creation. While fashioned as creatures, people were designed to intrinsically embody his likeness. This means that humankind has a myriad of finite potentialities that reflect God's infinite reality. These include the ability to love, to create, to rule, to relate, to design, to reason, and so much more. People were designed to reflect the essence of God's character expressed through God-imaging capacities. According to the Genesis account, we were fashioned to experience purposeful, blessed lives.

But then tragedy struck. In our first parents' desire to rule, not only over the rest of creation but over themselves, the fall of humanity occurred—adversely impacting every aspect of creation. As Paul says in Romans 8:20, “The creation was subjected to frustration, not by its own choice.” Our world became an abnormal world. For the first time in human experience, brokenness and difficulty were introduced. This marring of creation permeated not only the spiritual, but also the physical, the intellectual, the emotional, the psychological, and the social. The effects carry over today into our work, our world, our bodies, and our relationships with self, others, and God. Reflecting on this, the apostle Paul notes in Romans 8:22, “The whole creation has been groaning.”

What does this mean in practical terms? Does this mean that everything in human experience is ruined by the fall? Absolutely not. But it does mean that everything in human experience is affected by the fall. On every level of every dimension of the human experience, there is a mixture of both the blessedness of creation and the brokenness of the fall. By God's common grace, we participate in the damaged but not obliterated blessings of being created in God's image and being endowed with purpose. At the same time, our experience is permeated throughout with the effects of brokenness. This is true for every person. Yet much of our energies in life are directed toward denying this reality.

For some people, the effects of brokenness are more noticeable or more dramatically experienced in one part of life over another. For example, for a person battling cancer, the impact of brokenness on the physical dimension of being human stands out in bold relief. However, all of us are inching toward death on a daily basis. It has been said that “Health is just the slowest form of dying”—and so it is! At the same time, the person fighting cancer may experience more spiritual wholeness than their counterpart who is relatively physically fit but perhaps increasingly corrupted from pursuing a blatantly immoral and self-centered lifestyle.

What does this imply then about disability? Disability is essentially a more noticeable form of the brokenness that is common to the human experience—a normal part of life in an abnormal world. It is a difference of degree along a spectrum that contains difficulty all along its length. Due to God’s common grace, no one exists in the extreme of complete brokenness. Due to the fall, no one enjoys the extreme of complete blessing. We all experience some mixture of the two in every aspect of our humanity—including the spiritual, the physical, the intellectual, the emotional, the psychological, and the social.

	Modernist Perspective	Postmodern Perspective	Biblical Perspective
Disability is	abnormal	normal	normal (expected)
The world is	normal	normal	abnormal

Fig. 1.1. Comparing worldview perspectives

Many people with disabilities can testify that a disability in one aspect of their being has produced tremendous blessing

in another aspect. Jon is an adult in our local congregation who was born with spina bifida. Due to the nature of his condition, he uses a wheelchair and requires assistance for many daily living activities. In response to these challenges, Jon has nurtured a positive attitude, a warm sense of humor, a deep faith in Christ, and a notable quality of patience that outshines his “able-bodied” peers in many ways. As Jon testified at a Sanctity of Human Life service, “I just focus on living one day at a time, taking each day for what it brings. And God will just lead me through. Whatever I face, I’ll face with Him.” For Jon, physical disability has been a catalyst for tremendous spiritual growth. He has taken something that is a normal part of life in an abnormal world, and redeemed it for God’s glory.

In a comparable way, a person with Down syndrome may tend to learn more slowly or require things to be explained more concretely. However, that same attribute, which is defined by society as an intellectual disability, can have beautiful spiritual ramifications that put to shame those who may be more intellectually capable.

Several years ago, our family received a letter from a relief organization that contained a graphic depiction of individuals living in dire poverty. The photograph conveyed the reality of the extreme deprivation in which families attempt to scratch out an existence surrounded by shacks and boiling pots of palm oil in a barren, mud-packed place. I shared the photo with my two sons that evening while we were sitting around the dinner table, and both of them were visibly moved. While I described the root causes of this type of poverty, Timmy was silent. Then his eyebrows furrowed. Quietly and deliberately he asked, “Do we have money? Couldn’t we send them some?” Timmy’s need to see things concretely is a gift in the realm of the spiritual. Guess whose family mailed a donation that week?

TRUTH SETS THE STAGE FOR SUCCESS

We slipped into the back row of Reformed Presbyterian Church of Ephrata during the morning announcements, with newborn Timmy tucked into the infant seat resting beside us. In contrast to our wedding day, we were in a different church, in a different decade, and under very different circumstances. As we sat down, we heard our close friend and youth pastor announce, “Timothy Robert Hubach was born last Sunday morning. Fred and Steph have asked me to let you know that he was born with Down syndrome.” The audible gasps of our church family gave voice to the raw pain in our own hearts. “But, Fred and Steph also want you to know that your condolences are not expected. Instead, they want you to celebrate with them the life of this child of the covenant.”

After the service, our friends greeted us with congratulatory hugs through tears. It was a wonderful way to introduce Timmy to his church family. Even as our hearts were wracked with sorrow at the diagnosis and all its implications for Timmy’s life and ours, we focused on the precious value of his personhood. “Joy and sorrow . . . plenty and want . . . sickness and health.”

This is the stuff of disability, which is simply the stuff of life. It’s time To Tell the Truth about disability: it is a normal part of life in an abnormal world. We are all recipients of the blessedness of creation and the brokenness of the fall. Upholding a biblical perspective of disability really matters, because when we see our world truthfully, we can view ourselves more correctly. When we view ourselves more correctly, we can also regard others more accurately. And when we regard others more accurately, we are more likely to respond to them appropriately.

As the South African proverb goes, truth and the morning become light with time. Well, it’s time.

APPLICATION AND DISCUSSION QUESTIONS

1. If you are honest with yourself, which worldview perspective of disability dominates your thinking? Is it the modernist view, the postmodern view, or the biblical view?
2. Why does a biblical view of disability allow us to grieve the diagnosis of a person's disabling condition while celebrating the individual at the same time?
3. In what ways have you personally experienced the blessings of creation and the brokenness of the fall in different areas of your life?
4. How does accurately perceiving disability as a "normal part of life in an abnormal world" hold the potential to improve the lives of those touched by disability?