"What the world sees as adversity, God sees as an opportunity for blessing. Stephanie Hubach has discovered this, as I have with my fifteen-year-old autistic grandson, Max. In this book Stephanie makes a very important contribution to equipping the church for its ministry to people with disabilities and their families. It is well rooted theologically and, to my delight, grows out of her well-formed biblical worldview. I hope it will be used as a tool by churches to minister to the least of these—and in the process to reflect God's glorious Kingdom."

—CHARLES W. COLSON, Founder and Chairman, Prison Fellowship

"Stephanie Hubach masterfully and winsomely develops a scriptural framework to help God's people think biblically and live convenantally in all of life, including our response to disabilities."

—Susan Hunt, Author and Consultant, Christian Education and Publications, Presbyterian Church in America

"Her superb book tells us how to transform the church into a place of hospitality and welcome for children and adults with disabilities and their families. The starting point of this transformation is the gift of genuine friendship. Heartwarming stories and discussion of a biblical view of disability make this book both pleasurable and instructive."

—GINNY THORNBURGH, Director, Religion and Disability Program, National Organization on Disability

"'Do you love Jesus?' asked the young man with Down syndrome, peering intently into the face of each elder in the room. If you love Jesus, Stephanie Hubach's book Same Lake, Different Boat is the book for you. While writing about coming alongside individuals and families touched by disability, she has actually penned a call for the church to become an inclusive community for all people, a 'hospital for sinners,'

where justice, mercy, and grace set people free to become God's true body. If your family, like ours, is touched by having a 'least of these my brethren' member, you will resonate with Stephanie's understanding of the peculiar challenges, dynamics, and opportunities that come with having disability as an uninvited guest. If disability has not yet become your experience, this book will catapult your growth as a son or daughter of the Most High, and will galvanize you to see and to foster true community."

— JOSEPH "SKIP" AND BARBARA RYAN, Senior Pastor and wife, Park Cities Presbyterian Church, Dallas

"I have not been this excited about a book in 38 years of disability ministry! Steph Hubach draws on her tremendous love for the Lord and for people with disabilities to present a compelling challenge to include people with disabilities in the life of the church. I cannot recommend this book more highly."

—TIMOTHY D. SHEETZ, Director, Handi*Vangelism Ministries International

"Same Lake, Different Boat is a heart-wrenching book by an author who has lived its message. It will equip you . . . to serve as instruments of healing and hope, to accept the reality of disability with joy and thanksgiving, and to appreciate the privilege of loving people with disabilities. Stephanie Hubach has given us a goldmine from a solidly biblical and theological perspective. This book is about ministry, caring, listening, coming alongside, and helping. This book is priority reading for every leader in the church, as well as families of the disabled."

—CHARLES H. DUNAHOO, Coordinator, Christian Education and Publications, Presbyterian Church in America

"Steph has given a great gift to the church. She calls on the faithful congregation to look at and identify with persons

with disabilities who are part of the church. She uses Scripture and personal family vignettes to reinforce the value of all persons. Her discussion teasing out the distinctions between a normal and abnormal world and the normal and abnormal results we live with is worth the price of the book."

—George B. Stoltzfus, M.D., CEO, Friendship Community

"Stephanie Hubach's thoughtful challenge to the Christian community is strong but full of grace, clearly articulating our biblical responsibility to nurture individuals and families with special needs. She balances our need to rely on one another for help with our mandate to look for and celebrate every individual's dignity and giftedness. She assures us that God is not afraid of hard questions."

—Pamela A. Harmon, Associate Director, Young Life's Capernaum Ministries

"Stephanie Hubach clearly explains in her well-written, and insightful book how we can extend our hands and hearts to people with disabilities. Stephanie wonderfully reminds us that grace enters into our lives in the most unexpected ways. I highly recommend this spiritually sound and practical book."

—CHRISTOPHER DE VINCK, Author, The Power of the Powerless

"Stephanie Hubach has given the church a good gift to equip the church in ministry to and with people with disabilities. It is set apart by its vision, strong theological and biblical worldview, and the gift of laughter. The reader is given a window into a family who, though touched by disability, is living, loving, and growing, in their love for Christ, one another, and his church . . . a must-read."

—Jane Patete, Women's Ministries Coordinator, Presbyterian Church in America

"Same Lake, Different Boat is an exciting read. Veteran disability ministers will be refreshed by new insights, beginning workers will be inspired by the concepts, and church leaders will receive clear purpose for disability ministry."

—JIM PIERSON, Author, Speaker, and President of The Christian Church Foundation for the Handicapped

"What should the Church look like? How should the gospel shape our lives, our relationships, our worship, and our communities? In this wonderful book, Steph Hubach offers us a glimpse of what should be, what could be, what would be, if only the riches of God's grace would fully captivate us. Biblical and practical, *Same Lake, Different Boat* beautifully demonstrates the great paradox: in the Kingdom the least and the last are in fact the first and the foremost."

—George Grant, Author and Co-Pastor for Ministries of Christ Community Church, PCA

"Stephanie Hubach's stories of her son will delight you. How she weaves those into a solid biblical framework will encourage you. Everyone who *doesn't have* a disabled child should read this book!"

—Paul Miller, Author, Love Walked Among Us: Learning to Love Like Jesus; Director, seeJesus.net.

same lake, different boat

same lake, different boat

Coming Alongside People
Touched by Disability

Stephanie O. Hubach

Foreword by Joni Eareckson Tada



© 2006 by Stephanie O. Hubach

All rights reserved. No part of this book may be reproduced, stored in a retrieval system, or transmitted in any form or by any means—electronic, mechanical, photocopy, recording, or otherwise—except for brief quotations for the purpose of review or comment, without the prior permission of the publisher, P&R Publishing Company, P.O. Box 817, Phillipsburg, New Jersey o8865-0817.

Unless otherwise indicated, all Scripture quotations are from the HOLY BIBLE, NEW INTERNATIONAL VERSION®. NIV®. Copyright © 1973, 1978, 1984 by International Bible Society. Used by permission of Zondervan Publishing House. All rights reserved.

Italics within Scripture quotations indicate emphasis added.

We Are God's People. Words by Bryan Jeffery Leech. © Copyright 1976 Fred Bock Music Co., Inc. All rights reserved. Used by permission.

Printed in the United States of America

Library of Congress Cataloging-in-Publication Data

Hubach, Stephanie O., 1960-

Same lake, different boat : coming alongside people touched by disability / Stephanie O. Hubach ; foreword by Joni Eareckson Tada.

p. cm.

Includes bibliographical references

ISBN-10: 1-59638-051-9 (paper)

ISBN-13: 978-1-59638-051-6 (paper)

1. Church work with people with disabilities. 2. Disabilities—Religious aspects—Christianity. I. Title.

BV4460.H83 2006

261.8'324—dc22

2006043288

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

Contents

Foreword 9 Acknowledgments 13 Introduction 15

Part 1: About the Foundations

- I. On Truth: The Four Missing Words 21
- 2. On Identification: Same Lake, Different Boat 33
- 3. On Respect: Common Grace, Special Needs 43
- 4. On Relentlessness: Dante's Circles of Disability 53
- 5. On Restoration: *Thy Kingdom Come* 67

Part 2: About the Families

- 6. On Coming to Terms with a New Reality 81
- 7. On Negotiating a Path to Acceptance 97
- 8. On Living a New Normal Life 113
- 9. On Grappling with the Great Opportunity 133

Part 3: About Facilitation in the Church

- 10. On Hospitality: No Room at the Inn 151
- 11. On Belonging: Same Body, Different Parts 169
- 12. On Wisdom: Questions Every Church Needs to Answer 187
- 13. On Change: Revolution or Reformation? 209

Notes 227 Glossary 231

Foreword

People often ask me, "Who are your role models? Who inspires you?" I know they expect me to say Billy Graham or Amy Carmichael, but my role models are a little less lofty. Like my friend David. He uses a wheelchair and gets up extra early to take the public paratransit to church on Sunday mornings. Or Margaret, a single mom in a wheelchair who raises two young children, plus finds time to lead a women's neighborhood prayer group. Then there's Jeff and Jane, who are bending over backward to provide a sense of normalcy to their three children, all of whom are slowly dying of a degenerative muscular disease.

These people are saints who breathe celestial air. They show me what it means to follow in Christ's steps, endure hardship like a good soldier, welcome trials as friends, and rejoice in suffering. I sometimes forget how to do that. When that happens, I have David, Margaret, Jeff, and Jane to reignite my passion.

Even when they wrestle through discouragement, I am helped! I simply cannot stand—or sit—idly by. Their courage and perseverance inexorably drag me into the middle of their circumstances, challenging me to come alongside and practice Christianity with its sleeves rolled up. I'm *helped* by that. I'm all the richer, all the better for it.

It's a Polaroid snapshot of the way the church should be. When the bus doesn't let off David on Sunday mornings, our whole church knows it. And we, as a body, move into action. David enriches the congregation—perhaps more than he or the people in the pews realize. His participation in our midst is not just expanding "disability ministry"; it's changing the

FOREWORD

character of our church. He provides the inescapable reason our people serve, and do so sacrificially. Our whole church is stronger for it.

I wish more of my brothers and sisters in Christ could experience this heartwarming and potent exchange between families affected by disability and those who are, well . . . affected by other things. I'm convinced such relationships alter the landscape of the American church. But how do you make those relationships happen? I can't force people to get engaged with David, Jeff or Jane, or Margaret and her children; only the Holy Spirit can do that.

This is why *Same Lake*, *Different Boat* is so timely. I have read more "how to" books on disability ministry than I care to mention, but Stephanie Hubach's work is *different*. It goes deep. It speaks to our *relationships*—with God, with each other, and especially with those we're not typically drawn to (that's the important part). The book you hold in your hands will not only enlighten your thinking, but will speak to your heart and spirit, as well as open your eyes to the Jeffs and Janes in your world. You, too, will be pulled inescapably by the Spirit to embrace those the Savior especially loved when he walked on earth.

I have sat under Stephanie's teaching at our Joni and Friends workshops. As a mother of a child with Down syndrome, she speaks with authority. She's *been* there. It's why I listened so intently. As Stephanie spoke, I so wished my quadriplegic hands were able to scribble down all the fresh insights (I'd share a few here, but I don't want to spill the beans).

Stephanie has a high goal. She seeks the best for the bride of Christ. She asks us to move into relationships with people with disabilities. She underscores how we can find much greater joy in treating everyone as citizens of equal standing in Christ's kingdom. Same Lake, Different Boat is about the hope that she and I share: that Christ's church will someday embrace all of its members. As Chuck Swindoll told his congregation one day, "Disabled people are not in our way; they are a part of our way."

Foreword

Actually, I would rephrase that. They *are* the way to creating a caring church that truly reflects the love of Christ, as well as his power. It will happen when we consider weaker members as indispensable. After all, God's power shows up best in weakness. It's something I think about every time I see David get off the bus and wheel into church.

Joni Eareckson Tada Founder, Joni and Friends Spring 2006

Acknowledgments

My first expression of gratitude goes to my local church family at Reformed Presbyterian Church of Ephrata. Without their willingness to heed the Scripture's call to ministries of mercy and justice—preached so faithfully by our pastors, Rev. Thomas E. Nicholas and Dr. William L. Graybill II—there would not have been a book for me to write. I am sincerely thankful for the elders, deacons, Special Needs Committee members, and The Explorers Sunday school class. Their collective desire to be a family of grace-based learners who seek to be faithful to the gospel, in word and deed, is truly inspiring.

In the larger Lancaster County Christian community I am indebted to my fellow partners in disability ministry who have been my teachers, and yet have been willing to allow me to serve alongside them as a leader in this arena. To my friends at Friendship Community, Handi*Vangelism Ministries International, Joni and Friends of Eastern PA, Love INC of Lancaster, and No Longer Alone Ministries—I extend my genuine thanks.

As a member of the Presbyterian Church in America (PCA), I would like to express my heartfelt gratitude to Jane Patete, Susan Hunt, Barbara Thompson, Charles Dunahoo, and Joni Eareckson Tada for their invaluable assistance in helping me to secure a publisher, and for regularly validating to me the importance of this project. I deeply appreciate them. I would also like to thank Fred Marsh for his unwavering support of, and vision for, disability ministry in the denomination.

Without my devoted editor, Thomas A. Nicholas, I would still be buried alive in a myriad of technical details. For his

ACKNOWLEDGMENTS

excellent skills, his great wisdom and insight, his good humor, and the immense gift of his time—I am inestimably thankful. I will miss having a regular excuse to visit with Tom and his lovely wife, Emily, who always showered me with gracious hospitality during our editing sessions. I plan to continue to visit regularly, if only to listen to Tom's latest corny jokes while I watch Emily roll her eyes in feigned disbelief. Through the process of writing this book, they have truly become my friends, and I love and respect them both.

For all of my readers, who are too numerous to list, "you know who you are." Their honest comments have made this a much better book than it would have been otherwise. In addition, their encouraging feedback motivated me to keep writing even when I was uncertain that the manuscript would ever see the light of day beyond the hard drive of my computer.

Finally, I want to thank my family. My parents, Darrah and Everett Opdahl, and my parents-in-law, Fred and Wilma Hubach, have been four of my greatest cheerleaders. My precious sons Freddy and Timmy—who have matured into Fred and Tim while I've been writing this book—well, I love them more than they will ever know. They have been tremendously good sports: willing for me to share their stories, helping around the house, and simply being the fascinating and wonderful young men they each are. They make their mother proud! Last but certainly not least, I owe my deepest appreciation to my beloved husband Fred, who-countless timesassured me, "Yes, I think you should keep writing. And yes, I'm sure it will be published." In response to my anxious queries of "How do you know?" he always smiled and patiently replied, "I just know." Our hearts beat as one for our God, our children, and the ministries we engage in together. Truly, what more could I ask for?

Introduction

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? 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

INTRODUCTION

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 has 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 16), is academically gifted, relatively serious, philosophically reflective, and immensely caring. Timmy (now age 14)—my younger son who has Down syndrome—is bright in his own unique way, has a hilarious sense of humor, is occa-

Introduction

sionally 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

About the Foundations

1

On Truth: The Four Missing Words

Truth and the morning become light with time.

—South African Proverb

It was truly the quintessential spring day, balmy and seventy-two degrees, in Timonium, Maryland, on April 30, 1983. 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 Holy,
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 Thee 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. In retrospect, I still can't believe that I didn't anticipate the possibility. 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, and doughboy-like 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 post-delivery tasks as usual, I dismissed my concerns as irrational. Quite uncharacteristically, I never even voiced my thoughts to my husband Fred.

I suppose 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

ON TRUTH: THE FOUR MISSING WORDS

room and in a patronizing voice stated, "It's OK to hold them, you know." I felt irritated and annoyed by her mysterious comment, but chose to dismiss it. Soon thereafter, 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 theme of inexplicable sadness and solemnity hovered over the proceedings of the afternoon. Alone at the hospital while Fred was at home caring for Freddy, I felt slightly confused, and a tad lonely—all of which I attributed to the fact that I was quite fatigued.

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 somehow being spoken through a funnel in another place. As he began to talk to me about Down syndrome,* the hot tears streamed down my face. How could this be? I am 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.

^{* &}quot;Down syndrome is a genetic condition that causes delays in physical and intellectual development. It occurs in approximately one in every 800 live births. Individuals with Down syndrome have 47 chromosomes instead of the usual 46. It is the most frequently occurring chromosomal disorder." (Source: National Down Syndrome Association)

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*. On the show three contestants were presented to a panel of questioners. Each of the contestants claimed to be telling the truth about his or her 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 as to what is true about the nature of disability and about the nature of our world at large. Let's explore these three views and determine which is consistent with reality.

The Historical View: Disability Is an *Abnormal* Part of Life in a *Normal*World

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 mainstream of the expected. You've heard the questions; if we're honest, we can admit that we've all asked these questions (or at least ones similar to these):

"Pssssst! Mommy—what's wrong with her?"

"What's his problem?"

"What is that child's birth defect?"

ON TRUTH: THE FOUR MISSING WORDS

What is the underlying assumption in these questions? It is this: the routine of the world in which we live is the baseline—and, therefore, that which is "normal." Differences from the norm are then regarded as something *other*—something *ab*normal. This does not have a positive connotation. It does not take much imagination to understand why people with disabilities resent being seen this way. No one wants to be defined exclusively by his or her 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. Consider the words of a well-known disability advocate:

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. Clearly, how people are viewed affects how they are treated. The historical 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: Disability Is a Normal Part of Life in a Normal World

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 sense of frustration. Determined to improve the lives of people affected by disability, activists are attempting to reframe the debate. In predictable postmodern* fashion, this is being accomplished by resorting to changing the language of disability. This alteration cannot be overemphasized. If you listen carefully, you can hear the dramatically shifting terminology. Ponder these statements from the writings of a nationally known speaker at a recent Down syndrome conference:

Having a disability is a difference like any other human characteristic. 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 here? The new language confuses everything and solves nothing. Does this person really mean what she said? Is disability to be regarded with no greater acknowledgment than hair color? Of course 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, then why don't more people attempt to acquire traumatic brain injuries? In response to an appropriate desire to celebrate the *individual*, the postmodern view instead 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 would have occurred if you had entered, stood by my bed, and greeted me with, "Hey!

^{*} *Postmodernism* is a philosophy that rejects the existence of absolute truth and the associated ability to reason on the basis of what is known to be true. Language, therefore, is not considered to be a vehicle to convey truth but, instead, is viewed as a tool that is employed so that one individual or group might exert power over another individual or group.

ON TRUTH: THE FOUR MISSING WORDS

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.

The Biblical View: Disability Is a *Normal* Part of Life in an *Abnormal*World

Those with a postmodern perspective are capturing 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 the following 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 mankind 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)

Human beings were God's crowning act of creation. While fashioned as creatures, people were designed to intrinsically embody his likeness. This means that mankind 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 Adam and Eve's desire to rule, not only over the rest of creation but over themselves, the fall of mankind occurred—adversely impacting every aspect of creation. As Paul states 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 continue to carry over today into our work, our world, our bodies, and our relationships with self, others, and God. Reflecting on this, the apostle Paul again notes in Romans 8, "The whole creation has been groaning" (v. 22).

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

ON TRUTH: THE FOUR MISSING WORDS

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 face the slow, incremental process of 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 be experiencing 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 just 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.

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 congrega-

tion 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 was so moved by the photo that I felt compelled to share it with my children that evening while we

^{* &}quot;Spina bifida is a neural tube defect that happens in the first month of pregnancy when the spinal column doesn't close completely." (Source: Spina Bifida Association)

[†] Physical disabilities is a broad category of disability encompassing disabilities that affect movement.

[‡] Intellectual disabilities is the current terminology for the condition formerly referred to as mental retardation. "Mental retardation is a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before the age of 18. In regard to the intellectual criterion for the diagnosis of mental retardation, mental retardation is generally thought to be present if an individual has an IQ test score of approximately 70 or below." (Source: American Association of Mental Retardation)

ON TRUTH: THE FOUR MISSING WORDS

were sitting around the dinner table. As I displayed the picture to our two sons, both of them were visibly moved. While I was describing the root causes of this type of poverty, Timmy was silent for a moment, and then his eyebrows furrowed. Quietly and deliberately he questioned, "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, it was a different church, in a different decade, and under very different circumstances. As we sat down we heard the words of our close friend and youth pastor, "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." At this point the audible gasps of our church family could be heard around the sanctuary, giving 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." Greeted after the service by the congratulatory hugs of our teary-eyed friends, we could not imagine a more wonderful way to introduce Timmy to his church family. Even as our hearts were racked with sorrow at the diagnosis and all of its implications to Timmy's life and ours, we chose to focus 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 states: "Truth and the morning become light with time." Well, it's time.

Personal Application Questions

- I. If you are honest with yourself, which worldview perspective of disability dominates your thinking? Is it the historical 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?