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 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.

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* "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*?"

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!

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* *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.

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