Introduction

I Didn't Sign Up for This God!

Have you ever had one of those dreams where you can't move? The car is racing toward the edge of a cliff and you can't lift your foot to press the brake pedal. An attacker is breaking down the door to your house and you can't raise your arm to dial 911. Your child is about to run in front of a truck and you can't open your mouth to scream.

My bad dream became a reality in 1982. My husband and I stood beside our son's isolette in the neonatal intensive care unit. An IV needle pierced Allen's tiny arm, and angry red scars crisscrossed his chest. One end of his feeding tube hung on a pole beside his IV bag. The other end rose from the soft skin of his tummy. Pain etched his wide forehead and tugged at the corners of his perfect rosebud mouth.

More than anything, I wanted to reach out and take his hurt away. But I was trapped in a bad dream. Immobilized. Inadequate. Helpless. Though God had assigned me to love and care for this beautiful child, I could do nothing to minimize his pain. My thoughts were an inward scream. This isn't what I signed up to do, God! I don't want to be a helpless onlooker. I want to parent my child. How can I care for him? What can I do?

As the parent of a child with special needs, you've probably experienced the same sense of helplessness. Whether your child is critically or chronically ill, mentally or physically impaired, develop- mentally or behaviorally challenged, you want to do something. You want to ease your child's pain, but you don't know how. You want to help your child realize his or her full potential, but you don't know where to begin. You want to ask God about your child's suffering, but you don't want to be condemned for questioning His wisdom. You want to believe God is with you, but you don't know how to find Him.

You're stuck in a bad dream. You can't move. You can't speak. You want someone to shake you awake and tell you everything will be okay. Instead, you wake up and must become the parent you never expected to be. You doubt that you're up to the task. You're worried about your child's future. And you're wondering, Does anyone understand what I'm experiencing?

The answer is yes, many parents understand your situation. In the United States,

- 10–15 percent of newborns, or 431,000 annually, spend time in neonatal intensive care according to the March of Dimes.
- 12 percent of children between ages 1 and 17 had medical conditions serious enough to require hospitalization between 2004 and 2006, the most recent years for which statistics are available at the Centers for Disease Control and Prevention.

- 13.6 percent of students between ages 6 and 21 were enrolled in some kind of special needs program according to the National Center for Educational Statistics. That's 706,000 of our country's school-aged children.

Lots of kids mean lots of parents, dads and moms who are valuable sources of information and advice. In this book, dozens of them share with you the wisdom they gained while parenting kids with special needs.

Support can also come from the surprising number of professionals who work with families of kids with special needs. These professionals—and the resources they've created—are available at hospitals, medical facilities, government agencies, private organizations, businesses, schools, churches, and more.

This book brings you advice from professionals around the country and provides information about national organizations and resources. It also gives tips about where to start searching for state and local resources. More often than not, your problem won't be a lack of resources, but a lack of awareness of them or inability to access them.

Different Dream Parenting contains six sections: Diagnosis, Hospital Life, Juggling Two Worlds, Long-Term Care Conditions, Losing a Child, and Raising a Survivor. Each section is divided into four chapters. Three chapters address practical issues. The last chapter in each section addresses spiritual concerns.

Parents of kids with special needs often wrestle with prickly spir- itual questions. I sure did. Sometimes I still do. So do all the parents interviewed in this book, and most of the professionals, too. Every day, we continue to ask questions about our kids' lives and futures. Gradually, we learn more about how to trust God's timing and wait for His answers.

As you read this book, please ask your faith questions. Read about how parents and professionals learned to ask questions, wait, and listen. Consider the answers they have discerned and their suggestions about how to find comfort and courage in God's Word. When you are ready, try out their ideas about how to pray and use Scripture to hear God's answers to your hard questions. The thirty-day prayer guides in appendix A are designed to help you engage in conversation with Him.

But even with prayer guides and Scripture to guide you, I know how hard it can be to trust the God who is allowing your child to suffer. So I won't condemn you for asking prickly questions. Instead, I'll encourage you, cry with you, and support you when your faith grows weak. When you can't hang on a minute longer, I'll hold you close until your strength and your faith return.
I hope this book helps you break out of your bad dream, wake up, and move forward with joy and confidence. I pray that the stories of parents and professionals in this book will give you hope and strength.

Most of all, I hope you discover the truth God has revealed to me and many other parents. Raising a child with special needs isn't a bad dream. It's just a different dream. And surprisingly, a different dream can be the best dream of all.

This excerpt was taken from *Different Dream Parenting: A Practical Guide to Raising a Child with Special Needs*
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