

INTRODUCTION: RAISING THE BAR OF EXPECTATIONS FOR CHILDREN WITH SPECIAL NEEDS

Anyone who does anything to help a child in this life is a hero to me.

—Fred Rogers

Welcome to *Breakthrough Parenting for Children with Special Needs*.

If you've been searching for an empowering, motivational, and user-friendly resource to help you parent a child with special needs—you've just found it.

Whether your child received his or her special needs diagnosis at birth or at some other point during childhood, teen, or young-adult years, *Breakthrough Parenting for Children with Special Needs: Raising the Bar of Expectations* was written for you.

A New Way of Looking at Your Situation

This book challenges parents and professionals to maximize the potential of children and young adults with special needs by using a motivational, how-to approach that *gets results*. It includes parent-tested strategies, valuable resources, and inspiring success stories to help provide families and professionals with renewed hope for creating better lives and greater independence for millions of children with special needs.

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Breakthrough Parenting for Children with Special Needs is not about *fixing* children with special needs; it's about changing the way in which families, professionals, and society *view* and *interact* with these children. That powerful shift in thinking helps make this book special.

This book is about personal empowerment and making the kind of changes that lead to better lives for all kids no matter what role you play on a special needs team. It's about taking individual responsibility for your impact on a child.

Professionals working with the special needs population may gain greater sensitivity about the challenges facing these families—and further insight into their demanding lives.

My hope is that this book will challenge all professionals to reexamine how they interact with families. My suggestion is that they work harder to look beyond disability and focus on a child's value, potential, and abilities, while sharing valuable resources and expertise with the families they serve.

How This Book Works

This book is filled with inspiring personal success stories from families who have triumphed over a wide range of special needs, including cerebral palsy, multiple sclerosis, Down syndrome, autism, and hearing and sight impairments. These stories will energize and motivate you, make you stand up and cheer—and maybe even move you to tears.

This book recognizes the valuable role of siblings.

Readers will benefit from The Special Needs Bill of Rights for Children, Parents, Siblings, and Professionals, which offer the people most affected by the demands of special needs the permission to embrace their valuable roles. This family-friendly resource also allows readers to quickly access valuable resources and special tips for success at the end of each chapter.

From chapter to chapter, you will learn from the experts—the families facing special needs parenting challenges day in–day out,

24/7, 52 weeks a year, including weekends, holidays, and Christmas—*for life*.

This book is a comprehensive, valuable, and timeless resource guide for all parents and professionals, which will help them better understand the value and potential of children and young adults with special needs, as well as their siblings. All challenges are viewed as having equal importance.

Although not every special needs diagnosis or parenting situation is directly identified in this book (you wouldn't be able to lift it!), all special needs challenges are considered important—whether spoken or unspoken.

The book's solid focus on parent empowerment and making decisions that help all children succeed makes *Breakthrough Parenting for Children with Special Needs* of value for anyone who cares about helping children live more fulfilling lives, whether they face physical, behavioral, emotional, medical, or developmental challenges.

Who Am I to Write This Book?

Within each chapter, you will find parent-tested strategies from a mom with more than a decade of special needs parenting experience. Me. For nearly thirteen years, I successfully parented a child with cerebral palsy, a wheelchair user with limited speech and few motor skills.

My son passed away suddenly in 2003 at age twelve.

Parenting Eric was the most difficult and most rewarding thing I have ever done in my life. This book is a tribute to my son's remarkable life and to his many impressive achievements—some of which I will share with you in these pages.

I wrote this book for Eric so we could help change other children's lives.

This resource will encourage you to reach for the parenting stars, while reminding you of the need to face and address some critical facts about your child's diagnosis. You will be challenged

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to change your focus from what you *can't* change to what you *can* change.

Empowered parents are the key to creating better lives for *all* children, including those with special needs. You are the *real* experts regarding your child. This book recognizes and validates that important fact, while challenging you to up your parenting game.

This guide challenges the perception that having a child with special needs is a fate worse than death. It will encourage parents to celebrate and value their children's existence as a remarkable parenting gift.

Three Things I Already Know About You

Before we get started, allow me to share three things I know for sure—and I didn't learn them in kindergarten, college, or the workplace!

- *If you are just starting out on this often-unpredictable and emotional parenting road, I have a pretty good idea about where you are.* You're overwhelmed, scared, confused, angry at yourself, your child, the world, or God. You're trying to be hopeful and wanting more for your child, but you're afraid to dream.
- *I've got a pretty clear idea about where you're headed and what awaits you when you get there.* You'll find societal roadblocks, accessibility challenges, outdated stereotypes, funding and political debates, and professional arrogance, which will test your creativity, patience, endurance, sanity, blood pressure, and anger management skills. Fortunately, there is an ongoing disability rights movement that helps fuel all of these much-needed societal changes.
- *I'm darn sure that you can survive—and even thrive—in your new parenting role.* You'll need to do a lot of hard work, have a positive attitude, and get the right kind of parenting support. I am

living proof that it can be done. If I can take on this unexpected role and thrive, so can you!

Why Do I Believe All This When I've Never Met You or Your Child?

Because I was where you are now, and I know where you are headed. I have walked many challenging miles in your parenting shoes. I was the same unsure-but-hopeful, loving, dedicated parent of a child with special needs, hungry for the validation, support, and positive examples of other families. I went searching for good resources and came up empty-handed, discouraged, and outraged. More than once, the frustrations of navigating public education tempted me to home school my child.

I was that parent who didn't know which way to turn next, who had to try to figure it all out by herself, without the benefit of good resources like this one. (They didn't exist when my son was born.) But I refused to ever give up on my child.

My special needs parenting demands caused me to fall to my knees more than once, while allowing me to become a much better human being than I ever imagined possible. The demands of special needs challenged me to the limits of human endurance—and helped me realize my most heartfelt life dreams, too.

It was the intensity of my own parenting challenges that made me decide to write this book. I want to reach out to those families who are coming behind me. I want them to have something to hold on to—tightly and securely—as they walk what can be at best an uncertain parenting path.

Because of Eric's needs, I became a more educated and empowered parent. I learned how to love unconditionally and redefine perfection and disability. I now understand fully the sacred and tremendous responsibility of being a child's parent.

Today I focus on possibilities and solutions, not on problems or dismal statistics. I learned to celebrate my son's *imperfection* as a

blessing. Parenting Eric was the most life-changing and demanding experience of my life. I would do it again in a heartbeat.

How to Use This Book

When I first began this uncertain and challenging journey, I was a novice. But I became a master at successfully addressing my son's significant needs so he could have a better life. Far too many families are living lives of desperation and hopelessness. This is an injustice, unworthy of our children, and I want to change it, with your help—and this book!

I will be asking you to step up to the parenting plate big time! Raising children with special needs is not for the squeamish, the complainers, the unforgiving, the overachievers, or the control freaks—unless they want to change. You need to have a *Rocky-like* and *Mother-Teresa-like* mentality, which you can develop by *using this book*.

You must be willing to embrace change without moaning and groaning too loudly, if you are going to be able to effectively help your children recognize their full potential in a world that often devalues them, then looks the other way.

Offering your children every opportunity to have the life they deserve demands pit-bull determination. But throughout the pages of this book, I will walk you through every step of the way. I will support and challenge you, provide friendship and understanding, and share your tears—and I'll celebrate with you, too.

I will walk you through some of the most difficult transitions, stages, and unnerving meetings, by providing you with the information and resources required to help you become an *increasingly empowered parent*. (Note that I've redefined the term *IEP*.)

Finally, I will challenge you to get back into the parenting ring when you've been delivered a knockout punch from which you are certain you can never recover.

I *know* you can—I've been there. Not a single day goes by when I don't miss Eric deeply. I will never, ever forget the impact he had

and continues to have on my life—and on my work. He taught me so many profound lessons that continue today.

How did I reach such acceptance and love for my son? First, I had to come to terms with my new parenting role by doing necessary grief work. I had to let go of old parenting dreams to make room for the new. I made tough personal choices that led to personal empowerment. I refused to embrace a life of despair. I became outraged by all the societal intolerance and discrimination that I witnessed. And I was determined to use that raw energy to create positive social change. I allowed myself to be guided by strong personal faith and the saving grace of humor.

But my most important life decision was choosing to view my son as a child first, not as a disability. That decision freed me to raise him as a regular kid, with special challenges, instead of as a *handicapped* child. My attitude shifted from grieving his disability to celebrating one child's amazing abilities. That difference was huge.

I refused to ever give up on my dreams—or on my son.

Before Eric's death in 2003, he was fully included in the sixth grade in his neighborhood school, something I had been told would never happen. He had claimed his place on the school honor roll and had appeared in full-page color in *Parents* magazine, part of a pictorial of confident children with special needs from across the country.

Near the end of his life, Eric was composing music during his weekly music therapy classes. I could not have envisioned this reality when he was first born. Having special needs was just a small part of who my son was.

When I first began this journey, my perception of my new role as the parent of a child with a disability was clouded over by fear and an overwhelming sense of inadequacy. Both were fed by a lack of upbeat, motivational parenting resources and deeply ingrained societal stereotypes that devalued my son.

Rigid societal systems, public policies, and discrimination are not easy to rise above, nor are personal exhaustion, the loss of parenting dreams, and the threat of financial ruin. The trick is to learn

how to move forward and make good decisions, no matter what challenges you face each day. It is possible.

After my son's birth, I was frustrated because all the best parenting magazines appeared to totally ignore families facing special needs. I went searching in vain for upbeat, motivational resources to help me parent my son and came up empty-handed. I remember thinking that it should not be this difficult to raise *any* child.

In the months following my son's birth, I dreamed of writing a motivational book to help parents and professionals do a better job of raising children with special needs. It would be attractive, upbeat, and inspiring, filled with good information and great resources. It would provide the emotional support that many parents need just to get out of bed in the morning. It would make us laugh at the absurdity of our daily demands.

For thirteen years, I lived out the pages of that book. The book that is now in your hands is the result of my amazing journey. I wrote it so you and your child could have better lives. It fulfills a big promise that I made to my incredible son. I wish he were here to see it . . .

Avoiding Quick and Easy Fixes

Breakthrough Parenting for Children with Special Needs: Raising the Bar of Expectations doesn't promise you magical parenting solutions or quick fixes. There are none.

Raising children with special needs to achieve their full potential is hard work. The information here will not cure a child's special needs, nor should it be used as a substitute for medical treatment. Children may still require the use of a wheelchair or other adaptive equipment, tutoring services, and intensive therapy, including drugs or outside placement. Parents may struggle with sleep deprivation for years. Marriages may still end.

What *will* change is how parents and professionals view their situations and how they choose to address their challenges in increasingly empowered ways. That gives me hope for the future of all children with special needs.

You may decide to read this book from cover to cover, or you may find it helpful to jump from chapter to chapter. Do what works best for you. What matters most is that you use it!

To recognize the increasingly rich and diverse definition of the term *family*, whenever *parent* is used, it means the adult legally responsible for a child's daily care, well-being, and legal guardianship.

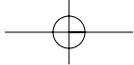
The term *parent* recognizes, validates, and honors all adults raising children with special needs—whether that role falls to the birth, adoptive, foster, or single parent or to grandparents who have unselfishly given up their own retirement years to take care of a child. All adults who take great care of our kids are heroes in my book.

Is This Book for You?

Before continuing on, please answer the following questions:

- Are you tired of searching for the encouragement, understanding, and validation that you deserve in your role as a parent or as a professional?
- Are you willing to stop complaining about your role and instead start embracing tough personal change to become a more dynamic and empowered parent or professional?
- Are you willing to work harder than you have ever worked in your life to ensure that a child's future (and your own) is the best it can be?
- Are you willing to stand up for a child and for that child's future?

If you answered yes to these important questions, then this book is for you! It's time now to get into the best parenting shape of your life. You have nothing to gain but a brighter future—for you, and for your child.



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The choice is yours.

Now let's turn to Chapter One and see how you can embrace some brand-new parenting dreams—and address Asperger's Syndrome. You are beginning a challenging and rewarding journey that leads to parenting empowerment. Welcome aboard!

