

the  
elephant  
in the  
playroom



Ordinary Parents Write Intimately and Honestly  
About Raising Kids with Special Needs

**Denise Brodey**



A PLUME BOOK

## PLUME

Published by the Penguin Group

Penguin Group (USA) Inc., 375 Hudson Street, New York, New York 10014, U.S.A. • Penguin Group (Canada), 90 Eglinton Avenue East, Suite 700, Toronto, Ontario, Canada M4P 2Y3 (a division of Pearson Penguin Canada Inc.) • Penguin Books Ltd., 80 Strand, London WC2R 0RL, England • Penguin Ireland, 25 St. Stephen's Green, Dublin 2, Ireland (a division of Penguin Books Ltd.) • Penguin Group (Australia), 250 Camberwell Road, Camberwell, Victoria 3124, Australia (a division of Pearson Australia Group Pty. Ltd.) • Penguin Books India Pvt. Ltd., 11 Community Centre, Panchsheel Park, New Delhi - 110 017, India • Penguin Group (NZ), 67 Apollo Drive, Rosedale, North Shore 0632, New Zealand (a division of Pearson New Zealand Ltd.) • Penguin Books (South Africa) (Pty.) Ltd., 24 Sturdee Avenue, Rosebank, Johannesburg 2196, South Africa

Penguin Books Ltd., Registered Offices: 80 Strand, London WC2R 0RL, England

First published by Plume, a member of Penguin Group (USA) Inc. Previously published in a Hudson Street Press edition.

First Plume Printing, March 2008

10 9 8 7 6

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REGISTERED TRADEMARK—MARCA REGISTRADA

The Library of Congress has catalogued the Hudson Street Press edition as follows:  
Brodey, Denise.

The elephant in the playroom : ordinary parents write intimately and honestly about the extraordinary highs and heartbreaking lows of raising kids with special needs / Denise Brodey.

p. cm.

ISBN 978-1-59463-035-4 (hc.)

ISBN 978-0-452-28908-6 (pbk.)

1. Children with disabilities—Family relationships. 2. Parents of children with disabilities. 3. Parenting. I. Title.

HQ773.6.B75 2007

306.874087—dc22 2006039393

Printed in the United States of America

Set in Garamond

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## A View from Within the Whirlwind

My four-year-old son, Toby, was spinning like a top, howling, and we were all just going about our business as if there was nothing extraordinary going on in the living room. This was typical—by this, I mean the “ignoring him” part was pretty much routine. After months of practice, my husband and even my six-year-old daughter could watch Toby lose it and still continue on with our day-to-day lives. It’s not that we weren’t moved or shaken—we’d just seen this happen *Groundhog Day*-style one too many times.

I was waiting out the storm in the hall, tying my daughter’s shoes. We were getting ready to go to a friend’s barbecue. I yelled to my husband, Jeff, who was in the kitchen, “Bring a milk in the backpack and make sure you have a sippy cup and Motrin in there, too. You know how Toby gets a headache when he’s in a loud group.” I heard the *kathunk* of my husband dropping the supplies in the backpack and letting out an exhausted grunt. I must have grimaced, because my daughter asked me, “What’s wrong, Mommy?”

I have no idea what my response to her was that day, but I remember what went through my mind: *What’s WRONG? Your little brother is throwing a hissy fit for the umpteenth time today. His behavior is unmanageable. We have tried time-outs, rewards, behavior*

*charts—everything. And did you know Mommy and Daddy's marriage is hanging by a thread?*

I normally look forward to spring the way some people look forward to Christmas. I love the season of bike rides and park picnics and meeting the ice cream truck after dinner. But May 2003 was not the same. I was not in the mood for Mister Softee—or anything else, for that matter. I was in a foul state of mind.

Over the past few months I had become a bundle of nerves. Nothing I'd read about raising a kid told me how to deal with *this*. Toby's hour-long, completely unpredictable tantrums made me feel anxious, like a bad mother, a helpless failure. And *everything* seemed to set him off: I described him to my best friend as a mini-control freak with a mighty rage. Daily, sometimes hourly, his need to control people and his surroundings disrupted our lives. And that spring, starting with the first barbeque of the season, would mark a turning point. That weekend I realized that the problem was bigger than Jeff and me, that we needed professional help.

Once Toby's tantrum finally ran its course a half-hour later, we wiped away his tears, had a cold drink, and started off for the barbeque. When we arrived at my friend Ellen's home, Toby studied her kitchen. I could see his mind ticking: *What are those weird cooking smells? What are they going to make us eat for dinner?* He checked out the gaggle of kids playing tag and ball in the garden below. *Too chaotic*, I bet he thought. So he wandered inside and poked around with a set of colorful magnetic letters on the fridge. Seconds later, a precocious preschooler zoomed into the kitchen. I cringed, realizing he was headed straight for the refrigerator. He screamed, "Toby! I can spell *Toby!*" and grabbed the letter *O* from my son's fist. I leaned in and tried to explain to the other child how much Toby wanted to spell his own name. My friend stopped her cooking to watch me out of the corner of her eye, with a look that said, *Denise, don't interfere.*



I tried not to, but a duel for the O was already under way. Finally, Toby relinquished his letter—but not without a monster tantrum. Other moms chatted and cut cheese wedges and poured wine and tried to ignore the chaos beside them. When Toby refused to be quieted, I took him to the bathroom. He continued hollering into the toilet, telling me he was going to throw up. I took him outside to a quiet front step. He wailed and pounded me with his fists. Through the glass door behind us, I made hand signals to my husband that I was leaving. He cracked open the door and tossed me our house keys. We headed up the block. Toby stumbled and kicked and fell and whined as I cajoled him, distracted him, told him that I loved him. But I can honestly say, at that moment, I couldn't have hated him more. (I am guessing that I am not alone in having this love-hate feeling—while I always deeply love my kids, I can absolutely loathe their behavior and their presence when they push me too far.) I felt confused and furious and so frustrated that I kicked a rock, hard, and stubbed my little toe. Focusing on the throbbing inside my sneaker felt better than dealing with my raging son. I went to sleep with a pain in my foot and an even bigger ache in my heart.

The next day, a Sunday, was no better than the day of the barbeque. By midafternoon, we'd argued over getting dressed, brushing teeth, bike riding in the rain (not an option, I told him), and everything else in between. Every transition was either cause for a battle or a tantrum or both. During our final afternoon argument, Toby again fell on the floor sobbing. My husband gave me a look from the doorway of Toby's room that mirrored my own thoughts: *What the heck was going on with this kid?*

Parents I've told this first-barbeque-weekend story to usually fall into two camps: Camp A would be the "And What the Heck Is Wrong with Your Parenting Skills?" group. These parents are raising kids who have tantrums but accept discipline. These parents pat themselves on the back when their child learns a lesson within a reasonable amount

of time and stops the nonsense. Don't get me wrong—members of this group offer well-meaning, constructive advice and commentary: *Maybe more routines would help? Is he feeling sick? What if you . . .* But I'd heard and tried these tactics before; my firstborn was a kid who actually *got* the behavior rulebook in utero and stuck to it most of the time. Camp B, the "We Feel Your Pain" group, on the other hand, can see, almost instinctively, this is no ordinary kid. These parents are almost all moms and dads of special-needs kids. They know life within the whirlwind.

I couldn't stand to struggle with my son like this any longer—or to see the rest of my family take a mental beating, either. A few weeks after the barbecue incident (and many subsequent others), my feelings of hopelessness and stress propelled me to get help—for me and for Toby. A few weeks after that, in late June, a psychologist diagnosed my son with sensory integration dysfunction. She was not the first therapist we consulted—but her observations struck a chord with us. They seemed sensible, fitting. We went with her diagnosis, which in layman's terms means that Toby is highly sensitive to light, noise, sound, and touch, and has problems with learning, organizing his thoughts, and behaving appropriately when his senses are overwhelmed. She sent us to a psychiatrist, Dr. Nieder, who said that the anxiety that all these problems produce led him to believe that Toby also suffers from childhood depression. He prescribed Prozac.

While the idea of giving Toby antidepressants was difficult for me, it was extremely depressing to my husband. Jeff was dubious about medicating a child—but he was also overwhelmed, which made him more open to the idea of Prozac combined with therapy. Jeff's response to trauma had always been: Be silent, wait it out. In the months leading up to Toby's diagnosis, whenever I told Jeff I thought we were in crisis mode and needed help, he would get this shell-shocked deer-in-the-headlights look that is usually reserved for walking in on your wife cheating with the plumber. I did finally get it out of him that he

was willing to try Toby on medication, but that was about it. As we began couples and child therapy, Jeff could see the benefits of talking out conflicts and sorting through feelings; he did a lot less silent brooding and displayed fewer looks of horror and shock, although, to this day, listening, not talking, is his forte.

My parents, on the other hand, are talkers *and* listeners—they're both therapists. So when things got especially hellish that pivotal summer, I often turned to them to vent. But we were all so busy. Remembering to call at exactly five of the hour (when my parents were free between patients) or after bedtime, when I could barely form a sentence, proved nearly impossible. It was also draining to try to explain my reality to people who weren't living it themselves.

Before, during, and in the months following Toby's diagnosis, I had never felt so alone. Out of that desperate loneliness came the idea for this book. I wanted to know how other parents of not-so-normal kids made it through the day. I craved real moms' and dads' opinions, solutions, setbacks, and successes. So I began asking a few insightful parents of quirky, less-than-average kids—acquaintances from around the neighborhood I'd gotten to know over the years—to write out their stories for me in an e-mail. As I read each one, I was riveted. Sure, we'd talked "issues" casually at birthday parties, but, *wow*, there was so much in their stories that was, honestly, shocking to read. Being privy to the details of what other special-needs parents go through daily provided a kind of comfort that I hadn't found in books or friends with less quirky kids. I suspected other parents would benefit from hearing these stories as well.

I am a magazine editor, and unearthing compelling stories about real people is what I have done for the past fifteen years. Inspired by the few stories moms and dads that I knew had sent to me, I decided to put my professional skills to the task and expand my search to a broader network of parents. I began my hunt by inviting contributions from those who logged on to special-needs Web sites; then I



posted flyers and did mass mailings to special-needs schools and programs across the country. I put out feelers to respected national associations, including the National Institute of Mental Health, Yale Child Study Center, and the Schwab Learning Organization. I tapped into psychologists and occupational therapy practices across the country. I asked for essays that were short, honest, and personal, and could in some way be helpful to other parents. I suggested topics, including the stresses of parenting, school dilemmas, the trials and triumphs of giving a child medication, the ways in which a special-needs child had affected a marriage or friendship, and the unexpected joys of being a mom or dad to a kid who poses certain challenges. I suggested these topics because they were the ones I felt most in need of hearing about. But I was very open to ideas; I ultimately wanted this book to be about what no one was talking about—hence, the title, *The Elephant in the Playroom*.

The reception from those initial parents, educators, and therapists I contacted was overwhelmingly positive; many wrote back enthusiastically, in support of the idea—and many wanted to contribute. Inspired by this initial feedback, I expanded my outreach even further, contacting dozens more therapists, neuropsychologists, child-study centers, and online special-needs communities. My calls for stories brought in contributions from ordinary moms and dads hailing from Florida to Alaska, all of whom were raising kids with extraordinary challenges, including ADD, ADHD, autism, bipolar disorder, schizophrenia, selective mutism, oppositional disorder, and everything in between. While I occasionally encountered some resistance, the nastiest comments zapped back at me asked why I would even think of taking advantage of vulnerable parents for my own gratification. Those people had missed the point: Overwhelmingly, contributors gave selflessly of their time and insights because they wanted to help other parents. Many said they found the writing itself therapeutic. Others commented in e-mails that putting their family's story into



words had sharpened their focus, helping them hone in on a problem. This nation of parents, it seemed, was ready to talk.

My research also proved to me that there were *a lot* of these parents. Nearly 5 percent, or an estimated 2.7 million children, are reported by their parents to suffer from definite or severe emotional difficulties,\* and the World Health Organization indicates that by the year 2020 childhood neuropsychiatric disorders will rise by over 50 percent.† Fifteen percent of parents with children between the ages of five and eighteen report giving their kids psychoactive medication daily for those special needs.‡ During the spring that I began writing, a landmark medical study showed that more than 46 percent of Americans suffer a mental disorder during their lifetime, and many receive inadequate treatment. Autism made the cover of *Time*. And every day that I read the news, it seemed that a new study was surfacing that acknowledged the “hidden handicap” of mental illness was on the rise in children in this country.

### **How to Use This Book**

In this collection you'll find essays by real moms, dads, and even a few siblings—essays full of honest, engaging, eye-opening stories from people who know life in the trenches. You can read the collection from cover to cover, or pick and choose from a section that peaks your interest or is particularly relevant to you. This book covers topics that often get brushed under the rug—emotional topics, like the guilt or confusion involved in giving your child medication

\**America's Children: Key National Indicators of Well-Being, 2005*. See [www.childstats.gov/amchildren05/index.asp](http://www.childstats.gov/amchildren05/index.asp).

†The Executive Summary, Report of the National Advisory Mental Health Council's Workgroup on Child and Adolescent Mental Health Intervention Development and Deployment.

‡New York University Child Study Center. See also “Finding What Works,” [www.msnbc.com/id/7528650/site/newsweek](http://www.msnbc.com/id/7528650/site/newsweek).

and the frustration with friends who don't understand your parenting style. Unlike diagnostic books, in this collection you will not find expert opinions or checklists for assessing your child's disorder. And you will not find case studies or a blow-by-blow of how and why kids are diagnosed with mental illness. Instead, you will read about ground less covered: pages of parents' perspectives and feelings.

You'll read about the experiences of a four-year-old girl from Texas who told her mom she wished she could make herself go away forever, and of a teenage girl hell-bent on meeting older men on the Internet as a way to ease her loneliness. There is a contribution from an Indiana mom who nearly took her own life when the special needs of her child overwhelmed her. You will also meet Nadine, a New Jersey mother whose son's major issues have always centered on food. The day when this athletic little boy decides to try a new food, even something as simple as chicken nuggets, is one of celebration. You'll find the moving story of a father who upended his entire life to care single-handedly for a baby born with severe disabilities. These eye-opening stories are not meant to scare or outrage parents; they simply bring a real voice to the epidemic of childhood mental illness that has just begun to show up in statistics and studies.

### **How This Book Is Different**

I am not a therapist. I do not have a degree in early-childhood education, nor have I ever worked at an accredited day-care or a child-study center. I am an editor at a national women's magazine, and I am a reporter, a digger of facts and stories by nature. I understand different diagnoses because I have read several diagnostic "what to do if"-type books—from *The Difficult Child* to *The Out-of-Sync Child*—while trying to comprehend my child's behavior, and I am grateful to the authors who wrote them. But, again, this book is not meant to be

diagnostic. I think we can all gain as much knowledge from parents as we do from professionals.

You probably picked up this book in part because you already believe that every child is unique and that the way every child is affected by a disorder varies. The goal of this collection is not to give generalized advice on these disorders, but to provide a source of solace, connection, and community to moms and dads raising special-needs kids. Parents of children who do not have special challenges often rely on peers and the culture they see around them as a guide to raising their families. Special-needs parents, however, watch their children's behavior and challenges morph so quickly that parenting them demands new inspiration almost daily. Not to mention, finding other special-needs parents in some areas is not so easy. The nearest special school or playgroup is often hours away.

Finally, I need to confess that in the last couple of months of working on this book, I've felt like an imposter. Back in the days when I conceptualized this book, my life was truly a disaster. Today my son seems every bit a success story—and his special needs, particularly his anxiety, can go undetected to the naked eye many days. But it has been quite a haul to get where we are (or, I should say, he is) today. For whatever reason you have this book in your hand, I hope that these original works, penned by other concerned, insightful, and wonderful parents all across the country, provide that feeling of connectedness and community I know so many of us need.