

FOREWORD

by Richard Ellenson

For a few minutes during my son's birth, his body stopped getting oxygen. What was supposed to be a routine birth turned into something quite different. Tom barely made it out of the womb through an emergency cesarean section. Instead of the billing, cooing and nuzzling one envisions after a birth, my memories swirl with bright lights, glaring metal, harshly whispered voices and the tense, worried faces of the Operating Room staff.

Tom spent nearly two weeks in the Neonatal Intensive Care Unit before we took him home. And it was another nine months of missed milestones and slightly off-kilter movements before we found out that the lack of oxygen had created something called basal ganglia involvement; the parts of Tom's brain orchestrating fine motor skills and gross motor skills had died from lack of oxygen. Tom had cerebral palsy.

The journey of our experience is a long one. As one might expect, it contains moments of sadness. But perhaps unexpectedly it contains far more moments of joy. Moments of profound appreciation of another individual, moments of wonder at how many other ways a person can accomplish things and, naturally, moments of what I can only call that gentle thunder of love.

Our son Thomas can't speak and he needs a wheelchair. I expect those two facts to remain that way. But other parts of his brain are fine. The part that holds intelligence, the part that allows receptive language and, certainly, the part that allows an individual to communicate that most elusive of traits: charm.

On top of that, Tom emerged from the firestorm of desperation that surely blazed along his brain's neurons as they felt the chill of dying out with enough determination to still believe in one last lucky tumble of the genetic dice. Tom is a cute kid. Everyone falls for him.

At least that's true now, while he's 8 years old. The wheelchair. The inability to speak. The drool that falls from his mouth and pools up on his shirts. The abnormal movements that sometimes flail about him. None of it matters.

Even when kids don't know quite how to connect with Tom, they are happy to enter that magical space that here, in this book, is so well coined: DisabilityLand. It is as if anyone under the age of 8 breathes some special air that allows him or her to feel natural in Tom's world. They naturally chant the mantras that allow one to navigate this vast and special place, and they embrace its wonders.

However, that isn't always so with adults. People watch Tom and me as we go down the street. We get looks that one can only call sympathy or, at best, empathy. We are, as this book will tell you, *always looked at*.

But you all know the laws of physics: You can't see something's movements if you're on it. The world is spinning at 1,000 miles per hour, but you're sitting on the beach, watching the waves roll forever in front of you.

I have walked beside Tom so attentively now for so long that for me, all else

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vanishes. We go down streets together, Tom in his wheelchair and me walking beside, and we check out the neighborhood. If it is checking out us, we are unaware of it. We sit over dinner and Tom tells me stories about school or how he wants to be a chef like Emeril or about his latest girlfriend in class; and although this conversation takes places through taps to icons on his wheelchair tray, nods of his head, gazes of his eyes, through low guttural approximations of words—all nuances and milliseconds—that others can't see, for us it is all perfectly natural. It is our life. My heart beats with my son's.

I walk so far into DisabilityLand that I am sometimes taken aback when I journey out.

Our family has worked with the New York City Department of Education to try to improve schools for Tom and so many other amazing kids. As a result, Tom has gotten a fair bit of media exposure. And each time I see my son on TV, I am startled. I want to holler to my wife, Lora, "Look! Look at those abnormal movements. My God! Did you know there might be something wrong with our kid?" It shocks me. When I am in DisabilityLand, I just can't see it.

Lora is a doctor and scientist. She is trained to observe. She understood early on, well before I did, what would be the dance of Tom's life. But I spent my career in advertising. I saw only what the *brand* of disabilities stood for. And, to date at least, that brand stands for unrealized potential and limited ability.

That didn't work for me. For living with Tom, I had been to an amazing place—a place I didn't know existed until I read this wonderful book. Clinging to my hopes and dreams for my magnificent, charming, optimistic and glorious son, he

had dragged me right along with him into something even more profound: his reality. An amazing place right at the center of DisabilityLand.

And in the marvelous place about which Alan Brightman writes with such compelling insight, I quickly began to learn and embrace much of what had been out of reach for me.

I am dazzled by the abundance of images and events one finds throughout this book. And, perhaps even more so, by the clearly voracious humanity that has experienced, remembered and shared them all. Alan asks:

“Are people with disabilities that different from any of the other nondescript folks wandering around just like you who you pay no attention to at all?”

“In fact, yes. They’re different from you and me.

“But you’re not supposed to say that in The Land of Disability, where the prevailing motto is ‘They’re just like everyone else.’ So be safe. Stick to the dictum.

“Unless you really, truly, meaningfully want to get to know a few people. And learn how terrifically different they really are.”

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How could one not be amazed by the twist of logic that leads one to reexamine not just disability but, of course, life itself?

For that is surely what this book is all about. We are all residents of DisabilityLand. If we cannot feel comfortable with the differences of others when they are extreme, how can we feel comfortable with the differences when they are subtler?

Life is about difference. It is about being one of six and a half billion people. About understanding the near infinity of what is possible to do and feel, about experiencing the soaring spirals within which we all come together and then separate again into our own arcs.

Think of it. You are one in six and a half billion. And yet we have the persistent need to feel the acute sense of what it is to be ourselves: an individual. Is it any wonder that so few of us feel truly comfortable within our own skin? Is it any wonder that the journey of life is so daunting until we make the effort to look, with truth and determined honesty, outside of ourselves?

There is no place I would choose to live except in this Land. And to share it with my son, my wife and my daughter. What good fortune to find we have built our home so near one of this Land's great wizards, who has charted this Land so well in the following pages.

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