THE POWER OF DISABILITY

10 LESSONS FOR SURVIVING, THRIVING, AND CHANGING THE WORLD

AL ETMANSKI

Bestselling author of
Impact: Six Patterns to Spread Your Social Innovation

"This book reminds us of what we have in common, the power to create a good life for ourselves and for others no matter what the world has in store for us."

—Michael J. Fox

Praise for *The Power of Disability*

"*The Power of Disability* celebrates the way people with disabilities can change the world—not in spite of their disability but because of it. It spoke deeply to me because I have a disability called depression. I don't know how I came through three major bouts with this mental illness and lived to tell the tale. But I do know this: when you've had such an experience, you want to make meaning of it by sharing hope with others who suffer. This book is filled with the stories of many kinds of 'wounded healers,' told wonderfully well by Al Etmanski. I'm very grateful to the author and all whose stories he tells for reminding me, once again, of the power to be found in the places where we feel most vulnerable."

—Parker J. Palmer, author of *On the Brink of Everything*, *Let Your Life Speak*, and *Healing the Heart of Democracy*

"This book challenges the dominant discourse that persons with disabilities are incapable by focusing on their collective achievements. It is well researched and full of many moving stories of people who have made a difference despite the structural barriers and inequities they faced."

—Catalina Devandas, UN Special Rapporteur on the Rights of Persons with Disabilities

"In a world defined by accelerating change and interconnection, those who recognize their differences and give themselves permission to make a difference have a powerful advantage. The stories in this book illustrate how people with disabilities are seizing their power. They will help all of us see and seize ours."

—Bill Drayton, CEO, Ashoka

"This is a landmark book. It opens the door to a vibrant world we hardly know and seldom think about—the world of disability—and reveals disability to be the invisible force that has shaped the world. Yes, there is power in disability. There is also wisdom, passion, and practical advice for navigating the turbulent times we live in. *The Power of Disability* is an instruction manual for becoming truly human and a manifesto for transcending all our differences and creating a world where everyone thrives. The stories are readable and highly compelling, suitable for young and old. There should be copies in every school and business on the planet."

—Caroline Casey, founder of The Valuable 500, disability activist, inclusion advocate

"I know Al from two contexts: as a thinking partner for our overlapping work on social change and as a family friend when my beautiful grandson Sinai was born with Down syndrome. This brilliant book shows us Al at his best: incisive, humble, loving, tenacious, practical. He helps us all recognize and reach for what is best in the world."

—Adam Kahane, Director, Reos Partners, and author of *Collaborating with the Enemy* and *Power and Love*

"This book is a who's who of fascinating people who say adapting to disability—their own or that of a loved one—is a wellspring of their creativity and ability to think flexibly. It will change the way you see the world."

—Louise Kinross, *BLOOM* Editor and Special Projects Manager, Holland Bloorview Kids Rehabilitation Hospital

"*The Power of Disability* invites us to examine how the lives of people with disabilities can and should be more integrated into the regular flow of society. The book is informative and introduces practical ways for us to engage in conversation about disability in ways that bring us all together as humans. It's a one-of-a-kind read."

—Steve Hanamura, President, Hanamura Consulting

"Al Etmanski is a master storyteller. This book is fun to read, inspiring, and filled with a remarkable wisdom for everyday life. Reading it will make you a better caregiver and a better leader and most importantly will compel you to be a better person."

—Paul Born, Co-CEO, Tamarack Institute

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Berrett-Koehler Publishers, Inc.
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To Anderson

Preface

THERE IS A pretty good chance you are directly or indirectly connected to the power of disability. The majority of people are. For starters, one-seventh of the people on the planet have a disability, which makes people with disabilities the largest minority group in the world. When you factor in their family, friends, and allies, which I conservatively estimate as another three in seven, the disability community comprises four-sevenths of the world's population.

What you might not know is the full extent of the collective achievement of people with disabilities.

That's because the history books have largely ignored them, aside from notable exceptions like Beethoven, Helen Keller, Stephen Hawking, and Temple Grandin. Or credit has been given to someone else. That's why I have written this book. The time has come to recognize people with disabilities for who they really are: authoritative sources on creativity, resilience, love, resistance, dealing with adversity, and living a good life.

As you are about to read, people with disabilities have been instrumental in the growth of freedom and the birth of democracy. They have produced heavenly music and exquisite works of art. They have delighted children and the young at heart with some of the most popular stories ever written. They have made us laugh, touched our souls, and taught us how to love. They have unveiled the secrets of the universe. And they have been on the front lines fighting for justice.

They are still doing all those things and more.

This book has two audiences. The first is those who haven't given people with disability much thought, other than to be inspired by the occasional feel-good story. Before my daughter Liz was born with her disability, I was in this category. I would like this book to enrich your life the way the disability community has enriched mine.

The second audience is people in the disability community. I would like this book to bring us together and to make disability a greater force to be reckoned with.

The Power of Disability is designed to be a source of everyday wisdom for the everyday reader. Each of the ten lessons in the book has a short explanation of why I chose it, followed by multiple real-life stories, many of them about people you know. These are sprinkled with quotations and “Did You Know . . .” facts. Each profile is a bite-sized chunk of a well-rounded and fascinating life.

My hope is that after reading this book, you will help rewrite history and change the conversation about disability.

INTRODUCTION

The Disability Advantage

The world is like a big round ball.
What bounces the world?
—LIZ ETMANSKI

THIS ISN'T REALLY a book about disability. It's a book about life: Where it comes from. How to live it. Savor it. Celebrate it. And make it better. It contains a treasure chest of good judgment, clear thinking, and street smarts that can help you survive and thrive whatever your trials and tribulations—and, if necessary, change the conditions that created them. The big difference between this book and other social-change, management, and self-help books is that the stories and lessons come from an untapped and underappreciated source, people in the disability community. Here is one of my lessons:

If I could have stopped it, I would have.

She strode onto the stage as cool as a cucumber. Without notes. Without preparation. Seemingly without a care.

A hundred pairs of eyes were watching and waiting.

A recipe for disaster.

A disaster I had tried to prevent from the moment she was born.

It was the scene of my undoing.

"Hey, everybody. Before I begin, I'd like to tell you a little about myself. My name is Liz. I'm an artist, a poet, and I have Down syndrome. What that means is that it takes me a little longer to learn some things. Sometimes.

"OK . . . enough about me."

She snapped her fingers.

The jazz guitarist who sat behind her picked up the beat.

She began, snatching from her memory words and fragments of conversation she had absorbed throughout the conference. She served them back as spoken word poetry. The crowd cheered in recognition. She beamed.

Her confidence shook me open, exposing my lack of confidence. Was it in my daughter's ability to live up to my idea of her? Or worse—in the daughter I had? This daughter who swaggered. Whose taste in clothes, tattoos, and men I hadn't always liked. Who lived by herself in a place that could have been a lot cleaner, with a closet she turned into a studio. And who was more than getting by. Without me. Despite me.

What was I supposed to do now?

I spent many hours when Liz was first born searching for a cure for Down syndrome. I read an article by a doctor who claimed that Down syndrome could be cured with megavitamins. I wanted the formula. I wrote him letters (these were the pre-internet days), tracking him throughout the Midwest to New York, then across the ocean to Glasgow and finally to Stockholm, where his trail evaporated, along with his credentials and my hope in miracles.

After that, I became a zealot for anything that would help Liz fit in. I reasoned that the more she looked and acted like everybody else, the easier her life would be. I bought her expensive clothing with designer labels—anything that would make her acceptable to her peers. I was trying to make her normal, something I had never considered necessary for my other children.

I suppose some good can come from searching for a cure. But not if you miss the true miracle of becoming—of becoming who you are, not someone else's version. Some good can probably come from conforming in some things and at some times. But not if it distracts a dad from the blossoming of his daughter's character.

Since then, I've asked myself why I thought my beautiful and precious baby daughter needed to be fixed. Part of the answer is personal. I was a driven idealist who pursued perfection at all costs in my personal and work lives. I strived to be strong in everything I did. I was impatient if others didn't measure up. To be blunt, I was indifferent to people with disabilities, although I didn't mind helping out those I met. I couldn't understand why some of my university classmates were so keen to pursue a career in the disability field. I wince when I think of the hard-hearted person I was back then.

I have also come to appreciate that I was under the influence of inaccurate stereotypes about people with disabilities. You are probably familiar with some of them: People with disabilities as childish innocents and eternal children, or endowed with superpowers sent to save and amaze us. People with disabilities as Frankenstein-like menaces, unlovable and dangerous, best kept separate from society for their safety and ours. I'm guessing you can think of movies and pictures that reinforce these stereotypes. The doctor who delivered Liz and who told Liz's mom and me that he had bad news for us was under the same influence. So were the nurses and social workers at the hospital who asked us whether we would be bringing her home with us or giving her up to foster care. Imagine asking new parents such a question. Sadly, it still happens.

Even though the representation is getting better, it is still uneven. I recall when Kevin McHale, who played the character Artie Abrams in the television show *Glee* got up from his wheelchair in a dream sequence and began to dance. I was so disappointed. That would not have happened if the actor had actually used a wheelchair. We lost a chance to be introduced to the elegance of wheelchair dancing and were left with the mistaken impression that every person with a disability dreams of not being disabled. By contrast, Lauren Potter played her *Glee* character, the cheerleader Becky Jackson, in a feisty and convincing way. Without doubt that's because both she and her character experienced Down syndrome.

After Liz was born, I became a full-time disability advocate. I used my community-organizing skills to help close institutions and segregated schools for people with developmental disabilities. We blocked roads and took government to court. We also used the courts to establish the right of people with severe disabilities to receive medical treatment. I learned that broad-based coalitions that attracted public support were necessary to get politicians to make bold political decisions. Some of my other involvements include establishing one of the world's first Family Support Institutes for parents of children with disabilities and securing the funds for a five-year national dialogue on redefining citizenship from the perspective of people with disabilities.

In 1989, my wife, Vickie Cammack, and I cofounded Planned Lifetime Advocacy Network (PLAN) to help families answer the question: What happens to their sons and daughters with a disability when the parents die? PLAN does this by creating networks of friends and by developing wills, trusts, and estate plans that protect the wealth of people with disabilities from government encroachment. The PLAN model has spread to more than forty locations around the world. While at PLAN, I proposed and led an antipoverty campaign to create the world's first savings plan for people with disabilities. The collective individual deposits now total more than $4 billion. They can be used on whatever the person wants and can't be clawed back by the government.

Along the way, I began collecting stories, articles, and anecdotes about people with disabilities—anything that would help me understand the daughter I was getting to know and the disability movement that had welcomed me. I found gems of insight in the usual places—newspapers, magazines, books, movies, and television. Nowadays I also find them in blogs, podcasts, YouTube videos, TED Talks, concerts, sporting events, art galleries, songs, Instagram, and Twitter. They were everywhere, once I started looking.

I discovered that people with disabilities have been major players throughout history. If you were to take away their contributions, you wouldn't recognize the world. It would be a much different place and in much rougher shape, even though the history books have missed most of these achievements or have given credit to someone else. I also discovered a debt unpaid. People with disabilities have given the world far more than the world has given them. They have made their contributions throughout history while contending with mistreatment, neglect, and terrible atrocities. They have had to fight for every ounce of support and opportunity in order to survive, let alone thrive and change the world. That's at the best of times. At the worst of times, people with disabilities have been sterilized, locked up, and killed. Few people realize that the Nazis practiced their mass killing methods on people with disabilities first.

The good news is that the golden age of the disability movement is approaching. And it couldn't come soon enough, because the advantages that people with a disability offer, and there are many, are the perfect remedy for the troubled times we live in. The movement includes people whose disability is related to their mobility, mental health, sight, hearing, flexibility, memory, or intellectual development. I describe this in more detail in "A Word about Words." It also includes their partners, lovers, friends, and family members, particularly their parents. Although it is not always the case, most adults with disabilities appreciated their parents' advocacy on their behalf when they were younger. Later in life, as Liz taught me, not so much. Finally, the disability movement includes professional allies such as teachers, therapists, doctors, and service providers as well as champions from government and business.