

∞ 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 for people with developmental disabilities and segregated schools. 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 under-

stand 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 them 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.

This book focuses on five powerful disability advantages.

☞ **The Power of Majority**

One in seven individuals worldwide has a disability. At 1.2 billion, that makes them the largest minority group on the planet. That's the population of China and almost four times the population of North America. Another three in seven are their families, friends, and allies. In total, four in seven people in the world have a connection to disability. That's a potent majority. Those kinds of numbers translate into an audience, a base, and a market that's too large to ignore and just waiting to be mobilized, especially since it represents \$8 trillion in annual disposable income.¹ By comparison, the much-sought-after teen market is relatively small at \$220 billion.²

☞ **The Power of Inclusivity**

The disability world intersects with every gender, race, ethnicity, color, creed, class, sexual orientation, income level, health condition, living arrangement, and age group. This predisposes people in the disability world to understand difference as a natural fact of life to be welcomed and celebrated, not curtailed or cured. This sensitivity enlarges and enlightens. It encourages us to focus on a person's contributions rather than his or her condition, limitation, or identity.

☞ **The Power of Ingenuity**

There is no group in history with more consistent experience at making their mark, despite the deck being stacked against them, than people with disabilities. People with disabilities wake up every day to a world not designed for them. They are constantly inventing themselves out of adverse circumstances. They are the original hackers. Many of the innovations we take for granted were solutions to challenges they faced that went on to benefit the wider population. The bicycle, the typewriter, and curb cuts are three examples. There is nothing like a dash of disability to increase your ingenuity and resilience, and to help you deal with the inevitable hiccups and setbacks that accompany everyone's life.

☞ The Power of Authenticity

Our culture is inexhaustible in its capacity to ignore our reliance on others. It promotes the myth of individualism, independence, invincibility. Problems are sanitized, simplified, and easily resolved if we just have the right attitude or if we find the right savior. More and more of us are rejecting that view of the world. We want hope that is qualified by authenticity, and we are looking for stories that we can relate to. The fact is that more and more people are struggling to get by or are worried about the future, and we expect to see that reality reflected in our leadership, media, stories, and social movements. The disability movement offers a refreshing alternative to the lone hero, usually a man, overcoming overwhelming odds. It reminds us that justice emerges from the bottom up, not the top down, and always in the company of so-called ordinary people who disrupt the status quo in big and small ways.

☞ The Power of Unity

The ultimate power of disability is as a unifying force. We live in tumultuous times, with the world increasingly fractured and polarized. People want to know they are not alone, that they can be part of something bigger than themselves. The disability community has the power to bridge our divides and bring us together. After all, disability is the world's most common condition. It encompasses diversity, exudes ingenuity and authenticity, and is in the majority! That's an unrivaled combination and force for change.



I've written this book for three reasons. First, I want to change the popular story about disability because too much of it remains shrouded in myth and misunderstanding. I want to do that by correcting what history and media have overlooked and by giving credit where credit is due.

Second, I want to connect the dots and introduce you to a culture as rich as any religion, philosophy, or self-help movement. Actually, I want to connect the polka dots. I do that to honor Japanese artist Yayoi

Kusama, who is known as the “priestess of polka dots.” She is considered the most popular artist in the world today, based on gallery and museum attendance, although she was ignored for decades.³ During the 1960s, she was part of New York’s avant-garde art scene and became friends with Andy Warhol. Georgia O’Keeffe was her business adviser. In the early seventies, she returned to Tokyo and became a voluntary patient in a Tokyo psychiatric institution to help her deal with the obsessive images that have pursued her since childhood. She still lives there. I don’t want to romanticize the challenges that Kusama had to deal with in order to return to megastar prominence. I do want to validate her experience and to learn from her and many others who have been touched directly or indirectly by disability.

Third, I’d like this book to contribute to the grand awakening that is underway within the disability movement. In my last book, *Impact: Six Patterns to Spread Your Social Innovation*, I concluded that for social change to have lasting impact, it’s important to link everyone’s actions, big and small, and to get as many people moving in the same direction as possible. People with disabilities shouldn’t have to carry the full weight of removing the barriers to their full participation in society—barriers like poverty, inaccessible buildings, inadequate health care, and job discrimination. No amount of positive thinking by individuals will fix those big problems. They are do-it-together, not do-it-yourself, projects.



The following pages will introduce you to funny, talented, loving, wise, inventive, and artistic people—proof that human ability knows no boundaries when the boundaries are removed and the opportunities to make a difference are available. Like the rest of us, they haven’t figured everything out, although the bits they have figured out are impressive. Otherwise, their lives are as messy and full of doubts, failures, and contradictions as those of the rest of us.

Some are lucky in love, some aren't. They worry about getting a job, what will happen to their kids, what people think about them, and lots of other big and little things. Their opinions differ on what to do about climate change, the economy, divisive politics, and a host of other matters. Some vote one way. Some vote another. Some don't vote at all.

You will recognize many of the celebrities and personalities who are profiled in this book, although you may not be familiar with the parts of their lives that I will share, perhaps even their connection to the world of disability. They include Michael J. Fox, Helen Keller, Stephen Hawking, Temple Grandin, Abraham Lincoln, Stevie Wonder, and the Swedish schoolgirl Greta Thunberg. As I was finishing this book, Thunberg had just made the cover of *Time* magazine for encouraging students around the world to go on strike to raise awareness about our climate crisis.⁴ On the other hand, you may not know about the relationship between singer Joni Mitchell and jazz legend Charles Mingus after he was diagnosed with ALS. Or about the influence of author Bonnie Klein on her daughter Naomi Klein's activism. Or about rocker Neil Young's lifelong and multiple experiences with disability. Or the reason Anna Sewell wrote *Black Beauty*. Or why Richard Branson, the founder of the Virgin Group, has just joined forces with Caroline Casey, the first woman from the West to ride an elephant across India by herself.

I will also introduce you to people you will want to know more about. People like classical musician Evelyn Glennie, who is the world's first full-time solo percussionist. Glennie is deaf, plays in her bare feet in order to "hear," and is on a mission to teach the world how to listen. Then there is Chinese poet Yu Xiuhua, who is considered the Emily Dickinson of China. Her poem "Crossing Half of China to Sleep with You" has been read by millions and has made her the voice of feminism in her country. And Jean Vanier, who gave up a life of privilege to launch a worldwide movement of compassion. He is hailed as one of the world's greatest "spiritual entrepreneurs," in the same company as Billy Graham, Mother Teresa, and the Dalai Lama. And Alice Wong, the

writer and media maker who is reinventing activism for the twenty-first century. And Robert Munsch, who wrote Oprah's favorite children's story, "Love You Forever." And Pearl S. Buck, the first American woman to win the Nobel Prize and who changed the course of history by writing openly about her daughter Carol, who had a disability, and why she defied the advice of doctors to place her in an institution and forget about her. I will also profile several people who can spice up your love life.

Whether or not their stories and experiences are recognizable, you will have no trouble relating to them and applying their insights to your everyday life and work.

There are many ways to receive an education in the world. The experience of disability is definitely one of them. *The Power of Disability* distills that wisdom into ten lessons. The lessons blend, overlap, and reinforce each other, as all good lessons do. I didn't invent these lessons. They emerged from what I observed over four decades of activism in the disability movement.

As for Liz, she continues to paint, write and perform poetry, and teach art. She's also in demand as a graphic recorder, whereby she captures the proceedings of meetings and conferences by drawing on big sheets of paper fastened to the wall. Recently she landed a small role in a new Apple TV series. Her force of character has been strong enough for her to eject herself from my orbit and attract a network of family members, friends, and supporters into her own. She continues to grow in confidence. Sometimes I think I can see it expanding right in front of me. She thinks Down syndrome is "so radiant." It is both no big deal and the real deal to her. I have learned that there is a big difference between sameness and acceptance. It's pretty clear that Liz never did need fixing. Her difference simply needed a home.

Perhaps that's the power and meaning behind Yayoi Kusama's obsession with polka dots. Polka dots are like people, she says: They can't stay alone. It's in their nature to come together, and to find their place in the universe.

May the following pages help you find yours.