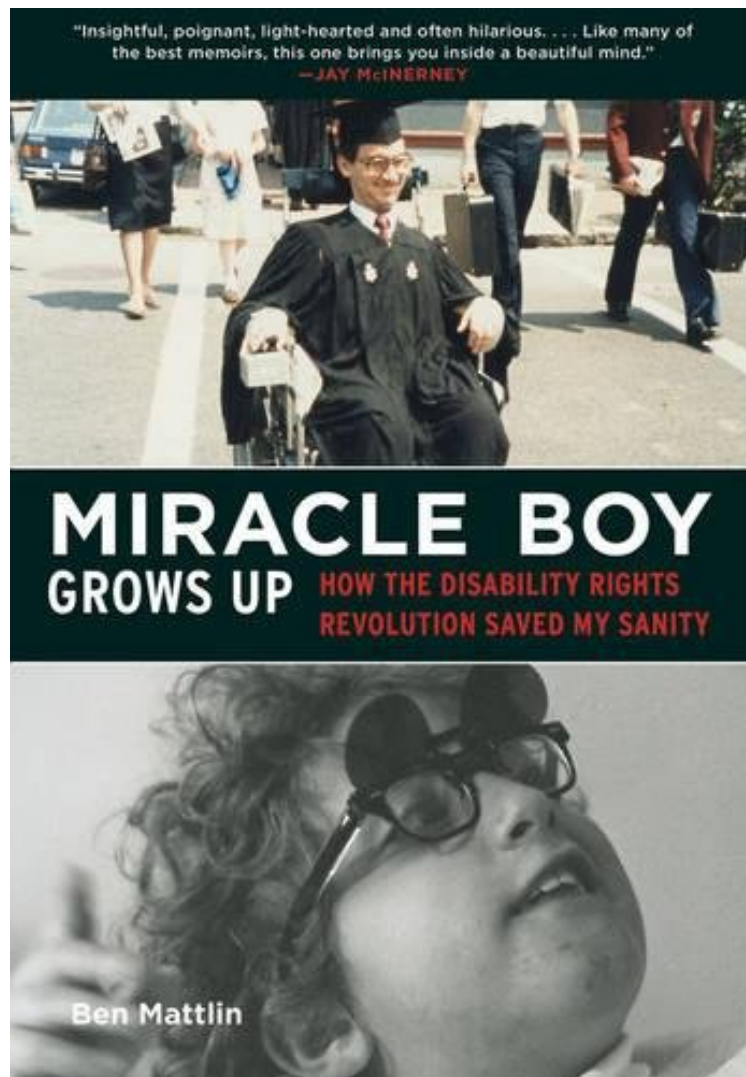


[Ebook free] Miracle Boy Grows Up: How the Disability Rights Revolution Saved My Sanity

Miracle Boy Grows Up: How the Disability Rights Revolution Saved My Sanity

Ben Mattlin

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Ben Mattlin : Miracle Boy Grows Up: How the Disability Rights Revolution Saved My Sanity before purchasing it in order to gauge whether or not it would be worth my time, and all praised *Miracle Boy Grows Up: How the Disability Rights Revolution Saved My Sanity*:

40 of 40 people found the following review helpful. Gives knowledge and hope to those who read it By Emery JI came across Mattlin as I was desperately searching for information on "mixed ability" relationships. My partner has SMA and has since a child and I am able-bodied (or TAB). I was worried about whether or not we could make it work,

whether I would be able to handle it; the list of worries go on and on...This book eased my worries, but also gave me more than just information on mixed ability relationships. The historical research and presentation about the disability rights movement fostered my interest in disability advocacy and gave me a thorough background of the movement. Mattlin's story is about him growing up and, like I said, the disability rights movement. He shares the challenges that he faced in a time where people with differing abilities from the mass culture were still stigmatized and discriminated against. Throughout the book, both the readers and Mattlin learn just how lucky he was to come from the background he did. A few times, he gets a glimpse into the world of other disabled people at hospitals, rehabilitation centers, camps, etc...He discovers that not all of them have parents who advocate or even want them. You learn of the case of "Baby Doe"--two parents were allowed to starve their child to death because it had a disability. Luckily for readers and for Mattlin, that did not happen to him. There are now legal protections against this, but there is still a cultural battle against prenatal testing and the ability to abort a child simply on the fact that they will be disabled (I go back and forth on this as an extremely pro-choice person). For someone who didn't really know much about the disability rights movement aside from the ADA, Mattlin provides a great explanation of what happened, when it happened, and the context in which it happened. The other facet of his story is about his personal life, which for my purposes, was initially more important (this is now not the case. I love everything about the book!). A stone is not left untouched; Mattlin discusses his childhood background, his Big Deal (the spinal fusion he received), his parents' divorce, going to Harvard, his mother's struggle with ovarian cancer, struggling to find work and trustworthy caretakers, his personal life with his wife, and much more. From the sections about his wife, I learned about how his family made/makes it work--I now know that there is an example out there! Mattlin says towards the end of his book that he wanted ML, his wife, to preview the book and correct him if he was wrong about her perspective--she declined. I so wish that I could hear her side of the story, too. It would be interesting to see how they both reflect back on their life together. Overall, a fantastic book. Mattlin's voice, yes he found it, makes you want to keep reading it (half a day, one sitting for me). His educated research doesn't give you that feeling that most autobiographies give you, that feeling that they just sat there and made up a bunch of shit for it to sell. You get the feeling that he's talking to you and trying to convey important messages. But you'll have to read it to find out what they are! :) 20 of 20 people found the following review helpful. Illuminating, Humorous, Powerful Autobiography By Patrick B. Marren Ben Mattlin is a professional journalist, a Harvard graduate, husband to an attractive accomplished woman, and father to two daughters, and he lives in Los Angeles. So by any reasonable standard, he is a disgustingly accomplished human being with a pretty sweet existence. Far worse, he has accomplished all this without ever taking a step. He complains about being seen as a heartwarming inspirational story by people who don't know him, but if you ask me, he need not worry. To be frank, his story made me wonder what the hell is wrong with ME and what I have been doing with my own life. Tip: Don't let your spouse read this unless you want him/her to start looking askance at you 24/7 with a gaze that clearly says, "Why are you on that couch watching Dog the Bounty Hunter when you could be running down freelance work or publishing an extremely flattering portrait of me?" All right, now to be serious about this very, very good book. "Miracle Boy Grows Up: How the Disability Rights Revolution Saved My Sanity" is a revelatory account of the author's life (to date) against the broader background of the revolution in recognition of disability rights in the United States. If you are like me, you will have had very little previous consciousness of this neglected movement, which has been quite comparable in scale and significance to the other great civil rights struggles of the past century. (We've all heard of Martin Luther King and Gloria Steinem; until this book, I had never heard of Ed Roberts or the Rolling Quads.) 51 million Americans have some sort of disability; as Mattlin notes, each of us is merely temporarily ambulatory. Decades of agitation and demands by courageous people with disabilities simply to be recognized for what they are -- fully human beings deserving of respect and all the rights and opportunities any American citizen should expect as a matter of course -- have changed this country for the better, allowing it to tap the potential and energies of this extremely large segment of the population. More important, like its predecessors and other contemporary civil rights movements, it has brought this country and all of us just a little closer to our founding ideals of equal justice under law, and universal opportunity for life, liberty, and pursuit of happiness. But the account of the civil rights struggle hardly dominates the book, nor is that what makes it truly memorable. It's Mattlin's unsentimental straightforwardness and unsparing honesty about himself and the everyday material facts of his existence that lends this book its power and, occasionally, its deep humor. Everything he has accomplished has been made more difficult by his disability; but that disability seems to have been more than offset by a singular ability: an uncommon level of personal determination and a steadfast refusal to be put off by obstacles that would almost certainly deter most "normal" people. Yet as "Miracle Boy" has grown older and his physical abilities, like a lot of ours, have very gradually degraded, his perspective on the world in general and his fellow people with disabilities in particular has broadened, and his ability to be introspective about himself has deepened, to the great benefit of his readers. He'll never be a fireman. But he's a heck of a writer. Read this book; you'll think, you'll feel, and you may even learn something. But for Ben's sake, try not to be inspired...and try not to be too jealous. 24 of 24 people found the following review helpful. It's hard to be a superhero in a wheelchair By Paul A Matson As a kid, Ben loved physically invincible superheroes, but being born with spinal muscular atrophy put a crimp in that as a career plan. That's what the book is

about. Written in a warm and funny style, Ben talks about the situations created by his health, his interactions with those more ambulatory (but less funny) than himself, and the obstructing curbstones of love and parenthood that we all might face. I'd recommend this book to those who: 1. know someone in a wheelchair, but don't know how to act around that person 2. have an interest in disability rights 3. are ambulatory, for now anyway

"An insightful, poignant, light-hearted and often hilarious memoir" (Jay McInerney). Ben Mattlin lives a normal, independent life. Why is that interesting? Because Mattlin was born with spinal muscular atrophy, a congenital muscle weakness from which he was expected to die in childhood. Not only did Mattlin survive, he became one of the first students in a wheelchair to attend Harvard, from which he graduated and became a professional writer. His advantage? Mattlin's life happened to parallel the growth of the disability rights movement, so that in many ways he did not feel he was disadvantaged at all, merely different.

"In *Miracle Boy*, Ben Mattlin pulls off a nearly miraculous feat: creating an insightful, poignant, light-hearted and often hilarious memoir about life as a paraplegic. Mattlin's resilience, his curiosity, and his steadfast refusal to see himself as a victim are inspiring; his prose is deft, wry and self-aware. Like many of the best memoirs, this one brings you inside a beautiful mind." - Jay McInerney "Fantastic! Funny ... interesting ... beautifully done!" - Jolie Mason, "Access Unlimited," KPFK radio, March 13, 2013 "Quite delicious ... Mattlin's timing is perfect, never over-analyzing or dwelling too long on any one subject. ... A compelling writer... poetic without being sentimental." - Roxanne Furlong, *New Mobility* magazine, January 2013 "Ben Mattlin could be called many things: Iconoclast, sidesplitting, and wise, among them. In *Miracle Boy Grows Up*, Mattlin demonstrates perhaps his greatest skill--as a master storyteller." - Lawrence Carter-Long, National Council on Disability "In *Miracle Boy Grows Up*, Ben Mattlin spins the limitations of his genetic disease into literary gold. He tells his story with grace and candor, each beautifully crafted sentence illuminating not only his rich inner life but also the complex history of the disability rights movement." - Hamilton Cain, Author of *This Boy's Faith* "Mattlin tells the fascinating twin stories of his own life and the history of the disability rights movement. ... Deeply intelligent, utterly honest, funny, irritable, raunchy, companionable ... it is a love story, the story of a son, a father, and writer. This book is a pleasure." - Elizabeth McCracken "Mattlin is candid about his challenges (e.g., finding a job, hiring attendants) but he isn't looking for pity, just understanding. ... Those who do pick up this memoir will find a unique perspective that compares with Harriet McBryde Johnson's *Too Late to Die Young*." --Library Journal "Born with a severe neuromuscular condition, writer and NPR commentator Mattlin pens the story of his life so far... While most people with this illness are unlikely to live to adulthood, Mattlin's story is filled with details of how he managed to beat the odds." - Kirkus sAbout the Author Ben Mattlin was born in New York in 1962 with spinal muscular atrophy, a congenital neuromuscular weakness. He graduated from Harvard in 1984 and became a freelance writer. He's a frequent contributor to *Financial Advisor* magazine. His essays have appeared in *The New York Times*, *Los Angeles Times*, *Washington Post*, *Chicago Tribune*, and *USA Today*, and been broadcast on NPR's "Morning Edition." He's also written for *Self* magazine and is a former contributing editor at *Institutional Investor*, the late *Windows In Financial Services*, *Dealmaker*, *Buyside*, and *Individual Investor* magazines. He lives in Los Angeles with his wife, two daughters, a cat, and a turtle.