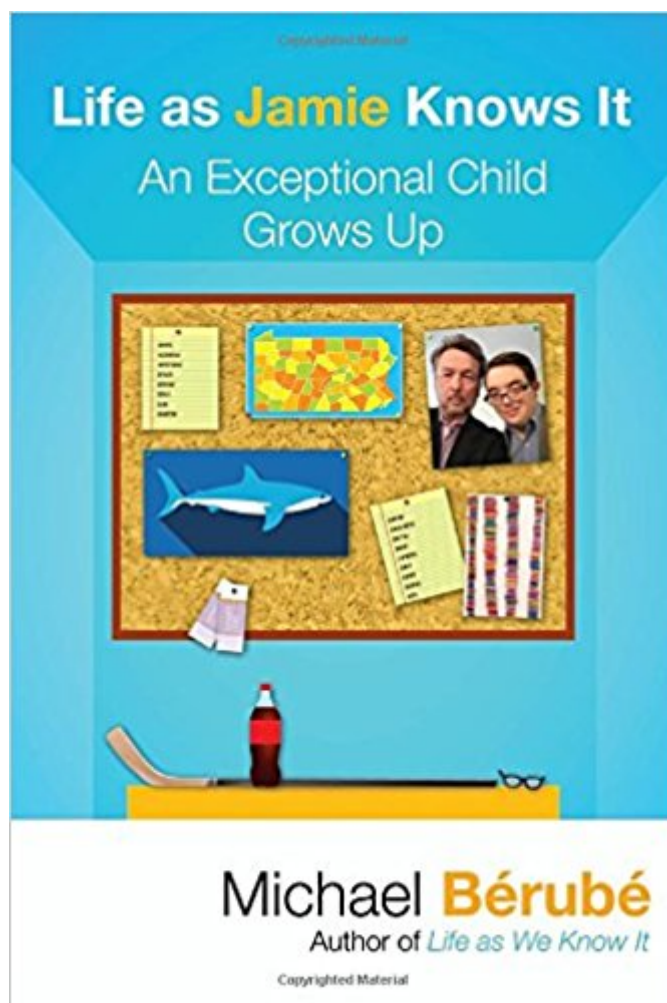


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Life As Jamie Knows It: An Exceptional Child Grows Up



Synopsis

The story of Jamie Rubenstein's journey to adulthood and a meditation on disability in American life. Published in 1996, *Life as We Know It* introduced Jamie Rubenstein to the world as a sweet, bright, gregarious little boy who loves the Beatles, pizza, and making lists. When he is asked in his preschool class what he would like to be when he grows up, he responds with one word: big. At four, he is like many kids his age, but his Down syndrome prevents most people from seeing him as anything but disabled. Twenty years later, Jamie is no longer little, though he still jams to the Beatles, eats pizza, and makes endless lists of everything from the sixty-seven counties of Pennsylvania (in alphabetical order, from memory) to the various opponents of the wrestler known as the Undertaker. In *Life as Jamie Knows It*, Michael Rubenstein chronicles his son's journey to adulthood and his growing curiosity and engagement with the world. Writing as both a disability studies scholar and a father, he follows Jamie through his social and academic experiences in school, his evolving relationships with his parents and brother, Nick, his encounters with illness, and the complexities of entering the workforce with a disability. As Jamie matures, his parents acknowledge his entitlement to a personal sense of independence, whether that means riding the bus home from work on his own, taking himself to a Yankees game, or deciding which parts of his story are solely his to share. With a combination of stirring memoir and sharp intellectual inquiry, Rubenstein tangles with bioethicists, politicians, philosophers, and anyone else who sees disability as an impediment to a life worth living. Far more than the story of an exceptional child growing up to be "big," *Life as Jamie Knows It* challenges us to rethink how we approach disability and is a passionate call for moving toward a more just, more inclusive society.

Book Information

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Customer Reviews

“While the author clearly paints the life of an adult with Down syndrome as one hinging on the compassion and understanding of others, he also paints Jamie’s experience and immersion into the world as a story of triumph, bravery, independence, and great self-awareness. An inspiring family scrapbook offering hopeful reinforcement for parents in similar situations.” • Kirkus Reviews “Bárfá succeeds warmly at humanizing his son.” • Booklist “In brilliantly illuminating prose, Michael Bárfá’s joyful and heartfelt book about his son, Jamie, describes with grace and passion the humanity that we all share, no matter how many chromosomes we possess.” • Marianne Leone, author of *Jesse: A Mother’s Story* “Twenty years after *Life as We Know It* • his groundbreaking memoir of raising a son with Down syndrome • Michael Bárfá’s narrative is loving, unsentimental, and sharply funny, and his insights into disability are unmatched. A necessary book.” • George Estreich, author of *The Shape of the Eye* “In this poignant and genuine collaboration between father and son, Michael Bárfá draws from Jamie’s lived experiences in school, at work, and on the playing field to reflect on the profound philosophical dilemmas surrounding how we measure human worth. Touching and witty without being sentimental, *Life as Jamie Knows It* should be required family reading.” • Rachel Adams, author of *Raising Henry: A Memoir of Motherhood, Disability, and Discovery*

Michael Bárfá is the Edwin Erle Sparks Professor of Literature at Penn State University. The author of ten books, including *The Secret Life of Stories: From Don Quixote to Harry Potter*, *How Understanding Intellectual Disability Transforms the Way We Read*, he lives with his family in State College, Pennsylvania.

A thoroughly delightful and deep reflection on life with a marvelous young man, Jaime. Also a pleasure to read, always full of surprises that shatter stereotypes about people with cognitive

disabilities. Berube has done it again--written the definitive parent-of-a-disabled-(this time adult)-child book.

Professor Michael Berube and his wife, Janet, are both well-known scholars and college professors. Apart from their professional accomplishments, their younger son, Jamie, has Down Syndrome. Michael Berube has become a parent and activist for exceptional children and adults. Jamie Berube is a remarkable young man who happens to have Down Syndrome and the Berubes don't dwell on his situation. In this short book, there are chapters such as "Reintroducing Jamie Berube;" "His Brother's Keeper;" "To His Health;" "Brainstorming;" "On The Fields of Play;" "School/Work;" and "The Meaning of Life." Jamie's life has been blessed with a loving family including an older brother and a support system. For all those who know somebody with Down Syndrome, our lives have been enriched with their presence. Jamie like other exceptional children faced health and social obstacles in life. But Michael and Janet Berube have become exceptional parents as well. This book does go into details about how politics and the current social system fails the exceptional children and adults to become independent as well. Exceptional adults like Jamie should have no problem in becoming independent if they are capable too. This book will teach you the most important lesson about life isn't measured in I.Q. points but how we live our lives and treat people of all walks of life.

In this book Professor Michael Berube discusses his son, Jamie's, coming of age. Jamie has Down Syndrome, and Berube discusses how Jamie, now in his twenties, has met the challenges of growing up. Berube focuses on a variety of topics: health, relationships, sports, school, to talk about the ways a young man with Down Syndrome can thrive. There's a great deal in this book about the topics you would expect in a memoir about parenting adolescents (parental anguish when Jamie and his cousin wanted to take the New York City subway on their own for the first time), along with the some of the more specific challenges their family faces, like making sure Jamie has had appropriate educational and work opportunities. Berube, as an English professor, is also well-versed in disability studies literature, and there is a fair bit of theoretical discussion in this book too. Berube uses the literature to explain why certain programs, approaches, and opportunities are essential to people with Down Syndrome. Overall, this is a smart and interesting book. There are a few things that weren't really of interest to me. It seems like a good portion of this book is devoted to sports, which I found to be a bit dull. I understand that sports are an important bonding point for Jamie and Michael Berube, but this part lost my interest. There's also a bit of a tendency to fall into a "my kid is very exceptional" narrative, which is reasonably common when parents write about their own

children. Overall, though, this is a good book, of interest to those who like family memoirs and those who are interested in disability studies.

Michael Ruben is a scholar of disability studies and father of a young man with Down Syndrome, his son Jamie who is now out of school and trying to make his way in the adult working world. Ruben chronicles the passage of Jamie through school, sports, family life, travel, and becoming independent. In one way, Jamie was lucky to be born to two such academic parents who bring many tools and knowledge into the challenges of raising a disabled child. On the other hand, they have no doubt become more resilient and accomplished as a result of these challenges. Ruben states that he "learned to do stuff I didn't know I was capable of doing." Ruben writes that Jamie is "bright, gregarious, even ebullient in social gatherings". Ruben discusses many aspects of bearing and raising a disabled child, including whether life is worth living with a significant disability. He states that their journey has been more complex and wonderful than they could have dreamed, but he doesn't purport that their choices are the choices all parents should make. He speaks warmly of Special Olympics and their motto that people with intellectual disabilities are "human beings, deserving of love, opportunity and acceptance just as they are." He discusses very bluntly the pressure to terminate pregnancies rather than deal with a disabled child. He also discusses the societal pressure to find a "cure" for Down syndrome. He constantly reminds us that disability is not the same as disease. While diseases may be treated or eradicated, disabilities will continue to exist. Now that Jamie has become a young adult, Ruben has become an advocate for ways to integrate people with disabilities into the community and to find meaningful employment. The final chapter of the book titled "The Meaning of Life" was rather too academic for me, but I appreciated the overall tone of this well written book on an important topic.

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