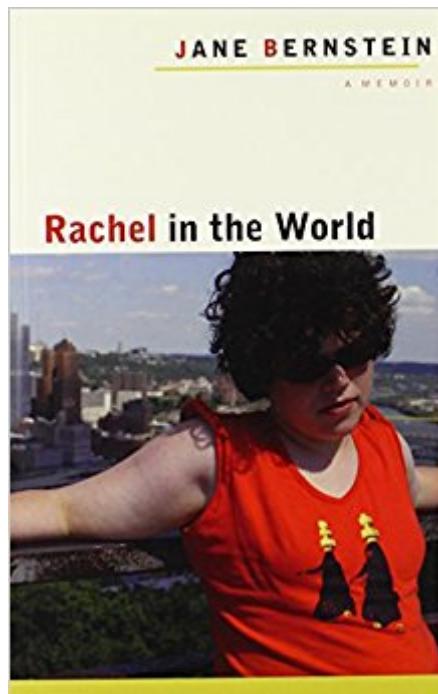


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# Rachel In The World: A Memoir



## Synopsis

What happens when love is no longer enough? Jane Bernstein thought that learning to accept her daughter's disabilities meant her struggles were over. But as Rachel grew up and needed more than a parent's devotion, both mother and daughter were confronted with formidable obstacles. *Rachel in the World*, which begins in Rachel's fifth year and ends when she turns twenty-two, tells of their barriers and successes with the same honesty and humor that made *Loving Rachel*, Bernstein's first memoir, a classic in its field. The linked accounts in part 1 center on family issues, social services, experiences with caregivers, and Rachel herself--difficult, charming, hard to fathom, eager for her own independence. The second part of the book chronicles Bernstein's attempt to find Rachel housing at a time when over 200,000 Americans with mental retardation were on waiting lists for residential services. As Rachel prepares to leave her mother's constant protection, Bernstein invites the reader to share the frustrations and unexpected pleasures of finding a place for her daughter, first in her family, and then in the world.

## Book Information

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## Customer Reviews

"Jane Bernstein's *Rachel in the World* is a remarkable book about tough love--about the many challenges of raising a child with special needs, and about the woeful inadequacy of terms like "special needs." It is a fearlessly honest book about disability and family life, in which children with disabilities are not heaven's special angels, and in which children with disabilities grow up to be adults with disabilities. It is a necessary book, in which parents of children with disabilities worry about the world of social services and group homes

and uncomprehending strangers. And it is a bracing book that reminds us how tough a parent's love can be-- and how the power of love can sustain us in even the toughest times. --Michael B. Rubin --"The battles and triumphs of motherhood are featured in Bernstein's compelling account of life with Rachel. The honesty is apparent, as is the love, the pain, the hope--always the hope." --Eva Feder Kittay, author of *Love's Labor: Essays on Women, Equality, and Dependency* "Refreshingly unsentimental, wrenchingly candid sequel to the author's previous memoir about her developmentally challenged daughter, *Loving Rachel* (1988). . . . A bracing testimony--not at all self-flattering--to parental love and advocacy." --Kirkus, July 15, 2007

What happens when love is no longer enough? Jane Bernstein thought that learning to accept her daughter's disabilities meant her struggles were over. But as Rachel grew up and needed more than a parent's devotion, both mother and daughter were confronted with formidable obstacles. *Rachel in the World*, which begins in Rachel's fifth year and ends when she turns twenty-two, tells of their barriers and successes with the same honesty and humor that made *Loving Rachel*, Bernstein's first memoir, a classic in its field. The linked accounts in part 1 center on family issues, social services, experiences with caregivers, and Rachel herself--difficult, charming, hard to fathom, eager for her own independence. The second part of the book chronicles Bernstein's attempt to find Rachel housing at a time when over 200,000 Americans with mental retardation were on waiting lists for residential services. As Rachel prepares to leave her mother's constant protection, Bernstein invites the reader to share the frustrations and unexpected pleasures of finding a place for her daughter, first in her family, and then in the world.

This book is a gift to the world, especially for those in this world who are doing their best to love and care for and raise a child with "special needs." Jane Bernstein brings her considerable gifts as a writer to the task of sharing her own immense challenges raising her developmentally disabled daughter Rachel. We follow Bernstein's successes and struggles -- at home and within the bureaucratic maze -- from the time Rachel is five until she's in her early twenties, ready to go out "in the world." In the end, Bernstein finds a place for her daughter, and she concludes her beautifully written account on the wings of hope: "My daughter, my Rachel, funny, unruly, mysterious -- she's all grown up now, living and working on her own. As for me, I'm like a giant, unseen bird, circling above her..." I recommend this book to every caring parent -- no, every caring person. -- Bonnie Lee Black, author of *Somewhere Child* and *How to Cook a Crocodile*

I have to admit, I was expecting something a little different from this book. Jane does say in the introduction that this is Rachel's story, not hers. But what I loved most about *LOVING RACHEL* was Jane's perspective--her emotional journey throughout the process of Rachel's diagnosis. In this book, Jane is still the lens through which we see the story, but the focus is definitely on Rachel. That said, this is a very well-written book, and I enjoyed reading about Rachel growing up. I also enjoyed getting to read more about Charlotte, Rachel's older sister. A good friend of mine has a little sister with special needs, and she also had to go through this--getting her sister ready to move out, to be "independent." While my friend's experiences were not exactly the same as Jane and Rachel's, there was an underlying foundation of struggles that they shared. What really impacted me while I was reading was realizing just how constant the battles are for parents of kids with special needs. They don't ever get rest, because the system is constantly changing, which means they have to stay on top of it and make sure their child is getting the best possible care. By the end of the book, I had this mental image of Jane's family--as a boat, a ship, a great ark that is trying to weather a great storm. The boat makes it to shore, but definitely a bit battered. On a personal note, it was interesting to realize that Jane wrote this book while she was my teacher. At some points I could map my relationship with her to the events that were happening in the story. She mentions once feeling like she is doing everything badly--parenting, teaching, writing, living. But I can say this with certainty: she was not teaching badly. She was, from the start, one of the professors that I most enjoyed and admired. Overall a good read, and I am glad that they included pictures. I don't think this book has the universal appeal of *LOVING RACHEL*, but anyone who read that book will want to finish out the story with this one.

Bernstein is honest in this moving portrait of family life. She asks the difficult questions many of us often forget. Families who have children with disabilities face many obstacles in schools, but what happens after graduation? What does that life encompass, and how do mothers and daughters achieve freedom from each other when their lives depend upon this connection and advocacy? Honest, thought-provoking, and real.

I've long been a fan of Bernstein's work, from her novels to her scorchingly brave memoir about her sister's murder, *Bereft*. *Rachel in the World* shows the same kind of bravery. This is no treacly feel-good tome about what it is like to raise a special needs daughter and send her out in the world. Instead, Bernstein shows both her love and her irritation, and her anger at a system that doesn't

exactly make it easy to do what is best for Rachel. Beautifully written and filled with photos that are like prose poems.

I am very pleased. This is a inspiring and humbling book. I would recommend it to all my friends. Very well written too.

I can't say I felt uplifted after reading this memoir, and that is not the point. It's a book that badly needed to be written, about what happens when children with special needs grow up, stop being adorable and need to have a life in the world. Anyone can love almost any small child, regardless of how severe their needs are, but when that small child becomes a teenager, or a young adult, or middle aged, suddenly a lot of that love dries up. It's family who is left with the child's best interests at heart, and this book tells of how hard it was for a family to find the right place for Rachel---who talks non-stop about nothing that is actually going on, who has partial vision, who needs medication, who is unable to fix a meal or take an effective shower or dress properly. I of course thought often during my reading about my own daughter. She is 5 and is autistic. She is of course at this point beautiful, much loved by those who work with her, but already, she can wear us out. Sometimes I dread seeing her get bigger and older, get to the age where people are going to expect her to answer questions, to not cry for hours, to be able to take care of herself. I have the hope every parent has, that these things will come with time, but there is a part of me that does know that's unlikely. However harsh the word sounds, she is retarded, and she will probably stay that way. And the world is not a kind place for children like her when they are no longer children. I am encouraged by the ending of the book, the perfect setting found for Rachel, that is of course not perfect, but I can see how it would feel like it was. I hope the rise in autism will make it necessary for the government to address what exactly will happen to autistic adults when the time for miracles in their life has passed, and they just need to be able to live a decent life. I thank the author for her book.

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