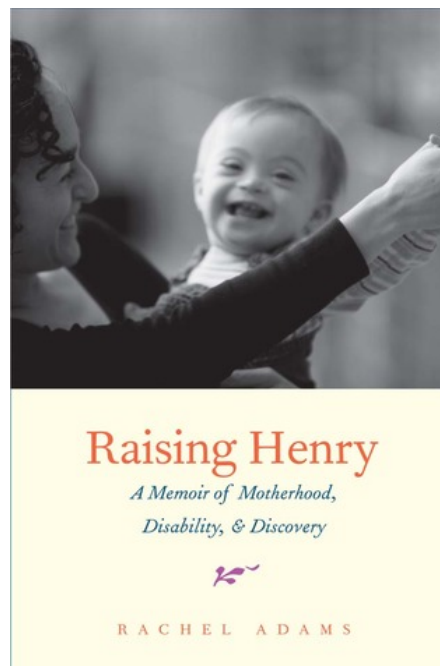




Raising Henry: A Memoir of Motherhood, Disability, and Discovery

Rachel Adams

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Raising Henry: A Memoir of Motherhood, Disability, and Discovery Rachel Adams

Rachel Adams's life had always gone according to plan. She had an adoring husband, a beautiful two-year-old son, a sunny Manhattan apartment, and a position as a tenured professor at Columbia University. Everything changed with the birth of her second child, Henry. Just minutes after he was born, doctors told her that Henry had Down syndrome, and she knew that her life would never be the same.

In this honest, self-critical, and surprisingly funny book, Adams chronicles the first three years of Henry's life and her own transformative experience of unexpectedly becoming the mother of a disabled child. A highly personal story of one family's encounter with disability, *Raising Henry* is also an insightful exploration of today's knotty terrain of social prejudice, disability policy, genetics, prenatal testing, medical training, and inclusive education. Adams untangles the contradictions of living in a society that is more enlightened and supportive of people with disabilities than ever before, yet is racing to perfect prenatal tests to prevent children like Henry from being born. Her book is gripping, beautifully written, and nearly impossible to put down. Once read, her family's story is impossible to forget.

Raising Henry: A Memoir of Motherhood, Disability, and Discovery Details

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Cherie Cawdron says

Enjoyed this book immensely. As the mum of a child with high needs, I could identify with the author's stories and enjoyed her philosophical approach to discovering herself in this role as well.

Clare says

Any book that keeps me up until 2 in the morning on a school night deserves 5 stars. This is the first book since Michael Bérubé's *Life As We Know It* that has really spoken to me about the experience of parenting a child with a disability. It doesn't surprise me that they are friends and colleagues. What I like about it is the author's constant struggle between what she knows and how she feels, what her research tells her, and what her mothering tells her. It's a battle we all wage: When I was pushing for a more inclusive high school experience for my son I questioned myself constantly because I knew the congregated classes would give him a sense of community we'd have to build in other ways. When I let him quit school before he was 21 I worried I was denying him opportunities only school could provide. My own experience and life circumstances are quite different from this author's but I felt a real connection with her struggle against societal norms about which she hadn't given a second thought before her son's birth. Well-written, movingly self-aware, this book is one I will read more than once.

Julie says

I've read a number of reviews of this book where people talk about the author being an academic and the writing style being dry and how it doesn't talk about the child, instead focusing on the mother.

I really liked *Raising Henry*. If you continue reading the title, it says "A Memoir of Motherhood". It doesn't say "Henry's Story" or "My Husband's Experience".

While my child doesn't have Down Syndrome, I completely identified with having to schedule multiple therapists, losing your privacy in your own home to the people coming in and out all day long, the stress of an IEP meeting, doctors looking at your child as an "illness" instead of a child and so much more.

This is a mother's story which resonated deeply with me. If you want more about Down Syndrome, go elsewhere.

Elizabeth Joseph says

I had ignored this digital copy for sometime, but somehow found myself reading this one last day. Surprisingly this was an easy read though the subject is a tough one.

Rachel speaks from the perspective of an academic and so-called modern mother who failed to find out that

her son has Down's syndrome before birth. For some people, Henry is a blessing no matter what, for some people Henry's birth is a mistake that should not have happened. How does a mother feel about it?

I liked this book very much. It is about a modern working mother's struggle to get things going in tough times. It is the story of a mother who is trying to do her best in certain circumstances.

There are lots of things that I could not connect in this book, but this book is worth your time!

Laurie says

Interesting but a little dry for a "memoir." I suppose the fact that the author is a professor and the book is published by a university press should have prepared me, but I wasn't expecting so much exposition on the author's past research (which was on "freaks," so I can't say it was exactly boring), and her current work in disability studies. A lot of the "memoir" part of her son's first three years was about his therapies and education; I didn't get a real feel for her emotions and feelings about Henry himself, only about his education, his opportunities, his future, and how others perceived him. I also didn't get much of a sense of her relationship with her husband or her older son. Perhaps what this book needs is a different subtitle.

* I received an e-galley from the publisher through NetGalley in exchange for an honest review.

Ann says

Perhaps it goes without saying that this book is beautifully written -- Professor Adams is, after all, someone who works with words every day. I thought that this book's particular value was in providing new insights into educational supports and services available to those who qualify for Early intervention (EI). The glimpses into Rachael's too-short relationship with her mother add so much to the book, and the mention of achievement as a measure of not only success but often love in her childhood were nearly as heartbreaking as the glimpses of her mother's life and her passing.

I came away from this book assured that not only will Henry grow up to have a fulfilling, intellectually and emotionally rich life, those around him will value his contributions to the world and will also work to improve the EI system and extended education for young people with intellectual disabilities (transition programs, college participation, community living placements) I hope that there might be a follow-up book in ten or twenty years, as so many of the biographies and autobiographies I have read introduce us to a person at one stage of life, but never return to that same subject later in life.

Nikki says

I was so happy to receive this book as part of a Goodreads First Reads giveaway. Having worked with many children with different abilities for well over a decade I was excited to read this mother's honest, no holds barred account of becoming a parent to gorgeous Henry, a child with Down Syndrome. Rachel Adams does not glamorize; she is open, honest and refreshing, delving into the murky areas many people would hesitate to explore, questioning anything and everything and above all else she is mother - fierce, loyal, and loving.

Adams' writing is intelligent, thought provoking and engaging. I was often moved to tears. We are

wholeheartedly welcomed along on the journey with her and are offered a personal and intimate glimpse into the day to day struggles, accomplishments and the wonderful randomness that is being a parent.

I hope, as his Mother does, that one day Henry will pick up this book and read each and every insightful word. "Raising Henry" is a book that does not focus on limitations, that does not seek sympathy or wallow in what could have been. Instead, Adams' words weave a tapestry of compassion and triumph, of family and fellowship of community, of tribulation and triumph. Ultimately, we learn that living beyond your "limitations" isn't determined by your genetic structure but by determination and by the people who stand behind you through it all.

The End.

Romy Wyllie says

This is a well written book by a professor of English literature. For some readers it may be too academic and too focussed on the author's own experiences as a mother of a child with Down syndrome. From my own experience of having a son with Down syndrome, born in 1959, when there were no early intervention programs, I see a danger in mothers becoming too dependent on the therapists who help their child get started in life. My daughter is an early intervention therapist and she explains that much of her role is helping the parents accept their disabled child and carry on the therapies introduced by specialists. It is especially important to strengthen the relationship of mother and child and, as in our case, integrate the special needs child into regular family life. As a young doctor at a British hospital for the mentally handicapped told us, "Treat your son as much as possible as a normal child."

Christi Benney says

I found this book enlightening. I have helped coach and volunteered to help people with disabilities. However out of that scope are the younger formative years, it was informative to see what tests, programs and therapies were available.

I do wish that there would have been more details and stories of her interaction with Henry and her family. I did feel like there was too much emphasis on her book about freaks. It was as if she were promoting it.

I respected her brutal honesty about her raw emotions and feelings toward Henry. Painful and difficult to read at times, but never being in this position before I can't say how I'd feel.

In sum I would recommend this book if you are hoping for ideas and suggestions of programs that are out there and to know what others have experienced this is a great resource.

Angie Flom says

I received this book through a give-away at goodreads. There was much written that I was not aware of about this disability, which was very interesting. However, I felt that the author focused mostly on herself and her

previous book than her son and how his disability affected the family dynamic. I grew tired of hearing about a more privileged life - she was tired scheduling the appointments that the nanny would take Henry to - and really wanted more raw emotion in this book. That said, I did finish and was more invested in the family by the end.

Alyson Bardsley says

A book designed to share these experiences is a gesture of generosity. That said, one can't generalize much from life on the Upper West Side of Manhattan.

Lise says

As someone who has spent her life with a younger sibling with special needs, and worked with the mentally challenged, including many Down syndrome children, youths and adults, I was particularly intrigued to hear about this book. Rachel Adams is an academic, her husband is a lawyer and when their second child is born their world is thrown into surreal chaos when he is diagnosed as suffering from Down syndrome. Raising Henry is her memoir of the first three years of Henry's life, during which she is forced to navigate the medical, educational and social service worlds in pursuit of the best care for her child. This is a beautiful tale, but also a sad one. A joyous one but also a bitter one. Which is fitting as the experiences she relates run an almost unimaginable gamut. She doesn't just write about her own life, but offers insight into the past treatment children such as Henry would have received. It is chilling to see how recently - the 1970's - the standard advice was: Institutionalize your child. That we have come as far as we have in welcoming children with disabilities into our society, rather than hiding them away, attempting to give them everything they need to be as whole and successful as possible, is heartwarming. But there is still much more to be done, and Rachel Adams shines a light on how one woman can make the difference, and how one little boy can instill such determination, and such love, not only in his mother and father but in everyone who meets him. Adams doesn't shy away from making admissions that may not shine a good light on her. She talks about her own frustrations and reactions. But she also introduces you to a wonderful cast of characters, and some not so wonderful, and you are welcomed into her world by virtue of her honest story. If you do not know anyone who has a child with Down, if you have never contemplated the world and the struggles of the disabled, this book will illuminate so much. And if you do, as I do, then this book will be equally as powerful because you will see yourself in much of Adams' story.

Tornike says

good

Joan Colby says

Thought-provoking memoir by Adams, mother of a child with Down Syndrome. Having given birth to a normal child previously, Adams didn't see the necessity to have amniocentesis so Henry's diagnosis was a surprise. Her expectation of a charmed family life (she is a professor, her husband a professional) was derailed. Rather than mourn, Adams set out to ensure that Henry get the necessary services to attain his

potential. This journey meant that, despite her protestations that “normality” should take precedence, Henry’s needs dominated the family and at times, Adams efforts verged into obsession. I give credit to anyone taking on such a task and while Adams is honest in assessing her emotions, the love she develops for Henry can’t help but influence her viewpoint. Her goal, to change the way the world sees the disabled, is noble; the commitment to making that happen must be overwhelming. The opportunities for Down’s Syndrome people are certainly extended, beyond the bad old days, when most babies born with the Syndrome (then known as Mongolian idiocy) were institutionalized.

Ann says

For me, this was more of a memoir of how a privileged academic lives than how a parent deals with Down's syndrome. There was a fair amount of name dropping and having the nanny take the child to his therapists, and I didn't get a good sense of Henry himself. I am reading around for other Down's accounts now, and so far I enjoyed *_Expecting Adam_* by Martha Beck much more.
