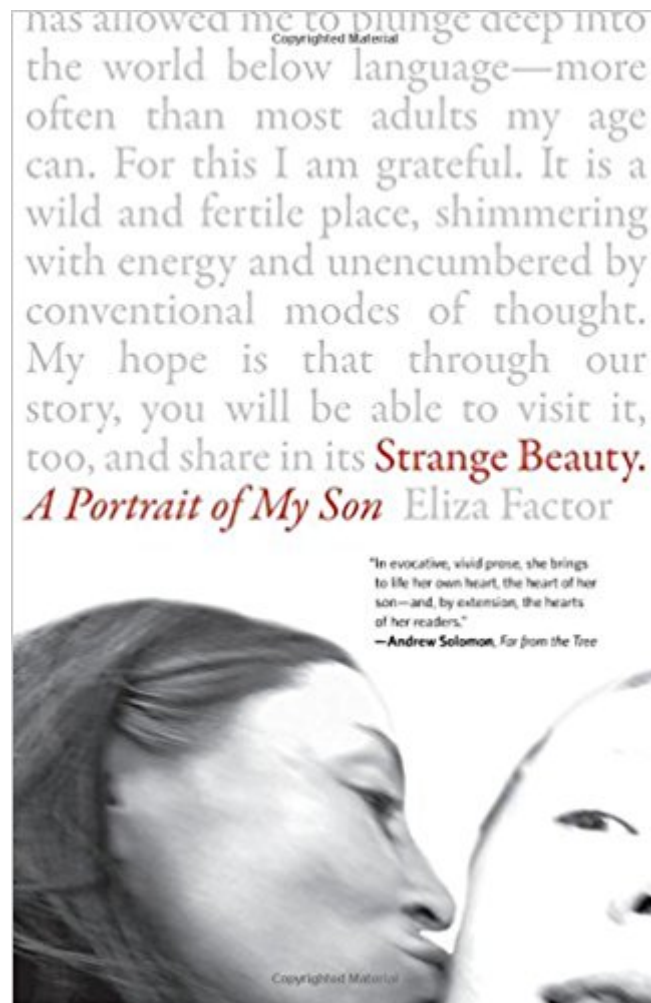




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Strange Beauty: A Portrait Of My Son



Synopsis

A unique and hopeful story of how one woman and her family were transformed by her child's multiple disabilities and inability to talk and how she, in turn, transformed a community. This intimate, "no-holds barred" memoir shares one family's experiences with a child who is both autistic and physically disabled. It is a story of infectious laughter, blood on the floor, intense physical conflict, and of two little girls growing up in the shadow of their charming and fitful brother. And it is the story of a mother and writer and the illuminating effect of imagining the world through the eyes of her beautiful, charismatic, and nonverbal son, Felix. Felix and his sisters inspire Eliza to start Extreme Kids, a community center that connects families with children with disabilities through the arts and play, and transform how she saw herself and the world. She writes of the joy this project brings her, as well as the disconnect of being lauded for helping others at the same time that she cannot help her own son. As Felix grows bigger and stronger, his assaults against himself grow more destructive. When his bruised limbs and face prompt Child Services to investigate the factors for abuse, Eliza realizes how dangerous her home has become. *Strange Beauty* is a personal story, but it shines a light on the combustible conditions many families are living in at this moment. The United States offers parents whose children are prone to violence very little help. That Eliza's story ends happily, with Felix thriving at Crotched Mountain School, is due more to luck than policy. There are few such schools and many such children. When children are violent, we fail to account for the internal and external pressures that lead to violence. This is both cruel and counterproductive, for people with disabilities have much to teach us, if we will only listen.

Book Information

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Customer Reviews

Eliza Factor is author of the acclaimed novels *The Mercury Fountain* and *Love Maps*. Eliza and her husband have three children, the eldest of whom is multiply disabled. She is founder and President of the Board of Extreme Kids & Crew, a non profit community center that connects families with children with disabilities through the arts, music and play in Brooklyn. Factor was named New Yorker of the Week by NY1 in 2012 for creating the city's first drop in sensory playspace for children with disabilities. Eliza Factor lives in Brooklyn with her family.

A beautiful memoir that is simultaneously unvarnished and full of wonder. Ms. Factor has distilled community, love, exhaustion, despair, and hope, and even the mundane tasks of parenthood, to haunting, moving effect. Highly recommended!

No one plans to have a child with disabilities. When Eliza Factor's son began missing developmental milestones and exhibiting atypical behaviors, it dawned on her that his childhood was not going to be like most kids. In her book *Strange Beauty: A Portrait of My Son*, she chronicles the challenges and joys of life with Felix, her oldest child. Felix, who lives with cerebral palsy, autism, and endures self-destructive fits of slapping and hitting himself, has been a puzzle for Factor and her family to unravel. Other parents of children with disabilities will cry and laugh with Factor as she describes the slow realization that Felix has a disability, the mix of pain and pleasure she experienced when a label was finally placed on him, and the challenge of finding the right doctors, specialists, and therapists. Navigating the health care system is tough enough, but when a child has a variety of disabilities, it can be especially tough. She writes, "Even I, in New York, with a good insurance plan, extra money when our insurance plan refused to cooperate, and a flexible schedule, could not perform up to par." I was reminded how thankful I am for my wife who, like Factor, has had to fill out countless forms (repeating the same information about medical history again and again), spent long hours on the phone with insurance companies and social service agencies attempting to get the right care and benefits, and keeping up with the various programs for which our children qualify. One of their great challenges was finding the right educational setting for Felix. After some truly horrible experiences, where the schools had no idea how to handle his dangerous fits, they found some schools that supported him well. They worked with the Department of Education, which of course has bureaucratic challenges galore, but also with private schools, as they have the means

to pay tuition if needed. Yet finding the right fit was still a great challenge. As the book ends, Factor determined that the schools Felix has attended aren't the best place for him, and home school isn't a good option, so she has found a residential school a few hours drive from home. Given the tone of the rest of the book, I was surprised when she even started considering residential placement for Felix. But as she describes the school where he ended up, it sounds like a place where he will thrive. A large part of Factor's story is creating a space where Felix and other kids with disabilities can socialize and play in a setting that suits their unique needs. She created a new organization with play rooms that feature large swings, ball pits, bean bag chairs, and other equipment on which kids with sensory integration issues, mobility issues, autism, and other disabilities and challenges can play, relax, and socialize. In this setting, she has taken the challenges she has faced as a parent and directed her knowledge and energy to enrich other families. I love the idea. It's inspiring and encouraging. (If you're interested, check out extremekidsandcrew.org) Factor doesn't hold much back as she describes her life with Felix. Parents who have children living with disabilities will be encouraged by her steadfastness and her determination to find what is best for Felix and to let her experiences spill over into other families' lives. Thanks to NetGalley and the publisher for the complimentary electronic review copy!

A moving story about a mother and her son, about the different permutations of disability, and about the world beneath language. Factor is a novelist as well, so the writing is very strong.

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