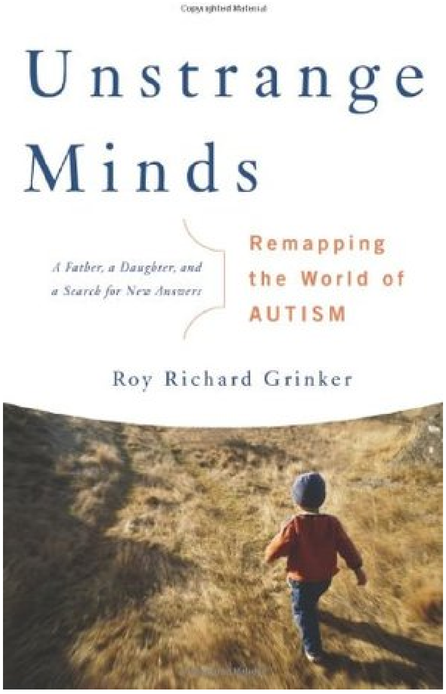

Unstrange Minds: Remapping the World of Autism

Roy Richard Grinker

Unstrange Minds: Remapping the World of Autism

Roy Richard Grinker

Unstrange Minds: Remapping the World of Autism Roy Richard Grinker
Unstrange Minds documents Grinker's quest to find out why autism is so much more common today, and to uncover the implications of the increase. His search took him to Africa, India, and East Asia, to the National Institutes of Mental Health, and to the mountains of Appalachia. What he discovered is both surprising and controversial: There is no true increase in autism. Grinker shows that the identification and treatment of autism depends on culture just as much as on science. As more and more cases of autism are documented, doctors are describing the disorder better, school systems are coding it better--and children are benefiting. Filled with moving stories and informed by the latest science, *Unstrange Minds* is unlike any other book on autism. It is a powerful testament to a father's quest for the truth, and is urgently relevant to anyone whose life is touched by one of history's most puzzling disorders.

Unstrange Minds: Remapping the World of Autism Details

Date	:	Published January 22nd 2007 by Basic Books (first published 2007)
ISBN	:	9780465027637
Author	:	Roy Richard Grinker
Format	:	Hardcover 352 pages
Genre	:	Nonfiction, Psychology, Science, Education, Health

From Reader Review Unstrange Minds: Remapping the World of Autism for online ebook

Jay says

My aspie-self has chosen not to rate this with stars, as I have entered into paradox with my reactions to this book:

I deeply appreciate:
*The deconstruction of the "epidemic" model
*The historical views of psych and autism, in critical dialog
*The cross-cultural research of how societies' treat people labeled (and not labeled) on the autistic spectrum, including frequent reminders that Westernization doesn't equal integration and "less development" doesn't equal not.
*The deep respect and learning of the author from his autistic daughter. I love the stories about her preschool life and love of art.

What bothers me about this book:
*While I appreciate the parental perspective, I would like to hear far more input from adults and children on the spectrum directly.
*The uncritical dismissal, with only one source, of all facilitated communication. The non-cited source chosen highlights a particular example of abuse of facilitated communication, without any acknowledgment that it has been used effectively and been a stepping-stone to independent communication for many autistic and otherwise communication-impaired people. This is particularly striking given the author's careful citation and research on many of his assertions.
*In addition to missing the voices of the community that self-identifies as autistic in dialog with the parental/researcher voices which are primary in this book, Grinker's assertions could have been greatly strengthened by dialog with the disability rights/cultures/independent living movements. In particular, this could be a counterpoint to some of his calls for segregated living as an alternative and viable inclusive model which better mirrors his own experiences.
*Grinker and the other parents make many unquestioned assumptions about the "fates" of their children as lacking independence, both in functioning in the world and in living away from family. Many people all over the autistic spectrum do this, and the IL movement reminds us that "independent" does not necessarily mean without family or other supports.

My reluctance to rate this book comes from my desire to applaud the new direction in moving out of the epidemic framework, but I wish that Grinker would have gone farther into the culture of autistic communities themselves.

Sim says

The worst book on autism I have ever read. Biased, unproven "research", propoganda, and all the way through a sense of deep invalidation of those of us whose children have severe, disabling autism.. autism isn't a tragedy for HIM- HIS child is bilingual, winning awards. How can he possibly represent those of us with profoundly disabled children? How can he be arrogant enough to assume that he possibly could?

Lindsay says

This book has something for almost everyone interested in some aspect of autism: there's a history of the discovery and evolving definition of autism, there's a description of how autism is understood, and what it's like to have a child with autism (i.e., what kind of services are there, is there much social or cultural support for parents, is there much of a stigma, do autistic children have much of a chance at integrating into the larger community as they grow up, etc.), in South Korea, India and South Africa, there are vignettes describing the author's daughter, Isabel, and her development, and her influence on her younger, non-autistic sister, there's a description of the author's battles to get Isabel into the special-education programs he thought were right for her, and there's a discussion of the epidemiology of autism: how we count how many people are autistic, and how those methods have changed over the years to yield different estimates of how common autism is. It's an engaging mix of the technical and the personal, with not only the author's stories of his own life with his daughter but also the stories of mothers and children in each of the countries he visits.

The one thing I found kind of lacking in it was any treatment of "autism from the inside" --- any perspectives from the autistic people themselves. I thought he *described* his daughter with great insight and empathy, and occasionally he lets her speak for herself, but mostly the personal parts of this book are about caring for an autistic child, not *being* one.

I thought the discussion of other cultures was absolutely riveting, though. He tells you all sorts of things you would never have guessed would be true, like that Bruno Bettelheim's outdated, mother-blaming psychoanalytic theory of autism is enjoying a second life overseas after a generation of being repudiated here; or that, in some places (South Korea is where he found this to be true), autistic children in the poorest, smallest, most isolated rural villages do better than their counterparts in even the biggest, richest, most cosmopolitan cities.

There are also a ton of fun and interesting tidbits about the history of psychiatry, which Roy Richard Grinker is particularly well-situated to describe, being the scion of three generations of psychiatrists and psychoanalysts.

Nelia says

Dr. Roy Grinker, himself the father of an autistic daughter, makes a logical and convincing case that we do not have an autism epidemic. The population percentages of autistic people have remained the same, but they are now diagnosed correctly, as our knowledge and recognition of autism has greatly increased in the last 25 years.

Jon says

Written from an anthropological viewpoint. While most books on Autism fall into either the dry textbook category of autism or the weepy emo category, this one strikes a nice balance. By far the best on the subject I've read to date (and I've read a few)

Ariane Zurcher says

Loved this book, an honest look at autism from an anthropological and tempered view, away from the hysteria.

Readyourselfhealthy says

This again is a book that I really wanted to like--it won awards and notice from the academic community and thought to look at autism from an anthropological point of view. The book spends a lot of time initially trying to explain why autism really isn't increasing. And though it does have some valid points, such as the fact that many older people are being diagnosed (having been misdiagnosed with other disorders in the past), there is really no believable way to explain away the fact that autism diagnoses has gone from 1 in 10,000 fifty years ago to 1 in 100. It's ridiculous to even contemplate that this explained away. The author also attempts to look at autism from a historical and anthropological standpoint, but most of the points he raises where first brought up in work by Uta Frith and brings nothing new to the debate. The rest of the book deals with the author's own experiences with an autistic daughter, especially her experiences in the public school system. This part is interesting as it shows the many things that could be encountered in the school setting and offers ideas about how to be well prepared to meet some of these challenges. His daughter was, I believe, able to have some good educational experiences because of her parent's preparation. Ultimately, however, the book is a disappointment. To not acknowledge the fact that we are in a midst of a crisis at this stage in the game is both unhelpful and unrealistic. We need to move forward by not only acknowledging the crisis, but to offer solutions. No longer can we let anyone bury their head in the sand, which is what this author would have us do.

Mark says

This review is going to be a little different from my regular review. Normally, the books I review are all fiction. I should also explain that I have a personal bias towards the subject of autism as my own son has been diagnosed with autism spectrum disorder. (There is a spectrum of autism. On the lower end, you have people who sit in the corner, rocking back and forth, with a vacant stare...never talking, never looking you in the eye. On the higher end, you have relatively normal people who just can't take the hint that you don't care about their World of Warcraft character and that you want them to step away from your desk and go back to managing the company website).

The danger for me in my personal bias is that I'm constantly teetering on the edge of lapsing into a heartfelt blog-style post about my own personal struggles with having a child with autism and calling for increased funding for autism treatments and for group homes and research into autism. Any parent with autism will tell you that their number one concern with their children with autism is: "What's going to happen to my child when I am gone?" I am no exception.

If you're not a parent of a child with autism, or even a parent at all, it may seem that there's not much motivation for you to pick up and read this book. Personally, I think everyone should read it because, chances are, you know someone or are related to someone who is affected on a daily basis by autism. This book will help you understand a little better what's going on with them. What works in this book's favor as far as reeling in potential readers is the author Roy Grinker's economy with words: the book comes in at right around 300 pages (not including references) and that's a relatively quick read for such an important subject.

The book itself is very well written and captured my attention. It is far from a dry treatise on autism and instead puts a human face to this disease. The most interesting aspect of the book is that it analyzes how autism was diagnosed in the past as well as how it is currently being diagnosed around the world.

Grinker first got pulled into the world of autism by having his daughter diagnosed with the condition. He decided to use his profession and personal training, as that of being a Harvard-educated sociologist, to investigate autism.

What he came up with is fascinating to me. The fact that it seems like we have an epidemic of autism all of a sudden here in the United States has a simple explanation: we only recently have achieved an "official" diagnosis for autism with reliable criteria in the scientific/medical community. Autisim used to be diagnosed a myriad of different ways...ranging from mild schizophrenia to "PDD-NOS (Prevasive Developmental Disorder - Not Otherwise Specified)" which sounds like a fancy doctor way of saying "we don't know what the heck is going on with this kid".

Also, you have to count the fact that, until recently (like within the last 10 years), certain parts of the world have been reluctant to "come out of the closet" with their children who have autism and have heretofore been hidden away, because having a kid with any kind of noticeable defect is considered shameful and even contagious in certain parts of the world. And I'm not talking about deepest darkest Africa...I'm talking about highly modern urbanized "First World" areas.

Governments are also slow in acknowledging the existence of autism, preferring to classify these kids as something more manageable. I mean, it's easier to just put the kid in an institution, make sure he doesn't die of starvation or thirst, and just forget about him, right? It's easier to do that than actually try to formulate and perform any kind of therapy to make them self sufficient.

Well...maybe it would be if autism wasn't as prevalent as it actually is. Epidemiology seems to suggest anywhere from 6 in 1000 to 1 in 100 kids are born with some kind of autism. Therefore, it becomes in our best interest to help as many of these people become self sufficient as possible.

Grinker starts off the book by telling the reader about his own introduction to autism with the diagnosis of his daughter. He then gives a pretty well written overview of the history of the autism diagnosis and the prevalence and known causes of autism. He does address the vaccination and diet issues but doesn't give them much creedence, saying that the reason there's more diagnoses of autism in kids is because we've only just come up with an official diagnosis for autism as well as accompanying criteria for the diagnosis.

One of the more interesting things I learned from the book is that ultra-low doses of anti-depressants have been effective in treating some of the more disruptive and counter-productive behaviors characterized by autism. I had no idea this was going on, but now that I do, I'll certainly investigate it as a treatment option with my pediatrician when the time comes, but only if there seems to be a need for it.

The subsequent chapters of the book consist of Grinker going around the world and revealing to the reader what autism is like in other cultures and governments. This is where the book really gets personal, with case studies and personal anecdotes of parents of children with autism all over the world. Interspersed in these case studies are episodes with his own child and her autism.

One of the more personally affecting stories to me is the one he told about the South Korean lady with a child with autism. She kept her child hidden away until, finally out of desperation, she began going to the local Methodist church. These Methodist Christians, in stark contrast to the prevailing attitudes, accepted the mother and her child with open arms and without judgement. They even took care of the child with autism, playing with him and working with him while the mother was able to have a much needed break from the public and private pressures of a South Korean woman with a child who has autism. It warmed my heart and brought tears to my eyes to realize that there exists at least one church in this world that gets it. There is a church in this world that lives out what they preach and exercises in practical living what they purport to believe. The woman in question still identifies herself as non-religious and it's a probable certainty that her lack of religion, coupled with the financial pressures of having a child with autism and just life in the big city in general, that she's probably not giving money to this church. However, there they are, doing what Christ would do without any expectation of reward (at least from the mother and her child).

The book ultimately ends with a message of relative hope. There's never been a better time in history to be diagnosed with autism than right now. There's never been a better place to be diagnosed with autism than the USA. If autism is indeed as prevalent as 1 in 100, then it follows that, in a representative government consisting of hundreds of people in power, most of them are (or at least know someone) personally affected by autism on a daily basis. This daily struggle will hopefully translate to more funding for the prevention and treatment of autism, and, God willing, a cure someday. Until then, I and thousands (if not millions) of other families in the world will struggle on out of love and duty to our kids to help them become self sufficient...because what happens to my son after I am gone? I wish that question had a definite and positive answer.

Ross says

I had to read this for class. I found it to be a great guide through the history of autism and provides a good explanation for the present state of diagnosis as well as discussing the effects an autism diagnosis has on the family. It is an excellent read for any parent or family member who may have a child recently diagnosed with autism.

Erin says

Being a Special Education teacher, I read a lot of books about disability and particularly about autism. This is probably the best book about autism that I have read to date.

Roy Richard Grinker's book looks at autism from a variety of angles: historical, international, and personal. This is probably the only book on autism I have read so far that truly discusses how our culture came to know autism as it is today. A truly fascinating read that look at the past, present, and future of autism in our society and around the world.

Even if you've never read another book about autism, even if you know absolutely nothing about autism, I cannot recommend this book highly enough. And if you are lucky enough to have been touched by a person living with autism -- well, all the more reason to read.

Janet Leszl says

The perfect counterpoint to the emotional hysteria propagated by conspiracy theorists that are panicking parents into fear of vaccines inducing autism.

The author is an anthropologist and father of a daughter with autism. At times it is clear he is a professor; particularly in part one. Rational explanations of how individuals in the past would either have no diagnosis or improper ones are presented through his detailed history of the progression of the field of psychiatry. The information is both fascinating and eye opening.

Part two is even more eye opening as he reveals how cultural biases affect diagnosis (or lack thereof) and the quality of life for individuals on the autism spectrum and their families around the globe.

Nancy says

An interesting book on autism that has three threads:

1)A discussion of the changes in definition and regulations surrounding access to treatment that are fueling much of the increase in children diagnosed with autism

2)Travels around the world to see how autistic children are viewed and treated in other countries

3)A sort of memoir chronicling getting treatment and education for Grinker's autistic daughter and the life long challenges of getting the best life for an autistic child

I dithered between 3 and 4 stars, settling on 3 because of the blurring of anecdote and science.

Tobinsfavorite says

I heard the author of this book on the radio shortly after I had given up "autism books" as horrifyingly depressing, and I decided I would read it. I'm very glad I did. It is divided into two sections, one by Grinker the Anthropologist, and one by Grinker the Parent. Both were informative, entertaining, and enlightening. I learned a lot of details about the history of autism diagnosis around the world, a little bit about different cultural views of the same, and a few new ways of thinking. Some of Grinker's experiences with his daughter are similar to mine with my son, and his happiness and contentment with his family situation was uplifting. With a knowledge that his child's differences may limit her interactions with others, he doesn't see her as limited and knows she can achieve a fulfilling life within and without her family structure. (Can any of us really ask for more?)
I appreciated the descriptions of educational and psychiatric practices in other countries and the wandering history of diagnosis through Freud and beyond. I really appreciated all the anedoctes from different families. Oh, and the writing was pretty good, too.

Kayla Shields says

What I learned:
And epidemic is not what we know it to be used in modern day language. It is supposed to represent an increase in rate of a diagnosis at a particular time. In Africa diagnosis of Autism is thought to be an evil spirit inhabiting the child because of a wrong doing by ancestors. In India there is a close nit relationship between mother-child and there are sparse professionals who will actually diagnose autism. In Korea there is a huge stigma with autism so much that the extended family and society disowns the child. Their property value may decrease, may not bring their child in public, and may not be able to have a sibling of a child with autism marry because of the shame and low status that comes with diagnosis. Possibly the most beneficial way for someone with Autism to live a meaningful life is to have a role/job in their community in which they have purpose. Last quote from the book, “Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it’s the only thing that ever has” - Margaret Meed

---

Lars Guthrie says

A subtitle on the cover of Richard Grinker’s ‘Unstrange Minds,’ ‘A Father, a Daughter, and a Search for New Answers’ might give you the idea that his book is a memoir. And in part, it is. The struggles and rewards Grinker and his family go through as they raise, and grow with, their autistic member, the unforgettable Isabel, are touchingly told.

‘Unstrange Minds’ is much more than that, though. Grinker is an anthropologist, and he knowledgeably writes about how the definition and treatment of autism differs in relation to culture. He recounts his journeys to South Korea, South Africa and India, where he interviews the parents and educators of autistic children. He investigates the way different societies and governments deal with developmental and mental disorders.

It was interesting to learn that people with such disorders are more likely to be become participating members of their community in rural areas than they are in cities. It was also encouraging to find out that even though we still stigmatize and have a long way to go, America is probably one of the better places to be if you are autistic.

The first half of ‘Unstrange Minds,’ however, is neither memoir nor anthropological treatise. It is an excellent, and invaluable, primer on the history of the diagnosis of autism, the study of its causes, and the treatment of its symptoms. Looking at that history, Grinker questions whether the increasing recognition of autism is the sign of an epidemic, or the result of more sophisticated diagnostic tools. He comes down on the side of the latter.

The history of autism as a diagnosis is quite a recent one, starting with the work of Leo Kanner and Hans Aspberger in the 1940s, and moving into the infamous work of Bruno Bettelheim in the 50s and 60s. Bettelheim, who was neither an MD or a psychiatrist, whose clinical studies were without scientific merit, was a superb self-promoter. On the basis of a popular book, ‘The Empty Fortress,’ he became an ‘expert’ pursued by media—an expert who blamed autism on bad mothers.

Diagnosing diseases of the mind through subjectivity and moral judgment is, of course, nothing new. Grinker points out that the DSM (the Diagnostic and Statistical Manual of Mental Disorders)—what people in psychiatry, psychology, medicine and health insurance use for diagnoses—didn’t exist until the 1950s, when it included homosexuality as a mental disorder. Autism and ADHD—not even mentioned.

Homosexuality was not downgraded to normal human behavior by the psychiatric establishment until the 70s. It took until the 1980s and 1990s for autism and ADHD diagnostic criteria to be listed. These changes are the reason you see DSM-II, DSM-III and DSM-IV, and taking it further, editions with an R added, for further revision. DSM-V is on the way, with more, and major, changes.

Clinicians who make use of these diagnostic criteria have a lot of latitude in their interpretation. It's never going to be completely objective because evaluating behavior like ‘lack of social or emotional reciprocity’ is by nature subjective, and because clinicians often diagnose to the category that gets resources from insurance companies, school districts, etc., etc. The DSM hedges its bets even further with the ‘NOS’ qualifier, as in PDD-NOS (pervasive developmental disorder, not otherwise specified), used for diagnoses close to autism that don't present the complete range of symptoms.

All of this, Grinker points out, is heavily influenced by changing social views toward mental and learning disorders. An obvious example is our attitude toward the word ‘retarded.’

The benefit in realizing the labeling is confused at best is that it means doctors and clinicians are working toward more objective analysis and categorization. That’s progress. Grinker is hopeful because the medical establishment is paying more and more attention to an identifiable set of symptoms, rather than beginning with causes. How can we know what causes something until we really know what it is? More importantly, how can we treat it?

The problem with the confusion for American parents with autistic kids, and for that matter any kids with learning differences, is the great difficulty they face in having our society and its educational system recognize, and do something about, the differences. All children should have the opportunity to measure up to their potential.

The Individuals with Disabilities Education Act (IDEA), Grinker notes, ‘wasn’t set up with the expectation that parents would be involved in extensive litigation, or that pit-bull attorneys would try to reduce witnesses to tears over the correct placement of a child with special needs.’ It often seems we are spending more to keep kids from moving forward than we are on helping them to do so.

Grinker takes the reader through his own frustrating trials to give Isabel the best possible chance of success, and the disillusionment it causes him. In the end, he still believes that ‘things have improved since autism became a more popular diagnosis.’

And he finds solace in looking for light instead of darkness in the love he has for his wonderful daughter. Isabel has helped Grinker realize ‘there is no pure, natural, or singularly correct way of seeing, and ‘to think more creatively about the kinds of meaningful relationships that are possible, and beneficial.’ Besides that, she is a pretty good cellist (with perfect pitch!) and an accomplished amateur zoologist.

Grinker has combined the personal and the professional parts of his life to produce an extremely well-written introduction to autism.