

Unstrange minds: *Remapping the world of autism*

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Book Review

With incendiary dialogue dominating the discussion of autism these days, an enlightened perspective is truly welcome. In *Unstrange minds*, Roy Richard Grinker, an anthropologist and parent of a child with autism, offers that perspective. Grinker tackles the most controversial issues — etiology and epidemic — and describes his experience raising a daughter with autism. Moreover, Grinker presses the reader to understand autism as shaped by culture and the historical framework through which it's been viewed over the past 50 years. Reading *Unstrange minds* couldn't be a more timely exercise. One would have to be living underground not to have seen and heard a thousand media messages about autism and its epidemic proportions. Everywhere one turns there are pronouncements and advertisements describing how common the diagnosis has become, and virtually every major media outlet in the United States has run a story on the experiences of families of children with autism or the controversies surrounding causality and treatment. With regard to research, an increasingly fractious tone dominates the politics of the NIH; private foundations are wrangling for control of funding and the research agenda. These events seem to signal abject desperation — which has taken hold, perhaps, in just the last ten years. So what's this all about? To answer the question, Grinker examines the impact of the word epidemic, which [...]

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Unstrange minds

Remapping the world of autism

Roy Richard Grinker

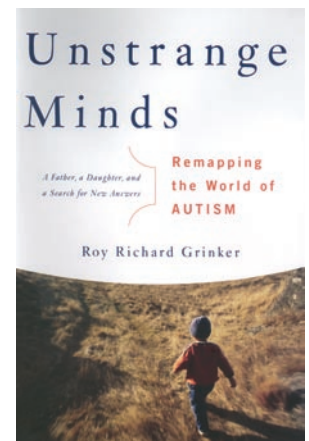
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With incendiary dialogue dominating the discussion of autism these days, an enlightened perspective is truly welcome. In *Unstrange minds*, Roy Richard Grinker, an anthropologist and parent of a child with autism, offers that perspective. Grinker tackles the most controversial issues — etiology and epidemic — and describes his experience raising a daughter with autism. Moreover, Grinker presses the reader to understand autism as shaped by culture and the historical framework through which it's been viewed over the past 50 years. Reading *Unstrange minds* couldn't be a more timely exercise.

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To answer the question, Grinker examines the impact of the word *epidemic*, which incites fear and evokes images of catastrophe. The focus on the emotional valence of the word forces us to step back and consider why, at this point in time, a disorder whose hallmark is *profound lack of social awareness* looms so large? Is the world a worse place than it used to be, as far as ruthless and callous behavior are concerned?

Grinker deals with the issue of the autism “epidemic” with a minimum of polemic, describing the methodological complexities that have led many to believe that the increase in autism prevalence signals a staggeringly increased incidence. After a reasoned account of these issues, he dares to ask, “Why are people so resistant to the idea that true autism rates have remained stable over the years?” This is a bold question. There are frequent challenges to the view that autism rates are increasing. Here, Grinker challenges those who hold this view, suggesting that they have some kind of psychological or emotional resistance to the facts. *Unstrange minds* made me wonder if this lack of candid confrontation is residue from a contentious time in autism's history. After all, who can deny the impact of Bettelheim's “refrigerator mother” theory, that emotionally frigid mothers are responsible for autism, on a generation of parents?

A similarly thoughtful approach addresses the issue of psychiatric diagnosis from the standpoint of helping the reader understand that diagnoses are constructs in which certain signs and symptoms are gathered into a meaningful whole, presumably something more than the sum of its parts. But of course, what is meaningful is continually shifting, and thus, the diagnoses of a time reflect the meanings of that time. As the psychoanalytic context spawned a hypothesis of maternal neglect as the source of autism, other societies impose their own meanings on these symptoms. The South Korean mother of a child with autism describes the disability as an inevitable consequence of *han*, the trace of injustices and misfortune of her ancestors. The Haredi, ultra-orthodox Jews, view the communications of nonverbal children with autism as messages from spirits. Are

mainstream Americans any less subject to cultural biases and interpretations?

Grinker addresses this question with an account of his realization that his daughter had autism and of the enormous efforts he and his wife have made to help her realize her potential. Their experience as they sought diagnostic clarification mirrors the experience of parents everywhere. Grinker describes his escalating worry as the couple moved from doctor to doctor, until finally someone said the word *autism*. Even professionals who knew what was wrong seemed afraid to say the word, as though it would rain down shame on child and family. The vestiges of stigma remain.

With regard to educating their daughter, Grinker recounts the strenuous efforts that all parents of children with autism will recognize, from debating with school personnel to coping with derisive comments about poor parenting. The couple's extraordinary response to their daughter's preoccupation with a story about Monet's garden in Giverny illustrates the choices they made for intervention using conventional methods as well as their creative efforts to enlarge their child's world.

Unstrange minds succeeds. The book comes at the issues from a new angle, pushing parents and scientists to step back from a singular viewpoint to consider the whole. Scientists look for solid data and rigorous reasoning, dismissing assertions that don't fit the picture. As a parent, the primacy of one's own experience takes precedence over what health professionals or scientists may say, even if those sources seek to characterize one's views as biased or uninformed. Grinker shows us that it's possible, and perhaps valuable, to deconstruct autism as a means of understanding and addressing it. Given the desperation so evident today, this is a welcome perspective.