

Interview with Roy Richard Grinker

Author of *Unstrange Minds: Remapping the World of Autism*

BENJAMIN RADFORD

There are many myths and much pseudoscience surrounding the diseases now called autism. Some have to do with vaccines, as the pieces by Steven Novella and Richard Judelsohn discuss in this special section. Other myths include the long-discredited practice of facilitated communication, in which “facilitators” help illiterate autistic children type out words and sentences—as well as occasional unfounded accusations of abuse. Yet many myths and questions remain, especially related to the prevalence and underlying diagnosis of autism.

In a new book on autism, Roy Richard Grinker (a professor of anthropology at George Washington University and himself the parent of an autistic daughter) examines the disease from a social and anthropological perspective. Here is an interview based on his book *Unstrange Minds: Remapping the World of Autism*.

How did you first become interested in the subject of autism?
I wear two hats. I am an anthropologist and the father of a child with autism. So, as autism awareness grew, more and more people said, “So you’re an anthropologist, what does autism look like in other cultures? Is the prevalence the same as it is here? What do people do about it?” I wrote *Unstrange Minds* so that people can see that autism is universal and that autism awareness is increasing everywhere in the world. But the most important reason for writing the book—though this was not my original intention—was to tell the world a

Benjamin Radford has investigated ghosts, psychics, lake monsters, UFOs, mass hysterias, and many other paranormal phenomena for over a decade. He is the author or co-author of three books; his latest (with fellow investigator Joe Nickell) is Lake Monster Mysteries: Investigating the World’s Most Elusive Creatures. His Web site is at www.RadfordBooks.com.

simple message: the increase in autism diagnoses is not a crisis but rather evidence that we’re finally beginning to address a kind of human difference that has for too long been misunderstood, misdiagnosed, and mismanaged. More than six decades after autism was first described by Leo Kanner, we’re finally getting it right, and counting it right.

Why do you challenge the idea that autism is an epidemic?
Because so many Americans and Europeans are in a panic that there is a true epidemic, and that if there is an epidemic there must be some new, identifiable cause out there somewhere to be found and eradicated. I thought I could articulate some of the cultural and scientific reasons behind the increase in rates and give a positive message: the higher rates are due to positive changes in the way we understand and treat neurological and psychiatric disorders.

If autism is not an epidemic, how did it come to be viewed as one?

Autism became viewed as an epidemic for the same reason there have been fears of epidemics of other illnesses: there is a dramatic increase in prevalence. But prevalence is just the number of cases counted at a particular point in time and is not evidence of true increases in a disease. The same happened with melanoma and prostate cancer. There were huge increases in prevalence in those diseases, because they were being diagnosed so much more (skin cancer, due to increased awareness and more biopsies of early stage cancers; prostate cancer because of the invention of the PSA blood test, as opposed to the painful method of inserting a tool through the tip of the penis all the way to the prostate). It really is confusing to see diagnosis rates of three or four in ten thousand twenty years ago change to rates of 1 in 150. On the surface it sounds frightening.



So it's the public's lack of understanding about the methodology?

I think scientists have not done a good job of explaining to the public that comparing these rates is like comparing apples and oranges. The rates in, say, 1980, were derived using a narrow definition of autism and using administrative statistics (mostly numbers of kids enrolled in programs under the category of "autism") at a time when autism was not a popular diagnosis. Today's rates are derived using a very broad definition of autism (people from the severely mentally retarded to people who marry and hold jobs and may even be college professors) and using reliable and valid measurements that have only recently been developed.

In Korea, where I'm doing an epidemiological study, we cannot even try to use administrative statistics, because autism is unpopular as a diagnosis. If you used the enrollment figures, you'd think autism was almost nonexistent in Korea. Yet, we're finding rates not out of line with the rest of the world. Second, the increased awareness has meant that people see autism more—the decreased stigma has helped too, since people don't hide their kids anymore. So it feels like an epidemic. But a feeling is different from science.

So what accounts for the apparent increase in the prevalence of autism?

They are described carefully in my book: new epidemiological methods yield many more cases; a much larger number of people are being diagnosed with autism today because autism is a spectrum that can include the profoundly mentally retarded person but also a brilliant scientist; more and more physicians are giving the diagnosis and then kids are being coded in the school system with autism (some epidemiologists who do records-based research then rely on the school records for their information); people who were once called mentally retarded or schizophrenic or a host of other things are now being diagnosed with autism. There is no single factor among all of these that trumps the oth-

ers, but I think the least understood is the change in epidemiological methods.

What do you think are the biggest misconceptions that the public has about autism?

One misconception is that we need to have an "epidemic" to call attention to a disorder. Some parents and philanthropic organizations have called me a traitor and accused me of betraying the autism community. On the one hand, I don't agree with the way philanthropic organizations have fueled the fears of an epidemic. An epidemic is a useful fiction for fundraising. On the other hand, the organizations do so much for autism awareness, research, and services that sometimes I feel a little guilty, as if by telling the truth some people might be less likely to give money. But that guilt is fleeting.

The reality is that (1) the higher rates mean that autism is a bigger public health issue than we ever realized; and (2) there is nothing mutually exclusive about saying there's no epidemic and at the same saying that we've finally figured out what's going on with people on the autism spectrum, and we need more research and services. I recently received an e-mail from a parent who decried my stance: "How can you say there is no epidemic of autism?" she wrote. "When I was in school, there were no kids with special needs in my school. Today, in my daughter's school there are dozens." Actually, that is my point. In the past autistic people were not included in our schools. Today they are. And that's a very good thing.

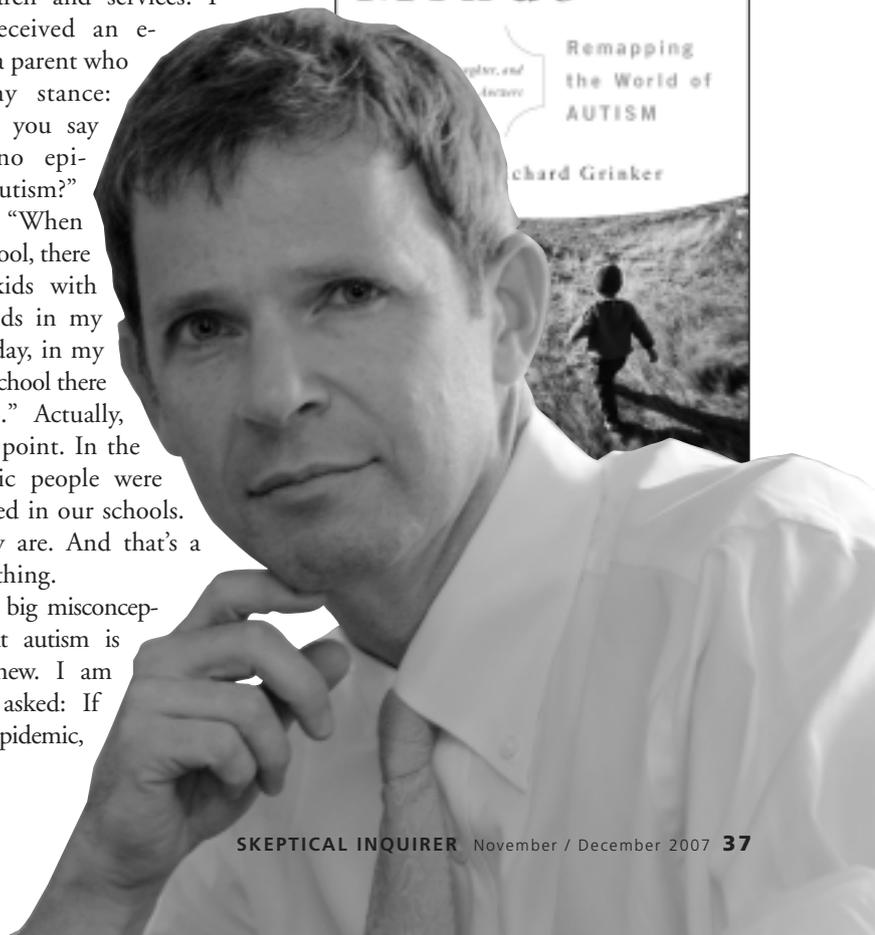
Another big misconception is that autism is somehow new. I am frequently asked: If there is no epidemic,

then where are all the adults with autism? The answer is easy, but also complicated. Finding adults with autism is very hard, not because they do not exist but because they are dispersed in our society. Some live in group homes, others in institutions, others are living and working among us in our everyday lives. Kids are easy to count because they are all in school, neatly recorded in school records. But adults are a different story. Counting adults with autism would be like trying to count adults with speech and language disorders. You can count kids, but where would we find the adults? So many people with speech and language disorders don't get speech services as adults—they've learned to adjust, adapt, and manage. No one "missed" or "ignored" autistic people in the past. They were just called something else, or in some cases (like people with Asperger's) called nothing at all.

Unstrange Minds

Remapping the World of AUTISM

Richard Grinker



An additional misconception is that an environmental factor equals an environmental toxin. Environment probably plays some very small role in causing autism, but environment can mean everything in the world, from chemicals, to our diet and way of life. No environmental factor has yet been identified by scientists to account for autism, let alone changes in autism prevalence. Looking for environmental factors in autism at this stage in our knowledge is really like looking for needles in haystacks.

Why do you think the news media have engaged in such misleading and alarmist coverage about autism?

Fear, panic, and deep parental concern get a lot of attention. Compare the two messages: “There’s an epidemic and we don’t know what is causing it!” and “More people are being diagnosed with autism today because we understand it better.” Plus, autism in the news is usually about autism in children (despite the fact that autistic children grow into adults), and children are very engaging as television, radio, and newspaper subjects. Advocacy by organizations whose membership is convinced there is an epidemic caused by an environmental toxin has been well funded and supported by politicians, especially by politicians in the states with the most autism services (and hence, because of those services, the highest rates of diagnosis).

What has been the reaction to your book, both by medical professionals and by parents of autistic children?

The scientific community, from what I can tell so far, supports my work strongly (e.g., reviews in *Nature* and the *New England Journal of Medicine*). Much of what I’m saying about the reasons for the so-called epidemic has been said before in scientific journals. What I’ve done is to put all those arguments together and place them in a larger context of American social change in a way that is accessible to a wide audience. The fact that the book

is being reviewed in both scientific journals and in the popular press, such as *People* magazine, is an indication to me that I’ve succeeded in reaching a large readership. Among parents of children with autism, the reception has been mixed. Many, many parents find *Unstrange Minds* to be inspiring because I talk about how many families in the world have turned something potentially devastating into something uplifting and rewarding. Others have sent me hate mail and left angry telephone messages on my answering machine at work. I have been called every kind of name.

What does the science suggest are the causes of autism?

There are probably several different kinds of autism caused by several different genetic pathways. There may be, in total, several dozen different genes involved. Scientists at Cold Springs Harbor Laboratory in New York have generated one of the most interesting genetic models, suggesting that some cases are heritable, but usually over the span of a couple of generations through a nonaffected carrier, and other cases are *de novo* mutations. But the bottom line is: it is largely genetic, so much so that environment probably plays [only] a small role. One way scientists estimate the role of genetics in a certain disorder is to look at concordance of that disorder in identical twins, that is, two people with identical DNA. The concordance, or percentage of people with identical DNA who both suffer from an autism spectrum disorder, is as high as 90 percent in some studies. That’s higher than the concordance for coronary artery disease, depression, or breast cancer. Then, when the scientists look at fraternal twins, who don’t have the same DNA, they find a concordance as low as 0 percent and as high as 10 percent. That makes ASD strongly genetic.

If autism is partly genetic, should there be prenatal testing to determine if a fetus is autistic?

That is a huge ethical question, but perhaps it’s premature. We know that schizophrenia, bipolar disorder, breast cancer, and many other disorders have a strong genetic component, but they cannot be tested for in the womb. Multigenic complex disorders are very different from, say, Down syndrome, which is an identifiable mutation in which there is extra genetic material (a twenty-first chromosome), so it can be tested for. Autism is a totally different kind of condition.

In explaining how disease diagnosis is culturally dependent, you draw from many cultures and countries, including the Navajo and family lines in China and Peru. What are two of the most vivid examples in your mind?

The Korean case is one of the most fascinating to me. This is a country in which scientists and doctors and government officials have said that autism is a rare or nearly nonexistent disorder in Korea. The school and clinic records support that contention, because one seldom finds any mention of anyone with “autism.” Autism, when it is diagnosed, is highly stigmatizing because it is seen as a genetic disorder. If a disorder is genetic, the family feels that the entire family is damaged, and this brings shame and stigma. So parents would rather see themselves as bad parents who caused autism in their child through bad parenting than see the disorder as genetic. This is the opposite of what happened in the U.S., where mothers and fathers used to be blamed, but we now see the disorder as genetic. At any rate, I went into Korea with a team of epidemiologists and psychiatrists and psychologists, and we have screened thirty thousand kids and done extensive testing. And we’re finding lots of autism. The kids just are not called autistic. They are undiagnosed or diagnosed with something else. So, in Korea, we’re seeing a culturally different version of what has already happened in the U.S. and higher prevalence rates in Korea are on their way: not because autism is new as a condition, but because autism is new as a concept. □