

# The Anti-Vaccination Movement

*Despite the growing scientific consensus that vaccines are safe and that neither vaccines nor mercury cause autism, a stubborn vocal minority claims otherwise, threatening the effectiveness of this public health program.*

STEVEN NOVELLA

Michelle Cedillo has autism, which her parents believe is the result of her childhood vaccines. In June 2007 they had the opportunity, along with eight other families, to make their case to the Autism Omnibus—a U.S. Court of Federal Claims that was presided over by three “special masters” appointed for the purpose. These nine cases are the first test cases that will likely determine the fate of 4,800 other claims made over the past eight years for compensation for injuries allegedly due to childhood vaccines.

Vaccines are one of the most successful programs in modern health care, reducing, and in some cases even eliminating, serious infectious diseases. Public support for the vaccination program remains strong, especially in the United





States where vaccination rates are currently at an all-time high of >95 percent (CDC 2004). Yet, despite a long history of safety and effectiveness, vaccines have always had their critics: some parents and a tiny fringe of doctors question whether vaccinating children is worth what they perceive as the risks. In recent years, the anti-vaccination movement, largely based on poor science and fear-mongering, has become more vocal and even hostile (Hughes 2007).

Of course, vaccines are not without risk (no medical intervention is), although the benefits far outweigh those risks. Because vaccines are somewhat compulsory in the United States—although opting out is increasingly easy—a National Vaccine Injury Compensation Program was established to streamline the process for compensation for those who are injured due to vaccines (USDOJ 2007). It is this program to which the Cedillo and 4,800 other families are applying for compensation.

In the last decade, the anti-vaccine movement, which includes those who blame the MMR (mumps-measles-rubella) vaccine

for autism, has largely merged with those who warn that mercury toxicity is the cause of many of the ills that plague mankind. The two groups have come together over the issue of thimerosal, a mercury-based preservative in some vaccines. They believe that it was the use of thimerosal in childhood vaccines that led to the apparent autism epidemic beginning in the 1990s.

Autism is a complex neurological disorder that typically manifests in the first few years of life and primarily involves a deficiency of typical social skills and behavior. In the 1990's, the number of autism diagnoses significantly increased, from between one and three to about fifteen cases per ten thousand, although the true incidence is probably between thirty and sixty per ten thousand (Rutter 2005). During this same period, the number of vaccines given in the routine childhood schedule also increased. This led some to assume, or at least speculate, causation from correlation—perhaps the vaccines or something in them created this “epidemic” of autism.

We can now say, from multiple independent lines of evidence, that vaccines do not cause autism. For one thing, the autism “epidemic” probably does not represent a true increase in the disorder, but rather an artifact of expanding the diagnosis (now referred to as autism spectrum disorder, ASD) and increased surveillance (Taylor 2006).

In 1998, researcher Andrew Wakefield and some of his colleagues published a study in the prestigious English medical

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journal *Lancet* that claimed to show a connection between the MMR vaccine and autism (Wakefield 1998). Wakefield's theory was that the MMR vaccine, which contains a live virus, can cause in susceptible children a chronic measles infection. This in turn leads to gastrointestinal disturbances, including what he calls a "leaky gut" syndrome, which then allows for certain toxins and chemicals, like those from bread and dairy that are normally broken down by the gut, to enter the bloodstream where they can access and damage the developing brain.

Although the study was small and the evidence was considered preliminary, this article sparked a firestorm. As a result of the study and the media coverage that followed (and continues to this day), MMR compliance in Great Britain plummeted, resulting in a surge of preventable disease (Friederichs 2006).

Subsequent to the seminal article in the *Lancet*, many follow-up studies were performed testing the autism-MMR vaccine correlation. As the follow-up studies began to be published, however, it became increasingly clear that there was no link between MMR and autism. For example, a study in the *British Medical Journal* found that autism rates continued to climb in areas where MMR vaccination rates were not increasing (Taylor 1999). Another study found no association with MMR and autism or GI (gastrointestinal) disorders (Taylor 2002). Other studies showed no difference in the diagnosis rate of autism either before or after the MMR vaccine was administered (Honda 2005), or between vaccinated and unvaccinated children (Madsen 2002). Most recently, a study found that there was no decrease in autism rates following removal of the MMR vaccine in Japan (Honda 2005).

In 2001, the Institute of Medicine (IOM) reviewed all of the MMR-autism data available to date and concluded that there was no association and essentially closed the case (IOM 2001)—a conclusion confirmed by still later studies, such as the Honda study in Japan cited above.

If Wakefield had simply been wrong in his preliminary findings, he would be innocent of any wrongdoing—scientists are not faulted if their early findings are not later vindicated. However, in May 2004, ten of Wakefield's co-authors on his original paper withdrew their support for its conclusions. The editors of *Lancet* also announced that they withdrew their endorsement of the paper and cited as part of the reason an undisclosed potential conflict of interest for Wakefield, namely that at the time of its publication he was conducting research for a group of parents of autistic children seeking to sue for damages from MMR vaccine producers (*Lancet* 2004).

It gets worse. Investigative reporter Brian Deer has uncovered greater depths to Wakefield's apparent malfeasance. Wakefield had applied for patents for an MMR vaccine substitute and treatments for his alleged MMR vaccine-induced gut disorder (Deer 2007). So, not only was he allegedly paid by lawyers to cast doubt on the MMR vaccine, but he stood to personally gain from the outcome of his research.



Andrew Wakefield. (Credit: Tom Miller) [Photo via Newscom]

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Further, during the Cedillo case testimony, Stephen Bustin, a world expert in the polymerase chain reaction (PCR), testified that the lab Wakefield used to obtain the results for his original paper was contaminated with measles virus RNA. It was therefore likely, Bustin implied, that the PCR used by Wakefield was detecting this contamination and not evidence for measles infection in the guts of children with autism who had been vaccinated, as Wakefield claimed. And finally, Nicholas Chadwick testified that the measles RNA Wakefield



Author of the book *Evidence of Harm: Mercury in Vaccines and the Autism Epidemic* David Kirby (center) speaks as president Harvey Fineberg (left) of the Institute of Medicine listens during an interview by moderator Tim Russert (right) on NBC's *Meet the Press* August 7, 2005, at the NBC studios in Washington, D.C. Fineberg and Kirby talked about the rising number of autism diagnoses among children and the controversial charges of a government conspiracy to allow mercury exposures from childhood vaccines to more than double between 1988 and 1992. The Institute of Medicine reviewed all MMR-autism data and concluded that there was no association. (Photo by Alex Wong/Getty Images for Meet the Press) [Photo via Newscom]

found matched the laboratory contamination and did not match either any naturally occurring strain or the strain used in the MMR vaccine—a fact of which he had informed Wakefield (USCFC 2007).

All of this, plus other allegations still coming out, has caused Britain's General Medical Council to call Wakefield before its "Fitness to Practise" panel for review of his alleged professional misconduct (GMC 2007).

Believers in the MMR-autism hypothesis dismiss the findings of the larger and more powerful epidemiological studies that contradict a link. Instead, they have turned Andrew Wakefield into a martyr, dismissing the evidence of his wrongdoing as a conspiracy against him designed to hide the true cause of autism from the public. Wakefield is unrepentant and maintains his innocence (Gorski 2007).

With the MMR-autism hypothesis scientifically dead, attention soon shifted to thimerosal, a mercury-based preservative found in some childhood vaccines (although not the MMR vaccine). There is little doubt, and no controversy, that mercury, the major component of thimerosal, is a powerful neurotoxin, or poison to the brain. However, toxicity is always a matter of dose. Everything becomes toxic in a high enough dose; even too much water or vitamin C can kill you. So the real question is whether the amount of mercury given to children in vaccines containing thimerosal was enough to cause neurological damage.

Proponents of the mercury hypothesis argue that the ethylmercury found in thimerosal was given in doses exceeding Environmental Protection Agency limits. This load of mercury should be considered with prenatal vaccine loads possibly given to mothers, and to other environmental sources of mercury,

such as seafood. Furthermore, underweight or premature infants received a higher dose by weight than larger children. Some children, they argue, may have a specific inability to metabolize mercury, and perhaps these are the children who become autistic.

Fear over thimerosal and autism was given a huge boost by journalist David Kirby with his book *Evidence of Harm* (Kirby 2005). Kirby tells the clichéd tale of courageous families searching for help for their sick children and facing a blind medical establishment and a federal government rife with corruption from corporate dollars. Kirby echoes the core claim that as the childhood vaccine schedule increased in the 1990s, leading to an increased cumulative dose of thimerosal, autism diagnoses skyrocketed.

In the end, *Evidence of Harm* is an example of terrible reporting that grossly misrepresents the science and the relevant institutions. As bad as Kirby's position was in 2005, in the last two years the evidence has been piling up that thimerosal does not cause autism. Rather than adjusting his claims to the evidence, Kirby has held fast to his claims, which has made him a hero alongside Wakefield of the mercury-autism-connection crowd as he has squandered his credibility.

There have now been a number of epidemiological and ecological studies that have all shown no correlation between thimerosal and autism (Parker 2004 and Doja 2006). I have already mentioned that the current consensus holds that there is no real autism epidemic, just an artifact of how the diagnosis is made. If there's no epidemic, there's no reason to look for a correlation between thimerosal and autism. This has been backed up by The Institute of Medicine, which has also reviewed all the available evidence (both epidemiological and toxicological) and concluded that the evidence does not support the conclusion that thimerosal causes autism (IOM 2004).

Especially damning for the thimerosal hypothesis are the recent studies that clearly demonstrate that early detection of autism is possible long before the diagnosis is officially made. Part of the belief that vaccines may cause autism is driven by the anecdotal observation by many parents that their children were normal until after they were vaccinated—autism is typically diagnosed around age two or three. However, more careful observations indicate that signs of autism are present much earlier, even before twelve months of age, before exposure to thimerosal (Mitchell 2006). In fact, autism expert Eric Fombonne testified in the Autism Omnibus hearings that Michelle Cedillo displayed early signs of autism clearly visibly on family video taken prior to her receiving the MMR vaccine (USCFC 2007).

Meanwhile, evidence is accumulating that autism is largely a genetic disorder (Szatmari 2007). This by itself does not rule out an environmental factor, but it is telling that genetic research in autism has proven so fruitful.

Mercury alarmists, in the face of this negative evidence, have been looking for rationalizations. Some have argued that



A demonstrator carries a sign protesting the use of mercury in vaccines past the U.S. Capitol in Washington July 20, 2005. Some three hundred people marched demanding that mercury not be used in vaccines anymore amid concern that it is the cause of autism and other neurological diseases in children. However, numerous studies show no correlation between Thimerosal and autism. (Nicholas Kamm/AFP/Getty Images) [Photo via Newscom]

the thimerosal in prenatal vaccines may be to blame, but recent evidence has shown a negative correlation there as well (Miles 2007).

What we have are the makings of a solid scientific consensus. Multiple independent lines of evidence all point in the same direction: vaccines in general, and thimerosal in particular, do not cause autism, which rather likely has its roots in genetics. Furthermore, true autism rates are probably static and not rising.

The only researchers who are publishing data that contradicts this consensus are the father-and-son team of Mark and David Geier. They have looked at the same data and concluded that thimerosal does correlate with autism. However, the hammer of peer-review has come down on their methods and declared them fatally flawed, thus rendering their conclusions invalid or uninterpretable (Parker 2004). Also, like Wakefield, their reputations are far from clean. They have made something

of a career out of testifying for lawyers and families claiming that vaccines caused their child's autism, even though the Geiers' testimony is often excluded on the basis that they lack the proper expertise (Goldacre 2007). The Geiers were not even called as experts in the Autism Omnibus hearings.

The Geiers are now undertaking an ethically suspect study in which they are administering chelation therapy to children with autism in conjunction with powerful hormonal therapy allegedly designed to reduce testosterone levels. Chelation therapy removes mercury, and so it is dependent upon the mercury hypothesis, which is all but disproved. Moreover, there is no clinical evidence for the efficacy of chelation therapy. The treatment is far from benign and is even associated with occasional deaths (Brown 2006).

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With the scientific evidence so solidly against the mercury hypothesis of autism, proponents maintain their belief largely through the generous application of conspiracy thinking. The conspiracy claim has been made the loudest by Robert F. Kennedy Jr. in two conspiracy-mongering articles: *Deadly Immunity* published on Salon.com in 2005 (Kennedy 2005), and more recently *Attack on Mothers* (Kennedy 2007). In these articles, RFK Jr. completely misrepresents and selectively quotes the scientific evidence, dismisses inconvenient evidence as fraudulent, accuses the government, doctors, and the pharmaceutical industry of conspiring to neurologically damage America's children, and accuses scientists who are skeptical of the mercury claims of attacking the mothers of children with autism.

Despite the lack of evidence for any safety concern, the FDA decided to remove all thimerosal from childhood vaccines, and by 2002 no new childhood vaccines with thimerosal were being sold in the U.S. This was not an admission of prior error, as some mercury proponents claimed; instead, the FDA was playing it safe by minimizing human exposure to mercury wherever possible. The move was also likely calculated to maintain public confidence in vaccines.

This created the opportunity to have the ultimate test of the thimerosal autism hypothesis. If rising thimerosal doses in the 1990s led to increasing rates of autism diagnosis, then the removal of thimerosal should be followed within a few years by a similar drop in new autism diagnoses. If, on the other hand, thimerosal did not cause autism, then the incidence of new diagnoses should continue to increase and eventually level off at or near the true rate of incidence. In 2005, I personally interviewed David Kirby on the topic, and we both agreed that this would be a fair test of our respective positions. Also, in an e-mail to science blogger Citizen Cain, Kirby wrote, "If the total number of 3-5 year olds in the California DDS [Department of Developmental Services] system has not declined by 2007, that would deal a severe blow to the autism-thimerosal hypothesis" (Cain 2005).

Well, five years after the removal of thimerosal, autism diagnosis rates have continued to increase (IDIC 2007). That is the final nail in the coffin in the thimerosal-vaccine-autism hypothesis. The believers, however, are in full rationalization mode. David Kirby and others have charged that although no new vaccines with thimerosal were sold after 2001, there was no recall, so pediatricians may have had a stockpile of thimerosal-laden vaccines—even though a published inspection of 447 pediatric clinics and offices found only 1.9 percent of relevant vaccines still had thimerosal by February 2002, a tiny fraction that was either exchanged, used, or expired soon after (CDCP/ACIP 2002).

Those who argue for the link have put forth increasingly desperate notions. Kirby has argued that mercury from cremations was increasing environmental mercury toxicity and offsetting the decrease in mercury from thimerosal. The Geiers simply reinterpreted the data using bad statistics to create the illusion of a downward trend where none exists (Geier 2006). Robert Kennedy Jr. dodges the issue altogether by asking for more studies, despite the fact that the evidence he asks for already exists. He just doesn't like the answer. Kennedy and others also point to dubious evidence, such as the myth that the Amish do not vaccinate and do not get autism. Both of these claims are not true, and the data RFK Jr. refers to is nothing more than a very unscientific phone survey (Leitch 2007).

The Autism Omnibus hearings have concluded, and while we await the decision due early next year, I am optimistic that science and reason will win the day. Just as shown in the 2005 Dover trial of intelligent design where the full body of scientific evidence was given a thorough airing in court and subjected to rules of evidence and the critical eyes of experienced judges, science tends to win out over nonsense. By all accounts, the lawyers for those claiming that vaccines caused their children's autism put on pathetic performances with transparently shoddy science, while the other side marshaled genuine experts and put forth an impressive case.

But the stakes are high, and not just for the 4,800 families. If the petitioners win these test cases despite the evidence, it

will open the floodgates for the rest of the 4,800 petitioners. This will likely bankrupt the Vaccine Injury Compensation Program and will also risk our vaccine infrastructure. Pharmaceutical companies will be reluctant to subject themselves to the liability of selling vaccines if even the truth cannot protect them from lawsuits.

Thimerosal still exists as a necessary preservative in multi-shot vaccines outside the United States, especially in poor third-world countries that cannot afford stockpiles of single-shot vaccines. Anti-thimerosal hysteria therefore also threatens the health of children in poor countries.

And of course a victory for the anti-vaccination activists would undermine public confidence in what is arguably the single most effective public health measure devised by modern science. This decrease in confidence will lead, as it has before, to declining compliance and an increase in infectious disease.

The forces of irrationality are arrayed on this issue. There are conspiracy theorists, well-meaning but misguided citizen groups who are becoming increasingly desperate and hostile, irresponsible journalists, and ethically compromised or incompetent scientists. The science itself is complex, making it difficult for the average person to sift through all the misdirection and misinformation. Standing against all this is simple respect for scientific integrity and the dedication to follow the evidence wherever it leads.

Right now the evidence leads to the firm conclusion that vaccines do not cause autism. Yet, if history is any guide, the myth that they do cause autism will likely endure even in the face of increasing contradictory evidence.

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# Vaccine Safety: Vaccines Are One of Public Health's Great Accomplishments

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RICHARD G. JUDELSON

Over the past decade, the public has been presented with a large amount of information about the safety of vaccines. Among the reasons for this interest is the widespread success of routine, universal immunization of infants and children, beginning in the 1940s. Previously common, dangerous, handicapping, potentially fatal diseases (vaccine-preventable diseases) have been wiped out with this policy (see table on next page). As the last century drew to a close, immunization was declared the greatest public health achievement in the United States in the twentieth century.

The list of licensed and recommended vaccines has been growing, and not just for infants and children. There are now schedules from professional societies, such as the



American Academy of Family Physicians (AAFP) and the American College of Obstetricians and Gynecologists (ACOG), and public agencies (e.g., the U.S. Centers for Disease Control and Prevention—CDC and most state health departments) that indicate what vaccines should be given and when for adolescents, adults, and specific vulnerable populations.

The considerable focus on vaccines and their safety in our information-overloaded society is not surprising, with a surplus of articles in magazines, books, parenting guides, and on the Internet, and stories on radio and television. While these occasionally highlight the benefits of immunization, “No One Got Sick or Died from a Vaccine-Preventable Disease Today” is not a very exciting story, so more often the emphasis in the media is on speculation that a vaccine *caused* a health problem. Furthermore, the widespread availability of litigation and liberal tort in the U.S. has encouraged lawsuits claiming harm from vaccines. Finally, it’s human nature to assume cause and effect when something bad happens, so a vaccination is an attractive target when administered before the onset of a medical condition.

Unfortunately, most of the public receives a lot of health information from lay sources rather than their physicians. Professional knowledge of immunization is grounded in science—microbiology, immunology, epidemiology, and statistics. Vaccines are licensed by the U.S. Federal Drug Administration (FDA) only when proven safe and effective. Recommendations for use are promulgated by committees of scientific

experts composed of academics, clinicians, and other caregivers who are passionately devoted to our citizens’ health and safety. The committees’ conclusions, and the rationale for them, are shared with practicing physicians, who are the most reliable source of information for patients. This process is the founda-

**Despite scientific proof and a long track record of vaccine safety, we see public policy based on junk beliefs, misinformation, fear, and mass hysteria.**

tion that has led to the conclusion that licensed vaccines are safe, and the fears that vaccines are harmful are unfounded.

Nevertheless, to address these unfounded fears, these and other groups of scientific experts have undertaken investigations

## Reduction in Morbidity: Vaccine-Preventable Diseases

Disease	Maximum Cases	2004/5	Change(%)
Diphtheria	206,939	0	-100.00
Hepatitis B	200,500	17,358	-73.80
Hepatitis A	35,200	4,488	-79.33
Measles	894,134	66	-99.99
Pertussis	265,269	25,616	-87.05
Polio (paralytic)	21,269	1	-100.00
Rubella	57,686	11	-99.99
Congenital rubella syn.	20,000	1	100.00
Tetanus	1,733	34	-94.12
Hib (<5 years)	20,000	30	-99.94
Varicella	83,500	11,250	-86.53
Pneumococcal Disease	63,933	37,775	-41.00

CDC,MMWR 54(47);1214.12/2/05,NIC,3/5/07

## VACCINES & AUTISM: Myths and Misconceptions

to determine possible relationships between vaccines and autism, asthma, diabetes, multiple sclerosis, SIDS, and other diseases. *No studies have yet established a causal link between vaccines and these diseases.* For example:

- Does hepatitis B vaccine cause SIDS (sudden infant death syndrome)? Looking at the numbers of doses of the former administered and cases of the latter, one would conclude the opposite, that hepatitis B vaccine prevents SIDS, since 90 percent of U.S. children have received hepatitis B vaccine, and SIDS cases have dropped dramatically in the past decade (probably due to the American Academy of Pediatrics [AAP] recommendation that infants sleep on their backs).

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- Does MMR vaccine cause autism? This question received extraordinary attention after it was raised in an article in *The Lancet* in 1998, by Dr. Andrew Wakefield and colleagues. The co-authors and *The Lancet* both have since retracted the article and its conclusions, and Wakefield is currently on trial in the U.K. for conflict of interest at the time of its publication. (He was on retainer from lawyers suing for vaccine damages.) More important, an Institute of Medicine (IOM) expert panel evaluated the issue and concluded that the evidence favored rejection of a connection between autism and MMR vaccine. Fourteen epidemiologic studies have been performed, all demonstrating the absence of a relationship between increased rates of autism and frequency of use of MMR vaccine. It is unfortunate that the speculation of a relationship between MMR vaccine and autism has resulted in the occurrence of vaccine-preventable diseases (especially measles) in children whose parents refused to allow them to receive the vaccine and has diverted atten-

## Recommended Immunization Schedule for Persons Aged 0–6 Years—United States, 2007

VACCINE ▼	AGE ►	Birth	1 month	2 months	4 months	6 months	12 months	15 months	18 months	19–23 months	2–3 years	4–6 years
Hepatitis B		HepB	HepB			HepB			HepB Series			
Rotavirus			Rota	Rota	Rota							
Diphtheria, Tetanus, Pertussis			DTaP	DTaP	DTaP		DTaP					DTaP
Haemophilus influenzae type b			Hib	Hib	Hib <sup>a</sup>	Hib		Hib				
Pneumococcal			PCV	PCV	PCV	PCV					PCV	PPV
Inactivated Poliovirus			IPV	IPV	IPV							IPV
Influenza					Influenza (Yearly)							
Measles, Mumps, Rubella						MMR						MMR
Varicella						Varicella						Varicella
Hepatitis A						HepA (2 doses)				HepA Series		
Meningococcal												MPSV4

Range of recommended ages

Catch-up Immunization

Certain high-risk groups

This schedule indicates the recommended ages for routine administration of currently licensed childhood vaccines, as of December 1, 2006, for children aged 0–6 years. Additional information is available at <http://www.cdc.gov/hip/recs/child-schedule.htm>. Any dose not administered at the recommended age should be administered at any subsequent visit, when indicated and feasible. Additional vaccines may be licensed and recommended during the year. Licensed combination vaccines may be used whenever any components of the combination are

indicated and other components of the vaccine are not contraindicated and if approved by the Food and Drug Administration for that dose of the series. Providers should consult the respective Advisory Committee on Immunization Practices statement for detailed recommendations. Clinically significant adverse events that follow immunization should be reported to the Vaccine Adverse Event Reporting System (VAERS). Guidance about how to obtain and complete a VAERS form is available at <http://vaers.hhs.gov> or by telephone: 800-822-7967.

Centers for Disease Control and Prevention. *MMWR*. 2006;55(51&52):Q1-Q4.

tion from research into the real causes of autism, which has been shown to have prenatal origins.

- Is thimerosal a cause of neurologic abnormalities, including autism? The preservative thimerosal, consisting of ethyl mercury, was used in multi-dose vaccine vials. At present, most infancy and childhood vaccines are supplied in single-dose vials, and all such routine vaccines are thimerosal-free. Studies to answer this question, including five epidemiologic surveys, came to the same conclusion as the MMR vaccine-autism analyses, that there is not a relationship. A pivotal study at the University of Rochester quantifying thimerosal in childhood vaccines stated that administration of vaccines containing thimerosal does not seem to raise blood concentrations of mercury above safe levels in infants.

Many of us recall that only two generations ago we had schoolmates who limped or had withered arms due to the paralytic polio they were infected with. That disease is now extinct in the U.S. because of the universal use of polio vaccine. During my training, I cared for children made deaf from

measles, infants blind and retarded from rubella, and those who died from bacteria like pneumococcus and meningococcus. With vaccination, those conditions no longer occur. As a physician in my early years of practice, the threat of infection with bacteria called Haemophilus influenza type B (Hib) loomed large for my patients and their families, the outcomes of brain damage or death being distinct possibilities. A vaccine was invented, adopted as policy, and given to U.S. infants and children. I'm pleased to say I no longer worry about Hib infection.

Despite scientific proof and a long track record of vaccine safety, we see public policy based on junk beliefs, misinformation, fear, and mass hysteria. In 2006, a number of legislative bodies passed, and executives signed, bills prohibiting use of vaccines containing thimerosal. From a practical perspective, these restrictions mean little, since all but a few influenza vaccines do not contain thimerosal. But such policies send a bad message: that the vaccines that have virtually eradicated many diseases, constituting one of the greatest public health accomplishments of the past century, are dangerous. Furthermore, these policies denigrate our informed medical and scientific communities. This is a disservice to our citizens and endangers us all.

## Recommended Immunization Schedule for Persons Aged 7–18 Years—United States, 2007

VACCINE ▼	AGE ►	7–10 years	11–12 YEARS	13–14 years	15 years	16–18 years	
Tetanus, Diphtheria, Pertussis			Tdap			Tdap	Range of recommended ages
Human Papillomavirus			HPV (3 doses)			HPV Series	
Meningococcal		MPSV4	MCV4		MCV4 <sup>3</sup>	MCV4	Catch-up Immunization
Pneumococcal			PPV				
Influenza			Influenza (Yearly)				Certain high-risk groups
Hepatitis A			HepA Series				
Hepatitis B			HepB Series				
Inactivated Poliovirus			IPV Series				
Measles, Mumps, Rubella			MMR Series				
Varicella			Varicella Series				

This schedule indicates the recommended ages for routine administration of currently licensed childhood vaccines, as of December 1, 2006, for children aged 7–18 years. Additional information is available at <http://www.cdc.gov/hip/recs/child-schedule.htm>. Any dose not administered at the recommended age should be administered at any subsequent visit, when indicated and feasible. Additional vaccines may be licensed and recommended during the year. Licensed combination vaccines may be used whenever any components of the combination are

indicated and other components of the vaccine are not contraindicated and if approved by the Food and Drug Administration for that dose of the series. Providers should consult the respective Advisory Committee on Immunization Practices statement for detailed recommendations. Clinically significant adverse events that follow immunization should be reported to the Vaccine Adverse Event Reporting System (VAERS). Guidance about how to obtain and complete a VAERS form is available at <http://vaers.hhs.gov> or by telephone: 800-822-7967.

Centers for Disease Control and Prevention. MMWR. 2006;55(51&52):Q1-Q4.

# 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

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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.

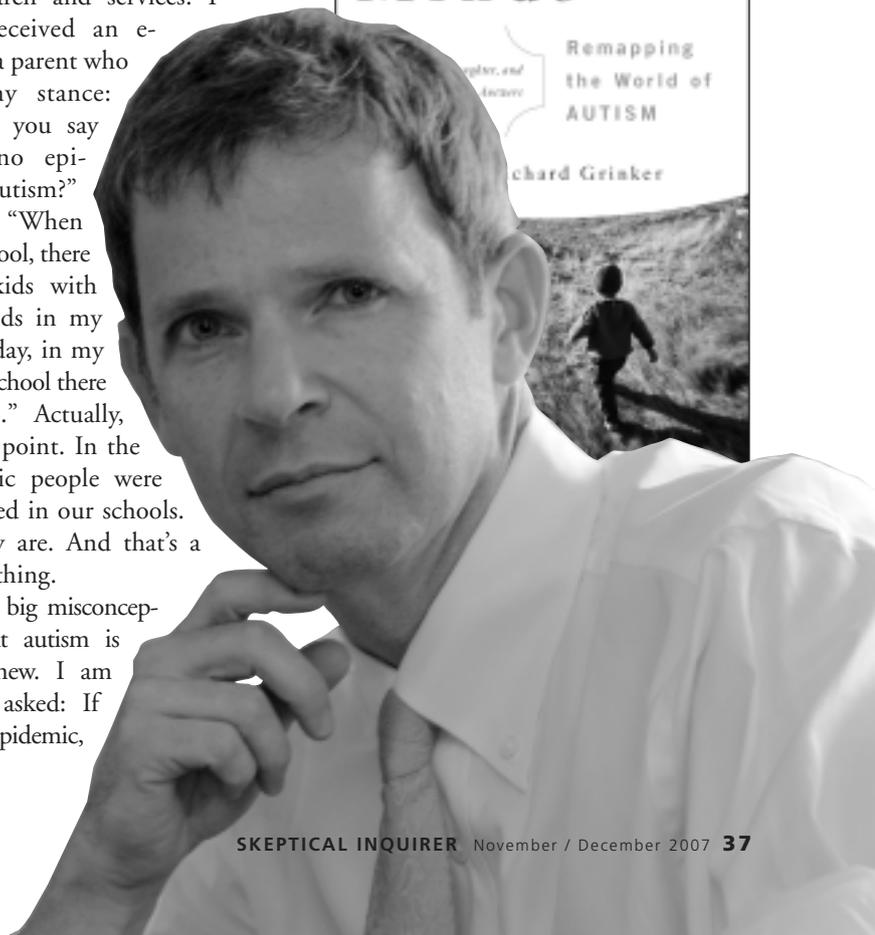
Another big misconception is that autism is somehow new. I am frequently asked: If there is no epidemic,

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. □