Why Does the Vaccine/Autism Controversy Live On?

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Research has soundly disproved the alleged connection, yet fears about vaccines continue to be a major risk to public health.

by Chris Mooney

Vaccines do not cause autism. That was the ruling in each of three critical test cases handed down on February 12 by the U.S. Court of Federal Claims in Washington, D.C. After a decade of speculation, argument, and analysis—often filled with vitriol on both sides—the court specifically denied any link between the combination of the MMR vaccine and vaccines with thimerosal (a mercury-based preservative) and the spectrum of disorders associated with autism. But these rulings, though seemingly definitive, have done little to quell the angry debate, which has severe implications for American public health.

The idea that there is something wrong with our vaccines—that they have poisoned a generation of kids, driving an “epidemic” of autism—continues to be everywhere: on cable news, in celebrity magazines, on blogs, and in health news stories. It has had a particularly strong life on the Internet, including the heavily trafficked Huffington Post, and in pop culture, where it is supported by actors including Charlie Sheen and Jim Carrey, former Playboy playmate Jenny McCarthy, and numerous others. Despite repeated rejection by the scientific community, it has spawned a movement, led to thousands of legal claims, and even triggered occasional harassment and threats against scientists whose research appears to discredit it.

You can see where the emotion and sentiment come from. Autism can be a terrible condition, devastating to families. It can leave parents not only aggrieved but desperate to find any cure, any salvation. Medical services and behavioral therapy for severely autistic children can cost more than $100,000 a year, and these children often exhibit extremely difficult behavior. Moreover, the incidence of autism is apparently rising rapidly. Today one in every 150 children has been diagnosed on the autism spectrum; 20 years ago that statistic was one in 10,000. “Put yourself in the shoes of these parents,” says journalist David Kirby, whose best-selling 2005 book, Evidence of Harm, dramatized the vaccine-autism movement. “They have perfectly normal kids who are walking and happy and everything—and then they regress.” The irony is that vaccine skepticism—not the vaccines themselves—is now looking like the true public-health threat.
The decadelong vaccine-autism saga began in 1998, when British gastroenterologist Andrew Wakefield and his colleagues published evidence in The Lancet suggesting they had tracked down a shocking cause of autism. Examining the digestive tracts of 12 children with behavioral disorders, nine of them autistic, the researchers found intestinal inflammation, which they pinned on the MMR (measles, mumps, and rubella) vaccine. Wakefield had a specific theory of how the MMR shot could trigger autism: The upset intestines, he conjectured, let toxins loose in the bloodstream, which then traveled to the brain. The vaccine was, in this view, effectively a poison. In a dramatic press conference, Wakefield announced the findings and sparked an instant media frenzy. For the British public, a retreat from the use of the MMR vaccine—and a rise in the incidence of measles—began.

In the United States, meanwhile, fears would soon arise concerning another means by which vaccines might induce autism. Many vaccines at the time contained thimerosal, a preservative introduced in the 1930s to make vaccines safer by preventing bacterial contamination. But thimerosal is 50 percent mercury by weight, and mercury is known to be a potent neurotoxin, at least in large doses. In 1999 new federal safety guidelines for mercury in fish stirred concerns about vaccines as well.

The U.S. government responded by ordering that thimerosal be removed from all vaccines administered to children under age 6, or reduced to trace amounts. (Some inactivated influenza vaccines were exempted.) The step was described as a “precautionary” measure. There was no proof of harm, government researchers said, just reason to worry that there might be. Meanwhile, scientists launched numerous studies to determine whether thimerosal had actually caused an autism epidemic, while some parents and their lawyers started pointing fingers and developing legal cases.

Within weeks of this year’s federal court decisions—which examined and vindicated both the MMR vaccine and thimerosal—environmental lawyer Robert F. Kennedy Jr. wrote a column in The Huffington Post in which he continued to press his case that the government has peddled unsafe vaccines to an unsuspecting public. It is a cause he has championed since 2005, when he published “Deadly Immunity” in Rolling Stone and Salon magazines. The article was a no-holds-barred denunciation of the U.S. public-health establishment, purporting to tell the story of how “government health agencies colluded with Big Pharma to hide the risks of thimerosal from the public...a chilling case study of institutional arrogance, power, and greed.” Half a decade after the original thimerosal concerns were first raised, Kennedy claimed to have found the smoking gun: the transcript of a “secret” 2000 meeting of government, pharmaceutical, and independent researchers with expertise in vaccines. Kennedy’s conclusion: The generational catastrophe was real; our kids had been poisoned. If true, it would be perhaps the greatest biomedical catastrophe in modern history.

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But for Kennedy to be right, a growing consensus in the medical establishment had to be wrong. Indeed, Kennedy blasted a leading organ of science that had just vindicated both the MMR vaccine and thimerosal, the Institute of Medicine (IOM). “The CDC [Centers for Disease Control and Prevention] paid the Institute of Medicine to conduct a new study to whitewash the risks of thimerosal,” Kennedy wrote, “ordering researchers to ‘rule out’ the chemical’s link to autism.” In reality, the IOM—a branch of the National Academy of Sciences (NAS), the government’s top independent scientific adviser—carefully creates firewalls between the funding it receives to conduct scientific assessments and the results it ultimately produces. “Funders don’t control the composition of the committee, and they don’t meet with the committee,” says Harvard public-health researcher Marie McCormick, who chaired the IOM vaccine-safety committee in question. “And on no NAS or IOM committee are the members paid; they all work pro bono. There’s no reason for them not to look at the data.”

The same year Kennedy’s article came out, journalist David Kirby published Evidence of Harm—Mercury in Vaccines and the Autism Epidemic: A Medical Controversy. He followed a group of parents from the Coalition for SafeMinds, an autism activist organization. They had grown convinced that vaccines and other environmental factors had caused their children’s conditions. Kirby’s chronicle of the parents’ efforts to publicize the dangers of vaccines became a best seller and greatly advanced SafeMinds’ cause.

Yet even as vaccine hysteria reached a fever pitch in the wake of Kennedy’s and Kirby’s writings, the scientific evidence was leaning strongly in the other direction. In discounting the dangers of both the MMR vaccine and thimerosal, the IOM had multiple large epidemiological studies to rely on. For MMR, the IOM examined 16 studies. All but two, which were dismissed because of “serious methodological flaws,” showed no evidence of a link. For thimerosal, the IOM looked at five studies, examining populations in Sweden, Denmark, the United Kingdom, and the United States (studies that vaccine critics contend were flawed). Since then, further research has strengthened and vindicated the committee’s original conclusion. It is a conclusion that has been “independently reached by scientific and professional committees around the world,” as a recent science journal commentary noted. Either the scientific community has found a clear, reassuring answer to the questions raised about thimerosal in vaccines, or there is a global scientific conspiracy to bury the truth.
Whether the public is hearing the scientific community’s answer is another matter. “It’s not hard to scare people,” says pediatrician and leading vaccine advocate Paul Offit, who himself coinvented a vaccine. “But it’s extremely difficult to unscare them.”

A backlash against vaccine skeptics is beginning to mount. Standing up to fellow celebrities, actress Amanda Peet, who recently vaccinated her baby daughter, has become a spokeswoman for the pro-vaccine group Every Child by Two. Offit’s book *Autism’s False Prophets* has further galvanized vaccine defenders—not only by debunking the science of those who claim vaccines are dangerous but also by contending that the parents of autistic children and the children themselves are indeed victims, not of vaccines but of medical misinformation.

The provaccine case starts with some undeniable facts: Vaccines are, as the IOM puts it, “one of the greatest achievements of public health.” The CDC estimates that thanks to vaccines, we have reduced morbidity by 99 percent or more for smallpox, diphtheria, measles, polio, and rubella. Averaged over the course of the 20th century, these five diseases killed nearly 650,000 people annually. They now kill fewer than 100. That is not to say vaccines are perfectly safe; in rare cases they can cause serious, well-known adverse side effects. But what researchers consider unequivocally unsafe is to avoid them. As scientists at the Johns Hopkins Bloomberg School of Public Health recently found while investigating whooping cough outbreaks in and around Michigan, “geographic pockets of vaccine exemptors pose a risk to the whole community.”

When it comes to autism, vaccine defenders make two central claims. First, the condition is likely to be mostly genetic rather than environmentally caused; and second, there are reasons to doubt whether there is really a rising autism epidemic at all.

It is misleading to think of autism as a single disorder. Rather, it is a spectrum of disorders showing great variability in symptoms and expression but fundamentally characterized by failed social development, inability to communicate, and obsessive repetitive behavior. Autism generally appears in children at early ages, sometimes suddenly, and its genetic component has long been recognized. Studies have shown that if one identical twin has autism, there is at least a 60 percent chance that the other also does. “From my point of view, it’s a condition associated with genetic defects and developmental biology problems,” says Peter Hotez, a George Washington University microbiologist and father of an autistic child. Hotez, who is also president of the Sabin Vaccine Institute, says, “I don’t think it’s possible to explain on the basis of any vaccine toxin that is acquired after the baby is born.” Still, scientists cannot fully rule out environmental triggers—including various types of toxicity—that might interact with a given individual’s preexisting genetic inclination. Autism is a complex disorder with multiple forms of expression and potentially multiple types of causation that are incompletely understood.

As for whether autism is rising, a number of experts say it is hard to know. Is the increase real, or is it largely the result of more attention to the condition, an expansion of the autism spectrum to embrace many different heterogeneous disorders, a new focus on children classified as autistic in federal special education programs during the 1990s, and other factors? It could be some combination of all these things.

But if environmental triggers of autism cannot be ruled out, the idea that those triggers can be found in the MMR vaccine or in thimerosal has crumbled under the weight of scientific refutation. Epidemiological studies have cast grave doubt on Andrew Wakefield’s MMR hypothesis—and so have subsequent scandals. Nearly all of Wakefield’s coauthors have since retracted the autism implications of their work; *The Lancet* has also backed away from the study. A series of investigative stories published in *The Times* of London unearthed Wakefield’s undisclosed ties to vaccine litigation in the U.K. and, more recently, suggested he fabricated his data (which Wakefield denies).

+++ As for thimerosal, government precautions notwithstanding, it was never clear how threatening it might be. The federal mercury standards that first heightened concern were developed for methylmercury, not ethylmercury, the form contained in thimerosal. Ethylmercury has less risk of accumulating to a toxic dose because it does not last as long in the body. And, according to the IOM’s 2004 report, there had never been any evidence of a major incident of mercury poisoning leading to autism.

The strongest argument against the idea that thimerosal poisoned a generation of children does not emerge from the body of published studies alone. There is the added detail that although thimerosal is no longer present in any recommended childhood vaccines save the inactivated influenza vaccine—and hasn’t, beyond trace amounts, since 2001—no one is hailing the end of autism. “If you thought thimerosal was related to autism, then the incidence of autism should have gone down,” Harvard’s McCormick explains. “And it hasn’t.”

In 2005 David Kirby stated that if autism rates didn’t begin to decline by 2007, “that would deal a severe blow to the autism-thimerosal hypothesis.” But as McCormick notes, despite the absence of thimerosal in vaccines, reports of autism cases
have not fallen. In a 2008 study published in Archives of General Psychiatry, two researchers studying a California Department of Developmental Services database found that the prevalence of autism had actually continued increasing among the young. Kirby concedes that these findings about the California database represent a "pretty serious blow to the thimerosal-causes-autism hypothesis," though he does not think they thoroughly bury it. In an interview, he outlined many problems with relying on the California database, suggesting potential confounding factors such as the state's high level of immigration. "Look, I understand the desire to try to end this and not scare parents away from vaccination," Kirby says. "But I also feel that sometimes that desire to prove or disprove blinds people on both sides."

Kirby says—and even some vaccine defenders agree—that some small subgroup of children might have a particular vulnerability to vaccines and yet be missed by epidemiological studies. But the two sides disagree as to the possible size of that group. "If one or two or three children every year are getting autism from vaccines, you would never pick that up," Offit says. Kirby, in contrast, feels that while the idea of thimerosal as the "one and only cause of autism has gone out the window," he still believes there is an "epidemic" with many environmental triggers and with thimerosal as a possible contributing factor.

Meanwhile, in the face of powerful evidence against two of its strongest initial hypotheses—concerning MMR and thimerosal—the vaccine skeptic movement is morphing before our eyes. Advocates have begun moving the goalposts, now claiming, for instance, that the childhood vaccination schedule hits kids with too many vaccines at once, overwhelming their immune systems. Jenny McCarthy wants to "green our vaccines," pointing to many other alleged toxins that they contain. "I think it's definitely a response to the science, which has consistently shown no correlation," says David Gorski, a cancer surgeon funded by the National Institutes of Health who in his spare time blogs at Respectful Insolence, a top medical blog known for its provaccine stance. A hardening of antivaccine attitudes, mixed with the despair experienced by families living under the strain of autism, has heightened the debate—sometimes leading to blowback against scientific researchers.

Paul Shattuck did not set out to enrage vaccine skeptics and the parents of autistic children. Currently an assistant professor at the George Warren Brown School of Social Work at Washington University in St. Louis, he has dedicated the last decade of his professional life to helping people with autism in their families. "Some of my dearest friends have kids with autism," he says.

But in 2006 Shattuck came under fire after he published an article in the journal Pediatrics questioning the existence of an autism epidemic. No one doubts that since the early 1990s the number of children diagnosed with autism has dramatically increased, a trend reflected in U.S. special education programs, where children enrolled as autistic grew from 22,445 in 1994–1995 to 140,254 in 2003–2004. Yet Shattuck’s study found reasons to doubt that these numbers were proof of an epidemic. Instead, he suggested that "diagnostic substitution"—in which children who previously would have been classified as mentally retarded or learning disabled were now being classified on the autism spectrum—played a significant role in the apparent increase.

Shattuck did not reject the idea that rising autism levels might be in part due to environmental causes; he merely showed the increase was largely an artifact of changing diagnostic practices, which themselves had been enabled by rising levels of attention to autism and its listing as a diagnostic category in special education. Yet simply by questioning autism epidemic claims in a prominent journal, he became a target. "People were obviously Googling me and tracking me down," he recalls. Shattuck emphasizes that most e-mails and calls merely delivered "heartfelt pleas from people with very sick kids who’ve been led to believe a particular theory of etiology." The bulk weren’t menacing, but a few certainly were.

Others attacked Shattuck’s research on the Web and insinuated that he had fabricated his data or committed scientific misconduct. "It was dismaying to feel like people were calling me a traitor to autistic kids and families," he says.

"If there has been a more harmful urban legend circulating in our society than the vaccine-autism link," University of Pennsylvania bioethicist Arthur Caplan wrote in The Philadelphia Inquirer, "it’s hard to know what it might be." One type of harm, as Shattuck’s story shows, is to individual scientists and the scientific process. There is a real risk that necessary research is being held back as scientists fear working in such a contested field. Shattuck’s experience is not unique. Offit cannot go on a book tour to promote Autism’s False Prophets because of the risk involved in making public appearances. He has received too many threats.

Yet another cost comes in the rush toward unproven, and potentially dangerous, alternative therapies to treat autism. It is easy to sympathize with parents of autistic children who desperately want to find a cure, but this has led to various pseudomedicines whose efficacy and safety have been challenged by science. These include facilitated communication, secretin infusion, chelation therapy (which involves pumping chemicals into the blood to bind with heavy metals such as mercury), and hormonal suppression. It is estimated that more than half of all children with autism are now using "complementary and alternative" treatments.
Disease, however, is the greatest danger associated with holding back vaccines amid the ongoing investigation of dubious claims. Both the vaccinated and the unvaccinated populations are placed at greater risk. Given enough vaccine exemptions and localized outbreaks, it is possible that largely vanquished diseases could become endemic again. (That is precisely what happened with measles in 2008 in the U.K., following the retreat from the MMR vaccine in the wake of the 1998 scare.) The public-health costs of such a development would be enormous—and they would not impact everyone equally. "If vaccine rates start to drop, who’s going to get affected?" Peter Hotez asks. "It’s going to be people who live in poor, crowded conditions. So it’s going to affect the poorest people in our country."

Paradoxically, the great success of vaccines is a crucial reason why antivaccination sentiment has thrived, some scientists say. Most of the diseases that vaccines protect against have largely been licked. As a consequence, few people personally remember the devastation they can cause. So with less apparently on the line, it is easier to indulge in the seeming luxury of vaccine skepticism and avoidance. Even before the recent spike in attention to thimerosal, members of the public were alarmingly skeptical of vaccines. In a 1999 survey, 25 percent felt their children’s immune systems could be harmed by too many vaccinations, and 23 percent shared the sentiment that children receive more vaccinations than are healthy. There is every reason to think that those numbers—gathered before the vaccine-autism controversy reached anything like its current intensity—have risen since.

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In the United States, population pockets with low vaccination rates (such as in Boulder, Colorado, and Ashland, Oregon) have existed for some time, and the great fear among many governmental medical authorities is that high-profile claims about vaccine dangers will widen the phenomenon, with potentially disastrous consequences. Already, medical and religious vaccination exemptions are climbing: In New York State they totaled 4,037 in 2006, nearly twice as many as in 1999. In New Jersey they came to 1,923 in 2006 versus only 727 in 1990. It is not just exemptors: The far larger concern, according to McCormick and others, is those parents referred to as “vaccine hesitaters.” They have heard all the noise about vaccines and will probably get their children shots because they feel they have to, but their skepticism is growing.

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Offit points to still another threat: litigation. The wave of autism-related claims filed with the U.S. government’s Vaccine Injury Compensation Program is unprecedented. Since 2001 autism claims have outnumbered nonautism cases almost four to one. Following the science, the court has now dismissed many of them, but there is the possibility that civil litigation will follow. “I still think it’s going to be another 10 years before this really washes out in litigation,” Offit says. If the legal atmosphere becomes too difficult for vaccine manufacturers, they could stop producing them or be forced out of business.

Ultimately, that is why the vaccine-autism saga is so troubling—and why it is so important to explore how science and so many citizens fell out of touch.

“It wouldn’t have been possible without the Internet,” says journalist Arthur Allen, who has covered the vaccine-autism story since 2002, when he wrote a high-profile New York Times Magazine article that took the thimerosal risk seriously. Over time Allen changed his mind, coming to reject the idea that vaccines are to blame. Still, he recognizes why it persists. “If people believe something happened to them, there are so many people on the Web you can find who believe the same thing.” The Internet has become a haven for a number of autism support groups that continually reinforce the vaccine-autism argument. This has led to the radicalization of some elements who have denounced scientists as “vaccine barbarians,” “pharmaceutical and medical killers,” and so on. And after all we have heard about environmental and chemical risks—some accurate, some not—people are now easily persuaded about all manner of toxin dangers.

But if the Internet has made it easier for pockets of antiscience feeling to grow and flourish, scientific authorities also deserve some of the blame. “I don’t think they woke up that this was a serious problem until maybe 2008,” David Gorski says about the growing antivaccine sentiment. George Washington University’s Hotez notes that “the office of the surgeon general, the secretary of Health and Human Services, and the head of the CDC have not been very vocal on this issue.” True, the CDC, the Food and Drug Administration, and other governmental organizations feature accurate and up-to-date information about vaccine risks on their Web sites. But that is very different from launching a concerted communications campaign to ensure that the public retains faith in vaccination.

Some outspoken scientists may have actually increased the polarization on this issue. For example, calling those against vaccines “scientifically illiterate”—or, as CDC vaccine expert Stephen Cochi reportedly put it to one journalist, “junk scientists and charlatans”—may just lead to a further circling of the wagons.

The most promising approach to the vaccine-autism issue comes from the government itself. Consider the work of Roger Bernier, a CDC scientist who turned to emphasizing the public-engagement aspects of the vaccine problem after hearing one parent declare any new government research on the topic “dead on arrival.” The central problem Bernier has
confronted: how to deal with a situation in which so many parents are unswervingly convinced that their children have been harmed, in which they could be harming their children even more by using untested therapies, and in which dangerous misinformation abounds.

“There’s no end to the kind of noise people can make about vaccines,” he observes. “And so if you’re in the vaccine community, what’s the best approach to this? I don’t think it is ignoring people.” Instead, Bernier has headed up a series of award-winning projects that bring together average citizens with scientists and policymakers to reach joint recommendations on vaccines, holding public dialogues across the country to break down boundaries between the experts and everybody else, literally putting multiple perspectives around a table. His example suggests that while science’s first and greatest triumph in this area was to develop vaccinations to control or eradicate many diseases, the challenge now—not yet achieved, and in some ways even more difficult—is to preserve public support for vaccine programs long after these scourges have largely vanished from our everyday lives.

“The problem is not only research,” Bernier says. “The problem is trust.”

*Chris Mooney will continue to report on the vaccine-autism controversy on his blog, The Intersection.*