

The Legitimacy of Vaccine Critics: What Is Left after the Autism Hypothesis?

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Abstract The last dozen years have seen a massive transnational mobilization of the legal, political, and research communities in response to the worrisome hypothesis that vaccines could have a link to childhood autism and other developmental conditions. Vaccine critics, some already organized and some composed of newly galvanized parents, developed an alternate world of internally legitimating studies, blogs, conferences, publications, and spokespeople to affirm a connection. When the consensus turned against the autism hypothesis, these structures and a committed membership base unified all the organizations in resistance. This article examines the relationship between mobilization based on science and the trajectory of legitimacy vaccine criticism has taken. I argue that vaccine critics have run up against the limits of legitimate scientific argument and are now in the curious position of both doubling down on credibility-depleting stances and innovating new and possibly resonant formulations.

Introduction

Do vaccines cause autism? This question has been the focus of dozens of studies, multiple congressional hearings and Institute of Medicine reports, and many failed claims for legal compensation. The British measles-mumps-rubella (MMR) lawsuits began nineteen years ago, and the Omni-

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bus Autism Proceedings (OAP) in the U.S. vaccine compensation court are still sorting out attorneys' fees after the petitioners lost all their claims in 2009 and 2010 (Day and Kelleher 2005; e.g., *King v. Secretary of HHS*, No. 03–584V, 2010 WL 892296 [Fed. Cl. Spec. Mstr. Mar. 12, 2010]). The British litigation cost over £15 million in public funds (over \$24 million in today's currency) (Deer 2006) but never went to trial, and the cost of the OAP, financed from an excise tax on vaccines, will be in the millions as well. Millions and millions of federal research dollars have been spent in response to parents' and their advocates' calls for answers. The mainstream consensus from scientists and the courts has been overwhelmingly against any connection between vaccines and autism. Although all of these expenditures may now seem a waste of resources on a discredited hypothesis, we must remember that uncertainty existed initially and that the question was extremely urgent.

But what should we make of vaccine critics now, who have had such power to activate a research agenda, command political attention, and conduct years of litigation, as the consensus has settled against them?¹ Studies of social movement politics devote much more attention to how and why mobilization happens than to stagnation, decline, or fragmentation (Majka and Majka 1992). The two main groups I discuss here, the National Vaccine Information Center and SafeMinds, have become the go-to representatives for vaccine concerns in the policy process and have no real competitors, clear indicators of success (Rochon and Mazmanian 1993). What has changed is the terrain of legitimacy around them. Just looking at the resources that critics have does not suggest any shifts; instead, I argue that legitimacy has been lost because of the rejection of the autism hypothesis. When a social movement uses the language of science, mobilizes the legal and research world, and gains a seat at the policy table, its legitimacy is ineluctably tied to the consensus that mobilization produces. Repeatedly refusing to revise views in the light of that consensus undermines legitimacy. The puzzle to be explained is why, after so much successful mobilization and access to high-level policy-making forums at the start of the autism-vaccine crisis, have vaccine critics been unable or unwilling to adapt their message to maintain legitimacy? The obvious answer is that they do not accept the conclusions of the scientific and medical mainstream, but that raises the obvious question: why not?

1. To draw distinctions within the movement, my umbrella term will be "vaccine critics" or the "vaccine-critical movement," changed to "vaccine safety advocates" or "antivaccine" as appropriate.

In this article, I trace the trajectory of the vaccine-critical movement's legitimacy since the emergence of the consensus against the autism hypothesis. Rather than ask why individuals believe what they do (Kahan, Jenkins-Smith, and Braman 2010), my focus is on why organizations remain on a fixed path despite slipping legitimacy. I show how vaccine critics have run up against the limits of legitimate scientific argument and are now in the curious position of both doubling down on legitimacy-depleting positions and innovating new and possibly resonant formulations. Recent exchanges suggest vaccine critics are not considered trustworthy partners in policy making because of their adherence to discredited theories. Their leadership must remain committed to these theories to hold the organizations together (and are no doubt sincere themselves in their beliefs), making it impossible for them to adopt more moderate positions and regain legitimacy in the world of vaccine policy making.

This work is drawn from a larger study of vaccine injury litigation, compensation, and regulation in the contemporary United States. The study uses qualitative research techniques such as participant observation at movement events, public government meetings, and interviews, and analysis of primary sources such as advocacy materials, legal documents, public comments by advocates at government meetings, legal transcripts, advisory commission minutes, and government reports. This article draws mainly on those primary sources and public events that showcase movement rhetoric, priorities, and strategies. My focus is on the organizational leadership, not grassroots members or ordinary parents.²

Recent History of the Vaccine-Critical Movement

Vaccine-critical movements have a long history, and historians have well documented their appearances, arguments, and impacts in Europe and the United States (Johnston 2004; Durbach 2005; Colgrove 2006; Willrich 2008). But what does the movement look like today? It targets not only the states and the federal government as the source of vaccine mandates and regulation but also the culture of mainstream professional medical care, dominant cultural notions of disease, and the scientific authority structures that undergird the honored place of vaccination in public health governance. Some of their goals are straightforwardly political, such as

2. There is a rich literature on parental anxieties about vaccines. See, e.g., Freed et al. 2004; Gust et al. 2005, 2009; Kennedy, Brown, and Gust 2005; Benin et al. 2006; Shui, Weintraub, and Gust 2006; Salmon et al. 2009; Freed et al. 2010; Kaufman 2010.

getting state-level vaccine exemptions expanded or mandates removed, but others are more broadly cultural, such as moving individuals' relationships to risk and disease away from experts and back into the private family, and making medicine more holistic and individualized. Most vaccine critics are educated middle- and upper-income whites. These features are different in important ways from the classic picture of a social movement: deprived outsiders such as the poor or racial minorities seeking policy change or inclusion first and perhaps "expressive" cultural change only as a secondary goal (Armstrong and Bernstein 2008: 75–78). Vaccine critics are more similar to other middle-class movements that blend health, science, and politics such as the fat acceptance movement (Saguy and Riley 2005), AIDS activism (Epstein 1996), or breast cancer activism (Klawiter 2008).

Right now, autism advocacy and vaccine criticism are tightly intertwined, but it was not always this way. The contemporary American movement of vaccine critics has two versions: what was in place before the current autism causation controversy and what came in response to autism. The older organization is the National Vaccine Information Center (NVIC), formed in 1982 by parent-activists concerned about the reactivity of the whole-cell DTP (diphtheria-tetanus-pertussis) vaccine (Coulter and Fisher 1985; Offit 2010). The NVIC (2011a) is "the oldest and largest consumer led organization advocating for the institution of vaccine safety and informed consent protections in the public health system." It helped pass the National Childhood Vaccine Injury Act of 1986 (42 U.S.C. §§ 300aa-1 to 300aa-34, Public Law 99–660) with bipartisan support, which put in place the foundation of our current vaccine safety and injury compensation system, including what is known as the vaccine compensation court (1986). Historian Robert D. Johnston (2004: 260) emphasizes the "high level of respect, intellectual engagement, and at times celebration in the common culture" that the NVIC and its leaders, particularly cofounder and current president Barbara Loe Fisher, enjoyed in the 1990s and early 2000s.

But autism diagnoses were increasing and would soon become the metanarrative of vaccine fear. The schedule of childhood vaccines also expanded during the 1990s, and it was not long before parents began to see a connection (Kirby 2005). Vaccine criticism grew its second arm, composed primarily of parent-activists from the autism community. The controversy about vaccines and autism grew from separate streams in the United Kingdom and the United States, with the British variant indicting the MMR vaccine because of the work of Dr. Andrew Wakefield and the

U.S. variant more focused on the mercury-containing preservative thimerosal (Baker 2008).³ SafeMinds, an organization dedicated to mercury-induced neurological disorders, was founded in 2000 by American parents concerned about thimerosal. The SafeMinds (2011) mission is “to restore health and protect future generations by eradicating the devastation of autism and associated health disorders induced by mercury and other man made toxicants.”⁴ There are other lesser-known autism-vaccine organizations as well, and in February 2010 they formed the Coalition for Vaccine Safety (which includes SafeMinds, Generation Rescue, the National Autism Association, Autism One, Autism Action Network, Talk About Curing Autism, the Center for Personal Rights, the Elizabeth Birt Center for Autism Law and Advocacy, and Unlocking Autism). The coalition’s focus has been to criticize the vaccine court decisions that vaccines did not cause autism and the Supreme Court’s decision in *Bruesewitz v. Wyeth* (562 U.S. ____ 2011) that the 1986 vaccine act shields vaccine manufacturers from design defect lawsuits.

Invoking science has been the primary route to credibility for vaccine critics, but it became much more difficult for advocates to plausibly claim to have science on their side in the vaccine-autism controversy starting around 2003. There had been genuine unknowns about the possibility of vaccine-caused injuries from mercury in thimerosal, a vaccine preservative, or from the MMR vaccine (which never contained thimerosal) from about 1998 to as late as 2003 (Allen 2007: 375–383; Baker 2008). Thimerosal was removed from vaccines beginning in 1999 as a precaution (American Academy of Pediatrics and the U.S. Public Health Service 1999). Vaccine critics reacting to that news seemed like legitimately concerned parents demanding accountability in a vaccine safety system that had clearly stumbled. A flurry of scientific papers published beginning in 2003, however, concluded that evidence did not support a connection between thimerosal-containing vaccines and autism (e.g., Hviid et al. 2003; Madsen et al. 2003; Stehr-Green et al. 2003; Verstraeten et al. 2003; Andrews et al. 2004; Heron, Golding, and the ALSPAC Study

3. The MMR vaccine has never contained thimerosal, so these two hypotheses were initially in competition with each other (a detail easy to forget now) (Kirby 2005: 92). The thimerosal-containing vaccines were hepatitis B, DTP (diphtheria, pertussis, and tetanus), Hib (*Haemophilus influenzae* type b), and influenza (some of which still contain thimerosal).

4. Generation Rescue, another prominent organization promoting the idea that mercury in vaccines causes autism, was founded in 2005 by businessman and parent J. B. Handley (who later handed over the named association with his group to comedian Jenny McCarthy). This organization is oriented to serving parents much more than it is focused on policy, so it is not as important to this analysis.

Team 2004). A number of publications soon questioned the validity of Wakefield's 1998 *Lancet* article that triggered concerns about the MMR vaccine (e.g., Takahashi et al. 2003; Chen et al. 2004; DeStefano et al. 2004; DeStefano and Thompson 2004; Horton 2004; Honda, Shimizu, and Rutter 2005). As I noted, these theories were also subjected to an extensive legal process in the United States and the United Kingdom that came to the same conclusions. And perhaps most importantly for consolidating mainstream medical opinion in the United States, in 2004 the highly respected Institute of Medicine published a report also concluding that the evidence was not on the side of a vaccine connection to autism.⁵ By 2004 it had become nearly impossible to be a respected scientist and be associated with the claim that vaccines cause autism.

A barometer of the changed context was the very public rise and fall of Wakefield. One common problem for social movements, after all, is overreliance on a charismatic leader (Majka and Majka 1992). In 2004 ten of Wakefield's coauthors distanced themselves from the paper after it surfaced that Wakefield had not disclosed that the research was litigation-driven (Murch et al. 2004), and in 2010 the *Lancet* formally retracted the paper (Editors 2010). The publicly funded U.K. Legal Services Commission decided in 2004 to cut off funding for litigation against pharmaceutical companies based on the MMR-autism hypothesis because, after reviewing about sixty expert reports, they found the claim to lack merit (Day and Kelleher 2005). The General Medical Council in the United Kingdom found in February 2010 that Wakefield had committed professional misconduct in his work with the twelve children from the 1998 study (subjecting them to unwarranted interventions to search for the measles virus in their guts and spines, among other things) and subsequently removed him from the registry of physicians licensed to practice. Wakefield has now been widely labeled a fraud (Godlee, Smith, and Marcovitch 2011), but enjoys strong devotion from the leaders and members of the vaccine-critical organizations, who feel that he has really listened to them when mainstream physicians did not.⁶

5. The Institute of Medicine had previously published other safety reviews on immunizations and immune dysfunction, the MMR vaccine and autism, vaccines and Sudden Infant Death Syndrome (SIDS), and thimerosal and developmental disorders. The 2001 report on thimerosal-containing vaccines (TCV) had concluded that a connection was "biologically plausible," and the evidence was "inadequate to accept or reject a causal relationship" between TCVs and autism because there was not enough research at that time (5). By 2004 the review committee felt confident enough to favor "rejection" of a hypothesis connecting vaccines and autism, the strongest possible negative judgment it could have given (Institute of Medicine 2004: 16).

6. Wakefield (2010) has continued to insist that his research is valid and that the GMC charges were unjust.

Policy makers and experts in the vaccine program believe vaccines are a lifesaving intervention backed by a proven system of pre- and post-licensure testing and surveillance, and that adverse events are rare. Critics believe that vaccines are damaging on a wide scale and promoted in bad faith by corrupted officials. All the vaccine-critical organizations have doubled down on the autism hypothesis and continue to embrace its discredited expositors (Habakus and Holland 2011; Fisher 2010). This gulf has been unbridgeable. There is no alternative organization that is scientifically mainstream yet independent and critical. It did not have to be this way. One can imagine a diverse movement of vaccine critics who could represent a range of scientific attitudes and political ideologies and who might gain considerable policy-making access. To understand why this is not our reality, we have to look carefully at the membership and reasoning of vaccine critics.

Methodology

My analytic method was designed to explain the most prominent arguments of the vaccine critics and the worldviews underpinning them, to chart the broad resources of the movement (people, money, interactions between organizations), and to reveal the tensions leaders confront in constructing legitimate and intelligible arguments (Williams 2004: 102–105). Vaccine-critical groups share an *internally* bounded world in which both individuals and ideas enjoy legitimacy, but undercut the groups' *external* legitimacy in the policy and governmental world. My approach carefully explicates the internal world of vaccine-critical organizations, showing what is legitimate within it, and compares that with the legitimacy standards of the mainstream scientific and policy world. Tensions appear where advocates fail to dictate the terms of the debate, such as framing the current vaccine safety system as hopelessly corrupt, or where certain options are not selected by movement leaders, such as disavowing publicly discredited scientists. I draw on a wide range of observational and primary sources to connect people and resources to specific arguments and pay careful attention to the upward or downward trajectories of those arguments. I have observed leaders addressing their own members as well as addressing government officials and the public. Going back and forth between internal arguments and public presentations captures exactly the theoretical trouble at the heart of this article: how do commitments within an organization undermine its legitimacy over time in the policy world?

I gathered much of my data by attending the 2009 NVIC conference.

There are other conferences organized by vaccine critics, most notably Autism One, which meets every May in Chicago. That conference is geared to a parental audience interested in biomedical treatments, while the NVIC event was explicitly broader and more political.⁷ My focus on the NVIC event is fitting because this is a study of movement leaders and the arguments they make. Since that conference, I have heard some of those same activists make public comments in advisory committee meetings, conferences, and court events, where they are attempting to muster legitimacy to influence policy. For example, among the public events I attended was a June 2011 meeting of the Vaccine Safety Working Group, a subcommittee of the National Vaccine Advisory Committee, at which both NVIC president Barbara Loe Fisher (2011) and Sallie Bernard (2011) of SafeMinds argued for policy changes in the vaccine system.

Legitimacy is attached to individuals, and the makeup of an organization shows what interests are powerful within it. Closely categorizing the people who make up the public face of the NVIC, the organization with the clearest history of policy legitimacy, helps reveal the tensions in its legitimacy maintenance. There were forty-two speakers and moderators at the NVIC event, resulting in more than thirty-three hours of speeches, and a claimed six hundred participants attended. I categorized each speaker as activist (13, or 30 percent), alternative health practitioner (9, 26 percent when combined with health gurus, distinguished by their commercial enterprises), mainstream scholar or doctor (7), media (6), critic scholar or doctor (6), health guru (2), or lawyer (5).⁸ Everyone but the mainstream-denoted speakers was strongly critical of the entire vaccine program (and even a few of the latter voiced opposition given my forgiving classification scheme), most of them in strong enough terms to be called antivaccine

7. Autism One is also known for excluding journalists perceived to be hostile to the conference's message, while the NVIC event was explicitly open to the public. My IRB approval does not include any deceptive presentation, nor would I have been comfortable posing as a parent of a child with a disability.

8. A few speakers were placed in two categories, for example, a chiropractor who had a law degree and spoke about health freedom using examples from legal decisions involving chiropractors was classified as both alternative health and lawyer. To be mainstream the speaker had to have training and a position that would be credible outside the conference and at least endorse the notion that vaccines work. This was a fairly low bar and if there was a close call, I classified the person as mainstream. Dr. Bob Sears (2007), famous for his alternative vaccine schedule, was counted both in mainstream doctor and critic doctor because he believes vaccines work and that some diseases are worth vaccinating against, but his reputation is built from his alternative vaccine schedule, which implies that the CDC-recommended schedule is unsafe (Offit 2010: 171–190). Critic scholars or doctors were those who have made reputations out of criticizing vaccines, who subscribe to conspiracy theories, or who make arguments that vaccines do not work.

(i.e., arguing that vaccines as a whole are dangerous, do not work, and should be avoided). This scheme forms the basis of my typology of vaccine critics below.

I attended many sessions in person and took notes or, for the ones I missed, listened to the official audio recordings that I purchased. Three of the more foundational speeches were professionally transcribed; otherwise I have relied on my own contemporaneous notes and the purchased recordings for content analysis. Because of the variation in my notes (some handwritten, most typed, only three transcribed), I did not use software such as NVivo for coding. Instead I defined which arguments were most prominent by combining techniques of counting appearances on the program, noting relative arrangements on the program to see “star power” (e.g., those scheduled at the height of attendance on midday Saturday), crowd reception and numbers (e.g., standing ovations versus a relatively empty room), and Internet searches to see which speakers were regulars on this circuit and were well connected to the organizers. Many assertions were repeated by different speakers in relatively straightforward terms. Recording was not permitted at any of the other legal or governmental settings I observed, so I have relied on handwritten notes.

My method here is limited in that it does not include interviews with vaccine-critical leaders. Key figures politely declined my requests for interviews. Moreover, conference speeches, press conferences, and public testimony are staged events, so I can make claims only about the public face presented. I have no access to internal decision making or to leaders’ feelings. The quality of the primary sources on which I rely is nonetheless very high, representing leaders’ own words, publicly presented at length in several contexts over two years (from the 2009 conference to a 2011 government meeting), combined with my own personal exposure to the contexts in which those words were uttered.

A Typology of Vaccine Critics

I present the different types of critics here in descending order of their importance within the movement. From a distance, it seems puzzling that vaccine-critical organizations would continue to take legitimacy-depleting positions and fail to differentiate themselves from each other, passing up opportunities to gain policy influence. But once we understand the composition of the membership and the reasoning behind their worldviews, it becomes clear that personal and ideological commitments made other outcomes highly unlikely.

Activist Parents

All of the most prominent vaccine-critical groups of the past three decades were founded by parents. Many of the parent leaders also overlap with members of the other categories, of course, but they deserve mention as the most important force behind vaccine criticism. Most have a mobilization story linked to their child's diagnosis with disabilities they attributed to vaccines. For Fisher, it was her son's reaction to the DTP vaccine; for the new wave of SafeMinds and Generation Rescue, it is regression into autism (or sometimes attention deficit disorder or learning disabilities). These leaders tend to be white and middle to upper income with college degrees. Some, like Fisher, are professionals in the true sense of the word, drawing a salary and a career from their advocacy. Others use their prior professional skills and flexibility to reinvent themselves, as Louise Kuo Habakus did when she left a high-powered career as a senior business executive, became an alternative health practitioner, and founded LifeHealthChoices.com and the Center for Personal Rights. Stay-at-home mom Dawn Richardson's work in Texas to expand vaccine exemptions (2003) and to fight off the human papillomavirus (HPV) vaccine mandate (2007) shows how effective parents can be (NVIC 2011b).

Allied Professionals with Long-Standing Antivaccine Views

The next most influential and important base of opposition to vaccination comes from alternative health professionals and entrepreneurs with long-standing philosophical, ideological, and political disputes with the mainstream medical and public health establishments. There are in turn two differently motivated subgroups here: alternative health care providers like homeopaths and chiropractors who oppose vaccinations for reasons traceable to the principles underlying their profession (Wiese 1996; Campbell, Busse, and Injeyan 2000) and traditionally trained medical doctors who oppose mandatory vaccination as part of a libertarian political ethic. Members of this two-pronged group are thus not necessarily parents and may have no personal link to anyone who has had a problem with a vaccine. There have been internal tensions between activists working for mainstream attention and some more radical alternative health promoters, termed "fringies" because they attack the germ theory of disease and embrace conspiracy theories (Johnston 2004: 279).

These professionals provide critical funding and publicity to the NVIC,

and they are a common alternative source of credibility for parents' decisions not to vaccinate (Campbell, Busse, and Injeyan 2000). They have been a core part of the NVIC for many years and are less linked to the autism-focused arm of the vaccine-critical movement. The NVIC received a donation from a group of chiropractors in 1993 that saved the organization from being shut down and focused Fisher's attention on, in her words, "a larger fight for freedom of choice in health care" waged by alternative care providers like chiropractors and homeopaths (Johnston 2004: 271). The 2009 NVIC conference program was filled with advertisements and thank-yous to these professional groups and to the generosity of such health gurus as Joe Mercola (also a funder of the Times Square Jumbotron ad that questioned vaccines) and Gary Null, both successful authors, speakers, and purveyors of supplements and alternative health products. Speakers from these professions (or adopting its perspectives) were featured prominently and repeatedly throughout the conference schedule.

These professionals share an antiregulatory political agenda that keeps them in opposition to government regulation of supplements by the U.S. Food and Drug Administration or to health care reforms like the Patient Protection and Affordable Care Act or the creation of registries and tracking of vaccination rates. The libertarian physicians are opposed to electronic medical records, for example, and no one who shares their perspective would support participation in the public health surveillance that would help to monitor postlicensure safety of vaccines and drugs (e.g., a national vaccine registry). Members of this group hold the most extreme views, such as denying that HIV causes AIDS (Null 2001), so managing the balance between pleasing them and keeping their views from hurting wider credibility is a big challenge. There is not a vaccine safety movement separate from the influence and funding of these antivaccine subgroups, and they are not likely to diminish in strength or to change their views.

Donors

Donors overlap considerably with other categories but deserve mention on their own. Wealthy parents of children with autism have created and sustained Generation Rescue and SafeMinds. SafeMinds (2010) has given nearly \$1 million in research support for projects linking vaccines and autism and claims to be the largest nonprofit private source for research on that connection. Critical donors to NVIC come from across the political spectrum, which probably explains the leadership's careful management

of a nonpartisan image. The biggest funder of the 2009 conference was the Albert and Claire Dvoskin Family Foundation (NVIC 2009). The foundation was also the source of a \$75,000 challenge grant announced at the conference. The grant's purpose is to enable the NVIC to fund its own research into vaccine injuries, such as a much-touted study comparing the health of vaccinated and unvaccinated children. The Dvoskins are major Democratic Party donors, hosting frequent fund-raisers and attending dinners at the Barack Obama White House (Farnstrom 2007). Generation Rescue founder J. B. Handley has also given generously to Democratic Party candidates.⁹ Other funders for the NVIC are Republican Party donors or supporters of libertarian candidate Ron Paul. Paul was by far the most frequently mentioned politician at the conference, with enthusiastic applause each time.

Researchers

Even though it is spurned by mainstream scientific and medical organizations and journals, the vaccine-critical movement gains an essential tool for credibility from its own cadre of researchers. They are funded from within the vaccine-critical movement, as I noted above, though some also maintain mainstream research grants. The published research they produce is used in litigation and publicity to criticize the government's assertions that the vaccines have been shown to be safe. Some of these researchers are located outside mainstream organizations and universities, and lack access to grants and publication sites seen as legitimate. They publish in such journals as *Medical Hypotheses* and the *Journal of the American College of Physicians and Surgeons*, which are not carried in libraries or listed in search engines, do not use traditional peer review, and receive little respect from mainstream scientists. The most famous member of this group is Wakefield, but the father and son team of Dr. Mark Geier and David Geier are a primary source of widely cited articles about vaccine damage and links to autism. The Geiers have been the only source of epidemiological research purporting to show a connection between vaccines and autism, but their work carries no weight whatsoever outside anti-vaccine circles, and not even the statistician testifying for the families in the OAP would endorse them (*King*: 87). Mark Geier has recently had his medical license revoked in multiple states, and his son has been charged

9. All data on individual political contributions are from searches on the Web site Open Secrets.org, run by the Center for Responsive Politics.

with the illegal practice of medicine, but they were both featured speakers at the May 2011 Autism One conference sponsored by Generation Rescue (Tsouderos 2011).

Other researchers whose work is touted as pointing toward a vaccine-autism connection come from the mainstream of academic research, such as Mady Hornig at Columbia's School of Public Health (Hornig, Chian, and Lipkin 2004), Jill James at the Arkansas Children's Hospital Research Institute (James et al. 2004, 2009), and Richard Deth at Northeastern University (Deth et al. 2008), who testified for the petitioners in the autism compensation cases. All of them have also been active in the antimercury autism cause for some years, however, and have been funded by and worked closely with SafeMinds (Kirby 2005: 337, 346–348). Critically, their studies are animal models using mice or primates or *in vitro* studies of mercury in cells, in contrast to the evidence that the mainstream understands to be much more definitive: the large-scale epidemiological studies of human populations that show no association between thimerosal and autism.

Moreover, any expert willing to opine that vaccines cause autism has already been through the compensation court hearings and has been found to be unpersuasive. An activist mother who believes vaccines cause autism pleaded with the special masters at a recent vaccine court question-and-answer session to help parents find experts to testify on their behalf because, as she put it, that is where the cases “fall off a cliff.” At that event, the special masters cautioned petitioners' attorneys not to bring back any more of the same unpersuasive experts or to rehearse the same arguments that had been unsuccessful, but they made it clear that they would be willing to hear new evidence from new experts in new cases. Vaccine critics continue to try to produce new research, but the big question is whether there are any credible researchers left to act as conduits and translators of it. The National Institute of Allergy and Infectious Diseases (NAID, part of the National Institutes of Health [NIH]) put out a program call in 2008 to fund research into vaccine safety, which is exactly what critics have been asking for. It was clear during a recent government advisory committee meeting at which this initiative was presented, however, that the response from the mainstream academic research community had been disappointing (perhaps because continued availability of the funds was not guaranteed). Credible research into vaccine adverse events is going to have to come from the bench scientists of academia, with their established labs, graduate students, and postdocs, and will require an ongoing funding commitment from such sources as the NIH and NAID.

Journalists, Bloggers, and Other Media Producers

While the leaders of the vaccine-critical organizations have popular blogs and Web sites, there are also media professionals with high profiles who include vaccine-critical articles as a major component of their product. The book *Evidence of Harm* (written by the journalist David Kirby) and Robert F. Kennedy Jr.'s *Rolling Stone* article "Deadly Immunity" (2005) were important publications for the thimerosal-autism thesis, and both men continue to be associated with it.¹⁰ The most important current media sources (based on their validation in survey and interview research about where parents get vaccine-critical information, Internet prominence, and their prominence according to speakers at the NVIC conference) are Peggy O'Mara's *Mothering Magazine* and Arianna Huffington's Huffington Post blog. Parents mention *Mothering Magazine* as a trusted source in their decision to delay or refuse vaccines (Fredrickson et al. 2004; Benin et al. 2006). At the 2009 NVIC conference, O'Mara (who received an award for promoting and protecting nonvaccination) explained how the blog magnifies and validates Internet news critical of vaccines: "First it's on Huffington Post, then it's on Larry King." With the news of the AOL/Huffington Post merger, a big question is how the "strip mall for quackery" (Whelan 2011) on the blog will merge with the more mainstream AOL content: will it give antivaccine views an even wider readership or force them to take a backseat in the interest of AOL's mainstream legitimacy?

Both O'Mara and Huffington direct media enterprises known for other topics and causes, thereby enabling their antivaccine messaging to reach a wider audience and to share the patina of the host's credibility. Besides simply getting antivaccine messages out widely, these popular sources nurture the issue on the political left while leaving the impression that it is a progressive cause. The fact that the readership of HuffPost and *Mothering Magazine* probably does not overlap at all with the membership of the American College of Physicians and Surgeons helps explain why there has not been more fracturing along ideological lines within vaccine-critical circles; the opposing groups do not encounter each other because of media and organizational specialization and fracture. Another compelling explanation is that the healthism and lifestylism so popular on the left has elevated personal empowerment and individual responsibility so much that it is hardly distinguishable from right-wing health libertarianism.

10. The Kennedy piece has been widely criticized for its inaccuracies and has since been retracted by Salon.com, which had copublished the piece (Lauerman 2011).

Celebrities

There are several well-known celebrities who promote vaccines as the cause of autism, particularly Jenny McCarthy, her former partner Jim Carrey, Don Imus, and Robert Kennedy Jr. I place celebrities last in influence within the vaccine-critical movement, however, because activists repeatedly expressed frustration that anyone would think they could be so easily swayed by a celebrity and insisted that their concerns were based on real science. Neither SafeMinds nor the NVIC has a celebrity counterpart to McCarthy for Generation Rescue. As I have noted above, there is indeed a complex community of researchers, journals, and articles to point to, facts to recite, conferences to attend, and professional groups to connect with that supply a great deal of internal legitimacy. There is no need for McCarthy for anyone with these ties, and her visibility has been somewhat problematic for legitimacy when leaders would prefer to present their objections as scientifically grounded.

Competing Underpinnings of Vaccine Criticism

What are the underpinnings of antivaccine and vaccine-critical views? I present the three dominant and competing frames for vaccine criticism, showing how legitimate safety concerns are undercut by persistent anti-government sentiment and alternative health visions, both of which are deeply antithetical to mainstream approaches to vaccine policy.

Holistic Health Ontology

The holistic health ontology undergirding the most radical antivaccinationists is a profoundly oppositional view of what vaccines do in the body and what health is. I call it an ontology because it proposes a different account of reality from the mainstream medical story of health and disease. The holistic health ontology has an accompanying historical narrative about how vaccines do not work and have systematically caused widespread damage since their invention. Eleven of the forty-two speakers at the NVIC conference came out of this tradition (classified as alternative health practitioners and gurus), and many of those classified as activists (thirteen of forty-two) explicitly endorsed it as well. On this view, diseases of the past were actually defeated by sanitation, homeopathy, and nutrition, not vaccines. Attributing their vanquishing to vaccines is part of the orthodoxy of mainstream medicine. The foundational disagreement

is whether the germ theory of disease is central to medicine (for a book-length treatment, see Baker 1994, Appleton 2002, and Trebing 2004). As Palevsky (2009) put it in his conference address: “So, in our conventional teaching, there’s this germ theory. And the theory is that microorganisms are the cause of many diseases. . . . Might I say that this is just a theory. Germs may play a role in children getting sick, but they may not be the reason that children get sick.”

So when vaccine critics claim to be opposed to the germ theory of disease, what exactly does that mean? They are not denying that bacteria and viruses exist. Rather, they wish to reorient health toward maintaining a robust balance in the individual who will then not be susceptible to diseases, infectious or chronic. The argument is really about what causes ill health—something from the outside, like a pathogen, or imbalance on the inside? And what should be done to fix it—go to an expert and take a pill or take responsibility for maintaining balance and defenses ourselves? The key concepts in this account of health are balance, susceptibility, toxicity, and fragility. Palevsky’s account is a fascinating bricolage of chiropractic theories, mainstream and alternative medicine, and environmentalism. Balance and susceptibility have been foundational concepts in chiropractic approaches to disease for over a century (Wiese 1996), and the NVIC has had long-standing ties to the conservative wing of the chiropractic profession since the 1990s when a donation from a group of chiropractors saved the organization from financial ruin (Johnston 2004). Likewise, the notion that vaccines and medicines are pollutants that block self-healing within the body is a long-standing part of the chiropractic approach (Campbell, Busse, and Injeyan 2000). Fragility means assessing small exposures as potentially devastating to a body that is easily overwhelmed and in need of attentive caretaking and detoxification. Concerns about environmental pollutants have been widespread for decades (Brown 2007), and SafeMinds’s mission grows from this source rather than from the alternative health professions. All these pieces together help explain how antivaccine views have remained dominant within these organizations. Not only do they tap into widespread concerns about overuse of consumer products and contamination, but they have roots in professional disputes that are over a century old.

The Libertarian Health Freedom Perspective

A second version of a radical antivaccine underpinning comes from the libertarian health freedom movement. This movement is built on a polit-

ical theory of government illegitimacy in all health care matters. Any structures of national health care including Medicare, tracking systems or registries of any kind, infant heel blood collection, vaccine requirements, and even the whole edifice of national administrative agencies dating from the New Deal (as one attorney argued at the conference) are considered illegitimate. Eleven of the forty-two speakers at the NVIC conference explicitly invoked these antigovernment themes from health, legal, and activist perspectives. Speakers included activists from the Citizens' Council for Health Freedom ("a free market resource for designing the future of health care"), whose primary targets were registries ("tagging and tracking") and collection of infant DNA for genetic screenings. Vaccines are barely mentioned on their Web site (and only an outdated link about smallpox from 2002), with most of the attention focused on opposing "Obamacare" and any government monitoring of health records or medical information (Citizens' Council for Health Freedom 2011). The Citizens' Council for Health Freedom appears to be composed of non-physicians, while the American College of Physicians and Surgeons is an ideologically right-wing private doctors' group that opposes government intrusion into health care in any form (2010). The group's journal has been a mainstay of antivaccine research publishing, though vaccine criticism does not appear on its Web site's list of issues (American College of Physicians and Surgeons 2011).

Why, if vaccines themselves are not a major policy focus, is the health freedom movement nonetheless closely linked with vaccine criticism? First, both movements share the same enemy: the public health establishment backed by the power of the state. Vaccine mandates enforce a collective good of population-level immunity. Second, the libertarian politics of vaccine skeptics fit very well with the holistic health ontology because both place responsibility with the individual. The vaccine-critical movement is quintessentially neoliberal, blending holistic self-care with the elevation of the individual and the private family over collective goods. A mother's management of every possible risk to her own children becomes paramount (Kaufman 2010). The phenomenon of strange political bedfellows in vaccine opposition is no longer mysterious once we consider how the politics of health have joined the Right and the Left together in the agreement that personal vigilance is the key to lower health care costs (Blume 2006; Kirkland 2011).

The Vaccine Safety Perspective

The vaccine safety view, by contrast, does not overtly dispute the basic presumptions that vaccines work and that germs can be dangerous and are thwarted by immunization. Critics who work with policy makers on vaccine safety issues could maintain legitimacy and influence, but that depends on their maintaining distance from more radical holistic health and libertarian viewpoints. Safety advocates insist that the lives and health of the small number of children who will experience an adverse reaction should not be sacrificed for the good of the majority, and that they matter just as much as the children who may come down with a vaccine-preventable disease. The concerns of these advocates center on information, accountability, and choice. The theme of choice is easily explained: in the absence of adequate assurance of safety, critics argue, individuals should be able to choose freely whether to assume the risk of vaccination for themselves or their children (without consequences like exclusion from school or the need to jump through hoops for exemptions).

The argument based on information is that we do not have enough reassurance that vaccines are really safe. Two calls for more scientific research on vaccine safety are the most important in the movement now: what I call the “vaccinated versus unvaccinated study” argument and the “hypersusceptible genetic minority” argument. The study that critics want is one comparing children who have had no vaccines at all with those who have had the full schedule at the recommended times. As Vicky Debold, an NVIC board member who also sits on a federal advisory committee, put it: “We ask that the government begin to fund research that evaluates the effect of vaccination, against no vaccines at all, on biomarkers of immunity, biomarkers for metabolic dysfunction, neuro-developmental outcomes, including autism, immune-mediated illnesses of all sorts, autoimmunity, allergies, asthma, epilepsy, intellectual and learning disabilities, all the things that we know are epidemic in our children. We ask for all of that [applause].” The National Vaccine Advisory Committee (2009: 82), responding to Debold and others, recommended that a body such as the Institute of Medicine look into the feasibility of doing a comparative study of vaccinated, vaccine-delayed, and unvaccinated children. The NVAC report marks a unique moment of cooperation between vaccine critics and government, and shows that there can be legitimate disagreements and some common ground.

Vaccine safety advocates also want more information about whether a subpopulation exists that is much more susceptible to vaccine injury

than others, how to find them, and how to protect them. This subpopulation is a minority group requiring rights protections, Fisher argues. The NVAC (2009: 69, 71) report advised collecting data on which reactions are more likely in populations such as children with siblings or parents who experienced a vaccine reaction or those with mitochondrial dysfunction. The Vaccine Safety Working Group is also dedicated to expanding basic research to discover susceptibilities to adverse reactions. There is general agreement on this goal, but it does not include as broad a definition of susceptible minority as advocates describe, nor is it clear how susceptibility would be determined and who would decide. Advocates would prefer parents decide and simply opt out if they suspect they may be in the susceptible group.

Vaccine safety advocates also argue that the government's vaccine program needs more accountability. They maintain that the current system is beset with conflicts of interest, since the same government agencies both promote vaccine use as well as regulate adverse events. Both SafeMinds and NVIC (2011a, 2011b) want Congress to hand vaccine safety monitoring over to a new independent agency, wholly separate from licensing and promoting vaccines. Another frequent criticism is that the vaccine manufacturing industry works too closely with government policy makers. (While the Institute of Medicine does not allow its committee members or their families to have any ties to pharmaceutical companies, two of the seventeen members of the NVAC are representatives from the vaccine industry.) And finally, critics note that the vaccine injury compensation system has become more adversarial and less likely to compensate petitioners (Holland 2010; Willner 2010).

Grounds for Engagement?

The main question for policy makers about the safety advocates is whether their recommendations can be separated from their past history of supporting delegitimized science. The few leaders who hold seats on federal advisory committees are clearly respected as individuals, but they are in the difficult position of representing a much more radical membership. The NVIC membership present at the conference absolutely believes that any comparative study would reveal that vaccines cause illness and disability in children on a wide scale and that corrupt officials conspired to conceal it. Would their membership support an independent agency for vaccine safety or a new NIH-funded study if these measures did not affirm that vaccines cause autism and a host of other chronic illnesses?

Under what conditions could we imagine leaders reporting back at a later conference that the right study had finally been done and proved them wrong? This audience hissed at George Annas's assertion that the science was clear on thimerosal and groaned at Dr. Bob Sears's limited defense of vaccination. Given the makeup of the organizations and their reasoning, they seem unlikely to disavow all the internally legitimating structures they have built (their own studies, journals, and scientists).

Everyone agrees there should be more research into vaccine safety, particularly vulnerability to adverse reactions, but policy makers and critics hold incommensurable views of the details of such studies. For instance, no study that randomizes children to go unvaccinated would pass ethical muster in the mainstream (though critics who think vaccines do not work anyway would not see the ethical problem). Vaccine defenders point out that there are not even enough fully unvaccinated kids in the entire country to enroll in a retrospective study that would command the statistical power to change anyone's mind (Prometheus 2008).¹¹ Moreover, critics do not trust any researcher who has taken government research funds (e.g., NIH grants), so it is difficult to see how any study produced through the usual channels (government-, university-, NIH-, or pharma-funded, for example) would be credible to them. The independent researchers associated with NVIC and SafeMinds such as the Geiers and Wakefield are considered completely illegitimate in the scientific mainstream and among policy makers. As my typology makes clear, there is virtually no agreement on who counts as a credible expert.

Strategies at the Limits of Legitimacy

Vaccine critics have built an alternative world of internal legitimacy that mimics all the features of the mainstream research world—the journals, the conferences, the publications, the letters after the names—and some leaders have gained access to policy-making positions. Mixing an environmentally inflected critique of vaccines and Big Pharma with a libertarian individualist account of health has been a resonant formulation for some years now, with support flowing in from both the Left and the Right. Critics have had a significant impact: surveys show significant

11. Indications are that a vaccinated versus unvaccinated study might not show what advocates want anyway. A recent study from Germany compared completely unvaccinated children with those who had had at least one vaccine and found no significant differences in allergies or colds except that the unvaccinated ones were more likely to get vaccine-preventable diseases (Schmitz et al. 2011). The study did not look at autism.

pockets of people who think vaccines cause autism (Freed et al. 2010); rates of vaccine uptake in some areas are significantly down and outbreaks are more likely to occur there; exemption requests are up (Omer et al. 2006); state laws allowing exemptions became more permissive (Salmon et al. 2006); and government response has included outreach to understand vaccine hesitation as well as expanded funding for studies of vaccine safety (National Vaccine Advisory Committee 2009). Resources within the movement—committed, experienced activists, donors, and allied professionals—remain stable and even reenergized by recent legal setbacks.

But arguments justifying nonvaccination on the grounds that vaccines cause autism have been well outside the mainstream since at least the mid-2000s. Claims that were reasonably testable have been tested and rejected by the research community. The most prominent scientists still arguing in favor of a connection have been ritually dismissed from their professions and from all respectable scientific company. There are no more credible experts left willing to publicly defend the connection. All the test cases in the OAP were lost, and news of pertussis and measles outbreaks have reminded the public that vaccine-preventable diseases can return (Mnookin 2011). The favorable political climate of a decade ago has evaporated. A bill to expand exemptions in New Jersey has stalled while the religious exemption has been tightened up (Friedman 2011), Washington State (with the highest opt-out rate in the country) enacted a stricter exemptions law (Washington State Department of Health 2011), and a New Hampshire House committee recently killed a philosophical exemption proposal (Schoenberg 2011). Oklahoma and California have new requirements for a whooping cough booster before school enrollment in the fall (California Department of Public Health 2011; Oklahoma State Department of Health 2011).

The autism hypothesis galvanized significant resources and attention for vaccine criticism, but its dramatic specificity caused movement legitimacy to rise and fall with it. Commitment to the autism hypothesis among the parent-founded groups like SafeMinds has meant they must characterize the vaccine governance program as complicit in poisoning children and covering it up. SafeMinds's public rhetoric is consistently more inflamed than the diplomatic tone Fisher of the NVIC strikes in public presentations. The interesting counterfactual to consider here is whether the NVIC, the oldest vaccine-critical group with a past record of success in enacting policy, might have been able to differentiate itself from the parent-founded autism groups and manage the legitimacy trade-

offs differently.¹² The NVIC predates the autism controversy, had political access worth protecting, and would have had plenty of other vaccine safety policies to promote. Other health movements that have achieved high levels of policy influence and legitimacy accomplished it by combining lay scientific mastery that experts themselves respected with moral and political mobilization they could not ignore (Epstein 1996). This route would have meant backing off from the autism connection as well as promoting a much narrower conception of vaccine injury than the NVIC has embraced, however. Organizations rarely frame their goals in ways that diminish their sphere of influence or fail to position themselves at the vanguard of new social problem. The most important reason for this path not taken, however, is the NVIC membership base. As I have argued, once the NVIC focused its membership base on alternative practitioners with a long professional history of antivaccinationism and on health libertarians, it fostered an internal legitimacy but sacrificed external legitimacy in the policy world.

There are some hints that activists are moving away from some of the discredited arguments of the early part of the last decade. New rhetorical frames that do not rely so much on scientific validity may harness legitimacy from other arenas. Emerging leaders in the Coalition for Vaccine Safety have adopted a rhetoric of human rights to protest vaccine mandates, which may resonate with progressives and help globalize their cause (Habakus and Holland 2011). Perhaps searching for a broader rationale for its antimercury activism, SafeMinds (2009) has adopted the goal to “eliminate coal as a fuel for energy generation” because coal-fired power plants are a major source of environmental mercury. SafeMinds’s dilution of emphasis on vaccines could capitalize on the environmentalist, Left-leaning strengths of the vaccine-critical movement and help leaders ease away from less credible claims. The activist-parent base of the Coalition for Vaccine Safety may be more progressive on environmental regulation and human rights than the more libertarian base at the NVIC, and this could undergird future differentiation among the groups. At the NVIC, Fisher’s attempt to frame people who experience vaccine reactions as an oppressed minority may gain more traction if evidence develops to help

12. Paul Offit (2010) takes up a similar counterfactual about the NVIC, asking why it missed opportunities in the 1990s such as pushing the switch from the oral polio vaccine, which caused polio in a few children every year, to the inactivated polio vaccine, which does not. The parent-activist John Salamone, who does not agree with the NVIC’s premises or approaches, spearheaded this effort instead.

constitute such a new identity group. There is broad support in government for finding out how adverse events happen at the biological level, which individuals might be likely to experience them, and how to approach those individuals (U.S. Department of Health and Human Services 2011: 22–25). A safety organization devoted to the interests of a vulnerable subgroup that everyone agrees exists would have a highly legitimate mission. The big question about all these shifts is their relationship to the autism hypothesis. Are these movement goals reformulated in the service of continued insistence that vaccines cause autism or part of a broader agenda in which the purported link will have diminished importance?

There will no doubt continue to be a vaccine-critical movement composed of all the parts described here, but it will be interesting to see how different components manage this new context of diminished scientific resonance for the claims of the last decade. One view of the role of advocacy groups in democratic government is that they play a critical role in keeping important items on the agenda, synthesizing information for the general public, and promoting accountability. Vaccine safety is a critically important public concern, but I fear we have not been well served by leading groups who currently own the issue. My hope is that vaccine safety advocates will reorient themselves toward critical yet epistemically responsible collaboration with vaccine policy makers. Unfortunately, that route looks increasingly difficult because of the alliances that have held the movement as a whole together.

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