

Boundary Work and the Construction of Scientific Authority in the Vaccines-Autism Controversy

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Abstract

The controversy about vaccines and autism presents an opportunity to explore how science is constructed in public debates about health and medicine. Rhetors who argue against a connection between vaccines and autism insist that their opponents are irrational, while rhetors arguing for a link insist that their fears are rational indeed. This analysis poses an alternative way of understanding the vaccines-autism controversy, suggesting that it is partly fueled by differing perceptions of the boundary between science and non-science. Using the concept of boundary work as a lens, this article uses generative rhetorical criticism to examine artifacts within the controversy and explores rhetorical constructions of scientific evidence, the forum of scientific discourse, scientific expertise, and the scientific capability. The findings suggest that rhetors' awareness of disciplinary boundaries is just as important in the construction and reception of their arguments as their knowledge of scientific facts and principles.

Keywords

rhetoric of science, boundary work, rhetorical criticism, vaccines, autism

The controversy about vaccines and autism began in earnest in 1998 with the publication of a case series in *The Lancet*. The study, conducted at London's Royal Free Hospital by Wakefield et al. (1998), suggested the possibility of a link

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between the measles–mumps–rubella (MMR) vaccine and autism. Coupled with reports of rising numbers of autism diagnoses, the study breathed new life into old anxieties about vaccine safety. Fears about the ethylmercury-based vaccine preservative thimerosal fueled the controversy as well, particularly in the United States. Although several large-scale epidemiological studies have failed to find any evidence of a connection between vaccines and autism, many parents delay or refuse vaccines for their children, which has resulted in the reemergence of once-rare communicable diseases such as measles and pertussis. The persistence of the vaccines-autism controversy among members of the public presents an intriguing rhetorical problem. How have so many become persuaded that vaccines are unsafe? And how were they convinced that the risk for vaccine damage outweighed the risk for potentially fatal diseases to reemerge?

To examine these questions, I conducted a generative rhetorical analysis of five artifacts within the vaccines-autism controversy, all nonfiction books that were written by an important figure in the controversy or that drew significant media attention to the issue. Three of these works argued in favor of a vaccines-autism link, and two argued against a link. The five artifacts were the following:

1. Kirby's (2005) *Evidence of Harm*, one of the earlier works written on the controversy, which follows a group of parents seeking acknowledgement of and compensation for the damage to their children allegedly caused by vaccines;
2. Wakefield's (2010) *Callous Disregard*, in which Wakefield attempts to refute the many allegations made against him in the aftermath of the 1998 *Lancet* study;
3. McCarthy's (2008) *Mother Warriors*, a compilation of McCarthy's own story of treating her son's autism and stories from numerous parents who believe their children's autism was caused by vaccines;
4. Offit's (2008) *Autism's False Prophets*, in which Offit (inventor of the rotavirus vaccine and prominent figure in the controversy) points to the many ways in which those who advocate a link between vaccines and autism have taken advantage of parents seeking answers for their children's difficulties; and
5. Mnookin's (2011) *The Panic Virus*, which argues staunchly against a vaccines-autism link and earned a great deal of favorable coverage in major media outlets.

Together, these five texts provide representative examples of the many claims and reasons offered for and against a vaccines-autism link.

I analyzed these works using generative rhetorical criticism as described by Foss (2009), in which the critic codes the artifacts generally, identifies major categories, recodes the data, then develops an explanatory schema based on the results of coding and analysis. This article discusses one cluster of my findings: representations of science in the vaccines-autism controversy. I argue that rhetors on either side of the controversy differ significantly in their constructions of science, evidence, and expertise, and that these differences play a key role in

shaping the controversy. Those who believe in a connection between vaccines and autism have often been characterized by their opponents as irrational and anti-scientific; meanwhile, rhetors who argue against a link between vaccines and autism valorize science and the scientific method, and harshly critique those who seem not to share their faith in scientific principles. I suggest in this analysis that the controversy is not merely a case of rationality versus irrationality. Rather, the controversy in part concerns the rhetorical process of distinguishing science from nonscience, what many scholars have called “boundary work.” I begin with a brief overview of scholarship in this area.

Boundary Work and the Construction of Scientific Authority

Many scholars have referred to science as orthodoxy, which Miller (2005) defines as “a body of doctrine and practices adhered to by a group that protects the doctrine and defends its own authority to determine both the doctrine and group membership” (p. 486). The term *orthodoxy* is typically associated with religion, but sociologists such as Bourdieu (1997) have picked up the term and extended it to nonreligious groups that share specific belief systems, norms, practices, and values. All groups have insiders and outsiders, and orthodoxies find it useful and important to mark the boundaries of membership—that is, who belongs to the group and who doesn’t. Orthodoxies use discourse to maintain these boundaries, and that process has been labeled *boundary work*. Although science is not the only field in which boundary work takes place, much of the scholarship on boundary work has emerged from scholarship in the philosophy, sociology, and rhetoric of science.

Gieryn (1983) defines boundary work as the “attribution of selected characteristics to the institution of science (i.e., to its practitioners, methods, stock of knowledge, values and work organization) for purposes of constructing a social boundary that distinguishes some intellectual activities as ‘non-science’” (p. 782). Scientists use boundary work to “enlarge the material and symbolic resources of scientists or to defend professional autonomy” (Gieryn, 1983, p. 782). In other words, to maintain the authority of science as an institution, rhetors seek to distinguish between what does and does not count as science, and to drive out those who threaten the orthodoxy.

Miller explains that boundary work is a rhetorical process that often results as a response to those who challenge orthodoxy, what Bourdieu and others call “heretics”:

The response to heresy, as Lessl explains it, often strengthens orthodoxy, creating internal clarity and solidarity. The challenge of heresy makes it important to clarify not only doctrine but also the boundary between doctrine and heresy. Thus, there may be much attention to what sociologists call boundary work, and what

philosophers of science have called the demarcation problem: heresy is often driven out by defining it as nonscientific. (Miller, 2005, p. 487)

The labels “scientific” and “nonscientific” are powerful markers that Gieryn (1983) says are “useful for scientists’ pursuit of authority and material resources” (pp. 792–793). Moments in which orthodoxy is challenged present opportunities for its members to rhetorically redraw the lines of who belongs and who doesn’t.

An example may be useful here to demonstrate the rhetorical aspects of boundary work. Sullivan offers such an example when he explains that science maintains its boundaries at least in part through forum control, which he defines as “a supervision of official publications and speech, which may result in the denial of access to the community’s authorized means of communicating with its members” (Sullivan, 2000, p. 125). Processes such as peer review, retraction, and public ridicule are some of the rhetorical means by which members of a community maintain control over the forum of discourse. Sullivan explains:

Forum control of this kind need not be considered sinister even though it is nothing short of censorship. Religious or ideological groups, special-interest groups, or specialized groups (such as professions or disciplines) should have, in my opinion, the freedom and responsibility to define their own boundaries, control their own definitions of membership, and certify that publications that receive their imprimatur represent orthodox views. (Sullivan, 2000, pp. 125–126)

In other words, forum control is neither good nor bad; it is an essential element of any group’s activities. But, Sullivan adds, the means of forum control are worth exploring and critiquing because “[a]lthough techniques of forum control are necessary, they are, nevertheless, exercises of political power” (Sullivan, 2000, p. 126). The decision to authorize someone to participate in the conversation affords that speaker a certain degree of power; likewise, the decision to exclude a speaker from the forum limits access to power. Boundary work is therefore about power maintenance, and this maintenance occurs through rhetorical means.

There are some important caveats here that are worth noting. First, although this article focuses on the boundary between science and non-science, science is by no means monolithic. It is, of course, divided into numerous disciplines and sub-disciplines, with even more numerous specializations in between. Boundary work happens between science and non-science, but it also happens within science when those from different disciplines interact (Miller, 2005; Wilson & Hemdl, 2007). Second, boundary work does not always privilege science. For example, a study by Wainwright, Williams, Michael, Farsides, & Cribb (2006) found that scientists working in embryonic stem cell research defer to the

authority of non-science as they draw distinctions between what is and is not ethical—a reversal of the typical construction.

Third, boundary work is not always about exclusion and controversy. Wilson and Herndl (2007) find through their study of interdisciplinary projects at Los Alamos National Laboratory that “boundary work can sometimes become a struggle for understanding and integration rather than a contest, controversy, and demarcation event” (p. 132). They illustrate that boundary objects—rhetorical objects meant to facilitate collaboration between different groups—can “encourag[e] cooperation and mutual understanding” (p. 144). It is entirely possible for boundary work to be something other than contentious.

In this article, I explore how rhetors arguing for a vaccines-autism link attempt to expand the boundaries of science, and how rhetors arguing against a link attempt to maintain those boundaries. Each of the sections in this analysis focuses on a specific site where this boundary work takes place. The first section focuses on the question of what counts—or should count—as evidence for a vaccines-autism link. The second explores the boundaries of the forum of scientific discourse, particularly what counts as a scientific publication. The third section discusses the boundaries of expertise. The fourth and final section addresses expectations of what science can and cannot do.

The Boundaries of Evidence

To begin this exploration of how rhetors on either side of the controversy define science, I feel it is important to start at the ground level: what counts as evidence for rhetors on either side of the controversy. Rhetors on either side of the controversy disagree about what kinds of evidence should be admissible into the discussion around vaccines and autism—in other words, they dispute the boundary between evidence and nonevidence. I illustrate this dispute by exploring a specific example: the regression narrative.

The Regression Narrative and Pattern Recognition

The regression narrative is an essential component of the argument that vaccines cause autism. In this narrative, which appears repeatedly in the artifacts examined here, a child (usually a boy) is born healthy and meets developmental benchmarks, then suddenly changes within hours, days, weeks, or even months of receiving a vaccination. The following passage from Kirby is typical of this narrative:

Liz made sure that Matthew was taken to the pediatrician on schedule for all his routine visits and vaccinations. Then, at fourteen months, he was brought in for another round of shots, including his first of two scheduled vaccines against measles-mumps-rubella (MMR). Almost immediately afterward, Matthew began

to fall apart. The first night after his shots, Matthew developed a fever that spiked to over 101 degrees . . . The fever broke a few days later. Before Matthew could fully recover, he erupted in a rash of little red spots all over his torso . . . One day Liz came home from work to find Matthew staring up at the light fixtures, spinning like a top on the floor. In the next few days, she realized that Matthew did not always recognize her right away when she entered the room . . . Liz also noticed that Matthew had stopped learning new words. Not long after that, he stopped talking altogether. (Kirby, 2005, pp. 26–27)

The deterioration in skills and behavior observed in recently vaccinated children is an oft-repeated narrative in artifacts suggesting a link between vaccines and autism. The repetition of the regression narrative works to transform anecdote into evidence, allowing it to be employed as part of a larger argument connecting vaccines to autism. Wakefield, for example, cites this narrative as the impetus for his research, reporting, “In May 1995, parents started contacting me with the story that their normally developing child had regressed into autism or an autism-like state, with onset in the majority of cases soon after MMR vaccine” (Wakefield, 2010, p. 9). The plurality of anecdotes eventually is transformed into evidence of a larger problem. As McCarthy puts it succinctly in her introduction to Wakefield’s book *Callous Disregard*, “You hear this story once, it’s disturbing, a dozen times it starts to feel like a pattern, a thousand times and you begin to wonder why this is still a debate” (Wakefield, 2010, p. iii).

The concept at work here is pattern recognition, the ability of the human mind to see connections between phenomena. In artifacts claiming a link between vaccines and autism, these moments are represented as epiphanies, as leaps of intuition that reflect the intelligence and expertise of parents. Pattern recognition is what enabled parents to make the association between vaccination and their children’s subsequent regression into autism. It also enabled parents to see their own children’s experiences reflected in studies suggesting the possibility of the link, as parent Liz Birt does when she reads the Wakefield study in 1998:

Liz read the description and thought, “My God, this sounds like Matt.” Then she remembered that Matthew had received his first MMR vaccine at fifteen months. Within hours, he’d developed that soaring fever and, a week later, the red body rash and his still endless battle with diarrhea. At the time, it never occurred to Liz to connect the vaccination dots to her son’s illness. Now, she vowed to pursue the question with haste. (Kirby, 2005, p. 29)

These moments in which parents suddenly connect the dots between their children’s vaccines and autism are significant because the claim that vaccines cause autism originates with pattern recognition, moments in which two seemingly unrelated phenomena suddenly connect. And rhetors expect their audiences to accept the premise that the human ability to recognize patterns is a reliable source of evidence.

Doctors who promote a link between vaccines and autism uphold pattern recognition as a reliable means of identifying new phenomena, and they emphasize its essential role in science and medicine. “From modern medicine’s classical roots, pattern recognition has been a fundamental part of good medical practice and essential in the detection and description of new disease syndromes,” writes Wakefield (2010, p. 41). Citing the stories of several children’s regression into autism, he adds,

Emergent patterns will have been evident to those reading the children’s stories above. Genius is not required, but skilled, unbiased attention to the history and clinical findings is . . . [I]t was our duty as well as readily within our grasp to recognize and document emergent patterns of disease presentation. (Wakefield, 2010, p. 41)

In other words, Wakefield’s ability to recognize the repeating pattern of children regressing into autism gave him the means to identify what he claimed to be a new disorder. Humans’ capacity for pattern recognition is represented as a reliable tool for understanding the world, one that can lead to valuable new insights. Rhetors who believe in a vaccines-autism link, therefore, believe that parents’ observations should be considered valid evidence of that link.

But rhetors who argue against a vaccines-autism link do not consider the observations of parents to be valid evidence of a connection. They are unconvinced that the cognitive processes enabling humans to recognize patterns are consistently capable of producing meaningful information. Although it sometimes leads us to new insights, they argue, pattern recognition can also lead us astray; the seemingly causal relationship between a child’s vaccination and subsequent regression into autism is an example of the “after this, therefore because of this” logical fallacy. Mnookin offers this hypothetical tale of an ancestor of modern humans to help readers understand the origins of the human tendency to recognize patterns:

Imagine a primitive hunter-gatherer. Now imagine he sees a flicker of movement on the horizon, or hears a rustle at his feet. Maybe it was nothing—or maybe it was a lion out hunting for dinner or a snake slithering through the grass. In each of those examples, the negative repercussions of not taking an actual threat seriously will likely result in death—and the end of that particular individual’s genetic line. On the other hand, the repercussions of bolting from what turns out to be the shadow of a swaying tree or the sound of a gentle breeze will likely be nothing worse than a little extra exercise. (2011, p. 193)

The ability to recognize patterns serves an important purpose, allowing us to learn from our experiences and avoid hazards. But like many characteristics of the human mind, pattern recognition is an imperfect tool. It is “a tendency to connect the dots even when there are no underlying shapes to be drawn”

(Mnookin, 2011, p. 193). Patterns identified through personal experience are constructed as flawed, the result of human fallibility, and therefore do not count as evidence of a vaccines-autism link.

Because of their distrust in pattern recognition, rhetors who argue against a link between vaccines and autism are reluctant to accept the regression narrative. In *The Panic Virus*, Mnookin repeats some of Kirby's narratives about children regressing into autism, but these narratives mean something different in the context of an argument against a link between vaccines and autism. Mnookin and Offit's purpose in including such narratives is to illustrate the multitudinous ways in which autism becomes apparent in a child's behavior. Offit explains that parents often miss the subtle signs of autism early in their children's lives; in some cases, "children with autism could be detected even earlier [than their first birthday]. While looking at home movies taken before a child's first birthday, Canadian researchers found abnormal behaviors in some children as early as six months of age" (Offit, 2008, p. 219). But most parents don't notice the signs of autism until their children are at an age when language skills typically develop, leading the parents to implicate vaccines:

Because MMR is given soon after a child's first birthday, when children first acquire language and communication skills, it was a statistical certainty that some children who got MMR would soon be diagnosed with autism . . . But parents of autistic children perceived that their children were fine, got the MMR vaccine, and weren't fine anymore. (Although most children with autism show problems very early in life, about 20 percent will develop normally and then regress. It was this regression during the second year of life that caused some parents to blame MMR.) (Offit, 2008, p. 210)

Offit illustrates that emergence of autism symptoms around the time the MMR is given is an inevitable coincidence and distinguishes between parents' perceptions and the realities of child development. In other words, parents who connect a recent vaccination to a change in their children's behavior are seeing a pattern that isn't there.

One of the key differences, therefore, between rhetors who believe in a link between vaccines and autism and those who do not is what kinds of information they believe should count as evidence. Underlying this difference seems to be a disagreement about the reliability of human cognition—can we trust our senses, our observations, and our inferences? Rhetors who believe in a link between vaccines and autism uphold parent experiences and pattern recognition as the key to solving this dilemma. Rhetors who don't believe in a link consider these observations and inferences alone as unreliable, pointing to the significant potential for human error and our natural tendency to see patterns whether those patterns are actually present or not. If a claim is only as good as the reasons supporting it, rhetors on either side of this controversy fundamentally

disagree about what makes a claim valid or invalid. The result of these conflicting views on what counts as evidence ultimately shapes what counts as science.

A Broader Definition of Evidence

The regression narrative is one of many examples of parents coming to conclusions about the source and treatment of their children's autism based solely on their own observations and experience. These observations and experiences are valorized in the artifacts promoting a link between vaccines and autism. Implicitly and explicitly, these artifacts and rhetors seem to argue for a more inclusive view of evidence. Exemplifying this attitude, DAN doctor Jay Gordon writes in his introduction to *Mother Warriors*:

Evidence doesn't spring just from medical studies funded by drug companies and supervised by MDs and researchers on their payrolls. Evidence can come from the hundreds of families and doctors who have watched children with autism get better and even fully recover from the symptoms that have kept them from mainstream education and social opportunities. This is hard evidence and to deny it is specious reasoning and bad science. (McCarthy, 2008, pp. xvii–xviii)

Gordon's claim that evidence can come not only from institutionally sanctioned medical research, but also from individual experiences, morphs into an argument for a more inclusive definition of science. In fact, he goes as far as to label science that doesn't include this kind of evidence as *bad* science, attempting to not only expand the boundaries of science but redefine quality of scientific pursuits.

McCarthy conveys a similar belief during an appearance on *Oprah*, in which she discussed her claim that vaccines caused her son's autism:

Oprah finished with a statement from the CDC, which said there was no science to support the connection between vaccines and autism . . . I replied with all the love that I could muster in my heart. "At home, Evan is my science." (McCarthy, 2008, p. 9)

McCarthy's declaration that her son is her science exemplifies the way that the observations and experiences of parents are constructed as scientific evidence. The language choices rhetors use to discuss evidence reflect this transformation of personal experience into data. For example, in *Evidence of Harm*, Kirby describes how parents took it upon themselves to collect information they felt could be used as evidence to support their claims. The following passage, which describes how parent activist Lyn Redwood collected information through her personal website, exemplifies this shift:

Lyn included a link [on her website] where parents could send in reports on their autistic children. She was looking for accounts of children who had been tested for

mercury and undergone chelation therapy. She wanted to see how much mercury they had received, how much they had excreted, and if chelation made any difference in the child's condition.

Information from parents of affected children began flooding in, and Lyn was overwhelmed with data. (Kirby, 2005, p. 272)

In this passage, the information provided by parents is first labeled as "reports" and "accounts," but by the end of the paragraph, this information becomes "data." This use of the word "data" seems to be an attempt to appropriate the language of scientific discourse and gain entrée to that conversation, or at least align Redwood's information collection with the language of research.

By advocating for a more inclusive view of science and scientific evidence, rhetors who argue for a link between vaccines and autism push at the boundaries of what is and is not science. They also seek greater participation in the scientific community and greater access to its resources, part of their larger effort to be included as part of that community.

The Boundaries of the Forum

The parents whose stories are shared in *Evidence of Harm*, *Callous Disregard*, and *Mother Warriors* have in common a sense of frustration with scientific research and its failure to produce evidence of a link between vaccines and autism. As a result, they seek avenues to make their own views heard. They meet with National Institutes of Health (NIH) and Centers for Disease Control (CDC) representatives, attend Congressional hearings, and create nonprofit organizations and websites to promote their views. But all these efforts seem not to garner the results they seek, and they choose to pursue additional avenues to gain support for their cause.

A key example of this effort to participate in the conversation is described in Kirby's *Evidence of Harm*, in which parents decide to write and publish their own article in a scientific journal. The effort is spearheaded by Albert Enayati and Sallie Bernard, both of whom believe their children's autism was triggered by the ethylmercury-based preservative thimerosal in vaccines. Kirby explains their motivation through a passage about Sallie Bernard:

"A paper will give us entrée," Sallie told her husband. Yes, the idea of a group of parents writing a medical paper seemed audacious, maybe even ridiculous. "But sometimes you get so fed up, because the researchers are supposed to be helping us find answers to our kids' problem. I know there are exceptions out there, Tom, but as a group, they just aren't doing their job." (Kirby, 2005, p. 60)

Sallie believes that publishing a paper will allow the parents an avenue to join the conversation, an opportunity she believes has been denied to parents. Furthermore, publishing the paper is constructed here as an attempt to do a “job” that scientists are failing to do—presumably, finding out what causes autism and how to cure it.

Kirby’s description of the process of writing and publishing the paper reflects further assumptions about the nature of scientific discourse—who is allowed to participate, and on what terms. Sallie and Albert seem to understand that they need to find a venue in which to publish their paper and to reflect the discourse of the community they wish to enlist in their cause. That is, they seem to understand Sullivan’s point that “[t]o be relevant, a contribution to the growing body of doctrinal knowledge must be woven into the fabric of existing knowledge, and the writer must use the language conventions of his or her audience (Foucault; Overington)” (Sullivan, 2000, p. 129). An example from Kirby’s book illustrates this understanding:

Sallie insisted on crafting the report in the most professional and scientific manner possible. She was serious about getting it published in a peer reviewed journal, and harbored no illusions about the scrutiny that would be brought to bear on their work. “Unless you can publish what you write,” she told her friends, “you’re only talking to yourself, talking to the wind.” And even if they did manage to publish, she added, “Nobody is going to pay any attention if we don’t speak in their language. Scientists aren’t going to read anything unless it’s written in scientific jargon.” (Kirby, 2005, p. 94)

Sallie understands that using specialized language is one of the markers of belonging to a scientific community. Disciplinary jargon is treated here as a sort of secret code that enables a person to automatically gain entrance to a community. But this view of jargon is a misunderstanding of disciplinary boundaries. Many researchers have shown that disciplinary jargon emerges from the activity of a particular group—although it does assist in the effort to identify insiders and outsiders, it did not necessarily develop to serve that function (Bazerman, 1998; Thralls & Blyler, 2004).

Eventually, Sallie, Albert, and their coauthors complete the article comparing mercury poisoning symptoms to autism. The article was accepted to the journal *Medical Hypotheses* and was published in 2001 (Bernard, Enayati, Redwood, Roger, & Binstock, 2001). Kirby offers a few additional details about the journal:

Sallie had been asked to submit a shortened version of the paper to a Scottish journal called *Medical Hypotheses*, published by Elsevier, a global multimedia publisher of scientific and medical information, including the *Lancet*. The journal wholly admits to taking a “deliberately different approach to peer review,” and according to its Web site will “publish radical ideas, so long as they are coherent and clearly expressed” . . . The *New England Journal of Medicine* it is not . . . Sallie

was listed as lead author, followed by Albert [Enayati], Teresa [Binstock], Heidi [Roger], Lyn [Redwood], and Woody [sic]. To this day, the controversial paper is often referenced as Bernard et al. (Kirby, 2005, p. 108)

Kirby acknowledges that the journal in which the article appeared, *Medical Hypotheses*, is not a mainstream journal, but attempts to legitimize it by linking it with the much more reputable *The Lancet* through its distributor and by referring to citation practices that a reader unfamiliar with academic documentation may find impressive. For Kirby, the publication of the paper is a success for the parents—they have successfully gained entrance to the conversation.

Rhetors who argue against a vaccines-autism link are quick to point to *Medical Hypotheses*' radical tendencies; though it may appear legitimate to outsiders, it lacks credibility within the scientific community. Their critique is reminiscent of Sullivan's description of "shadow forums":

Driven from legitimate scientific forums, some scientists considered to be heretical by orthodox science seek out other forums . . . These shadow forums seldom achieve legitimacy in the scientific community, but they give the appearance of legitimacy to people outside the academic world. (Sullivan, 2000, p. 140)

As nonmembers of the scientific community, Bernard and her coauthors consider the publication of the mercury paper as a success, but rhetors who argue against a link disagree. Offit, for example, dismisses the journal on the basis of its circulation:

The *New England Journal of Medicine*, one of the most influential medical journals in the world, is read by more than 200,000 doctors and health professionals. On the other hand, *Medical Hypotheses*, where Redwood and Bernard had published their paper, has a circulation of about 200. (Offit, 2008, p. 83)

He intends to show that the journal is not widely accepted in mainstream medicine implying that the article's publication should not be read as an indicator of the validity of Bernard et al.'s argument.

Mnookin also attacks the credibility of *Medical Hypotheses*, using its self-description to undermine the authority of those whose views are published there:

Medical Hypotheses proudly eschewed peer review, a process it said disapprovingly "can oblige authors to distort their true views to satisfy referees." In the "Aims and Scopes" section of its guidelines to writers, the journal emphasized that it had no desire to "predict whether ideas and facts are 'true'"—in fact, it was eager to print "even probably untrue papers" so long as they spurred discussion. (Mnookin, 2011, p. 143)

Mnookin and Offit point to the boundary work conducted within the scientific community. By noting to the specific ways in which the journal *Medical Hypotheses* does not conform to scientific norms and values, they mark it as outside the mainstream and imply that any article published in the journal should not be taken seriously. Although they are not controlling the forum themselves, they direct our attention to forum control in practice, suggesting that it is an appropriate means of designating insiders from outsiders. In doing so, they discredit the Bernard et al. study and attempt to maintain the boundary between the views of these parents and legitimate scientific knowledge.

The Boundaries of Expertise

Rhetors who argue for a link between vaccines and autism claim that they have been denied a place in the conversation about the issue, and they argue that their observations deserve to be taken seriously. Rhetors who argue against a link not only seek to challenge that argument, but also attempt to explain where that notion comes from—that is why those who believe vaccines and autism feel empowered to speak on the subject of what should and shouldn't count as science. This aspect of the controversy seems to be a conflict about expertise: who is and is not an expert. The boundary between expert and nonexpert is both challenged and maintained through rhetoric.

Preoccupied with a need to explain how the controversy emerged and why so many found the claim of a vaccines-autism link compelling, Mnookin and Offit both seek answers in the social and historical context of the controversy. One of the most important factors, they argue, is the accessibility of information on the Internet. The ability to find a wealth of information quickly and easily, combined with the difficulty of discerning good information from bad, shapes the origins of the vaccines-autism controversy, specifically by complicating perceptions of expertise. Mnookin writes:

Over the past two decades, the instant accessibility of information has dramatically reshaped our relationship to the world of knowledge . . . the vernacular of twenty-four hour news channels and Internet search engines is freeing us to take on tasks that we'd long assumed were limited to those with specialized training. Why, after all, should we pay commissions to real estate brokers or stock analysts when we can find online everything we need to sell our houses or manage our investments? And why should we blindly follow doctors when we can diagnose our own ailments? (Mnookin, 2011, p. 8)

The do-it-yourself culture that has emerged around the internet enables people to assume they can make decisions on their own without input from experts or specialists. That is, the perceived boundary between expert and

nonexpert is eroding. The problem with that situation, Mnookin continues, is the absence of context: the internet “unmoor[s] information from the context required to understand it. On the Internet, facts float about freely and are recombined more according to the preferences of intuition than the rules of cognition” (p. 8). And as noted earlier in this analysis, Mnookin doesn’t believe intuition to be a source of accurate interpretations. The ability to understand highly complex information requires specialized training, he claims, and non-experts lack the requisite knowledge and skills to accurately interpret that information. Thus, rhetors who argue against a link once again attempt to keep more rigid scientific boundaries in place.

An example of this conflict over expertise can be seen in *Evidence of Harm* when a group of parents form a nonprofit organization and file a Freedom of Information Act request to gain access to the Vaccine Safety Datalink (VSD), a database maintained by the CDC and health organizations. They believed that they could make sense out of that data themselves and interpret it accurately. The CDC did not release the data to the parents for two main reasons, according to Kirby. First, the CDC also noted that “release of the data, even with names removed, would ‘constitute a clearly unwarranted invasion of personal privacy.’ There were still ways to determine the identity of patients, which would be a serious breach of legal and ethical codes”(Kirby, 2005, p. 184). Second, the CDC

was opposed to releasing data until the VSD study was published in a medical journal. The analysis contained “preliminary findings” that were “pre-decisional.” Release of the data would interfere with the agency’s “deliberative and decision-making process.” Critics said this argument was bogus. Data are data, they countered. Data cannot be altered through the “deliberative process” (Kirby, 2005, p. 184).

After the parents’ repeated attempts to gain access to the database, the CDC then proposed new rules about access: “Under the rules proposed by the CDC, access to the database would be granted only to bona fide scientists with institutional affiliations working on approved and funded studies. In other words, parents and lawyers need not apply” (Kirby, 2005, p. 204). This scenario is read by the parents as a cover-up. They believe that because the CDC attempted to limit access to the database, the organization must have been actively manipulating data and hiding numbers.

But an alternative explanation of the rule change could be based on the notion of boundary work. The CDC’s proposed rule change would limit access to those who know what to do with the data—that is, those who have the specialized training necessary to analyze it and make sense out of it. Mnookin claims that there is much room for error when nonexpert readers confront highly technical content, emphasizing that even experts find it difficult

to reach conclusions in the face of huge amounts of data. Using the example of cause and effect, he writes:

Determining cause and effect can be difficult even when conducting laboratory research, and epidemiologists don't have the luxury of setting up controlled experiments with a minimum of variables: They need to factor in the uncontrollable actions and unpredictable behaviors of anywhere from dozens to millions of individuals. It's no wonder that the ambient statistical noise can prove deafening even to professionals who have spent decades processing information on such a large scale. That's exponentially truer for lay practitioners untrained in statistical analysis. (Mnookin, 2011, p. 138)

His point here is that if experts would find it difficult to draw conclusions from a body of data, the interpretations of a nonexpert would probably be unreliable at best. Kirby unwittingly gives readers a reason why this exclusivity might make sense when he describes an attempt by non-orthodox researchers Mark and David Geier to gain access to another CDC database, the Vaccine Adverse Event Reporting System (VAERS). Kirby (2005) writes:

Just two days before their appointment, a CDC technician called to make sure they were fluent in the programming language SAS, which is used in the VSD database. The Geiers had never heard of it before.

"You must not be epidemiologists," the technician said. "They all speak SAS."

If that were true, it was news to the Geiers. (2005, p. 280)

Kirby constructs this situation as an attempt to reveal the CDC as exclusive and potentially corrupt, but perhaps by accident reveals that the Geiers are likely unqualified to interpret the data. Statistical analysis system (SAS) has existed since the 1970s and is used in statistical analyses across all disciplines that rely on quantitative research; therefore, it seems unlikely that anyone claiming to be an epidemiologist would not have at least heard of it. Still, among rhetors arguing for a vaccines-autism link, the CDC's decision to limit access to the database is read as an indicator of conspiracy and cover-up, not an act of maintaining disciplinary boundaries. But regardless of one's reading of the situation, the example reflects the importance of forum control in maintaining the boundaries of expertise: By limiting access to information, they limit access to the forum.

Like Mnookin, Offit is concerned that information will be misinterpreted by nonexpert readers of scientific research. This concern is rooted in the difficulty of comprehending highly specialized information like that found in many studies of vaccines and vaccine safety:

"I've done my research," parents will say, "and I don't want my child to have that shot." By "research," the parents usually mean that they have perused a variety of

Web sites on the Internet. But that's not research. If parents want to do genuine research on the subject of vaccines, they should read the original studies . . . This would take a lot of time. And few parents have the background in statistics, virology, toxicology, immunology, pathogenesis, molecular biology, and epidemiology required to understand these studies.

. . . Parents can't be blamed for not reading the original studies; doctors don't read most of them either. And frankly, few doctors have the expertise necessary to fully understand them, so they rely on experts who collectively have that expertise . . . But if you're looking for a quote guaranteed to anger the American public, you need look no further than one delivered by Congressman Henry Waxman during Dan Burton's hearings. "Let us let the scientists explore where the real truth may be," said Waxman. In other words, let the experts figure it out.

Waxman's plea doesn't have much traction in today's society. Because of the Internet, everyone is an expert (or no one is). (Offit, 2008, p. 203)

Offit worries that the availability of these studies to nonspecialist audiences will erode the notion of expertise. He laments, "For many parents, the advice given by health care professionals about vaccines is just one more opinion in a sea of opinions offered on the Internet" (Offit, 2008, p. 205).

This problem is intensified, claims Mnookin (2011), by the structure of online information and the potential lack of exposure to multiple points of view on the same issue:

In 1987, nearly three-quarters of Americans tuned into a nightly news broadcast from one of the three networks, creating a sort of national common denominator for information about the world. Now that figure has fallen below one-third, as consumers abandon the presumed neutrality of the networks in favor of cable news telecasts that gratify viewers by feeding them exaggerated versions of the opinions they already hold. An even more potent force in this regard is the Internet, where it's easier than not to fall down a wormhole of self-referential and mutually reinforcing links that make it feel like the entire world thinks the way you do. (2011, p. 198)

In a sense, Mnookin and Offit are concerned that the availability of information on the web gives readers a false sense of security in their knowledge of a particular problem or issue. It allows them to think of themselves as experts, when in actuality they fail to understand the complexities of the information they have found. Furthermore, although a broad range of information is available, mutually reinforcing sources give the impression of consensus where no such consensus may exist, making certain views appear closer to orthodoxy than they are.

The kind of disregard for expert opinions Mnookin and Offit describe in their books is evident in artifacts arguing for a link between vaccines and autism. There are multiple examples of parents choosing to ignore the advice of their doctors and implement various treatments for autism. The following passage from Katie Wright's narrative in *Mother Warriors* exemplifies this attitude:

I read the book *Breaking the Vicious Cycle* and learned about the Specific Carbohydrate Diet. When I asked our pediatrician about it, he said the same thing as before: "That's nuts, that's dangerous." So I decided to ignore him again and follow my hunch. I put Christian on the Specific Carbohydrate Diet and that made the biggest difference by far. (McCarthy, 2008, pp. 131–132)

The decision to go against medical advice, paired with a perceived improvement following the implementation of a treatment plan, supports the claim that expert opinion isn't all it's cracked up to be. Additionally, parents are at times constructed as having much greater expertise than medical professionals. Kirby's *Evidence of Harm* promotes this view when, after failing to procure a diagnosis for her son from a series of specialists, Lyn Redwood gets one from another parent:

One day while collecting Will at class, Lyn struck up a conversation with the mother of another boy enrolled in the program. The woman regarded Will . . . "You know something?" she said, wary but kindly. "Will looks and behaves very much like my son. He has the same demeanor."

Lyn was intrigued, even a bit heartened. Perhaps this mother knew the secret to unlocking Will's locked-in world.

"Really. And do you know what's wrong with your son?"

"Sure," the woman said, matter-of-factly. "He has autism." (Kirby, 2005, p. 14) Ultimately, it's the Redwoods themselves who diagnose their son with autism: One night in mid-1998, they got out the DSM-IV (Diagnostic and Statistical Manual of Mental Disorders—Vol. 4) and compared Will's symptoms with those listed in the book of mental maladies. Lyn and Tommy concluded that Will had pervasive developmental disorder, not otherwise specified (PDD-NOS), a moderately severe neurological illness that lies within a constellation of disease known as autism spectrum disorder, or ASD. (Kirby, 2005, pp. 16–17)

In the artifacts analyzed here, parents openly defy doctor recommendations and find their own answers to their children's problems when mainstream medicine fails them. These instances imply that the orthodox notion of medical and scientific expertise is flawed and that even those without specific training

can be “experts.” This is a notion that Mnookin and Offit work to counter by pointing to the problems with nonexperts attempting to deal with highly specialized information, highlighting the differences between experts and nonexperts.

The Boundaries of Scientific Capability

Another key difference between rhetors who argue for and against a link between vaccines and autism is their perception of what science can and cannot achieve. An intriguing phenomenon happens at this point that I did not expect to find: Although I assumed that those arguing for a vaccines-autism link would underestimate the capabilities of science—after all, they reject the many epidemiological studies showing no evidence of a link—I found that in actuality, these rhetors tended to overestimate its capabilities. Furthermore, rhetors who argue against a link end up arguing for what science can’t do rather than what it can. This section, therefore, focuses on the boundaries of scientific capability as a rhetorical construction in arguments about vaccines and autism.

A few examples illustrate the tendency to overestimate scientific capabilities apparent in artifacts arguing for a vaccines-autism link. For example, this passage in *Evidence of Harm* depicts a parent’s reaction to a piece of science news:

In late December 1996, while bracing for another New Year of upheaval, Sallie [Bernard] sat down for a rare moment of peace, clutching a glass of Chardonnay and a copy of *Time* magazine. It was the “Man of the Year” issue, honoring AIDS researcher Dr. David Ho. The scientist was selected for his groundbreaking work in lifesaving drugs, such as protease inhibitors to halt the replication of HIV. *Damn*, Sallie thought. *If they can do that for AIDS, then they can do it for autism.* (Kirby, 2005, p. 23)

There is an obvious logical problem with the comparison between autism and AIDS here. First, AIDS is a condition that results from infection with HIV; unlike autism, its specific cause has been identified. Second, AIDS has a single, identifiable cause—infection with HIV—whereas autism appears to be caused by a confluence of genetic and environmental factors. It is much easier to address a problem with a single, identified cause than a condition whose (probably multiple) causal factors have not been identified. Offit tries to refute this kind of claim by explaining that even if autism’s causes were identified, a solution may not immediately follow. Drawing a parallel to another genetic phenomenon, he writes:

Although children with sickle cell disease have benefited from the discovery of antibiotics and from advances in blood transfusion, knowing the exact single genetic change that causes the problem hasn’t improved the lives of its sufferers . . . even after the genetics of autism has been clearly defined, treatments might not be just around the corner. (Offit, 2008, p. 221).

Yet according to Bernard's reasoning, medical researchers talked about as if they can solve nearly any problem, no matter how complex.

A similar overestimation of scientific capability occurs in Kirby's description of a meeting with NIH researchers:

Dr. Marie Bristol-Power, NIH chief of autism research, outlined the agency's research under way and spoke glowingly of a new twenty-year longitudinal study that, she said, was the "best bet for collecting data on normal brains, looking at environmental factors, and so forth."

Twenty years? This was not what the parents had come to hear. In twenty years they might be dead. (Kirby, 2005, p. 103)

The implication here is that parents expect scientists to be able to find answers quickly, even though studies of complex phenomena like autism can take years, even decades. Their disappointment stems from an expectation that scientists can achieve just about anything, when in fact their work faces numerous material limitations, including time and access to resources.

The most significant example of this conflict about the boundaries of scientific capability is the title of Kirby's book: *Evidence of Harm*. In the book's introduction, Kirby writes that there is no evidence of harm from vaccines, but adds that "no evidence of harm" is not the same as proof of safety. No evidence of harm is not a definitive answer; and this is a story that cries out for answers" (Kirby, 2005, p. xii). The phrase seems to come from Lyn Redwood, the mother of an autistic son. Later in Kirby's book, she writes in a letter to AAP and CDC scientist Neal Halsey,

[W]hat is disturbing to me is that in many of the recent articles I have reviewed, there is a consistent theme that there is, 'No evidence of harm having occurred from thimerosal vaccine administration.' No evidence of harm does not equate with no harm having occurred. (Kirby, 2005, p. 71)

Redwood and other parents insist that "*Thimerosal has not been proven safe*" (original emphasis), and they become "tired of repeating the mantra that absence of evidence is not evidence of absence" (Kirby, 2005, p. 189). The insistence here is that science should be able to prove something to be 100% safe, and that anything that cannot be shown to be 100% safe shouldn't be used in children.

Rhetors who argue for a vaccines-autism link use this insistence on absolute safety to reinforce their own credibility and downplay the credibility of their opponents. Comparing vaccine safety to vehicle safety, Wakefield writes:

Those whose priority is *safety first* are not anti-vaccine. By analogy, those who ordered the recall of multiple Toyota brands for sticking gas pedals are not anti-car... In a free market, without mandates, what has happened at Toyota is

unlikely to boost public confidence and, therefore, the company's sales and profitability. Liability for deaths and injuries is likely to haunt them for many years to come. (Wakefield, 2010, p. 5)

Meanwhile, Wakefield claims, "Those who are a threat to public confidence, those who do not mandate a *safety first* agenda, are the greatest threat to the vaccine program; they are ultimately anti-vaccine" (2010, p. 5). Kirby quotes Mark Geier as saying, "What is occurring here is a cover-up, under the guise of protecting the vaccine program. And I am for the vaccine program. If you keep covering it up, you are not going to have a vaccine program" (Kirby, 2005, p. 318). By claiming that they are concerned about public confidence in vaccines, rhetors who argue for a vaccines-autism link counter the popular notion that they do not care about public health and disease prevention. But there is an easy solution to the problem of public trust, claims Kirby:

Parental fear of vaccines has threatened the viability of the U.S. National Immunization Program. But if scientists prove that mercury in vaccines was at least partly to blame for much of the autism epidemic—and that the culprit has been largely (or one day entirely) removed—then confidence in childhood vaccination should return to comfortable levels. (p. xv)

This passage is particularly telling because it does not allow for any alternative course of events: Either scientists prove the parents right or confidence will never be restored. Kirby's ultimatum overestimates scientific capability and ignores the possibility of an alternative outcome.

Mnookin challenges the notion of vaccine safety forwarded by Wakefield, the Geiers, and activist parents, who imply that any degree of risk of harm from a vaccine is unacceptable. However, rhetors who argue against a vaccines-autism link claim that this insistence on an absolute guarantee of safety is not only problematic, but downright impossible. Science is bounded by its inability to provide guarantees. Offit attempts to establish this point by explaining the concept of the null hypothesis:

In determining whether, for example, MMR causes autism, investigators form a hypothesis. The hypothesis is always formed in the negative, known as the null hypothesis. In the MMR-causes-autism case, the hypothesis would be, "MMR does not cause autism." Epidemiological studies have two possible outcomes: (1) Investigators might generate data that reject the null hypothesis. Rejection would mean that the risk of autism was found to be significantly greater in children who received MMR than in those who didn't. (2) Investigators might generate data that do not reject the null hypothesis. In this case, the risk of autism would have been found to be statistically indistinguishable in children who did or didn't receive MMR. But there is one thing those who use the scientific method cannot do;

they cannot accept the null hypothesis. In other words, scientists can never say never. (Offit, 2008, p. 208)

The idea that “scientists can never say never” is both a discursive guideline and a guiding principle in scientific work. As Mnookin explains,

There’s always the chance that someone, somewhere will discover a scenario in which they no longer apply . . . scientists with widely accepted theories spend their careers in a state of cautiously optimistic limbo: Regardless of how many times their work is corroborated, a single contrary result will cause it all to come crashing down. (2011, pp. 157–158)

Furthermore, the requirement of absolute safety is problematic and potentially dangerous:

This abstract notion of perfection is, of course, just that: an abstraction. In its most extreme application, a strict adherence to that standard would prohibit all medical care, since there is always the possibility that a given remedy will be improved, and every treatment carries with it at least some measure of risk. (Mnookin, 2011, p. 52)

For Mnookin, although there is much we can do to manage and minimize risk, it cannot be prevented entirely and refusing anything that carries with it some degree of risk is foolish at best. He adds:

One way to understand the distinction between science and the ideologies it superseded is through the theory of falsifiability, which states that in order for a hypothesis to be a legitimate subject of inquiry, it has to have a single, corresponding null hypothesis—that is, it needs to be disprovable . . . Since it’s impossible to prove a negative, the closest one can come to absolute proof for any theory is through an exhaustive, and unsuccessful, effort to prove the null hypothesis. (Mnookin, 2011, p. 155)

For that reason, the insistence on absolutely safety of vaccines is a standard that no one can meet. “No evidence of harm” is as close as scientific research can get to “proof of safety.” In the context of the vaccines-autism controversy, science’s limitations serve just as important a rhetorical purpose as its affordances. Rhetors who argue for a link between vaccines and autism try to stretch science beyond the boundaries of its capabilities, resulting in unrealistic expectations and creating a need for rhetors arguing against a link to reinstate the boundary.

Conclusion

The rhetorical dynamics of scientific boundaries are an important element of the vaccines-autism controversy. By attempting to challenge the boundaries around

what counts as evidence, who can participate in the forum, who can become an expert, and what science is able to achieve, rhetors who argue for a vaccines-autism link try to include under the heading of “science” many elements that their opponents prefer to exclude. Meanwhile, rhetors who argue against a link deflect these attempts to expand scientific boundaries by explaining why those boundaries exist and why they should be maintained.

One of the most common critiques of those who believe in a vaccines-autism link has been that they are irrational and unscientific. Although I somewhat object to that construction because it dismisses rather than engages public critiques of science, the examples I have shown in this analysis do suggest that there is at least a degree of misunderstanding of science among rhetors who believe vaccines cause autism. For example, Kirby reports on a congressional hearing on the topic of vaccines and autism in which Lyn Redwood declares, “It is time . . . for someone to step forward and acknowledge these facts and provide the science to fully investigate what has happened to our children and what can be done to help them” (Kirby, 2005, p. 135). Redwood puts the facts before the science, when numerous studies of scientific discourse illustrate that the elevation of an observation to the status of fact comes through the process of doing science (Kuhn, 1970; Latour & Woolgar, 1986). That is, facts don’t precede science, and the assumption that they do is a misunderstanding of how science works. I also found it troubling that scientists are often constructed as somehow separate from the rest of society. For example, Kirby quotes Congressman Dan Burton as saying in a congressional hearing that “CDC’s advisory committee has no public members—no parents have a vote in whether or not a vaccine belongs on the childhood immunization schedule. The FDA’s committee only has one public member” (Kirby, 2005, p. 124). The idea that a scientist could also be a parent and a member of the public is a notion that escapes both Burton and Kirby.

Like Mnookin and Offit, I tend to privilege science as a way of understanding the world and finding effective solutions to problems, and this stance shapes my reading of rhetors who argue for a vaccines-autism link. However, I do believe it is possible to over-privilege science. For example, Offit claims that “science is the only discipline that enables one to distinguish myth from fact” and that scientists are “bound only by reason” (Offit, 2008, pp. 207, 185). Most rhetoricians would probably object to these claims; I certainly do. Many disciplines—including rhetoric—enable us to distinguish myth from fact. Furthermore, scholarship in rhetoric of science and science studies has shown that the work of scientists is grounded in material, historical, and social contexts. Although science as a discipline should be able to maintain its own boundaries and decide who does and does not belong—as Sullivan says—it should remain possible for outsiders to raise questions and offer critiques of its norms and practices (Sullivan, 2000). But in order for

these critiques to be meaningful, they must be informed by an understanding of science's disciplinary boundaries.

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