

Introduction

Our Immunization Social Order

Vaccine Injury and the Immunization Social Order

When parents hesitate or refuse to vaccinate their children, it is often because they have doubts about vaccine safety.¹ They fear vaccine injuries. They have heard that vaccines can cause autism, allergies, immune problems, or attention-deficit disorder, for example. Vaccine injuries do happen, though the scientific consensus is that none of these conditions are among them. More obscure conditions, such as thrombocytopenic purpura, a very rare and transient condition characterized by low platelets and excessive bleeding and bruising, are agreed-upon adverse events after vaccination (in this case, the measles-mumps-rubella or MMR vaccine). The tetanus vaccine can cause brachial neuritis, an inflammation of the nerves in the hand, arm, and shoulder; the rubella vaccine can cause arthritis, particularly in women; and the measles vaccine can cause encephalitis, a potentially very serious irritation and swelling of the brain. I always watch my children carefully in the few minutes after they receive a vaccine because anaphylaxis and fainting are also rare but possible reactions to injections. We have very personal, embodied experiences within the broader political and legal context of vaccination policy in the contemporary United States.²

Vaccine injuries are a complex and fascinating problem. They expose tensions between parents and professional experts, between certainty and doubt, and between different ways of knowing and being sure. Vaccine injuries display the inevitability of the meeting between science, politics, and the law, giving us a case to explore how well our democracy manages this tense and productive collaboration. Experts and activists have widely divergent ideas about what vaccine injuries are and how to recognize them, and recent decades have seen a strong social movement mobilized around injury claims. American vaccines are embedded

within a robust private pharmaceutical economy, state-level vaccination requirements to enroll in school, a federal regulatory and safety monitoring regime, and an extensive health and medical research system. When vaccines cause injury, U.S. citizens can petition for legal compensation at a special court known simply as the vaccine court. A successful legal claim validates the harm, gives the injured person a sense of being heard, affirms governmental responsibility, and provides a proper ethical and financial response from the community.³

Throughout this book, I explore all the ways that we come to recognize a vaccine injury in the contemporary United States, asking who knows, how they know, how they prove it, who has the power to recognize it and how, and what they do about it. I place our vaccine court at the center of my analysis as the site where parents, activists, researchers, doctors, lawyers, and health bureaucrats come together to wrangle over what vaccine injuries really are. Our vaccine court is a useful institution for handling the recognition of vaccine injuries given that we regard them as posing simultaneously scientific, political, ethical, and legal problems. The vaccine court offers a desirable balance between openness to challenge and the stability of vetted expertise; it encourages peaceful social movement activism that must be presented as knowledge-driven, questioning, and public-spirited; and its design has allowed the vaccine court judges (called special masters) to give as much recognition as possible to people bringing claims while maintaining sufficient scientific credibility. The operation of our vaccine court since its first hearings in 1988 shows how rights claims and social movement activism are thoroughly intertwined with knowledge claims. Courts have always dealt in knowledge claims, of course, but the case of vaccine injuries shows exactly how legal actors work at the center of multiple knowledge sites to uphold and help constitute what I call the *immunization social order* in the contemporary United States.

Our immunization social order is the set of institutions, laws, pharmaceutical biotechnologies, and social practices that work together to produce high levels of vaccine coverage to prevent a wide range of diseases. It is both the freedom from vaccine-preventable diseases that we enjoy as well as the investments and social control necessary to maintain it. The Centers for Disease Control and Prevention (CDC) estimates that vaccination will prevent 322 million illnesses, 21 million hospital-

izations, and 732,000 deaths during the lifetimes of the children born in the United States between 1994 and 2013.⁴ During the time period 1994 to 2013, the U.S. government funded a consolidated effort to vaccinate uninsured and underinsured children. The CDC estimated that these immunizations saved \$295 billion in direct costs and \$1.38 trillion in total societal costs.⁵ A starting assumption for this book is that this widespread freedom from illness, worry, and death is a precious achievement that we often fail to credit adequately because it is an absence rather than a presence. No parent recalls the time she did not have to sit with her sick child in the hospital. Instead, contested power relations among resistant activists and those who uphold the vaccine policies of our immunization social order have emphasized the costs and compulsions behind our immunization social order. Sociolegal scholars have long observed that law and legal institutions are the primary ways of maintaining social order, and thus my focus here is the role of law in channeling social movement conflict and resolving the challenges that vaccine injuries pose to our immunization social order. I term this turn to law the legalization of vaccine injury, by which I mean its placement within a court setting for resolution in an adversarial process. We come to know what a vaccine injury is through the law, in other words.

Vaccine policies are formed within power struggles over individual liberties, health decision making, disease control, personal responsibility, and mothering. As Monica Casper and Laura Carpenter have pointed out, for example, the human papillomavirus (HPV) vaccine is a “gendered pharmaceutical technology” that “cannot be understood outside gender relations and attendant cultural politics” because of its initial targeting to young girls to prevent a contagion spread by sexual contact.⁶ “Politics,” Casper and Carpenter elaborate, “shape the ways drugs are produced, used, and so forth; but drugs may also instigate political struggles, and, potentially, social change over their lifecourses, as well as embodying extant conflicts.”⁷ The federal government licenses, regulates, promotes, and monitors the safety of vaccines, which are produced and developed by a web of university-based researchers, biotech firms, and large pharmaceutical companies. The federal government recommends a standard vaccine schedule for children from birth to age six that includes immunizations against fourteen diseases: chickenpox, diphtheria, *Haemophilus influenzae* type b (Hib), hepatitis A and B, flu,

measles, mumps, pertussis (whooping cough), polio, pneumococcus, rotavirus, rubella, and tetanus.⁸ State legislatures enact immunization requirements for school entry. Children cannot decide for themselves whether to get vaccines, and much of the benefit of vaccines would be lost if we vaccinated only adults capable of giving their own consent. Babies receive the same vaccine spread out over several different administrations in the first years of life because the body needs to build up immunity over time. That means parents who follow vaccine recommendations must bring babies to their pediatrician every few months to get multiple shots at once.

Both parents and children perform these acts of citizenship, but they secure the communal benefit only if enough other parents and children are doing it, too. No vaccine is completely risk-free, and some previously healthy recipients suffer painful or even rare but damaging adverse reactions to vaccines. People tend to overestimate these rare events and perceive risks from actively doing something (vaccinating a child) more keenly than risks from inaction (not vaccinating against a potential disease).⁹ From an individual's perspective it might seem best to avoid vaccines while everyone else gets them, but if enough people see it that way, vaccine-preventable diseases will come back. Nationwide, very few children are fully unvaccinated, but unvaccinated children (or, more commonly, children whose vaccines have been delayed) tend to cluster in like-minded communities or particular schools, making it possible for diseases to spread in those areas.¹⁰

If paying taxes were voluntary and not paying carried no penalty, we might expect that many people would rather keep all their money while still enjoying the roads, schools, and public services that others fund. Similarly, securing the benefits of widespread vaccination has usually meant some form of legal compulsion to avoid too much free riding in the form of exemptions. In the United States, vaccines are required at the state level for children enrolling in school (and in some states for day care attendance). All states offer medical exemptions for children if a doctor says they should not be vaccinated, and all states except for California, Mississippi, and West Virginia offer parents the opportunity to exempt their children because of religious belief. The most controversial exemptions are those offered in eighteen states on broader philosophical grounds, which allow parents to avoid vaccinating their children but do

not require them to claim a religious reason. Parents who choose not to vaccinate are still able to send their children to public schools and day care centers by using the exemption process, depending on how easy it is to navigate. Because obtaining a philosophical exemption can be as simple as completing a form in some states, our vaccine mandate system functions more like an opt-out system than a true mandate. The easier the opt-out process is in a state, the more parents use it, and rates of pertussis are higher in those areas.¹¹

Confronting fears about vaccine injuries is critically important, then, and any society that maintains widespread vaccination programs should both guarantee a very high level of safety as well as respond justly to injuries when they occur. The central issue in vaccine safety is determining whether an adverse event is causally linked to a vaccine. But the question of causation can be very hard to answer. Some infants and children will develop medical problems or even die suddenly for many reasons. Because they are also receiving regular vaccinations, some of those problems will likely appear soon after the shots. Many diagnoses that parents are most worried about, such as autism, attention-deficit disorder, learning disabilities, and other neurodevelopmental problems, do not have well-understood causes, are often subtle and contested as diagnoses themselves, and may emerge years after vaccinations were administered. These conditions are perceived to be widespread and to affect a child's ability to advance socially and economically in a competitive world and thus are highly salient to parents, particularly affluent and educated ones. To make matters even more complicated, some adverse events are so rare that their rates of association with vaccines are difficult to measure. The mainstream consensus is that our stable of vaccines is extremely safe, that adverse events are quite rare, and that reactions that cause significant injury are even more rare. Yet, no government since the invention of vaccines has been able to convince everyone. Vaccines and immunization have always been controversial for some people.¹²

The vaccine injury story illustrates how we settle disputes in U.S. society at the intersections of science, medicine, politics, law, and social movement activism. The vaccine court is the centerpiece of a no-fault compensation program that removes vaccine injury claims from the tort system and places them before special masters in the U.S. Court

of Federal Claims. Injuries claimed from vaccines regularly recommended for use in children are covered, and all awards, attorneys' fees, and costs are paid from a trust fund built up from a seventy-five-cent excise tax on each dose of vaccine sold.¹³ The vaccine court has been in place since controversy in the 1980s over the safety of the whole-cell pertussis vaccine mobilized parents, doctors, and industry into an unusual coalition to help pass the National Childhood Vaccine Injury Act (NCVIA) of 1986. Our national systems of vaccine injury recognition and redress were born in one conflict but have weathered many others, as I will show, including the autism-vaccine controversy of recent years (in which the vaccine court roundly rejected autism as a vaccine injury).

Whether a vaccine caused an adverse event may seem like a medical or scientific question, not a legal one, and so it might seem regrettable or misguided that we had to drag down such questions into the muck of the adversarial courtroom to be batted about by nonexperts. But what if we think of vaccines as social and political from the start, and in fact already the subject of a firestorm of claims about what they are and what they do? What if we think of law as a special sphere of the political where we send disputes for resolution through legitimated processes? If vaccine injury is a political question about an individual harm in a democratic society, then a court is a perfectly reasonable place to resolve it. Then law looks more like a useful mediating process for absorbing and creating new knowledge in complex debates, all within a legal framework that tries to take seriously the context of doing justice to an injured party. Forcing an issue to become a legal question in an adversarial process can have significant consequences, however. In the case of vaccine injuries, the legalization solution forces social movement activism and injury-based rights claiming into a framework of careful reason giving and mustering of evidence before well-informed judges. Professional fees and expenses are paid no matter the outcome, and the special masters will wait as long as the petitioners want to gather the evidence to make their case.

But from critics' perspectives the court has become too stingy with compensations, issues conflicting and baseless judgments, and combines the worst features of both an adversarial court and a mind-numbing bureaucracy.¹⁴ As Tom Tyler's influential work on citizen compliance with the law shows, people will obey the law even when a legal ruling

goes against their self-interest if they feel the process treated them fairly, if they had a chance to make their case and were listened to by fair-minded judges, and if they normatively endorse the overall fairness of the law.¹⁵ Though there is variation among critics' views, many mobilized parents believe not simply that the court is a tough hurdle, but that its requirements are part of a government plan to mislead citizens and to conceal vaccine injuries by denying claims. As vaccine critic and activist Mary Holland charges, "[The vaccine court] is stacked against families because let's face it, vaccine injuries make vaccines look bad."¹⁶ The activists who focus on the vaccine court do not share any of Tyler's normative commitments to the immunization social order because they regard vaccines as unsafe (rooted in beliefs about autism causation principally but not entirely) and thus they see the court as an illegitimate cover organization. Compensating for vaccine injuries does indeed create tension for our immunization social order because these cases are a concession that some people will suffer for the population-level freedom from vaccine-preventable diseases that we all enjoy. The vaccine court must do justice to those people—who may still accept the value of vaccines and the immunization social order overall—while managing the confrontations of a hostile social movement eager to exploit this tension.

Our vaccine court has been successful not because it has managed to please both scientists and activists, but rather because it has compromised between a vision of scientific certainty and a duty to compensate injuries to uphold the immunization social order. As Sheila Jasanoff reminds us, "The grand question for the law is not how judges can best do justice to science; the more critical concern is how courts can better render justice under conditions of endemic uncertainty and ignorance."¹⁷ The vaccine court has forged this compromise through its rules and practices (for instance, its openness to all kinds of evidence and expert testimony and its flexible and often lengthy decision process), through the labor of the people who work there (especially the special masters, who are nonexperts but who hear the same issues over and over again), and through their judgments about a wide array of evidence held to a legal standard of causation, which is lower than what constitutes certainty for most scientists but requires petitioners to prove that it is more likely than not that the vaccine caused the injury. Compromises often please no one, yet judges and lawyers are very good at negotiating them.

Sometimes it is not possible to know if a vaccine “really” caused an injury. But as Annelise Riles explains, sometimes legal knowledge can be generative when it is not working simply in the service of another field’s knowledge claims: “Law is out of touch with reality, as the critics routinely tell us, and that is precisely, if counterintuitively, its promise.”¹⁸ In many cases, especially the high-profile autism claims, the vaccine court has more or less reflected and amplified the scientific consensus, but sometimes it muddles along. It can never win over critics who reason from a different interpretation of the evidence or based on incommensurable first principles. But I argue it has managed uncertainty to do justice.

Our vaccine court stands as the exclusive forum for trials of vaccines for causing injuries. It draws on scientific expertise but has an explicit policy mission to dwell in uncertainties and to use a wide range of epistemic resources. Its flexibility and epistemic openness are its hallmark traits, yet its rulings ultimately promote accountability to sound reasoning and good evidence (as the special masters understand those boundaries). The vaccine court serves several critical purposes in contemporary American society. First, its rulings regularly affirm the mainstream consensus that our vaccines are safe while acknowledging some agreed-upon injuries. It has fulfilled its original mission of protecting our national vaccine supply from the unpredictability of the tort system. Second, the court is an audience for evidence of vaccine safety, but also an engine for producing it. The vaccine court in the United States was also notably the only public venue in the world for the debate over autism and vaccines to become formalized and legalized, and for the arguments to be fully heard, discussed, and reviewed. Third, it serves as the site for the meeting of the individual, the knowledge products of the scientific establishment, and the state. Most other areas of vaccine safety research are focused on the population, and activists, who often focus on the individual, do not otherwise get a chance to present an individual injured child before the state. What happened to this person? Fourth, the vaccine court channels dissatisfaction with vaccines into compensation rather than social movement activity, at least for some people. When the special masters deny compensation, as in the case of autism, they provide something for losing claimants to mobilize against in particular structured ways. Finally, those structures require

reason giving that promotes accountability. That accountability flows in multiple directions: activists can haul health bureaucrats before congressional committees to testify about vaccine safety, but their experts will also be mercilessly cross-examined in vaccine court. Of course none of these features of the vaccine court guarantee perfect knowledge, and it would be naïve to hope for that. But its imperfections and contested settlements should not keep us from acknowledging its profound public service to our immunization social order.

Many critical social scientists and feminist scholars would not celebrate the law's power over bodies and injuries as much as I do in this book. Anthropologist Sarah Lochlann Jain points out in her study of American personal injury law that law's recognition of injury seeks to frame it as exceptional within an otherwise well-functioning capitalist, consumerist culture.¹⁹ The interactions between bodies and products that cause injuries are inflected with inequalities, she emphasizes. Indeed, vaccines are understood to injure only in exceptional circumstances and to keep us healthy and working. I argue that robust vaccine safety requires a strong central state with surveillance powers to detect and investigate possible adverse events within de-identified medical records, yet Rachel Dubrofsky and Shoshana Amielle Magnet present the emerging field of feminist surveillance studies as identifying the nearly always oppressive and hierarchy-reinforcing nature of surveillance.²⁰ Critically, nearly all of the cases of surveillance they analyze as problematic involve "real people being watched, often unknowingly, doing real things."²¹ Vaccines, I argue, challenge us to be more nuanced and affirming of the power of the state to produce health and to recognize injury even as we accept the overwhelming scientific consensus that they are safe and effective for the vast majority of people. More privileged people are represented in the medical records being surveilled because they have employer-provided health coverage, for example, and so reducing inequality would mean adding better surveillance for adverse events among people using government programs such as Medicaid or health departments for immunizations, or for people who are uninsured. Vaccines certainly keep us showing up to work, but they also prevent pain and discomfort, remove the need for caregiving labor with high costs, such as the burden on single working mothers with sick children, and shield vulnerable people who cannot be vaccinated themselves, such as

those with suppressed immune systems from cancer treatments. Bringing an injury claim before the state legitimizes its often vast and subtle power arrangements, as Wendy Brown has compellingly argued.²² It matters quite a bit, however, what the forum for the claim is, what kinds of evidentiary mobilizations that forum invites and produces, and the worth of the underlying social order being defended. The case of the vaccine court, in the details of its daily work, should give critical scholars some reason for a bit more optimism.

Mobilization around Autism as Vaccine Injury

Fears that vaccines cause autism have framed the terms in which we have discussed vaccine safety for the past fifteen years, and thus the autism issue necessarily plays a large role in this book. And yet, I am convinced that many of the most interesting challenges of our vaccine safety regime have little to do with autism, predated it as a hot topic, and will be with us for many years to come. For instance, how will we manage an ever-crowded childhood vaccine schedule as new vaccines are invented and at the same time as a large subset of parents seem to be at their limit in terms of the number of doctor visits and the number of shots they will tolerate? So while I acknowledge the predominant position of autism in the vaccine debates, I pull the frame of this book back to bring in a wider perspective. Nonetheless, it is hard to overstate the importance of the autism issue in vaccine politics. It has forced advocates to reveal whether they will adapt to new information or double down on conspiracy theories, framed every government intervention and court ruling through the high-stakes suspicion of parents mobilized around autism, and deepened mistrust between government officials and vaccine activists. No scientist can be credible and assert that vaccines cause autism; no vaccine critic has backed down and said they were wrong. Every assertion, every report, every press release is bathed in the harsh, unflattering brightness of clearly drawn sides.

Do we know enough or too much about vaccine injury? Claims on all sides almost always come down to assertions about how much we know about vaccine injury and what policies flow from a correct assessment of the state of knowledge. Autism is very well studied as a possible vaccine injury and wholly rejected in the mainstream, despite critics' attempts

to muster alternative accounts and to insist there is still uncertainty, or what Claire Decoteau and Kelly Underman call “non-knowledge” about autism and vaccines.²³ For many adverse events that families and individuals have brought to the vaccine court, there is simply not enough published research about a possible connection and no population-level evidence of a problem, so it is very difficult to determine in a particular case whether the vaccine caused the problem or if it was coincidence. Activists mobilize for more research and emphasize all the studies that could be done but have not been done. Mainstream scientists and regulators, however, are reluctant to fund studies into pathways for vaccine injury that they do not think are biologically plausible and have not set off any official alarms in previous studies or ongoing safety surveillance.

Use of the law played a critical role in the emergence of what we know today as the vaccine-autism controversy. There are many places one could begin, but one critical point is the mid-1990s United Kingdom, where Dr. Andrew Wakefield’s research into autism, gut disorders, and the measles component of the MMR was supported by funding from the U.K. Legal Services Commission (LSC; formerly the Legal Aid Board, now the Legal Aid Agency) with the aim of marshaling evidence to bring a suit against pharmaceutical companies.²⁴ In 1998, Dr. Wakefield and collaborators published a paper in the British medical journal *The Lancet* that presented an uncontrolled study of twelve children with autism and gastrointestinal symptoms, noting that the onset of both was associated with their MMR vaccination.²⁵ The litigation-driven funding of the research significantly damaged its credibility when it became widely known, but at the start the effort was part of a general commitment by the British government to support claimants who might have a blockbuster case but just needed some support to build it. The Legal Services Commission ceased funding the litigation in 2003 after reviewing about sixty expert reports and concluding the claim was not sufficiently meritorious. The press release announcing the decision to withdraw funding noted that the MMR case was the first in which Legal Aid had funded new research to uncover scientific evidence to bolster a legal claim, and “[i]n retrospect, it was not effective or appropriate for the LSC to fund research.” “The Court,” the organization said, “is not the place to prove new medical truths.”²⁶ As I describe in Chapter 6, our own vaccine court would go on to be the public trial of vaccines for causing autism after the British case litigation collapsed.

Ten of Wakefield's co-authors distanced themselves from the paper in 2004 after it surfaced that Wakefield had not disclosed that the research was litigation-driven,²⁷ and in 2010 *The Lancet* formally retracted the paper.²⁸ The U.K. General Medical Council found in February 2010 that he 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 in the mainstream,²⁹ but enjoys pockets of strong devotion from supporters.³⁰

There was another path to critical mobilization around autism as a vaccine injury in the United States: mercury in vaccines.³¹ A preservative called thimerosal, about half ethyl mercury by weight, had been added to vaccines since the 1930s to prevent harmful bacteria from growing in multidose vials.³² U.S. mercury activists were initially mobilized by some unfavorable publicity about thimerosal in vaccines, capitalizing on and amplifying uncertainty about its possible effects. The hepatitis B vaccine, the DTaP (diphtheria, tetanus, and acellular pertussis) vaccine, and the Hib (*Haemophilus influenzae* type b) vaccine contained thimerosal, which could have delivered up to 187.5 µg (micrograms, 1/1,000,000 or a gram or 1/1,000th of a milligram) of ethyl mercury to an infant in the first six months of life (if she received an assortment of vaccines with the highest possible levels, that is; many combinations would have delivered less ethyl mercury).

After complying with a 1997 law requiring the Food and Drug Administration (FDA) to survey mercury additives in products, federal regulators realized in 1999 that an infant could potentially be exposed to more ethyl mercury (as thimerosal) through the recommended vaccine schedule than the Environmental Protection Agency (EPA) limit for methyl mercury, a different type of mercury that is a known environmental contaminant in fish. Methyl mercury was well studied at the time, but ethyl mercury was not, and it did not have its own safety standard. The American Academy of Pediatrics and the U.S. Public Health Service then recommended the removal of thimerosal from vaccines as a precaution.³³ This decision happened very quickly with heated debate about whether it was a reasonable precaution or a rush to judgment that

would only arm critics and scare parents.³⁴ If thimerosal was not harmful, why rush to remove it? The mercury-autism controversy emerged in a context of missteps and uncertainty, and worried parents quickly stepped up to try to fill the knowledge gaps.

The theory that autism is caused by mercury toxicity was first spelled out by lay advocate, mother, and marketing consultant Sallie Bernard and others in a 2001 article called “Autism: A Novel Form of Mercury Poisoning,” published in a journal called *Medical Hypotheses*,³⁵ a venue for publishing “radical, speculative and non-mainstream scientific ideas provided they are coherently expressed.”³⁶ One government expert witness would testify in the Omnibus Autism Proceeding at the vaccine court that Bernard’s article was “the only reason all of us are here today” (and go on to dispute its conjectures).³⁷ Bernard and other mobilized parents founded the group SafeMinds in 2000, which has continued to push links between mercury and autism and has given nearly \$1.5 million in research funds to promote the hypothesis.³⁸ A 2001 Institute of Medicine (IOM) report on thimerosal-containing vaccines held it was “biologically plausible” that thimerosal could be related to autism and that the evidence was inadequate to accept or reject a causal relationship due to insufficient research.³⁹ By 2002, there were sixty-eight lawsuits pending in sixteen states alleging damage from mercury in vaccines or requesting health monitoring after receipt of a mercury-containing vaccine, eleven of which were putative (uncertified) class actions potentially covering more than 175 million people. As I discuss in Chapter 2, the thimerosal lawsuits posed a significant threat to the ability of the vaccine court to absorb and adjudicate vaccine injury claims. Ultimately, these lawsuits did not progress nationwide because they had to move into the vaccine court and could not be brought as regular civil actions.

A couple of years of uncertainty combined with the energy and resources of the mobilized parents created a powerful second burst of energy for vaccine critics after the 1998 Wakefield paper, though both the MMR and the thimerosal hypothesis would not withstand scrutiny for long. The Bernard paper’s allegations that autism is similar to mercury poisoning were quickly debunked in the scientific mainstream.⁴⁰ By 2004 enough new studies had been published that an IOM review committee rejected hypotheses connecting either the MMR vaccine or thimerosal in vaccines to autism.⁴¹ A World Health Organization (WHO)

vaccine safety committee also monitored the thiomersal (an alternative spelling used in WHO documents) research beginning in 2000, reaffirming in multiple reviews that “there is no evidence of toxicity in infants, children or adults exposed to thiomersal in vaccines.”⁴² Activists have remained mobilized, but they have not been able to maintain enough credibility behind the thimerosal hypothesis to change policies,⁴³ and as I explain in Chapter 6, they would go on to lose their court claims. Furthermore, thimerosal’s usefulness in keeping vaccines free of harmful pathogens endures, both in the manufacturing process and particularly in a global vaccine program in which use of single vials is not always practical.

Polite Company: A New View of the Vaccine Wars

In October 2010, I attended a reception in Washington, D.C. in honor of the retirement of former vaccine court Chief Special Master Gary Golkiewicz. Special Master Golkiewicz had led the federal no-fault vaccine injury compensation court for twenty years and enjoyed broad rapport with the many different people who argued before him. I was there to observe a conference of vaccine court practitioners, which also drew social movement activists interested in the ongoing Omnibus Autism Proceeding, a set of trials about whether autism would be compensated as a vaccine injury. There were toasts to the former chief from Department of Justice attorneys (who represent the government) and from members of the vaccine petitioners’ bar. I recognized prominent activists who had gained national prominence criticizing the vaccine court and its rulings, such as Becky Estep from Talk About Curing Autism, who was widely quoted a few months before deriding the vaccine court as a place “where government attorneys defend a government program using government-funded science before government judges.”⁴⁴

We all stood around together, sharing drinks and hors d’oeuvres, politely chatting and clapping for the retirement occasion. Department of Justice attorneys mingled with petitioners’ attorneys, other special masters, Court of Federal Claims judges, the activists, and me. There were perhaps forty people in the room. At another one of the same yearly conferences I attended later, the lead attorney who had just litigated (and lost) the autism claims and the special master who had penned a par-

ticularly strong rejection of the case's merits joked about their karaoke duet the night before. After the government advisory meetings I observed, the representatives of parents of vaccine-injured children, the vaccine industry lawyers, the petitioners' lawyers, the pediatricians, and the government administrators of the program would go off to dinner together. Now, my point is not that these polite and even warm gatherings reveal some unseemly entanglements. It is perfectly natural to make the best of being stuck at an event with one's adversaries. Might as well have a drink and join in the toast.

These moments illustrate the ordinary and surprisingly close connections between the people who encounter each other over and over again as they manage and debate our vaccine injury compensation system in the contemporary United States. We hear so much about the "vaccine wars" and the unbridgeable gulfs between mistrusting parents and health officials and doctors. But there is another perspective in which it is not a war at all. To borrow Francesca Polletta's phrase, the vaccine debates at the level of government policy are an endless meeting.⁴⁵ Or, better yet, an endless series of sparsely attended, earnest, and sometimes tedious government meetings. If we think of the vaccine debates as a war, it all seems quite exasperating. If we think of them as a meeting or court hearing, they are an example of thoughtful yet adversarial exchange.

I gather together here the public officials, judges, lawyers, and activists who determine what counts as a vaccine injury. My methodological approach centers the institution and their work within it rather than the legal doctrine or even the individual stories behind the cases. This decision sacrifices some humanizing detail and makes this book into a story about how elite professionals decide what is a vaccine injury, which is the critical question for justice and politics and should be important to us all. I have spent the past six years systematically gathering and analyzing the records of their work and their debates with each other. I attended events at the vaccine court (in the U.S. Court of Federal Claims in Washington, D.C.), the advisory committees within the Department of Health and Human Services that oversee the Vaccine Injury Compensation Program (the National Vaccine Advisory Committee and the Advisory Commission on Childhood Vaccines), and a national public conference organized by the National Vaccine Infor-

mation Center (NVIC), the oldest vaccine-critical organization in the United States whose current leadership helped pass the original legislation that created our vaccine injury compensation and safety system. A more classically legal approach to the vaccine court would prioritize its rules and cases, assuming that the key to understanding how the special masters judge causation can be found in the case law about its causation standard.⁴⁶ Instead, I approach the court and its actors more sociologically and politically, investigating how they do their work, what points of contestation have been critical moments for creating knowledge about vaccine injuries, and what policy outcomes their conclusions of justice uphold. This approach goes well beyond a conception of law as a fulcrum that can push public health up or down. Law does not function so simply and thus an account of its role in our immunization social order must begin from a broad interdisciplinary perspective about where law appears and what it does.

Because my focus is on the public wrangling over vaccine injuries, my method prioritizes public testimony, documents, and events over personal interviews. There is a vast documentary record at the vaccine court and on government and activist web sites, and much available through Freedom of Information Act requests.⁴⁷ For example, I obtained and analyzed over five thousand pages of hearing transcripts from the autism litigation at the vaccine court and twenty-seven years of meeting minutes from the government advisory committee that oversees the compensation program. There was an office policy against granting on-the-record interviews at the Office of Special Masters, but I was able to speak with some people in the Vaccine Injury Compensation Program off the record. This book is greatly enriched by their perspectives, but I cannot quote from them or identify them here. Leaders in the vaccine-critical movement declined my interview requests, and so I rely on their speeches, publications, blogs, and press conferences instead.⁴⁸ I gathered interviews with a few leading petitioners' attorneys and observed a closed meeting of the petitioners' bar association.

Notably, this book does not focus on ordinary parents' views about vaccine injuries. Privacy protections and legal rules prohibited me from reaching out directly to the parents who bring cases to the vaccine court. Luckily, Jennifer Reich's detailed study of Colorado mothers who choose not to vaccinate and Chloe Silverman's account of parents of children

with autism in the vaccine court process have provided compelling accounts of these stories.⁴⁹ Feminist approaches to science studies have often adopted a methodology that permits a close examination of ordinary people's disease experiences, such as Janet Shim's study of the politics of race and gender in heart disease and Ruha Benjamin's work on patients' and activists' responses to the call for stem cell research, for example.⁵⁰ Law and society approaches also highly value the layperson's ideas and experiences with the law, exemplified in works such as Laura Beth Nielsen's study of people's experiences with street harassment and David Engel and Frank Munger's long-term inquiry into the meanings of disability rights law in the life experiences of people with visible and invisible disabilities.⁵¹ My own work on the civil rights consciousness of fat rights activists took such a path as well.⁵² By contrast, this project became much more about the vaccine court as an institution and therefore required a more synthetic, higher-up approach to considering the politics of courts.⁵³ The project evolved away from personal experiences and toward the politics of the vaccine court because of the unique methodological challenges here, but most of all because, in spite of all the attention to vaccines in recent years, the story of the vaccine court itself has yet to be told.

I approach the topic of vaccine injuries, as we all do, from a situated position that both extends and limits my understanding of the question. My mother was a subject in the early polio vaccine trials as a young girl growing up in New York, and she remembers my grandmother crying with joy and relief at the news that the vaccine worked. My father is a family physician, and my siblings and I received our vaccines in his solo practice office, sometimes from him and more often from his nurse colleague whom I have known my whole life. I even volunteered to be in a herpes vaccine clinical trial as a cash-strapped graduate student at the University of Virginia in 1996. Someone I knew had just contracted genital herpes, and I hoped I could be part of securing a vaccine against this really unpleasant experience. As it turns out, an effective herpes vaccine still eludes vaccine developers. My mother tells a sad story from a trip she made in the late 1990s as a nurse midwife to Uganda, where she bought a coffin for a thirteen-year-old girl who had died of measles. Perhaps these family memories about vaccines are unusual; it is probably unusual to volunteer for a vaccine trial, let alone to have two generations

of vaccine trial participation, or to know someone who knew someone who died of measles thirty years after U.S. access to the measles vaccine. More than simply giving me a positive posture toward vaccines, my perspective on the research and development reminds me that creating a vaccine is a long and uncertain process and that the benefits of our immunization social order do not extend to people in many poor countries. My accounts and arguments here are admittedly partial and situated, though that does not distinguish them from anyone else's.

Terms and Labels

One challenge in writing about the vaccine controversy is characterizing the people and groups who compose it. I refer to the medical and scientific establishment as the “mainstream,” “pro-vaccine,” or “immunization supporters.” The contentious label is for the other side: anti-vaccine or merely advocates for improved vaccine safety? Scholars generally refer to the people they study by the names the subjects choose for themselves. The argument for avoiding the anti-vaccine label is that in nearly all cases, the people and groups most associated with vaccine criticism insist repeatedly that they are not anti-vaccine. David Kirby, whose 2005 book argued that mercury in vaccines is responsible for the autism epidemic, made a point to say in a 2008 Capital Hill briefing that “I’m certainly not anti-vaccine, and this is not an anti-vaccine briefing.”⁵⁴ “[P]lease know,” he continued, “that if people speak about vaccine safety, about making the vaccine program better, that doesn’t make us anti-vaccine.” Barbara Loe Fisher of NVIC has repeatedly said she is not anti-vaccine. Her position is that vaccines should be like any other good in an open market, with people free to use them, but not compelled in any way. She refers to herself as a vaccine safety advocate or a consumer watchdog.

The argument for disregarding this self-labeling is that it is disingenuous. On this view, critics cannot openly call for banning or boycotting vaccines because it is not politically feasible to do so and retain much legitimacy, so they claim to be simply concerned about safety (which no one is against). At one point at the NVIC public conference I describe in Chapter 3, NVIC President Barbara Loe Fisher, holding the microphone, reassured the audience she was not anti-vaccine, but this framing was

clearly part of image management in the face of a more radical membership. A woman's voice could clearly be heard shouting back at her, "*I'm anti-vaccine!*" Red plastic bracelets distributed in every conference registration packet read simply "No vaccine for me." As I will discuss in detail in this book, the movement is deeply interdependent with those who are avowedly anti-vaccine and whose commitments are incompatible with any support for vaccines. There is not another wing of the vaccine-critical movement that disputes these avowedly anti-vaccine elements.

Well-known pediatrician, author, vaccine inventor, and immunization advocate Paul Offit points out that Fisher and NVIC have not contributed to efforts to make the vaccines we have any safer (such as the move to the killed-virus polio vaccine, which is incapable of causing vaccine-associated polio).⁵⁵ Pro-vaccine advocates in government and mainstream medicine also argue that without levels of vaccination coverage approaching 85 to 90 percent and sometimes higher, vaccine-preventable diseases will return.⁵⁶ Vaccine critics clearly mean to convince people to resist vaccination by telling them it is unsafe. Content review of websites critical of vaccines has shown that they promote inaccurate information,⁵⁷ and one German study found that viewing an anti-vaccine website for only five to ten minutes increased perceptions of vaccine risk and decreased intentions to vaccinate.⁵⁸ To call the groups and individuals behind such websites anti-vaccine is thus to associate them with the end result of their policy agenda, which from a public health perspective would be the widespread loss of herd immunity—that is, the loss of the primary goal of immunization programs—and the return of disease.

I agree that the activists I discuss throughout this book are not merely vaccine safety advocates (though some of them occasionally function as such). Though they have been highly mobilized to engage with the vaccine safety system, the basic underpinnings of their beliefs are not compatible with acceptance of mainstream medicine or the legitimacy of government regulation, and so it has been very difficult to construct a well-functioning partnership over safety issues. Federal government offices are filled with scientists and bureaucrats whose entire job is vaccine safety, but the activists I discuss here frame them as their adversaries and regularly accuse them of covering up the widespread poisoning of American children. But since activists resist the anti-vaccine label and at

the very least do not argue that vaccines should be banned or criminalized, I settle on the more neutral terms “vaccine critics” and “vaccine-critical movement” to describe them.

Another choice to make is whether to use the term “vaccine injury,” as many vaccine critics do, or to use the term more common in the public health and medical literature, “vaccine-related adverse event.” Vaccine-related adverse events are distinguished from “adverse events after vaccination” by their causal connection. “Related” adverse events mean that there is reason to think the vaccine *caused* the adverse event, but an adverse event that happened *after* a vaccine may be only a coincidence and not causally related. This distinction is critical in mainstream science. The medical terminology has the benefit of this extra precision, but I have elected to call the harms that are claimed to result from vaccines by the term “vaccine injury” even though I embrace the distinction throughout this book between causally proven adverse events and those that seem to be linked but turn out not to be. Indeed, most of this book is about how we as a society figure out the difference between something that *seems* to be vaccine-related and something that *really* is. I prefer to use a term from ordinary language, however, and in addition, the legal claims that are at the core of this book are fundamentally about injuries as understood by the people bringing the cases. The law that created the vaccine court was clearly labeled as the National Childhood Vaccine Injury Act. Vaccine critics argue that vaccines are widely injurious, but I do not believe that is true. Nonetheless, vaccine injuries are what everyone is arguing about.

Science, Social Movements, and American Law

Understanding how the vaccine court does its job informs broader scholarly debates about how well courts handle social problems generally and scientific or medical problems with controversial social aspects specifically. I also approach vaccine critics as leaders of an energetic health social movement whose arguments resonate deeply within many groups in our society, although ultimately I do not accept their arguments. My acceptance of the mainstream evidence about vaccines—that they work, that they carry some risks but severe reactions are rare, and that they should be credited with saving millions of

lives and considerable resources—necessarily informs my framing here, particularly its normative bent. Writing about vaccines for me is like writing about climate change or evolution, in which it makes little sense to pretend that the evidence for the mainstream view is anything other than overwhelmingly strong. Mobilization and attention are important for democratic engagement with science and expertise regardless of the merits of the underlying arguments, however. I weave the activists' contributions through the whole story, but I do not spare them my critiques.

I begin with the assumption that law, society, and science are dynamically interconnected rather than separate. Scholars of law and society have long argued that law does not stand separately and over the rest of our lives, but rather creates and is created by our values, politics, imaginations, popular cultural representations, ideological projections, and institutions.⁵⁹ Legal controversies over scientific, medical, or technical questions give us the opportunity to see how law and science interact to, as Sheila Jasanoff puts it, “co-produce the social order.”⁶⁰ This co-production is not only inevitable but, as I will argue, often desirable. Some commentators, however, note these interconnections between law and science only to lament them because they infringe on scientific expertise.⁶¹ As one doctor writing in the *Washington Times* as the autism test cases headed to trial put it, “I find it unsettling that the safety of vaccines must be put on trial before three ‘special masters’ in a vaccine court. . . . [T]he truth about scientific and medical facts is not, ultimately, something that can be decided either by the whims of judges or the will of the masses,” he wrote, noting with disapproval that the “three judges are not experts in medicine or science.”⁶² Lawyers, on this view, make strategic, one-sided arguments while scientists objectively seek the truth. Law is political, social, and adversarial, while science is disinterested and collaborative.

Assuming a mutually constitutive relationship between science and law, however, points to the social aspects of both while leaving plenty of room for their significant differences. As Jasanoff explains in her classic work on science and courts, *Science at the Bar*, “A core project of science and technology studies has been to display the fluidity of the divisions among the social, material, and natural worlds, showing that much of what we know through science or use as technology is produced and given solidity through socially accredited systems of rhetoric and prac-

tice.”⁶³ What we understand as reputable medical opinion about vaccinations emerges through structures such as research laboratories and their teams, competitive funding, peer review, and public presentation of conclusions in language meant to persuade. Credibility, for example, is something that must be built up and maintained, and scientific controversies often put these struggles on display as outsiders compete to establish credibility for their views that challenge the mainstream.⁶⁴ We must rely on expert knowledge to guide law and policy, but we cannot simply hand over power to scientific experts, who are also our fellow interested citizens in our democratic society. This is an ongoing puzzle: how to manage expertise in democracy, where it should be both cultivated and controversial.⁶⁵ The vaccine court is the focus of both expertise as well as social movement attention (and where precisely the expertise is found is part of the argument), letting us see how they might be fruitfully managed together.

The approach to the connectedness of law, science, and society I employ in this book combines Jasanoff’s approach to the knowledge-making projects of law and science with philosopher Elizabeth Anderson’s insights about how to evaluate knowledge claims in a democratic society. Jasanoff urges us to take note of the congruence between law and science: both are formal spaces with great power and legitimacy in which people try to discover the truth through entertaining assertions about reality, hold those assertions to standards, test them, and weed out liars and incompetents.⁶⁶ They are both “situated and purposive” ways of developing knowledge, but differ significantly as well. “[T]he law,” she elaborates, “takes the case as its theater of operation . . . and finds facts in order to settle disputes, whereas science makes claims to extend previous lines of inquiry and enable new ones to take shape.”⁶⁷ Jasanoff cautions us to keep law’s powers to do justice in mind and not simply transcribe scientific conclusions into law. By focusing on a court that has been explicitly tasked with upholding scientific credibility but also with doing justice to particular injured people, I show how the vaccine court crafts a balance beyond transcribing the scientific consensus. Anderson’s work on the epistemology of democracy proposes that there are some readily identifiable criteria that ordinary people can employ to see whether we are getting legitimate knowledge out of our social institutions.⁶⁸ Are there enough paths for dissenting views to be taken

up within the institution—here, the vaccine court—and can ordinary people make reliable second-order assessments about whether their rulings represent a trustworthy consensus? Reflecting on how the vaccine court attempts to satisfy Anderson’s criteria helps us understand how it produces science for justice in Jasanoff’s terms.

I accept that most often law operates to justify and sustain hierarchies of knowledge and power. Therefore, any sociolegal analysis must include a frank acknowledgment of those hierarchies. As Michael McCann notes, “virtually all scholars agree” that “law often significantly supports prevailing social relations as well as provides limited resources for challenging those relationships.”⁶⁹ Feminist legal scholars have long pointed out, for example, that abortion as a privacy right means being left alone without resources,⁷⁰ and that a police- and prosecution-focused response to domestic violence best assists those who can trust the criminal justice system not to exploit them further.⁷¹ Putting a dispute in legal terms also transforms it, often narrowing it and permitting only a limited view of the harms, rights, duties, and relationships involved.⁷² A central challenge for any social order, then, is to maintain compliance and the faith of the citizenry even in the face of legal requirements that put them in the losing position: getting a traffic ticket, losing a civil suit, having one’s vaccine injury claim denied, having to pay taxes, and so on. As psychologist and legal scholar Tom Tyler has shown, people will obey a legal decision even if it counters their interests if they feel they were treated fairly in the process and if they feel committed to the legitimacy of the legal authority generally.⁷³ Vaccine critics continue to argue against the basic legitimacy of the court’s rulings against them, but I show how overall the vaccine court has been an important part of the legitimation of the immunization social order.⁷⁴

In spite of the hegemonic power of the law to defend the status quo, social movements can sometimes mobilize litigation and the language of rights to accomplish their goals.⁷⁵ This book examines in detail how vaccine critics have worked both to produce and to challenge our immunization social order and the legalization of vaccine injuries. Organized vaccine critics were, after all, a primary mover behind all the vaccine safety law and compensation that we have today in the United States, starting with the NCVIA of 1986. They achieved a dramatic national success that has eluded many other social movements. Vaccine activ-

ists managed to break what Shobita Parthasarathy terms the expertise barrier to their participation in elite policy making by reading up on journal articles, introducing new facts about vaccine injury through their claims making, reframing vaccine policy as everything from an infringement on parental rights to an environmental harm, and attacking the vaccine court as illegitimate as it evolved to be more hostile to their claims.⁷⁶ Many of these parents became professional activists and continued to work at the state and national levels to organize testimony, elect sympathetic legislators, write and introduce legislation, lobby and fund-raise, produce and sponsor their own research, and operate sophisticated grassroots and social media organizations that continue to influence the vaccine views of millions of parents. They run blogs, produce documentaries, write books and articles, hold press conferences, and purchase billboard advertising in Times Square. Leaders have also been a part of every appointed government advisory committee that has monitored vaccine safety in the contemporary era, where they have had a vote and a voice as well as a chance to monitor and amplify what happens in government for their constituents nationwide.

Throughout the book, I show how vaccine critics have led a sustained health social movement for decades, forcing our laws, institutions, and politics to respond in ways that have ultimately strengthened our immunization social order (much to critics' chagrin). It is often a politically conservative movement (if one looks at the leadership, especially), and although there has been some study of movement conservatives and legal strategies, most scholars have studied social movements from the left of the political spectrum, such as the civil rights and feminist movements.⁷⁷ I argue that approaching vaccine critics as a legally focused health social movement helps us to see how libertarianism, individualistic mothering, and attention to personal health have come together ideologically, letting us trace the roots and effects of these ideologies and legal strategies. In a twist on the usual resources story, these are relatively elite biopolitical citizens who want *not* to consume the proffered technoproducts. Their activism, along with the uptake of some of their initial arguments within the U.S. health bureaucracy and courts, has "made rights real" in critical ways that have improved our vaccine safety system and probably would not have occurred otherwise.⁷⁸ Vaccine critics have also succeeded in attracting many ordinary people to

their views at the same time (and introduced popular social practices such as delaying childhood vaccines on an alternative schedule), but overall immunization rates remain high and the movement has had few political or legal victories in recent years.⁷⁹

Broader Contexts: Anxious Mothering and Feminist Health Activism

Scholars have long realized that controversies over scientific knowledge reveal important fissures in society over fundamentally political questions about access to power or the value of different ways of living or groups of people.⁸⁰ These are deep tensions over basic values, and they can only be managed rather than fully resolved. Mark Largent argues that we must understand how parents feel pushed along and overwhelmed by our extensive childhood vaccine schedule and that their concerns must be respected, particularly once we situate those fears in historical context and recognize that sometimes vaccines do cause adverse reactions.⁸¹ Many people mistrust pharmaceutical companies and resent the political advantages and great wealth these corporations enjoy. Vaccine controversies implicate the meanings and duties of motherhood, the power of citizens to control environmental risks they perceive as dangerous,⁸² the legitimacy of legal institutions that attempt to remedy these harms, and the trustworthiness of the government regulators and researchers who regulate them. Understanding the wide range of broader contexts to vaccine injury debates will disabuse us of the notion that there is a simple informational correction to parents' concerns, for example.

Contemporary debates about vaccine injuries take place within a much longer history of concerns about vaccines, situated within broader shifts in ideas about health and illness and the status of the mainstream and the alternative health professions. Historians have documented the history of vaccine controversies in the United States and Europe, highlighting how our societies have weighed public health imperatives against the problem of coercing resistant citizens.⁸³ Many vaccine critics today embrace alternative healing traditions that have a long tension with mainstream professionalized medicine in the United States, and pushing back against the dominance of the germ theory of disease as

an account of health has been part of vaccine opposition since its beginning. Rejection of a germ-based account of disease also connects to many larger conversations about health and disease prevention in contemporary American society, in which healthy living, exercise, and high-quality food are widely accepted solutions for chronic health problems. Vaccine critics uniformly maintain that healthy living makes vaccination unnecessary, extending the dominant lifestyle view of health one step over into the realm of infectious disease.

This concept of lifestyle control over one's health merges easily with contemporary understandings of intensive motherhood, individual responsibility, and the middle- and upper-class focus on maximizing the life chances of one's children.⁸⁴ Medical anthropologist Sharon Kaufman situates parental concerns within the terrifying freedom and responsibility that parents, mostly mothers, now have for children in a world in which every decision seems fraught but must still be made.⁸⁵ Critiquing a "one-size-fits-all" vaccine schedule binds nicely to the idea that health care should be highly individualized and that each child is unique, and perhaps uniquely vulnerable. I situate organized vaccine critics within their often-unseen gender, race, and class politics, guided by these feminist social science perspectives on mothering work and especially by Jennifer Reich's observations that contemporary mothers' vaccine resistance is often enabled by white middle-class privilege and the anxiety of mothering.⁸⁶ The desire to maximize children's life chances combines with the responsibility to become one's own expert, do one's own research, and micromanage the family's risks of harm, assisted by patterns of labor force pullback and financial resources. These priorities crowd out the benefits of herd immunity when enough parents with these views cluster together geographically, as they tend to do.⁸⁷

So while one might think that maternalism could promote a sense of duty to protect all children, in this context it is more easily mustered as part of a broader picture of feminized self-care and privatized motherhood. It is easy to see under this ideology how a mom who just goes along with the recommended vaccine schedule looks like she is failing to personalize it, to fully inform herself, and to take control over her family's health. Feminist scholars of the women's health movement have greeted this turn to personal responsibility with careful criticism, and I argue that this concept of privatized motherhood is a linchpin of

what I term the health libertarianism that unites the left and the right over vaccine resistance.⁸⁸ Health libertarianism often has a champion in mainstream public health discourses on other topics, however, as public health officials instruct us that we should all be making lifestyle changes to avoid cancer, to weigh the right amount, to make sure our children weigh the right amount, and to take responsibility for being healthy and not costing too much.⁸⁹

Vaccines and vaccine mandates contravene nearly every aspect of this very popular health libertarianism and intensive mothering. They are highly technical products used on us by experts and manufactured by powerful global pharmaceutical corporations. They are for everyone, and they work on the children of both supermoms and slacker moms. The fact that vaccines create an immune response in nearly everyone means that they cannot constitute individual health achievement through doing the right things, which I argue is the dominant view of health.⁹⁰ There is one recommended schedule for all children, and although authorities support some deviations for unusual medical conditions, vaccine recommendations are overwhelmingly unitary and communal rather than individual and variable.

The contemporary political and legal context for claims of vaccine injury, therefore, would not be possible without the feminist health activism of the past fifty years.⁹¹ While vaccine critics are often maternalist rather than feminist (that is, invoking motherhood as grounds of legitimacy and knowledge but not criticizing gendered power relations in structural ways), their achievements have been greatly assisted by the success of earlier feminist arguments that, for example, powerful male doctors should not dismiss women's knowledge and observations as irrational. The feminist health movement that began in the late 1960s and early 1970s has been enormously influential in shifting social attitudes about who should have power in medical care and in matters of personal health. Feminist health activists were pivotal in producing both much-needed social change as well as theoretical innovation as they showed how the body is political and health is gendered.⁹² They offered detailed and much-needed critiques of an overbearing medical profession and a device and drug industry with a record of damaging mistakes.⁹³ These feminist health activists touted their achievements in "requiring future meetings of the U.S. FDA to be made open to the public and to have

consumers as well as industry representatives and scientist/practitioners on the expert panels” and “us[ing] publicity to catch drug companies or device manufacturers in their lies and over-zealous medicalising, as well as to provide critical information to the public.”⁹⁴ The women’s health movement was a knowledge movement that was successful in altering the boundaries of expertise and the power relations in health care.⁹⁵ Feminist scholars celebrate it because we think the activists were right on the facts as well as energetic participants in democracy. Vaccine critics have modeled their activism after these successes and benefited from the pathways for participation laid by women’s health activists, but they have not been able to make their alternative knowledge claims credible in the same way.

The ways that vaccines and vaccine injury debates are racialized are not quite as obvious as their gendered dimensions but no less important. First, the movement of vaccine critics is overwhelmingly white in both membership and perspective. Practically every activist I have observed (save one, an Asian woman) has been white, and the various constituencies served by the broader movement are also overwhelmingly white (especially the libertarian wing, but also the holistic moms). Either movement leaders are very wealthy themselves or their organizations are supported by a small number of very wealthy donors. Parents of children in the United States who have received no vaccines at all tend to be over thirty (for the mother), white, married, and college-educated, with a household income of more than \$75,000 per year (in 2001 dollars, over \$100,000 in 2015).⁹⁶ Families who have refused at least one vaccine for any reason for a child are also wealthier and more educated than nonrefusing families.⁹⁷

Second, the critics’ rhetoric displays an awareness of the power of minority rights language in U.S. society, but they appropriate it to defend the privileges of the white middle and upper classes. This strange obliviousness stands in stark contrast to public health efforts at vaccine promotion, which figure racial and ethnic minority groups as the focus of targeted outreach (but also sanction welfare recipients in some states if they do not fully vaccinate their children). Children who are behind on vaccines tend to have multiple siblings and African American mothers with less than a high school education, without a child-rearing partner, and with incomes below 50 percent of the federal poverty level.⁹⁸

As Reich points out, privileged white nonvaccinating mothers' practices show little regard for the possibility that other children may need the protection of herd immunity, but instead describe how they are able to keep their own children away from disease (such as in day care) and to properly care for them so that vaccines are not necessary.⁹⁹

The people arguing about vaccine injuries are a small and elite group, and this national conversation entirely excludes poor people and non-white communities. On one view, this exclusion is a benefit if one sees the debates through the lens of the debunked, distracting, and wasteful search for an autism-vaccine link because there is no need to draw diverse communities into a debate characterized by misinformation. Another perspective, however, is that debates over vaccine injury are really about evaluating whether our immunization social order is worth upholding. Vaccine coverage for children is one of the few bright spots in an otherwise grim national picture of unequal access to health care by race and class, with no racial or ethnic disparities at all in MMR or polio vaccination rates since 2005, for example.¹⁰⁰ We have achieved this level of equality through a combination of legal pressure, federal funding, and public health outreach to underserved communities,¹⁰¹ but we do not have the data to know whether poor people or other vulnerable groups experience vaccine reactions at the same rates as the insured population because our safety surveillance systems draw on health care records in managed care organizations to which these groups may not belong. We do not know whether there are racial disparities in vaccine injury claims in the compensation program. The claims database does not track petitioners by race. Even if we understand our immunization social order to have achieved a level of economic and racial justice not seen elsewhere in our society—and I argue that the safety and efficacy of vaccines give us good reasons for seeing it that way—then we must hold back our self-congratulation until we know more about the perspectives of poor people and members of racial and ethnic minority groups within this social order, especially their abilities to be compensated for vaccine injuries when they occur.

This book addresses the immunization social order and the legalization of vaccine injury in the contemporary United States, a country that leads the world in vaccine development and in the reach of its legal mandates. Vaccines are also a global product, however, and as WHO puts it,

“vaccine pharmacovigilance is an international responsibility.”¹⁰² Vaccine safety debates appear transnationally as well, often intertwined with legacies of colonialism and confronting the wide disparities between the wealthy vaccine-producing countries and the poor countries with worrisome rates of diseases but little money to buy vaccines.¹⁰³ Promoting immunization in poor countries has such a high rate of return on investment that it has become a top priority of philanthropist and Microsoft founder Bill Gates. Vaccines in the transnational order emerge as tools of wealthy private individuals and global public-private partnerships that cannot create stable democracies but can immunize large numbers of people. Millions of lives can be saved and improved through these programs, but they also reveal what they cannot touch: the under-resourced state of the formerly colonized societies of the global South. A transnational perspective on vaccine injuries would have much to offer, but it is beyond the scope of this book.

The Plan of the Book

In Chapter 1, “How Are Vaccines Political?” I show how to think of vaccines as thoroughly social and political, that is, created through law, regulation, political will, and ideologies as well as through scientific development. This chapter explains how vaccines are approved and recommended, what the current recommended vaccine schedule for children in the United States looks like and how it has changed over time, and the state-level politics of school entry immunization requirements. I also detail the structure of our federal vaccine safety monitoring system, underscoring how federalism and our lack of a comprehensive national health care system create difficulties in detecting vaccine injuries. All these political features are crucial for understanding the struggles at the vaccine court over recognizing vaccine injuries.

Chapter 2, “The Solution of the Vaccine Court,” tells the story of the founding and shifts in the vaccine court over time, placing it in a rich context of parental protest against the diphtheria-tetanus-pertussis vaccine in the 1980s and showing how the scientific and legal conflicts that have riven it over time have shaped its responses to vaccine injury claims. In particular, I present the challenge that the potentially massive lawsuits claiming that thimerosal in vaccine caused autism posed and

note the court's flexibility over time and its shrewd balancing of science and policy in the face of panic and uncertainty.

Chapter 3, "Health and Rights in the Vaccine-Critical Movement," introduces the leaders, organizations, and underpinning ideologies of the social movement mobilized around the vaccine court. Activists understand fundamental concepts like risk, harm, health, and parental duty in ways that are incompatible with the mainstream, and these divergences in turn help explain why they do not see vaccine court evidence in the same way. They perceive themselves as fighting for individual health freedom at the same time as they muster an aggrieved and vulnerable minority status to protest vaccination and to criticize the vaccine court.

Chapter 4, "Knowing Vaccine Injury through Law," asks how it matters that we have legalized vaccine injury in the ways that we have and describes our institution in detail. I dwell here on the contemporary, ordinary business of the vaccine court, describing the kinds of professionals who work there and how they do their jobs. I focus on what I call the middle-ground cases, in which there is some reputable story of how a vaccine might have caused the injury and no studies accepted as definitive that rule it out, and so the court has adapted a way of compensating these people but without full agreement that vaccines are really the cause. Our vaccine court design is part of a globally shared understanding that some kind of vaccine injury compensation is appropriate, but I explain how ours stands out among the nineteen other systems set up across the industrialized world. Finally, I argue that comparing the vaccine court to other kinds of domestic alternative compensation schemes confirms the status of vaccination requirements as a national call to service in our immunization social order.

Chapter 5, "What Counts as Evidence?," returns to the problem of why activists and scientists cannot see vaccine injuries in the same way even after they have argued over the evidence in courtrooms and meeting rooms for years. I recount the full range of contested evidence the special masters draw upon to decide cases and show how incommensurate the competing views of that evidence often are. This chapter also sets out how activists tried to use the legal process and the vaccine court itself as a way of exposing what they see as conspiracy and misconduct. In turn, government scientists and bureaucrats also mobilized their story of vaccine safety through the vaccine court.

The autism cases are the court's biggest recent challenge, and the story of how the court found that autism is not a vaccine injury is the topic of Chapter 6, "The Autism Showdown." These cases were a showdown because the court had previously compensated for vaccine injuries without much population-level evidence but with a reasonably credible causal story of how they could have happened to individuals, and thus it seemed at the start that the claims could go either way. Instead the vaccine court strongly repudiated a vaccine-autism link in ways that delegitimized vaccine critics, who nonetheless argued that the vaccine court was hopelessly stacked against them.

The concluding chapter, "The Epistemic Politics of the Vaccine Court," offers reflections on what the vaccine court helps us know. Our knowledge is imperfect but perfection cannot be the standard. The vaccine court has helped to uphold an immunization social order in a legalized way that deeply reflects American political and cultural values and strategies for problem solving.