

Vaccine Hesitancy and Individualism

An Interview with Jennifer Reich

JENNIFER REICH, ANDREW S. GROSS

When Jennifer Reich's Calling the Shots: Why Parents Reject Vaccines came out with New York University Press in 2016, vaccine hesitancy was just beginning to receive national attention. The "Disneyland measles outbreak" had occurred the year before, and an increasing number of parents were switching to charter schools and home schooling in order to avoid the vaccine requirements of the public-school system. Reich interviewed many of these parents and took their reasoning seriously. She discovered that although their decisions do not make sense from a public health perspective, they were actually privatizing the healthcare decisions relevant to their families in ways being promoted by corporations and the government. What the privatization of health care means for the public sphere was one topic of our conversation. At the end of the interview, Reich links privatization with the growing distrust of governmental and scientific expertise to describe a crisis of knowledge that extends far beyond current vaccine debates.

Andrew Gross: Many of us think of “anti-vaxxers” as those refusing to get vaccinated against Covid-19. However, you started studying vaccine opposition long before the pandemic, pointing out in 2016 that a growing number of parents were refusing to let their children get shots. At the time you predicted this could precipitate a public health crisis. Well, the crisis is here. Could you talk a little about why people refuse vaccines and why the skepticism seems to be growing?

Jennifer Reich: I very seldom use the term “anti-vaxxer” because people don’t describe themselves that way, and I try really hard to represent people the way that they represent themselves, even if we disagree about what those representations mean in the end. I started thinking about vaccine refusal really a long time ago as I was finishing a book on the child welfare system and looking at how the

state interfaces with families and decides what it means to be a community member, what it means to take adequate care for children, and when the government can remove children for protection. That made me ask: where else are families making decisions about public policies? Where is the state dictating what it means to be a community member? What does it mean to be a good-enough parent?

At the time I was thinking about this, I was living in a region of California where parents were increasingly starting to question vaccines online and share information about why vaccines weren't really necessary for children. This was shortly after 9/11, and part of the response to the terrorist attacks was an expectation that there would be bioterrorism in the future, and that there needed to be new legal frameworks for how to prepare and respond to the possibility that viruses could be weaponized. Around 2005, the Bush administration championed a series of laws to redefine and lower the bar on what counted as a pandemic. They created a series of legal mechanisms to allow for the emergency authorization of vaccines or biologics in case of a terrorist attack or pandemic. This was around 2005, and not that many people thought these laws were particularly interesting at the time. Two years earlier, in 2003, there had been an attempt to re-inoculate first responders against smallpox (a disease that had been eradicated in 1968). I was a fellow at a medical school at the time, where people I was working with were debating whether they should get vaccinated against smallpox or not, and what that would mean for their families since it's a live-virus vaccine. I was listening to all these conversations in parallel—conversations about children not really needing vaccines, about how we should prepare for bioterrorism, and about hypothetical risks—thinking that this was a really interesting juxtaposition of risk perception and disease.

When I moved from California to take a job in Colorado, which has pretty consistently led the nation in the most numbers of families to opt out of vaccines by choice, it seemed like a really interesting place to start thinking about how parents come to make decisions about vaccines for their children, how they perceive risk and benefits, and how they understand social obligations.

In 2007, near the beginning of my research, not very many people thought it was a particularly interesting topic. Several of my grant proposals got rejected. I decided to pursue the project anyway, and it took me about nine years from when I started collecting data to writing the book *Calling the Shots*. Part of the reason it took so long is I was really committed to getting the story right. I talked to parents; I also talked to pediatricians about what they do in their practices; I

talked to attorneys who represent families in vaccine injury compensation cases; I talked to vaccine researchers and regulators to try to understand as many perspectives as possible. And at the time, there were a few books on parents who don't vaccinate their children, they were all written by men; they had a fairly dismissive tone towards the families—"they are anti-science, they are conspiratorial, they are ignorant"—and I really didn't want to write another book that was mean to parents because I had young children and I was aware of how hard parenting is. Mothers were telling me how hard they were working to do the best things for their children and how, for the most part, parents feel alone in the world. They don't get a lot of social support, and so I wasn't going to write another book attacking parents who were trying really hard to help their children.

AG: So many different factors come together in this story: the terrorist attacks, the social networking and research possibilities opened up by the internet in the early 2000s, not to mention your own experiences as a parent. Why is it, all of a sudden, that parents begin selecting vaccines or deciding against vaccination altogether? Our parents, the so-called baby boomer generation, all got the polio shots and measles shots, and they made sure we did too. That doesn't seem to be the case anymore. Why? Which factors, or combinations of factors, created a change in attitude big enough to have such dramatic social effects?

JR: It was hard to find parents to interview because they were fairly savvy about the research process and critical of science, so they didn't have a burning desire to be part of it. I was mostly finding white women with at least some college education, and initially I kept thinking I must be sampling wrong, because everything I know would say that families of color and low-income families trust the government less than wealthy families. Around that time, there were a couple of large epidemiological studies that identified characteristics of families who reject vaccines, and they tend to have a college-educated mother, higher family income, and they're more likely to be white and married. It turned out my sample did match that pattern, which brought me to ask: why is this the group that is rejecting vaccines?

The pediatricians who service low-income children would often tell me that families with other material concerns—like housing insecurity, food insecurity, concerns about the safety of the neighborhood or the quality of the school—do not tend to see vaccination as a big issue. There is a certain privilege involved in making vaccination an issue. Deciding against vaccines means you are willing to have

your children become infected and be sick and stay home from school. It also means you're someone who has the money and time resources to care for your children if their school enacts a twenty-one day quarantine in the case of, say, a whooping cough outbreak.

Researchers who work on vaccine hesitancy often point to 1982 TV documentary, made by an NBC-affiliate in Washington D.C. and screened nationally, called DPT: Vaccine Roulette [DPT is a combination vaccine against three infectious diseases: diphtheria, pertussis or whooping cough, and tetanus]. Parents were alarmed by a range of medical problems the documentary suggested might be linked to the vaccine. They began calling the network, which in turn began sharing phone numbers with other parents. The network put them in touch with each other. This group of parents began meeting in a living room in Washington, D.C., and they named themselves "Dissatisfied Parents Together," or DPT, which, of course, was the acronym for the vaccine they opposed. The members had very different backgrounds. Barbara Loe Fisher, who is the founder of the largest anti-vaccine organization in the U.S.—or organization that opposes vaccine mandates is how they would define themselves. She is a libertarian who is politically conservative. But there was also an environmental lawyer whose daughter had developed a serious disorder, and several other parents who had different political orientations, but who aligned in the belief that their children had been harmed by this vaccine. Their advocacy and willingness to file lawsuits against vaccine manufacturers led to a situation in which pharmaceutical companies threatened to simply stop producing vaccines. Prior to the 1980s, there were about thirty vaccine manufacturers in the United States, and the threat of lawsuits was a trigger point where the companies decided vaccines were not the most profitable product they had—many of these vaccines aren't even patented—and so they just stopped making them because it wasn't worth the liability risk. The result was that the United States was staring down the situation in which they would have no manufacturers making vaccines and, therefore, no supply of vaccines for childhood illnesses.

Federal law responded to this situation in several ways: it created a claims court for vaccine injuries so that every vaccine in the country is taxed 75 cents that goes into a trust fund, and the trust fund is administered by special masters; there are only eight special masters at a time. They have no particular scientific qualifications; it's a political appointment. The way it works is that parents or individuals who believe they've had an injury from a vaccine do not have to show causality; they just have to show probability, like temporal probability and the exclusion of other explanations. The idea was that if you participate in pub-

lic health and you're harmed, we should take care of you, and vaccine manufacturers cannot be sued until you've gone all the way through the special claims process defined by the claims court. This requirement has been challenged at the Supreme Court, which has upheld the claims court format, and protected manufacturers from most liability.

When the claims court was developed, it was really imagined as a solution for childhood vaccine injuries, and most of the claims today are things like influenza injuries like Guillain Barre Syndrome, damage to your shoulder from the injection itself. Now it's much more likely to be adults who are compensated, but at the time when they opened up the claims court, according to one of the special masters I interviewed, trucks arrived full of applications from people with polio injuries from the 1950s and 60s. When they opened up the claims court the idea was that they would process claim efficiently and quickly without it being an oppositional system to make it possible for public health to continue.

What's interesting about that moment in the 1980s—the claims court starts in 1986 and 1987—is that there is no way to think about this group of parents and their activism separate from thinking about the women's health movement, or thinking about the AIDS activism that was challenging the US Food and Drugs Administration (FDA) and pharmaceutical production and testing around HIV and AIDS care and medications. There is no way to think about vaccine hesitancy as separate from what was happening culturally, where we were increasingly seeing conversations about personal responsibility for health, accountability for disease avoidance, the jogging and aerobics crazes of the 70s and 80s, the rise of nutritional supplements as large sources of profit that are exempt from regulation, but culturally touted as part of promoting health. You know, there is no way to really think about this vaccine moment without thinking about a number of cultural strands that are interesting and really complicated.

AG: To trace one of these cultural strands, this sounds like a story about the unintended private consequences of public success. Vaccine hesitancy is a result of vaccination effectiveness, right? You talk about a whole generation of parents who are weighing the dangers of vaccination against minor risks because vaccines have been so successful in eradicating childhood diseases. How are we to understand this give-and-take between the individual—you know, protecting your kids, taking care of yourself—and the public good?

JR: I think one of the things that surprised me when I was working on my book was the extent to which both the culture of individualism around health and disease avoidance, really resonated with a culture of parenting that has accelerated in the last twenty years. This culture sees parenting as a kind of consumer production, something that aligns with, for instance, the privatization of public schools. In Colorado, where I live, we have a whole framework for school choice where parents can opt out of their neighborhood school and into other schools. And, if you really break down the movement towards school choice, it's really the belief that some children can have terrible schools as long as your kids don't have to go there, rather than saying we could work together to ensure that all children have quality schools. The notion of choice, of personal choice, is really powerful, but it also builds on a neoliberal logic that was taking hold in national welfare programs, which in 1996 was reformed and notably renamed the Personal Responsibility and Work Opportunity Reconciliation Act. The idea of personal responsibility has seeped into every aspect of both public and private life, and so, what I started to realize was that parents weren't making this up; they were drawing on the cultural threads around them, and vaccine hesitancy is the logical outcome. When every decision is a consumer decision, and the way you define who's a good parent is how seriously they've taken this decision-making process—then deciding not to vaccinate your kids is your choice, as long as you're not following medical advice blindly, as long as you're taking the time to learn the information for yourself, as long as you're “doing your own research.” This is an argument I heard repeatedly.

The idea that you can “do your own research” is also fascinating because people use it the way I research a new restaurant or a hotel before I travel, back when I used to travel, or when I use a website to read consumer product reviews. So, I gather information to make a consumer decision, but that's a really different kind of research than I do in trying to create generalizable knowledge with rigorous methods. We flattened out the word *research* by individualizing it in a way that detracts from its meaning.

During COVID we can see the acceleration of these same logics. It's been really hard to convince young people to get vaccinated because they perceive themselves as healthy, as able to handle infection, as not particularly vulnerable; and many people highlighted the quality of their nutrition, the fact that they take supplements, the fact that they exercise, as ways of explaining why vaccines are not an important tool—and that's the same kind of thing I hear from parents talking about their decisions to opt out of vaccines.

AG: Could you talk a little more about the “media studies” aspect of this story? Going back this NBC special and the way the network put parents in contact with each other: there is a sense in which this kind of coalition wouldn’t have been possible without social media or its precursors. Does it take something like social media to bring a libertarian in contact with an environmental protection lawyer? Does the kind of coalition-building enabled by social networks, cut across traditional party lines in ways we haven’t seen before?

JR: People are paying a lot of attention to social media platforms to social media platforms in the COVID era because bad information—misinformation and disinformation—can travel really quickly. In March 2020, this well-produced, glossy, and compelling video called *Plandemic* was produced; it argues that the COVID-19 pandemic was planned as part of a pharmaceutical and government collusion. I think I must have seen a link to the video thirty times in twenty-four hours from different people in my social network. A lot of the video-hosting sites and social media sites were actively trying to take the information down in ways they hadn’t actually done before, and it was a game of whack-a-mole, stop it here and it would show up somewhere else. So, it’s easy to say the problem is the media and the availability of information technologies.

Nevertheless, it is important to remember that there were anti-vaccine campaigns during the smallpox era that would pass out leaflets and booklets in town squares and go door to door, trying to make the same kinds of claims of government overreach or scientific uncertainty. There were political cartoons dating from the early nineteenth-century showing pictures of people sprouting cow parts because early vaccination drew on cowpox pustules. We’ve had the same kind of frames for a long time, and technology makes it easier for the information to travel, but it doesn’t necessarily mean it’s a whole new phenomenon. Lots of the claims have actually remained consistent over time: individuals know their bodies best, they know that their intuition about their own children is more reliable than expert knowledge, and that, at the end of the day, they will be accountable for whatever happens in their family. Some of that feels new today because we’ve had such an acceleration of a consumer logic around health promotion, but parts of it are old. When we think back on the early era of professional advice on parenting, and the efforts to dismiss midwifery, or when the federal government started publishing baby-care guidelines, some of which were medically questionable, like the promotion of formula over breast milk...people have always pushed back against that logic, right? You had individualist Americans listening to their

grandmother more than they were going to listen to a pediatrician. We can look back a hundred years and see very similar kinds of cultural tensions around expertise, cultural knowledge, and intuition, as other ways of “knowing” that have been really significant.

AG: How are these other ways of “knowing” different from science or public health? Should we be trying to encourage people to base their decisions on scientifically credible data?

JR: When confronted with certain data sets that show disease risk exists for unvaccinated children, some of the mothers I interviewed would say things like “but there’s not enough data to say that in my house, with my lifestyle, that my children are at risk.” And that kind of logic is really hard to challenge because we collect population-level data to get at trends, but those trends cannot predict the experience of any one person. Data tells us something about probability. With COVID, young people are less likely to be hospitalized or to die, but that is not to say no young people have died. Risk factors cannot fully explain how you should decide what to do. What’s challenging with vaccines more than, I think, other kinds of pharmaceutical technologies, is that vaccines are given to healthy people to avoid a hypothetical. They’re given to healthy people to avoid risk, which is different than pharmaceutical products that are given to sick people to treat illness. The expectation that vaccines must be exquisitely safe is reasonable because they’re given to people who are well—versus, we accept that chemotherapy is highly toxic because you’re already sick, and the effects of that toxicity is still potentially less harmful than the outcome of untreated cancer. That’s not the case with vaccines.

In the balancing act between mathematical probability and intuition, what it really comes down to is risk threshold. Some of us are catastrophic thinkers, where when the probability of disaster is two percent, we expect that we’ll be in the two percent; and there are other people who assume they’ll never be in the two percent. Knowing who you are also helps to shape this, which I think brings us back to privilege: if you imagine you can control your surroundings, it is easier to imagine disease risk as less terrifying. If you have a sense of control over your children’s nutrition, your children’s health, the ability to breastfeed as long as you want to; if you have control over your resources, it can be easier to imagine you have control over infectious disease even if that’s unlikely.

AG: In a sense, some of the people who hesitate are not wrong about their immediate families or themselves. If they live healthy lifestyles and take reasonable precautions, COVID may not pose much of a personal threat, although they run the risk of spreading the disease to others who are more at risk. What arguments might a public health official use to convince seemingly healthy individuals and families to get vaccinated?

JR: I think a lot about a woman in my study who had the most sophisticated explanation of her vaccine decisions. She had three boys, all unvaccinated. But she told me that if she had a girl, she would probably have her vaccinated against measles before she became a teenager. Her logic was that measles could be devastating for fetal development, were her daughter to become pregnant. As far as her boys were concerned, she did not really care about measles. She wanted them to contract mumps before they were teenagers because mumps can cause sterility in boys, and would have them vaccinated if need be, but mumps would not be a factor for girls. I don't know if her vaccine assessment is "wrong," but it is entirely reliant on seeing her children as the locus of evaluation, and not considering the way that they're part of a larger community. Those boys might be around pregnant women. They might be partnered with a woman who becomes pregnant. They might be at the grocery store with a pregnant woman. Their unvaccinated status increases the risk to others.

In my book I call the idea that less is always more and that vaccines are a necessary evil at best "therapeutic nihilism." People do not take this approach to over-the-counter drugs. It's interesting to think about what makes vaccines different. A lot of people say they don't want to get vaccinated every year. Parents tell their pediatricians that they do not want to vaccinate for everything. Some doctors have resorted to offering a cafeteria-style approach to vaccination—trading-off, say, the chicken pox for a more threatening disease such as whooping cough—in order to vaccinate at all. What this means is that doctors have customized medicine and come up with a market solution. I talked to physicians who customize vaccine schedules for every family (for cash—no insurance payments) as a way of making each child and each parent feel that they're getting personalized care. I had parents say to me, "every child has a unique immune system, so why are the vaccine schedules all the same?" Individual immune systems can have variations, of course, but the perception that every child is unique has ramifications beyond health care. For instance, when schools are expected to adapt to individual chil-

dren's needs rather than children adapting to school, with markets for extracurricular programming and tutoring and intervention services. Individualism has come to define what it means to raise children, and vaccines are not exempt from this way of thinking.

AG: We take medicines like ibuprofen for ourselves, but part of the reason we get vaccinated is other people. The kind of individualistic thinking you just described sounds libertarian. Once upon a time I would have thought that it was characteristic of the political right. But now it seems to be spreading beyond right-wing political groups. Does everybody think this way now?

JR: That's a great question. Historically, vaccine hesitancy and vaccine refusal has been one of those places where left meets right. I saw that in my research. Parents who defined themselves as politically progressive and environmentalist, who, you know, talked about their organic mattresses or their social volunteering in the community, said very similar things to families I spoke to who are part of the evangelical organizations, who are part of conservative political groups. They said similar things about distrust of pharmaceutical companies, distrust of government regulation, a sense of knowledge of their own children that they trusted more, and their ability to make the best decisions for their families. There was also a pervasive notion that the environment is toxic, that there are risks that you can't control; vaccines, however, are something that's controllable in a world where other risks might not be, which parents cited as one reason to reject them.

What's shifted during COVID in very profound ways is that vaccine hesitancy, vaccine refusal, have, for the most part, become highly partisan. In the United States, the best predictors for not getting vaccinated against COVID are identifying as Republican and evangelical. Something else that has shifted—and I attribute some of this to the Trump administration—is the aggressive messaging that experts cannot be trusted. People who have worked in government for ten or twenty years, people who are career scientists, were suddenly confronted with claims that the length of their experience proved they could not be objective. From the earliest promises to “drain the swamp,” people who understand systems have been held up as the problem.

That made it difficult to have broad-based trust in public health messaging around COVID. Something I did not expect to see—and I say this as someone who has been working in this field for twenty years—were the widespread attacks and death threats targeting county public health officers. My home state of Colorado has passed legislation to allow public health workers to have unlisted contact information because they have been so aggressively targeted for harassment and death threats. I have been learning about riots and protests against smallpox vaccines in 1885 in Montréal and two decades later in Detroit—so this kind of anger is not unprecedented, but it definitely hasn't been part of what we've been seeing in the last several decades. At the same time, there's been a rise in tele-health visits from providers who, after some kind of online consultation, take cash payments to provide prescriptions and healthcare alternatives for treatments that are unproven, or sometimes disproven, as a way of offering alternatives to mainstream healthcare. So, for example, accessing ivermectin prescriptions has become a cash industry, as has accessing hydroxychloroquine. Also, I am hearing folks who are claiming that the healthcare system—the Centers for Disease Control and Prevention or the Food and Drug Administration that is in charge of regulating safety of products is the problem themselves—are actually intentionally causing harm to the American people. It's one thing to say they're not doing a good job regulating products or safety; it's another thing to say that they are actively undermining public health. I'm currently hearing claims that they're actively undermining public health as part of a depopulation campaign. These kinds of accusations have made what is really an ongoing vaccination debate much more partisan, much more sharp-edged, and much angrier and more violent than what we've seen in recent history.

AG: Would you call this a crisis?

JR: I strongly believe that pandemics don't cause new problems but they magnify the ones we already had. What have we learned during COVID? We had healthcare inequality before COVID, and we have vast healthcare inequality with COVID. We had lack of support for families who needed healthcare and needed sick time and needed the ability to care for their family members, and those were all amplified in ways that contribute to worker shortages in the United States right now. COVID has amplified so many of the schisms and fractures we already had in our society: a lack of concern for other people; the belief that health is a personal responsibility and, therefore, people shouldn't be expected to band together to solve complicated problems.

Some of the heaviest hitters in the world of vaccine opposition have been people who have either medical degrees, or, in the case of, Robert Kennedy, who has been a life-long environmental attorney, have experience working with communities and community interventions. However, the sense of community seems to be changing. Even public health over the last several decades has become increasingly focused on behavioral change and not community solutions. Think about the amount of public health spending that goes towards smoking cessation, or goes towards getting people to wear seatbelts, or to exercise, or to managing their diabetes. These investments have important public health consequences in terms of shared resources, but they're not the same thing as making sure everyone's drinking water is free of toxins, or making sure every school building is free of asbestos. Public health agencies, which have been slowly defunded over the last several decades, and downsized, have really just been able to focus on public health messaging rather than actual intervention.

I just mentioned the surprising case of the environmental lawyer who comes out against vaccines. But then again one current cultural ideal is the environmental activist who speaks back to the corporation, like Erin Brockovich—the small person who takes on the global pharmaceutical company, the global chemical company. That kind of David-versus-Goliath narrative has become ubiquitous in how we think about relationships to governments and relationships to corporations. This contributes to the sense of heroism in vaccine opposition; individuals can perceive themselves as speaking truth to power. It was Andrew Wakefield, who was a gastroenterologist in the UK, who is most well-known for having promoted the hypothesis that the MMR vaccine causes autism. He had a small study of about a dozen children with autism and identified something in their gut that supposedly triggered autism. Later, when it was discovered that he had conflicts of interest and stood to profit from promoting alternatives, he was sanctioned and eventually lost his medical license. He's entirely discredited as a physician, as a researcher, but in 2009, I attended a conference of that group I mentioned previously, DPT (they eventually became the National Vaccine Information Center and define themselves as a parents' advocacy organization). At that conference Andrew Wakefield received a humanitarian award for speaking truth to power and being martyred for the cause of taking on corporate power. It was such a stark moment to realize how different people's perceptions are. At the time Andrew Wakefield was being sanctioned, I would get emails saying, "doesn't this finally convince people? Isn't this finally going to persuade people about vaccines?" In many ways it did the opposite. The more we see articles get retracted, the pre-prints that can't survive peer review taken out of the pub-

lic domain, the more we can say science is working, the peer review process is working, the more we also hear that minority voices are being squelched. The system that produces scientific knowledge is taken as evidence of a vast conspiracy, and the conspiracy theorists have their own heroes.

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