

Introduction

Minutes before the phone rang that Sunday evening, Tim was feeling good. His three-year-old daughter, Maggie, who had been diagnosed with leukemia months before, had survived multiple rounds of chemotherapy, lumbar punctures, and surgery to implant her port to make the next two years of treatment easier. Treatment had not been easy, with six hospital admissions, weeks in a local children's hospital, missed holidays, and the pain of the treatment itself. Now she had a three-week break from treatment to stay home with her parents and ten-month-old brother.¹ Tim was excited about what he called the “vacation from chemotherapy.” But then the phone rang.

A few days before, Maggie had been at a local hospital with her mother and brother for a lab test. Another patient at the hospital had been infected with measles, and unknowingly exposed those around her to the disease. The patient, a woman in her forties, had been infected by a stranger during a winter trip to Disneyland. As we now know, that outbreak infected about 150 people from twenty states and the District of Columbia, as well as travelers from Mexico and Canada (who subsequently infected more than 150 others in their home countries²). Although Maggie had been vaccinated before her cancer diagnosis, her immune system was indisputably compromised; she was also most vulnerable to serious complication. Her baby brother was simply too young to be immunized. The next two weeks would be a process of watching, waiting, and avoiding contact with others—not the “vacation” they had hoped for.

Tim and his wife, Anna, were panicked. “My biggest fear is that I’ll lose my child, or that she’ll become deaf,” Anna explained at the time. “My family has been through enough with cancer. I don’t want her to go through anything else.”³ Focusing her frustration on the large number of unvaccinated people implicated in the Disneyland outbreak,⁴ Anna imagined for a moment what she would say if she were facing a parent who opted not to vaccinate her children and increased risk to kids like Maggie:

“Your children don’t live in a little bubble. They live in a big bubble and my children live inside that big bubble with your children. If you don’t want to vaccinate your children, fine, but don’t take them to Disneyland.”⁵

Tim, a pediatrician, went further. Rather than imagining what he would tell a parent who rejects vaccines, he penned an open letter, “To the Parent of the Unvaccinated Child Who Exposed My Family to Measles,” in which he expressed his frustration that both of his children were exposed to a disease that had been deemed eradicated from the United States in 2000. Written initially for the blog he keeps about his daughter’s care, it was passed along to others by a nurse and subsequently reprinted multiple times, shared more than 1.3 million times on social media, and widely read.⁶ Some even felt compelled to reply.

Megan was one. A self-described naturopath, writer, stay-at-home mom, and cofounder and president of a nonprofit organization that focuses “on orphan care and poverty alleviation in Africa,” Megan says she has “developed the habit of researching everything from the toothpaste we use to the toilet paper we wipe our butts with.” Her blog describes how her information gathering “prompted us to throw out our microwave, ditch the gluten, sugar, milk, pork, and genetically modified foods, burn our medicine cabinet, wear our kids, breastfeed our babies, recycle our trash, up the probiotics, unschool our kids, and rip up the CDC’s vaccination schedule.”⁷

Speaking directly to Tim, but citing “the creators of the hysteria” and “measles propaganda,” Megan described the reasons for her frustration with Tim: “That you do not respect my choices, that you think my unvaccinated child is the only one who threatens yours, and that you would insinuate that my child should be sacrificed on the altar for your child.” Calling vaccines artificial immunity that has upset the natural order of disease and naturally occurring immunity, Megan reiterated that she has the right to decide what is best for her children and what risks she and other parents might choose to take:

When we take our child to a place like Disneyland, or any other public place for that matter (including a hospital), we assume the risk that we might come into contact with a sick person, someone who hasn’t washed their hands, a kid who has picked their nose, or rides that have not been properly sanitized between each use.

Megan replied directly to Anna and Tim's insistence that as members of a community, children live in the same large bubbles, retorting, "It is not fair to require that my child get vaccinated for the benefit of yours or to force my child to live in a bubble so that yours doesn't have to."⁸

Other parents shared her view, some more vocally than others. Jack, a cardiologist and father of two unvaccinated children, was among the loudest. Addressing Tim and Anna, he insisted, "It's not my responsibility to inject my child with chemicals in order for [a child like Maggie] to be supposedly healthy. . . . I'm not going to sacrifice the well-being of my child. My child is pure." Jack too challenged claims that vaccines promote health, arguing instead that disease is good for people: "We should be getting measles, mumps, rubella, chickenpox, these are the rights of our children to get it. . . . We do not need to inject chemicals into ourselves and into our children in order to boost our immune system."⁹ Also responding specifically to the notion of shared responsibility and individual parental rights, Jack made clear that he is comfortable in his commitment to rejecting vaccines, even if his child were to infect another child who became gravely ill. "It's an unfortunate thing that people die, but people die. I'm not going to put my child at risk to save another child."¹⁰

The measles outbreak at Disneyland in December 2014 and the subsequent online feuds about the vulnerability of one child and the rights of parents of other children reflect many of the existing tensions about vaccines. As Megan's and Jack's responses illustrate, parents who reject vaccines distrust claims of safety and necessity, believe that disease is natural in a way vaccines are not, and identify their primary role of parents as superseding obligations to others. They also make clear that they are experts on their own children—able to assess and manage risk—and thus uniquely qualified to decide what their children need.

For the past decade, I have followed vaccine refusal from the perspectives of those who distrust vaccines and the corporations that make them, as well as the health providers and policy makers who see them as essential to ensuring community health. In an effort to tell the story of vaccines and explore the tensions between these views, I sought out a variety of key perspectives. I started with parents, and was careful to include those who opted out of vaccines completely and others who consented to select vaccines on a schedule of their own choosing. Chil-

dren whose parents challenge vaccine recommendations are most likely to be white, have a college-educated mother, and a family income over \$75,000. For the most part, this is what the parents in this study look like too. Only about 15 percent of parents in this study are fathers, since children's healthcare decisions are overwhelmingly maternal terrain. (I detail the sample in appendix A.)

I then broadened my view by conducting in-depth interviews with pediatricians to learn how they address parents' questions about vaccines and strategize vaccinations in their own practices. Physicians serve as intermediaries between expert knowledge and individual experience, and are present at critical moments in families' lives.¹¹ Since many parents referenced their trust in complementary health providers, I sought out those perspectives as well, interviewing chiropractors, naturopathic doctors, and other lay healers, most of whom disapprove of vaccines.

To understand vaccine risk and liability, I interviewed attorneys who work in the federal Vaccine Injury Compensation Program (VICP), a relatively unknown branch of the federal claims court that is tasked with compensating any person who is adversely affected by a vaccine. Paid for with a tax on every vaccine in the country, this court system—with only eight special masters and fewer than a hundred attorneys—was designed to be nonadversarial and able to compensate individuals quickly to ensure faith in public health. The perspectives of those who develop vaccines, set federal guidelines, work in county health departments, and research vaccine policy are also important, and I interviewed many of those who have positioned themselves as leaders on this topic, writing books on alternative vaccine schedules or in support of federally established ones, or who advocate for or against vaccine mandates.

To add complexity to this discussion, I observed meetings of organizations opposed to vaccine mandates, pediatric lectures for doctors by doctors about vaccines, community events for parents about vaccines, meetings of the Institute of Medicine about vaccine safety, and conference calls of federal vaccine advisory boards. I also analyzed hundreds of e-mails, newsletters, and blogs from different stakeholders, including parents.

Disagreements about vaccines raise larger questions. To what degree are we obligated to protect the most vulnerable members of our com-

munities? Where are the limitations of our individual liberty? What defines good parenting? What counts as expertise? What do we owe others? These questions do not reside on the political left or right. They surround us always, but largely remain unheard. The parents I studied question, modify, or outright reject vaccines because they see them as unnatural, as tainted by the profit motives of big pharma, as inadequately tested and regulated, or as unnecessary for illness prevention. These parents engage in what we might call *individualist parenting*, expending immense time and energy strategizing how to keep their children healthy while often ignoring the larger, harder-to-solve questions around them. They tend to focus on the subjects of their own expertise: their own children. In the 1970s, when most of these parents were children, schools required vaccination against seven vaccine-preventable illnesses. By 2014, evidence of vaccination against thirteen vaccine-preventable illnesses became required for kindergarten attendance, with more recommended in adolescence. As the number of recommended vaccines has increased, resulting in more boosters and as many as two dozen shots by age two,¹² even parents who don't reject vaccines altogether have started to question their safety and necessity and seek modifications of the schedule.

I am a mother of three children with much in common with the parents who participated in this study. Although we have made different decisions about vaccinating our children, the same questions surround us—at children's birthday parties, in long-term care facilities visiting relatives, in hospitals, on international flights, on college campuses that require immunization for incoming freshmen, and in the homes of people in our communities. These questions feel pressing as I think of the newborn babies in my family, my father-in-law, who was immune-compromised after a transplant, or my friends infected with HIV.

Most people engaged in this debate believe passionately in the correctness of their positions for or against vaccines, and believe the other side to be woefully misinformed, and possibly even dangerous to their children and families. In this book I aim to fill the middle ground between them by providing a better understanding of how different people approach vaccines and make sense of the meanings of risk, benefit, and obligation in the context of vaccines—something that carries both individual and collective consequences. This does not mean that I equally support all positions and interpretations. Rather, I believe that if we can

trace the points of disconnect between these positions, we can improve our thinking about vaccine choice, and ultimately public health.

The Triumph of Modern Medicine

Immunizations against childhood illnesses are touted as one of the greatest achievements of modern medicine and are credited with drastically reducing, or virtually eliminating, incidences of polio, diphtheria, measles, mumps, rubella, haemophilus influenzae type b (Hib), tetanus, whooping cough (or pertussis), and more recently varicella (chickenpox) and rotavirus in the United States. Vaccines improve life expectancy and lower healthcare costs.¹³ About 90 percent of children in the United States receive most of what federal advisory groups define as the key childhood immunizations, even if they do not receive all.¹⁴ This high rate owes its success to compulsory immunization laws, passed in all fifty states, which require children to provide evidence of immunization before enrolling in schools or childcare settings.¹⁵ These laws have been around in their current form since the 1960s, with every state having one by 1981.

As mentioned, the number of vaccines that are required for school attendance has increased significantly between the 1970s, when there were seven, and 2014, when there were about sixteen spanning into adolescence. These can result in as many as twenty-four to twenty-six shots by the time a child is two years of age. A child can potentially receive up to six shots during one doctor visit, although there is no set upper limit (and some vaccines may be combined into fewer injections).¹⁶ Despite the virtual elimination of many infectious diseases in the last two decades, vaccines have become controversial. Celebrities opposing vaccines have continued to posit a link between vaccines and autism, and outbreaks of measles, which had been eradicated from the United States in 2000, are seen with increased frequency. Although relatively few parents reject vaccines, 25 percent of parents in one nationally representative survey shared the view that children's immune systems could become weakened by too many immunizations.¹⁷ Even more parents report concern about the pain of injections.¹⁸ Vaccine choices also reflect parents' relative levels of trust in biomedicine and practitioners, parents' perceptions of necessity, and fear of unknown long-term side

effects, with which children who did not consent to the vaccine would have to live.¹⁹ The parents I interviewed and observed for this book who choose to reject medical advice on vaccines also communicate more widely held anxieties about vaccine safety. Often, they express disbelief in the claims that a high proportion of a community needs to get vaccines to protect its members. They insist that children's bodies should be treated as unique rather than uniform. They also express distrust in the commercial production of vaccines and the regulatory agencies that oversee them.

This last point is not a small issue. Vaccines are currently manufactured by for-profit pharmaceutical companies. Five transnational companies (GlaxoSmithKline, Sanofi Pasteur, Merck, Pfizer, and Novartis) manufacture most of the world's vaccines, with fewer than ten companies manufacturing any. This is a significantly reduced number from four decades ago, when there were at least seven times as many companies working to develop, produce, and distribute vaccines.²⁰ These companies are not public health agencies and are driven by profits. Recently, we have seen vaccine shortages due to contamination in manufacturing, miscalculations in production and equipment replacement, and dysfunction in systems of payment and distribution.²¹

Outside the vaccine context, there are many examples of malfeasance or neglectful practices by pharmaceutical companies. We can see these issues in the recent example of Vioxx, a widely used drug Merck manufactured to treat arthritis or chronic pain that was withdrawn from the market in 2004 because of increased risk of heart attack and stroke in users; in problems with the blood thinner Heparin, which was contaminated during manufacture in China, killed eighty-one people in the United States, affecting hundreds more worldwide; in multimillion-dollar settlements; or in recalls because of contamination or production incompetence in products ranging from lifesaving medications to Children's Tylenol.²² Pharmaceutical companies engage in other questionable practices, including repackaging and repurposing medications to avoid the expiration of profitable patents that would allow more affordable generics to be produced or applying for expedited FDA approval with limited data or follow-up.²³ The current vaccine arrangement, in which states mandate the consumption of a for-profit health product, stokes parental skepticism. So while this book focuses most heavily on

those who reject medical advice about vaccines, it also examines anxieties about health, risk, and medical care that are more widely shared. Although some may dismiss these parental fears about vaccines as simply people who just don't understand how vaccines work, it behooves us to take their concerns seriously. As this book will show, when parents opt out of vaccines for their children, we are all affected. Our public health is at stake.

Vaccines as Public Health

Vaccines are a cornerstone of U.S. public health policy, which aims to protect the health and well-being of an entire population. For example, public health campaigns include efforts to ensure safe drinking water, inspect food, or monitor air quality, all of which would be difficult for an individual to accomplish alone on his or her own behalf. Public health campaigns also require individuals to give up some personal liberty or freedom to protect the well-being of the population. Sometimes public health campaigns limit individual preferences for the good of the individual or to save costs to those in the community. For example, the state can compel me to pay taxes to fund fire departments because, even though individuals might protect their homes or businesses with smoke detectors and fire extinguishers, they remain vulnerable if a neighbor's house burns quickly and spills over to their own property. Because nineteenth-century fire brigades were once private entities that would refuse to put out uninsured properties (a practice that led to uncontrollable fires), U.S. cities began to fund civic fire departments.

In some ways, public health law can be similarly justified, as it constantly aims to balance the distributive effects of a rule to improve the lives of members of a community against the cost to their individual freedoms. This can even take the form of compromising individual bodily integrity or privacy, as seen, for example, in legal requirements for directly observed therapy for tuberculosis; court orders to take anti-psychotic drugs; legal mandates to report sexually transmitted infections; or state power to quarantine individuals who might present infection risks.²⁴ These interventions benefit individuals, just as vaccines provide benefit to the child who receives them. Federal estimates are that vaccines prevent about 1.4 million hospitalizations and 56,300

deaths for each birth cohort that receives them.²⁵ This clearly shows individual benefits from vaccination, alongside public health costs that would be shared collectively. Yet the state's response to individuals who do not want to partake in lifesaving interventions is complicated; it requires finding a balance between preventing widespread infection that would detrimentally affect others and compelling an individual to consume a pharmaceutical product he or she may not want.

Understanding public health requires a keen understanding of the points where individuals have compatible or conflicting interests and needs. One such point is “herd immunity” against infectious disease. When a person receives a vaccination, she has a far greater chance of being protected from that illness—receiving individual benefit—but also helps to protect others in the community who are vulnerable to infection. Some vaccines benefit only the individual, like that for tetanus, which is a disease that is not contagious but results from exposure to a toxin in the environment that causes neurological damage and death and is difficult to treat. However, the majority of required vaccines do not just protect the child who receives inoculation, but also prevents exposure of life-threatening illnesses in the disabled, the aged, the immune-compromised, the infants too young to be vaccinated, and the pregnant women whose fetuses could be devastated by these illnesses, as well as those few individuals who did not gain immunity from a vaccine they received.²⁶

If a community-level immunity rate, known as herd immunity, of approximately 85–95 percent (depending on the disease) is maintained, virtually all members of the community are protected from infection. It is impossible to create immunity in 100 percent of a population. With herd immunity, diseases are blocked from reaching those who would be at risk by those who are vaccinated. As an example, if Child A has measles and Child C is unvaccinated, Child B is a fully vaccinated intermediary who protects Child C from infection. This is even more effective when a high percentage of the population are fully vaccinated, creating more Bs to protect the occasional C. Public health mandates to require vaccination for school attendance—where children are in dense quarters and likely to share risks of exposure to disease—aim to increase the numbers of vaccinated children who can protect that vulnerable Child C and buffer the risk of infection from the infected Child A. Herd immunity can absorb only a small portion of the popu-

lation failing to vaccinate. Therefore, the philosophy of herd immunity holds that the only exemptions should be for those who cannot safely receive vaccines because of a medical condition or because they are too young, or those for whom vaccines do not work. Essentially, those who can be vaccinated and generate immunity will help to protect the most vulnerable in their community. Parents who reject vaccines for their children benefit from herd immunity, but refuse to contribute to it, making them free-riders to other children's immunity.

Estimated Herd Immunity Thresholds for Vaccine-Preventable Diseases

Disease	Transmission mode	R0 ^a	Herd immunity threshold ^b
<i>Diphtheria</i>	Saliva	6–7	85%
<i>Measles</i>	Airborne	12–18	83–94%
<i>Mumps</i>	Airborne droplet	4–7	75–86%
<i>Pertussis</i>	Airborne droplet	12–17	92–94%
<i>Polio</i>	Fecal-oral route	5–7	80–86%
<i>Rubella</i>	Airborne droplet	5–7	80–85%
<i>Smallpox</i>	Social contact	6–7	83–85%

Source: CDC, “History and Epidemiology of Global Smallpox Eradication,” CDC.gov, 2003, <http://www.bt.cdc.gov/agent/smallpox/training/overview/pdf/eradicationhistory.pdf>.

^aNumber of new infections per infected person (known as R0).

^bPercentage of population to be vaccinated to achieve community immunity.

Public Health in the Age of “Have-It-Your-Way” Medicine

Vaccines are intended as a uniform healthcare intervention—provided at about the same age in similar doses to all children. A federal advisory group of experts recommends a schedule of when vaccines are to be administered, which is usually accepted by professional medical organizations like the American Academy of Pediatrics, and enforced through state laws. The federal Advisory Committee on Immunization Practices (ACIP) comprises experts in vaccinology, immunology, pediatrics, internal medicine, nursing, family medicine, virology, public health, infectious diseases, and preventive medicine, and a consumer representative who provides perspectives on the social and community aspects of vaccination; the committee examines all research on vaccine safety and efficacy when making the schedule.²⁷

The creation of an expert-informed schedule that states and professional organizations adopt makes state vaccine schedules safe and effective, and distribution relatively inexpensive and efficient. Yet the parents with whom I spoke instead see this schedule as impersonal and imprecise, providing a “one-size-fits-all” vaccine routine that may not be appropriate for their children. Even among parents who support vaccination, more than 20 percent do not agree that following the recommended vaccine schedules is the safest course for their children.²⁸ In short, there is limited faith in the official schedule.

We live in an age of personalization. A fast-food restaurant’s catchphrase promising that you can “have it your way” is emblematic of this. We see heightened efforts to personalize medical care to meet the needs and desires of the individual. This might include new methods of identifying individual risk of developing certain diseases, to genetically testing embryos before implantation for particular characteristics, or calculating risk of future health challenges. Although companies are beginning to offer racial and biological analyses of individual genetic material, and pharmaceutical companies promise to create personalized medicine that could eventually match drugs to individual personal genetic profiles, these innovations have yet to hold major practical uses or even hit the market.²⁹ Still, their development has contributed to a vocabulary of individualized medicine that shapes expectations of care and supports understandings of our bodies as unique.

From this understanding, health itself comes to be defined by personal choices and behaviors, often through consumption and risk management.³⁰ We understand that we must actively manage our lives, work hard, behave morally, and avoid calculable risk through informed decision making.³¹ The individual in a “regime of self” is expected to actively shape her or his life through active health choices, with socially defined good choices becoming the cultural norm against which an individual’s morality might be evaluated.³² (The condemnation of smokers or overweight people illustrates this as well.) From this springs the ideology of individualist parenting.

A commitment to individualist parenting contributes to heightened demands for personalized attention from institutions, including schools, tutoring centers, volunteer organizations, therapeutic courts, and, for our purposes, healthcare systems and providers. There are a great many

reasons that enhanced abilities to focus on individual learning styles and needs, health risks, or skills are beneficial and hold the promise of assisting individuals in reaching their full potential. Although individualized care does not necessarily yield better health outcomes, it may create a more positive experience of healthcare.³³ When it comes to vaccines, parents face both a social understanding that responsible parents vaccinate their children and an expectation that good parents advocate for their children and their individual needs. As they perceive their child's needs and bodies as unique, the parents I spoke with and observed view the state's efforts to compel vaccine use for the good of the community as unacceptable. Instead, they insist that as parents they have the right to make individual choices for their children.

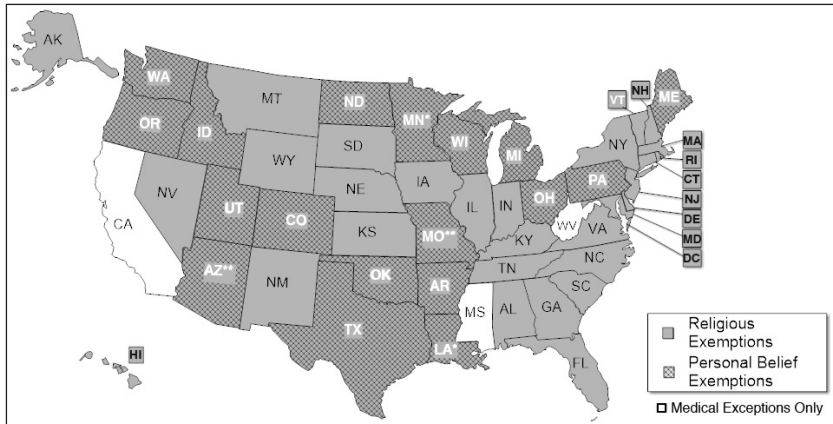
Rhetoric of individual preference proliferates in these parents' efforts to define themselves as good parents who want what is best for their children. This insistence on individualism directly contradicts the goals of public health, which expects parents to absorb a measure of risk to their own children in order to protect others in the communities in which they live or travel. Yet, as others have observed, parents often insist that they "should be 'empowered' to pursue their own self-interest as a condition of their rights (and obligations) as consumers of public resources," which places their desires for their own children ahead of others.³⁴ Ultimately, I will argue in this book that the emergence of an ideology of individualist parenting, which prioritizes individual choice for one's own children over community obligation, ignores how some families with fewer resources have fewer options, but face increased risk of illness.

The Limits of Parents' Rights

Parental concern for vaccine safety is not new. In fact, the power of the state to compel vaccines comes from a 1905 U.S. Supreme Court decision in which a father did not want to vaccinate his child against smallpox. When the father was fined for failing to participate in the mandatory vaccine program, he refused to pay the fine and appealed his case. In the decision of *Jacobson v. Massachusetts*, the Court ruled against the father and clarified that the state is entitled to use police powers to protect

public health. Highlighting the duty to protect community health, the decision states, “It was the duty of the constituted authorities primarily to keep in view the welfare, comfort and safety of the many, and not permit the interests of the many to be subordinated to the wishes or convenience of the few.” In doing so, the state’s power to require individuals’ participation in public health campaigns, even when they disagree, was set. (The *Jacobson* decision was notably also used to justify involuntary sterilization in 1927, further defining and refining state powers to act on the bodies of its citizens.³⁵)

Despite the articulation of the state’s right to compel participation in vaccines and other health programs, the United States maintains a strong ideological commitment to parental authority and individual autonomy. Every state has a mechanism that allows parents to opt out of required vaccinations. All states allow exemptions for medical reasons, almost always as verified by a medical provider. All states except West Virginia, Mississippi, and, as of 2016, California allow parents to exercise an exemption for religious beliefs, defined relatively broadly in most states, and not subject to verification. About eighteen states also allow exemptions based on philosophical, personal, or conscientiously held beliefs.³⁶ Exercising exemptions vary in process and requirement; some states require parents who claim philosophical or personally held beliefs against vaccines to apply those beliefs to all vaccines. Other states do not view as contradictory parents’ claims that they object to only certain vaccines, allowing parents to pick and choose which vaccines they want for their children. Some states require more cumbersome documentation for exemptions, including signatures from two parents, notarization, or extensive explanation, or countersignature from a medical provider, while other states simply require a signature on a form. Colorado, where I conducted my interviews with parents and providers, is a state that allows exemptions for medical, religious, or personal beliefs and requires little documentation. Colorado has among the highest rate of personal belief exemptions.³⁷ This state is an ideal place to examine the multifaceted meanings of vaccine uptake and refusal among parents as they craft their own solutions with less legal regulation, but nonetheless communicate the same anxieties expressed by parents around the country, whose choices may be more constrained.



States with personal belief exemptions, religious exemptions, or medical exemptions. Reproduced from National Conference of State Legislatures, <http://www.ncsl.org/research/health/school-immunization-exemption-state-laws.aspx>.

The Uneven Landscape of Parental Choice

Public health scholars divide children who have not received all vaccines required for school attendance (but who do not have a medical reason to avoid vaccines) into two groups. On one side, there are the children who are undervaccinated because they lack consistent access to medical care. These children are more likely to be children of color, have a younger mother who is unmarried and does not have a college degree, and live in a household near the poverty line. Children on the other side—those who are unvaccinated because of parental choice—look significantly different. They are more likely to be white, have a mother who is married and college-educated, and to live in a household with an income over \$75,000; they also tend to be geographically clustered.³⁸ What this means is that the choice to opt out of vaccines is almost exclusively made by families with the most resources and represents a fairly privileged parenting practice. These differences reflect broader schisms in how families with different resources have access to choices.

The “choices” families make exist within a public policy context that structures requirements. For example, school attendance is legally required but can be avoided through adherence to paperwork and certification; complementary health providers or birth attendants are outside

mainstream healthcare, often accessible only to those with private resources; work policies may inhibit or facilitate breastfeeding. Childhood vaccinations are legally required for school attendance, but parents can avoid these by filing forms for exemptions. Each of these regulations or requirements is enacted for the good of the entire community, but also allows alternatives so individuals with resources can exercise choice. As the sociologist David Cheal suggests, “Family members define their projects with reference to personal desires, rather than public goals, and they are free to implement them to the limits of their resources.”³⁹ Clearly, not all families are equally able to assert their preferences. Illustrating this, Colorado, which has among the most liberal legal frameworks for opting out of vaccines, until recently punished welfare recipients whose children were not fully vaccinated.⁴⁰ As families exercise their choice to opt out of vaccines, signing a form that entitles their unvaccinated child to attend school, they do so as educated parents with privilege—and without fear of public sanctions. In so doing, they also insist that they are the experts on their children and uniquely qualified to decide what they need.

Claiming Parental Expertise

The relationship between medical experts and parents has a long and contentious history. Early twentieth-century physician-authored texts highlighted mothers’ ignorance about caring for children and the need for parent education. Doctors dispensing scientific and medical advice to women developed a practice of “scientific motherhood,” which “refined and redefined what it means to be a good mother, a proper mother.”⁴¹ Throughout the twentieth century, women differentially embraced, challenged, or ignored the tenets of scientific motherhood, reflecting differences in class, ethnicity, family immigration history, experience, education, and region.⁴² By the mid-twentieth century, mothers had become savvy consumers of professional advice, and professionals needing patients, from Dr. Spock on baby care to Dr. Dick-Read on natural childbirth, began including mothers’ own insights and experiences in their “expert” advice. The medical historian Rima Apple suggests that this communicated approval of women’s views on childrearing and birthing, which reinforced women’s confidence as mothers and

empowered them to question medical authority.⁴³ These transformations happened as an emerging women's rights movement grew, yielding the women's health movement. That movement further challenged the role of the expert as it provided support for natural childbirth, facilitated the Boston Women's Health Book Collective's publication of *Our Bodies, Ourselves*, and saw the formation of La Leche League to provide feminist support for breastfeeding. These cultural forces repositioned expertise as residing within the individual, and women began to see expert advice as mere suggestions to incorporate into their own mothering practice. The market of parent-driven advice books exploded just as patients newly insisted on being able to shop for medical providers. This then forced physicians, particularly in obstetrics and pediatrics, to innovate in their practices in order to compete for paying patients.

Experts often encourage parents to become independent and self-efficacious, even to use online sources of information to become educated on an issue. In some realms, they design programs specifically to empower low-income or vulnerable groups to participate fully and advocate for themselves and their children.⁴⁴ In education and health-care specifically, efforts to "empower parents" to manage their children's asthma, diabetes, medications, learning disabilities, or education are ubiquitous. Most assume that empowering parents will lead them to choose for their children what experts believe is correct and will improve outcomes. However, much research on empowered parents, including studies of charter schools, school choice, or chronic disease management, show that the most privileged parents remain the most empowered to advocate for their own children, often furthering inequality. Parents with resources are most able to demand services, more likely to view providers as contributing advice rather than dictating behaviors, and less likely to be reported to state agencies like child protective services. They also receive more respect from providers as potential partners in their children's care.

In arenas as diverse as medicine, mental health, law, education, business, and food, self-help or do-it-yourself movements encourage individuals to reject expert advice or follow it selectively.⁴⁵ Avoiding experts and their institutions is possible in many of these realms. Vaccines, however, require a gatekeeper to administer them, forcing structured interactions between parents who reject expert advice and the professionals

who control access to medical technologies that parents at times may want or need.

Vaccines are not the only medical issue where patients demand individualistic treatment. The emphasis on individual choice reflects much of the rhetoric of U.S. women's health movements, including calls for greater challenges to mainstream medical advice.⁴⁶ Campaigns for abortion access in the United States, a procedure that also requires access to services through medical gatekeepers, claim, "My body, my choice." The historian Rickie Solinger suggests that in the context of abortion, the vocabulary of choice is too often reduced to images of "women shoppers selecting among options in the marketplace" without concern for the larger power relations at stake.⁴⁷ This form of "choice feminism" lays the backdrop for women's individual choices for their children's healthcare. Freedom from compulsion (in this case from vaccine requirements) rather than access to resources to create widespread access to care becomes the political goal.⁴⁸ As individual preference becomes synonymous with freedom, the unequal ability to exercise choice, particularly around state policy, is obscured.

Most parents who oppose vaccines are not part of a political movement. In the United States, a handful of organizations and grassroots groups politically mobilize against vaccine mandates, gain celebrity spokespersons and extensive media coverage, even as no similar movement exists to create equity in access to pediatric care. Those who reject expert advice on vaccines are not necessarily conservative or liberal, with a wide array of political affiliations and views of the state. They are generally well-intentioned parents committed to assessing the individual benefits of vaccines for their individual children and wanting to choose for themselves, without state mandates or expert advice proscribing their freedom of choice. As parents decide what is best for their children, they overlook—or explicitly deny—how their choices can be costly for other people's children.

Individualist Parenting and the Culture of Mother-Blame

Parents generally want their children to succeed, but their ability to facilitate their success is shaped by access to resources. The sociologist Annette Lareau shows how middle-class and affluent families embrace

an ideology of “concerted cultivation,” where they aim to actively manage their children’s lives so they might become successful adults who can outperform others.⁴⁹ This takes a variety of forms, from adult-organized play, to management of homework, to advocacy in schools. The overarching goal is to manage children’s development so they will be successful and to optimize their personal opportunities. Concerted cultivation is a class-based ideology that inspires cumbersome practices that fall more heavily on mothers than on fathers and differentially transmits advantage to children.

Regarding parents’ vaccine choices, children’s healthcare is intense and largely, although not exclusively, maternal terrain.⁵⁰ In fact, cultural expectations of mothering have become increasingly demanding—of time, energy, and money.⁵¹ While there is evidence that this ideology of intensive mothering has permeated the lives of mothers at all socioeconomic levels, this experience of motherhood is marked most intensely as that of middle- and upper-class mothers, who have the material and cultural resources to invest most heavily in their children’s development and most intensely fear their children’s downward mobility.⁵² Women receive cultural encouragement for this kind of individualist management. In prenatal care, for example, they are directed to develop birth plans because they are told they are entitled to consume information and services.⁵³ As mothers, they are told it is their obligation to manage risk and pursue success for both themselves and their children. Mothers are responsible for the physical, emotional, and psychological health of their children; healthy children symbolically represent good mothering, just as mother-blame proliferates in the lives of women with sick children.⁵⁴ In these ways, the tenets of scientific motherhood are reframed in a market economy, where informed mothers become consumers with a plethora of individual choices awaiting them.

This work of individualist parenting is overwhelming—both time- and resource-intensive. Yet there is also evidence that mothers acquire a sense of accomplishment from their ability to care for their children and take pride in crafting their sense of self as experts. We can see examples of this in research about “natural mothers” who reject consumerism, homeschooling mothers who dictate the pace of their families’ lives, or women who breastfeed their children—sometimes for many years—as a commitment to their children’s well-being. Each of these practices is

more readily available to women with private resources.⁵⁵ In the case of vaccines, parents choose to reject vaccines they do not trust in an effort to maximize their children's long-term health. As they do, they claim expertise over their own children and what they see as their unique bodies, even as they refuse to acknowledge how other parents may not be equally able to do so.

Much of the research on parents who refuse vaccines for their children focuses on what parents think, often according to surveys or focus groups. Although I too share an interest in understanding what parents think, I aim throughout the book to put these views in a cultural, historical, and social context. I argue that these views represent broader cultural trends that support a view of medicine as personalized and individualized. These views are rooted in ideas about middle-class and affluent parenting that expect parents to heavily invest in their own children, even at a cost to others. This ideology of individualist parenting is tightly bound to economic and social trends that privatize individuals and their bodies into informed consumers. Parents tout their commitment to informed individual choice as a way of expressing their commitment to their children, which overrides a commitment to community responsibility and social justice.

Overview of the Book

In searching for a full range of perspectives, I aimed to find sites of contested meanings about what vaccines are and whether and how they should be used. What are their symbolic meanings? How do they convey different notions of individual choice and collective responsibility? How do views of vaccines communicate perceptions of family, science, authority, and the state? I also identify the points of disconnect and place these different views in conversation. At times, I bring in the social history of certain diseases to add context to parents' views. My goal is to paint complex pictures of the meanings of disease, risk, fear, and health that are woven through all disagreements about vaccines. As a technology that provides individual benefits and risks, enforced by the state, and administered on young children's bodies, vaccines allow us to explore these complex and contradictory meanings and to examine challenges to expertise, choices of consumption, and the ways these

dynamics are structured by privilege. In each chapter, I weave parents' concerns, physicians' experiences, and the meanings of vaccines, with an eye to the role of the state in mediating these meanings and experiences.

First, I provide a broad historical overview of vaccine policy and controversy, including how vaccines were created and came to be legally required for school entry. Because vaccine mandates arose in the 1960s as a way to increase funding and provide access to low-income children, I point to the meanings of community health and access, even as vaccine mandates are no longer perceived this way. I also highlight significant moments when consensus about vaccines as a good and safe technology broke down. Each vaccine's invention has raised different issues about health, risk, necessity, and the relationship between citizens and the state. As such, this chapter provides a chronology of vaccine development so readers can better understand how these unique histories have led us to where we are today.

Beginning in chapter 2, I show how parents define themselves as experts on their own children, best qualified to evaluate vaccine risk and benefit claims. Parents filter information from myriad sources—books, websites, research, peers, providers, or their own intuitions—to weigh claims of risk of disease against the risk of the vaccine itself. They expend energy and resources assessing whether their children are at greater risk for complications from vaccination. Promoting an expectation that all parents should actively challenge medical experts to advocate for their own children, despite the unequal ability to do so, they reject vaccines when they perceive that risk outweighs benefit. Chapter 3 examines how parents define their sense of themselves as experts on their children and then deploy that parental expertise to argue that vaccines are unnatural, creating inferior immunity. Chapter 4 builds on these views and presents parents' perceptions that vaccines represent a voluntary introduction of chemicals into children's bodies. Drawing on the celebrity-led march to "Green Our Vaccines," the controversy over thimerosal, a mercury-based preservative that was until recently used in vaccines, and the now-discredited claims that vaccines can cause autism, I elucidate how some parents see vaccines as toxic and thus harmful.

Unlike other self-directed health movements, vaccines require physicians to serve as gatekeepers—to provide vaccines as well as the documentation needed to access childcare and educational settings. Parents

generally believe that medicine as practiced—with busy providers who have limited time with each patient—hinders practitioners’ ability to understand each child as unique and prevents them from serving as advocates. Chapter 5 examines how pediatricians view their role as medical experts in their work with parents who claim competing expertise. Chapter 6 looks at parents’ resistance to what many call the “one-size-fits-all” schedule of vaccinations and how they rework or reject the timing and dosage of vaccines. Using their own sense of expertise, parents demand slow or alternative vaccine schedules for their children against the illnesses they believe require protection at a time they view them as most relevant. As parents engage these processes, they do so with physicians who are differentially supportive of their claims as experts.

Disease risk intrinsically involves uncertainty. Chapter 7 looks at how parents aim to manage risk through intensive parenting practices that are resource-intensive and both claim and reproduce privilege, which include natural living, breastfeeding, and careful preparation of food. They also manage risk by enacting imagined gated communities from which they can control social exposure to those they believe might carry disease. Through these efforts to manage uncertainty and mitigate risk, I suggest, parents feel compelled to invest significant resources as a way of ensuring their children’s safety when they reject vaccines as well as maintaining a sense of control over their children’s well-being. In chapter 8, I take a close look at the criticism parents who opt out of vaccines face and how they manage social disapproval. This chapter engages the broader cultural meanings of vaccine refusal, from interactions with doctors whom parents see as disapproving, to possible legal and institutional sanctions, including from healthcare providers, schools, or public health agencies. Examining their perceptions of disapproval allows us to better understand the meanings of autonomy, compliance, and consent in medical encounters and the ways parents’ claims of expertise and authority do not always prevail. Finally, I return to the public health goal of herd immunity to demonstrate how parents understand claims of community obligation but do not prioritize it in their decisions, as well as how providers broach the topic with their patients’ families. In examining perceptions of state regulation and public health goals alongside parents’ desires to assert their own expertise, I show how perceptions of disease and risk reflect structures of race, class, and social distance.

Striking a Balance

Many books exist about vaccines, and there is much public debate about them. Yet each discussion seems to stake out and fortify one particular view. Some provide both historical and contemporary understandings of vaccine controversies. Yet, because they write with such certainty of their positions, they portray the parents who resist vaccines as foolish or ignorant at best, and sometimes even delusional or selfish. Correspondingly, the writings of those who oppose vaccines generally, or policies that mandate vaccines specifically, provide no more nuance and yield little ground to those who have experienced infectious disease firsthand or who have expertise built on the scientific method and decades of systematic research.

I am not neutral on whether vaccines are good or bad. I have opted to follow all mainstream medical recommendations and have fully vaccinated my own children. I do so because I trust that vaccines are mostly safe and I accept that we can each absorb minimal risk to protect those in our community who are most vulnerable. I support policies that encourage efforts to broadly vaccinate the population and protect public health. I also very much like and respect the parents I spoke with who laboriously question vaccines and medical recommendations, and who aim to do the best for their children. I know that these families will not agree with everything I argue in this book, but I hope they feel respected. I also accept that not all stakeholders will agree with my analysis, but I do hope this book can encourage better discussions of public health, community obligation, and individual choice. As we ideally find a place of mutual understanding, and even some common ground, perhaps we can then move together toward policies that support everyone's children, not just our own.