

# Vaccine-skeptical mothers say bad health care experiences made them distrust the medical system

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Why would a mother reject safe, potentially lifesaving vaccines for her child?



Popular writing on vaccine skepticism often denigrates white and middleclass mothers who reject some or all recommended vaccines <u>as</u> <u>hysterical</u>, <u>misinformed</u>, <u>zealous</u> <u>or ignorant</u>. <u>Mainstream media and</u> <u>medical providers</u> increasingly dismiss <u>vaccine</u> refusal as a hallmark of American fringe ideology, <u>far-right radicalization or anti-intellectualism</u>.

But vaccine <u>skepticism</u>, and the broader medical mistrust and farreaching anxieties it reflects, is not just a fringe position.

Pediatric vaccination rates had already <u>fallen sharply before the COVID-19 pandemic</u>, ushering in the return of measles, mumps and chickenpox to the U.S. in 2019. Four years after the pandemic's onset, a growing number of Americans doubt the safety, efficacy and necessity of routine vaccines. Childhood vaccination rates have declined substantially across the U.S., which <u>public health officials</u> attribute to a <u>"spillover" effect</u> from pandemic-related vaccine skepticism and blame for the <u>recent measles outbreak</u>. Almost half of American mothers <u>rated</u> the <u>risk of side effects from the MMR vaccine</u> as medium or high in a 2023 survey by Pew Research.

Recommended vaccines go through rigorous testing and evaluation, and the most infamous charges of vaccine-induced injury <a href="https://have.been.thoroughly.com">have been.thoroughly.com</a>. How do so many mothers—primary caregivers and health care decision-makers for their families—become wary of U.S. health care and one of its most proven preventive technologies?

I'm a <u>cultural anthropologist</u> who <u>studies the ways feelings and beliefs</u> <u>circulate in American society</u>. To investigate what's behind mothers' vaccine skepticism, <u>I interviewed vaccine-skeptical mothers</u> about their perceptions of existing and novel vaccines. What they told me complicates sweeping and overly simplified portrayals of their misgivings by pointing to the U.S. health care system itself. The medical system's failures and harms against women gave rise to their pervasive



vaccine skepticism and generalized medical mistrust.

# The seeds of women's skepticism

I conducted this ethnographic research in Oregon from 2020 to 2021 with predominantly white mothers between the ages of 25 and 60. My findings reveal new insights about the origins of vaccine skepticism among this demographic. These women traced their distrust of vaccines, and of U.S. health care more generally, to ongoing and repeated instances of medical harm they experienced from childhood through childbirth.

As young girls in medical offices, they were touched without consent, yelled at, disbelieved or threatened. One mother, Susan, recalled her pediatrician abruptly lying her down and performing a rectal exam without her consent at the age of 12. Another mother, Luna, shared how a pediatrician once threatened to have her institutionalized when she voiced anxiety at a routine physical.

As women giving birth, they often felt managed, pressured or discounted. One mother, Meryl, told me, "I felt like I was coerced under distress into Pitocin and induction" during labor. Another mother, Hallie, shared, "I really battled with my provider" throughout the childbirth experience.

Together with the convoluted bureaucracy of for-profit health care, experiences of medical harm contributed to "one million little touch points of information," in one mother's phrase, that underscored the untrustworthiness and harmful effects of U.S. health care writ large.

## A system that doesn't serve them



Many mothers I interviewed rejected the premise that public health entities such as the Centers for Disease Control and Prevention and the Food and Drug Administration had their children's best interests at heart. Instead, they tied childhood vaccination and the more recent development of COVID-19 vaccines to a bloated pharmaceutical industry and for-profit health care model. As one mother explained, "The FDA is not looking out for our health. They're looking out for their wealth."

After ongoing negative medical encounters, the women I interviewed lost trust not only in providers but the medical system. Frustrating experiences prompted them to "do their own research" in the name of bodily autonomy. Such research often included books, articles and podcasts deeply critical of vaccines, public health care and drug companies.

These materials, which have proliferated since 2020, cast light on past vaccine trials gone awry, broader histories of medical harm and abuse, the rapid growth of the recommended vaccine schedule in the late 20th century and the massive profits reaped from drug development and forprofit health care. They confirmed and hardened women's suspicions about U.S. health care.

The stories these women told me add nuance to existing academic research into vaccine skepticism. Most studies have considered vaccine skepticism among primarily white and middle-class parents to be an outgrowth of today's neoliberal parenting and intensive mothering. Researchers have theorized vaccine skepticism among white and well-off mothers to be an outcome of consumer health care and its emphasis on individual choice and risk reduction. Other researchers highlight vaccine skepticism as a collective identity that can provide mothers with a sense of belonging.



## Seeing medical care as a threat to health

The perceptions mothers shared are far from isolated or fringe, and they are not unreasonable. Rather, they represent a growing population of Americans who hold the pervasive belief that U.S. health care harms more than it helps.

Data suggests that the number of Americans harmed in the course of treatment remains high, with <u>incidents of medical error in the U.S.</u> outnumbering those in peer countries, despite more money being spent per capita on health care. <u>One 2023 study</u> found that diagnostic error, one kind of medical error, accounted for 371,000 deaths and 424,000 permanent disabilities among Americans every year.

Studies reveal particularly high rates of medical error in the treatment of vulnerable communities, including women, people of color, disabled, poor, LGBTQ+ and gender-nonconforming individuals and the elderly. The number of U.S. women who have died because of pregnancy-related causes has increased substantially in recent years, with maternal death rates doubling between 1999 and 2019.

The prevalence of medical harm points to the relevance of <a href="mailto:philosopher">philosopher</a>
<a href="Mailto:Ivan Illich">Ivan Illich</a>'s manifesto against the "disease of medical progress." In his 1982 book "<a href="Medical Nemesis">Medical Nemesis</a>," he insisted that rather than being incidental, harm flows inevitably from the structure of institutionalized and for-profit health care itself. Illich wrote, "The medical establishment has become a major threat to health," and has created its own "epidemic" of iatrogenic illness—that is, illness caused by a physician or the health care system itself.

Four decades later, <u>medical mistrust among Americans</u> remains alarmingly high. Only 23% of Americans express high confidence in the medical system. The United States ranks 24th out of 29 peer high-



income countries for the level of public trust in medical providers.

For people like the mothers I interviewed, who have experienced real or perceived harm at the hands of <u>medical providers</u>; have felt belittled, dismissed or disbelieved in a doctor's office; or spent countless hours fighting to pay for, understand or use health benefits, skepticism and distrust are rational responses to lived experience. These attitudes do not emerge solely from ignorance, conspiracy thinking, far-right extremism or hysteria, but rather the historical and ongoing harms endemic to the U.S. health care system itself.

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