

NEWS

# Unvaccinated teenagers fight for right to immunization

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In many ways, Ethan Lindenberger is like most other teenagers. A high-school senior in Norwalk, Ohio, he runs his school's debate club, is a member of his local church and is planning to start college in September. But unlike many of his peers, the 18-year-old did not receive several of what

are considered standard -- and, doctors and public-health officials say, crucially important -- childhood vaccinations. In the coming months, he plans to seek out these vaccinations for the very first time.

Lindenberger's records, which he shared with *Undark*, show that he has not yet received shots for measles, mumps and rubella (MMR), chickenpox or even polio, a disease that can cause paralysis and sometimes lead to death. He attributes this in part to his mother having been influenced by dubious anti-vaccination information online -- from theories that immunizations can cause brain damage, to the work of discredited physician Andrew Wakefield and his long-ago-**debunked study** claiming a link between the MMR vaccine and autism.

Wakefield's study and other false vaccination information, however, remain actively peddled on social media, where his mother, Lindenberger says, "kind of fell into this echo chamber and got more and more misinformation." His father, he says, espouses similar beliefs but takes a more laid-back approach.

Lindenberger's records do show he received two shots in 2002, though in an interview, his mother, Jill Wheeler, said this must be a mistake and insists her son only received a single immunization for tetanus after he cut himself as a child. After vaccinating her first daughter and starting immunizations for her oldest son, Wheeler -- who owns a local children's theater company -- says she learned she had the right to opt out. "If I have a choice, I want to know what my choices are and make the decision as an educated mom," she says. Based on reading arguments both for and against vaccination, she says, she chose not to continue with her other five children.

This was not a wise choice, according to most experts, who argue that stopping the spread of false information and getting infants and young children vaccinated **on schedule** offers the best chance at protection against disease. The U.S. Centers for Disease Control and Prevention (CDC) **sets this schedule** for children each year based on when they're likely to be most at risk. And vaccinations, of course, do not just benefit individuals -- they stop the spread of disease from person to person and help protect those who cannot receive certain vaccinations for medical reasons.

But as parents in some states increasingly take advantage of **non-medical exemptions** that allow them to forego standard vaccinations, more and more children are reaching their teenage years only to discover -- from their peers and teachers, and through Twitter, Facebook and other online platforms -- that their bodies are at the center of a roiling tug-of-war between science and pseudoscience. And this has increasing numbers of unvaccinated near-adults digging through literature and asking questions in online forums in an effort to discover for themselves the truth about vaccines, and what options are available to them as they approach the age of consent.

In spite of his mother's beliefs, Lindenberger -- who had been considering if certain vaccinations would be required for college admission -- says he conducted his own research and, after receiving

support from his science teacher, pastor and friends, made an appointment at his local health department to start catching up. But with a measles outbreak spreading through **unvaccinated children** in the Pacific Northwest, younger teenagers **facing** situations similar to Lindenberger's raise the question of whether they should be allowed to provide consent for themselves, too.

The best-case scenario, according to **Allison Winnike**, president and chief executive officer of The Immunization Partnership, a Texas-based nonprofit organization focused on eradicating vaccine-preventable diseases through education and community engagement, is for families to try to come to a resolution amongst themselves when disagreements over childhood vaccines leave a young person under-immunized.

"That's sort of like Plan A," she says. "But what we have to also think about is a Plan B."

## Minor consent:

Currently, there are **no federal laws** governing a minor's ability to consent to vaccination. Rather, it's up to states, to varying degrees of specificity, to determine if children can make healthcare decisions for themselves. Last year, a 15-year-old Minnesota student -- who when contacted by *Undark* requested to be identified only as "Danny" -- **turned to Reddit** for advice, noting that he had spent four years trying to convince his anti-vaccine parent that vaccines are safe. "I haven't succeeded," he wrote.

Minnesota, like many other states, allows minors to make certain choices related to pregnancy, sexually transmitted infections and alcohol and drug abuse. The allowances are broadened for minors who are living apart from a parent or guardian, those who are married and those who have children of their own. Apart from these circumstances, however, the only vaccination a typical teenager like Danny could **consent to** alone is hepatitis B. This vaccine, which is also normally first given before a newborn ever leaves the hospital, **protects against** a virus that can cause liver swelling and complications that may lead to organ damage and cancer.

California has a similar **statute**, signed into law by then-Governor Jerry Brown in 2011, which allows minors as young as 12 years to receive vaccination for hepatitis B, along with the vaccine for human papillomavirus (HPV), a major cause of cervical and other cancers. In **Alabama** and **Oregon**, wider statutes allow minors aged 14 and 15, respectively, to consent to their own healthcare.

But regulations focused on vaccination, according to Winnike, are few and far between.

"Most states do not have specific laws carving out immunizations," she says, although there have been some moves to expand minors' rights regarding preventative care -- which would include contraception and vaccinations.

In 2017, the Texas legislature **introduced a bill** that would have allowed minors aged 14 and older to consent to vaccinations specifically for **cancer prevention**, which -- similarly to California -- would have included hepatitis B and HPV. That same year, Minnesota introduced **a bill** solely focused on HPV. Neither bill moved out of committee.

Despite some parents' concern regarding the idea of a child consenting to a medical procedure, Winnike emphasizes that because all vaccines **recommended by** the CDC are held to rigorous standards, they "should be generally considered safe for a teen to consent to." In Texas, she points out, along with Alabama, Illinois and many other states, teenage parents are entitled to make medical decisions for their children without further oversight.

For now, however, teenagers who are still living at home and are not covered by a specific state statute may have to keep pressing their parents -- or simply wait. At the county health department in Lindenberger's hometown in Ohio, Christina Cherry, director of public-health nursing, says all they can do is provide a teenager with the appropriate information to share with their parent or guardian. "Additionally," Cherry wrote in an email, "we can encourage the child/teen to bring the parent or guardian in to meet with us or the child's/teen's primary-care provider to discuss the parent's concerns about vaccinating."

## 'A slap in the face':

Such an approach seems to have worked, at least in a small way, for Danny, who recently turned 16. The high-school sophomore says his mother did eventually allow him to get vaccinated against polio and tetanus following a conversation with his doctor. For any further immunizations, however, he says he'll likely have to wait until his 18<sup>th</sup> birthday.

For that reason, Danny says he supports lowering the age of consent to be able to get the rest of his vaccinations on his own, but he adds that this alone won't address the problem. "Stopping the spread of false information," he says, along with a handful of other factors, also have to be considered. Infants also need to be vaccinated, he says, and that remains, for the most part, entirely a parent's choice.

"The toughest aspect to understand is that they want the best for me," Danny says of his parents. "And that decision, in my opinion, was not properly researched or informed."

Lindenberger says it wasn't easy telling his mother about his choice to get vaccinated, even though he felt it was the smart thing to do. "I'm a very obedient child," Lindenberger says. "I don't really try and go against my mom. Even though I'm 18, I don't pull that card."

It helped a bit, he says, that his father reacted less harshly. Despite being in the "same camp" as his mother, Lindenberger says, his father told him, "Hey, you're 18; you can do what you want, and we can't really stop you."

So far, according to his vaccination records, Lindenberger has received one round of shots -- for HPV, hepatitis A, hepatitis B, influenza and diphtheria, tetanus, and pertussis (DTaP) -- and will return to the health department later this month for his second round. Cherry confirmed that an adult with no prior vaccinations needs to come in for at least three appointments over a six-month period.

For her part, Lindenberger's mother says her son's decision to seek out vaccinations for himself felt like an insult. "I did not immunize him because I felt it was the best way to protect him and keep him safe," Wheeler says of her son, calling his decision "a slap in the face."

"It was like him spitting on me," she says, "saying, 'You don't know anything; I don't trust you with anything. You don't know what you're talking about. You did make a bad decision, and I'm gonna go fix it.'"

## Educating parents:

Ohio, like the vast majority of states, allows parents to **exempt** their children from vaccines that would otherwise be required for school admission based on religious grounds, and it is also one of a smaller group of states that allows exemptions for personal or philosophical reasons. Wheeler says her exemptions have simply been for personal reasons and that she usually doesn't receive much pushback.

"She even told me when I asked about the college thing," Lindenberger says, "that if you push hard enough, they won't force you to get vaccinated." Even for universities such as Ohio State University -- which experienced **hundreds of cases** of mumps in 2014 -- students can gain **an exemption** solely based on 'good cause.'

Non-medical exemptions have been declining generally across the United States, but tens of thousands are still granted annually, and certain states, including Oregon, Idaho and North Dakota, are **seeing an increase**, putting those areas at risk for future disease outbreaks.

"We're seeing more and more anti-vaccine parents clustering in different regions around the country," Winnike says. Though these parents can cause a lot of damage, a larger group, she says, is made up of "vaccine-hesitant" parents. "Once you just talk to them, hear some of their fears and then explain to them the scientific benefits and the healthcare benefits, they are more open to getting their child vaccinated."

Still, Wheeler remains staunch in her dismissals, arguing that she believes many vaccines are unnecessary and even harmful. "Polio, if you really research polio, it was almost completely eradicated, almost gone; there was almost no cases of polio when they introduced the oral vaccine," she says. "The oral vaccine started giving people polio. And it went from almost completely eradicated to the numbers were shooting, sky-rocketing back up, from immunizations"

she says.

Like many anti-vaccine arguments, however, such thinking -- although surely rooted in a genuine concern for her children's health and safety -- is based on a faulty distillation of history. The development of the oral vaccine in the middle of the 20<sup>th</sup> century was, in fact, a vital complement to the injectable vaccine, helping to dramatically reduce global polio cases in part because it was comparatively easy to transport and administer. But because the oral vaccine uses a live, weakened form of the virus, it has the potential -- albeit small -- to also cause the disease, and sporadic outbreaks of vaccine-derived polio **remain a challenge in parts of the developing world**. The numbers, though, are telling: Roughly 100 cases of vaccine-derived polio were tracked globally in 2018, **according to** the World Health Organization. Before global eradication efforts began in 1988, 350,000 children **were paralyzed** by the disease each year.

Also of note: The U.S. has not used oral polio vaccine **for nearly two decades**.

And yet Wheeler says that her experience with her son has convinced her to start talking to her younger children about why she has chosen to skip their vaccinations. "It has opened my eyes," Wheeler says, "to say, 'I better educate them now. Not wait until they're 18.' But I need to start educating my 16-year-old and my 14-year-old now, saying *this* is why I don't believe in it."

Lindenberger says he's also discussed the issue with his siblings himself and has gotten mixed reactions. His 16-year-old brother, he says, "wants to get vaccinated the moment he turns 18," whereas his 14-year-old sister "fully, whole-heartedly agrees with my mom."

Follow-up conversations with his mother, Lindenberger says, haven't changed a thing.

"We both know where we stand," he says.

*This article was originally published on **Undark**. It has been slightly modified to reflect Spectrum's style.*