# Chapter 11 Vaccine Refusal: Stories from the Front Lines of Immunization Education



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Abstract One way that U.S. state governments participate in immunization governance is to mandate vaccination for daycare and school enrollment. In response to rising rates of vaccine refusal, and concerns about outbreaks of previously well-controlled vaccine-preventable diseases, Michigan has chosen to require parents or guardians to attend 'immunization counseling' prior to receiving nonmedical exemptions to their state's vaccine mandate. This chapter presents a brief memoir essay based on a composite of Michigan's public health immunization educators. We constructed this composite character from interviews we conducted with 39 Michigan immunization educators. This narrative raises pressing ethics questions about the benefits and burdens of mandatory immunization education.

 $\textbf{Keywords} \quad \text{Education} \cdot \text{Immunization} \cdot \text{Nonmedical exemptions} \cdot \text{Public health} \cdot \text{Vaccine mandates} \cdot \text{Vaccine refusal}$ 

## **Public Heath Ethics Issue**

In the United States, federal and state governments use diverse means to promote and govern vaccination. Federal laws, including the National Childhood Vaccine Injury Act (NCVIA) of 1986, require that persons receiving vaccines be presented

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with Vaccine Information Statements and have access to the Vaccine Adverse Event Reporting System (VAERS). The federal government also funds a majority of youth vaccines in the United States through the Vaccines for Children (VFC) program (Whitney et al. 2014). One way that U.S. state governments participate in immunization promotion and governance is by mandating vaccination for daycare and school enrollment.

Throughout the world, mandatory immunization policies take a variety of forms (Attwell and Navin 2019) and implicate a wide array of ethical values (MacDonald et al. 2018; Navin and Attwell 2019). State sponsorship of vaccination directly promotes individual health and, at high enough levels, indirectly generates community protection against outbreaks (commonly called 'herd immunity') (Anderson et al. 2018). Vaccine mandates can promote or undermine many other goods, depending on their structure and implementation. For example, mandates that require documentation of schoolchildren's immunization status may promote state supervision of vulnerable children, and mandates that require immunization education as part of nonmedical exemption schemes may promote the community's health knowledge (Leask and Danchin 2017; Luyten and Beutels 2016). In contrast, mandates that exclude unvaccinated children from daycare or school may undermine children's education and may contribute to some parents exiting the formal workforce in order to provide in-home childcare or homeschooling. Furthermore, coercive efforts to promote vaccination can restrict parental rights, undermine trust among vaccine hesitant parents, and may cultivate anti-vaccine sentiments (Bester 2015; Omer et al. 2019).

In light of the many values implicated by vaccine mandate policies, it is essential to weigh and balance these values, and to select policies that prioritize the most important values. In particular, governments should use only as much coercion as necessary to protect communities from disease outbreaks (Nuffield Council on Bioethics 2007). This Least Restrictive Means (LRM) principle favors public health efforts that emphasize education and use liberty-preserving nudges to influence behavior (Blumenthal-Barby and Burroughs 2012; Kass 2001; Menard 2010). Accordingly, we have good reason to pursue efforts that use mandatory education as a means to increase vaccine uptake while protecting parental rights to access nonmedical exemptions to daycare and school vaccine mandates, such as those in effect in Michigan and Washington (Navin and Largent 2017; Jones et al. 2018; Omer et al. 2018). However, these policies may be especially burdensome on the physicians or public health staff who the government tasks to deliver immunization education. Accordingly, further public health ethics discussions must address the efficacy of mandated education (relative to alternative policies) and the appropriate distribution of responsibility for providing immunization education. Executing public policies around these two issues will demand both respectful community engagement and effective collaboration to execute public health policies.

## **Background Information**

There is a wide spectrum of beliefs and behaviors associated with vaccination decisions, from complete acceptance to complete refusal, with many people occupying intermediate positions, including the refusal of only some vaccines or the use of alternative immunization schedules (MacDonald and Sage Working Group 2015; Bedford et al. 2018). In response to rising rates of vaccine refusal, and concerns about outbreaks of previously well-controlled vaccine-preventable diseases, many political communities across the world have recently revised their immunization policies (Attwell et al. 2018; MacDonald et al. 2018). In the United States, vaccine mandates for children take the form of enrollment requirements for daycare or school, but all states waive these requirements if children have medical reasons not to be vaccinated, most states waive those requirements when parents object to vaccines for religious reasons, and some states waive requirements in response to philosophical or personal belief objections (Immunization Action Coalition 2019). Recent reforms to U.S. children's vaccine mandates have usually focused on eliminating these nonmedical exemptions or on making them more difficult to receive. For example, California, New York, and Maine have eliminated nonmedical exemptions (McKinley 2019; Simko-Bednarski 2019; Willon and Mason 2015); these efforts seem to have led to increased immunization rates (Delamater et al. 2019). In contrast, other U.S. states—including Michigan and Washington—have chosen to require parents or guardians to attend 'immunization counseling' prior to receiving an exemption (Lillvis 2019); those states have seen dramatic declines in nonmedical exemption rates (Jones et al. 2018; Mashinini et al. 2020). (Michigan calls its exemptions to daycare and school immunization requirements 'waivers' (Michigan Department of Health and Human Services n.d.), which is also the term that our narrative's composite character uses.) When Michigan decided to implement mandatory immunization education, it had the fourth-highest nonmedical exemption rate in the country; Michigan reduced its waiver rate by 35% after 1 year of mandatory immunization education (Navin et al. 2020).

Governments that have implemented immunization education requirements may have hoped that vaccine-refusing parents would change their minds after nurses or physicians talked with them about vaccines. Unfortunately, it is often ineffective and emotionally taxing for health professionals to try to change the minds of vaccine refusers in one-off encounters (Block 2015; Henrikson et al. 2015; Kempe et al. 2015). In addition to concerns about staff 'burnout' in the face of this difficult work, we may also worry about forms of moral distress that staff can experience if they believe it is wrong for parents to refuse vaccines or for the government to threaten to remove unvaccinated children from school. We must therefore address whether the costs imposed on public health staff who provide mandatory vaccine education are justified by the health benefits their efforts generate. In particular, there is evidence that communities can reduce nonmedical exemption rates by increasing the burdensomeness of their application processes for patents (Blank et al. 2013; Omer et al. 2012), and requiring immunization education is one way to make it more difficult to receive an exemption (Navin and Largent 2017).

Research about mandatory immunization counseling has used both qualitative and quantitative research methods to identify the core attributes and consequences of these policies (Navin et al. 2018, 2019a, b). However, a focus on the *narratives* of immunization educators can both complement existing research and provide new information about the ethics issues involved in mandatory immunization education. A narrative is an ideal format for illuminating immunization educators' frustrations, hopes, resignations, and professional commitments; and reflecting on their stories can provide a richer sense of the practical and ethical difficulties involved in public health responses to vaccine refusal.

## Approach to the Narrative

This chapter presents a brief memoir essay based on a composite of Michigan's public health immunization educators. We constructed the character of Margaret from the experiences of 39 Michigan immunization educators whom we interviewed in 2017 and 2018. All of the emotions and events described in Margaret's memoir were drawn from our interview transcripts, and much of the text is direct quotation. Our interviews were part of an empirical research project, which resulted in two publications that reported our qualitative results (Navin et al. 2018; Navin et al. 2019a). Our original goal for that research project did not include the telling of stories. But we were struck by the fact that our research participants frequently responded to our focused interview questions with detail-laden tales about their successes, failures, and frustrations. While we did not include these rich narratives in our earlier papers, in the character of Margaret we have pulled many narrative elements of our research participants' responses into a single story.

We imagine that Margaret has written this memoir to provide a personal, on-the-ground perspective about an exciting, frustrating, and ultimately transformative change in the work her public health department does. Her memoir's narrative arc begins with a sense of hope and optimism about the potential for immunization education to change the minds of committed vaccine refusers. It then explores a period of doubt and bitterness that she suffered through as she faced repeated failures and frustrations in her work. The narrative concludes with Margaret reconceiving the goals of immunization education after reconciling herself to the belief that the work she is doing can make a difference.

We hope Margaret's vaccine waiver education memoir will encourage more nuanced and subtle normative judgments about complicated public health interventions, including state-mandated immunization education.

<sup>&</sup>lt;sup>1</sup>This research was conducted with approval from the Human Subjects Institutional Review Board at Oakland University (#904562).

#### **Narrative**

# Margaret's Memoir

"If I never have to talk to another person about a waiver in my life it will be too soon." That's what I would have told you about my immunization education work in August of 2015. I'm sure I said worse things, too. My colleagues and I were working extra hours to finish as many waiver education sessions as possible before the school year started. We wanted to make sure that as few children as possible would be excluded from school. Our work was hard, cognitively and emotionally, and it didn't seem like we were doing much good. My original optimism was long gone by then—I no longer thought I could talk parents into vaccinating their children—and I wasn't yet reconciled to the work. I hadn't learned to focus on the good things we were doing.

And now?

I still think it's foolish to try to convince committed vaccine refusers to agree to get their kids vaccinated, especially if you've only got 30 min to try, which is why I don't try to do that anymore. But I'm less angry and frustrated than I used to be. I've even started to think that I'm doing some good: I put a positive face on public health, and I find common ground wherever I can. Most importantly, I've come to believe that it's my job—that it's public health's job—to be a positive voice for immunization, even among members of our community who are reluctant or refusing. Because public health is what I'm all about.

This is a story about my experiences with state-mandated immunization education in Michigan. But it's also a story about how I stretched outside my comfort zone to help my state increase its immunization rates.

I have a Bachelor of Science in Nursing (BSN), and I started my nursing career in a private provider's office, where I ran their immunization program for 4 years. I took a few years off to stay home when my son was born. When I wanted to go back to work, there was a job in a public health department that seemed like a good fit. I've been here for the past 8 years. My first job was to work in our clinic, where I gave people shots 5 days a week. More recently, I have done antenatal and postnatal home visits for new mothers and babies or pregnant women. I always advocated for immunizations with the families I visited. And most people were really receptive to what I had to say. People might have had questions about vaccines, but they almost always agreed to receive the ones they were scheduled to get. My work with waivers would end up being really different. I'm going to start saying a lot about 'waivers', so you should know that a 'waiver' is what Michigan calls a nonmedical exemption to a daycare or school immunization requirement.

For decades, parents in Michigan have had to get their children vaccinated to enroll them in school or daycare. Vaccine mandates are nothing new. But it used to be the case that parents who didn't want to vaccinate—or had just not gotten around to it—could easily avoid that requirement. The school secretary would just have them sign a form saying that they had a religious or personal belief objection to

vaccines. It didn't even have to be an official state form, and sometimes a school district would have their own form that they'd be happy to have parents sign. These waivers were way too easy to get.

I think a lot of secretaries pushed waivers on parents to make their jobs easier. If parents hadn't finished the vaccine schedule, the secretary would say "Here, sign this, and then go get the shots whenever you can," even if the parents didn't have any objections to vaccines. In 2014, I think Michigan had a higher waiver rate than almost every other state in the country. It was time to do something new.

In December of 2014, I heard that the state government changed the rules for waivers. Parents could still send their kids to school if they weren't vaccinated, but they couldn't just sign a form with the school secretary. Beginning in 2015, they would have to come to the public health department to complete an education session with a public health worker. They could only get the form if they finished the session. And our form was the only one that would let unvaccinated children get into school.

I thought this was wonderful news. Vaccines are public health. So public health professionals should be enforcing vaccine laws and trying to change people's minds. It was time to get Michigan's school secretaries out of the vaccine waiver business. Public health nurses, like me, had work to do.

Waiver education was exciting, but it was new. Public health people have always been doing vaccines, but usually it's with families and individuals who have come to us for help, or who we've been assisting out in the community. There's often been a prior relationship, and a background of trust. Some people we work with have had concerns about vaccines, and we addressed those kinds of worries as they came up. But now we were going to provide legally *mandated* waiver education to people who didn't want to see us. They *had to* come to the health department, often for the very first time.

We didn't have much time to get ready. The new waiver rule was approved in December and my first waiver education session was on January 15, 2015. I had my nursing background to rely on, and think I did ok. But I quickly realized that we were not really prepared.

In August of 2015, the state had a conference in Lansing about how to do waiver education and how to talk to hesitant parents about vaccines. Part of the conference included a live feed with Dr. Paul Offit from Children's Hospital of Philadelphia (CHOP). We also went to the Pink Book conference in 2015. The Michigan Department of Health and Human Services distributed handouts to the local health departments to guide counseling sessions or to give to parents. These were sheets that addressed different concerns parents might have about vaccines. There was one for autism, one for mercury, one for fetal tissue, etc. We had other handouts about religious objections. For example, they told us what to say if a Catholic person said their religion was against vaccines.

There are certain things the state told us we *had* to tell parents. Things like "your child will be excluded from school if there is an outbreak," and "if you go to the Emergency Room, be sure to let your medical providers know your child is not

vaccinated." We also had to tell them about the risks of vaccine-preventable diseases and the benefits of vaccination.

But each health department got to do things in their own way. (In Michigan, the local health departments report to their local county governments; they don't work for the state health department.) My health department put together boxes with hanging folders, and each folder had handouts to address different concerns about vaccines. We used all kinds of materials: handouts from Centers for Disease Control and Prevention (CDC), and from its Advisory Committee on Immunization Practices (ACIP); Vaccine Information Statements (VIS); materials from Michigan Department of Health and Human Services; and resources from Children's Hospital of Philadelphia (CHOP). We also put together lists of reputable websites that parents could review if they wanted to learn more about vaccines. Some were government sources, but lots weren't. It was not perfect. It was done quickly. But we felt good about what we had done.

We were pretty optimistic at first.

Everybody thought, "We're going to convince them to go right over to the clinic, and they're going to get vaccinated." I originally had really high hopes and thought to myself, "I'm going to save the world and change all these minds." It was a really prescriptive mindset: we were going to give people valuable information, and then they were going to do the right thing, by agreeing to get their children vaccinated. Why wouldn't they? When my health department started offering waiver sessions, we required parents to bring their children, because we thought they would allow us to vaccinate their children *right after* the waiver session.

It didn't take long for us to revisit our original optimism and plans. The first thing we changed was to stop telling parents they had to bring their children. That requirement just seemed to make parents mad, and leaving the kids at home didn't make any difference, because so few parents were changing their minds.

But the biggest changes were in the attitudes of the waiver educators. After I did my first twenty or thirty sessions, I became a lot less naive. I was kind of in shock about what these parents were saying, and how they refused to see the truth. I would walk away from a session and go, "Whoa where are these people coming from?" I would provide reliable information, and they would just talk crazy to me. I mean, what do you say to people who won't see reason? I can provide all the facts in the world, but when you get a chiropractor who says, "We believe in manipulation, we don't give immunizations," what do you say? I've had nurses and even a couple of doctors in my sessions. What do you say to them?

I thought we'd be seeing uneducated people, disadvantaged people. All they'd need was some knowledge, and they'd do the right thing. But the people who come in for waivers were not the poor or refugees—those folks have probably seen these diseases and they wanted vaccines. No, it was the well-educated: "I'm a lawyer, you can't tell me what to do, I make my own decisions," or "my husband's cousin is a doctor and they believe in natural immunity," or "your body will take care of itself," or "people who get sick just don't take care of themselves; they maybe have dirty houses."

Some parents have said to me, "What's the big deal about this? We don't have these diseases anymore," and then I would say, "Why do you think we don't have them anymore? Do you realize that only 60 years ago many people were getting sick and dying from some of these diseases? Have you seen an iron lung? Do you have any sense of how afraid people were? They closed pools and schools. When the oral polio vaccine came out, and it was on a sugar cube, parents lined up around the block to get it at the school gymnasium!"

The ones that were really angry when they came in would tell me that their rights had been violated. A woman said to me, "I'd expect you to defend vaccines because you work for the government, and I don't believe anything that the government says." I would try to say something positive in response, like "you seem really concerned about your children," but there's not much moving forward with the antigovernment people. The more you talk, the angrier they get. One of the anti-government parents said to me, "How dare you tell me what to do with my children!" The first year, a lot of attorneys called us because parents didn't believe that the government had the authority to make them come to our office.

Some of the parents mention religion, but the things they say often don't seem connected to the teachings of any organized faith. A lot of people have said "God made our bodies to fight off disease." I used to argue with them. "Sure," I'd say, "God made our bodies to fight disease, but He also gave us the mind and the ability to create things like the computer and cell phones *and vaccines*." I tell them that I agree that God wants us to keep healthy, but I see Him as giving us the opportunity and the brainpower to make vaccines that keep us healthy so we can honor and praise Him. Once, a mother told me "the reason I don't want to vaccinate my children is because Jesus didn't get vaccinations." I was so taken aback. And I couldn't help myself—it just came out—I said "well, Jesus died very young." I meant to say something like "The life expectancy in Jesus' time was very low."

People gave us all kinds of kooky reasons. It's important that you get a sense that we weren't just talking about autism or thimerosal all day. One parent told me that her family owned a plane. Her husband was a pilot, and if anyone got sick, they would fly over six thousand feet. The non-pressurized cabin would kill any infections they had, so, no need for vaccines. What do you say to that?

Sometimes the line between eccentricity and mental illness was not so clear. There was a woman who came in and sat in my office, and with a straight face and all sincerity said that she believed that she got a flu shot and somebody injected her with a tracking device, and that they were tracking her, and she knew this because of things that came up on her phone. I was looking at her like, "Oh my God." I don't think any of us were equipped to deal with all of the needs that these people came in with. Some of them were way out of our realm.

I used to argue with people about how important it was for their children to avoid infecting other people. Even if their children were strong enough to recover from measles, some of their neighbors or classmates might not have equally robust immune systems. Most parents would just ignore me when I said that, but some would say "I do not care about other people's children and I don't care about other people." I don't know how you respond to that.

For a while, I absolutely hated doing waiver education. My colleagues sometimes had to put up with me yelling at them because I got so frustrated and tired with the parents we talked to. I'm not kidding! Because these are people that—you know at some point, you look at them and you go, "These people believe crazy stuff, they are bringing this crazy stuff in here and yelling at me," and I can't—it's like trying to reason with a two-year-old. There's no reasoning. How do you reason with somebody who is unreasonable?

Nobody likes being yelled at all day.

I think the first year was the worst. It was literally the worst. The schools did not know what they were doing. Some were still accepting the old forms, and some were not accepting our form. It was a confusing time. And the parents did not know what they were walking into. Some of them thought we were going to yell at them, or lock in them in a room to watch a two-hour video. Many parents seemed frightened or angry or just lost. To be honest, we—on the public health side—were not always as organized as we might have liked to have been. It took a while for everyone to figure out what we were doing.

The work was emotionally draining because I wasn't just talking about statistics and facts, but I was trying to connect with these people on an emotional level, to get them to see that they really needed to vaccinate their kids. Lots of times I walked out of here just shaking my head going, "how stupid, just how stupid." I later found out that one family that came in to get waivers sends their children to my child's school. So that just angered me even more: their kids were putting my kid at risk.

It was hard, and sometimes I got overwhelmingly mad and sad at the same time. I think the other thing for me that was emotionally wearing were the stories people would tell about how they thought vaccines injured their children. This story always went the same way: "My kid was fine until they got the shot. Something happened and I can't pinpoint it, but something happened and they were different." The first time I heard it I was like, "Yeah, ok, whatever," and then I heard it again. Then I heard it again. I had a woman pull out her phone and show me videos of her kid. It looked like a normal kid. It looked like a normal toddler just toddling around doing its thing. But the kid she brought with her to the waiver session was like a zombie. And then the mom says, "This is the same kid. This is why I don't vaccinate." How can I argue with that? I've heard it so many times now. I don't want to see any more videos.

I've worked hard to reconcile myself to doing waiver education. Things have gotten better.

I do a lot more self-care and mutual support with my colleagues. After you've had a long day of waiver appointments, we have to be able to talk to each other afterwards. We have that, even if it's just a few moments with one person to just decompress and say, "This is new that I heard today," or, "this is what this parent said and this is how I responded."

I also got more interested in learning from the parents who came in for waiver education. I study their body language, try to assess their educational level, and figure out how to get into really having a discussion. That kind of effort helps me avoid focusing on my own attitudes, feelings, and concerns. Maybe this sounds too

clinical, but I try to summon all of my best counseling skills and I sometimes find it exciting, even fun. I think that meeting all kinds of people from different backgrounds, languages, and cultures is extremely interesting.

When it goes bad now—and it still goes bad sometimes—I just remind myself that they are not really upset at me, but at the process.

I've got different goals now. I don't spend as much time talking about vaccines, but I focus on the diseases. A lot of parents come in saying, "I've done the research on the vaccine, I've done the research on the additives," and I always say to them, "But have you researched the *disease*? Do you know what the disease process looks like? Do you understand what complications can arise from getting measles? Do you understand?" A lot of them don't know as much about the diseases. So, a lot of my focus now is forward-looking. What do you need to know if your child gets a bad rash and you have to figure out whether to go to the emergency room? What should you tell the nurses and doctors once you get there? Few medical professionals have seen the diseases we vaccinate against today.

I do a lot more listening now. I always ask, "Can you give me your thoughts on vaccines?" I like to get them talking about how they feel about the vaccines first, and what they are worried about. Is it just because "it's a government issue and I don't want to be told what to do with my own children?" Or is it "I've done all the research and I don't want to put these chemicals in my kid's body?"

If they come with a stack of papers—their 'research'—I now try to diffuse things immediately. I'll say, "Did you bring some information to share with me?" And then I thank them, and I'll say, "I'll look at this later because I am on a time schedule here. I only have a half an hour for you and so we can't really get into great detail here." And I do look at what they bring. It's helpful for us to better understand where they're coming from, but it's also important to show that you respect the work the parents have already put into making vaccination decisions.

I've now got a longer-term perspective. I want parents to know that it's never too late to vaccinate. I want them to leave with a good feeling about me and about the public health department. I'm trying to open doors to the possibility of future relationships. I always tell them it's not my job to change your mind. We just really have a concern—the state does—about the number of waivers that we have.

I hope to plant a seed that they will actually take with them, and do some more research, and open their mind up to the other side of the story. That's my hope. But my bottom line is I'm always going to give them the waiver. I fill it out and sign it in the first moments of our meeting, so they know from the beginning that they're going to get what they came for. That usually drains the negative energy from the room. And it makes it easier for me to do my job, because I can educate about vaccines and diseases without being under a shadow of potential conflicts with parents.

I also hope that people will see the role of public health in a better light. Many people don't understand what public health is or they have a negative attitude about it. We're strangers to them, and for many of these people they're strangers to the health department. They never had to come here. Health departments used to be thought of as places where poor people went. There are still people that think that way. I had a mother call and say, "Am I going to get sick there? Are there a lot of

sick people in your waiting room?" If the people who get waivers leave our building feeling ok about us, then we've done something good for the perception of public health in our community.

Most of the people I have interacted with have appreciated what I have said to them, so they thank me. I always greet them, call them by name, and shake their hand. And then when we leave it is always on a positive note. Almost everyone goes, "Thank you so much for taking the time and being so kind and considerate."

I don't think as badly about these parents as I used to. I can see that they are trying to do what they think is best for their children. They've thought about their decisions and they've done some reading. I actually often say, "We all want to do the right thing. We know that you want to do the right thing for your children and keep your children safe and healthy, and so do we." Many of them are confused and afraid, and they've heard so many frightening stories about vaccines. My first job now is to show compassion and to listen.

I used to think mandatory waiver education was going to change the world overnight. Then I went through a period of being angry and frustrated about it. Now I think it's really important work for me and my colleagues to be doing.

Some of my public health colleagues say that it shouldn't be our job to do vaccine education. But where else are parents going to hear this information? Physicians' offices? The physicians don't know about the vaccines. They may know a little bit, but they don't really have the time to talk about this issue. Is there education that's going on in pediatric clinics? Not much, I think. And nurses are the most trusted profession in America—even more than doctors—and we should use that trust when our community needs us. And my community needs me now.

Public health is my calling in life. Waiver education is now another part of how I live my vocation. It's hard work, but I'm glad to be doing it.

## **Questions for Discussion**

The following questions aim to promote further reflection on ethical issues in mandatory vaccination policies, including mandatory immunization education. For each of the questions, we recommend that you consider how Margaret's story informs your responses.

- Is mandatory vaccination ethical? In thinking about this question, consider issues relating to balancing various interests and duties and the appropriate role of government.
- 2. Should parents have a right to refuse vaccines for their children and if they should, what should be included among 'parental rights'?
- 3. How does Margaret's story impact how you think about parents who refuse vaccines for their children?
- 4. How does Margaret's story highlight challenges and opportunities for communicating with parents who believe their child has been injured by a vaccine?

- 5. Immunization is both a personal medical decision and a vital tool for public health. Accordingly, who should be responsible for educating the public about immunization in the context of vaccine mandate policies?
- 6. How is state-mandated immunization education similar to or different from other kinds of education that public health professionals provide and how might these similarities or differences impact your consideration of the ethical issues?
- 7. How might state-mandated education impact trust in public health?
- 8. Do the potential public health benefits of mandatory immunization education outweigh the burdens (e.g. burnout, moral distress) that this work imposes on public health staff?

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#### References

- Anderson, Evan J., Michael A. Daugherty, Larry K. Pickering, Walter A. Orenstein, and Ram Yogev. 2018. Protecting the Community through Child Vaccination. *Clinical Infectious Diseases* 67 (3): 464–471.
- Attwell, Katie, and Mark C. Navin. 2019. Childhood Vaccination Mandates: Scope, Sanctions, Severity, Selectivity, and Salience. *The Milbank Quarterly* 97 (4): 978–1014.
- Attwell, Katie, Mark C. Navin, Pier Luigi Lopalco, Christine Jestin, Sabine Reiter, and Saad B. Omer. 2018. Recent Vaccine Mandates in the United States, Europe and Australia: A Comparative Study. Vaccine 36 (48): 7377–7384.
- Bedford, Helen, Katie Attwell, Margie Danchin, Helen Marshall, Paul Corben, and Julie Leask. 2018. Vaccine Hesitancy, Refusal and Access Barriers: The Need for Clarity in Terminology. *Vaccine* 36 (44): 6556–6558.
- Bester, Johan Christiaan. 2015. Vaccine Refusal and Trust: The Trouble with Coercion and Education and Suggestions for a Cure. *Journal of Bioethical Inquiry* 12 (4): 555–559.
- Blank, Nina R., Arthur L. Caplan, and Catherine Constable. 2013. Exempting Schoolchildren From Immunizations: States With Few Barriers Had Highest Rates Of Nonmedical Exemptions. *Health Affairs* 32 (7): 1282–1290.
- Block, Stan L. 2015. The Pediatrician's Dilemma: Refusing the Refusers of Infant Vaccines. *The Journal of Law, Medicine & Ethics* 43 (3): 648–653.
- Blumenthal-Barby, Jennifer Swindell, and Hadley Burroughs. 2012. Seeking Better Health Care Outcomes: The Ethics of Using the 'Nudge. *The American Journal of Bioethics* 12 (2): 1–10.
- Delamater, Paul L., S. Cassandra Pingali, Alison M. Buttenheim, Daniel A. Salmon, Nicola P. Klein, and Saad B. Omer. 2019. Elimination of Nonmedical Immunization Exemptions in California and School-Entry Vaccine Status. *Pediatrics* 143 (6): e20183301. https://doi.org/10.1542/peds.2018-3301.
- Henrikson, Nora B., Douglas J. Opel, Lou Grothaus, Jennifer Nelson, Aaron Scrol, John Dunn, Todd Faubion, Michele Roberts, Edgar K. Marcuse, and David C. Grossman. 2015. Physician Communication Training and Parental Vaccine Hesitancy: A Randomized Trial. *Pediatrics* 136 (1): 70–79.
- Immunization Action Coalition. 2019. State Mandates on Immunization and Vaccine-Preventable Diseases: Exemptions Permitted for State Immunization Requirements. June 14, 2019. https://www.immunize.org/laws/exemptions.asp.

- Jones, Malia, Alison M. Buttenheim, Daniel Salmon, and Saad B. Omer. 2018. Mandatory Health Care Provider Counseling For Parents Led To A Decline In Vaccine Exemptions In California. *Health Affairs* 37 (9): 1494–1502. https://doi.org/10.1377/hlthaff.2018.0437.
- Kass, Nancy E. 2001. An Ethics Framework for Public Health. *American Journal of Public Health* 91 (11): 1776–1782.
- Kempe, Allison, Sean T. O'Leary, Allison Kennedy, Lori A. Crane, Mandy A. Allison, Brenda L. Beaty, Laura P. Hurley, Michaela Brtnikova, Andrea Jimenez-Zambrano, and Shannon Stokley. 2015. Physician Response to Parental Requests to Spread Out the Recommended Vaccine Schedule. *Pediatrics* 35 (4): 666–677. https://pediatrics.aappublications.org/content/135/4/666.
- Leask, Julie, and Margie Danchin. 2017. Imposing Penalties for Vaccine Rejection Requires Strong Scrutiny. *Journal of Paediatrics and Child Health* 53 (5): 439–444.
- Lillvis, Denise. 2019. Managing Dissonance and Dissent: Bureaucratic Professionalism and Political Risk in Policy Implementation. *Law & Policy* 41 (3): 310–335. https://doi.org/10.1111/lapo.12131.
- Luyten, Jeroen, and Philippe Beutels. 2016. The Social Value of Vaccination Programs: Beyond Cost-Effectiveness. *Health Affairs* 35 (2): 212–218.
- MacDonald, Noni E., and Sage Working Group. 2015. Vaccine Hesitancy: Definition, Scope and Determinants. *Vaccine* 33 (34): 4161–4164.
- MacDonald, Noni E., Shawn Harmon, Eve Dube, Audrey Steenbeek, Natasha Crowcroft, Douglas J. Opel, David Faour, Julie Leask, and Robb Butler. 2018. Mandatory Infant & Childhood Immunization: Rationales, Issues and Knowledge Gaps. Vaccine 36 (39): 5811–5818.
- Mashinini, Duduzile P., Kieran J. Fogarty, Rachel C. Potter, and Mary D. Lagerwey. 2020. The Impact of Michigan's Nonmedical Vaccine Exemption Rule Change on Philosophical Exemption Rates. *Journal of Community Health* 45 (1): 148–153. https://doi.org/10.1007/s10900-019-00727-5.
- McKinley, Jesse. 2019. Measles Outbreak: N.Y. Eliminates Religious Exemptions for Vaccinations. *The New York Times* (June 13, 2019). https://www.nytimes.com/2019/06/13/nyregion/measles-vaccinations-new-york.html.
- Menard, Jean-Frederick. 2010. A 'Nudge' for Public Health Ethics: Libertarian Paternalism as a Framework for Ethical Analysis of Public Health Interventions? *Public Health Ethics* 3 (3): 229–238.
- Michigan Department of Health and Human Services. n.d. *Immunization Waiver Information*. https://www.michigan.gov/mdhhs/0,5885,7-339-73971\_4911\_4914\_68361-344843% 2D%2D,00.html.
- Navin, Mark C., and Katie Attwell. 2019. Vaccine Mandates, Value Pluralism, and Policy Diversity. *Bioethics* 33 (9): 1042–1049. https://doi.org/10.1111/bioe.12645.
- Navin, Mark C., and Mark A. Largent. 2017. Improving Nonmedical Vaccine Exemption Policies: Three Case Studies. *Public Health Ethics* 10 (3): 225–234.
- Navin, Mark C., Andrea T. Kozak, and Emily C. Clark. 2018. The Evolution of Immunization Waiver Education in Michigan: A Qualitative Study of Vaccine Educators. *Vaccine* 36 (13): 1751–1756.
- Navin, Mark C., Andrea T. Kozak, and Michael J. Deem. 2019a. Perspectives of Public Health Nurses on the Ethics of Mandated Vaccine Education. *Nursing Outlook* 68 (1): 62–72. https://doi.org/10.1016/j.outlook.2019.06.014.
- Navin, Mark C., Jason A. Wasserman, Miriam Ahmad, and Shane Bies. 2019b. Vaccine Education, Reasons for Refusal, and Vaccination Behavior. *American Journal of Preventive Medicine* 56 (3): 359–367. https://doi.org/10.1016/j.amepre.2018.10.024.
- Navin, Mark C., Mark A. Largent, and Aaron M. McCright. 2020. Efficient Burdens Decrease Nonmedical Exemption Rates: A Cross-County Comparison of Michigan's Vaccination Waiver Education Efforts. *Preventive Medicine Reports* 17 (March): 101049. https://doi.org/10.1016/j. pmedr.2020.101049.

- Nuffield Council on Bioethics. 2007. Public Health: Ethical Issues. London: Nuffield Council on Bioethics. https://www.nuffieldbioethics.org/wp-content/uploads/2014/07/Public-healthethical-issues.pdf.
- Omer, Saad B., Jennifer Richards, Michelle Ward, and Robert Bednarczyk. 2012. Vaccination Policies and Rates of Exemption from Immunization, 2005–2011. New England Journal of Medicine 367 (12): 1170–1171.
- Omer, Saad B., D.H. Kristen Allen, L. Beryl Chang, Robert A. Guterman, Alex Jordan Bednarczyk, Alison Buttenheim, Malia Jones, M. Claire Hannan, Patricia de Hart, et al. 2018. Exemptions from Mandatory Immunization After Legally Mandated Parental Counseling. *Pediatrics* 141 (1): e20172364. https://doi.org/10.1542/peds.2017-2364.
- Omer, Saad B., Cornelia Betsch, and Julie Leask. 2019. Mandate Vaccination with Care. *Nature* 571 (7766): 469–472. https://doi.org/10.1038/d41586-019-02232-0.
- Simko-Bednarski, Evan. 2019. Maine Bars Residents from Opting out of Immunizations for Religious or Philosophical Reasons. *CNN* (May 27, 2019). https://www.cnn.com/2019/05/27/health/maine-immunization-exemption-repealed-trnd/index.html.
- Whitney, Cynthia G., Fangjun Zhou, James Singleton, and Anne Schuchat. 2014. Benefits from Immunization during the Vaccines for Children Program Era—United States, 1994–2013. MMWR. Morbidity and Mortality Weekly Report 63 (16): 352.
- Willon, Phil, and Melanie Mason. 2015. California Gov. Jerry Brown Signs New Vaccination Law, One of Nation's Toughest. *Los Angeles Times* (June 2, 2015). https://www.latimes.com/local/political/la-me-ln-governor-signs-tough-new-vaccination-law-20150630-story.html.

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