

CASE STUDY

The anti-vaccine movement and public health

Science and Pseudoscience are at odds when it comes to the idea of a cause and cure for autism spectrum disorders. This is not a clear-cut case of science squaring off against the popular media, conducting shouting matches across the Internet, newspaper and academic journal boundaries as one might expect in such a situation. Why? The heroes and villains of this problem, and there are plenty, simply don't fall clearly into these categories. Science, in this case, has its share of villains, while the media has its share of heroes.

One of the clearest villains in the case of autism and misinformation is Andrew Wakefield, a former physician and surgeon at Britain's well-known Royal Free Medical School, who published a paper in 1998 connecting autism to a vaccine for measles, mumps and rubella (MMR) that is commonly given to toddlers.¹⁷ Wakefield was certainly not the first researcher to propose a cause or cure for autism, but he is the more commonly known. Soon after Wakefield's article was published, news of it began to spread, and parents of

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autistic children began to seek his help. If the cause of autism had been found, surely it could be cured and new cases could be prevented. Wakefield spent close to six years in the limelight, and became the golden boy of parents seeking a cure for their autistic children.

While Wakefield may have won over parent and advocacy groups, many scientists and physicians remained skeptical. They watched, and began to protest, as Wakefield conducted more trials on autistic children, going so far as to send autistic children to the United States where he could more easily order investigative spinal taps. His proclamations about the ills of vaccines created an anti-vaccine movement that sparked several public health crises.¹⁸ To be fair, Wakefield wasn't the only one promoting the idea that vaccines caused autism. U.S. politicians, such as Robert. F. Kennedy and Dan Burton, claimed that Thiomersal, a mercury-based preservative commonly found in childhood vaccines, caused autism, and held congressional hearings to prove their point. Over the course of a few years, Thiomersal was removed from many vaccines.¹⁹ Wakefield and other anti-vaccine advocates clearly seemed to be the heroes.

The fall from hero-like status, it seems, can happen as quickly as the ascension to it. Within a few years of Wakefield's article in *The Lancet*, and the onset of the sensational anti-vaccine movement, the scientific community grew more skeptical. First, a five-year-old autistic boy in Pennsylvania died of heart failure while undergoing chelation therapy, which some claimed to rid the body of the heavy-metal toxins such as mercury.²⁰ Later, during the 2007 omnibus hearing, physicians challenged anti-vaccine experts to account for the fact that there was no increase in autism rates in Minamata Bay, Japan, where, in the 1950s, a chemical plant was known to have dumped high levels of mercury, causing damage to humans and animals. They didn't have one case of autism in the community.²¹ In the U.K., Andrew Wakefield wasn't faring much better. Put under the microscope, his study began to show some major problems. Wakefield had neglected to acknowledge competing interests in the project, including the fact that parents of autistic children had paid him a large sum of money to conduct his study. Further scrutiny showed many more ethical conflicts with Wakefield's study, including that he had paid for blood samples from children who attended his son's birthday party, which may have skewed his results; that he had run invasive tests on children without approval from the proper ethics board; that he had marketed products to parents of autistic children based on his purported findings; and, perhaps most damning, reports from research assistants that he had falsified data.²²

In March 2004, ten of the thirteen co-authors of Wakefield's article published a retraction of the study in *The Lancet*,²³ however it wasn't until February 2010 that *The Lancet* would go on to publicly retract Wakefield's research. This retraction came on the heels of a report of over 100 pages released by Britain's General Medical Council (GMC), on 28 January 2010, which declared that Wakefield's work on autism and the MMR vaccine was unethical.²⁴ The final blow came for Wakefield in May 2010 when the GMC barred him from practicing medicine in Britain.²⁵

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Pseudoscience had its day in court, and lost. The defeat had little effect, however, on the damage that had been done. Scientists and the autistic community denounced Wakefield left and right, but many parents and media outlets paid no attention.²⁶ Recent studies have linked autism to genetics, but as of yet, no clear consensus over this exists.²⁷ Another extensive study on autism's relation to various environmental factors to date was published in 2010 and showed that there was no link between vaccinations and autism.²⁸

Regardless of the multiple studies that have debunked Wakefield's research and have proven that there is no link between vaccinations and autism, many parents still elect not to vaccinate their children or to delay their children's vaccinations until they are older out of fear their children may develop autism. This poses a problem because failing to properly vaccinate weakens what scientists refer to as 'herd immunity.'

Although there are various uses of the term, basically, herd immunity is that level of immunity to a disease present in a large group of people that protects those who are not immune to the disease from becoming ill and further transmitting the illness to others. As more and more people choose not to have their children vaccinated, there is an increase in other children contracting the disease and passing it on to others.

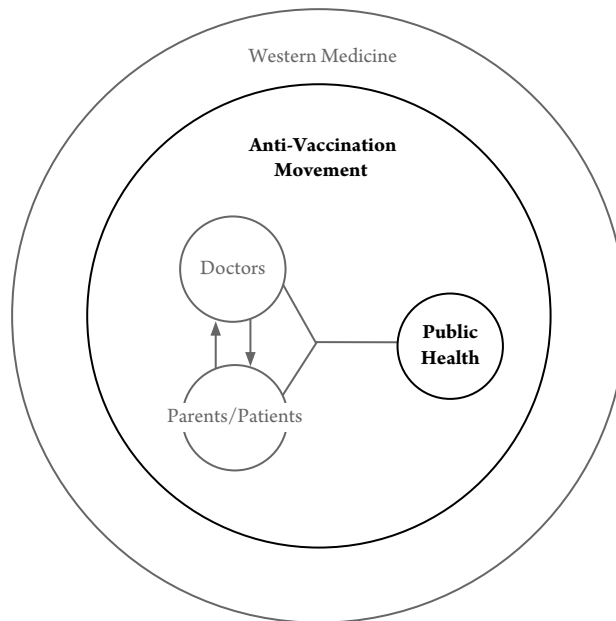
A classic example of the weakening of the herd immunity was the Disneyland Measles outbreak in 2014–2015.²⁹ Between December 2014 and February 2015 close to 150 people in the United States, Mexico, and Canada contracted the disease. Many of these patients had visited the Disneyland theme parks in California. In the Disneyland outbreak, the researchers estimated that the vaccination rate 'might have been as low as 50% and no higher than 86%.³⁰ Because measles is so contagious, between 96 percent and 99 percent of the population must be vaccinated to provide herd immunity.³¹ In addition, some people cannot be vaccinated for measles, such as infants and those with compromised immune systems. The elderly are also susceptible to the disease. Even then, about three percent of the population who are vaccinated may still be vulnerable to contracting the disease. Researchers determined that the disease spread so far and so rapidly because many of the parents visiting the park had elected not to vaccinate their children with the widely available MMR vaccine.³² And lest one thinks that contracting measles is not a big deal, consider that measles can lead to hospitalization and secondary infections, encephalitis (swelling of the brain) and even death. Regardless of the clear and present danger not vaccinating children poses, many parents still refuse to do so.

This trend has motivated many pediatricians to stop accepting patients who refuse or delay vaccinations for their children out of concern for their other patients and the general public's health. In response to this trend, The American Association of Pediatrics released a clinical report in 2016 stating:

The decision to dismiss a family who continues to refuse immunization is not one that should be made lightly, nor should it be made without considering and respecting the reasons for the parents' point of view. Nevertheless, the individual pediatrician may consider dismissal of families who refuse vaccination as an acceptable option.³³

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Figure 3.3 Five Components of Leadership Model applied to the anti-vaccination movement and the public health case study



But is it ethical for doctors to refuse to see a patient and therefore punish the child for a decision made by the child's parents? Enter utilitarianism.

From a utilitarian perspective, doctors refusing to take on patients whose parents refuse or delay vaccinations can be justified ethically as they seek the greatest good for the greatest number of people. As we apply this scenario to the Five Components of Leadership Model (see Figure 3.3), we can see that in this case the leaders are identified as the doctors. The followers are their individual patients and their parents or guardians. The goal is to have a healthy child free of disease. The context is the anti-vaccination movement. And the cultural values and norms are those that are influenced by industrialized nations, which values the benefits of modern medicine.

In this case the doctor (the leader) may choose to deny treatment to patients whose parents (the followers) refuse or delay to vaccinate their children. From a utilitarian standpoint, this action is ethically justifiable as the doctors seek the greatest good (protection from disease for the child) for the greatest number of people (the public). It is a classic utilitarian argument. In this case, the doctors are also considering the health of the child they refuse to see. The doctors' hope is that by refusing to take the child on as a patient it will force the parents to reconsider, thus, protecting the child as well as the public health.

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As we saw earlier, followers must also have the greatest good for the greatest number of people in mind when they pursue the common goal of protecting their child. They must be willing to research the evidence that dispels their notions that vaccinations may harm their child by causing autism. They must also be willing to pursue the greatest good for the greatest number of people and not rely on herd immunity to protect their child, essentially relying on other parents' willingness to vaccinate their children. As we saw in the Disneyland example earlier, between 96 percent and 99 percent of people must choose to vaccinate to keep the herd immunity in place. If too many parents choose not to vaccinate their children for measles, the herd immunity quickly breaks down. Followers (in this case the parents) must also take responsibility to care for the greatest good for the greatest number of people and not take the 'free ride' the herd immunity can bestow upon them or their children.

But why would parents refuse to vaccinate their children if all the research indicates that vaccinations are safe for the vast majority of people? Don't they have the best interest of their children in mind? Of course they do. A healthy child is the common goal for both the parents and the doctor. However, the context in this case is what makes this situation problematic.

Because of the misinformation that is present in the context, parents who are opposed to vaccines are convinced they are doing what is best for their child. This brings us back to the ethical responsibility of doctors to listen to these parents' concerns and seek to provide them with enough information and assurance that their child is not at risk for receiving the vaccine. It is noteworthy that in the same report mentioned above that suggested dismissing patients whose parents refused to vaccinate, the American Association of Pediatrics admonished doctors to listen to their patients' concerns acknowledging they share a common goal. The AAP writes:

It is important to present this safety information in a nonconfrontational dialogue with the parents while listening to and acknowledging their concerns. Misconceptions should be corrected, because both parents and pediatricians are in agreement in wanting the best for the children's health and well-being.³⁴

This brings us back to the heavy responsibility utilitarian ethics places on leaders to act ethically regardless of their personal stake in the matter. It would be very easy for doctors to simply deny treating patients whose parents refuse to vaccinate, but utilitarian ethics forces them to go the extra mile to try to persuade and convince these parents of the importance of vaccination for their child as well as the rest of society.

At least in the industrialized world, modern medicine is valued as a means to help individuals and society to live happier and healthier lives. Some would say that the doctors have an ethical responsibility to take on patients and provide medical care regardless of their parents' choice not to vaccinate. Why should a child be punished for his or her parent's

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decision, regardless of how misinformed that decision may be? That may be; however, this argument is informed more by deontological ethics than utilitarian ethics. Contrarily, another cultural influence on this debate is the distrust of science and personal relativism that is such a part of post-modern culture. The reasons for this distrust may range from economic to religious factors, but regardless of the reasoning behind it, it plays into the cultural values and norms that are affecting the discussion of vaccination. Yes, doctors must take the prevailing cultural values and norms into account when addressing this pressing leadership challenge. However, they must still do what they believe is going to be the best for the greatest number of people given the information at their disposal.