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# Commentary on Sally Jackson's "Arguing Over Evidence in Health Controversies"

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Sally Jackson has presented us with an interesting and provocative essay concerning evidence in health controversies. She uses three examples: the ongoing MMR vaccination debate, the AIDS research debate of the late 1980s and early 1990s, and the debate over sex education curriculum in the United States. Each of these demonstrates an interesting issue regarding the legitimacy of evidence, and, even more so, the accepted and acceptable sources of authority. Who is allowed to participate in health debate? Who will have attention paid to their position? These are some of the questions that arise from Jackson's paper.

The frame through which I will look at these examples is the idea of "voice," reverberating back to Carol Gilligan's sense in her book *In a Different Voice* (1982). That is, a group, social or political, may not be heard for any of a number of reasons. In particular, they may not either know the rules of the dominant group, or refuse to play by them, and as a result are ignored. This can lead to antagonism, aggression, and even war (Reygadas, 2001). It also, in today's Internet-lead world, encourages conspiracy theories stemming from the belief that certain voices are being suppressed for political reasons.

Consider the case of the "anti-vaxxers" who are isolated for two main factors: first, not having scientific support, and secondly, (mostly) being women. Science, after all relies on evidence and experimentation, at least theoretically. So, when a bunch of anti-science batty women come up with stories that they've heard from friends and on the Internet, they are not deemed credulous. "But the most interesting issue surrounding evidence in this controversy is the furor over what to make of firsthand observational reports of vaccine injuries" (p. 4). Firsthand, or observational reports, or, if you will, stories, are not considered useful or legitimate evidence. Consider that when I was young, a very long time ago, mothers would take their children to visit other children who had the measles or the mumps. They wanted us to become infected because they knew or believed this created immunity.

Measles parties were popular in the 1950s and 1960s, before the MMR vaccine program was introduced for measles, mumps and rubella. The practice of measles parties was based on the belief that infected children will build up immunity to the virus because once someone has the measles they cannot catch it again (ABC news).

So this was a group that was essentially voiceless, who strictly, by word of mouth, took MMR immunity into their own hands.

The groups that are considering the anecdotal evidence are the non-science groups, those without authority and, most importantly, without credentials. Like the scarecrow in *The Wizard of Oz*, he lacked a brain until he received a diploma (1939). But in the meantime, mothers (and sometimes fathers) are sharing horror stories about negative vaccination results with, sometimes,

the result of halting vaccinations of their children. In my own contribution to this conference I reference such a story (Freelackers, 2020). Jackson highlights this point and explains what happens is that the anecdotal accounts of parents are dismissed rather than investigated. This silencing easily leads to aggression and scepticism on the part of the voiceless group. As a side, it might be worth noting that financial aspects could be at play here insofar as acknowledging harm from vaccines could lead very quickly to major liability issues.

The marginalization of a group is important to its isolation and silencing. Jackson's second example also concerned a marginalized group, but one not so easily silenced. In this regard, the case of AIDS in the 1980s was different. Yes, the collectivity of homosexual men was a marginalized group, but there were other, important differences. First, they were mostly men, and, perhaps more importantly, many were professional, moneyed, and had scientific credentials. This made them, as Jackson explains, much harder to ignore. In the end their voice became dominant. Stonewall occurred in 1969, and the Gay movement was born. By the time the horror of AIDS arrived, much of the Gay community was organized. The doctors and researchers were confronted by advocates and even community experts. Jackson writes:

This controversy has the nature of expertise as an explicit theme. Activists repeatedly insisted “we are the experts,” explicitly called out “expertism,” and dared to challenge experts within the experts’ own domain. Through sheer argumentative prowess, they showed that they could not be forced into deference. (p. 5)

Rather than bow to the “superior” authority, the Gay community insisted that as stakeholders they must have a voice. Their articulateness gave them a voice, and their organizational expertise allowed them to use it.

A similar situation happened regarding the transgender community. The original group that laid out the rules for access to trans medication and surgery was called *The Harry Benjamin International Gender Dysphoria Association* [HBIGDA], founded in 1979 (<https://www.wpath.org/>). By and large, the directors and members who developed the Standards of Care, i.e., the rules for who had access to what, were medical doctors, psychiatrists, and cisgendered sex researchers. The rules were very stringent, especially as the male hierarchy could only be horrified by the idea that a man would become a woman. It was quite difficult to meet the requirements for hormones and/or surgery. With some exceptions, such as Dr. Benjamin, and a number of others, there was not huge sympathy for this transgender people.

Slowly, over time, more and more trans folk acquired the credentials and expertise to become first members and then directors. In 2007 the name was changed to World Professional Association for Transgender Health [WPATH], and most of those involved, including those writing the Standards of Care [SOC], were members of the trans community. Since then, the SOC have been loosened, making access to medical intervention, both hormonal and surgical, more available. One major factor, and what makes this example germane to Jackson's thesis, is the desire for self-diagnosis and assessment. Interestingly, much of the force for the changes came from female to male transsexuals. The majority of females seeking to transition had sharpened their skills in the lesbian community, and they were accustomed to activism and organization. Besides, they were men.

It is not necessary to go back in history to find examples of the roles of accepting and rejecting evidence. Today, in the midst of the Covid-19 crisis there are a multitude of debates regarding both treatments and precautions and their legitimacy. The tensions are between

science, politics, and wishful thinking. The scientists in the US and Canada are universally calling for caution, social distancing, and careful investigation of vaccines and medical aid. Others, most notably U.S. President Trump, cast doubt on the scientists and suggest ideas that range from the incautious to the ludicrous. Which raises the question: at what point should a suggestion be discarded as incredible and condemned and ignored?

Trump's recommending that imbibing bleach or disinfectant (aka embalming), was universally condemned. Even the makers of Lysol stepped in to say that the product should never be taken orally or even inhaled deeply. The suggestion itself would be laughable were it not made by the President of the United States. This raised a further question of when a voice ought to be stifled, when an outlier ought to be ignored. Cycling back to the anti-vaxxers, many believe that their positions are highly dangerous and giving space and time to their arguments can only lead to a resurgence of these dread childhood diseases. But I guess we have to argue about this.

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