

Public Ethics Radio

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Transcript of Episode 9, Michael Selgelid on Infectious Diseases

Released August 17, 2009

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MATT PETERSON: You're listening to Public Ethics Radio. I'm Matt Peterson. Let's get right to it.

You may remember the case of Andrew Speaker. This is a guy who flew off to his wedding in Europe in 2007 after being advised by the Centers for Disease Control that he had a drug-resistant form of tuberculosis. The CDC caused an uproar when it announced that it was trying to track down other passengers on the flights he had taken, since they may have been infected. And Speaker himself was the subject of fierce criticism for allegedly recklessly endangering other people.

What's interesting about this case, for our purposes, is that the CDC didn't choose to forcibly prevent Speaker from flying off to the wedding or from generally being in contact with other people. It essentially relied on the honor system, assuming that he wouldn't do something like take several flights while he was infected. In fact, the CDC did finally forcibly isolate Speaker—the first use of quarantine laws in 40 years—but this was only after he came back from the wedding and turned himself over to doctors.

Another aspect of this is that Speaker turned out not to be as sick as he was once thought to be. The CDC came to believe, while Speaker was on his honeymoon in Rome, that he was infected with the rare and essentially incurable form of TB known as XDR-TB, or extensively drug-resistant tuberculosis. In fact, he only had MDR-TB, or multi-drug-resistant TB, which is still dangerous, but treatable. So he wasn't actually as big of a threat as he was made out to be.

Cases like this one present a number of serious challenges for public health ethics. What should our responses to the unique threats posed by infectious diseases be? How much control should individuals have over their own fates when they're found to have such diseases? How do we weigh public and private interests here? And how do we do so in the face of uncertainty about diagnoses and the effectiveness of different medical interventions? These are of course the same questions we're grappling with in regard to the so-called swine and bird flu.

To help us sort through all this, we're pleased to bring you a discussion with Michael Selgelid. Dr. Selgelid was just named as the head of a brand new World Health Organization Center for Bioethics at the Australian National University, and he's written widely on tuberculosis and infectious disease ethics.

MATT PETERSON: Public Ethics Radio is podcast featuring conversations between our host, Christian Barry, and scholars and thinkers who engage with ethical issues that arise in public life. The show is a production of Yale University and the Centre for Applied Philosophy and Public Ethics, an Australian Research Council Special Research Centre, in association with the Carnegie Ethics Studio at the Carnegie Council for Ethics in International Affairs. You can find us on the web at www.publicethicsradio.org.

CHRISTIAN BARRY: Today we're joined by Michael Selgelid, who's a Senior Fellow at the Center for Applied Philosophy and Public Ethics at the Australian National University and is Deputy Director of the National Center for Biosecurity, also at the Australian National University. Michael, thank you for joining us.

MICHAEL SELGELID: Thanks for having me, Christian.

CHRISTIAN BARRY: Michael, about five years ago, a well-known philosopher and bioethicist, Baroness Onora O'Neil, made the following claim about the field of health ethics. She said that "most work in medical ethics across the last twenty-five years has centered on the ethics of clinical medicine," and that "even work on health and justice has, in the main, been concerned with the just distribution of clinical care for initial patients." And that "by contrast, the ethics of public health has been widely neglected."

Is that still the case, and what is distinctive about public health as an ethical issue?

MICHAEL SELGELID: I actually said something very similar at a paper I presented at a conference in 2002 about infectious disease, and I said that infectious diseases are among the most important problems, you know ethical issues that arise in medicine and health care, but they've only received a tiny amount of attention in bioethics.

So that was 2002 when I first presented that argument. Since then there's been a lot more attention to ethics in infectious disease, which has been part of you know an explosive growth of public health ethics as a subdiscipline of bioethics. So on the one hand things have really changed. On the other hand, the more things change, the more they stay the same. You know, infectious disease in particular, with SARS, with you know the events of Sept. 11, and the scare over avian influenza, and now H1N1, there have been a lot of infectious disease issues that have been receiving quite substantial attention by bioethicists.

On the other hand, there's still grossly neglected topics like TB. AIDS is another exception to the neglect of bioethics with regard to infectious diseases. AIDS is one that has received very substantial attention at least in certain contexts since the emergence of AIDS was first recognized in the early 1980s. So AIDS has received a whole bunch of attention; TB has received hardly any, but TB kills almost as many as AIDS each year. AIDS kills 2.1 million, TB kills 1.7 million.

And in a way the TB deaths are more tragic because economically speaking they're much more easily preventable. AIDS medications can cost you know even in best-case scenarios about 100 US dollars a year, and you need those every year. With TB it's just a \$10 or \$20 course of medicine for a cure, because the drugs have been around for a decade, they're off-patent and so on.

And also another thing, another reason to think that TB is more worrisome than AIDS, at least in some ways, is that it's contractible via casual contact, you know much more contagious, and more of a threat to public health in some ways.

CHRISTIAN BARRY: Well one of the preoccupations of medical ethics is very much been on protecting the autonomy of patients and the rights of patients from coercive interventions. Clearly some of the things that have come up in recent public health emergencies have been discussions of what types of coercive measures, what types of measures of control ought to be taken in the face of these risks. So issues of autonomy and coercion are coming up, but they seem to be coming up in a different way. What do you think are the most important issues to think about when we're trying to develop a plausible public health ethics for dealing with public health emergencies like the so-called swine flu.

MICHAEL SELGELID: Yeah, so the approach of bioethics traditionally is as you say focused on you know relationships between patients and healthcare providers. You know, pluralistic in the values that it appealed to, but real heavy weight placed on autonomy, and in many cases bioethicists would talk and write as though autonomy reigns supreme.

The approach of public health, like public health policy, for example, is quite utilitarian in orientation historically. So you know lots of public health measures are aiming at promoting utility in the way of public health. What public health ethics should do, and hopefully is doing, is to find a way to bridge the gap between the two values, the value of autonomy emphasized by bioethics traditionally and the value of utility emphasized by bioethics traditionally.

So you know one of the million-dollar questions in public health ethics is how do we strike a balance between the goal to protect the rights and liberties and autonomy of individuals on the one hand and promote the greater good of public health, i.e. utility, on the other. You know lots of public health measures in the context of an infectious disease are ones that can infringe on widely acknowledged basic human rights and liberties.

So what are basic public health measures? They're things like surveillance, reporting the infectious status of individuals to authorities, maybe notifying third parties, you know contacts of the patient that are in danger of being infected by the patient, that you know the patient is infected with a contagious disease, and maybe mandatory treatment, vaccination, and at the extreme end of the spectrum, social distancing measures such as isolation and quarantine.

So, depending on the disease, any one of things or maybe all of them might be called for, but each of things things conflict with basic human rights and liberties. So we want to find a way to strike a balance between the two.

CHRISTIAN BARRY: One thing, Michael, that is, seems to be more difficult in thinking about public health interventions than in the standard clinical patient–doctor situation is that although there are all kinds of uncertainties when it comes to an individual patient about whether a treatment will be effective or not there is something a little bit more identifiable about the risks involved.

So if you're thinking of course about promoting the—respecting the patients' wishes but also promoting their well-being, that could be a similar conflict that could come up in traditional bioethics. But at least there, we're usually in some—we have some sense of the magnitude of the risks suffered by the patient. A lot of the concerns that people have about things like the recent outbreak of swine flu is that it's very difficult even to think about this balancing of values, since the scale of the threat itself is largely unknown.

MICHAEL SELGELID: Yeah, you've put your finger on one of the central questions that myself and others working on these issues are grappling with. You know there are some frameworks about the conditions under which a coercive measure aimed at public health measure might be justified—

CHRISTIAN BARRY: Like quarantine or—

MICHAEL SELGELID: Yeah like quarantine, for example, I mean, let's take that as our focus. And so there's a question of evidence there, i.e., to what extent do we have good evidence that this intervention would work in this context. And quarantine, and the effectiveness of quarantine is something that notoriously we don't have great evidence with regard to the effectiveness of this kind of measure. One reason is that a measure like that is really tough to study, you know to do what you would often do in clinical medicine, and that is a controlled study. But it's really hard to do a controlled study with something like quarantine, so it's hard to have full confidence that it's going to be effective in any given context.

One idea that's been put forward is that the more basic the liberty we're infringing upon, the more evidence we need that the intervention in question would actually be effective. So one might think that, OK, quarantine is interfering with one of the most basic liberties, therefore for quarantine we need the highest standard of evidence. And that for reasons I just mentioned would be really hard to get.

But another reason, aside from that, that it would often be hard to have the highest level of evidence that would be effective in the context in question is that often with a disease outbreak we're talking about a new disease, a new pathogen, and we don't know that much about how transmissible it is, or how it transmits, or how deadly it is, and you know what is the outcome going to be for different patients. And therefore it's hard to predict how effective something like quarantine is going to be for a disease that's new that we don't know that much about yet. And if that's the case, then we're talking about a case where we have both kinds of uncertainty, there, i.e., the quarantine itself, difficult to study, and it's especially difficult to have evidence that it's going to work in the face of a new disease, then it would be imprudent to rely on that principle I just mentioned, the idea that we need the highest standard of evidence if we're talking about the most basic—

CHRISTIAN BARRY: Right.

MICHAEL SELGELID: —liberty infringement. So I would say we need another principle to go with that. And that other principle would be to say that the higher the utility at stake, then the less evidence we need, i.e., it would be imprudent to—

CHRISTIAN BARRY: So it would be more like regulation than like a criminal trial, in the sense of the kind of standard of proof that you would need to implement such a policy.

MICHAEL SELGELID: Yeah. Yeah, the point being that if there's a decent reason to believe that you know quarantine might work, and there's reason to believe that if we don't try it, you know millions of people are gonna die based on the anecdotal evidence that we have about some new, terrible nasty disease that's wiping out populations, or that seems to be incredibly transmissible and dangerous, then it would be imprudent maybe not to try something like quarantine.

CHRISTIAN BARRY: One thing that obviously, that the language of rights infringement brings up is the fact that an infringed right can in some sense be compensated for. What role do you think possible compensation could play in reducing the at least the initial tension between promoting social welfare or utility as you put it and respecting individual rights?

MICHAEL SELGELID: Yeah, so I think compensation is, could be quite essential or very important to public health policy when we're talking about coercive public health measures. So it seems like there's a clear fairness rationale for having a compensation program. Without a compensation program, the burdens required for the benefit of society as a whole wouldn't be shared fairly. Seems like you know there's a reciprocity principle that would apply here. They do something for society, so society should give back to them. I think reciprocity is an important principle that's getting quite a bit of attention in public health ethics, and it's surprising that it hasn't gotten a lot of attention in the ethics literature more generally because it seems you know quite plausible and promising in all sorts of ways.

Another thing about having a compensation system in place is that there could be utilitarian gains, i.e., if you have a system that's fairer because you have a compensation system in place if you have a system that's not going to be as costly for people to abide by—

CHRISTIAN BARRY: Then people would be more likely to comply.

MICHAEL SELGELID: Exactly.

CHRISTIAN BARRY: We're going to take a short break, and then we'll be back with more on public health ethics with Michael Selgelid.

MATT PETERSON: You're listening to Public Ethics Radio.

CHRISTIAN BARRY: Perhaps I could ask you about another potential conflict about a duty to treat and having an adequate long-term view of public health. One issue that I know you've written about is tuberculosis. And one of the, a very significant risk with tuberculosis is the emergence of multi-drug resistant forms of tuberculosis. And one way that the stains can arise is when people are given treatment, but don't take a full course of treatment.

Now, I know that there have been some debates in Médecins Sans Frontières about how to deal with this in their actual operations, since some of the oldest Hippocratic edicts are focused on the humanitarian imperative to treat, to actually deal with those in need and not to be thinking of what the epidemiological effects of treating in this one case are. But of course when we're talking about infectious disease, and we're talking about populations where we may not be confident their ability or their willingness to take full courses of treatment, the issue arises what is the responsible thing for a practitioner to do: to deny treatment, or to not deny treatment.

I remember a debate where Rony Brauman, who is the former head of MSF, argued that he refused to withhold treatment because this would be in the name of glorious epidemiological statistics as opposed to real flesh and blood human beings. Whether you agree with that or not, you can at least see the pull of that sort of consideration.

MICHAEL SELGELID: Yeah, right, so let me answer this question in the context of TB in particular, and let me just start by pointing out that TB historically is one of humankind's worst enemies. You know, sometimes said to have killed more people than any other infectious disease. I guess it's a rival with smallpox for being the greatest infectious disease killer in history. And it's, yeah, transmissible by casual contact, so coughing, sneezing, and talking. And now we have these really nasty strains of drug-resistant TB that are so drug-resistant that they're virtually untreatable. So it's as though we have returned to the pre-antibiotic era in the context of TB. Maybe we should call it the post-antibiotic era.

And so that's a real worry. It's a real problem for public health. And what causes drug resistance? One of the things that causes drug resistance is, as you say, people that start a course of medication and then they don't finish it. One reason TB patients aren't finishing their treatment, especially in rich countries—you know, think about the New York epidemic in the 80s and 90s—the reason why lots of people weren't finishing their treatment there and then, and the reason why we had such a bad multi-drug resistant TB epidemic then was because, you know, probably most of the people with TB in New York were like alcoholics and drug addicts, and you know homeless people, and people for whom their lives lacked order and medication-taking wasn't a big priority.

In poor countries, where most TB is, one of the reasons why people often aren't completing their treatments are that they're often just too poor to afford the medications for which they may need to pay out of pocket, or they may have a hard time getting to the clinic, you know getting time off work to afford travel and so on. And in any case, the kind of case that you described arises, and that is you know maybe there's a patient who's had a history of not turning up for their treatment, and that means if we keep giving them treatment that might drive drug resistance if they're going to keep not completing it.

And so what do we do? On the one hand, we think people have a right to health care. On the other hand, there's a public health rationale for treating patients, because if we don't treat them, then they remain infectious and they may pose risks to others.

It's not clear what should be done. I would say that in the difficult cases, we need to be more vigilant and try to do more to get the patient to finish their treatment, because it could be imprudent you know to let them remain infectious in a community untreated, as well as it may violate their right to treatment. So that's what I would say about these hard cases. In the hard cases, we should just try harder. We should do more to get them to finish their courses of medication.

CHRISTIAN BARRY: So again, lowering the cost—lowering the cost for them of doing so is an important part of the compact. Often when these things are presented, they're presented as a dilemma.

MICHAEL SELGELID: Yeah

CHRISTIAN BARRY: Either to treat or not to treat, as opposed to treat or threaten the withholding of treatment, but make it easier for someone to comply so that they can continue being treated.

MICHAEL SELGELID: Yeah, and a colleague, Lee Reichman, who you know I've been involved with as part of a WHO task force on ethics and TB policy-making, says maybe what we need to do in cases like is, you know, pay them. Pay people to complete their medicines. And provide you know, not just compensation but a financial incentive.

CHRISTIAN BARRY: Perhaps you could mention what, with respect to recent public health emergencies, and you can talk perhaps a bit more about TB, because I know it's something you're interested in, but also about the recent outbreaks of SARS and swine flu, although SARS is not so recent any more.

MICHAEL SELGELID: Yeah. So one important thing revealed by both of these incidents is the importance of communication to the public about the nature of the disease, and the measures that are being employed to fight it and, and you know the measures that individuals should be taking to prevent infection and so on. One thing that one might think about SARS is that it was completely overblown. You know it killed less than 1,000 people, less than is killed by seasonal, regular influenza every year. And all this fuss was made out of it, and it cost tens of billions of dollars because of you know travel that stopped because of the fear of SARS, and you know, things of that nature. And then all this quarantine and so on was imposed and some of this quarantine led to riots, even in China.

And one might think that gosh, for 700 deaths, or whatever it was, deaths, you know, all of that fuss was unnecessary and the whole thing was overblown. It wasn't even as deadly as lots of infectious diseases that are killing people every year. On the other hand, we don't know that it wasn't lots of those measure that led to the end of SARS. We normally say that smallpox is the

only infectious disease in history that was ever eradicated. But presumably the same thing can be said for SARS. SARS went away and there's no more human cases of SARS.

And maybe that was a result of all of these things that were done to fight SARS. So maybe it was a great success story. It's kind of hard to evaluate in retrospect because we don't know what the counterfactual situation would have been. This relates to what I was saying before about the difficulty of assessing the effectiveness of things like quarantine. We don't know what would have happened if we didn't do the thing in question.

MATT PETERSON: This is Public Ethics Radio.

CHRISTIAN BARRY: As we know, governments like anything, typically, that gives them more power. And in a way public health risks seem ideally suited, like the risk of terrorism, because it's so hard to evaluate these sorts of claims. Do you think that there—are there measures in terms of setting up commissions that evaluate responses and the reasonableness of responses that could create any sort of disincentive toward the potential exaggeration of threat?

MICHAEL SELGELID: Well, you point to an important issue. I mean, what some people have been arguing is that lots of quarantine policies and so on in lots of countries have been completely obsolete. You know, they're from another world, and we need new policies to deal with the contemporary globalized world. And so we need to do things like give public health authorities police powers. So when there's a public health emergency, then the public health authorities should have police powers, and should be able to order doctors to do certain things and order individuals to do certain things, and you know make calls about coercive isolation and quarantine and so on.

And so there's a real potential for abuse of power if we're not careful about who we give this kind of authority too. And if we don't have a good principled framework for the way that such authority can be exercised. You know there's an emerging debate about the securitization of infectious disease. And that debate is asking what is the danger of framing infectious disease threats as security threats?

The worry is that when we see something as a security threat or we say something is a security threat we're elevating it to this other kind of realm where normal decision-making procedures aren't required, where normal response mechanisms aren't required. Where we have an emergency response measure, you know we're talking about situations akin to martial law. And if we respond to infectious diseases in that way, the worry goes, then maybe we're not going to have normal human rights protections or the human rights protections that we should have. So there's a real danger for framing these things as security threats.

CHRISTIAN BARRY: We've already seen this to some extent with some of the treatment of Mexican passport holders in South American amongst other places, where they're refused entry onto planes and this sort of thing. They were treated as threats.

MICHAEL SELGELID: Yeah. There's a worry about this in the context of AIDS. So maybe there's clearer cases where there really is a security threat posed by infectious disease. And my

colleague Christian Enemark, he would say for fast-moving diseases like influenza, that's you know plausibly the most compelling case where we can really be talking about a security threat.

CHRISTIAN BARRY: When you talk about it being a security threat, what exactly is meant by that, just the idea that it would cause such great—allow an amount of illness that the—that the defenses of a country would be comprised. Or... ?

MICHAEL SELGELID: I guess the idea is that you know stability and maybe the fabric of society, you know, speaking metaphorically, can be challenged. And one of the reasons that can be challenged in flu is that maybe it just moves so fast, maybe one thing it can do is overwhelm hospitals and health-care provision facilities. So there's much more people that need the healthcare than can provide it, and maybe that can—

CHRISTIAN BARRY: Can lead to conflict and—

MICHAEL SELGELID: Yeah, panic and chaos. And you know people freaking out because they want medicine and healthcare and so on. And maybe the imposition of quarantine, which is more likely to be called for in a fast-moving disease than a slow-moving disease. That kind of thing. Maybe as revealed by SARS in China can lead to social unrest. The imposition of quarantine seemed to be the explanation behind some riots that occurred in China.

So that's the case for thinking maybe fast-moving diseases can be treated as security threats. What about slow-moving diseases? HIV-AIDS is quite slow moving. But in Sub-Saharan Africa it's often being portrayed as a security threat. Some might think that's a good thing. Maybe securitization, it's a double-edged sword. The CIA did a report that's called the *Global Infectious Disease Threat and Its Implications for the United States*. And the UN Security Council had a special session and report on HIV as a security threat. It's the first time an infectious disease was ever—

CHRISTIAN BARRY: And this could be positive, why, because it would drive up funding levels for treatment?

MICHAEL SELGELID: Exactly.

CHRISTIAN BARRY: OK.

MICHAEL SELGELID: So I might think, oh, that's a good thing. Normally rich people in rich countries don't care that much about health in poor countries. But if the HIV-AIDS situation in poor countries is a security threat, well then maybe we're all going to care more about it, and do more about it. You know, so I always thought this was a good thing, that it was being recognized and framed in this way. And then I started talking to my colleague Christian Enemark. Because when we frame things as a security threat, then we're less likely to have human rights protections and so on.

But the interesting thing about HIV and AIDS is that those have been advocating the idea that it's a security threat, haven't at all... for the most part—for the most part, those that are

portraying it as a security threat aren't saying we need restrictive measures to deal with it. They're saying it's a security threat, and therefore we need to improve access to care, and improve the situation in poor countries and so on. And so I'm not sure that calling something a security threat and therefore securitizing it, necessarily goes hand in hand with advocating or calling for rights violations.

There's a principle in public health ethics that says we should use the least restrictive alternative to achieve the public health goal in question. Well, even if HIV/AIDS in southern Africa is a security threat, that doesn't mean we need a security response if there's a least restrictive measures, i.e., improving healthcare and living conditions, that would achieve the same goal.

CHRISTIAN BARRY: And, if you wanted to think of that over time it could become interesting in that failure to take measures to prevent something at relatively low cost may then restrict the self-defense measures you can take later on. So if it becomes a security risk, a security threat because we're not providing enough access to medicines or something like that, then that, that then limits the kind of self-defense actions we can take later on. Or at least that's arguable.

MICHAEL SELGELID: You mean that we could justifiably—

CHRISTIAN BARRY: Yeah, justifiably take.

MICHAEL SELGELID: Yeah, well, ironically I think, and this is an idea that hasn't really been talked about very much, but maybe the least restrictive measure is redistributive taxation. Infectious diseases primarily affect the poor. And we say, OK, there's an infectious disease now, we need to use the least restrictive measure to deal with it. And that means we shouldn't use mandatory quarantine if voluntary quarantine of this person, this poor person, that is sick will be just as effective. But maybe an even least restrictive measure is to avoid the situation where we have so many infected with the disease to begin with, i.e, we would less often be faced with the situation where we need to choose between protecting utility on the one hand and protecting and individual's liberty on the other if there was less infectious disease to begin with. And there would be less infectious disease to begin with if the living situation of poor people was better to begin with, and if poor people had better access to medicine to begin with. So, to achieve the public health goal in question, maybe the least restrictive measure isn't voluntary quarantine of those affected, but is to take some money away from rich people and use it to improve health of poor people, you know in this country and in other countries.

CHRISTIAN BARRY: Michael Selgelid, thanks for joining us on Public Ethics Radio.

MICHAEL SELGELID: It was my pleasure, thank you Christian.

MATT PETERSON: Thanks for listening to Public Ethics Radio. Barbara Clare and I produced the show. Christian Barry is our host. Thanks to Nick Evans for web help. And thank you to the Australian National University's College of Arts and Social Sciences for financial support, and thanks as well to the MacMillan Center at Yale and the Center for Applied Philosophy and Public Ethics at the ANU.

We'll be back soon with another conversation about public ethics. In the meantime, you can find out more about us and our guests on the web at www.publicethicsradio.org.