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# INTERVIEW WITH STEVEN EPSTEIN

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Steven Epstein is a professor of sociology and the John C. Shaffer professor in the humanities at Northwestern University.

**WENDEL-HUMMELL:** We're going to start with an easy question here. Grad students are interested in how professionals and people who have really made it far in the field have gotten interested in the topics they're working on. So how did you initially get interested in AIDS activism, which turned you on to these other medical, social movements?

**EPSTEIN:** Well, when I graduated from college I moved to San Francisco, partly with the idea of living somewhere I hadn't lived before, but definitely part of the idea was to experience the kind of gay community that, particularly at that time, San Francisco represented in contrast to other parts of the country. I mean now I think one can find gay communities in lots of places. It was somewhat harder then. So, I arrived in 1983, which was an interesting time, but also a very complicated time because the AIDS epidemic had begun in 1981. And, by 1983, although in most parts of the country it was not entirely visible, in San Francisco it absolutely was. And there was a lot of worry, a lot of discussion. And right away I began to see people who looked very visibly sick, who had the lesions from Kaposi's sarcoma visible on their faces, on their arms, and so on. So I was very conscious of the

kind of impact the AIDS epidemic was having on the place I was living.

After spending a couple of years hanging out in San Francisco, I started graduate school just across the bay in Berkeley; and fairly early on, I came to the realization that most likely I would write a dissertation that took up the topic of AIDS. I felt that what sociology can do best is tackle pressing social issues, and I wanted to do something that had some relevance for the community that I was a part of at the time when it was gripped by something that was really quite overwhelming. So, I concluded that sociology really presented me with the opportunity to pursue a topic that mattered, and that was timely and urgent. At the same time, I had become interested in a set of theoretical questions inspired by the work of Foucault and Bourdieu that had to do with the politics of knowledge in different ways. And more specifically, I began to think about the politics of expertise. I then began to put this together with my observations. We're now looking forward a few years—it was 1987, 1988, 1989—as I witnessed in San Francisco the emergence of a kind of activism that impressed me tremendously, and that seemed to be centered around not just a challenge to conventional forms of expertise but also the assertion of a kind of lay expertise by the activists themselves, a sort of hybrid form of expertise. They were drawing on their own experiences, for example, as people living with HIV, but also they were appropriating the knowledge claims of the credentialed experts, the official experts. And so I would go to the activist events where people would give lectures about the clinical trial process explaining what a phase 1, 2, and 3 trial was, and then they'd begin their critique of AIDS research and everything that was wrong with it. Not just from an ethical standpoint, and not just politically, but also scientifically. And I found this kind of fascinating, that people could immerse themselves in these rarified domains of expertise.

And so, taking the substantive interest in AIDS together with this intellectual and theoretical interest in questions of knowledge politics and the politics of expertise, I began to fashion a dissertation that looked at credibility struggles in the domain of AIDS and AIDS research. I asked: Who managed to speak credibly about different aspects of AIDS at different times, from the beginning of the epidemic forward? Who was able to speak credibly about just what

this new disease was, and what caused it? Who was able to speak credibly about how we should be treating it, and how research in virology and immunology should proceed? I confess that in part this research angle allowed me to tackle an important topic without necessarily focusing on the most grim aspects of it. Even though I wanted to write about AIDS, I was relieved to be able to write about it in a way that was at least partly happy and inspiring. I mean the book still deals with a lot of difficult periods when the activism wasn't going well, when drugs weren't available. The story basically unfolds before the arrival of the combination drug therapies that are actually now keeping many people alive for long periods of time. So it was still not a happy story, but it was perhaps less grim than the stories that others were telling about the epidemic at the time.

**WENDEL-HUMMELL:** I think that connects well to your question.

**COULTER:** It does. So my question for you is, what do you think sociology can do to inform public policy? And what ought sociologists be doing to influence public policy, social policy, and peoples' perceptions of social issues?

**EPSTEIN:** I think it's a really important question. But, I think it's a complicated question, and I would very much reject the idea that there's any single answer or specific model that can be put forward that everyone ought to adopt for how to connect their work to policy, or to make it serve practical ends. When I was a graduate student at Berkeley, Michael Burawoy was one of my instructors and was on my dissertation committee. And when he became president of ASA [American Sociological Association] a few years back, he put forward a conception of public sociology that I think is quite useful and admirable. I do support the vision that he describes, one in which public sociology doesn't displace a sort of professional sociology, but where it intersects with it and can develop along with it. I think that's an important aspect of what we do, but I think there are different models of how one goes about that. Some scholars, for example, have been engaged in various forms of community-based participatory research. And that's something that strikes me as extremely interesting, but I've never

done it myself. But you can imagine various sorts of projects where the goals of community members are incorporated from the very beginning, from the get-go, and where the whole research process involves a lot of communication between sociologists and communities that are being studied.

My own work has been guided by a hope and a presumption that what I'm saying has a policy relevance that makes it politically useful, but not always in the most direct or immediate way. That is, I think that some scholarship produces, let's say, concrete pieces of data that are immediately available to be grabbed by policymakers and social movement organizations and used for their purposes. And in those cases, the research is enormously useful for those actors, but I do think that sometimes policymakers and social movements are too quick to want those kind of 'deployable facts.' You know, the sort of tidbits that academics can produce that activists can then paste into their press releases, or position statements, or what have you. And I think that what I've done in a lot of my work is take up relatively complicated questions where the answers are not so straightforward, and where I'm dealing with a lot of ironies, paradoxes, and unintended consequences, and where the bottom line, take home message becomes a little more difficult to articulate in sound bite form. And so I think that my work has tended not to generate those kinds of 'deployable facts.' But what I hope it does do is present a set of questions that people situated in political spaces of different kinds would then be able to take up and reflect on in their own practice.

So, I'm taking up what people do, and in effect giving it back to them with a different lens on that activity. So if you're an activist organization engaging in some way with science or technology, then I think the arguments I make about how AIDS activists became caught up in certain kinds of tensions around the politics of expertise—how it led to certain divides within the movement, for example—these are extractable lessons of a different sort that can inform activism through reflection on how certain groups have tried to accomplish certain things, what barriers they've run up against, where they've succeeded and where they've failed.

In the case of my more recent book, *Inclusion*, I look at how a particular case of addressing inequalities in the domain of health research may promote a more inclusive medical research and a more

inclusive society, but at the same time may reinforce strictly biological conceptions of difference in ways that make it harder to address health disparities that have social causes or where the social and biological causes are tightly intertwined. So, see it took me more than a second to say that, right? It's not a quick sound bite but it's a really important policy lesson, I believe. And it's one that I've tried to put forward when I've given talks about the book to different audiences, including health policymakers, people from the NIH [National Institutes of Health], and clinical researchers who carry out clinical trials and are interested in the question of diversity. And so, I think that pointing out complexity and pointing out the unintended consequences of well-intentioned reforms, which is very much how I see the story of *Inclusion*, is potentially a tremendously useful practice. Does that answer your question?

**COULTER:** Yes, definitely.

**WENDEL-HUMMELL:** I was wondering about your thoughts on a recent news event. In the news last night it came to light that U.S. medical researchers had injected Guatemalans with syphilis in the 1940s. The United States officially apologized to Guatemala for these experiments. What I found interesting as a medical sociologist is that this research was, quote, 'discovered' by medical historians. She found the records, publicized the research. In general, what are your thoughts on the news story? Whether it's the ethics of medical research, the work of medical historians, or this notion of 'discovering' unethical research?

**EPSTEIN:** Well, there are really interesting things to be said about all of that I think. I know Susan; I think she's a really good medical historian. I think it's really a credit to her that she brought to public light something that had gotten buried. And as you say, 'discovery' is a funny word to use here because this incident can't have been completely, not known about, right? So we're really talking more about something that I mentioned in my talk yesterday, the concept of agnotology, which is the study of 'not knowing.' How is it that certain things that ought to be known about get hidden from view? And then what kind of work is required to bring them to view? I think academics can play a

certain role in trying to correct those invisibilities, and discuss topics that have somehow slipped out of sight even though they seem overwhelmingly important, in this case quite momentous.

The recent news about the research in Guatemala is also a story about serendipity on some level. My understanding is that Susan was doing some loosely related research, focused more on her previous work on the Tuskegee Syphilis Study, when she discovered something about a scientist, John Cutler, who became involved subsequently in the Tuskegee study. And it just goes to show how a good archivist can be primed to serendipitously come across something that they're not even looking for and how that can be tremendously important.

Incidentally, I was very interested myself to notice this double role that Cutler played in the Guatemala story and in the Tuskegee story because in my medical sociology class I show a documentary film from 1993 called "Deadly Deception" that traces the history of the Tuskegee Syphilis Study, and by that point most of the investigators, the ones who had started the study, were no longer alive and couldn't be interviewed, but Cutler was. And he speaks in that documentary, so I have a face to connect to the name. And what's remarkable is how steadfastly in that documentary he defends the logic of the study and argues that of course it would have violated the intellectual and scientific logic of the study to have treated the men with antibiotics, or to have informed them that what they were a part of was, in fact, a study, because they didn't know, they thought they were being treated.

Cutler's assertions in the film are really quite startling, but they call to mind the tremendous sea change that has taken place in medical ethics over the course of the 20th century. The Guatemalan case is horrific, and I was really appalled to read about it. I did think that by now we had learned the worst about the history of medical experimentation in the 20th century in the United States. We've known for a while about Tuskegee. But you know, 'known' is a funny word. Tuskegee was never a secret. Findings from the study were published in medical journals beginning in the 1920s and all the way forward. But when I say 'known' I mean that this study became an element of public discourse at a time when all of the sudden what had seemed acceptable now became viewed as completely unacceptable. And we also knew about the other cases

that were disclosed in the 1960s, of what seemed like wildly unethical research involving prisoners, involving children with disabilities, involving hospital patients, and so on. And then in the 1990s we learned about the radiation experiments, the Cold War science that involved things like injecting people with plutonium. So, I really thought, okay, we've learned what there is to learn about the history of these abuses. But, clearly not. So now one has to confront the question: What else? What else is still out there waiting to be 'discovered'?

It's also a remarkable thing to recognize that this study in Guatemala, in which prisoners were given a sexually transmitted infection in order to test antibiotics—that is, they were made sick—was going on at roughly the same time as the revelations about the Nazi doctors and the beginning of the Nuremberg trials to condemn them. So, the means by which medical researchers from the United States were able to separate in their minds what they were doing and what was being condemned at Nuremberg are very hard to make sense of. And I think we've only begun to piece together the particularities of the therapeutic mindsets at particular historic moments that have enabled certain conceptions of ethics to prevail.

I don't think it's tremendously helpful to say that these things happen because these individual scientists were evil people. Maybe in the case of some of the Nazis we would use that language appropriately. I don't know if Cutler was an evil person. I mean, I think he did evil things from our vantage point, but the important sociological question is: How did a professional community construct a sense of its ethics and its research obligations in such a way that these experiments fell on one side of the line? And, how is this linked to a legal and regulatory apparatus that also condoned it? There are academics who have done interesting work on this. Sydney Halpern, for example, has written about what she calls the indigenous moralities used by groups of U.S. researchers at different points in the 20th century. You know, it's not like previously there were no ethics, and then all of a sudden with the Belmont Report in the 1960s we have a new framework governing the ethics of biomedical investigation. No, there were ethics before they were just not as firmly articulated. The question is: What precisely were those ethics? And, where were the lines drawn, what was considered acceptable and what was not? Obviously, to the extent that the lines

are now drawn differently, it owes a tremendous amount to social change and pressure of various kinds. This is in part a story of the 1960s, a critique of the rise of expertise, a distrust of medical paternalism, a suspicion of the notion that doctors know best and one can simply put oneself in their hands. And of course, it also reflects a changing political environment in relation to questions of social inequality. In these earlier phases of research it seemed that no one paid particular attention to the significance of the fact that, say, in the Tuskegee study every research subject seemed to be black and poor. And no one said, 'Hey, these Guatemalans, what is their capacity to protect their interests?' So we now have a more precise recognition of the different capacities of social actors to give what we now call informed consent, and that reflects broad social changes, including the civil rights movement.

**WENDEL-HUMMELL:** Okay, methods. So, in your recent book *Inclusion: The Politics of Difference in Medical Research*, you have a sort of very intensive research project, which combines several different kinds of qualitative techniques, including content analysis, attending conferences, and interviewing several professionals and advocates. What kind of general advice would you give for collecting, managing, and analyzing a wealth of data like this?

**EPSTEIN:** Well, it's a lot of work. And I think for me the heart of the project was the data collection and analysis, because what I was trying to do was trace certain developments by juxtaposing what was happening in distinct social worlds; in the world of activism, in the world of pharmacological research, in the world of federal policymaking and regulation, and so on. And the only way to really do that was delve deeply into documentary records from these different corners of social life and to juxtapose them. And then to really explore through interviews what meanings these developments had for the participants, for the people who were trying to bring about change or who were concerned about these changes or rejected these changes. So, I should say that the interviews for me were partly a fact-gathering opportunity, an opportunity to find out more precisely what went on, but partly an opportunity to engage smart people in reflection about their own

practice and about the meanings of activities they've been involved in.

As a practical matter I used a system of keywords to code the material that I acquired, and those keywords are mostly conceptual. So, I have a file for every data source and each file has a set of searchable keywords attached to it. Now, I didn't do it in a very technologically sophisticated way, but obviously there are several software packages available that people can use to do this on a more precise, line-by-line, paragraph-by-paragraph basis. My method was a little cruder, but it works for me. I mean, the important thing is having some way of being able to go back and find the material and then to be able to juxtapose very disparate sources that all seem to relate to very specific themes or events.

One very practical suggestion that I would make is that when you're in the field, you should process the data you're acquiring in a timely way, rather than letting it build up into an unmanageable pile. This is something that I always tell my graduate students. It's very important that you file, you sort, you code, you do whatever you're going to be doing to that data, as you gather it. It's very important that you transcribe the interviews as soon as possible after you conduct them while they're still fresh in your mind. That benefits you in a number of ways. One is avoiding that unmanageability problem of having the huge pile that then seems completely intimidating, but another is to ensure that your ongoing research really informs the subsequent stages. That is, the insights you acquire as you begin to code your data can lead you toward slightly different questions, and that makes the research more efficient from that point on. It might also lead you to the generation of new codes, so coding is an iterative process; you're going to change your codes and add new codes as you proceed. This is definitely true of interviews because I find that as much as I'm paying attention during interviews, I'm so intent on the performative aspects of an interview—and you can appreciate this because you're conducting one right now—that I often forget a lot of the things that are said because I'm busy thinking two questions ahead. So it's only when I look back at the transcript that I recall a lot of the interesting things that got said and that are quite useful for me. And then those insights do prompt me to revise my list of questions for the next interview. It also sometimes prompts me to stop interviewing. That

is to say, at a certain point you realize you've reached saturation around certain topics, or with certain kinds of interviewees, and that you need to do something different. To be clear, I'm describing a certain kind of interviewing where the sampling frame, so to speak, is determined by the particular issue that I'm investigating, and so I might be interviewing a bunch of doctors, plus a bunch of patients, plus a bunch of researchers, plus a bunch of activists, etc., and so the question is: How many of each sort of group do you need to talk to in order to gain an understanding and reconstruct a set of events? And it's a question that you can only really answer in the midst of doing it as you begin to realize that you understand, or that you're hearing the same thing over and over again, or that what a person is saying is confirming what you've read, or something like that.

Then, once I've got all this material, it's still very hard to make sense of it. And so what I try to do along the way is maintain a series of files on my computer where I'm constantly updating certain things. One of them is a chronology because my work often involves a historical narrative. So as I'm learning things and as I'm going through and coding my documents, I try to keep a chronology file open in the background where I put all the events in order. Another is a list of central themes, and I constantly try to remind myself of, and take notes on the key sources for particular themes. I usually accomplish that with my coding, but just to think through the relationships between themes I sometimes draw charts and diagrams for myself, things that don't actually end up in the final publication but are helpful for me. I also maintain a running list of names of people I've interviewed and people that have been suggested to me that I might interview. And I also have a file simply called 'thoughts' where I put my random musings, and I try to reread those periodically, and I actually find that quite helpful. Even once that's all done, I then find that after I have figured out what I want to say and constructed an outline, I then can't really write without going back through the data and picking out the pieces of data that are going to fit in that outline. So, I prepare an extended outline that might be almost as long as the chapter or article itself and that shows where each chunk of data is going to fit in the chapter. Then having done all that, I actually find the process of writing much, much easier. Then I tend to write fairly fast. So I'm slow and methodical

in the research and organization stages, and I'm relatively fast in the writing stage. Does that help?

**WENDEL-HUMMELL:** Yeah, that answers my question. Do you think maybe all those thoughts and graphs and charts will end up in a library some day?

**EPSTEIN:** I've probably thrown them out. I guess they're on my hard drive somewhere!

**WENDEL-HUMMELL:** I really only have one question left, and this was addressed a bit yesterday. Your recent research focuses on the HPV [human papillomavirus] vaccination. In discussing that vaccination with both students and colleagues, there are two questions that often come up and that concern the population that's being targeted. Students in particular want to know why males aren't being vaccinated for this, and among my colleagues, a lot of females are wondering why the cut off is so early. Why are we only targeting adolescents and young women? So what are your thoughts on why such a narrow population is being targeted for this vaccination when anybody can acquire HPV?

**EPSTEIN:** Well, anyone can acquire HPV and it is very prevalent in the population in both males and females. There is a rationale that can be put in public health terms for how certain groups have been the first to be targeted for the vaccination, and there's a certain rationale that can be expressed in terms of the marketing strategies, but the two rationales are perhaps not too far apart in terms of how they've pushed the development of the vaccine. From the standpoint of public health, the official argument, and it makes some sense, is that our primary concern just in terms of sheer numbers of deaths linked to HPV, is cervical cancer, and therefore we want to target women; we want to focus on those women before they contract HPV and therefore it's best to target them before they start having sex. And, in fact, a lot of data suggest that HPV rates climb a lot; there are high rates among the college population and so on and so the earlier the better. The public health experts also ultimately would like to see pretty much everyone vaccinated. They'd like to see boys vaccinated, in part because there are other

cancers linked to HPV that can affect boys, including penile, and probably oral cancers, but also because they want to bring down the viral level in the public as the whole by promoting what public health discourse calls, using a strange sounding term, 'herd immunity.' It's not actually that the public health folks don't want boys to be vaccinated, or older women for that matter, it's more of a question of where you start.

Now, in the case of the two drug companies that make HPV vaccines as I was describing in my talk, I think both companies in principle would be happy to double the size of their market, but they took different approaches. So Merck & Co., the maker of Gardasil, decided that it really wanted the male market, but that it was going to be easier to first get approval for girls. So they decided to narrow it down to girls of a certain age, partly because of the public health rationale, but partly because you want this sort of narrow group to collect your data quickly, to get approval from the FDA [Federal Drug Administration]. They wanted the vaccine on the market. They were trying to beat out GlaxoSmithKline, which had the other vaccine. So they decided, let's focus first on girls, but then subsequently they did a clinical trial with boys. And their strategy of how to eventually double the market gets built into the design of the vaccine. What they do is they create a quadrivalent vaccine. That is, it protects against four types of HPV, two of which are linked to cancer, and two of which are linked to genital warts. So now they're able to go to the parents of boys and say that it's of benefit to boys, too. Not just to help prevent girls from getting cervical cancer, but to protect the boys from getting genital warts and, after all, who wants genital warts? So that's their way of arguing a benefit for boys without having to talk about things like anal cancer, which, as I was saying in my talk, would seem to sexualize, and perhaps homosexualize, the vaccine in a way that would be problematic and promote controversy, while in fact their whole general strategy with regard to getting the vaccine smoothly on the market has been to desexualize it. By contrast, Glaxo decided that the issue of boys' use of the vaccine was too tricky, too complicated; 'Let's not even deal with the issue of boys.' So they made a bivalent vaccine that only protects against the viral types associated with cancers, not the genital warts. They haven't done the clinical trials in boys, and so they're not going to go after that market, at least not initially. They

figured that there was enough money to be made just marketing this to girls, and that perhaps the range, the age range for women, would eventually be expanded.

So what are the implications of all this? One implication is that, as you pointed out quite rightly, girls look at this and then say, ‘Hey, wait a minute. Why am I being made to bear this burden?’ And of course the public health response is, ‘Well, it isn’t just a burden, after all, girls are reaping the benefit.’ It is still a tricky question of which social groups should be targeted as the site of medical intervention, and why should girls bear this special responsibility if HPV is ubiquitous in humans. The other issue has to do with who is left out. Who may be demanding their own biomedical and sexual citizenship? Here I’m very interested in the advocacy of gay health advocates to promote the use of Gardasil in men who have sex with men and particularly in young men who have sex with men as a way to prevent HPV infections that can lead to anal cancer. Although anal cancer rates are low in the overall population, it appears—though the statistical work is a little tricky—that the rates are much higher among men who have sex with men. So in fact, the particular framing of the vaccine as being for girls or for women then creates this kind of extra burden that the gay advocacy groups have to overcome. And I’ve noted that in the media discourse around gay men’s attempts to gain access to the vaccine—and there hasn’t been much media attention, it’s mostly been a kind of undiscussible topic because of a lot of public discomfort around the issue of anal sex and anal cancer and anal anything—that what you find are curious statements about gay men wanting to take a vaccine ‘meant for women,’ as if there were a deep gendered intentionality buried into the vaccine itself. It shows how there is a lingering effect of the initial framing of the vaccine as a cervical cancer vaccine, as a vaccine for women, and that lingering perception can be quite problematic for other groups that are trying to promote inclusion and the addressing of a health disparity.