

Disability Visibility Podcast

Episode 81: Bioethics

Guests: Dr. Joe Stramando

Host: Alice Wong

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Introduction

[radio static, voices singing with hip-hop beat]

LATEEF MCLEOD: This is the *Disability Visibility Podcast* with your host, Alice Wong.

ALICE WONG: Greetings earthlings! Welcome to the *Disability Visibility Podcast*, conversations on disability politics, culture, and media. I'm your host, Alice Wong. We're right in the middle of the summer, and the coronavirus pandemic in the United States and other countries around the world continues to spread with little end in sight. What's a better time than now to talk about bioethics? Today I'm in conversation with Dr. Joe Stramando. Joe is an assistant professor of philosophy and associate director of the Institute for Ethics and Public Affairs at San Diego State University. His teaching and writing focus primarily on the intersection of philosophy of disability and bioethics. We spoke in late April of this year after we were both on *Ethics Talk*, a podcast by the *AMA Journal on Ethics*. Joe will describe how he got into philosophy and bioethics, what bioethics is, and some of his recent writing on the impact of the pandemic on disabled people. Are you ready? Away. We. Go!

[electronic beeping]

ELECTRONIC VOICE: 5, 4, 3, 2, 1.

ALICE: So, Joe, thank you so much for being on my podcast today!

JOE STRAMANDO: I am so excited to be here, Alice. This is really exciting. I've been a fan of yours for quite some time. And so, I'm really, really pleased to be here and have this exchange with you.

ALICE: I've been a follower of your work and your wife's work for quite a while. And the two of us were on another podcast very recently, and it was really wonderful that we were both kinda talking about the coronavirus, and clearly, bioethics is in the forefront now. And I thought it would be just a wonderful chance to kind of do a deeper dive on not only your work but more about bioethics in general. Because I think we say the word bioethics, but a lot of us, including myself, don't really know what that entails and don't really know what that means. So, it's perfect, kind of a convergence having you on the podcast today.

Getting interested in philosophy

ALICE: So, you're an assistant professor in philosophy at San Diego State University. And I was wondering, how did you become interested in philosophy?

JOE: Sure. So, I started undergraduate at a liberal arts college thinking that I would probably major in History and become a high school History teacher. That was sort of my plan. Actually, for a while, I wanted to be a radio disc jockey too! But I realized high school History teacher might be a little bit more of a stable lifestyle. And so, I was gonna go for that. That was sort of the original plan. And so, when I started undergrad, a series of courses in European Civilization as kind of like a minor. I wasn't really completely sold on a major yet. And so, I figured I'd test the waters and do sort of a variety of Humanities kinds of courses with a Euro Civ minor. And so, that was my first entry into philosophy because we started with the ancients in that program. And so, we were reading the ancient historians like Herodotus and the ancient poets like Homer. But then we also did some ancient Greek philosophy and did Aristotle and Plato. And so, that was sort of my discovery of philosophy, and I really enjoyed it. I already really enjoyed reading and writing argumentative kinds of papers. And so, I quickly figured out that, you know, hey, this is going to teach me how to do it really carefully.

And so, I switched over to a Philosophy major during my sophomore year. And during my junior year, I took a Bioethics class for the first time in the Philosophy Department where I went to school. And it was a lot of fun. I really enjoyed doing bioethics because it seemed to matter in a way to me that a lot of other philosophical discourse didn't seem to really speak to my experience all that much, have a huge impact on my life or the lives of people that I care about. And so, bioethics was different. It was fun, but it was also high stakes. And so, that's sort of how I started doing bioethics way back then. And at the same time, I actually took a course in Medical Anthropology. And that was sort of my awakening when it came to disability issues because it was in my Medical Anthropology class that I read a book, I don't know if you've ever read it or seen it, called *The Body Silent* by Robert Murphy. And so, I had a great professor for a Medical Anthro that that assigned to that book, and it was just a world changer for me.

ALICE: Mmhmm.

JOE: It was the first bit of Disability Studies that I had ever encountered, and it introduced me to the Social Model and got me thinking about disability as a social thing and as a cultural thing and as a political thing and not just sort of as a medical deficit. And so, it was weird because I read that book during the same time period, or the same semester even, that I was taking my first Bioethics course. And so, [chuckles] it was really fortunate because it gave me the ability to look more critically at what I was studying in the Bioethics course to sort of have in my back pocket all of this social science talking about disability as much more complicated than just an impairment or a medical thing. And so, I realized that, well, you know, Disability Studies had something to say that was important when it came to bioethics. And so, that's sort of very early on, I sort of became interested in doing both of these things at once.

What is bioethics?

ALICE: For those who don't know much about bioethics, and I'm somebody who's constantly trying to learn and understand it, I feel like I live it. So, like there's some aspects that are very personal to me. But, what is bioethics, for somebody who just doesn't really know much about it? How would you kinda describe it?

JOE: Sure. So, I like what you just said about living it. Because I think that whether we know it or not, we all live it. Anytime we encounter the institutions of biomedicine, we are living bioethics. And I think that that's more frequent of an experience for disabled people than for many others. And so, what I mean by that is, so, bioethics is the analysis of moral problems that arise within the life sciences, for instance, medicine, biology, even ecological research and practice. And so, what's important about bioethics or what's distinctive about bioethics, I think, is that it's an attempt to say something normative. And so, unlike other academic disciplines that sort of describe the world, like something like medical anthropology or medical sociology or even something like psychology, that sort of describes something about human behavior, human culture, bioethics tends to make prescriptions. And so, not just sort of say how things are, but rather how things should be. And so, that's sort of what's distinctive about it. It gets into the moral questions and doesn't sort of try to become sort of a neutral observer about some of these things.

[crashing ocean waves audio break]

Recent writing and advocacy on ethical issues in healthcare rationing

ALICE: So, we're talking in the late-April of 2020, and we're in the midst of the coronavirus pandemic. And I was wondering if you could tell me about some of your recent writing and advocacy on the ethical issues on healthcare rationing as hospitals and states have had to contend with constructing guidelines on how to allocate resources and capacity. Can you describe kinda the series of blog posts you've been writing?

JOE: So, I had to learn quickly. [laughs] I had done some work in thinking about distributive justice within bioethics. I have one publication about organ sales, arguing against sort of having a market for kidneys. But most of my stuff was sort of in other areas of bioethics. And so, triage sort of wasn't sort of my bread and butter, and I had no intention of ever it being my bread and butter. But like you said, we live bioethics as disabled people. And so, when all of this started going down and I started reading about the reports in Italy, honestly, my motivation was fear. I started thinking about myself and my friends and our vulnerability to these triage guidelines. And so, I thought to myself, well, I better give myself a crash course in triage ethics and try to say something useful. [laughs] And so, I knew that I had the privilege to be able to be heard, to be able to get my writing into some of these spaces, that it's appeared in the past few weeks. But it took me a while to get there, not only because there was sort of some reading and thinking that I had to do about triage ethics, but also just because I was scared, honestly.

You know, I had a—I hope she doesn't mind me talking about it—but I had a pretty intense series of conversations with my spouse Leah, where she was like, Dude, you gotta get a grip. You're really too dark on Facebook these days. [laughs] Just because, you know, I was really, really scared of the virus and scared of the implications for, you know, if things do go badly in the U.S. and we do need to make choices about who gets care. You know, it was a tough time, especially at the beginning where we didn't know that the response to flatten the curve would be effective.

I was able, over a few days, to sort of, I don't know, refocus some of that into some writing that you're referring to. And I guess the three blog posts that I have out right now, the first deals with quality of life as a criterion for triage and argues against the idea that we should use quality of life as a criterion for for triage. In other words, we shouldn't deprioritize someone for medical

treatment and withhold care to give it to someone else because we think that that person that we're deprioritizing doesn't have a good enough life to save, that they will still be suffering even if we treat them for COVID-19. And so, we ought to prioritize someone who is going to be able to have a higher level of well-being if they survive. Now, this isn't something that's usually this explicit within triage protocols. And so, what that essay tried to do was discuss how quality of life considerations can be dressed up in other costumes within triage protocols.

And so, instead of talking about things like, well, we aren't going to save this person's life because they have x, y, z disability, and everybody knows that people with that x, y, z disability are miserable. And so, we shouldn't bother. Instead of that, they say something more along the lines of, well, we don't wanna define survival as just mere biological survival. We don't wanna just sort of save anybody who's just going to be alive after the treatment. We wanna make sure that we are saving people that are going to be healthy after they're treated. And we want to define survival as healthy survival. And that was actually included in the triage guidelines that came out of the University of Washington that prompted some of the legal complaints that we saw early on. And so, my argument there was that, well, all this stuff about health is really just trying to smuggle in quality of life.

And then the second essay looked at a distinction that I tried to make between wasting resources and being inefficient with resources. And so, in other words, I tried to argue that you can coherently say within ethics that we ought not to use scarce resources like ventilators on people that have a very low likelihood of surviving because that might be wasteful, right? We don't want to use a vent for someone who might not, we are fairly certain, won't survive because you could be using that vent for someone else that will survive. And so, we might think of that as wasteful. But a lotta times in the bioethics literature, and to some extent even in the protocols, that idea is conflated with a related idea that if what we're trying to do is maximize the use of our resources, then not only should we not waste them on people that won't survive, but we should also try not to be inefficient with them by using them on disabled people who will need more of them in order to survive, OK?

And so, I tried to say, well, inefficiency is different than waste. And that we can justify inefficiency in that really, the entire disability rights movement is an argument for inefficiency as a justifiable thing to do when it means that we can create more equity and equality. And so, in other words, it might be inefficient to remodel a building, to install the ramp and install the elevator, or it might be inefficient to redesign a curriculum to accommodate different learning styles, or it might be inefficient to hire the sign language interpreter. But that isn't an argument against doing it. [chuckles] And so, when it comes to ventilators, we oughta think in the same way: that we ought to allow for some inefficiency and allow for people that might need more time on the vent to recover to have that time and not think of it as the same thing as wasting the resource by giving it to someone that won't recover.

And then the last piece was an argument that was inspired by my colleague, philosopher of disability, Shelley Tremain, who has a great book out right now from University of Michigan Press, called *Foucault: The Feminist Philosophy of Disability*. And she argued on Facebook and other social media platforms that the entire conversation around triage was something that we needed to try to refocus on, instead thinking about and using, especially as bioethicists, using our political capital and social capital to try and expand medical capacity so that we won't have to triage. So, in other words, in that piece, I tried to offer some very concrete ways that we as a

society might be able to do a better job of minimizing our need for triage, including things like a national shelter-in-place order and not lifting shelter-in-place orders too soon to try to flatten the curve. Or using the Defense Production Act to try to make sure that enough PPE and enough ventilators were being produced, but also distributed to the places that need them most.

And so, if there's things like that that we can do as a society, these are bioethical problems, right? And so bioethicists, if what we're really concerned with is saving the largest number of lives, we shouldn't only be talking about triage. Because you're going to save a lot more lives by pushing hard to try to expand medical capacity and flatten the curve than you are by formulating a triage protocol that is efficient in the use of the limited resources.

[crashing ocean waves audio break]

ALICE: I'm kinda curious about your own thoughts about how these conversations on healthcare rationing and just the pandemic in general is really a reflection of power and systemic oppressions, especially racism and ageism and ableism. Because they all are kind of intertwined, as we've seen with the latest reports about how Black and brown communities are, unsurprisingly, disproportionately impacted. Same with Indigenous communities. How are these kind of reflections or just commentary about the way our society's organized?

JOE: I think that one thing that comes immediately to mind is the idea that some people are disposable in order to try to keep the economy going, right? It's not an uncommon sentiment, right? But from the beginning of all of this COVID-19 pandemic, we heard a lot of people that would say things like, Well, don't worry. It's only the elderly or people with serious medical conditions that will die. And it's like, excuse me?! [laughs] You know? You're talking about me and my family and my friends. This is not OK. It's not an OK way to frame this issue.

And so, I think that those are sort of representative of the idea that, well, if you're, you know—and it's a really durable idea that's been embedded in our culture for a very long time that—if you're not productive enough, if you're not able to produce within the economy enough, then you're not worth saving. And so, if you're elderly, you're not gonna be working. Or if you're sick, then the assumption is that you're not going to be taking care of yourself; you're going to be taking resources from others. And so, this is just sort of another way of framing the same conversations that we're having about these triage protocols, really: whose life is worth making sacrifices for? And so, I think that that is definitely bound up with ableism and racism and ageism and all of the -isms, because these are all ways of identifying people whose lives are less important than the gross domestic product. And we've seen that. Time and time again we've seen evidence of that.

Hopes for what people will learn from the pandemic

ALICE: I think my last question for you is, what do you hope people will learn as we come out, out of this pandemic? Especially knowing that there will be future ones. So, what is your hope that people will at least come away with by experiencing and coming out of this?

JOE: Yeah. I hope people will get really angry at the lack of social supports in our country. I think that this has put into sharp relief the terrible state of the safety net in our country and that we need to do a lot more. I think that when it comes to things like single payer healthcare and the idea that lots of people are losing their jobs right now or not working, and so it's becoming pretty clear how fragile employer-based healthcare is, that there'll be more openness toward universal

healthcare that doesn't rely on you having a certain kind of job. So, I think that's one thing that I hope comes out of it. But also, just things like just basic income guarantee and other sorts of safety net features that people will realize that this doesn't have to be a choice between your livelihood and the lives of those that you love, right? With adequate safety net put in place by the government, we can have both. Of course, that's going to take some political will that we have to build to do that. And so, there's gonna be a lot of pushback from folks that have a lot to lose in order to redistribute wealth in these ways. But nevertheless, hopefully, people will be more open to that after this experience.

ALICE: Well, thank you, Joe. I really enjoyed this conversation. And I just hope it prompts people to explore a little bit more about bioethics. And it's clearly something that everybody lives, but I feel like, especially for disabled folks, we really live it every day being enmeshed in the medical-industrial complex. So, I just, I really appreciate all that you do in explaining things for us.

JOE: Well, I really appreciate that you're doing and do. Your podcast and your other efforts are just amazing. You know, I really admire what you're up to. And I guess we're just having a love fest over here. [laughs]

Wrap-up

[hip hop plays]

ALICE: This podcast is a production of the *Disability Visibility Project*, an online community dedicated to creating, sharing, and amplifying disability media and culture. All episodes, including text transcripts, are available at DisabilityVisibilityProject.com/Podcast.

You can also find out more about Joe on my website.

The audio producer for this episode is me, Alice Wong. Introduction by Lateef McLeod. Theme music by Wheelchair Sports Camp.

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Thanks for listening! And see you on the Internets! Byeeee!