

Philosophical Profiles

Elizabeth Barnes

Professor of Philosophy at the University of Virginia

IN BRIEF

Elizabeth Barnes is Professor of Philosophy in the Corcoran Department of Philosophy at the University of Virginia. She is author of *The Minority Body: A Theory of Disability* (Oxford University Press, 2016) and editor of *Current Controversies in Metaphysics* (Routledge, 2016). As those titles might reveal, Professor Barnes is interested both in the traditional, core analytic tradition of metaphysics and in social theory, and is particularly interested in areas of intersection between them. In this interview, we focus exclusively on *The Minority Body* wherein she defends the concept of disability against the charge that it is empty while at the same time arguing that one should not think of impairment and disability as distinct notions. She opens herself up to criticism on both sides, asserting both that disability is a socially constructed notion and that there is something essentially physical about being disabled. She also asserts both that disability in itself is neutral (neither bad nor good) and that it can be bad for individuals. In her spare time, Professor Barnes is enjoying being a crone and the company of neurotic rescue dogs, and is admirably tolerant of her running-obsessed sister.

DETAILS

Simon Cushing conducted the following interview with Elizabeth Barnes on 10 August 2018.

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Elizabeth Barnes

a philosophical profile

SC: So, I'm going to start with a question I ask everybody which is- When did you realize that you were destined for philosophy?

EB: I don't think I've had that realization yet!

All right - when did you realize that this was something that you could devote a significant chunk of your life to?

I think, for me, that was a realization that I had in stages. I actually got really interested in philosophy when I was in high school. Just reading around through books and things so I knew I wanted to take a lot of philosophy classes in college. Then I took a lot of philosophy classes in college and I knew I wanted to be a philosophy major and once I was a philosophy major, I just couldn't get enough. It completely changed my perspective on how I thought about things and I just loved it. It was like finally finding other people who thought about things in the way I did and who had this way of quasi-obsessive interest in weird things that nobody else seems to care about.

So, like what kind of weird things?

I think some of the problems that really gripped me were things like knowledge of other minds. How do I know that what looks like red to me, looks like red to you? How do I know that the word "red" as I use it refers to the same thing that it refers to when you use it? How do I know that when I'm talking about the sensation that something tickles, do I have any reason to think that you have the same sensation? So, this idea that every single person is stuck behind their own eyes and in between their two ears, and we can talk about things, but you don't ever know what it's like to be somebody else or to experience the world from behind their eyes. This leads to all sorts of interesting limitations on what you can really know and what you can know about how your experience generalizes. So, those sort of skeptical problems were some of the first problems that really gripped me.

I think the first philosophical problem that really, really, really fascinated me was Hume's Problem of Induction—is it rational to believe that the future will resemble the past? Well, it seems like the best reason that we have for thinking that the future will resemble the past is that in the past, the future has resembled the past. So, our belief that the future will continue to resemble the past sort of relies on the fact that the future will resemble the past. So Hume says that that's not that rational. And seeing that problem laid out for the first time, I was like "Whoa. That's incredible!"

So you fix that by going out for a nice slap up meal according to Hume.

That's right. I did always kind of love Hume's solution which is just like, "Eh. People aren't rational. Everybody relax. You are not as rational as you thought you were. That's life." There's something quite soothing about Hume's solution to it. But, by the time I was ready to graduate I just knew that I wasn't done learning about philosophy and that's why I wanted to go to graduate school. It wasn't necessarily because I thought I was capable of being a professor. I just felt like I had more stuff that I needed to know. It was a little bit like a drug. I just of kept needing that next hit.

It's interesting what initially pulled you in. I mean a psychiatrist might say that you had this view that you were alone in the universe and the world was just a simulation and that there were these things that look like other people making noises at you, but you couldn't quite believe they were real.

I think I probably had the experience of just being a little bit weird. You know? A little bit odd. Always asking questions and people would be like "why did you ask that question?" So, then, I think if you're a little bit odd and a little bit weird and your experience is a little bit different than people in your surroundings, then it leads you to wonder, "Well, does everybody experience the world the same way I do? Why do people think what they think? What is truth anyway?"

Well, those are the sort of hardcore philosophical issues. It's not the ones like "Should I eat meat?" Or the usual sort of entry-level stuff. It's right there with the inverted spectrum. So, you jumped in at the deep end.

I did. I'm one of those weird people who my philosophical interests have gotten more applied rather than less applied as I've gotten on in my career. I think a lot of people get into it by wondering "should I eat meat?" and then they end up wondering whether you know, tables are real. I got into it being pretty sure you probably shouldn't eat meat, but really confused about whether tables are real.

No, I went to grad school with a guy called Jim Stramel who was writing his dissertation on the philosophy of math and then he switched over to writing about gay issues and it reminds me of [Richard] Mohr who was sort of a pioneer [in analytic philosophy] writing on gay stuff. He got into it when he had to teach this summer class to mostly jocks but he's a Plato scholar and interested in those kinds of issues and only later [decided] "Well... I guess I better talk about this." In your experience, it sounded like you found reading some work by respected philosophers very upsetting and it sort of led you to want to rebut that. I mean Parfit and Singer. These are huge names and what they say about disability you seem to find very hurtful.

It bummed me out a little. I'm not gonna lie.

Particularly in a field that you've come to think of "This is my home" and people are talking shit in your home.

Exactly. For me, finding philosophy was this feeling of intellectually coming home. It was like "Oh, these are people who think like I think. These are people who approach

Philosophical Profiles

intellectual problem-solving the way I do," so the methodology of analytic philosophy just felt very natural to me. That was kind of how my brain works. If you're ever teaching a big introductory philosophy class that has a hundred and fifty students in it or something and you teach Descartes' skepticism problem or something like that and you know the majority of the class is just sitting there not like "Oh cool problem" right? Then, you got like that two kids down on the front row who are just like "My life will never be the same. You just blew my mind!"

Don't you feel a bit guilty at that point? "Oh God – I've ruined your life – you could have been rich..."

"You could have been okay." But I really did have this experience of coming home except that I'm a person with a disability and so I, quite excitedly, because I'd taken disability studies classes and I was under disability theory from the English department and things like that, so I was like "Okay, cool: what does philosophy have to say about disability?" The two biggest arguments, in fact the only argument that I encountered in philosophy classes when I was in undergraduate, are Peter Singer's argument that euthanasia is morally acceptable for infants in cases of disability...

Even Down's syndrome, kind of shockingly.

Or hemophilia is the case that he uses in *Practical Ethics*. That's like his example case, so we're not talking only the most severe cases of what-have-you. Then, Derek Parfit's handicapped child case which is the case where he says, "So imagine you could conceive a child now or conceive a child in a year's time. If you conceive a child now, the child will have a disability and if you conceive a child in a year's time, the child won't have a disability." This isn't actually a case that has anything to do with disability per se, it's meant to be this problem for person-affecting ethics, but the intuition that the case starts with is: obviously you do something wrong if you have a child now. So, obviously you do something wrong if you knowingly have a disabled child if you could have had a non-disabled child in a year's time. And then the idea is, how can we say that it's wrong if there's not a person that you harm? Those two cases combined that was the only talking about disability that I encountered in philosophy as an undergraduate. It was also that those are two huge names in analytic philosophy and they're also two people who I have tremendous respect for as philosophers and I have tremendous respect for their work. I also have tremendous respect for them. I didn't know them at all personally, but I've just tremendous respect for them as moral thinkers. That was in a way shocking to me and certainly in a way hurtful to me but also motivating. That was one of the first times when I thought, okay I might end of doing some philosophy that talks about disability because it seems like it was no longer quite so easy an option to be like, "Okay. I'm a person and I have a disability and I do philosophy, but I'm just not going to talk about it." When people start talking about disability in those terms, as you say, in your house, it becomes harder not to think about it and not to address it. So, it was motivating for me in a lot of ways.

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And the result was this book, among other things, which I'm going to ask you a lot about because this is your main product in your philosophical career so far. So, let's dive into that. I'm going to ask you to explain the difference between impairment and disability just to start off with. Explain why that is or isn't important.

This is a common theoretical distinction, both in academic discussions of disability, but also it's a distinction that's written into a lot of legislation on disability. The Americans with Disabilities Act, for example, presupposes a disability/impairment distinction. The basic idea, and a lot of this way of talking and way of thinking comes out of a family of views which are broadly known as the social model of disability. In answering your questions, I'm going to talk primarily about physical disability and when there might be differences with cognitive or mental disability we can flag that, but it's often easiest, and my book is specifically about physical disability. Impairment, for example in the case of physical disability, is just the biological condition of your body. The physical features that, and here's the million-dollar question of how you distinguish impairments from other things, but if we're just talking about paradigm cases of impairment; if you are a wheelchair-user because of a lesion on your spinal cord, that lesion on your spinal cord is the impairment. That physical condition is the impairment. The idea is that disability is what you get when bodies with impairments interact with the social environment. So, if you are in a wheelchair and you cannot access a space, you can't get into a building or you're in a wheelchair and you can't hold a certain job, etc., that is disability. Disability is the disadvantage that is created by having an impairment. That's the disability/impairment distinction as it typically is understood.

In this way of thinking, if we just look at a body in isolation, we can say whether or not that body is impaired, but we cannot say whether or not it is disabled because we don't know the context it will be in.

Yes. I myself don't like the disability/impairment distinction. I don't think it's necessary. Now, I think it's a great tool in a lot of pragmatic contexts. Like, I don't think there's any reason why laws like the ADA should stop talking about the disability/impairment distinction. It's a nice way to write laws. I also don't think ways in which there are convenient ways to write laws should obviously inform our theorizing. I personally think sometimes things get more complicated than we need them to be so a lot of times people make a distinction between disabilities and impairments. People make distinctions between disabilities, impairments and handicaps. It all gets very complicated.

Presumably the idea is that impairment is not relativized, but it has to be relativized to something because what makes any body impaired rather than just the body it is, is presumably its comparison with some archetype. So what if I wanted to say I was impaired reproductively because I cannot produce a baby? Are impairments-talk people opposed to that?

It depends. A lot of people who go in for talk about the disability/impairment distinction there's then this further move that says impairments we kind of pass over in silence. We don't really talk that much about impairments. This is one thing that has led people to criticize the disability/impairment distinction because the worry is that in focusing

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Philosophical Profiles

so much on the social dimension of disability (which is really important and the social dimension of disability is really undervalued), we end up kind of disembodied our discussion of disability. Impairments aren't the whole story about disability, but they matter. They probably matter more for some kind of impairments than they do for other kind of impairments, but for some ways of talking about impairments people just don't really have much of a theory there. It's the biological condition of your body and they don't say that much more. I would say the standard way of thinking about impairment is that impairment is just departure from normal function—whatever that means, because there's a whole lot of controversy about how we can define normal function and whether normal function actually makes sense in this kind of context. But impairment is departure from normal function.

But it already has to be harmful departure because LeBron James departs from normal function but nobody's going to call him impaired.

He's not going to be impaired, yes. There are lots of interesting biological abnormalities that are differences but we don't think are impairments per se. I think we lose our grip on the concept of impairment if we say any sort of departure from the statistical norm is an impairment. Also, there are lots of ways that you can have impairments when you're not a departure from the statistical norm. When we're thinking about statistical norms for bodies, you have to look at age-matched control groups because it's abnormal if I can't walk, but it's not abnormal if a 6-month-old baby can't walk. Things like this.

When it comes to impairment, the vast majority of people over the age of 70 have some type of physical impairment. That's "normal." That's common. That's what happens to these decaying meat sacks that we inhabit. It becomes very hard to just define them in terms of statistical typicality. Watch any high level sports event and you're going to see a lot of people who are departures from statistical typicality in terms of function. They're not impaired.

What was the motivation for the distinction? I mean was it just so that we could talk about ableism as context-dependent? What was the motivation and why are you opposed to it? Is it all right for normative reasons or because it doesn't solve the problem it was meant to solve?

I think there are two separate motivations. One is a theoretical one and one is a pragmatic one. The theoretic one is trying to distinguish between the biological condition of bodies and then the social dimensions of disability. The social model of disability says that there's impairments, which is just what your body is like, but then there's disability. Disability is the social disadvantage that arises from the fact that we've set up our society in a way that doesn't accommodate certain types of impairments. Disability is entirely about social disadvantage to certain types of bodies. Then the thought is often in the absence of limited access, barriers, stigma, prejudice about disability, we would still have impairments but we wouldn't have disability. Disability arises because of prejudice against certain types of bodies. By prejudice here I don't mean just how you think about people. Prejudice here isn't just in the mind. It's also if

you build your buildings without thinking about how some people are going to get into them, that counts as prejudice.

You could speak up in favor of this distinction because you can say at least it's not saying the solution is to change the bodies. Presumably a eugenicist would say the problem is impairments; let's get rid of the impairments. Whereas this is saying at least "No, we want to allow people to have the bodies that they have and our job is to accommodate them rather than to make them fit a mold." You can see that there's something to be said in favor of the distinction.

Yeah, and my own view about this distinction and my view about the social model more broadly is that while I think it's false, I don't think it's the right way to think about disability, I also think it's been such a tremendously useful, influential, helpful way of thinking about disability that it might well have been a phase that thinking about disability absolutely needed to go through politically.

Kind of like Marx with capitalism.

I think there's a sense in which you see this a lot with progress in social movements so I think the "born this way" rhetoric about sexual orientation is almost certainly false. There's probably some genetic components to sexual orientation, but there's also a lot of other components to it. It's probably a little bit different for women than it is for men. People are different. We're probably not going to find a gene that tells you whether or not you're gay or straight and I think there's more to sexual orientation than just being gay, straight or bi. Nevertheless, I think the idea of sexual orientation being natural, of people being born this way, I think that was overwhelmingly useful, important kind of phase for thinking about sexual orientation to go through, and politically, it accomplished so much. I kind of feel the same way about talking about disability as though it's just the social disadvantage that ableism creates. I think part of the reason why it's so important is that in a lot of ways the social disadvantages of disability are invisible to those who aren't disabled. They sort of look at disabled people like "Oh. That's a medical problem. The solution for this problem is March for the Cure or better technology."

There's a whole series of videos that you can see—I've seen several different instances, they keep cropping up—of people having cochlear implants for the first time and bursting into tears of joy. I'm always a little bit torn by this because this seems to be an instance of "Hey, fixed that one."

Even the rhetoric around cochlear implants, the idea that what cochlear implants do is turn deaf people into normally-hearing people. That's not what they do. They allow people who are deaf to cognitively process sound. But if you process sound by a cochlear implant, it doesn't sound anything like what you and I would hear.

We're back to the problem of other minds.

There's a lot of controversy in the deaf community surrounding cochlear implants—more so because the way in which they're framed as solving deafness. And, when

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Philosophical Profiles

cochlear implants are given to children, parents are encouraged not to give their children access to sign language and all these kind of things, that people think are quite harmful. One thing, as a disabled person going about in my daily life, and I live in the South, so random people will often say something like, "Well, I'll pray for you" or "I'll pray for a cure." If you want to pray for something, pray that Donald Trump doesn't gut the Affordable Care Act. That is what will make a difference to my life as a disabled person. I don't feel going through my daily life that I need a cure. I do feel that I need access to affordable health care.

If you say that, they'll pray for your change of attitude.

Yes. I feel like there's a strong overlap between strangers that stop you in the street to tell you they'll pray for you and the voting base of a certain President.

I think it's so valuable to focus on the social dimensions of disability partly because they are so invisible and I think non-disabled people don't tend to think about the problems of disability in those terms. I think it's hard for a lot of disabled people to think about the problems of disability in those terms, especially if your disability is kind of conceptualized as a medical issue. Like "Oh, this is my own little private medical tragedy and if I've got a problem, that's something I go to a doctor for rather than something you write to your congressperson about." I think that insight of the social model is incredibly valuable and both as a scholar and as a person with a disability I'm incredibly grateful for it.

I do think it goes too far. Because I think for a lot of people, especially people who deal with medically complex impairments, impairments that will get worse over time, impairments that require a lot of ongoing maintenance or medical intervention and care, part of your lived experience as a disabled person is the experience of your body. A lot of the struggle you deal with is socially mediated, but if you have to deal with a condition that is medically complicated, or degenerative, or painful, or any of these things, you know your life is going to be different and complicated and interesting in a lot of ways that are somewhat separable from how society treats you. We could live in an ableism-free paradise and my experience of my body would still be more complicated and different than a lot of able-bodied people's experiences would be. It's really important to talk about that as well. And talk about that without saying that it doesn't make me worse off automatically. I think there's kind of a push to say, sometimes in theoretical circles, to say that all that harms of disability are social because that's the only way people think that you can say that disability is not by itself something that is bad for you. But I think that we can say that disability is complicated. Disability is a many-splendored thing. There might be things about disability that are not socially mediated that are, in a restricted sense, harms and that's compatible with disability not being something that automatically makes you worse off or automatically makes your life go worse. Lives are complicated.

On the pragmatic issue for why the disability/impairment distinction was really important, I think it's just really important for writing laws because you get these questions like "Is asthma a disability? Should asthma be covered by the ADA?" Well, it

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depends. It depends on what the social context is. It depends on how bad your asthma is. It depends on what your job is. It depends on the interaction between your socio-economic situation, your job, the demands on your body and your time and what's going on in your lungs. You don't want to have a law that says, "OK, you can get disability benefits for all and only these physical conditions." That's not going to be a very helpful law so you want something like you need to have an impairment, but it also needs to be disabling in some sense. That's the sort of really handy thing for writing laws. Our ways of doing legislation for disability are so very far from perfect but that's why it's kind of a useful tool there.

Of course there are worrying cases. There was a white guy who claimed that he became very anxious amongst black people and got job severance and, I don't know if it was disability, but got recompense from the government because he argued that he couldn't continue at his job because there were too many non-white people around. If we preserve the impairment/disability distinction though, it sounds like you could say well that's not really an impairment.

It's tricky. Once we start talking about psychological impairment things just get...

Let's stipulate that it was a physiological reaction: he became sweaty, his hands trembled.

This is one of the reasons I'm really glad I don't work in policy. As much as I'm skeptical of the idea of "normal function" as a sort of scientifically workable concept, or something that we can actually define impairments in terms of, you at least have a sense of, speaking in folk terms, that what your immune system is supposed to do is attack pathogens. If your immune system starts to attack your central nervous system, that is a dysfunction and you have MS. That's what an autoimmune process is. The autoimmune processes that leads to multiple sclerosis. So we can at least have some sense of some paradigm cases of what you might think of as harmful departures from normal function even if you're skeptical of the normal function paradigm more broadly. But, when it comes to psychology, it's kind of like the idea of what's the difference between having psychopathology and just being "kind of weird." Just having personality. Just being a little odd. I think we have far less of a sense of what would constitute something like biostasis or normal function when it comes to the human mind than we do when it comes to just the system and organ function in the human body. So, things get really complicated in a hurry. You have to talk about this stuff because mental illness is just as real as physical illness but I think it just becomes much harder to quantify in ways that make me glad I don't work in policy.

Now, one of the upshots of the early chapters of your book is that it's incredibly difficult [to define "disability."] It's like the experience in every Socratic dialogue where they ask "What is (say) piety?" and end up back where they started. I tend to think the Socratic dialogues have a very skeptical bent in that you can't come up with a workable definition. But, you want to preserve the notion of disability, and yet it ends up pretty battered and bruised by the time you're finished with it. What's

the worth in keeping it? Why shouldn't we be eliminativists about disability? Do you want to take the position of someone who's a social constructivist, like about race, who argues, "Yes, of course it doesn't carve nature at the joints, there is no such thing as race, but, of course, there is such a thing as race in our lived experience so it would be misguided to say, as some people want to, that because there isn't any race, there isn't any racism." Of course there's racism and there's the reality of race even though it's not a biological reality. Is that something like you want to say? Or alternatively you can say it frays too much [when you try to unpick it] and there's no longer any useful concept?

Battered is a good word for it. I think the puzzlement that I started with in thinking about disability was in wanting to talk about disability as a kind. Thinking it's interesting to talk about disability as a kind, but then also thinking about how I hang out with a lot of disabled people, I have a lot of disabled friends, and thinking about the variety of physical conditions, the variety of bodies that get classified as disabled. Just among my friends who self-identify as disabled I know someone with achondroplasia, I have a friend that's deaf, I have a friend with MS, I have a friend with lupus, I have a friend that's an amputee, I have a friend that has a congenital "birth defect" and I have a friend that's blind. Then there's me. I have an inherited condition, a genetic condition of connective tissue. I'm sitting there and I'm thinking about what do all these bodies have in common with each other? I don't think there is a natural kind. I don't think there's a unified story and I go through some of the common ways of trying to say I don't think it's "departure from normal function." I don't think you can say it's "loss of an ability." I don't think it's any of the standard ways of doing it. I don't think there's a good way of saying what it is that people who we think of as not just disabled but as paradigm instances of disability, I don't think there's a good way of saying what they have in common. Just in terms of talking about the physical condition of their bodies. That being said, if you ever hang out with disabled people, when you get a group of them together in a room, they won't shut up about talking about, "Oh right if you had this experience with access." And, "If you go to doctors. Doctors are the worst." Socially, we have a lot of experiences in common. Now intersectionality matters. It matters a lot. What your class background is. What your socio-economic background is. What your race and sexuality, all these things. But as disabled people, we do have a lot of experiences in common. So, I think what I wanted to do is say, OK, is there a way of preserving talk about a social kind, talking about a way in which we might have something in common without saying there's some way that your bodies all have something in common? Like, "these are all just the busted people" or something like that. It's tricky because as I'm trained in feminist philosophy, the default is always something like "Well it's how people perceive you," or "It's your social role," or something like that. I don't think that can be quite the right story for disability. Being disabled is partly how people perceive you but it's not entirely about how people perceive you. It's also partly just to do with what you are like physically. What your body is like. I ended up trying to argue that disability is a social kind that's interesting really insofar as it's been useful in organizing people in a civil rights movement. It's a social kind based entirely on the idea of solidarity so that people can get together and say, "Oh, right: because of what our bodies are like we have these shared social experiences." So, in a sense, disability is a matter of what your body

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is like, but it's kind of a socially-constructed matter of what your body is like. We think of certain types of bodies as particularly defective, or wrong, or medically something's up with them, or they're broken in some way, that way of thinking about certain types of bodies creates a sense of common experience for people with those types of bodies. That was the view I ended up with. Basically, if you want to read an exercise in philosophical struggle and unhappiness, you should read the first chapter of my book. I wound up at this option of, "This is the only view that I've not been able to come up with counter examples that I'm so wildly unhappy with." I hope other people can do better than I did.

You wouldn't want it to wither away is what I'm saying.

Exactly. I think I wouldn't want to be an eliminativist. I wouldn't want to be an error theorist because I think disability is real. What Appiah says about race, or Naomi Zack says about race—race isn't real, but we have racial identities, or something like that. I think when it comes to disability we have to say more than you have disability identity. You can be disabled and not have disability identity. Interestingly, you can have disability identify and—at least on my view—not be disabled.

The Rachel Dolezals of disability?

People are weird. The human mind is a complex thing.

This is different from Munchausen syndrome?

Yes. Crash course in ways in which physical disability and certain types of psychology interact. Munchausen syndrome is when you harm yourself in an attempt to mimic a medical diagnosis or to receive medical care.

It involves self-harm?

Yes. Munchausen by proxy is when you harm someone else.

Your kids, usually.

Yes. Your kids. Munchausen syndrome seems to be a desire to receive medical care or medical treatment. People take poison. People hit themselves. People do these kinds of things in order to receive medical care. Factitious disorder is when you don't engage in self-harm. You just fake all the symptoms of an illness or a disability.

When you say fake, do these people think they're faking? If there was a lie detector that worked) would they pass it?

It's very difficult because all we have to go on is what people say. There seems to be very much a difference between what we think of factitious disorder and somatoform disorder. Somatoform disorder is when you have physical symptoms that don't seem to have any kind of organic cause, but there's no intentional mechanism behind it.

Philosophical Profiles

It's not like our minds are separate from our bodies. One way that various types of anxiety, stress, emotional pain can sometimes manifest is in physical symptoms. Just like sometimes the way that physical symptoms can manifest is in psychological symptoms. One difference between fictitious disorder and somatoform disorder is that people know that they're doing active things. They are faking blood test results. They are doing things to intentionally make themselves look a particular way but they often think that they're doing this in the service of having their true self recognized. It's not 100 percent clear what that means and I'm not a psychologist. I don't know enough about the literature there. People with factitious disorder seem to be aware that there's an element of intentional trickery going on but I don't think they would go so far as to say, "Oh yeah, I'm just making this up." They think there's an element of truth going on and they are then engaging in some mimicry to get their true self recognized.

This is then different from people who identify as trans-abled. People who identify as trans-abled, and typically it is with respect to a particular type of physical disability, the most famous cases are the amputee cases. There are people who identify as being a T4 paraplegic. A T4 spinal cord injury. There are people who self-identify as being blind. That's actually quite common. One that's quite common is deaf. They call them the "deaf wannabes." So, people feel very strongly that this is their true self.

But they don't, for example, puncture their eardrums, or anything like that?

They sometimes will try to. They will often seek medical treatment.

I know there are cases of people who feel like their limbs are not their own and they want those removed.

Yes. Body integrity identity disorder. The term that people who have bodily identity integrity disorder often prefer is trans-abled. They will seek confirmatory surgery or confirmatory medical treatment.

How are these individuals viewed by disability rights activists? It sounds like they would have similar issues like trans-women used to have. There's a camp in Michigan that was a women's festival.

Yes. The Michigan Womyn's Festival. Women born women. "Womyn" spelled with a Y.

Right. Is there a similar thing in the disability community?

As all communities are, there is very wide spectrum of use.

Which is the danger of defining disability in a way that is socially constructed because then you get these disputes about who gets to come in.

I think border disputes are unavoidable and they're also just so tricky, so hard. I think issues of gatekeeping are particularly difficult in cases like disability where unfortunately,

the world we live in is one in which accommodation is a scarce resource. Oftentimes, by claiming disability, you are claiming the right to accommodation and the need for accommodation. In situations where that's a scarce resource, I think sometimes the kind of grumpy gatekeeping that you will see from some disabled people is moderated by the fact that there's a limited amount of resources to go around. I think where you see the most amount of grumpiness from disabled people is toward what you might think of as "trendy diagnoses for the worried well." It's just incredibly fraught and complicated because so many times, especially for diseases that more commonly affect women, or the symptomatology is more vague, we think of them as less important or less real and the people who have them are pathologized.

The disability community has an unhappy history of this. For example, there was a very long period in which they didn't want to have anything to do with people who were HIV positive. It's like no, not those people because it was thought of as...

Something you could only acquire through sinning?

Exactly. They're like no. We're good cripples.

Except for the hemophiliacs presumably.

Yeah. They were in the club already. These kinds of boundary policing and gate-keeping issues are incredibly complicated. In the case of trans-ability, one thing the disability community has pointed out that is interesting is the way in which people react. It is incredibly, ethically complicated what kind of interventional treatment you would provide for such a person. One thing that's at least interesting and a lot of disabled people have pointed out as interesting is that non-disabled people are so floored by the idea that someone might want to become disabled that it just really doesn't make sense to them. "It must be some of the most extreme type of psychopathology if you wanted to become disabled." If you think about all the things that doctors do and are totally legal- I could walk into any plastic surgery clinic and have so much stuff put into my body. I could have all sorts of surgeries under general anesthesia that carry the risk that any surgery under general anesthesia has, and we know there are long-term risks of various injections. I can walk into, not even a doctor's office, but just a massage clinic or salon and have toxins injected into my forehead so that I can't move my face. People are like, "Cool! Yeah, you wouldn't want to age. That would be awful!" And this is all completely legal and nobody talks about the Hippocratic Oath. It's just, you know, "It's patient well-being." Then, the second that somebody wants to become disabled and to be clear, I'm not taking a view on these cases. I'm not a doctor. I'm not a medical ethicist. These cases are incredibly complicated, but I think people just react in horror. Like, "How could you ever? 'First do no harm.' How could we ever consider interventions [like this]? Surely, the goal of medicine is to make people non-disabled." I think that reaction and those asymmetries are interesting and I think they're certainly interesting to a lot of people in the disability community. At the same time, my own view of the complicated issue of what does it take to be a member of a social kind? Does it just take self-identification? That's one thing that a lot of feminists tend to say about gender. Sincere self-identification. Identification over time. If you say that you're genderqueer. I

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Philosophical Profiles

might not have a particularly good phenomenological sense of what that means. I might not have an internal sense of what that gender is, but if you say you're genderqueer, I'm going to take your word for it. If you say your pronouns are they and them, those are the pronouns I'm going to use for you and I'm going to treat you as an expert. I'm going to think that your self-identification is what matters the most in that context. Whereas, if you say, "Really, I'm deaf." I think it matters whether you can hear.

"Call me old-fashioned, but..."

I think that self-identification isn't the only thing that matters when it comes to disability. I think that what your body is like matters. I think that what we should say about trans-abled people is that they want to become disabled.

But then it sounds like you're relying on a distinction between impairment and disability.

No. I think what I'm doing is just saying that disability is partly a function of what your body is like. So disability has as a necessary condition a certain type of bodily feature. So, it's partly a matter of what your body is like, but not entirely a matter of what your body is like.

Charles Mills has this great view about the metaphysics of race. He thinks, in a sense, race is a matter of certain things that are ancestral or biological. Things that have to do with your lived experience in your body. Your ancestry. Your phenotype. Your skin tone. Face shape. All of these things.

It is a matter of those things because of your culture right? So in Brazil, it's not ancestry, it's skin tone.

The reason his view is social constructionist is he says you have to have these features, but the only reason those features matter to us, the only reason we think they have anything to do with race, the only reason we think these particular features go together, and we think they go together and form the kinds they do, is because of how we think about them. I think something similar about disability. In order to be disabled, you've got to have one of this family of conditions that we tend to think of as bodily deviance. But the only reason that these conditions form a kind or form a cluster is because of how we think about conditions like this, rather than anything biological that bodies like this have in common or any notion of normal function or something like that.

Presumably in a culture that was much simpler (I should avoid saying simpler, but you know what I mean—say Kalahari Bushmen, with small tribal groups, very non-technological lifestyle), who would count as disabled would be different from someone here. For example, if you're part of a very cohesive group, you can get away with being deaf perhaps and you don't need very good eyesight provided there are good hunters in the group or you don't need it to read or for a small tiny task.

I have a two-part answer to that question. The way that I think about the concept disability is that I am bifurcating on the actual and present norms that our current civil rights movement has for thinking about a concept, so for thinking about what a disability is. There are a lot of different things you could use the term disability to refer to. It means different things in a medical context than it does in a legal context than it does in a philosophy seminar context. I think there's a particular social kind that's picked out by the activities of a social justice movement and that's what I'm using the term disability to refer to, and I think you're a member of that kind just in case these facts about norms and stigmas apply to you. That doesn't mean that this concept of disability or this social category of disability would be particularly salient in your social context or useful in your social context or the thing that the word disability should refer to in your context or that kind of thing.

Cultural context is an interesting variable here. There's been some interesting anthropological work in regions of Central Africa is one good example, where they wouldn't recognize anything like the category of disability that we have. Because basically they have a distinction between, roughly translated, people who are faulty and people who are bad. There's a small subset of disabilities that are morally laden in some sense that are meant to be signs of bad looks and malfeasance. Then, there's another thing that's just life. People who are faulty are significantly less stigmatized than you might think of disabilities in a lot of Western context, but people who have the conditions that they think of as bad, it's a really big deal. In a culture like that, probably the category of disability that I'm talking about wouldn't be the most interesting social category to talk about. That being said, I think I could truly say, as a person sitting in Charlottesville, Virginia, "Oh. All those people are disabled and they have this interesting way of carving a distinction between disabled people."

Another really interesting cross-cultural example that social anthropologists have done a lot of interesting work on is Hmong society in Vietnam, where there's a family of neurological disorders, but most famously epilepsy, that they don't recognize as bad things at all. They see them as signs of divine blessing. They're kind of surprised and confused when people want to clump these disorders together with other things that people think of as disorders or diseases because that's like a good way to be and these other things are bad ways to be. I think, again, that's a context in which the concept of disability that I'm employing in an American Western context probably wouldn't be all that socially useful, but at the same time, I think it makes sense for me to say, "Oh right. All those people are disabled and they have a different way of carving up disability than I do." That's how I would approach that question.

Next question about your book. What is your Value-Neutral Model and your answer will have to take in Dostoevsky and the cancer survivor who is glad that he or she has had cancer.

What you often hear in disability rights and disability pride communities is the idea that disability by itself is not a bad thing. It's not something that automatically makes you worse off. You may hear, even more positively, disabilities are a natural part of human

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Philosophical Profiles

diversity. There's been fascinating studies on disability rights activists who are offered the following question: "If you could take a magic pill that would instantly remove your disability with no side effects, would you take it?" This was a study that looked at activists with the civil rights organization Adapt. The majority of the people surveyed said they wouldn't take it. It's quite common within disability rights circles to have this attitude to disability that says I don't think my disability is bad for me. I don't think I would have been better off without it. I don't think that disability is something that by itself intrinsically makes your life go worse for you. Also, people tend not to think it's something that automatically intrinsically makes your life go better for you. I'm sure you get that view somewhere. But, it's one of these things. It makes you different, but it doesn't automatically make your life better or worse and it depends on what you combine it with. It depends on what it's combined with and what you're doing with your life.

Do you think that the culture we have, particularly in the United States, is particularly bad for disability in that we have this very Protestant work ethic and this horror of reliance on other people. We have this idea that we should be as independent as possible and one of the things that seems to be a common thread in disability is that you need help.

I do not think that we are particularly bad in terms of being an outlier compared to other societies. For example, it is significantly more common in Southeast Asia than it is in the United States when there's a prenatal diagnosis of disability for a doctor just to say abortion. I'm very pro-choice. I think that any woman should be able to have any abortion that she wants, but I also think reasons why can be complicated. What it's more common to see in Southeast Asia than it is in the United States, for example, is to not even have it presented as an option that you might want to have this kid.

I guess that's the flipside because in cultures where the society is seen as caring for the person more than the individual family then they could say well the society gets more of a say and you'll be expensive, so we get to decide to abort you.

I don't know if you remember the summer of 2016 so many awful things happened. One of the things that happened was there was a really violent incident at a care home in Japan. It's the most single day instance of violence in Japan since the subway attacks. A lot of people were stabbed in a care home by a worker at the care home. The worker later said that he thought it was better that disabled people should die. It was clearly a hate crime against disabled people. The names of the victims were not published. Typically, in Japan, names of crimes are published but in this case the names of the victims were not published. The reason these names weren't published is because they didn't want to shame the families. So to know that you had a family member that was at this care home would be shameful. Disability discrimination and stigma is very much not unique to an American context, to a Western context and I don't think we're particularly an outlier although I think it can look different here. Sometimes the subtlety of it can almost be a little bit more insidious. I do think you're absolutely right that the Protestant work ethic and the myth of independence is a huge part of the stigma about it. Of course

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nobody's independent. We're all radically dependent on other people all of the time. But disabled people are dependent in ways that are often a little bit non-standard or more visible and that's very much seen as wrong or bad or not what you should aspire to.

You see this a lot in politics where the rhetoric of independence is used to blame people for their lives. What do people say when they're complaining about welfare programs? People are dependent on the government. I don't know—do you drive on roads? I feel pretty dependent on government infrastructure, but we have this idea of there's normal dependence—that's acceptable—and then there's pathological dependence, there's stigmatized dependence. I think a lot of times when it comes to disabled people it's pathological dependence, it's stigmatized dependence. Even when a lot of disabled people don't experience it that way in their lives. They don't experience the way in which they need people as pathological because everybody needs people. We need to be a part of community. Eva Kittay has wonderful work on this, but people who are disabled can experience their dependence as a very life-affirming thing, and as a very emotionally affirming thing, and as a very positive thing. That's an uncomfortable thing to talk about because we have this idea that you're supposed to be independent and we can measure the value of a life by how many hours you can work and how much you're contributing to the global economy.

Also, if you're disabled presumably you feel that those on whom you depend, like your family members are doing something that they didn't sign up for.

Yeah. And, there's a difference between sort of expected and unexpected dependence. We expect dependence at the endpoints of life. We expect babies to be dependent and we expect old people to be dependent. When somebody in their thirties is dependent, this is not what we expected. I think for a lot of disabled people there is a lot of guilt and there is a lot of shame that you shouldn't have to rely on people. It's exactly how you put it. This isn't what these people signed up for. It is complicated and I don't want to downplay the fact that in our society, caregiving roles, including caregiving roles for disabled people, disproportionately fall on women. They are not financially compensated and they are not plugged into a wider structure of social care and social support and that kind of thing. Being a caregiver or a care worker can be emotionally exhausting, physically exhausting. It can be financially draining. This stuff is a big deal. It's great when we're doing disability theory to sit back and say "Society should be changed and really the fault is capitalism!" but at the same time there are real issues here. It's very important when we're talking about disability and saying things like there can be value to an experience of dependence. That isn't for everyone. Some people hate it. To not undersell the problems that affect people's lives. The real financial and social problems that can affect people's lives.

Could something like that be said in defense of people like Peter Singer? For example, as you mentioned in your book, there's a very famous article by Harriet McBride Johnson in The New York Times who confronted Peter Singer because of the things Peter Singer says about infanticide. I remember reading this and being sympathetic toward Singer because I thought she was overstating the case. She has this discussion

of how she's talking to her sister and her sister says, "How can you even talk to this man? That's like talking to the Nazis. It's like people in concentration camps going to talk to Nazis." I kind of bridled at this—Peter Singer? And she, of course, goes to talk to him and she presents him as someone who is nice on a person-to-person basis but holds abhorrent views. It's like a nice concentration camp guard, someone who brings you chocolate while you're in the lines to be gassed. Now, presumably what he would say is, "Look, I value your existence because you're an adult. You're obviously an intelligent person. You're happy and you have desires and all that business. It's just that from the point of view of your parents, you're very expensive and they could have an easy kid." What do you say to something like that? It seems like you're kind of torn because as you say you don't want to get in the way of a woman's right to choose to have an abortion and that's the kind of things that you consider. I mean women want to have abortions when they think that they are too young to care for their child. They want to put it off to have a job, so do you think that this complicates it? Because the way it's sometimes presented is that this is cultural genocide. That if you have an abortion precisely because you don't want a disabled child this is cultural genocide. It seems like you're in an uneasy middle ground about issues like that.

I'm in a very uneasy place with issues like this. Partly because we spend so much time judging women's reproductive choices and blaming women for the reproductive choices that they make and if I'm going to spend my time on something, it's not going to be that. There's a lot of things that make me angry and upset in the world that I think deserve my time and I think that I don't particularly want to spend my time looking into the individual choices of women about reproduction and blaming those choices. Especially because I'm not a mother, I've never made that choice for myself and that's such a personal decision. It might be radically different for different women in different contexts.

But suppose someone came to you and said, "What do you think? I am torn about this. What do you say?"

I think that there are a lot of reasons why it's incredibly complicated. I think a lot of reasons why you get the framing in terms of cultural genocide is that disabled people have enough experience of the way that disabilities are looked at in the world to really have the worry that any time we can make a choice between improving situations in society for disabled people or getting rid of disabled people, not getting rid of as in killing people, but trying to eliminate disability as far as we can, people are going to want to make the choice to try to eliminate disability as far as we can. I think a lot of disabled people feel like not only is that going to have bad effects on the disabled people that actually exist but that's just bad for society. In an important sense of people whose bodies are viewed as defective have something that we as a society need. Something to tell us about the human condition. Something to tell us about the wide variety of which you can build good lives.

“ I think a lot of reasons why you get the framing in terms of cultural genocide is that disabled people have enough experience of the way that disabilities are looked at in the world to really have the worry that any time we can make a choice between improving situations in society for disabled people or getting rid of disabled people. People are going to want to make the choice to try to eliminate disability as far as we can. ”

That sounds very Millian. It directly parallels his argument for free speech. Or “experiments in living.”

I’m going to take that as a compliment. That’s one important piece to the puzzle. I’m thinking of particular instances of reproductive choice and then what you would say is sort of like the broader, Singer-style, consequentialist argument. For particular instances of reproductive choice, I think one thing that is so important to emphasize is that as close as we can know anything in psychology of course, is the replication crisis is a thing. The empirical data here is shaky, but we have a really solid base of evidence that suggests that non-disabled people are just really bad at thinking about disability and thinking about well-being in the context of disability until they’ve experienced it for themselves or their children.

When I was a kid, I remember writing a story about someone who was blind. I was a teenager and I really threw myself into it. It was like despair and misery and I thought this was one of my better stories. It was achingly, almost suicidal and my teacher just said, “You know, I don’t think blind people are really this miserable about being blind.” And that was an early lesson in this point. As a teen I thought it would be terrible. It would be absolutely appalling. I can’t imagine wanting to go on. The things that I loved to do that would be stolen from me, but then there’s all these studies that after something catastrophic happens to you like an impairment or paralysis, within a year, your level of happiness is pretty much the same as before.

I think we tend to think about it solely in terms of limitation and in terms of lack, and of course, you don’t want that for your children. Nobody wants that for their children. For a lot of disabilities, and I mean certainly for mine, there absolutely is limitation. There is lack. There is loss. There is profound loss. There’s gain. There is all kinds of gain. There are experiences that I never would have had. There are ways of living that I never would have been exposed to, and if I’m thinking about how my parents would have seen my future, they would have seen all the loss and they wouldn’t have been able to think about the gain. The gain would have been invisible so that’s kind of the way I tend to think about disability—it’s just one way of being human. Having a body that is any particular kind of way is having a body that’s limited. Having a body that is lacking some things and not gonna let you do some things, but will let you do other things. One of the ways that is kind of troubling about how we think about disability is that we don’t see the gain if we haven’t had the personal experience of it. We don’t see the uniqueness if we haven’t had the particular experience of it.

Have you seen “Nanette,” Hannah Gadsby’s Netflix Special?

I have about five friends who are about to disown me, but I have not seen it.

It’s not unique to this, it’s just how she reconciles with her mother. Having grown up in Tasmania, in a very conservative, Christian environment, and she comes out as gay. Her mother feels bad about the way she raised her, but she says something like, “I just felt so bad because I knew life would be so hard for you,” and that so directly parallels the views about disability. Like, “It’s not that I didn’t want you, it’s that I

didn't want your life to be hard." If you can say that about being gay, and you push this parallel several times in the book, that nobody says that therefore we should abort gay children.

Yes and absolutely. All you have to do is look at the suicide rates for gay teenagers. Life in a lot of ways is harder if you're gay. And harder in a way that's not strictly limited in some cases to social dimensions. If you're gay, given the way our world currently is, and our science currently is, you know you're not going to be able to have a biological child with your partner. A lot of gay people don't care about that. A lot of gay people do. For some gay people that is a grief. That's something that is just a loss that they live with. That doesn't mean that it's "all the goods of straight people minus the baby having and you get gay people." No. Lives can be different. You can take a loss here but get a gain here such that on the whole, things are different. There are ways in which lives can be harder without obviously being worse, but it seems like the solution isn't: "so we need to minimize this feature." So, there are ways in which pretty soon we probably would be able to select, say, skin pigmentation. If genetically you and your partner can combine and have a range of skin tones. We know enough about colorism to know that life for the darker end of the skin pigment, especially if maybe your kids are going to be mixed race, and they could come out a wide range of skin pigmentation, so they might look quite dark-skinned or they might look quite light-skinned, life for the dark-skinned person is going to be substantially harder than for the light-skinned person in a lot of ways. Now I want to be super clear in saying the following that I'm not trying to say that racism and ableism are the same thing. They are radically different issues here, but I think it would be really troubling to conclude from "darker skinned person is going to have a harder life" to, if you can run a test for skin phenotype, "so it seems like selective abortion for darker skinned fetuses is morally unproblematic."

So, just the claim that it's harder, just the claim that a person might have a more challenging life, doesn't license the idea that selection is always okay. There might be some cases where what you need to change is society rather than changing individuals and in fact, the more you change individuals in some cases you might be entrenching prejudice. You may be making prejudice harder to change. I think that's part of what some disabled people are worried about when they think about selective abortion. When it comes to this sort of broader consequentialist argument that Peter Singer makes, where in a lot of cases your baby is going to be more expensive or they're not going to be the baby that you wanted or this kind of thing, so you want to be able to choose. I am not a consequentialist which is why I find this headspace sometimes hard to get into, but I think surely the consequentialists, if they're going to have a workable consequentialism, have got to play the long game. You've got to think about how are we thinking about the consequences of our actions as we're thinking about society in ten years time, twenty years time. One of the things that we've seen is that accommodation for disabled people makes lives easier for a whole range of people in ways that we might not have expected.

When you're making a world that's more accessible to disabled people, in a lot of cases, all sorts of people are limited sometimes temporarily sometimes not. My favorite

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example of this is that the ADA forced ramps to go up all over the place. Far and away the most use gotten out of ramps is not from wheelchairs, it's from strollers. Suddenly, women could take strollers out everywhere. Strollers can go in buildings that they did not used to be able to go into. If you look at strollers in the 80's and they were prams. They were these delicate little things for pushing around on the sidewalk. Suddenly, you look at strollers now and they're basically like tanks.

The wheels getting bigger was a huge advantage.

They can take them all over the place and you can be out with your baby. And then, actually people have done some like quasi empirical research on this- the cooler that strollers got, the more you saw men with strollers. The cooler the stroller got, the more that you could take strollers all sorts of places, the more common it was to see men with strollers. You had all these knock-on effects of just making spaces more accessible. None of these people were covered by the ADA. And of course, the God's honest truth that no one likes to talk about when they talk about disability is that most people will be disabled before they die.

That's another thing I wanted to bring up. Does being old count as being disabled?

It depends on who you ask. I don't care about this question very much. But, most people will have bodies such that they will need accommodation. They will need the kind of accommodation that people with disabilities are arguing for and fighting for. They will need help. They will need caregiving. Most people will have that kind of body before they die. Now, do you want to call that "disability" or do you want to say we shouldn't call it disability because it's normal aging and it's not pathologized in the same way? That's kind of a terminological question that is not a hill I want to die on. Most people will need the kind of accommodation or benefit from the kind of accommodation that disabled people are arguing for and promoting before they die. People are living longer but they're not living in what you might think of as full, unimpaired health for all that period. You're going to need it for a significant period of your life if you're lucky. You should consider it a privilege if you have a long period of your life where you need these accommodations. In a way, this is something that I think a lot of disabled people argue, especially as our population ages. People are living longer. This is just something that we need. This is something that promotes general well-being. We're not that nice to disabled people. We're pretty crappy to old people too.

As I get older, I'm getting more radical.

I think the experience of struggling with your body comes pretty close to universal.

But, on the other hand, it's very common for old people to moan about being old. Perhaps there are some exceptions, for example in book I of the Republic, where [Cephalus] says, "Whew. I'm glad to be old so that sex isn't an issue anymore. I don't have to worry about it. I don't feel the urges anymore and it's sweet." But, other than that, it's very common for old people to bitch and moan about being old. Should

Philosophical Profiles

there be an old person's identity where they say stop bitching and moaning about it and embrace their identity? There was a "Grey Panther" movement wasn't there?

I think so.

That seems to be presumably what the bad difference people can say well, "Hey, look at the old people: they're all complaining, they want to be young." That's directly parallel to being disabled because the reason why they want to be young is that they're losing abilities and life is more painful. Billy Crystal said he was going to call his biography "Everything Hurts."

There's a great episode of Parks and Recreation where Leslie Knope is working with a senior center and she talks about their number three social complaint was "lack of ramps" right behind "everything hurts" and "I'm dying." Obviously, there are a lot of ways in which aging isn't the same as having a disability in the sense of there are a lot of things about it where it represents change from what you used to be. It also represents for a lot of people, some of the meaning attached to it, is decline and decay and you age until you die. Most people don't want to die. A lot of the stuff around that is going to be emotionally really fraught and complicated. That said, I do think in our society, we valorize youth so much in a way that's kind of weird and gross. I don't know about you, but there's no amount of money you could pay me to be 23 again.

It depends.

But there's this idea, especially for women, I actually hear this from my female students a lot, like, "Oh God. I'm 22. This is as good as it's gonna get. I'm in my prime and it's all downhill from there." I think that's definitely an idea that we should resist. At the same time, you don't want to expect people to be like, "Aging is amazing." Sometimes, the human body is annoying.

This is a silly example, but it's kind of funny to watch great old Kung Fu movies of the 70's. Like the early Jackie Chan movies. The big boss is always an old guy. It's presumed like he will be at the pinnacle of his Kung Fu abilities. But, I'm sitting there thinking why are you picking on this old guy?

Differences of mastery. One thing that we certainly see a lot for disabled people is that the positive sense of disability that people often have is often closely linked to community and closely linked to a sense of disability identity. That's not to say that disability identity is what a positive thing is. In many cases there are particular things that people point to—"This is what I like about being disabled," "This is what I value about being disabled"—but often what facilitates that is a positive sense of yourself as a disabled person. When you can say, "I'm disabled," and that's an identity that you claim and that's an identity that you value.

One disanalogy with aging is that people don't tend to form self-identities for ages, because we know that all ages are transient. You probably have met people in your life that did form a self-identify for an age and it's always just really sad.

“ Obviously, there are a lot of ways in which aging isn't the same as having a disability in the sense of there are a lot of things about it where it represents change from what you used to be. It also represents for a lot of people, some of the meaning attached to it, is decline and decay and you age until you die. Most people don't want to die. A lot of the stuff around that is going to be emotionally really fraught and complicated. ”

But then there's the generations that carry it along like "I am a Generation Xer."

But at least all the Xer's can sort of age together. Occasionally, you have people that somehow they formed that sense of self circa age...

Like Tom in The Great Gatsby, high school football was his peak.

That was his thing and he just can't get over it. For most people, your sense of self evolves over time and evolves as you move through life. It's not particularly tied to age. My experience of talking to people who struggle with aging—and of course different people react differently—but it's always like, well, they had things that were really important to their sense of self. That has been taking away from them and that's what frustrates them. Whereas what you see for a lot of disabled people is very much the disability becomes "a part of who I am. This is part of how I live my life." It wouldn't surprise me if that's going to lead to differences in how people respond.

But what if somebody says to you that all of the good things about being disabled are extrinsic to being disabled?

That just seems totally false to me. To go back to the question you asked about the grateful cancer survivor; one thing that I wanted to set out to do when talking about disability as a neutral concept was to be able to say more than "sometimes bad stuff can have good consequences."

It's like a theodicy that drives me berserk when I do philosophy of religion. "Well, you gotta have a bit of vinegar for the sugar to taste sweet."

Yeah. You've got to have that bit of struggle. This is actually a really common way of thinking about disability for disabled people who live good lives. This is the narrative that a lot of non-disabled people want to impose: "Oh, the struggle! You've been refined through fire!"

"What does not kill us..."

"Makes us stronger." Nietzsche was an asshole.

Apparently, his sister made him look worse than he was.

Interesting, but he did say that women are basically like cows when it comes to reasoning, so he's not my favorite philosopher. There's this worry that the view is going to melt down to.... there're all sorts of things that people say like, "Oh. I never had a positive sense of self or self-esteem until I was bullied and I learned to stand up for myself." Well, that doesn't mean that it was good that you were bullied. It was bad that you were bullied, but maybe overall the net consequences for you were good. Or, "I never appreciated the good things in life until I was in that horrible car accident and it reshaped everything." Well, we don't want to say horrible car accidents are good. There's a difference between saying that a thing itself is neutral or a thing itself is good, and saying sometimes bad things can have consequences for your life so that overall

Philosophical Profiles

you're sort of not sorry that you experienced it. Also, one of the things we know about people in terms of how they talk about their lives is that people don't really express regret all that often. People tend to say something like, "Oh. I'm glad it worked out the way it did." We say this for all sorts of things.

I was worried about the case of the grateful cancer survivor who's like, "Oh. I never really appreciated my life," or "I never really had a good work-life balance," or whatever, "until I got cancer. That made me change things." This person is not saying cancer is a valuable part of human diversity. This person is not saying "Hooray cancer!" There's some things that are not directly related to my experience of having cancer cells in my body and going through chemo therapy. I care about work-life balance and I care about mindfulness.

So, you're contrasting them with disability rights activists who say, "No, no. It's the disability." So, the response is going to be "You don't actually mean the disability. You do mean some of the things related to it." For example, Dostoevsky. Now, Dostoevsky makes me envious of this—is this a special kind of epilepsy?

We don't know for sure what type of epilepsy Dostoevsky had because we don't have his fMRI results, but people have speculated based on his first-person accounts of his pre-seizure auras that he had temporal lobe epilepsy.

That just sounds amazing. But, that seems kind of rare. That seems like a special case. That's just sort of over here and even then, presumably someone could say "Well, let's imagine you could get that through a pill form without having to have the seizures and the effect on your life. So, it's not the seizures, it's the ecstasy that you like."

I guess when it comes to embodied experience. I don't have that much patience with those kind of hypotheticals. Imagine I could put you into an experience machine that tricked your brain into having the taste sensation of tasting chocolate. "It's not really eating chocolate that you enjoy." I mean if the world were very different, we might say different things about what I enjoy. But, the world as it actually is, I enjoy eating chocolate. I don't really all that much. I don't know why I picked that example.

What kind of monster are you?

It's not that I dislike it. I just don't care about it all that much. In a lot of these cases, given what we say about most types of physical, sensory experiences, I think that insofar as I enjoy drinking coffee or you enjoy going for a run, or these kinds of things that people enjoy.

That's your sister. That's not me.

Yeah. She's my favorite case for talking about these things. I think Dostoevsky, sincerely valued this type of pre-seizure aura, and he valued it in a very interesting way because

he did think it was essential to his art. But, you're right, that's an extreme case. We don't want the neutrality of disabilities to stand or fall on weird pre-seizure euphoric artists.

That sounds like what you call "the X-Men."

Exactly, that you have these like special extra super abilities.

Which they seem to be pushing for autism particularly hard.

Yes. Which is interesting. I think the most interesting cases are the more mundane cases like what could you value about being blind. Like Kim Kilpatrick says, being an adult woman and having no sense of what it would even be like to be self-conscious about your appearance. Just not even phenomenologically understanding what that is. As a woman who does understand what it's like, I can get why that would be a valuable thing. Or not being able to judge people based on what they look like. I can understand how that would be an incredibly valuable thing.

I have a friend who is deaf, but has sort of high-level hearing aids and she says, the older she gets the less she uses them because she just can't be bothered. She says one of the sensory experiences that she really values is being in a really busy city like New York or London and being overwhelmed with a mass of people, but in just taking it in visually.

I can totally see that. Perhaps an analogy would be when I was a kid, if you told me that there would be things like [smartphones], handheld computers that you can do all of these things. That you can play the most amazing games, I would have been over the moon. Whereas now, I want to go on a vacation where there is no cell phone connection. I want to go stay on an island where I can't get the internet, despite the internet being a magic window into a galaxy of everything desirable, it's the cause of anxiety and overload. So, I can kind of see that, but at the same time, you sort of talk a little bit about this, don't we really want a world in which we can really sort of sample these different kinds of ways of being without that being it for your entire mortal existence.

There's something to that idea. But, again, going back to what it's like to be a human being that has a body. Any way that your body is going to be is invariably going to come with limitations. This is kind of the body that you're stuck with. Now, I like science fiction. I like to read about what might be ideal. Have you ever read the culture novels by Iain M. Banks? These are basically novels in which super, super, far future and people can be, like body mods are so advanced that any way you want your body to be, it can be. There's this kind of sampling. I think that's fun to think about. It's interesting. Would that be the sort of ideal? I can think of virtues. I can think of vices.

What would a disability rights activist's view of heaven be? Because when you talk about heaven—I teach a "Mortal Questions" class, and we talk about that—what kind of immortality would be the one you wanted, and with my students the age 25 keeps coming up. "Perfect, healthy, me, age 25. That's the way I want to be." Well,

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but suppose we take a Cartesian view and you are totally disembodied so disability presumably is no longer an issue. Is the disability rights view that that would be okay or that that's a bad view of heaven? Obviously, it's a view of heaven that if you propagate it is going to be damaging. It's bad in that respect, but if it turned out that that's what heaven was like, would that be a disappointment?

That's an interesting question. It's interesting as well because when I was writing the book, I was looking for really strong anti-cure stances, anti-cure just being like a personal statement of like "I wouldn't take a cure," because one of the things I was finding was that a lot of times when disabled people make some kind anti-cure statement, they are disbelieved. "Well, you don't really mean that. You're just saying that for political reasons," or something like that. There's an amazing theologian named Nancy Eiesland who was a Christian theologian, she was a disabled woman, and she believed in the bodily resurrection. She believed very strongly that she would have her disability in Heaven, because she said basically "it needs to be my body and it wouldn't be my body," because people always told her "in Heaven you'll be healed," and she just really rejected that. She had all these descriptions of what she pictured Heaven as and what Heaven would be for her as a disabled person. That's an interesting case for me because I think she meant it, as a disabled person, that wasn't a purely political posturing thing she was saying. She wrote this book called *The Disabled God* and it was the idea about physical perfection and disability. She used the image of the resurrected Christ that's both perfect and has giant holes in his hands and feet. She had to try to motivate this liberation theology for disability. This idea that a body could in some sense be perfect in the eyes of God, but also disabled in the ideas of most people. I found that incredibly interesting to think about. The question of, does disability positivity require, insofar as people talk about heaven, do we need to talk about bodily resurrection, or something like that? I don't think I would go that far because I think it depends on what you think about personal identity and that kind of thing. I think it would be better if we didn't go around telling disabled people things like, "Oh. Well, don't worry you'll be cured in Heaven." That's like a less helpful thing to say to people. I don't think I have any stronger views than that.

There's also the question of what about someone with Alzheimer's?

What about various psychological disabilities which would still crop up in the Cartesian case even in like, I hope people aren't depressed in heaven...

Except are they the product of humors? Too much black bile?

Nancy Eiesland's work was actually a really wonderful source of pointing these kinds of things out. The issue of which of the values of disability that we might think of as intrinsic and which we might think of as extrinsic, is often a very slippery issue. There's not necessarily a hard and fast line that we can draw, because for a lot of disabled people I think some of the things that we find most valuable are just ways in which having a body that's stigmatized as defective can in a way kind of free you from certain social norms. There's all these pressures of you ought to be a certain way and you need to be a certain way, but there's also the sense that kind of ought implies can.

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It's like having a Goth body, or a Punk body.

I had this conversation that we recorded for Philosophy TV, with my friend Joe Stramondo who's a wonderful philosopher of disability. He's a dwarf and we were talking about ways in which we value disability and I was talking about for me as a woman, it's been tremendously liberating to just realize that all of these ways that society tells you your body has to be, I can't even play that game, so I might as well just walk off the field. In a way that I don't think there's any way I could have gotten there on my own.

Joe said that he's felt very similar things for just pressure that people have. He's like, "I just don't feel the pressure that I see a lot of men feel for how you're supposed to look." The way he put it, which I will never forget, he's like, "I don't care if I have a six-pack—I'm three feet tall!" It's just this way in which once your body is just obviously outside, once you've colored outside the lines in these very particular ways, the lines start to matter a little bit less. And of course there's this sense of, "Well, isn't what you really value just not attaching much value to norms about women's bodies?" Well, in a sense, sure. But certainly for me as this particular woman, there's no way I would have gotten to the level of nonchalance I have about certain norms about the female body without having a body that just kind of disqualified me. Is that extrinsic? Is it intrinsic? I think that's not a particularly good question. It's certainly a fundamental part of how I experience myself as a disabled person. Given that I think disability isn't just what your body is like. It's about norms that we place on certain bodies. For me, that seems like a part of what it is to be a disabled person.

The last-but-one chapter of your book deals with a specific criticism which is that your view seems to make it okay to cause disability, or in some sense make it bad to attempt to cure it or prevent it, or something like that. What would you say about the extent to which large parts of our medicine is based on a kind of horror of disability? That we do want to avoid this. For example, polio had to be eradicated. Obviously, polio killed kids, but even when respirators were invented and it no longer kills them, we want to inoculate kids so that we don't have people with polio. We don't have someone like FDR anymore. We would have "Healthy FDR" or whatever. What do you say in response to the criticism?

I would say it's complicated.

That seems to be a lot of your answers, but we want it to be simple!

I know. I preface all of this by saying that I have tremendous respect for doctors and the medical profession and have relied at various points in my life on them to keep me alive and I like being alive, so...

I'm guessing you're not an anti-vaxxer?

Oh, God no. I think biological dysfunction is real and it makes sense that medicine would want to treat it. The overall industry of medicine does a lot of good for a lot of people. I also think, in many cases, probably the bigger thing driving medicine rather than horror

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Philosophical Profiles

of disability, is horror of death. You're absolutely correct that a big part of how we organize treatment, and how we prioritize treatment, and how we fund treatment—I could go on a whole extended discussion of the QALYs (quality adjusted life-year) and the DALYs (disability adjusted life-year) measures and how health economists tend to value treatment intervention and value the quality of lives based on “how many years have you lived with a disability?” and that kind of thing. So, there are a lot of things going on that I think are reasonably unfortunate and unhelpful. This is a tension that I live with in my own life. I don't wish that I wasn't disabled, but I go to doctors all the time to deal with various, what you might think of as symptoms of my disability. You know, my ass is in physical therapy all the time and I do exercises and all kinds of things to basically manage aspects of the condition and also manage the degenerative aspect and the decline. Do I want to get worse? No. Absolutely not. I don't want to get worse. I'm pretty sure that if I do, I'm gonna be fine, but of course people don't want to change. People don't want to change their lives. It makes absolute sense that even while we might think that disability is a valuable and important part of human diversity, it makes sense that people don't want to join that team. It makes sense that if you're very attached to your life as a non-disabled person, you don't want to become disabled. There's something wrong with stigma, and there's something wrong with the way we somewhat attach stigma to disabled people's lives, but there's nothing wrong with not wanting to be disabled. There's nothing wrong with taking a lot of measures to attempt to avoid disability. I also think that people often misinterpret when people with disabilities do various things to their bodies. “Oh, so that means you really don't want to be disabled because you're doing all these things to modify symptomatology.” No. Of course there are some things about this experience that I don't like that much or that I wish were different. I do a lot of things as a female-bodied person to manage my menstrual cycle and honestly if you could give me a pill right now that says you will never have a period again, I'm going to take that pill in a heartbeat.

Menopause is that pill.

It's coming. Just gotta wait.

But you don't want to be old. That's your trouble. That's your prejudice.

I don't care that much about being old. My able-bodied friends who are aging are being very precious about getting old. I'm like, oh that's funny. You're used to your body doing what you expected it to do!

You get to gloat!

It's like, oh this is just it's gradual process of decay and decline until we all die. Such is the human condition. Have you not accepted that yet?

That reminds me of something. Have you ever read- there's a series of books by a guy called Jonathan Stroud called The Bartimaeus Chronicles. They're actually rather good. It's around the idea of genies only they're called djinns and Bartimaeus is the

genie and they interact with various humans. It was very wittily written. I think he sold the first one for millions and it was going to be a movie and then I think they discovered oh, only Harry Potter and The Hunger Games works and all these other franchises don't. I'm gonna give it away- one of the things that happens in it is a female human protagonist who is a young woman, is made very old. That's one of the side effects. She becomes an old woman and I remember thinking that, this is terrible, but she takes it very well and it was an interesting thing for the author to do that she didn't so much mind suddenly becoming old. Or at least she took to it very easily.

Actually, one of my very close friends teases me. I don't have children. I'm child-free by choice and I walk with a cane, and I started using mobility aid when I was 28 maybe. She teases me that basically in the great female life cycle, I just skipped over mother entirely and went straight from "maiden" to "crone." Crone is just suiting me really, really well. It's much more conducive to my personality than either of the two previous ones were. I have no idea what I was talking about...

Causing disability.

Right. Of course when I take steps to modify my menstrual cycle or modify the effects of my menstrual cycle, it's not that I wish I was a guy. I like being female. I like having a female body. There are some aspects of having a female body that frankly are the worst. They're just terrible. I wish that those aspects of a female body could be moderated, but there are other aspects of a female body that are fantastic and all of it is better than being permanently attached to a scrotum your whole life!

It's not necessarily permanent.

I think that in general, we're comfortable with the idea that you can like an embodied thing about yourself without liking every part of it. For a lot of people who are disabled, people think that when you're attempting to modify symptoms or modify this- "Oh. So that means you secretly want to be non-disabled." No. You're trying to have some agency and some locus of control and manage the parts of your body that you don't like so much. Or have some more control over them. Or have some more say in functioning. Also, of course, it's really important that if disability is as, I've argued, neutral, then that's consistent with it being something that's bad for individuals in a specific context. My disability doesn't interfere with my job at all. In fact, I think it enhances my job. If I was trying to be a firefighter, it would interfere with it a lot. I should not be a firefighter for many reasons. You don't want me to rescue you from a burning building. But, if that was my passion. If that was my life dream. If that was my goal, then having a body like this would be a real bummer. If that was what I had worked towards. It's not and I think there's something to be said for having goals that are reasonably flexible. Deafness isn't bad for a lot of people in my view, but I'm pretty sure it was bad for Beethoven. It was heart-breaking for Beethoven and I think we need to have enough nuance and a view of disability to say look, something can be neutral but can be bad for individuals. Especially in a world that stigmatizes disability, you might have a job that requires you to perform physical functions and you might need that job to feed your family and of course, you

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Philosophical Profiles

are going to want all the physical treatments that you can get in order to try to allow you to have a level of functioning that allows you to do that job. There's nothing wrong with that. That is not stigma. Where we get into trouble, I think, and you see this a lot in medicine, is where we prioritize treatments that get people to some sort of simulacra of normal functioning rather than treatments that are going to help people live well as a disabled person. Often the treatments that people pursue will be harmful. They will have a lot of iatrogenic side-effects. So rather than just saying, "well, let's see how we can get you to a good level of functioning as a disabled person," they will say "well, let's see what surgery we can try," or "let's see what high-powered drugs we can give you because obviously the goal is to get you as close to the normal standard as we can." When that's not obviously what's best for people's well-being. You see this a lot just with the structure of funding in medicine. If you are trying to research a new highly invasive surgical procedure, you can get all sorts of funding for that. If you are researching a new assistive technology, funding for that is on life support.

Like you said about the people who object to the Jerry Lewis Telethon and autistic activists also oppose Autism Speaks because it's the same thing.

It's all about the cure. In a perfect world there's nothing wrong with that. Scientists do the research that you're interested in doing, but the idea is like when all the money goes to these things that aren't necessarily gonna make people's lives better and there's a lot of practical things we could be doing that would actually be helping disabled people live better lives and we don't give money to that because that's not what we think an intervention should look like. That's not what we want for people. I think that's where it gets really unfortunate and in a way that just makes people's lives worse.

So, to wrap up, how would you situate your view, well you have several views, but how would you situate yourself in this sort of spectrum of views about disability? You reject, obviously, the "bad difference" view of disability, that disability is a bad thing, the ideal world would have eradicated disability. But you also don't seem to be on the other end where you, for example, would chastise a woman for aborting a child that she knew was disabled. Like, for example, if somebody discovered she had a mixed-race child through some kind of sperm donation mishap and aborted it for that reason, presumably we would look more morally askance at that person than, or at least on your view, than if she aborted it because she knew that it would have MS or something like that. Would you say that's right?

Yeah. It depends on her financial situation and it depends on her work situation. And it depends on all sorts of things that are complicated.

Well, she could make the same arguments about a mixed-race child. Suppose she lives in a, well you do live in Charlottesville, which is unfortunately famous.

We're coming up on the one-year anniversary. Yes.

So, couldn't you make similar arguments that, "Hey, I'm not racist myself, but I don't want a kid that..."

I think you could and I think the analogies here are interesting. Again, I think, for me personally, people spend enough time blaming women for their reproductive choices.

Let's say a couple working as one.

Invariably though, unless there's complicated trans issues going on, it's usually the woman that's pregnant. For me, personally, I wouldn't want to make a blanket statement of what's right or what's wrong there, because it might depend a lot on what other kids you have. That's not the hill I want to die on.

So, you want to both say that a world in which there are disabled people is a good world because different ways of living are good. There are good things that you cannot get in a non-disabled existence. But, on the other hand you want to say it's still the case that disability can be thought of as in some sense a strain on your body.

Yeah. So, basically, what I have tried to do with the view that I've defended is kind of tread a middle ground between what I think was like a standard medicalized view of disability, which is just disability is a medical problem and it's bad, and the social model which is disability is purely a social phenomenon and if we could get rid of ableism we would get rid of disability. You just have people with impairments but impairments would be kind of like a nuisance at most. On my view, I want to say, what does a future utopia look like if we're just thinking about it in terms of disability? Is it a world in which we've eradicated disability? Or is it just a world in which we've made society fairer? Are there still people with Downs in that future? Are there still people who might use wheelchairs or mobility aids? My view is definitely that in thinking about what we would want a future utopia to be like, disability is an important part of human diversity. I think it's a valuable part of human diversity. I think it's a part of the human condition and I think what we ought to be working for is a world that's more accommodating of disabled people rather than a world in which we've eradicated disability because I think disabled people bring something valuable that you would be missing if you didn't have them around. That being said, I think that there are ways in which, it might depend on the particular disability, but that is compatible with saying that there are ways in which there can be harms and costs associated with having a body that's considered disabled, that are independent of social prejudice against disabled people. You could be as nice to me as you wanted to be. Both like personally and socially and give me all the accommodations in the world and I'm still going to have to have surgery on a reasonably regular basis. I don't like surgery. Surgery sucks. And even if I didn't mind it, that's obviously going to make demands on my body and my time and how I live my day to day experience in a way that is different from most people. And in a way that is not just a mere nuisance. It's complicated and it's profound in a lot of ways. Now, that doesn't mean that it's all bad. The very same thing that causes loss or harm in one place can cause gains and benefits in another. So, it's like, it's not better off not worse off, just different. But, I think it's consistent with saying that disability is a natural part of human diversity and a valuable part of human diversity and not something that by itself makes

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Philosophical Profiles

you worse off. I think it's consistent with saying that you can also say that yeah, there are some ways in which a disability can harm you that's independent of society being prejudice against disabled people. It can be complicated to live in certain kinds of bodies.