

The Life Worth Living with Joel Reynolds

Christiane Wisehart, host and producer: I'm Christiane Wisehart, and this is Examining Ethics, brought to you by The Janet Prindle Institute for Ethics at DePauw University.

[music: Blue Dot Sessions, Golden Grass]

Christiane: On today's show, we're exploring the fascinating and complex world of disability and ethics on the show today with philosopher Joel Reynolds.

Joel Reynolds: Disability is not simply a universal and essential aspect of human life. It's a universal and essential aspect of how we think about organizing social life and how we think we ought to organize social life. There's the normative or the ethical component coming out. And one of the reasons why I think disability is so powerful as a touchstone for ethics, for how we think the world ought to be, how we ought to act, how we ought to organize our social and political institutions. One of the reasons I think it's so essential is because the experiences of disability tell us things about what it means to be human.

Christiane: Stay tuned for our discussion on today's episode of Examining Ethics.

[music fades out]

Christiane: Joel Reynolds is Assistant Professor of Philosophy and Disability Studies at Georgetown University. Their new book, *The Life Worth Living: Disability, Pain and Morality*, explores disability from a philosophical perspective.

[interview begins]

Christiane: I'm going to ask you a question that I normally ask at the end, but I kind of want to know it right now with you, which is why do you care about this topic? What brought you to this particular work?

Joel Reynolds: I didn't realize it for many, many years, but I had been thinking about disability in a political sense, in a philosophical sense, in all sorts of senses as far back as I can actually remember because my brother and best friend Jason was born with cerebral palsy, muscular dystrophy, and hydrocephalus, among other things. We were very close. I was one of his primary caregivers in addition to us being best friends. And I saw from an extremely young age, the ways that people would treat Jason differently than they would treat me or others, and the way that people would regularly make assumptions about the sort of life he was leading and his quality of life. The way his bodymind worked, he was very visibly disabled, and he also required care for all of his basic needs, whether it was eating or you name it.

And then my mom became disabled when I was 9 or 10 or so, it's a little hard to put an exact date on. She developed TMJ, fibromyalgia, degenerative disc disease, and ended up being a chronic pain sufferer, which is as the book tries to make very clear, a unique, a distinct way of being disabled. One that does come along with certain, perhaps even necessary, impacts on quality of life in a negative way. And the way my mom was treated was quite different and quite distinct from Jason and yet had again, negative ramifications in all sorts of ways. In her case, there was very clear combinations of ableism with misogyny. There was all sorts of stuff going on.

Talking about and researching and doing work in philosophy or disability, for me is personal because my whole life has been one of experiencing and thinking through the way in which disability is treated in the world. And of course as happens to so many people, I became disabled later in life, in my case, through psychiatric disabilities, depression and severe GAD, and these sorts of things. In working on this project, when all is said and done, it's not just about my family. It's also about me personally. It's all of these things are there. So this is a very, very personal project, even though there's moments that I get very theoretical, it's very practical and very personal as well.

Christiane: Why does disability need to be looked at, from a philosophical perspective, from the perspective of the field of ethics, as opposed to maybe just from a political perspective or maybe a medical perspective?

Joel Reynolds: Disability is not simply a universal and essential aspect of human life. It's a universal and essential aspect of how we think about organizing social life and how we think we ought to organize social life. There's the normative or the ethical component coming out. And one of the reasons why I think disability is so powerful as a touchstone for ethics, for how we think the world ought to be, how we ought to act, how we ought to organize our social and political institutions.

One of the reasons I think it's so essential is because the experiences of disability tell us things about what it means to be human, and what it means to be human with regards to all sorts of aspects of human life across the life course. To give a very concrete example, every single person, even if they never across the course of their life identify as disabled. Every single person is going to experience states of impairment and experience states of dependency and interdependency that will require for most people, an extremely complex set of caring procedures. And it doesn't matter where you live in the world, we are communal organisms and we require a massive amount of labor and a massive amount of attention and a massive amount of all sorts of resources for any single one of our lives.

So when you think about disability in this expansive way, as an essential aspect of being human, one of the things that follows from that is an appreciation of the nested networks of dependency and interdependency that are the condition of the possibility of human life full stop, but certainly the condition of the possibility of a good life, of one that allows people of all sorts of

bodyminds to flourish in the ways that best fit them. So this is all to say, I think that careful reflection upon, and engagement with, the experiences, the vast and varied experiences of disability, with the amazingly rich resources of disability studies, an interdisciplinary and multidisciplinary set of debates and literatures that span the humanities and social sciences, and engagement with disability activism. I don't care what someone works in, whether they're a political scientist, whether they're in public health, whether they're in government, whether they're in, it doesn't matter what you do. If what you do relates to human life. I think engaging with these things is going to enrich one's understanding of the world.

Christiane: And you write that philosophers have actually thought about disability before from almost the beginning of philosophy, right? Aristotle, Socrates, you help us understand what they thought of disability. But you write that the problem is that they almost always are sort of fusing the idea of disability with pain, and you call this the ableist conflation. So can you help us understand why the ableist conflation might do harm? Or what's wrong with that conflation of pain and disability?

Joel Reynolds: Yeah, the ableist conflation is one of the oldest and most intractable problems historically, like in terms of intellectual history, that people who take the phenomenon of disability seriously face. Things are getting better, don't get me wrong. But I still think it's the case that in 2022, many people grow up being taught that to be disabled means something is just wrong with you, that you would rather not have.

There is something to this, right? So let's take a very famous historical example, Oedipus. How does that story, that myth really, how does that myth begin? He's born with a clubfoot. And in Greece, in ancient Greece, children with quote, unquote, physical deformities or physical abnormalities were left out in the countryside to die. The practice was called exposure. And Oedipus Rex starts with a shepherd seeing this kid and being like, "Oh, maybe I'll not let this kid die. Just because his foot looks a little different, or works a little differently." The practice of exposure was not uncommon. That was common across the ancient world. Similar sorts of practices like that. If you were born in a way that we would today refer to as disabled, it was assumed that you will either live a life of pain or suffering due intrinsically to whatever the condition was or because of the impact it would have on your engagement with the social world. Impact either negatively or impact in the sense that you were thought to not contribute to society in some way, you're better off dead.

Most people in the 21st century can see that that basic linkage, "you're disabled, therefore you should literally just die," is almost always problematic. But the link between disability and pain and suffering more generically that still holds for people. Just think about the 1990s, you have the Jerry Lewis telethon being streamed across the world and you have what disability studies scholars and activists will call inspiration porn, or in the telethon case, it's closer to, it's pity porn as well as inspiration porn. And if you look carefully at the kind of tropes that the telethon would use, it essentially says, "Look at this poor person, look at what they're dealing with. Please help them, please give money." You know, and that's a framework that it still pops up today, especially in more local journalism. The core, the theoretical core there, is linking disability with

some sort of pain and suffering. And then by virtue of that, "Oh, if you do something normal, that's like amazing." You know, that it all relies on the ableist conflation.

That assumption, that default assumption that disability is linked with pain and suffering is false. That is one of the primary arguments of my book. There are cases of disability that come along with pain and suffering, but to assume that from the beginning, and to assume that of all disabilities, is a fundamental error that we have to, we humans, all human societies, whatever cultural differences might be at play, that general assumption has to stop being made.

So when people talk about disability, especially at a high kind of political level, national, international, there's this phenomenon that cognitive linguists call hypocognition, where there is a lack of either a concept or set of concepts or a lack of distinctions to fully appreciate whatever you're referring to. And I think this is one of the biggest issues facing disability justice, is that when you invoke disability, what will happen in many people's minds is some paradigmatic case will pop up and then count as everything disability is. So maybe the person thinks of someone with Down syndrome or maybe the person thinks of a person who's paraplegic and uses a wheelchair for mobility or fill in the blank. And then that case ends up coloring the entirety of what the person is thinking about when they refer to disability full stop.

And this is a huge issue because disability is one of the most heterogeneous, one of the most complex, arguably nonunified sorts of phenomena that humans experience. Disability is every bit as fluid and complex as any other primary way of marking the way a human is, or the way a human could be. If the paradigmatic case that a particular person is thinking about is one that comes along with constitutive pain and suffering. So let's use a different example here. Maybe Alzheimer's or ALS, or a condition that will come along with either literal physical pain or certainly psychological suffering of some sort. If that then becomes the stand-in for all disability, we immediately have a problem. And if there aren't cases to balance it out.

So one, a case that people who teach disability studies often introduce very early on in the course, is deafness and conversations around Deaf culture. It is still the case that many people will think of deafness simply as audiological loss, right? Deafness as a lack of something one would otherwise want to have, namely hearing. That is just false, for many people who are d/Deaf, their experience is not of a lack or a loss, their experience is of a gain, of being part of a signing community. Deafness as a benefit by virtue of the worlds that it opens, the communities that it opens, the art that it opens, the history that it opens for a person.

And just appreciate for a moment how wildly different it is to think about deafness on the one hand, as a fundamental lack, and on the other, as a fundamental gain, a fundamental bonus. There's a wild, think about how wildly different that is as a paradigmatic example, versus thinking about Alzheimer's where it is going to primarily be shaped by a certain sort of loss. It gets complicated once we..memory gets very complicated that brings up unique issues. But hopefully those, do those examples kind of bring to the surface, the sort of distinctions I'm hoping to make clear?

Christiane: Yeah, and I love that explanation, and I love your book for sort of widening and broadening what disability means, but if it is such a difficult thing to define, how's it possible to examine it through the lens of ethics or through the lens of philosophy? Because, and I'm not a philosopher, I have a very small understanding of what it is to be a philosopher, but I always think of philosophy as being so concerned with precision.

Joel Reynolds: My first response is to say that the idea that philosophy is all about precision is a historical oddity, certainly philosophers, across intellectual traditions, Western, Eastern, near Eastern, you name, it will place value on precision of certain sorts. But poetry is every bit as much a part of philosophy as logic chopping analysis is. Having said that, there is a very serious question when it comes to studying disability about whether or not there's a there, there, right. Is there an actual unified phenomenon, unified in some sense, phenomenon that we're pointing towards? And I take that question extremely seriously. I don't think that should be brushed to the side, but here's the way I kind of finesse it. Even if it is the case that I do not think I could give a necessary and/or sufficient set of conditions, such that the phenomenon of disability can be clearly picked out in the world, even if that's the case.

That doesn't mean I can't talk about it with respect to how it's being used in the world, with respect to the role it plays in things like international treaties, the United Nations Convention on the Rights of Persons with Disabilities. Or how the concept is used in national anti-discrimination laws, like the Americans with Disabilities Act, or the DDA in the UK, or with how disability is being used and leveraged on the ground. I think that good philosophical analysis doesn't require, necessarily, the phenomenon in question to fit some high, high bar that we might need, I don't know, mathematical definitions to fit or whatever it might be. Because it's a social phenomenon, and social phenomenon are inherently, I think, messy and they're inherently, in certain senses, going to be contingent, and they're almost always going to be inherently contested.

Christiane: You take what you call a phenomenological approach to looking at and understanding disability. So I've always struggled with that word. So could you help me and maybe some of the listeners understand what phenomenological means, and then also, why is it important to look at disability in that way?

Joel Reynolds: I think everyone is a phenomenologist, whether or not they know it, and everyone should love and practice phenomenology. And here's why, phenomenology simply is the study of the general structures of experience, or if you prefer, of existence. There's lots of disagreement over the precise method, there's lots of disagreements across the tradition as a whole. What phenomenologists are interested in doing is trying, to the best of one's ability, to describe how we actually find ourselves in the world and how we experience things and then see, "Okay, well, what does this tell us about the structure of experience as such?" Or, "What does this tell us about various things in the world?" Whether it's pieces of art, whether it's architecture, you name it, "What does this tell us about the world as we find it?"

And I love this method for lots of reasons, not least of which is its fundamental humility. There is no claim about truth capital T, about absolutes. There is no set of first principles that, "This is how things are, and then we're going to try and deduce or whatever the rest of the world from it." Phenomenology is humble in the sense of saying, "Let's just see how we actually experience things."

Here is why using phenomenology as a tool to think about disability is so powerful is that it doesn't make any of the general assumptions about disability that we were just complaining about. Because you can't start with those sorts of general assumptions if you're a good phenomenologist, what you have to do is start with the actual phenomenon. And this is why, for example, I don't give a phenomenology of disability full stop. Chapter three is a phenomenology specifically of degenerative multiple sclerosis, and the whole analysis—where I'm relying extremely heavily on the pioneering work of S. Kay Toombs—the whole analysis is rooted directly in her actual experiences and then tries to abstract or generalize a bit to say, well, what does this tell us about mobility, what it means to move through the world as a human? What does this tell us about social relations and how ableist assumptions can negatively impact a life? What are the general structures, more general, either again at the level of human existence full stop or something more narrow, like in Toombs's case being a white woman, going to the airport with her husband and being treated as though she's non-existent just because she's using a wheelchair.

You know, it's always that move from the particular to the more general, not necessarily fully general. And this I think is a perfect way to enter into conversations about disability that is humble, that is appropriately particular to whatever sort, whatever type of disability is we're talking about. And that's why I like it.

Christiane: What are some of the harms that come along with looking at disability from an ableist perspective?

Joel Reynolds: One definition of ableism, a working definition of ableism, is simply the assumption that based upon the abilities that someone has, that those abilities determine and define their worth. And that insofar as someone is not able-bodied, in quotation marks, that they are worth less, comparatively worse off, et cetera. That's, no two disabilities studies scholar give the exact same definition of ableism, but that will work for the purposes at hand here. One of the powerful things about phenomenology is in starting with lived experience, you can't begin by having ableist assumptions built into your analysis. Then you're not doing a phenomenology, right? You're starting with some set of principles. And yet if you're not careful, ableism can jump right back into one's analysis. And the reason for this I think is on the one hand profoundly simple. And it seems almost obvious, but it's on the other hand, extremely complex.

With a default understanding of ability. Of the, "I can," even if you're non-linguistic, I don't know how you could be a human without having some operative concept of ability because the concept of ability is one of the most basic relational concepts that human organisms use to understand their world. I mean, just try to talk about anything, the cup of coffee that you're

drinking, the sky outside. Try to talk about anything without having some operative concept of ability. I dare you. It's it's going to, the I can is a ubiquitous aspect of human experience. Because that is so, problematic understandings of ability, problematic understandings of the I can, can slip back into our analyses and understandings. So to give a very concrete example here, there is in S. Kay Toombs's essay, "The Lived Experience of Disability," she has this almost passing line about how someone who has tremors for whatever reason. The bowl of soup is no longer an object to be used in order to gain nourishment or sustenance, it is a problem to be solved. And from a phenomenological perspective, this is not word play. We're not just redescribing an object, the point is that what the bowl is, what it actually is at the level of someone's lived experience is different. Note that to claim, "Oh, a person with tremors can't use a bowl of soup." That right there, I think already has missed. That's a mistake, descriptively, because it's not an object of use for the person with tremors.

What we should be saying is something like, a person with tremors engages with bowls as obstacles to be overcome in their environment, or we could finesse the language, but the point is it's so natural. It feels so easy to make a claim about the ability of the person, when what's going on here is actually a change in the relationship between an organism and its environment. But we default back to this, "Oh, well, it's a question of ability." And this is I think very, very easy for even me, even people who think about this stuff obsessively, to fall back into that because the concept of ability and this default commonsense understanding of the I can, is so ubiquitous for the way that most of us conceptualize—I'll say most of us in the West, since that's the tradition I'm working out of, quote, unquote West—the way we conceptualize the world.

Christiane: And so how should we think about ability if we want to avoid the ableist conflation?

Joel Reynolds: Abilities are not properties of individuals. Abilities are relationships between organisms and environments. And if we can appreciate the depth of that sort of a claim, I think it would require us remaking the world, completely rethinking our societies and our institutions.

A world based upon the principles of liberty, equality, fraternity, et cetera, is one that completely misunderstands the nature of ability because liberty, equality, and fraternity are all thought as properties that individuals in the given society, in this case the US, are supposed to hold and supposed to have as rights. But that's just, I think, asinine. What we should be fighting for, and what we should want is a world in which the relationships between the target organisms, in this case we'll say, humans. The relationships between the organisms and the environment is one that is supportive for all. And that would mean, for example, not rights to liberty, equality, or fraternity, but rights to shelter, rights to food, rights to healthcare, rights to a healthy environment. Those are the sorts of conceptualizations that take ability as a relational concept seriously, and don't reduce ability erroneously to some property that humans have.

In other words, there is no pure "I can." Every time you say the sentence, "I can do X," it's a philosophical mistake, because there is nothing at all that one can do purely and solely on their own. One of the examples I use in the book is just oxygen in the air. You take oxygen out of the air, all of the quote, unquote I cans of any human organism disappear. That proves, as

completely simple and obvious as that example is, it demonstrates how there is no pure “I can,” their abilities are not solely in the individual, they are relations between an organism and their environment.

Christiane: So would another way to think about that be that, it's not that a person who uses a wheelchair can't enter a really old building with a bunch of stairs, it's that there's a bunch of stairs-

Joel Reynolds: Yes.

Christiane: ... in a really old building that is blocking access for a person who uses a wheelchair, is that a?

Joel Reynolds: That is a perfect example of what I'm talking about. And I'm so glad you brought that up because that also demonstrates how the social model of disability, although in many respects, very simple, overly simplistic, still represents the most radical rethinking of the human, I'd say in history. Because what the social model did that I think even some disability rights people and some disability study scholars don't fully appreciate what it did for the first time in modern history, was finally place the onus on how we organize the world in an explicit and almost undeniable way that I'm not sure other social movements as successfully have made clear. The way you put it is perfect, to say that the person using a wheelchair that they cannot get in the building, is just inaccurate. It's philosophically indefensible. It relies upon an indefensible, misguided, wrong understanding of the nature of ability. What we have to say in those cases, if we want to be accurate and philosophically not just sophisticated, but something that can pass the most basic reflective, critical inquiry, we have to say something about interaction. And we have to say something about the relationship between organism and environment.

[Interview ends] [music: Latché Swing, Songe D'Automne]

Christiane: If you want to know more about our guest's other work, or some of the things we mentioned in today's episode, check out our new and improved show notes page at prindleinstitute.org/examining-ethics.

Examining Ethics is hosted by The Janet Prindle Institute for Ethics at DePauw University. Christiane Wisheart wrote and produced the show. Our logo was created by Evie Brosius. Our music is by Blue Dot Sessions and can be found online at sessions.blue. Examining Ethics is made possible by the generous support of DePauw Alumni, friends of the Prindle Institute, and you the listeners. Thank you for your support. The views expressed here are the opinions of the individual speakers alone. They do not represent the position of DePauw University or the Prindle Institute for Ethics.

Joel Reynolds: ...it's just a...How do I put this? What's the meanest way I can put this? No, I'm kidding.