

[Music by Molly Joyce 00:02 - 00:15]

Bonnie: Welcome to *Included: The Disability Equity Podcast*, brought to you by the John Hopkins University Disability Health Research Center. This podcast challenges stereotypes of disability by sharing stories, data, and needs. Each season digs deep into topics offering multiple perspectives and will expand your view of disability.

We are your hosts. I'm Bonnielin Swenor, director of the Johns Hopkins Disability Health Research Center.

Nick: And I'm Nick Reed, assistant professor at Johns Hopkins University Bloomberg School of Public Health.

On this episode of *Included*, we talk with Joe Stramondo, associate professor of philosophy and the director of the Institute for Ethics and Public Affairs at San Diego State University. Dr. Stramondo's work focuses on how social and political forces shape the institutions and practices of biomedicine in morally significant ways.

In this work, he studies how various systems of oppression, especially those pertaining to disability, have influenced bioethical thought, education, policy, and practice. He has published more than 20 scholarly articles and book chapters. Currently, he's coauthoring a book tentatively titled *Learning How to Look in Bioethics: Race, Gender, Disability, and Sexuality*, and has a second book proposal under review, *The Ethics of Choosing Disability*. Lastly, he is the current copresident of the Society for Disability Studies.

[Music 01:52 - 01:59]

Dr. Stramondo, thank you so much for joining us today.

Joe Stramondo: It's such a pleasure to be here, Dr. Reed and Dr. Swenor. I'm just really excited. I'm a big fan of the podcast and your work, and I was honored to be invited. Thank you.

Bonnie: Well, thank you. You can call us Bonnie and Nick. We are huge fans—huge fans—of yours and really grateful for you taking time to be here today.

Today we want to focus our conversation on your work stemming from a paper that you coauthored with Stephen Campbell titled "Causing Disability, Causing Non-Disability: What's the Moral

Difference?" One of the first sentences of this paper states, "For many of us, the idea of making a person disabled often raises moral alarms that the idea of preventing or removing disability does not." That sentence really sets the tone for this entire piece.

In this paper, you start out with a discussion about what you refer to as the "Standard View" of disability. Can you start by sharing with our audience what that is? What is the Standard View of disability?

Joe Stramondo:

Yeah. This is a term that we actually borrowed from one of my mentors, Professor Ron Amundson, who's emeritus from the University of Hawaii at Hilo. He uses this term in some of his work just to describe the way in which most of society operates on the assumption that disability is unequivocally a bad thing always. That's why we call it the Standard View. It's standard because it's so commonly held. It is sort of the default view. It has sort of a long history that people that are smarter than I am can outline in greater detail. You might talk about its origins within the history of thought regarding religion, and it's oftentimes cross-cultural. It's just this belief that is very commonly held—and quite frankly, ancient—that disability is a bad thing.

Of course, it bubbles up throughout all of our cultural institutions. Whether you're talking about education or biomedicine or government—whatever the case may be—most of our social structures adopt this view sort of as the baseline. This paper is, in a sense, a kind of follow-up to an earlier coauthored piece that Campbell and I did that was called "The Complicated Relationship of Disability and Well-Being," where we really go after that Standard View and try to call it into question and try to make the argument that this Standard View ought not to be standard. It's a much more complicated picture than just sort of assuming that disability is in general a bad thing for a person.

This paper builds on that by raising this question of, "Well, if we are putting the Standard View on the table as a object of critique, then what does it mean for our social practices of avoiding disability or prohibiting the causation of disability?" We do this, of course, in so many different ways, both within bioethics and sort of beyond. It's sort of just the standard assumption that's what we ought to do.

Nick:

Thank you for sharing that. I think that standard view doesn't always jive with what people's assumptions are in the world. It's kind of hard to understand. I love the way how clearly you

describe it. You also go on to the outline in your piece where there's a moral asymmetry between the concept of causing a disability and not causing a disability. I think this is kind of a complicated topic, actually. Can you describe what that means for our audience?

Joe Stramondo:

Absolutely. It's actually some fancy language for a rather simple idea. Causing non-disability is just sort of another way of saying "curing or preventing disability," right? There is this assumption that I think is at least largely undergirded by the Standard View. While there are other reasons that one might hold this assumption that we'll get into—the Standard View is sort of part of it—there's this assumption that it's obviously a good thing to cause non-disability, to cure or prevent disability, and it's obviously a bad thing to cause disability. In other words, to make someone disabled who would otherwise not be. That is the moral asymmetry. This idea that you're talking about two causal actions with very different moral evaluations.

The paper is raising this question of, "Well, what's the basis of this commonly-held belief that there is this moral asymmetry between these two actions, especially once we call the Standard View into question. Is there sort of any other set of reasons for why we ought to just assume as basic moral fact that causing disability is a bad thing or preventing and curing disability is a good thing?"

Bonnie:

Yeah. You know, I think this is such an important topic that impacts so many aspects of life, right? I think that us as public health researchers in the medical research space, and policy like you're talking about—I just think that it's critical. I'm just so grateful for this work. I just want to say that.

In this paper, you outline what you refer to as seven putative differences to explain why people have moral asymmetry between causing disability and causing non-disability. Can you give a top-line summary of what those differences are for our audience?

Joe Stramondo:

Absolutely. Before I do that, I'm actually gonna back up just a little bit. When you mentioned your work in public health, it queued me in to say something about the scope of what this paper is about and what this argument is trying to cover. I think that it's important to note that when we talk about the moral asymmetry—and the way that we are in this paper—what we're trying to do is think about it in terms of individual choices: individual choices of the medical practitioner, of the parents, of the disabled person and so on. I

think that you probably would write an entirely different paper if you were talking about public health policy.

At the end of the day, what we argue in this paper is that we need to have careful, contextual, nuanced decisions that just aren't available when making public health policy. I wanted to just sort of hedge my bets a little bit before I go [*unintelligible* 09:59] sort of the arguments here because I don't think they apply broadly to public health policy and the way that they might to clinical bioethics, for instance.

The seven putative differences—basically, what we were trying to do here with outlining these seven factors that explain the moral asymmetry, is we were trying to say, "Well, once we sort of set aside the Standard View, which is what we just talked about—this generalization that disability is usually or always a bad thing—are there any other reasons why we might be inclined to just assume that causing disability is bad and causing non-disability is a good way to go at the individual level?"

We came up with these seven possibilities. We don't [*unintelligible* 11:00] they're necessarily exhaustive. There might be other ones that folks can come up with. But just sort of looking at the literature and thinking about our own experiences and conversations that we've had with folks we came up with these seven as sort of plausible ones that we wanted to think about.

The first one is related to the Standard View but not the same as with the Standard View. That's because it's put in terms of probability. The first reason why there might be a moral asymmetry between causing disability and causing non-disability is that causing disability might increase the likelihood of having lower well-being. Now, this is different than the Standard View because, like I said, it's framed in terms of probability or likelihood. This isn't arguing that, in general, disabled people are worse off and non-disabled people are better off, but rather having a disability makes it more likely that you will be worse off than otherwise.

This is actually a view that we're pretty friendly toward. We think that it is probably true at some level that having a disability makes you likely to be worse off. However, when you unpack why that's true, it seems like it doesn't provide the kind of justification needed for the moral asymmetry. We'll get into that in a minute.

The second reason is this thing about the risk of having very low or negative well-being. This is the belief that some folks have that if you are disabled then you might not be worse off as you are right now, but having a disability puts you at risk for being worse off because bad things compound, right? If you are disabled—let's say you have—I don't know. Let's say that you are blind. Then, being blind you might learn to navigate the world. You might learn to live independently. You might have a family and a job and sort of all the things that many people value, and you might have a very good life. But the idea here is that it puts you at more risk of having a bad life than someone who wasn't blind.

For instance, if you were blind and then got in a car accident as a passenger and became a quadriplegic, the idea here is that it would be hard to be both blind and a quad. Then you can sort of add on these other disabilities and these other bad things that collectively make you worse off. This argument is that, while we might not be able to generalize that being disabled is bad for you, perhaps we can say that being disabled puts you at a risk of having a bad life in that way. Okay? Again, I think there's answers to that that make it much more complicated, but it's a plausible idea.

The next alleged reason is what we call the reason of irreversibility. This is just the idea that many times—not always, but many times causing non-disability is reversible whereas causing disability is not. There's something to do with the permanence that might create the moral asymmetry. There's a variety of examples and ways to think about this, but the basic idea is that if you choose to—let's say that you have a deaf couple that you're working with as a genetic counselor. The idea here is that if you counsel them in such a way that they decide to have a deaf child, then that is going to be sort of an irreversible choice. They'll always be sort of removed from mainstream hearing culture. Whereas if you counsel them to have a hearing child, it will be up to them whether or not they want to participate in deaf culture and learn ASL and do these other things.

The benefits of disability, it's alleged, are something that you can sort of choose later. Whereas the benefits of non-disability are not. This is sort of an irreversible asymmetry, okay?

The next line of reasoning has to do with the capacity of a person to choose autonomously and wisely. Here, it's just sort of basically the idea that someone who wants to be disabled and wants to sort of cause disability in themselves—this ought to be reason for us to think that there is something going on that is distorting their

preferences. Sometimes we can see examples in the media of someone perhaps that's transabled—that identifies as being disabled even though their body-mind doesn't reflect that, and they want to cause disability in themselves and become disabled. I think the medical diagnosis for this is body dysmorphia disorder or something. I'm more familiar with the dialectical term or disabilities studies term—transabled. But the idea here is that you see someone that has this desire and that desire in and of itself is taken to be irrational. Having that desire by itself is enough to call their capacity to make good choices into question is the idea.

That's part of this asymmetry, right? We don't have that attitude toward people that are wanting to cause non-disability in themselves. You don't go to the doctor with an ear infection and say, "I want to prevent future deafness by getting some antibiotic." The doctor doesn't say, "Oh, well, that's just crazy. You're obviously acting irrationally." No, it's presumed that causing non-disability is rational—is sort of an autonomous choice that someone is making free from any kind of interference from anything else including their own psychiatric quirks or whatever. Whereas, if you go to the doctor and tell them, "I want you to cut my cochlear nerve so I become deaf," that's going to raise this red flag of, "Wow, where does that come from? Are you feeling okay?" and this thing about irrationality.

The next one is question of motivation in the third party. This has to do with parents or physicians that agree to cause disability. There is this sort of presumption that if a parent wants to prevent disability in their future child that they're a good parent. It's the right, good, thing to do to make sure that you take all of your vitamins if you're a pregnant woman and you don't smoke and you don't drink and so on and so forth to try to cause non-disability in your child. Whereas if you want to cause disability in your child—let's say—there was that famous case. The names are escaping me right now, but there was that famous case—I believe it was in Washington DC area—of two women that wanted to have a deaf child. They were both deaf and wanted to find a sperm donor who was deaf because of genetic causes in order to produce a deaf child. This caused a huge stir. They were accused of being abusive to want to have a child like themselves. This is another possible source of the asymmetry. There is this assumption that, as a third party, if you want to cause disability in someone else there must be something profoundly wrong about your decision-making process.

Next, there is this idea that the moral asymmetry exists between causing disability and causing non-disability because of the way in

which causing disability subjects someone to stigma in a way that causing non-disability does not. Here the argument is, "Well, we can admit that—and set aside—the idea that being disabled isn't always bad for you or isn't generally bad for you. Perhaps the idea that the cause of the badness for being disabled is socially constructive, right? There's nothing intrinsically bad about being disabled." Yet, even still, we might say that there's a moral asymmetry between causing disability and causing non-disability because regardless of the cause of the harm you're still exposing someone to harm by making them disabled.

Even if we say it's really stigma and discrimination all the way down when it comes to the badness of being disabled, and there is no medical cause or medical model of disability, even then we might have the intuition that causing disability is the wrong thing to do because it unnecessarily subjects someone to the harms of stigma and discrimination.

Then, finally, the last one is the idea that social costs should come into play. This one, I think, probably is the one that has sort of some bearing on the public health field, but it still in this paper is framed in terms of individual choice. Should someone be allowed to cause disability when it's likely that it will have a higher social cost than causing non-disability will? In other words, social costs can include things like equipment that you might need or services that you might need to exist in the world. Power wheelchairs are expensive, right? Hearing aids are expensive. Different kinds of, not only assistive devices, but long-term care services are expensive. The idea here is that you ought to think about the social burden that you create when causing disability that you don't when you create non-disability.

Those are the seven alleged lines of reasoning that we analyze in our paper in trying to think through why this asymmetry might exist between causing disability and causing non-disability. That was a mouthful. I don't know if that was the high-level overview that you were looking for, but yeah.

Nick:

That was great. As you were talking, not only was I super engaged, but in the back of my mind I was like, "Wow. We just asked him to summarize two thirds of a paper, and he somehow did it with one question."

That was wonderful because I think these are not all self-evident. I mean, this just is—you said it earlier. Sometimes we're using complex words for relatively simple things, but they're just not

self-evident when you read it. It doesn't jive with what the Standard View is—the public view. Whether that's incorrect or not is not what I'm saying, but it doesn't jive with what someone might know. Outlining that is extremely useful, I think, for our audience.

Now, what I sort of wanna ask is, "Okay, you've got these seven putative differences, and as you analyze them, what are your conclusions?" I guess the gold question is, "Is there a moral difference between causing disability and causing non-disability?"

Joe Stramondo:

The answer is, "Kind of." *[Laughter]*

As we work through these seven differences, we end up finding that, morally speaking, none of them are always true. But many of them can sometimes be true, right? For instance—I'm not gonna work through all seven of them again to sort of explain how and why that's the case, but you might look at something like—here we go—the likelihood of lower well-being. The first one.

Like I said, it is true that it might be more likely that someone has lower well-being because they become disabled for a variety of reasons, but likelihood doesn't matter when it comes to individual cases. That's not the judgment that we're trying to make here when you're doing clinical bioethics. In other words, you might say that if you look at disabled people as a category and their average level of well-being, it's perhaps slightly lower than the average well-being of non-disabled people.

The empirical evidence doesn't even bear that out by the way, but let's just sort of say that that was the case. Why would the likelihood be that any random disabled person has a lower level of well-being because the average is lower? Well, for one thing there might be some disabilities that do drastically and fundamentally lower your level of well-being that make you very poorly off. They might not be the disabilities that people automatically think of, but they might be there. For instance, something like clinical depression—that might really lower someone's well-being. I've had friends that have had friends that have had clinical depression, and it's life-threatening if it goes untreated. It's a bad way to exist in the world, and I doubt that there are many people that would say, "Ah, clinical depression—disability pride," or something.

Now, if there are a few of these sort of disabilities that actually do make you worse off, there probably aren't sort of counterbalancing disabilities that make you so much better off that they would bring the average back up again. I mean, I can think about disability gain

and the ways in which my disability, which is dwarfism, makes my life go well. I can talk about how it might make me a better parent or how it might make me a better philosopher or whatever. But I don't think that having dwarfism just in general makes someone drastically better off than not having dwarfism does. If that's not the case, then the overall average of well-being across all disabilities is going to be brought down by these very bad ones. That's one reason.

Another reason why the overall average might be brought down is stigma and discrimination, which plays into all sorts of things regarding intersectionality and so on and so forth. My well-being as a straight, well-educated, cis, white man is going to be impacted by my dwarfism a lot differently than someone else that doesn't have the enormous set of privileges that I have. The idea here is that the social discrimination that someone experiences, not only as being disabled but in combination with other discriminated-against identities, is likely to bring well-being down on average for disabled people.

You might be able to generalize and sort of say, "Okay, well for these kinds of reasons, the average well-being of a disabled person is likely to be less than the average well-being of a non-disabled person that doesn't have these other factors working against them. However, averages don't matter when you're trying to decide about a particular case—about this deaf couple that wants to bring a deaf child into the world. It doesn't matter what the likelihood of any random disabled person is to be worse off because of their disability. What matters is—in the context that this child will be raised—will they be worse off if they're disabled or if they're non-disabled? That's a very different question.

What we end up coming up with is the idea that-- for pretty much all of these alleged differences between the causing disability and causing non-disability—all of them need to be considered when making a particular judgement about whether or not to cause disability in someone. But none of them are deal breakers.

Nick: Yeah. A hundred percent. I feel like I say this in so many podcasts, but Bonnie and I are both—we go on mute and we're just nodding our heads "yes" extravagantly while Dr. Stramondo talks here. No, I thought that was beautifully put.

Joe Stramondo: Thank you.

Bonnie:

Yeah. You know, you sort of wrapped this up well. I do wanna say to our audience one of the last sentences in your paper just to hammer home what you just described. You write, "Whenever we encounter a choice about whether to cause disability or non-disability in another person, we should aim to base our decision as far as possible upon the nuanced details of that particular case and its context in order to judge whether or not it's permissible or a impermissible thing to do."

You described that well in what you just answered, and I do wanna ask, sort of off-script though, Joe—to our earlier point about thinking about an individual case. After what Nick said, yeah, I think this is very clear. You've laid this out so well, and it's—forget the averages. It's a case-by-case basis. It's thinking about the person in front of you kind of a decision point.

But I've gotta ask you a little bit more as public health professionals is what you would've done differently. So much policy, particularly when we're thinking now and COVID, is based on population-level data. We're making decisions for the population. This is something I admit I struggle with—I struggle with responding to. Do you have a—and I'm not asking you to over-extrapolate here, but from your expertise or your thoughts what do you think—how does this situate in that context with public health? What more work would need to be done?

Joe Stramondo:

Yeah. I think that the problem here is that disability is not a monologue. There's so many kinds of disabilities. There's so many different things that we can think of as disability. When you're thinking through how all these various ways of being in the world impact someone's well-being, you have to still think with care about the differences between—and this might not be politically popular—but the differences between kinds of disability and the alternative ways we might respond to them when it comes to trying to help people live well.

This gets complicated. I think that when you think about something like—even at the public health level. When you think about something like becoming disabled because of something like COVID—sort of getting long COVID. Well, I just went on and on about how it's not always a bad thing to become disabled and so on and so forth. "How can we possibly justify vaccine mandates?" one might say.

Well, I think that that is also an overgeneralization because I think that when you look at something like long COVID and how it

impacts someone's life, it's very, very different than something like deafness or dwarfism. I think you can't take some of the arguments that I'm making and just apply them everywhere always. That's where the contextualization comes in even with something like public health.

Looking at Elizabeth Barnes's work, she has a wonderful paper called "Causing Disability, Valuing Disability." *Ethics*—the journal *Ethics*. In it, she argues that causing disability can be a bad thing even if being disabled is not a bad thing. The reason why she makes that argument is because of the way in which becoming disabled can be bad for you even if being disabled is not bad for you because of this idea of transition costs. She makes the argument that profoundly changing your life can be a difficult thing to go through even if that change is not a bad thing.

Moving across the country—nobody wants to move. Moving sucks, but that doesn't necessarily mean that you're gonna be worse off once you get there. It just means that the transition is really, really hard, and if it can be avoided, perhaps it should be. Something like COVID—you don't have to believe that ending up with long COVID is gonna be some terrible tragedy that is going to be horrible for someone to at the same time believe that, "Well, we should probably prevent it if we can because that transition is gonna be awfully rough."

You don't get that kind of set of concerns when you're talking about something like preventing dwarfism or preventing deafness or even preventing autism. You don't get those kinds of concerns about transition costs and so on and so forth. Without those kinds of concerns, then maybe our public health response to these other disabilities ought not to be about prevention and cure but ought to instead be about how do we provide people with the services, with the technologies, and so on and so forth, that they need in order to flourish in the world?

I think that's a very different orientation for public health professionals that could be motivated by the kinds of arguments that I and Campbell and Barnes and others are making.

Bonnie:

Yeah. Well, thank you so much for that. I think the Cliff Notes of this are it's nuanced. It is a bit complicated, but we can do hard things, right? I think for so long people have backed away from these discussions 'cause they can be hard discussions. It takes getting to know the community and a willingness to have discussions with experts like you, I think, to move this forward. I

am truly grateful for your work—for pushing these conversations forward. I think we have to start having them. We have to start having them in so many spaces. What you just described, I think, has to be the future of this work. We can no longer just pretend that all disability is bad in all cases, and it is complicated.

Just thank you. Thank you so much for talking to us—for all the things you're doing. It's incredible.

Joe Stramondo: Well, thank you so much for having me. Not only did I really enjoy this conversation—I mean, I love what I do. I love thinking about these things and talking about them with smart folks like yourselves. Thank you also for doing this work and giving these issues a platform which they always are looking for and don't always have access to. Getting some of these careful kinds of arguments out into the world where people are hearing them—and it's not just sort of in some obscure journal somewhere—is really critical, and I really appreciate it. Thank you.

Bonnie: Thank you so much.

[Music]

Bonnie: You have been listening to *Included: The Disability Equity Podcast*, brought to you by the Johns Hopkins disability health research center.

Nick: Thank you for our *Included* podcast team, and everyone who made this podcast possible, especially Prateek Gajwani, Curtis Nishimoto, and our guests. Music is by Molly Joyce. This podcast is supported by a Johns Hopkins Ten by Twenty Challenge grant.

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