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Disabilities and Definitions

Something that seems to be common when reviewing disabilities in biomedical ethics is writers who aren't disabled talking about disabilities. Creating a definition of disability isn't something that can be avoided, because the theory behind our definition can influence the practice we see in reality (in the medical field, in society, etc.). However, at some point we should ask: who is allowed to define what it means to be disabled? When people have to discuss this matter (and therefore what comes as a result of it), there seems to be a large population of non-disabled people choosing how to define the term. In this paper, I'm going to argue that there should be more weight given to disabled voices when defining disabilities. I plan to examine mistakes often made by non-disabled writers defining disabilities, how our current society shapes the way we define disability, and how disabled people have come to contrast our common views of disability.

Defining disability, and what it means to be disabled, is rightfully considered a difficult topic. It asks us to categorize what we believe to be disabling, whether medically or socially. It asks us to draw a line in the sand between what 'qualifies' as a disability and what might be a minor hinge on our abilities. It asks us to determine if disabilities are inherently 'bad,' if causing them is bad, and if we should view the differences we create as significant.

There are a few problems that we run into with allowing non-disabled people to work alone on deciding what it means to be disabled. One comes with determining what qualifies as disabling. We have a sense of what makes someone ‘disabled’ and ‘not disabled’ (socially). Someone who relies on a wheelchair is considered disabled; someone who has hands that are smaller than normal wouldn’t be classified as that. (Obviously, where we draw that line should be examined, but I’m not going to focus on that in this section. When I added the “socially” comment, I mean that if you asked people on the street, there might be a ‘general agreement’ on what disables someone.) But, for example, once we get into looking at the group we define as ‘disabled,’ sometimes we run into the issue where we view disabilities as “the same,” and we overlook the fact that disabilities have a wide array of impacts. Sometimes, it seems like the social definition of disabilities creates an “us” and a “them,” a “true” or “false,” that doesn’t fully account for what it means to be disabled. No two people with disabilities have the same needs, but this feels overlooked sometimes when examining our current viewpoints on disability and how we define it. Especially if we’re asking people who aren’t disabled, with no experience with disabilities, to examine the topic. When we examine this philosophically, I think that this idea gets overlooked. It’s hard to find fair quantification for disabilities; you could ask if there ever will be, based on the amount of literature about disabilities.

That’s one social definition problem, but there are others. In her paper ‘Unspeakable Conversations,’ Attorney Harriet McBryde Johnson was caught off-guard by her fellow philosopher Peter Singer’s discussion that infants with conditions like hers should be killed off. (Not ‘should be killed off.’ Just that it would be morally permissible if parents choose to kill infants with her condition, or similar ones.) She was born with a degenerative neuromuscular disorder but has survived well into her adulthood. According to her accounts, “At this stage of my life, [Peter Singer] says, I am a person. However, as an infant, I wasn't. I, like all humans, was born without self-awareness. And eventually… I'll lose my personhood and therefore my right to life. Then… my family and doctors might put me out of my misery… [and it won't be seen as murder]." (McBryde-Johnson, p. 1)

Inherently, there seems to be a problem with this take and with this quote. As infants, we all suffer from the same lack of self-awareness that makes adults seem like people. As we age, we risk our own deterioration– we risk losing that self-awareness that once made us 'people'. What is the factor that makes us lose our right to life? What about being born disabled can make someone believe that? Harriet McBryde-Johnson is a person now. She is (as she mentions on pg. 2) unique in the sense that thirty years ago, the technology didn't exist to help her survive into adulthood. But that doesn't make her (or anyone like her) less of a person currently. Do we risk children– future people– like her risk never getting to become people? Don't they deserve a future like we do, even if in some ways they could suffer in some way; don't we respect them as people with futures?

"All babies are born without the capacity to make conscious choices about their preference for life, and so Singer does not consider that they have a right to life in the same way as humans who are capable of this choice. This is especially true, he says, where the infant has a disability," (Young pg. 1) writes journalist Stella Young for Ramp Up, a part of the Australian Broadcast Company. What could Singer say that can convince us that disabled children deserve less of a right to life than non-disabled children in this sense? Her osteogenesis imperfecta makes her, in some sense, unideal to Singer. But for Young, her disability doesn't make her life worse. She argues that this view is based on prejudice that won't consider the broader social context around her life. There's nuance that should be assessed when considering this. Activists like

Young emphasize that someone doesn’t need to meet external standards of physical or cognitive ability to have a quality life, but Singer’s view is based on utilitarianism where quality should be maximized. It’s hard to both hold Singer’s view that we should optimize our wellbeing while also holding the alternate view that this “optimization” isn’t always inclusive and what counts as “quality” doesn’t always consider every dimension of being disabled. Young says that “I won't pretend that my life has been all beer and skittles…. [but] I don't believe that my life has involved ‘suffering’, a term Singer uses a lot to describe lives like mine… Singer is simply misinformed about the quality of our lives because he doesn't live it. “ (Young, pg. 2) The disjunction in viewpoints could be caused by several factors, the most obvious being the distinct definitions for what it means to have a quality life. Singer is, arguably, misinformed about disabilities. He does not live life as someone who’s disabled; he won’t have their perspectives or experiences. Perhaps no non-disabled philosopher will. He defends his argument using utilitarianism based on the life he knows, and he’s likely not alone in his view or theory. McBryde-Johnson challenges all of his notions because she believes that subjective experiences and individual autonomy have just as much power here.

Maybe it was against McBryde-Johnson’s best will that she had to accept his offer to discuss with him in-person, but conceding to that discussion is recognizing that whatever Professor Singer has to offer is worth recognizing. There’s a point when it comes to this debate where she must recognize why he might be valid; she has to accept why some people believe that she should be dead. And even if Singer claims it isn’t, his views feel personal. His views don’t have the same consequences to him that they do for people like Harriet McBryde-Johnson or Stella Young or any number of disabled people. Maybe the way the public interprets Singer’s words are different than his intentions, but that doesn't take away the fundamental impact of his views. This is more personal than he knows.

I believe there's a problem in that, after all this time, we've gained a view on disability that hinges on the non-disabled view of disabilities. Because we can see based on numerous accounts that disabled people agree with this consensus that their lives aren't miserable. They're not worth any less. Maybe they're harder, or have more challenges, but this belief that they have worse lives is usually inaccurate. Because of these reasons, defining disabilities should give more weight to disabled voices. There's no fairness if we allow philosophers like Singer to dominate the conversation.

Above I discussed reasons it might be unfair that non-disabled people define disabilities; now, I believe we should look at the larger image. As a society, we've come to lean on our social definitions of disability in many ways. Different societies and cultures are going to understand disabilities differently. "Definitions of disability reflect the underlying understandings of the phenomenon itself… Understanding can generate different conceptions of … how worthy a person is of being classified as disabled." (Hedlund 14)

This is true in our legal definitions. Norway has a process for defining disabilities in conjunction with welfare programs (and in conjunction with the restraints put into these programs). The US adjusts the Americans with Disabilities Act to clarify who is disabled under the law. Manytimes, laws like the ADA are a benefit to disabled people. However, our society isn't accessible and equitable for everyone. According to Stella Young, "If the system for care and support was better, as we hope will be the case under the National Disability Insurance Scheme, will the birth of a disabled child constitute the same kind of catastrophe it does now? I don't think that it will." (Young, p. 2) Programs like the ones that Norway and the US describe disabilities legally, but having these requires us to put certain constraints on what ‘makes someone disabled.’

Alternatively, look at it from an economic standpoint. Writer Martha Russel spent her life reviewing the relationships between disability and capitalism under our system. “Despite the availability of advanced assistive technology and an information-age economy that has expanded the realm of jobs disabled persons could readily perform, body politics under standard business practice are still a part of the employment struggle of disabled persons. Economic discrimination-the structural mechanisms that permit and even encourage systemic discrimination against disabled workers— has not been fully confronted.” (Russel, pg. 11) Capitalism intersects with disability in the worst ways. We see productivity as profit, and capitalism prioritizes profit over the well-being of disabled people. People who function differently are hurt. This furthers social and systematic discrimination against them, and she suggests that we need a more inclusive economic framework to address the challenges that disabled people face.

From both a legal standpoint and an economic standpoint, disabled people are disadvantaged. What it means to be disabled isn’t in their hands. Physical infrastructure needs to be updated, legal gaps still need to be closed, healthcare access needs to be challenged, and employment barriers need to be examined. We can imagine a system that provides better care and support, and this existing system might call into question whether disabled children will be seen as bad. Disabilities will likely still be seen as being bad to obtain for yourself, but they won’t be seen as detrimental if you’re born with them or gain one later as life progresses. Disabled people don’t have the majority voice; non-disabled people do. This is something that should change.

It’s clear that change is necessary, and I want to discuss the definition of disability and how disabled people let it define them. Margaux Wosk is a Canadian speaker and advocate with autism and ADHD who works under the username @retrophiliacart online. They posted an image to Instagram on April 19th, 2024, with the text “Autism is a disability. I may not feel disabled by it myself. Some autistic people have support needs that surpass mine. They deserve those resources. This is in response to calling it a different ability and not a disability. This is how we include everyone.” There was moderate consensus in the comments: People can choose whether or not they want to call their disabilities ‘a disability.’ However, this shouldn’t take away accommodations from others who have it and call it a disability, for they might need accommodations that others don’t need. I believe this is important to include because it shows *consensus*. Most of her audience is disabled; they share goals and beliefs with her. No two disabled people are going to have the same view on being disabled and how it defines them. It’s a complex spectrum that can’t be divided up like so many definitions out there seem to try and do. I’m not offering a complete definition here. Instead, I want to provide insight that the current ways in which disabilities are discussed isn’t enough. Has it ever been?

In August 2016, Peter Singer was interviewed and asked about his views. Part of the transcript reads:

“CELESTE LIDDLE: I think, you know, just over and over again we see… how the broader society is not accessible to these groups of people… I would much prefer to see a society that is capable and accessible to every single, you know - every single life that can be born and people can thrive within it, rather than a view that, you know, could take support away from that.

PETER SINGER: But certainly I don't want to do that, right. I want the state to support people with disabilities and, as I said, enable them to live full, rich lives.

CELESTE LIDDLE: I think culturally it sets it up where people who are born that way are seen as a burden rather than seen as a joy that can access society.” (ABC, p. 4)

Peter Singer advocates for his view through and through, despite all the negative interpretations of his work. Maybe he’s alone in the view, but he might not be alone in the rhetoric. Liddle has a point– broader society isn’t accessible to disabled people. Is the right solution really what Singer proposes? Aren’t there other solutions to provide ahead of time? Isn’t there more conversation to be had and exploration to be done? The goal of my paper was to discuss the challenges we face with these definitions of disabilities that so far have been embraced. We need to change the way we evaluate disabilities, and the easiest step one towards our solution is listening to those most impacted by our views: disabled people.

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