

Disability

Adapting to and Embracing Disability

You can view this presentation at: youtu.be/6GP6E3nSM_Q

[00:00:05] **Dr. Cyrena Gawuga:** My name is Cyrena Gawuga. I am technically a doctor. I have a PhD in molecular pharmacology. I'm sure you saw the MSW on the slip. I am not here to talk to you about how to get disability. I'm not that kind of social worker. I don't like people enough for that.

[00:00:24] So, what I'm here to talk to you about today is the concept of disability. And you might be thinking, "What do you mean by the concept of disability? Disability is what disability is." And it's not so much like the physical fact of having a disability, or maybe, if you have a psychiatric disorder, the mental fact of having a disability.

[00:00:51] It's more like what disability means in our society. So, a lot of us live with the concept of disability being a failure to function or a lack of, say: you lose your ability to walk, you may lose your ability to talk, you may lose your vision, and that, therefore, is a failure of some kind; and especially if it's caused by a medical condition.

[00:01:23] And so, when we talk about that in the discourse of disability -- that's what we call the medical model of disability -- illness causes disability. There's another way of looking at disability, which is the social model of disability. So, what that means is: instead of it being some failure of your body, which means it's your fault, it means that society is not set up to support you.

[00:01:51] So, we had a -- and I'm sorry I didn't get her name -- but the mother talking about how the beds here are too high, and, therefore, it's difficult to get her daughter into the bed. The social model of disability would say, "There should be a way for you to adapt that bed so it can be used by many different people."

[00:02:14] And often, able-bodied people benefit from the advocacy of disability community to get changes. If you think about curb cutouts, for example, right? So, they had to be advocated for, for probably decades before they were done, but guess who uses them a lot? People with strollers, people with carts, people who are able-bodied, but need assistance.

[00:02:41] So, it's a concept that is very challenging to process initially because we've spent so long being told our disabilities are our body's fault, our disabilities are our fault, and us not being able to achieve to a

level of able-bodied people is because of some failing of our own. And I think it's really helpful, when I'm talking about this, to give a little, quick summary of how I got to this point, and how I started thinking about disability in this way.

[00:03:24] So, I started out on that straight path we saw earlier today, like that straight arrow. I had a 15-year plan, and there were so many different points at which it started turning. I had a severe depressive episode in undergrad, so it turned a little bit.

[00:03:43] And then, I ended up going to medical school. It was an MD-PhD program. But then, I got diagnosed with lupus and was told, "Maybe you can't stay in this program." So, it turned again. And then, I was in my PhD program. Ironically, I was studying stress and immune system, but that was also when I had my first TM episode. And so, it turned again. And it just kept turning and turning.

[00:04:14] And I didn't really think about this until I got into social work school and had the language and the tools and were surrounded by people who were thinking about all of these social structures that we live in and assume are normal and cannot be changed. And I sat and I thought, "Well, why can't disability fit into this area?" And I found out there's a whole area of people who have been thinking about these issues for decades.

[00:04:49] How is it that disability has not been recognized as something that can be changed in the eyes of society? And it was mind-blowing. It really was. And so, I started to see all of these different turns in my life and not as these really oppressive symbols of my failure, really oppressive symbols of: 99 people were able to do it; why was the one person who couldn't do it?

[00:05:32] It must have been because of my illness, and I must not have been able to finish that program because of my illness. That's a medical model. The social model would say, "You should have been able to finish. They should have given you the tools and the resources to be able to do it."

[00:05:53] And therefore, we would have a population of physicians perhaps who would better understand what it means to be sick. And so, often when I tell people about this model, they have this, "Well, that doesn't make sense." And then they say, "Why don't other people know about this? Why aren't other people talking about this?"

[00:06:17] And I really believe that if more people, in our community and outside, were able to claim that mantle, if you will, and say, "I am not a failure. It's society that needs to change around me." And I know that we're working on this, right? We have a lot of patient advocates in this room, but I just -- I don't know, I'm starting to turn into social workers, super social worker -- but I really believe that there's only so much that individuals can do.

[00:07:07] There needs to be a greater societal change, which is great. We always say that, "We want to burn it down and build it all up." That's like social work thing, but we can't all do that. This is not in our power to do. So, what we can do instead is, on a smaller scale, start reclaiming that identity.

[00:07:37] And on the other side as well, counter those people who think of you as inspirational. I think, probably, at one point or another, a lot of people in this room have been told they're so inspirational. You're just living your life.

[00:07:55] There is a video that you can look up on YouTube by Stella Young, who was a disability advocate who died a few years ago. It's called, "I'm Not Your Inspiration." And so, it's talking about all of those situations in which people think they're complimenting you for living your life.

[00:08:23] You go grocery shopping in wheelchair: "Oh, you're so inspirational." Like, "No, I need groceries." "You're so inspirational. You're able to walk 2 miles." It's like, "Yeah, I am. I'm actually capable of it. I use a cane, but guess what? I can do it." And all of these factors of living everyday life are thought of as inspirational.

[00:08:52] There's a term for this, and I'm sure a lot of people have seen these photos on posters and things like that. It's called inspiration porn. So, people get really excited about seeing people in wheelchairs doing things, seeing people on crutches doing things. It's offensive. And this is the issue that disability advocates and disability pride is really fighting against.

[00:09:19] You're not inspirational, you're not pitiful, you're simply trying to live a productive and healthy life, and society often gets in the way. So, what can we do about this? Well, on a larger scale, I don't know. I would love to hear what people have to say about this.

[00:09:48] But in my life, what I have done is really engage with people who say things like that. Like, "Oh, you're inspirational." "Well, why do you think I'm inspirational? I'd like you to tell me, why am I inspirational?"

[00:10:05] And when you do that, they stumble and they can't answer. It's because they're confronted with the fact that you know now how they think about you. And the first thing that comes to their mind is not you just living your regular life, but you somehow magically being able to live your life as a disabled person.

[00:10:34] So, I think that what is happening now is more of a comprehensive discussion about what it means to be disabled. What is the language that we use? Is there a way to promote a larger community of disability? Like, what does it mean to have disability pride? Does it mean that somehow, it's great that I have a disability? Am I celebrating it?

[00:11:19] Well, it's more the idea that you are celebrating yourself as a person who has a condition that is on the trajectory of life. Everyone is temporarily abled, and some of us just hit that disability earlier than others. It's fine to say that, "I like my body as it is. I like how I've been able to adapt to how I want to do things in my life. I'm proud of what I've been able to do."

[00:11:58] I wouldn't be sitting here, and there's a lot of other things in my life that I wouldn't have done without illness. Is it fantastic all the time? Am I not sometimes really bitter about it? Sure. I would be lying if I said that wasn't the case. But I think, more so, I'm fairly proud of it. And there's nothing wrong with that.

[00:12:28] I think more people should be given the space and the time to recontextualize their lives, their disabilities, and think about them in a different way. And instead of merely living in a space where we're constantly thinking about how our bodies live in a medical space, to also think about how our bodies live in a social space, who we are as people.

[00:13:06] We are, frankly, symbols of success. And that's because every day you get up and you live your life. That does not mean you are an inspiration. Okay, there's a difference between that. Being successful and being an inspiration are different things.

[00:13:26] What that means is you have made a decision every single day to go out into the world as a disabled person and live your life, and that's something to be proud of. That is something to say to other people, "I'm not an inspiration, but damn it, I am a really awesome person."

[00:13:48] So, you can go out there and say, "Yes, I'm a disabled person and I'm proud of it," because everyone here has been touched by disability in some way, shape or form. And you should be proud of what you've

managed to accomplish. You may think you haven't accomplished that much because you don't have an MD or you don't have a PhD. It doesn't matter.

[00:14:13] I'm going to tell you, at my job, they really don't care. Nobody cares. That's why I said I haven't been called 'doctor' in ages. No one cares. What they care about is what you can do, right? And that means you are defined, and you can define yourself, really, however you want -- however you want to say, "I can do this."

[00:14:43] It doesn't necessarily mean how the outside world says you should be able to do stuff. It's what's in there that defines how capable you are, and that's really what disability pride is. And so, for people with rare neuroimmune disorders, I think, I've met some really awesome people in the two conferences that have been here.

[00:15:11] And I am so proud of what people in this room are able to do. And I hope that you're proud of what you're able to do too. And that's really what disability pride is all about. Just to say, "I'm disabled and I'm proud of it. I have a cane, and it is really multicolored, and I'm proud of it."

[00:15:39] I used to hide my canes and fold them up in my backpack. I don't care anymore because it is a symbol of what I am able to do. It's a symbol of what I've been capable of doing. And if you've ever seen me running for the commuter rail in Boston, that's a sight to behold. But I do it.

[00:15:59] And I don't care anymore if people see me because I have a train to make. So, I don't look glamorous doing it. I have a foot drop, and you can ask me to look at my boot that I'm wearing. It is really ugly. But, the fact of the matter is, I make that train. It's not beautiful, I need a cane to do it, but I am damn proud of it.

[00:16:24] And I think everyone has that thing in their life in here that they're disabled, but they're still proud of it. And you need to celebrate that. And even if you have days where you don't feel like you are a superstar, that's fine. You can still be proud of yourself.

[00:16:47] And you can recognize that there is pride in survival, there's pride in thriving, and sometimes, there's pride in just not being able to get out of bed and do anything at all. However it is that you want to live your life, and not have other people tell you how you should be living your life because you're disabled, that is something to celebrate and to be proud of.

[00:17:20] This is not prescriptive. This is not to say you should always celebrate. This is not to say that you have to confront every single person who calls you an inspiration -- although I do, but I'm a very confrontational person -- but what it means is you have a small opportunity every day to just give yourself a hug and say, "I am a winner. I am so awesome. I'm awesome. Yeah, my spinal cord is not cooperating, my optic nerve it's really inflamed."

[00:18:00] There's so many things that can happen to us. I've had two relapses and a pseudo-relapse. I've been on chemo for a year. I'm on Imuran now. And I always tell, "I don't care anymore." I tell people basically, "I have a sledgehammer being taken to my immune system all the time."

[00:18:23] And so, if I'm having a bad day, I'm going to tell you, and I may tell you why because it's just part of that whole spectrum of me being proud of my disability. It is who I am. It has really shaped my life more than any other factor, and I am happy to be here, and that's part of the reason why.

[00:18:48] And I think I'm going to stop before someone comes and tells me to stop, because I will just keep going, and I will start getting into academic literature and you do not want that. So, I'm going to stop and

maybe there'll be like 1 or 2 questions. You can come and find me. I am not hard to find on Instagram. I'm the only one. So, I don't know if there's like 1 or 2 questions.

[00:19:20] **Audience Member 1:** My name is John, and I have an invisible disability. And all I can say is thank you. It took me a long time to realize what you're saying. And I think maybe it was even harder because nobody can see it, but thank you. Yeah.

[00:19:38] **Dr. Cyrena Gawuga:** Yeah, I will answer that, actually. So, I had lupus for many years before I had my first myelitis incident, and I felt people understood my disability so much more because it was externalized -- I have a cane now. So, I'm officially disabled. And that's one of the things that we really fight for: is to make sure that people with invisible disabilities get to be part of the community, get to be recognized also for what they're dealing with.

[00:20:13] **Audience Member 2:** Yeah. I'd like to say one thing that we, as presenters and researchers, words matter. We're not trying to prevent disability. Disability is an identity, and a qualifier for under the law. Disability is not a condition. We do treat disease. We do try to cure disease. We try to prevent disease and dysfunction. We try to improve function. But we do not, and absolutely do not, try to discount us as individuals because we're loud and proud and disabled.

[00:20:51] **Audience Member 3:** Hi, I have one just comment, and thank you for doing this. I think, as someone who took a while to identify as disabled, it's something that I wish I had learned about earlier. But, yeah, just really appreciate you also differentiating between the idea of disability pride doesn't mean that every day I'm like, "Oh, I feel so great that I have nerve pain right now or, like, my spasticity is [inaudible]."

[00:21:20] But it's part of my identity in a way that has gotten me to a place in life that I wouldn't be otherwise that I'm proud of it. So, I appreciate you differentiating between the pride aspect and then also just the reality of living with a condition. So, yes. And then one other point just, if you have any thoughts about how medical education or how that might impact society's view of disability?

[00:21:51] **Dr. Cyrena Gawuga:** Sure. So, I know that I'm going to keep this short, but I am probably aging myself, but I don't know if people remember the show House. So, it was a running joke on House: "It's not lupus," right?

[00:22:08] So, when I was in medical school, and it was at a point where I was wearing a hat because I had lost huge patches of my hair. I was in a pulmonology class, and we were doing evidence-based learning, and they're going through all the reasons why someone might have clots in their lungs. And someone said, "Lupus," and everyone started laughing because that was the running joke on House: "It's not lupus."

[00:22:39] Well, there are more schools, kind of, bringing up disability -- maybe like a one- or two-hour lecture. I think one of the struggles is that disability is still such a high barrier for getting into, and, more importantly, getting out of medical school, that there isn't the presence to advocate for more inclusion of this discussion and thinking about disability beyond the illness and as something to cure.

[00:23:21] Like you said, "We're not curing it." Oh, I also want to plug this on SRNA's website. I did two podcasts about this. So, if you want to hear more, there's podcasts available on their website, and there's a whole lovely series as well. So, you should listen to it. Not much as mine, but everyone else's.