

Disability: Adapting to and embracing disability

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Dr. Carlos A. Pardo: [00:00:05] The last part of our symposium is going to be very important, very exciting, because we have different topics for discussion, but perhaps the important one in terms of discussion is a panel that is going to be coordinated by Dr. GG deFiebre. Okay. And this is the A and E. A for adapting, E for embracing disability. And it's a great honor to have not only GG, but Paul, Cyrena, and Janelle. So please, Dr. GG.

Dr. GG deFiebre: [00:00:51] Hi everyone, thank you for joining us today. Thank you, Carlos. So today I'm really honored to be on this panel with these wonderful folks here. We're going to be talking about disability. So to start, I'm just going to give kind of a little bit of an overview of my experience and what it's been like and I'm going to ask everyone to share as well.

[00:01:11] So my experience with disability has changed over time through my now almost 13 years of having transverse myelitis. I was diagnosed in 2009 and quickly became paralyzed from the chest down. In the hospital, they tried to connect me with people with spinal cord injuries or other disabilities and I didn't really want to do that at the time. It wasn't something I was super interested in. I think I still thought that this wasn't going to be my life moving forward. I was kind of rejecting that. And I think part of that is because I was taught that disability was bad. That it was a bad word, that it was something that we didn't want.

[00:01:51] And after some time when I realized that this was probably going to be my life, I was going to be a wheelchair user for the foreseeable future, I started to process that and accept what my future was going to be. And what really changed things for me was seeing other people with disabilities, meeting disabled people and seeing how amazing they were. And that's really when I became proud of my disabled identity.

[00:02:13] And while being disabled is challenging, the world is not built with us in mind I would say, there's a lot of barriers, it really has brought me so much. It has brought me here with all of you today on this panel, has brought me so much perspective and gratitude. And I come from a public health background where a lot of what we do is preventing disability. The discussion is that. And I think in medical education too, there is not a lot of discussion about disability. So I'm so glad to be here on this panel today with everyone here. And so I'd like each of our panelists to kind of share a little bit about your story with your diagnosis, your experience with disability and all that.

Janelle Hewelt: [00:02:56] Yeah. Hi everybody, my name is Janelle. I was diagnosed as well with transverse myelitis back in 2013. So almost 10 years now. Similar to GG, my onset was very rapid. It was within the span of eight hours, I was a complete quadriplegic from my C2 to C7 and I also just was highly optimistic that I would not have any disabilities. I was going to have a complete recovery. I was going to be that one third, because back then they did the one third full recovery, one third partial, one third none.

[00:03:34] So that was me. I was in that mindset and it took a while to really come to terms even when I was in my inpatient rehab for a few months, I was set on walking out of there, I was set on not using any adaptation devices. I didn't want to like brace, I didn't want a wheelchair, I didn't want any of it. And unfortunately, that's life. Sometimes you get what you don't want. And so for me it's just kind of been a slow process. Even I don't know how long potentially it took for you guys to really come to terms with your lingering disability or limitations and for me it took probably five years before I was ready and willing to hang out with people with disabilities, to get involved with SRNA, TMA at that time and to just really feel comfortable in my own skin and it's still a process.

[00:04:28] And I think that's the biggest thing that I feel with disability identity at least is some days I'm super proud of my disability and I'm an advocate and I want to change the world and other days, I just want to get to the bathroom on my own and it's really frustrating when I can't. And those days are harder and I think that's part of life as well. It comes in waves. And I think that's a really important part to remember.

Cyrena Gawuga: [00:04:59] So, hi, I'm Cyrena. I would say I actually had a fair amount of experience with disability before my transverse myelitis diagnosis. So I had lupus for, I would say I was diagnosed with lupus in 2008, and prior to that, I would say about 2003 or so, I was actually diagnosed with bipolar disorder. So I would say actually, by the time, it's kind of ironic, but by the time I got my transverse myelitis diagnosis, that was kind of the easiest one.

[00:05:40] I would say, just like, you guys, I was effective from T1 down, paralyzed on this side and like really persistent neuropathic pain on the other side, but I'm flopping around, I had rapid onset. It was about five hours from like this like searing pain in my back to paralysis, but I flopped myself in the shower. I was like, "I'm not going to the hospital. I'm showered, right?" So totally I'm very stubborn. I took the bus to the hospital. I'm extremely stubborn.

[00:06:17] And I think that really helped me get through the transverse myelitis. I was determined to walk out of the hospital, which I actually did with a cane after about three weeks of inpatient rehab, and I think that there was something about confronting an illness that had a physical manifestation. That made it easier to be disabled, because all of a sudden people could see it. I had a cane. It was validated in a way. But at the same time, all of a sudden you're an inspiration, right? I'm not an inspiration.

[00:07:07] I was in graduate school at the time and working on my PhD and all of a sudden I'm in the hospital for six weeks. And I come back and I've got a cane and, oh, wow, it's amazing that you're doing this. Like what else am I supposed to do? What are my options? Like I either get it done or go home and wait to die. So I think that is what really solidified this idea of having a disabled identity and I really find it extremely important that we come together as a disabled identity, because there's really power in numbers.

[00:07:51] And so I really fight very hard for disability justice to make sure that people recognize that this is a community that deserves respect and deserves support. And like GG mentioned, there often isn't very much education in medical school about thriving with disability. I spent a couple of years in medical school, so I can say that from personal experience. There's a lot of stigma and I think everybody in this room can show that disability is just another part of yourself and how you develop and progress through life.

[00:08:36] So I fully embrace it. I'm not ashamed of it. Like I've run for commuter rail with my cane like just hopping. I don't care. So I just would say that it's part of how I thrive and how I live and how I've gotten to the point where I can sit in front of a room of people and just be honest about what I deal with every day.

Paul Garrett: [00:09:07] Hope for another. Hi, I'm Paul and I'm really honored to be here and on this panel with these wonderful people and a group of such wonderful people I've met. When I was driving home one day, for some reason it came to my mind and I thought to myself, what can affect you? What can hurt you? What malady might happen to you that would break you down? And I suppose when you get to around 60 and start thinking like that.

[00:09:35] But anyway, I thought of big C and I don't have to say any more about that. I thought about my heart, I thought about my liver and all those things, but I never in a million years thought about this. And it was an amazing thing that when I got up at 8:31 Saturday morning and I was going out to do I believe an estimate on a couple of contracts I was working on. And I got up, I went to make coffee, because I always did take one up to my wife, have a coffee, quick talk, good morning, and then out the door. Well, my foot started going numb, tingling in my leg. It worked its way up and around my butt and down the other. And I went upstairs with my feet were slapping down on the stairs. And I remember looking over thinking, this might be the last time I walk upstairs. I don't know why. I was losing control.

[00:10:29] So I got back in the bedroom and I said to my wife and said, "Tell you what?" I said, "Let's hold off. I got people to see. So we're not going to cancel that yet, because I think if I just rest for a few minutes, I'll be okay." So I did rest for a few minutes and I tried to get up and I went down pretty quickly. I was paralyzed from the waist down. That happened within 30 minutes. That was acute onset transverse myelitis.

[00:10:54] It was the fanatical ride to the hospital, of course, trying to figure out what was wrong with me. And I let myself go to people that are professional. The guy in the ambulance was wonderful. He took me, there's a stroke protocol, which means I was smothered with very high priced talent right away. Really I was stripped off and I'm going, "Okay, can you feel that? Can you see that?" Yeah. And they determined that it wasn't that and even they had a neurosurgeon come in and he says, "I'm a mechanic. If I could fix you, I'd take you in and do it right now."

[00:11:26] And of course I'm still thinking they'll give me a shot and I'll be out of here. I got to work on Tuesday. And I really thought that something like that would happen. And then as I'm sitting, all of a sudden, I find myself getting about a gallon and a half of blood taken out of me in observation and sleeping well as you're woken up every five minutes to get more blood. One of the nurses says, "I'm not going to take any more out of you." And I said, "Somebody else will." So I stood accepted to be honest with you, because the day after I was sitting there and I thought to myself, I was sitting up in the bed, tubes all over the place and I thought-- And I'm a pilot. So I'm thinking, okay, I know what's not working. Let's work on what is working.

[00:12:14] And that was that quicker revelation. I had known at home when I went to get up and couldn't that my life was changed. It was never going to be the same again. I just knew it. I cried a bit, because I knew my business was gone, what I loved. There were several things that were gone, which also meant money into the household, that extra money. I was not ready to completely retire. And so so many things gone.

[00:12:38] So in the hospital, I said, "Okay, my lovely wife, she's been with me, Brenda, right beside me the whole way, and I said to her, "Honey," I said, "Give me a bowl with some water and I'm going to shave and I'm going to wash myself every day and we're going to see and as soon as I can, we're going to get dressed every day." Because the idea of being is no matter what the adversity is. You got to get your head around it, you got to think square about it and you can't let it win. You've got to be the one that is more diverse than it is.

[00:13:07] And I was determined. I was back into that two thirds thing and I was thinking I would make top grade. And I figured that would happen in a couple of weeks. I would be walking around. And then I heard about this-- So they didn't give me a shot and I was there for three weeks and I remember I was standing and they were all discussing my future and going to rehab, and there was a doctor there that was on for a week and I had my nurse practitioner and they were all backing me to get into Parkwood, which is difficult to get into, because there's so many few beds you see.

[00:13:38] And this one doctor said, "Well--" And they didn't realize I was standing there, sitting there in the wheelchair, because I used to boot around, because they gave me steroids. So it was sort of spinning. And he was standing there and the nurse practitioner, she was lovely, she was saying, "He's got all it takes to get in there. He's going to do well." And he said, "Well, he's on steroids now. That's kind of placebo. The man's not going to walk again."

[00:14:03] So this comes out of a doctor, which believe it or not, gave me even more strength, because what's that got to do with you whether I walk or not? So he actually, even though in all fairness, it wasn't bedside manner, because he didn't know I was there, but I remember the nurse practitioners saying, and I said, "You're talking about me and Paul is behind us." So we went to Parkwood and again, which is rehabilitation. I figured I'd be out in two weeks and I'd be walking and they told me and I learned very quickly and it's a life thing that you have to remember is in order to learn something, I was doing everything. I want to do everything fast. I was trying to transfer fast and I couldn't and they were trying to say, and I learned very quickly within a few hours that if you want to succeed, to get fast, you got to go slow, slow and easy. And that's what we did.

[00:14:58] When we came into that rehabilitation side, they're all on your team, embrace them, they're the professionals, they know what they're doing. And when I was there the first day and I was trying to do everything too fast, the fellow said to me, he says, "Paul, what do you want to do?" And I said, "I want to walk out of here. Simple as that." And he said, "Well," he said, "Never see a can't." I said, "I don't intend to. So let's get this on." And two and a half years later because of all the people surrounding me, my family, my physicians, everyone that was on team Paul that we used to call it, even my neurologist, it was team Paul and you have to go two and a half years later with sticks, I walked out of that hospital with that fella that I said I was going to do whatever, and there was 30 or 40 people lined up. All my caregivers were lined up.

[00:15:52] And that gives you an idea of how kind and how wonderful the world is really. The people are there that dedicated for you. And I believe that that's what I want to give back now. I want to give that dedication back to everyone to show that the ones that can miss the mark, the ones that sort of go underground, we got to make sure we pull them up and keep them with us. So that's what my life's about right now.

Dr. GG deFiebre: [00:16:18] Thank you. Yeah. So I've just been taking some notes because of what you've all been saying has been resonating with me. For example, all of this kind of coming out of nowhere is kind of shocking situation, right? Paul was talking about thinking about all the things that could go wrong, and then Cyrena, talking about your experience with other disabilities before and then not expecting necessarily this to happen. Also really focusing on what's working. I don't know if you all feel this way too, but obviously, I am not able to walk around, right? But I'm grateful for my one hand that works and all it does for me. And that's kind of given me a new perspective.

[00:16:53] Also there's a lot of stubbornness in this and over here too, right? I also was like, "I'm not going to go to the hospital. I'm going to be fine." I was in the car with my grandmother and she's like, "We're going to the emergency room." I was like, "No, no, it's okay. I'm going to be fine." Yeah, that was not right. And then, yeah, the idea of inspiration. People saying you're inspiring for just existing. I'm just outside and someone says, "You're inspiring." And I'm like, "Why? Why are you saying that to me?" So yeah, so just kind of a summary

of some of the things that really resonated with me. I guess I just wanted to know what you all wish others knew about your disability or about disability in general.

Janelle Hewelt: [00:17:36] For me it's kind of convoluted, because in a way, I wish they could experience just like 30 minutes of my life, but then I also wouldn't wish it on anybody, because I know how frustrating it is for me at times. Even when you do have a positive outlook and you are appreciative, there is just still some things that are a struggle and it's frustrating. There's no other way to describe it. But for me, I think the biggest thing, and I was very fortunate in having an amazing support with my family when I was diagnosed. They were there the entire time. I now have a significant other who was very understanding and compassionate.

[00:18:13] And I think that's the most important in my opinion is just having that-- They don't know it, but they try to understand at least what you're going through and they want to empathize as best as they can. And the biggest thing is I love my husband for it, but he'll let me struggle for a few minutes trying to open a water bottle or a jar when I'm trying to cook, and then when I am ready to ask for help, he lets me ask for help. And I think that's the best thing is just listening, whether you are a caregiver or listening to your own stubbornness whenever you might need potential help is just knowing when to ask for it and when to offer the help, because you-- At least I don't want to lose more of myself and my independence for what I have.

[00:19:00] And so by having people that respect that self-imposed boundary, I guess you can say, really makes the difference, because it's hard to fully understand it until you're in it and you struggle with the fatigue and just the me I don't walk normal, but I can walk. So it's hard, because you want to walk, but then you're like hurting yourself by walking. So having that fine line and just really finding the people that can support you and just having that overall compassion for others. Even if their recovery is different, you still know that they still have struggles and just trying to understand that of others.

Cyrena Gawuga: [00:19:40] So I am at the end of the road here. I'm a social worker. And so whenever I think about these things, I think about them in terms of systems. And so disability is part of a system and it's an underrecognized part of many different systems of oppression that we experience. And I think probably whenever I'm talking about disability and not just my own, but just in general, I think it's really important to emphasize that there really are two ways of thinking about disability, two different models.

[00:20:17] And most of us know the medical model of disability. You've had an injury, you had an illness. Most people in here understand that we have rare neuroimmune disorders, and so we've sustained some kind of disability subsequent to that. And so the medical model in many ways says that you're broken and you're dysfunctional because of your disability, whatever. For me, I still have some weakness in my leg, I have clonus, I have drop foot. That's just is what it is. So in many ways, people with disabilities are seen as broken, that they are incapable of functioning in normal society. And if you are capable of being outside and just living your life with some sort of appliance or whatever it might be, you're an inspiration.

[00:21:13] There's this really great video on YouTube that some people may know about and some people may not, but a disability activist called Stella Young, and forgive me, I'm going to use this word, I don't know if it's offensive to people, but she really talks about inspiration porn. So the idea that like a little girl coloring with no fingers, it's like there will be a meme that says, "Oh, she's doing this. You're able bodied. What's your barrier?" That's inspiration porn. She's just living her life.

[00:21:49] And so I really subscribe to the social model of disability. So the social model of disability basically saying that we are not incapable of functioning in society, because we are broken. We're incapable of functioning to the level that we would like to in society, because society has not provided the adaptations that we need to live to our potential. You can say for example, COVID-19. People with disabilities for many,

many years have been asking about ways to work remotely. All of a sudden COVID-19 comes about and lo and behold, entire multibillion dollar companies can work completely remotely. Why couldn't we do that two years before COVID-19? Everything was there. We had Zoom, we had Citrix, we had like super fast internet, but because it was a small population of people who were seen as deficient or as broken, it wasn't important.

[00:22:56] And so that's the thing I really want people to understand is that you can feel like you're broken, you can feel like you're not functioning, you can feel like time is leaving you behind. And there's this concept, it's called crypt time, right? So it's the idea that we have our own way of dealing with time. So some people, for example, may feel like they didn't graduate in time, They're may be a year behind, two years behind, whatever. That's where you are. You did it, it just took you-- You're existing in a different timeframe, because you're dealing with different challenges.

[00:23:40] And so I think not only for the disabled community, but people outside the disabled community, it's really to recognize that our society right now is not set up for disabled people to survive and thrive and that's really what we need. We shouldn't have to ask for things that really will benefit society at large. And that's kind of equity for disabled people is not only helping us, but look how many people walk up ramps all the time. It's the same kind of thing. And so I really think that and I'd like people to think about their disability in a different sense. It's not that you're not functioning or you're not capable, it's that the world is not recognizing what you need and what you're asking for to function to the best of your potential.

Paul Garrett: [00:24:39] I like being on this end of the table, in here. The biggest thing I found with it is that I have the ability to accept that I have a disability. I can accept that. I barged through barriers. We all have to do that. The problem is people don't realize that you still have the abilities when this happens to you. I found that people suddenly thought that I didn't know anything. I couldn't even instruct them on what I've done most of my life, because they were going, "Oh, Paul," because I could no longer do. And it's true, all my tools and that went to my son and part of my business went to him as well as it was supposed to and so on.

[00:25:26] So the idea that really upsets me is the fact that people do not appreciate or have respect and tolerance even for you. And I won't even talk about Costco, because you go in there and bounced off the walls, but like I don't have to go and retrain here to become part of life again. You do because you've got to figure out that I'm coming here and I'm coming strong. I've had to make a decision that you haven't had to make and that decision is to move on and be strong about it. So cut me a little slack and I'll cut you some slack for being ignorant. Thank you. And not everybody is and I know a lot of people that are not going to get carried away.

[00:26:10] Anyway, but you have the people that love it that they say, "We're so proud of you," and everything else. My wife's been beside me this whole time. She's been with me. She's pretty much coordinated. She went almost to a single mother by the time I came out of the hospital. So yeah, I just think that people need to learn more about who we are, because I sure as heck know very quickly who you are. So be courteous, be tolerant, be understanding. And please just because someone is sitting in a wheelchair, it doesn't mean their IQ is less than yours at 12 or whatever it is. So I'm saying tolerance, a little appreciation, and how about a whole lot of love should help people out. Sorry, I didn't live up to what you said. That's all I got.

Dr. GG deFiebre: [00:27:03] Thank you. Yes. And I think in thinking about the world and access and stuff, everyone has access needs, right? If you live on the 36th floor of a building, you need an elevator to get up there. Who's going to walk up and down 36 flights of stairs no matter what? So just thinking about that's how I kind of put that into perspective when I've felt bad about the things I need to get around and these things like ramps benefit everyone. So yeah, I don't know if we have any questions from the audience or anyone

has any last comments before we end? Anything from online. Oh, over there. Do we need another-- Okay, we got the mics. Yes.

Audience Member: [00:27:55] Yeah. So thank you guys for that, but also for the medical professionals in the room, we do not treat disabilities. We treat diagnosis and medical conditions. We do prevention of medical conditions. Disabilities and identity for qualification of services, and disability identity is a choice of the individuals. Sometimes I identify as a disabled OT, sometimes I'm Sandy, because I just want to participate, but that's my choice. In the health profession, just because someone has a diagnosis, we call them disabled. That's the individual's choice and their choice and where they are and how they meet that. And as health professionals, we have to stop perpetuating the stereotype that disabled needs fixed or healed or cured, because disability is part of naturally occurring.

[00:28:50] And so I encourage health professionals to rethink how they talk and how they phrase disability and respect that and help people who are newly diagnosed to embrace a new identity and maybe want to identify as disabled or not and know the difference. I think that's our role and that medical model has set disability back so far that we've got to get over ourselves. Yes, we love you, because you help us heal, but we're more than that.

Paul Garrett: [00:29:25] Okay.

Janelle Hewelt: [00:29:27] Yeah. Kind of going off of what you said as far as helping form their disability identity, I'll be honest, my medical team didn't help it. It's actually when I did adaptive sports out in Colorado and I worked with the Adaptive Sports Center. Their therapeutic, rec therapist, actually helped me see that there isn't a negative connotation to being disabled. You're still able to find all new passions, different ways to complete tasks and that's really when mine formed and I was ready to kind of accept it and move forward and learning more and how to live more independently.

Audience Member: [00:30:02] And to feel part of a community.

Janelle Hewelt: [00:30:06] Yeah. And Sandy said and to feel part of a community.

Dr. Carlos A. Pardo: [00:30:10] Well, this is great. Thank you so much all of you for sharing these important messages. And I am on the heck side point of view. So I got it. Actually, I frequently joke to my residents, medical students and fellows, because say I am from the 20th century still, and one thing that we are forgetting with a lot of technology is that we are human beings and we are treating human beings. We are not treating diagnosis, we are not treating cases, we are not treating these rare disorders, we are treating human beings that needs the support and we are part of a team facilitating that support. Great. Thank you very much.