DEHEM Self-Advocacy Panel Transcript

By Disabled in Higher Ed as part of DEHEM Week 4

[Linda]

Okay. Awesome. Well, welcome everyone.Welcome to our panel on self-advocacy. My name is Linda Corcoran, I am with the executive team of Disabled in Higher Ed. My pronouns are she/they and I am a research masters student in Ireland studying food science. So with me today are four awesome people and we are going to have a fantastic conversation about self-advocacy. So first step, why doesn't everyone introduce yourselves and say where you are in higher ed and in the world currently.

[Linda]

So, Syreeta?

[Syreeta]

Awesome. So hi, my name is Syreeta Nolan. My pronouns are she/her/hers. I'm honored to also serve on our executive team for Disabled in Higher Ed. And I'm currently at UC San Diego in University of California, so I'm here, in La Jolla and I am currently an undergrad studying Psychology with a specialization in human health and applying to PhD programs in prevention science and health policy.

[Linda]

Awesome, umm, Ariana?

[Ariana]

Hi, my name is Ariana. My pronouns are she/hers/her. Sorry, I'm having a coffee and oh my goodness brain fart. Sorry. I got my bachelors of science in meteorology at Texas A&M University. I am now currently a PhD student at Harvard in Earth and Planetary

Sciences with a focus in atmospheric science and dynamics and chemistries, stuff like that.

[Linda]

Awesome. Lisette?

[Lisette]

Hi everyone. I am Lisette Torress-Gerald. My pronouns are she/her/hers.I'm in Lincoln, Nebraska right now. I'm probably the oldest one on this panel, I think. I have a doctorate in higher education with a certificate in social justice, and a master's in zoology with a certificate in ecology. I'm currently running a writing center, and that's a whole long story. But I'm a Latina, with glasses and short hair, and I'm weighing a black shirt that says ableism is trash.

[Linda]

Awesome. And finally, Staci.

[Staci]

Okay. Yeah, hi. I'm Staci. I am currently in, oh my pronouns, are she/her/hers.I am currently in Vancouver, British Columbia. So I got my undergrad from Dartmouth College in the States in anthropology. I'm now working towards my master's in the School of Kinesiology at UBC. It's a research degree and then I'm currently applying to Counseling Psychology PhD programs. So yeah, that's a bit about me.

[Linda]

Awesome. So, umm, really cool that everyone is here, so excited about it. I guess to start off, obviously with disability and self-advocacy in grad school, in life, it's nearly essential. So I guess, do you think that self-advocacy is required for people in higher ed to get by or to thrive? And I guess why did you become a self-advocate? I know that's

two questions. [laughter from panelists] Maybe if we can start it off [continued laughter] with Syreeta? Do you want to start?

[Syreeta]

Sure, so self-advocacy, yes. Is like absolutely a requirement for higher ed for me. Like, I've only identified as disabled for about six years now, so it's been its own journey to really like breathe, remembering able-bodied me and knowing that I now have limitations and I need help. So, it's like that journey of self-acceptance is really the first step to really self-advocacy. And like self-advocacy. I started when I realized I couldn't write. But then self-advocacy takes on a life of its own when you realize that something is seriously wrong at my institution, and it's not, it can't just be healing the loss of like, for example, not having a mentoring program for students with disabilities to get into grad school. It's like, I feel like sometimes my university surprised we're here, so that's why disability and the DI statement is inequitably executed.So self-advocacy is something that's really required to not just survive higher ed,but to thrive in higher ed.

[Linda]

Awesome. Umm, Ariana?

[Ariana]

Yeah. So I guess a little bit about me before I answer this question, I've always struggled with mental health my whole life, but I was officially diagnosed about 2.5 years ago, so I was able to cope with my illnesses for a long time until I couldn't anymore. So I'm also in the same boat of like looking at my previous being of things that I used to do and that things I can't. And so learning how to cope with that, like how to navigate that in the middle of my undergrad was really difficult. Yeah.I found that I had to advocate for myself because I realized no one else would advocate for me. And umm, at the beginning, it's lonely because you think you're the only one. But I've come to notice

once I started speaking out and being assertive, not only about myself, but other folks as well, in higher ed, I've noticed other people starting conversations, I mean, like "Wow, like, I didn't realize you can speak out about that! Like, I was so scared to do that." And, so it's been really, I mean, it's heartbreaking that we have to do this, but it's also really fulfilling because there's other people out there who often feel like they've been silenced because they feel like they can't speak up for themselves. And so yeah, it's been essential for me and especially finding where I need to be in graduate school. Yeah, that's my answer.

[Linda]

Great. Lisette?

[Lisette]

I just want to say I love, love the fact that you guys are recently been diagnosed cuz I am too. So, similar to Syreeta, mine, I was diagnosed in about five years ago after the birth of my son. And, I think self-advocacy, for me, I think is incredibly important in higher education. I mean, prior to my diagnosis, I also have a mom who is legally blind, so, you know, trying to advocate for her as well. But, in terms of my own journey, like, I have been given the privilege, I guess, of being able to "pass" in a lot of circumstances and so initially, kinda like Syreeta, uh, you know, you mourn the ability to do the things that you used to do. And then navigating the new identity and it's like, you have to make decisions. And so, initially, I tried to keep things on the down-low and you know. So when people would say, hey, can you do X, Y, and Z, I, I would think about how many spoons do I actually have to give to this? And then, you know, I would say, I would make up some kind of excuse, like, oh, I can't do today because x, y, and z.

But now, being with and being a part of the, the National Coalition of Latinxs with Disabilities and just being more vocal, kinda like Ariana was saying. You just you find people and you come into your own. And I do think though, that there's a difference between graduate students and life as a faculty or staff member. I think folks are very

open to students being advocates for themselves. But when it comes to faculty and staff, I think it's way more challenging. I, for example, I was challenged in terms of getting accommodations for myself and to the point where like they didn't have any policies in place for faculty and staff. They had things available for students. But for faculty and staff there was no policies or practices. So basically, when I ask for accommodations, they had to figure it out on the fly to the point where they used, they used the Family Medical Leave Act forms as a place holder for an actual accommodation form. And so that was, navigating all of that and trying just fighting, like fighting to get the ability to work remotely, which is ridiculous, especially now, has been challenging. So just, you know, sadly, I think self-advocacy, the sooner you learn it, the better prepared you'll be when things like this actually happened.

[Linda]

Yeah. I think that's definitely an important point and we're definitely gonna come back to what you were, what you were just talking about. But, um, Staci, do you want to talk about yours?

[Staci]

Yeah.Yeah. So I bring a bit of a different perspective to this panel because I am legally blind and I've been legally blind for my entire life. So, it's always something that I've been learning to deal with. I mean, it's something I'd been learning to deal with and learning to advocate for myself since I was a young kid. But, I think in terms of self-advocacy in higher education, I spent a lot of my undergrad just kinda feeling I didn't belong in higher education because of the way that I needed to advocate for myself. I think there's this big transition from high school where you have rights and other people fighting for those rights. And then, higher education where it's really on, it becomes on you to vocalize what you need. And sometimes that can be really challenging, especially considering there's a big learning curve there. Like, I don't think I even realized everything that I needed until I kind of had to ask for it or until things started to go poorly. And so, that's really unfortunate. But I think one thing that has

come out, as a theme in all of these responses is like the ability to lean on the community around you in order to advocate for yourself. So I think for me, I was really lucky in that I had a really strong community of people. And even within higher education, I've been very lucky in that I've had incredible mentors in my undergrad, but also now in my graduate studies who really create a space for me in higher education, which, like, has made me realize that, oh, I can get a Masters, I can get a PhD. And like there's room for me in this kind of crazy culture of higher education. And so I think something really powerful about this community, but also, you know, your personal community, but also this kind of online community of people with disabilities in higher education is having that group of people to say, "Okay, this has been done before. What can we learn from past experiences, and how can we move forward?" And so that's something I'm quite excited about being a part of.

[Linda]

Yeah. So that is really, it's really great, but also a little bit sad to hear people's stories. And I always use the same words when I'm talking about, I guess, stories I hear from people who are disabled in higher ed and that is always, "shocked, but not surprised," in that they're always shocking. We always hate to hear them, but nobody is surprised that it's happened because it's happened before and it's probably going to happen again. So I guess just to tell you a little bit about myself, I have both disabilities from birth,I guess, becoming, I gained disabilities later on in my life as well. But I wasn't actually diagnosed with anything until I was in my teens. Mainly due to my parents' ableism and them deciding that they didn't want me to be "labeled" as disabled, which led me to having massive internalized ableism that I had to work on before I could even go near advocating for myself and getting my accommodations because there was always this, "You're not disabled though." And I think that can be a big thing for a lot of people. Or even if they do accept disabled, they're like, "oh, but I don't want to bother anyone." And, like Staci said, with this whole leap to higher ed of, "It is all on you. And you need to seek these out and you need to know what you need." And even if you go back and

you find out what you thought you needed was different from what you actually need. They're all like, "But we asked you before,"

[Lisette]

Yeah, exactly.

[Linda]

"Why are you coming back to us again?"
So I guess, does anyone have experience being like that where, where they want to talk it,about looking for accommodations or even just overcoming internalized ableism and how you dealt with it?

[Syreeta]

Umm, I'll start. Like, I actually acquired my disabilities later but I always had a sister who is visibly handicap with cerebral palsy and epilepsy it was quite severe like, the last 14 years of her life, she's spent in a sub-acute unit, with tracheotomies, Foleys, feeding tubes, just nothing. And like it's, it's like that internalized ableism is like, going "Am I disabled enough to really call myself disabled?" Because it's not visible. Like, as Lisette was saying I can pass easily. Like, I can just be like, "Dee-dee-da-oo! Hi, my pain is hidden! All the brain fog is hidden." And it's like "Yes, perfect, ableism able-costume." It feels like an "able" costume, like I think that is my biggest struggle, I feel like a fraud as I walk around, [Lisette - "Yes!"] living my truth as a disabled person, like, I don't look disabled unless I break out emergency cane when my balance is gone. But otherwise, I struggle a lot with it and like, I remember my sister and I'm just like, No, maybe I can't be disabled." But then like someone shared with me this article on Black feminist disability framework. Most amazing read ever. Like, I never thought about it. Because Black people from the beginning of American history had been characterized as strong, as able. We like slave over stuff. And we are the strong Black women. Nothing in the rhetoric of being Black allows for the rhetoric of weakness, of disability. It's like we don't

exist. And in the disability frameworks, you have a lot of white people, advocates, and I'm like, "Do I even belong here?" And so, I end up as a Black woman who's disabled being like, "Ahhhh! I don't know!" [Syreeta laughing] Because I see no one celebrating, like even on campus, I was in Black Surf Week. I was talking openly about my disability in a group of people. And when, like, over half of the group that people had walked away, it was me and this other faculty member that was also Black. She's like, "I also have fibromyalgia as well. I'm not open about it." Like, these hushed tones of like almost being like ashamed and not being able or not even knowing of something called pride in the community of being disabled, like a community that didn't exist. And I think that breaks my heart I think as I've been looking at disability Twitter, like knowing that there's, these IEP programs in high school where you are protected with your accommodations you get, and you get them. Then you have to go through self-advocacy in undergrad. Then in grad school, "Crap!" The shit ship hits a fan. Like it gets worse. You might be a student, you might be an employee, but who is doing your accommodations? Nobody knows! Then, like if you somehow surpass your PhD, the barriers get higher where some schools like mine, like UCSD actually has this disability, this disability counseling, and consulting within the human resources that does Faculty and Staff accommodations. Like, for the Crip Camp event then that will be in the past, when people see this, but that's coming up on Tuesday for us. Is, is actually sponsored by them, and their office. They're doing all the ASL up there. They already got all the ASL and the captioning for it. I see that support here, but knowing that it's not like "a thing" everywhere that's kinda scary, like "Okay. So, if I somehow make it into grad school make it to faculty, than this (is only going to be more difficult.)" And I don't know why there are no bridges to each of those different aspects in higher ed. There's just holes in the pipeline, that dropped from 26% of disabled people in the population 19 in undergrad, maybe 8% make it to a masters, making seven, make it to PhD. And then like 3.6 in tenured faculty. Like when you talk about affirmative action here in the US, Disabled people need it. Like Black people have had it, other races have had it here. But I mean, don't we deserve to be able to have affirmative action, not just in employment, but employment and in education because most employment requires college. So how dare affirmative action just ignore education for disabled people, and

not being able to track statistics, on how many disabled students you have, how many disabled faculty you have? How is the growth going, the decline going? Especially if there's a health science campus that I literally started here as a patient at University of California, San Diego because my healthcare team is amazing. And that's why I choose it. But then they forget. And I think that's what's broken my heart most. And I'm sorry for going so long. [Syreeta laughing]

[Lisette]

That's totally okay.

[Linda]

I mean, like, to be honest, this is, I think self-advocacy and internalize ableism are so intertwined for a lot of people. And. Maybe less so for people who grew up or have a disability from birth, but I I don't know because even though I'm kind of in that category, I'm kind of not in that category as well. So does anyone else want to share anything? Ok, Ariana.

[Ariana]

So, I'm, my background's kinda I guess interesting when I think about talking with other people. So, I identify mostly as Latinx. But my father is Latinx and my mother is white. And so being Latinx on my father's side, but also on my mother's side, you know, Texas. You know, South, very conservative, very religious. And so I grew up in both of those environments where I've had family struggle with mental health and it's kind of it's very hush, hush. And so a lot of that, you know, it's like you're a sponge and you kinda just absorb all of that energy and all of like what people have told you. And it just, bunches up and bunches and bunches up until you're so full you don't know what to do. Once, for my situation, I was diagnosed and I was just kinda like, "Oh my gosh, like what do I do? Like, do I have to, you know, live hush-hush for the rest of my life?" And there's also my Latinx side where mental health and disability just, it's kind of a taboo. I hate using that

word but Lisette's nodding her head. So I think I'm good here. [Lisette laughing] People just don't acknowledge it. And I don't like going to the doctor and that's definitely like a Latinx thing as well that I've learned and you know. It's a lot. The sponge is really full. And, you know, I've kind of had, you know, with therapy and getting treatment and things down the road, which I'm very privileged to have received. I will say that right now, it's a privilege, especially in this American health care system. And with my undergraduate university that I was able to get treatment. I've kind of had to re-teach myself and kinda rewire my brain and kinda whack that sponge against the wall to get things out. [other panelists laughing] And though, yeah, it's just it's a battle. I have good days and bad days like, oh, you know, I pass, I have the privilege of passing except on like really bad days where it's pretty obvious, but, umm, a lot of people don't know and like am I disabled enough or if I'm not. And I think it was Krystal Vasquez, she runs the Chronically Invisible Twitter account. I was kind of having a little conversation with her like, I don't know if I consider myself disabled and kind of like talked about it. And, she's, like, "No, Ariana, like, you know, you have disabilities too." And so, like, whenever she told me that I was fine at that validation, I was just like, "Okay, let's start working with this." And so that's kinda just my story. And, you know, you can't just pray your disability away. That's just not how it works. [Other panelists laughing] A lot of it's traumatic too, like, a lot of internal ableism is trauma and so it coping with that stuff helps you. And so yeah, sorry. I talked for a long time, but that's just where I'm coming from in my story. The sponge.

[Linda]

That sounded really good, I think it's a really good analogy.

[Syreeta]

Yeah, and may I share, jump in for a second as well? Like I actually dealt with severe mental health conditions from seventeen. I'd never (wheezing laugh) myself disabled until the point when it became a physical disability. Like it kicked me out of higher ed for

like ten years. We may be somewhat similar in age (Lisette). Like, because Black don't crack. [laughing]

I'm actually 34 so... Yeah. So essentially like being Black, you're a hush-hush about mental health too like people told mom that like, "Just kick her out of the house. So it's not going to get better. She's going to go spiral down." Like, I was like, I'll throw out my trigger warning about suicide and cutting. But every day, like it was either cutting or suicide attempts for ten years. And I didn't know. that that actually was a disability. Like for some reason it never clicked because no one ever would open with me about disability. I never knew there was community. So it just felt like this vacuous hole being alone. And I think any disability is so much worse when you feel alone? [Lisette] Yeah

[Syreeta] By really just whacking that sponge against the wall as hard you can like having it shatter and letting everything free about their disability. Frees yourself to not feel like you're living some, some truth for your family, for your culture, whatever is acceptable within that you have to do that. You do, what you need to do for yourself. And you really create a new version of reality that is the reality you need to thrive, survive and invite others to also thrive. Like, I was having a similar conversation like you were talking about, Ariana, with one of my friends who's also Black and disabled, like, she has POTS, like "Yes. You get to call yourself disabled. You really do." And then I went through like, "Look, there's a community too, we have support, we have a system-wide like ad-hoc committee that I co-chair. We have a community on disability Twitter. You don't have to be alone. You don't have to hide anymore. I'm here. We're here. So yeah, sorry for jumping back in. [laughing]

[Linda]

No, you're fine. I think I think this, like disabled and disability have been seen as nearly taboo words in some cultures or in most cultures, I think and definitely higher ed. They're kind of like "Unless you have a noticeable disability," they're like "If you were actually disabled, you wouldn't be here." Which is something I guess I get a lot as

having learning disabilities as well. It's kinda like, "If they were actually disabilities, you wouldn't be at this stage. You would have been filtered out before this," which is just absolutely ridiculous.

[Staci]

I find that to be the most, like, That's what frustrates me the most is because when we start to make those assumptions, then you perpetuate this culture of people with disabilities don't belong here. And like I think, so I'm a sociologist,like that's the research that I do, I study athletes with disabilities and like, I'm happy to be having this conversation because like even just from the work that I do, like these narratives matter, like the fact that all of you guys are going into higher education and hopefully sharing these narratives and changing the way that we're thinking about it. That's what matters and that's what kind of will, in my eyes... I'm blind. So that's funny. [laughing]

But will start to shift that culture of who belongs in this space of higher education because people with disabilities should belong there. And the fact that you don't see a lot of people with disabilities is a testament to how challenging it is to navigate this space and not a, and not a reflection on the fact that people with disabilities like aren't qualified or aren't smart enough to be here. In terms of, sorry, I didn't I don't think I answered the question at all. But in terms of issues of internalized ableism like something I, a transition for me that was quite challenging was when I got a guide dog. So I have quite a bit of vision for someone who has a guide dog. And it's always very interesting to me to think about, "Okay, if I'm walking around with my friends, I probably won't use any type of mobility device." But when I'm, I, I moved from New Jersey to Vancouver and I have traveled all over the place. And so when I'm on my own, I typically use my dog. And so that's kind of very challenging because in one way I can like, as you guys have all been sharing stories of passing as someone who isn't disabled. So when I'm with my friends and don't have a mobility device, it's very interesting to see the different...how people treat me very differently, as opposed to when I have my guide dog. And so that was something that I I got Smidge right before I left for college. So I was 18 and that was something I had to deal with in college, like

taking on this new identity as someone who's very visibly disabled as opposed to someone who could kind of pass as being sighted. And so I think that's challenging and something I've always been like, "If I have, if I'm privileged enough to be able to walk around with my dog, like, should I have a guide dog?" And at the end of the day, it's something I've thought about quite a lot, but something that like, I know that she has given me so much independence and there are definitely like,I would never have had the confidence to pic dog that I know is always looking out for me and always picking up on the things that I don't see. And so I guess that's sort of how I've like, a little bit of my story. And in terms of being burdensome, sorry, the question is quite broad,so I'm going to answer [laughing] them, but I've definitely felt burdensome in asking for what I need in college. Because you're always trying to fit this like, normative understanding of what you should and shouldn't be able to do And I think that it was really challenging for me to always be asking and it's exhausting to always be asking it, always using your voice and feeling like you're never being heard. And so that was definitely a huge challenge for me in undergrad. But at the end of the day, I always thought of it as, "Okay. I'm the only one that's suffering here." Like if I don't ask for what I need, I'm the one that's being, that's compromised. It's my education. I'm in control of my own education. So by not asking, I'm really just hurting myself. And that's kind of how I always sort of convinced myself that I was worth it and that the people that I was dealing with needed to step up and give me the things that I was asking for because I've also run into that issue a lot where I ask for things and did not receive them, which became a whole legal situation, however, yeah, that's sort of how I always justified when I was feeling like I was burdensome. I always justified it by saying like, this is my education and I'm the one that's suffering from not having these things, not anyone else. So that's kind of how I advocate for myself, I guess.

[Linda]

But I think, I think, that it's been proven psychologically. It's a psychological thing, but there's always this, there's someone worse than me, idea, that people will try and use to say that you don't deserve things. But the fact of the matter is that no matter what people think accommodations are they are there to remove the advantage everyone

else has and they're personal for a reason. Because you do hear a lot that for some people think that accommodations are a privilege and that they're making things easier for you. But that's just not true. And I guess when we look at higher ed and we talk about not fitting the mold, we always have to remember that mould is an able cis straight white man. So a lot of people weren't fitting in there anyway.

[Lisette]

So, this is Lisette. Related to what you just said, Linda, and connected to what everyone else is shared, like, we also have to consider neoliberalism. I hate that like, abstract start throwing theory into everything, but neoliberal higher education views people as commodities and things that produce. And so being disabled Plus then you throw on gender and race is, just makes everything so much more complicated. So I've been trying to process things through my writing. And so one of the things that I'm hoping will get published is related to what Ariana was saying in terms of the intersection of Latino culture and neoliberal ableism And so what I call it is the narrative, a "sacrificial." So this idea that neoliberalism plus our cultural identity, especially Latino culture, this idea that sacrificing is what we should be doing and how we perpetuate that in the Academy by talking about how tired you are. We work in comparing each other, how much we're getting done and "Oh, I have like 50 projects and I was up until three" or, you know, things like that. And how we need to kind of push back against that. And so I do think we need more of us, in the academy to kind of push, push and confront and highlight these narratives of sacrifice that the academy keeps trying to make us embrace as something that we should be doing. When in reality it's even hurting "able" people, "able" I put it in quotes. "Able people." Because it, it's not healthy, it's just not a healthy way to live. But that's my 2 cents.

[Syreeta]

Can I add two more cents? [Lisette - Sure.] But I loved the idea of neoliberalism. I also think of it in this frame of diversity, equity, and inclusion. Because we see Latinx, we see Black because it is on the surface. You see it , then like "Okay, there's a whole bunch of

white people. We need to fix this." So here's diversity, equity and inclusion coming to include the people you find acceptable to include: the strong, able. Like even though disability is there. It feels like an add-on, like it doesn't feel like something that's valued. And in reading this remarkable paper about disability, about Black feminist disability framework, I found out that Kimberly Crenshaw's envisionment of like intersectionality and the establishment of the ADA in United States they're one year apart. Just one. So learning that it's almost like, wow, they're like intimately together. ADA and 1990 and intersectionality in 1991. Like, I feel like if our higher education system really wants to say that disability is something that they value, and I hope that one day we can push that and make it be seen. Because like that hashtag, that my disability made me good at, Like I think it crushes ableism. Literally. It shows that disability isn't just some liability, but capabilities to really overcome life's challenges. And with Covid-19, like there are going to be some like challenges. Those who are abled, but recover from Covid-19 will go through like I'm now using those air quotes too because disability isn't something that just happens at birth, like it happened to Staci. But to most of us here who acquired disability later, the disability community can be a supportive community to those who are entering that, this the disability journey. Those who are going through the nightmare of diagnosis, like [laughs] sometimes that needs support. And since nobody's talking about it, nobody knows we're here to support them. And since nobody seems to appreciate people with disabilities in higher ed, there are no programs, no scholarships, no. Like here is a program to help you prepare for grad school for disabled people. Like I mean, I just got a message from someone that saw me post about like national coming out day and the disabled roll call, being like, how do I talk about disabilities in my personal statement without it becoming like a kiss of death. Like the fact that we can phrase disabilities as kiss of death. Like it's really flipping sad. Because it's like the death of moving forward, mostly because each presented solo. I'm wondering if it's more likely for some other random, super rare thing happened to make it in higher ed as a person with disabilities. So yeah, we really need to start... the higher education system creating this infrastructure that values disability, that doesn't just go, "Okay. [laughter] You're here. [sigh] guess we'll do something. We'll, like just see you through the medical model and we'll just give you some accommodations and maybe we'll make things a

little bit more accessible for you so you can somewhat survive, but we don't really see you making it get anywhere else. So all those programs we give every other person we see within the disability, within the diversity, equity and inclusion statement, what they have? You won't have it. You won't have community centers, you won't have programs. You won't have scholarships, You won't have programs that prepare you. Because, we're just surprised you're here."
[lots of affirmative noises]

[Staci]

Good point about external factors that drive diversity. Because like, I know what something that really frustrates me is when we think of diversity and it just becomes these boxes that we can check off. And disability doesn't always isn't always like that simple, right? I mean, we've just heard what, I don't even know how many people are on this call, five different perspectives, in five different ways that people are thinking about this and so on, five different people. So it's not as easy as just checking a box and, and I think you're totally right in that this is an institutional changes. This is, and this is not just, I've done quite a lot of advocacy work at the undergrad institution that I did. And if this is not just about administrative change on the level of a one institution, this is administrative change like in higher education broadly. And I think that's a huge thing to ask for, but truly, I think that's only, the only way you're going to see is institutional change of how we're thinking about who belongs in these spaces and the stories that are appropriate. And the stories that should be told and how they're being told in those spaces basically.

[Linda]

Absolutely and definitely, I think one thing that would need to change is something but Lisette mentioned earlier and not as that, even a lot of the times they feel that they are legally required to provide accommodations to students. And then they just all disappear. When you graduate. And they just pretend that disability don't exist. And it's partly the reason why there are so few people with disabilities in higher ed and also

why most of them, if they can, at all, don't get any accommodations.Because they feel like if they asked for them, their contracts won't be renewed or there'll be seen as lazy. Or even if they ask for them, they'll just say no. So they just don't bother. So I guess. Do you want to talk a bit about that because you, Lisette, you have experience about that?

[Lisette]

It is challenging.I think some, what's what I think related to Staci was saying in terms of changing higher education to embrace disability. I think sadly, it's starting to happen now, at least in terms of there's been some creation of disability cultural centers at some institutions. And I know recently the Spencer Foundation is now looking to provide grant, grants on disability and supporting disabled scholars. There was also, I think that the Ford Foundation was recently looking for someone, a program officer to focus solely on disability. So I think change is coming. I don't know how quickly it'll happen. My, my bud ,Leroy Moore, would probably say it's never going to come. I don't know, Syreeta, do you know Leroy? [Syreeta - No.] He is a Black disabled activist [Lisette] and I love him because he's so real. [Lisette] And he is one of our, [Lisette] I would say elders [Lisette] in the disability community. [Lisette] He's been speaking out about this since, [Lisette] like the 80s and he's just an amazing guy. [Lisette] But, you know, just I think disa..., [Lisette] disability is getting more visibility. [Lisette] But then I think also [Lisette] I think it's gonna take a while [Lisette] though for that intersection. [Lisette] So for example, [Lisette] my organization that we co-founded in 2015, [Lisette] the National Coalition of [Lisette] Latinx with Disabilities, [Lisette] I think we're the first [Lisette] national organization to try [Lisette] to bridge the Latino community and [Lisette] the disability community and have [Lisette] a conversation of what does it mean [Lisette] to be a disabled Latinx [Lisette] person in this country and you know, [Lisette] like Ariana had mentioned you know Latino [Lisette] community, there, disability is something [Lisette] that you ignore, minimize, pray away. [Lisette] If you have relatives with disabilities, [Lisette] especially visible disabilities [Lisette] is you don't really talk about them. [Lisette] Or when you do talk about them, [Lisette] it's kind of patronizing. [Lisette] And so it's like, [Lisette] I think it'll be a while for us to hold [Lisette] conversation in the Latino community where [Lisette] people will start to [Lisette] embrace the social model

because right [Lisette] now it's very much stuck [Lisette] in the medical model. [Lisette] And so building, "What does that mean? [Lisette] What does disabled [Lisette] Latinx mean?" is gonna take awhile for us. [Lisette] And I'm sure, as Syreeta [Lisette] sees something similar in [Lisette] in the Black community as well. [Lisette] And Leroy talks all about it. [Lisette] So you need to, to check [Lisette] out whatever. [Syreeta] You shared with me. [Lisette] I love him because he's [Lisette] just so real. But, [Lisette] you know, it's, I [Lisette] think it's going to take us and making [Lisette] connections with elders that are still with [Lisette] us to have that generational conversation [Lisette] of what does it mean to be disabled? [Lisette] But also, you know, [Lisette] making those connections to those intersections. [Lisette] So talking BIPOC, [Lisette] talking to queer communities, because I know [Lisette] especially online and in [Lisette] the disability justice arena [Lisette] our queer BIPOC folks [Lisette] are leading the way, [Lisette] so we gotta give them props. [Linda] All that is absolutely [Linda] great and it's fantastic. [Linda] It's always fantastic when we see [Linda] any of that sort of disability, [Linda] visibility we're all [Linda] kind of rushing towards it. [Linda] But I guess talking [Linda] from obviously a European perspective, [Linda] we, some countries don't even [Linda] have the protections which I know are not, [Linda] even though they're in the ADA, [Linda] they're not always given . Many [Linda] people have told me this. [Linda] But a lot of countries don't [Linda] have any real protections, [Linda] which is a big problem. [Linda] Or they're very vague and it is a thing. [Linda] But one thing I've noticed, [Linda] I think that Covid has brought up is [Linda] some university departments that [Linda] I've been in touch with in Europe anyway, [Linda] got a shock when they found out [Linda] how many professors they had that [Linda] were actually disabled that [Linda] they didn't know about. [Linda] Because when we had locked down, [Linda] they were all like, "I can't come back to work. [Linda] I have this thing. I need to work from home." [Linda] They've got a massive shock and I've [Linda] spoken to several and they're all like, [Linda] "Oh, you know, damn, we need to do something here." [laughter] [Linda] So at least they got a kick up the ass [Linda] about doing, getting some framework in place. [Linda] So that is something good that's [Linda] come out of Covid. [laughter] [Syreeta] Another good thing that's come out of Covid [Syreeta] is I feel like [Syreeta] my university is more open to the [Syreeta] like, I think self advocacy. [Syreeta] I really

expanding it to casting [Syreeta] visions for my campus and [Syreeta] the University of California because [Syreeta] there will be more people with disabilities. [Syreeta] Because no matter how you are reporting, [Syreeta] like disability is, like, [Syreeta] as we go through this Covid crisis, [Syreeta] as people recover to [Syreeta] actually deal with chronic disabilities, [Syreeta] you need to really start by [Syreeta] honoring the people with disabilities [Syreeta] currently in your institution [Syreeta] and supporting them with more. [Syreeta] To be able to increase [Syreeta] your capacity to really [Syreeta] support people after they're [Syreeta] dealing with Covid because [Syreeta] for my institution, I don't know if [Syreeta] your institutions are similar, [Syreeta] we have this program called ready to [Syreeta] learn here at UCSD. [Syreeta] So it goes through how to protect yourself, [Syreeta] wear your mask, like go get tested. [Syreeta] We have this many quarantine [Syreeta] dorms, this many isolation dorms. [Syreeta] And then there's this weird [Syreeta] thing that happens. [Syreeta] Nothing. [laughter] There's no about [Syreeta] like what to do if [Syreeta] you recover and you are disabled. [Syreeta] How do we got about this? Like what does disabled [Syreeta] life look like? Here's [Syreeta] a support group, nothing. [Syreeta] Like I mean, I, I met with my couns... [Syreeta] my counseling and psychological [Syreeta] services like the leadership of this. [Syreeta] And I'm literally teaching them [Syreeta] about the grief journey in [Syreeta] disability because grief is [Syreeta] not just someone died. [Syreeta] A piece of me died that I knew I was healthy, [Syreeta] able enough to think about [Syreeta] how many spoons I had to go about my day. [Syreeta] Do you really, really [Syreeta] have to learn what happens [Syreeta] when I hit a wall [Syreeta] where the spoons are gone. [Syreeta] Like I hit that wall because [Syreeta] my internalized ableism is like [Syreeta] try surfing this not going to be that bad. [Syreeta] Kiss of death. [laughter, chatter in background] [Syreeta] Like we have to really just do better. [Syreeta] It's critical in this time of Covid, [Syreeta] while everything is closed to [Syreeta] open your mind to disability, [Syreeta] as higher education system because yeah. [Linda] So I think that leads really on, [Linda] on really well to [Linda] the last question that I have, [Linda] which is that mental health [Linda] is more than just mental health disabilities. [Linda] And I know in [Linda] disabled in higher ed [Linda] we are talking about that today, [Linda] which will be weeks ago when we hear this. [Linda] And it's that minority stress

also [Linda] happens to every minority group. [Linda] But disability, [Linda] which has only been researched in [Linda] the past few years or [Linda] the models have even applied [Linda] disability in past few years. [Linda] And self-advocacy is something that [Linda] is massively energy draining. [Linda] So if you were to give one tip to people [Linda] about self-care and [Linda] conserving your mental health [Linda] during self-advocacy, what would it [Linda] be? [Panelists - Hard question!] [Syreeta] And then other people can try out this question too. [Syreeta] Yes. Self advocacy and self-care together. [Syreeta] My my, self-advocacy is a lot of spoons [laughs] because [Syreeta] sometimes it's [Syreeta] this frustrating thing when you feel [Syreeta] yourself hitting the walls of yeah, well, [Syreeta] you understand it [unsure?] of trying to [Syreeta] self advocate to [Syreeta] the vice chancellor of equity, [Syreeta] diversity and inclusion here at [Syreeta] UCSD about why don't [Syreeta] we have programs, let alone break [Syreeta] down crying in front of her [Syreeta] about the inequities [Syreeta] in our diversity statements? [Syreeta] And she's like, "Let me contact [Syreeta] some people to help YOU with [Syreeta] your personal statements ." I'm like [Syreeta] "You didn't hear my statement [Syreeta] did you? As a community, we have nothing." [Syreeta] You think it's helping me, [Syreeta] is really going to be what [Syreeta] makes me feel better. No. [Syreeta] [laughs] [Syreeta] I'll end up going into [Syreeta] that on the Crip Camp panel, [Syreeta] which will be weeks ago from them. [Syreeta] But what really helped [Syreeta] to make my self-care and [Syreeta] self-advocacy is empowering others [Syreeta] to self-advocate with me. [Syreeta] To self-advocate as a community toward [Syreeta] one common goal so [Syreeta] that it's not just your energy expense, [Syreeta] it's not just your mental health. [Syreeta] It's, it's you having to [Syreeta] support system around you, a community [Syreeta] around you, and making that community [Syreeta] yourself like I have [Syreeta] to UCSD and I finally am [Syreeta] starting to see a community a year [Syreeta] into being here at UCSD and feeling alone and [Syreeta] disregarded by my Black student union like [Syreeta] when they're making demands of [Syreeta] the faculty about, after all, [Syreeta] of everything happened [Syreeta] around Black Lives Matter, [Syreeta] I tried to say something about [Syreeta] disability and it's like "Whatever. Next." [Syreeta] I just felt disregarded. [Syreeta] And having those people [Syreeta] that you can talk to openly, [Syreeta] honestly and really come [Syreeta]

together and realize this one aspect needs to be improved. How we do this, it's not just about, I it's about we as the problem is that many of us deal with as a disability community are common and go beyond us. Goes beyond our experience. It's into we are as BIPOC communities, who we are as LGBTQ communities, being bisexual as well. Who we are as religious communities being Christian, as well. So, I'm oil and water. That's how I call myself because the bisexual part does not fit [laughter] very well into the Christian part, so. And it being Black and disabled is like oil and water again, because they don't fit together well either. It's about finding ways that you can advocate but have support as you advocate. And then I also recently submitted a paper to Disability in Society on the compounded burden of being Black and disabled during the age of Covid-19, that really calls for that higher education changes. Calls for programs, calls for living and learning communities. And I'll be like a month out from hearing something about my first paper, so throw some good thoughts at my first paper. But like, I feel like the more we publish as a disabled community about our challenges and we're open about them, the more we can really catalyze a change into higher education that goes beyond where we are now to where we all are together. So that it can really be disseminated, cited by each other, shared by each other. To go into the abled communities to really see us as something beyond the problems that the accommodations and accessibility like that they think are fixed. We, our problems are not fixed in accommodations and accessibility. We're just on the same level with you. Those who are able. And I call on the higher education system just to see us truly and to see our capabilities and not to see our liabilities. So don't self-advocate alone. That's my tip.

[Staci]

Lots to build on that. Just because you mentioned like seeing us as just accommodations to fix the problem. And I actually think Covid-19 is a great opportunity to start to reframe the way that we're thinking about that a little bit. Just because when we offer things on online platforms, we actually open a lot of doors to make things more accessible in ways that are quite, I don't want to say easy, but like very straightforward and actually makes it so that the material that is being offered is already accessible as

opposed to trying to take this material that is inaccessible and creating, making it accessible for specific students. So for example, like being able to have the live captioning on PowerPoints. A fairly easy thing to do that professors can just turn on and then we, it's much more accessible for someone like me who's visually impaired. Like having the PowerPoint right in front of me on my computer or having the whiteboard right in front of me on my computer is something that's way easier than it has ever been before because we're offering it online. And so I think it's a great opportunity to rethink how we offer these materials and to consider accessibility before we even start to create them. Because that will also open doors in terms of having us, like making it accessible and not having to be such a challenge for students to get accommodations. And then in terms of self-care and advocating the actual question, sorry. I agree in terms of like finding a community for me. I was really lucky. I had a really strong community of friends when I was in my undergrad and advocating for myself. But I also think finding advisors and people already in higher education who are in your corner and who are willing to go to bat for you. It's something that I've found to be really, really helpful because it makes me just feel like validated in that. Okay, I'm not crazy. This experience was outrageous. I'm really like just to be able to talk to those people who have been through it and who are in higher education and who are willing to, who you know is standing, are standing in your corner.So that's been very helpful for me and yeah, sorry.

[Linda]

I think it's all super important stuff to say. Like, it needs to be said.

[Lisette]

If Ariana is okay, could I say something? And then, thank you [Ariana - No worries] it became, I don't wanna be like jumping in. So related to what both Syreeta and Staci were saying it's really important to have a community. To have folks on your side. Something that my coalition does intentionally is that for every project or thing that we have to do as a coalition, we have two people on everything. So that when one person runs out of spoons, the other person is kinda like the backup support. So if you can find

a way to do that in your daily life, having somebody to kinda like, "Hey, I got this, do you have this?"and kinda like supporting each other that way, that's really extremely helpful. And then in terms of self care, I would say, listen to your body. Like I think a lot of us, especially when we get sucked in to the academy and [laughs] and the culture. And we start being socialized to, to see things in a particular way. We kind of forget ourselves and we forget our bodies and our backgrounds and what I've been trying to be mindful about, and this is coming as a Buddhist. Coming as a Buddhist, I have been trying to be more intentional about how I do things and listening to when my spoons are getting low. And even if something is due being like, "I just can't do it. Like I need a nap." Like I just... like it if my body says I need a nap then I need a nap. Like I can feel myself when my spoons are getting low, I can feel a shift in my mood. I can just feel like the fatigue setting in and I know I just can't push anymore. And so just knowing where your limits are and being comfortable with saying no, and being comfortable with making decisions that are right for you. So if that means you need to only work between 9 and 5, then so be it. That's how I kinda, I kinda see the world now. And I think disability has been a blessing for me in that way because it's made me prioritize to the point where it's like higher ed is not going to take care of me when I'm sick. If I am about to die. I mean, it's very it's been very eye-opening, but also not surprising that there have been institutions telling their faculty, "Hey, in this time of Covid, make sure you have somebody, a backup person to teach your course, and let us know who that person is going to be." So I am, I am very real. I see the academy for for what it is. And I know that they are not going to be at my bedside when I fall ill or if something happens to me, so it's on me. To make sure that I'm doing all I can to take care of me and my community.

[Ariana]

Awesome. Okay. I'm next, right? Self-advocacy and self-care go hand in hand, but they also defy each other. I will elaborate on this. Self-advocacy, I tweeted this yesterday on World Mental Health Day, is exhausting. Like mentally exhausting, emotionally exhausting, physically exhausting. And it's just a it's a bundle of like a lot of stuff. And I was talking to Syreeta about this the other day. We were DMing on Twitter, you know, advocating for yourself, even though it's all those things I just said, like all the spectrums

of exhaustion. It's a form of self care. Being assertive about yourself, even though it's difficult in the moment, is a form of self care. Because you deserve to put yourself first. You deserve to be healthy, you deserve to be happy. You are worthy of those things even though, you know, institutionalized ableism and internalized ableism tell you that you shouldn't [Ariana] be those things, you're a liability. [Ariana] You are not like [Ariana] a quote, unquote, normal person. [Ariana] You deserve and you are [Ariana] worthy of those things. [Ariana] And I didn't really see it that way. [Ariana] I just thought, "I have to do this [Ariana] because like no one else will." [Ariana] And I've kind of had to shift my mindset, [Ariana] like I said, throwing that sponge [Ariana] against the wall and be like, [Ariana] "I'm worthy and I deserve these things and, [Ariana] you know, other folks in [Ariana] the disabled community do too. [Ariana] You know, like everybody does." [Ariana] And so yeah, it's exhausting [Ariana] and but it is part of my self-care and I think, [Ariana] you know, at the same time though, [Ariana] you have to learn [Ariana] a balance and as Lisette said you [Ariana] need to listen to your body [Ariana] and listen to your signals. [Ariana] If you're tired, like it's okay, [Ariana] just take a step back and rest. [Ariana] Because you're also really at rest. [Ariana] And especially in higher education, [Ariana] people work all the time, [Ariana] you know, lack of sleep and overworking. [Ariana] I say this about STEM but it's [Ariana] for higher ed in general, [Ariana] they're worn like badges of honor. [Ariana] It's a very cultural thing in higher ed. [Ariana] And I've learned like [Ariana] higher ed wasn't built for us. [Ariana] I want to say, but it is built on a colonial [Ariana] white, cis-male perspective. [Ariana] And, like it wasn't built for us?! [Ariana] So why do we have to completely follow [Ariana] the culture and the [Ariana] foundation on which it was built. Like no. [Ariana] And so yeah, you're worthy of rest, and like, [Ariana] I think I talked about this [Ariana] on Twitter the other day. [Ariana] Like there's days where [Ariana] I just have so much sorry, [Ariana] pardon my language, Shit to do. [Ariana] And like, if my body's telling me like, [Ariana] I can't do that right now, like I'm anxious. [Ariana] I, you know, all these things like I [Ariana] need to take a step back [Ariana] and listen to my body. [Ariana] And I know it's [Ariana] like it goes hand in [Ariana] hand because like [Ariana] the system won't recognize that [Ariana] and they'll see that as, [Ariana] "Oh, you're being lazy. [Ariana] You're procrastinating." But I [Ariana] just want to tell you, like [Ariana] whoever's here, or will

[Ariana] be listening to this, [Ariana] in the future, [Ariana] "You're not lazy, you're not procrastinating. [Ariana] You're in a system that sees you that way, [Ariana] but you are not that way." [Ariana] And so, yeah, just I [Ariana] think maybe it's just like balance, like. [Ariana] You don't have to go with [Ariana] this system that wasn't built for [Ariana] you and isn't going to help you [Ariana] unless you self advocate for yourself. [Ariana] And I guess just some forms [Ariana] of self-care I've found to be useful. [Ariana] I've been fidgeting with this little putty thing the [Ariana] whole time because it [Ariana] helps me with my anxiety. [Ariana] Like just things like that. [Ariana] Going outside, getting some vitamin D like. [Ariana] I do art. I take a nap. [Ariana] I have, like, lotion [Ariana] but something that smells good [Ariana] that soothes my anxiety [Ariana] and soothes whatever I'm feeling. [Ariana] Just things like that have [Ariana] just been really helpful. [Ariana] Even kind of stepping [Ariana] back from social media. [Ariana] And from my standpoint, [Ariana] as identifying with as a [Ariana] Latinx, queer, disabled woman, [Ariana] like it's kind of hard to like [Ariana] avoid everything but where I'm like, [Ariana] it's going to just take a little [Ariana] step back and still, you know, [Ariana] stay informed and still, you know, [Ariana] stay on top of everything, [Ariana] but just take a step [Ariana] back and focus on yourself. [Ariana] Like it's...I know a lot of [Ariana] people view the word selfish [Ariana] as like a negative term. [Ariana] But when I see like be selfish, [Ariana] like that's a good word to use. [Ariana] Like it's okay to focus on yourself. [Ariana] Like it's a good word. A lot of people [Ariana] are like, "No, that's a bad word." I'm like no, I'm saying [Ariana] to be selfish. Focus on yourself. [Ariana] like that's a good thing, [Ariana] like we're saying it's a bad thing [Ariana] like, no, it's not. [Ariana] And I'm sorry, I went on a tangent, [Ariana] but like this is something [Ariana] I'm super passionate about. [Ariana] And yeah, so I [Ariana] think that's all I have to say. [Ariana] Thanks.

[Linda]

Amazing.

[Syreeta]

[other words missed] One last thing! Like I think it's not about being selfish, as a person with disabilities. When we do take that moment to take that midday nap. Yeah. It's just it's so awesome when you listen to your body and actually do it. But being selfish, sometimes as a person with disabilities, it's not selfish. It's selfless. It's honoring yourself, honoring your disability, denying the undertones of internalized ableism, institutionalized ableism, and you don't have to be a superhero. You don't have to over achieve to show your worth, to be here because you are worthy. You are meant to be here, We as people with disabilities and the intersections that we live at we add so much more to the, to the higher education, we have perspectives that aren't currently here. So I really want all of us to feel it strong enough to really self, selflessly, fight for ourselves, to be here, to be seen, to be amplified. To be empowered within higher education. Because higher education is not just for the abled, it's for all of us. And never forget that.

[Linda]

That is so awesome. And I know we've gone slightly over time, so I apologize for that, but I didn't want to stop anyone talking because everyone had awesome things to say. So I want to thank you all so, so much for being here today and for sharing so openly. Thank you so much. And I guess that's the end. So bye-bye.