

Disability Visibility Podcast
Episode 98: Disabled Students

Guests: Alena Morales

Host: Alice Wong

Transcript by [Cheryl Green](#)

For more information: DisabilityVisibilityProject.com/podcast

Introduction

[radio static, voices singing with hip-hop beat]

LATEEF MCLEOD: This is the *Disability Visibility Podcast* with your host, Alice Wong.

ALICE WONG: Hey there, all you beautiful people! Happy Year of the Ox, y'all! Welcome to the *Disability Visibility Podcast*, conversations on disability politics, culture, and media. I'm your host, Alice Wong. Today, I'm in conversation with Alena Morales, who will graduate with a Bachelor's degree in Nutritional Sciences with a minor in Disability Studies at UC Berkeley in Spring 2021. Alena is a queer disabled advocate of color and the former Chair and Co-Founder of the Disabled Students Commission. And through loving interdependence and collective labor with her fellow crips, she co-created one of the few Disability Cultural Centers in the country at UC Berkeley. You'll hear Alena talk about developing her disability identity, finding community, and getting involved in student activism at school. You'll also hear about the importance of creating space for the broader disability community with the formation of the Disability Cultural Center and the years-long process that made it happen. Are you ready? [electronic beeping] Away. We. Go!

ELECTRONIC VOICE: 5, 4, 3, 2, 1.

ALICE: So, Alena, thank you so much for being on my podcast today!

ALENA: Yeah, thank you for having me.

ALICE: So, why don't we go ahead and start with, if you don't mind just introducing yourself and just sharing anything you'd like about your background and who you are.

ALENA: Yeah. My name's Alena Morales. My pronouns are she/her. I'm disabled, I'm queer, Filipina, Latina, and I go to UC Berkeley. I'm a 5th year, and I'm studying Nutritional Science. I'm in the Registered Dietitian program, and I'm also studying Disability Studies. And I'm also a wheelchair user and a port user, if anyone else is out there.

ALICE: That's right, port pride, right?

ALENA: Yes! Pump pride all the way. [laughs]

Pride in all aspects of who Alena is and finding community

ALICE: I read about that an interview with you, and I love this idea about, you know, just you're really kind of open and just very visible about all the aspects of who you are.

ALENA: Thank you. Yes, it's something I definitely had to take a bit of time. I became disabled in high school, and there was a bit of a mourning period there for sure. But, you

know, I definitely feel pride now. And the wheelchair, you can see it in an instant, but that's a bit of more of a nuanced accessibility device and something that I don't really talk about as much. So, when I talk to my friend Katie Savin about it and she also had a pump, we were like, "Pump pride!" [laughs]

ALICE: Yeah, and that's the thing about pride too, and identity, where I think there's not a linear path, right? Like so many of us struggle with feeling comfortable within our own bodyminds, but I think that's OK too. I mean, everybody's got their own path. And I don't think just to be a member of the disability community, I don't think you have to be expected to be this very openly proud and loud person. What are your thoughts on that?

ALENA: No, that's so true. And I think, you know, because there are so many types of folks in our community, there's just so much nuance there. And I know for myself, like because my disabilities are based on chronic illness and they're very unpredictable, very some days are good, some days are bad. And because of that, I think the pride definitely goes up and down, and there are moments where it's really hard. But at the same time, the beauty of it, right, is that you get to connect with other folks that have been through similar experiences as you, different experiences, but maybe have a similar perspective, all sorts of folks that you can talk to. And I think with me, just being able to meet someone like Katie that also had a pump and just to be seen was really, it was really big for me because it's not always out there for us.

ALICE: Yeah, I feel like that also speaks to, the kind of, right now, the very narrow ideas of what we think about the word "disability" is still very much about apparent disabilities, and it leaves out so many people who have chronic illness, who are neurodivergent, who have invisible disabilities. And I think what I've noticed in the last at least 10 years, it just seems like to me, there's a much more kind of organizing and communities for people with chronic illness. And it's just been really wonderful to see, because people do crave connection. And what has been your journey like in terms of finding community with others like yourself?

ALENA: Yeah, that's a great question. I think with me, so, a fun fact: I actually started out as an athlete before disability. I did martial arts competitively. So, I was on a whole other spectrum, right? [laughs] So, for me, disability, that I had disabled folks in my family, and I think for me that helped my family support system. When I was really young, my grandma, she had myasthenia gravis, and I took care of her. My whole family took care of her. And she called herself the Disabled Diva. So, for me, I kind of had that perspective as well, just being a family member. And my mom also is disabled, and my brother is disabled. So, we were, I was able to find community in my home at first. And for me, that helped me be more comfortable to just see what's out there and look on the Internet, go online, see if anyone else is kind of going through the same things as me. Because the isolation was pretty big.

It wasn't, there wasn't a lot of disability representation in my school at the time, so. And because I was part of that athletic environment, I didn't have a lot of friends that were going through that, if at all. So, I went on the Internet, and I started just talking to folks in the Spoonie community. And that's kinda where I got started with an external community. And I really identified as a Spoonie very strongly in high school, and I still do 100%. But then I did a school project my senior year about Ed Roberts and about UC Berkeley and kind of how that kickstarted the disability rights and independent living movement. And for me, that was like this light kind of dinged on of, wow! There's so much out there, and there's so much history. And just, it was just incredible. So, that kinda kickstarted the wheels of disability.

And for me, because I didn't start using a wheelchair or having a port till I was 16, 17. So, I had an invisible disability. So, when I started using those more visible devices and my access needs were a bit more apparent, that's when I started really learning more about disability as an identity and leaning into that community, kinda just making my own mix of community. And when I got to Berkeley, then I met just so many folks. There's so many different types of folks here. So, for me, that was really important.

And being at Berkeley has helped me develop my sense of community more, but also kind of figure out more about myself as well and my identity: Where do I stand in all of this and what are my access needs and how do I say them loud and proud? And especially in my field, doing STEM, there's barriers that I faced being a student in STEM kind of at the time when I was a freshman. And so, then I was finding more community to support me through that as well. So, it's, there's a lot that's gone into it. But I think, for me, that was great because I got to meet a lot of people and learn from them and in that turn, learn more about myself, but also help other people and advocate for us.

[bright electronica music break]

Expectations for being at UC Berkeley and issues disabled students face on campus

ALICE: Yeah, and since you mentioned your high school project about Ed Roberts, and UC Berkeley is the premier flagship campus, and it has a reputation in terms of really a long history of not only student activism, but disability culture. Was that the draw in terms of applying to UC Berkeley, or just was it everything that you expected or thought about? Did it meet your expectations when you arrived as a first-year student, or do you feel like there were things that kind of surprised you?

ALENA: Right. Yeah, when I was doing my research, I was thinking the whole time like, oh my gosh, UC Berkeley must be the most accessible campus ever because all these amazing activists came out of it. And we kind of spearheaded these conversations and access on a campus, on a university campus. And so, I really thought it was gonna be this ginormous disability community with the most access out there, no ableism. [laughs] But obviously, that was not the case. So, I got there, and yeah, just I didn't— So, I was interested in advocacy. So, I went to my first meeting at the Disabled Students Union, and there was only a couple people there. And I was like, whoa. I was expecting dozens of people, and the community was just not as visible as I thought. And I was having some issues with accommodations and just professors. And in STEM I was having a lot of lab accommodation issues. So, it really surprised me. And I think that's when I got more into activism, was because I was seeing kind of the problems that were arising.

And I knew that the community was there because I was meeting so many people, disabled staff, disabled students, and community members. And they were there, and they have these underground spaces. But it wasn't really visible on campus. And that's when I knew that I wanted to be part of what was going on and the activism that was happening. Even if it was not as visible at the time, I wanted to help make it a bit more out there. And also, you know, that helped me as well, because I learned a lot from other folks, and I was able to self-advocate better. Because I wasn't getting what I needed. So, I was able to get the accommodations I needed and learn how to advocate for myself in classroom spaces as well.

ALICE: And as a fifth-year student, you must have a pretty good sense of kind of, overall, some of the broader issues that students face. Is there anything that, in addition to what you think you've faced yourself, but also other disabled students, what are some of the

major things that students are dealing with right now, especially in the midst of the pandemic at UC Berkeley?

ALENA: Yeah. I think there are a couple main themes that kind of lead to some issues. So, the biggest thing is that I've experienced, that I've heard, and just what you kind of see on campus, is the isolation that disabled students experience on campus. Because the structure is designed to, the Disabled Students Program, which is where we get our accommodations at UC Berkeley, and the Disability Access and Compliance Office, those are compliance-based spaces. And when you get your accommodations, they don't reveal your identity. You just give your letter of accommodation directly to your professor. And so, students aren't able to really find each other, DSP students. And just in general, because of the way that system is designed, you could be sitting next to a DSP student in your class of 500 people, and you wouldn't even know that they're also disabled. So, that lack of ability to find each other makes it really difficult to feel like, you know, you feel like you're the only person out there dealing with this. And because those are really the only spaces on campus and they are compliance spaces, it's hard for community members to find each other.

And that's where we really got into advocating for other types of spaces that were more community- and culture-oriented in our advocacy. So, that's a really big thing. And with that lack of visibility, like I said, the isolation is just it's really difficult. And some people, when we were doing, we've done a lot of town halls over the years, and just different community events, socials and things. And it's really nice. People say, "It's so nice to just be talking with other disabled folks because I feel like it's just me. I'm the only one out here, you know?" And that's just wild to me because if you think about it, Berkeley has tens of thousands of students. And if at least 20% of the population has disabilities, you would imagine that there'd be thousands of students on campus and the ability for us to meet so easily. But it's hard. And, yeah, you wouldn't expect that from the birthplace of the disability rights movement.

ALICE: Yeah, and I also think a lot about students that do receive a request, students that do request to receive accommodations through DSP, how many of the top reasons why it feels like such a lonely or individual experience. One of the things that feels intentional to me is the sense that students can't organize to have an impact or have a direct say in the kind of policies and practices. People, I think, go through these things where they have to fight so hard for their own kind of access needs and that really, it's about systemic change. And that's where longer institutional change happens. But students, if they don't know how to find one another, it's hard to organize.

ALENA: Definitely. Definitely. Yeah. And that's the first thing I noticed when I went into my first Disabled Students Union meeting is the place wasn't, the space wasn't accessible. So, how the clubs are designed at UC Berkeley is you request a meeting or a room to meet in, and then they allocate us a space randomly. And the space wasn't accessible to one of our members. And then a couple months later, we had an event where, at Berkeley, you know, all the clubs, they go on the Sproul Plaza, and they recruit new members. And they have all these tables. And our table wasn't wheelchair accessible. So, we were having a lot of issues just getting to the table to be able to talk to people. And it's all very intentional for sure. And the fact that we can't organize, there's no accountability measures for the administration to be able to listen to us and make the changes that we need to expand the resources for disabled folks.

[bright electronica music break]

Starting the first Disability Cultural Center

ALICE: Yeah, and related to this, as you mentioned about the need for different kind of cultural spaces that are not about accessibility per se or just accommodations, I read a interview about you and your activism along with lots of other people at UC Berkeley establishing the first ever Disability Cultural Center on campus! And first of all, congratulations on that.

ALENA: Thank you!

ALICE: For those who are unfamiliar with Disability Cultural Centers, could you describe kind of what they are? Because they do exist currently at various universities throughout the United States. And it's kind of amazing to think that UC Berkeley only recently established this. But what is a Disability Cultural Center, and what's unique about them as a entity versus other kind of registered student organizations and other kinds of offices and entities?

ALENA: Yeah, that's a good question. Since disability is an identity that is so broad and so complex and nuanced, I think to me, I see Disability Cultural Centers as kind of that social, cultural, and super visible starting point for folks to get involved in the community and in disability in general. Really, just a place where folks can show up and do whatever they need to do to feel empowered and also just get through this rigorous academic environment, whether it's I need to go in and take a nap in the quiet room, or I really just need to vent to someone that's been through a similar experience as me, or I wanna get more involved in advocacy and join this group that's organizing in the conference room.

So, I really just want it to be a hub for the community and what it is at the time. So, that also means expanding it one day. Obviously, Katie and I and other folks, we spent a lot of time doing town halls and getting input from the community and just making sure that everyone's voice was kind of in these proposals that we submitted about the cultural space, but that's, of course, the class that exists now. So, hopefully, as more folks come in and have their wants and needs for the space, then it will develop into something even more amazing. But, yeah, really just a space that is visible and shows that we are here and this is a home and that UC Berkeley is a place that is meant for disabled people because having a space for us to just be and organize as well, because it's been so difficult to find space to organize over the years, just sends messages to the community that we belong here.

ALICE: I love it. And can you tell me a little bit about that movement and kinda the years of organizing it took? Because I think a lot of people don't realize how much work it takes in terms of getting anything established. Could you share a little bit about your own kind of involvement in this whole effort?

ALENA: Yeah. And you're absolutely right. It was so much work. It was years and years of proposals and then protests, etc. So, what happened is, so, I was advocating with the Disabled Students Union, which had changed their name to the Student Coalition for Disability Rights, and I was the president. And I was also doing a campaign in the student government, the ASUC, and we were doing a campaign on disability visibility. And one of our action items was to get a Disability Cultural Center. And other folks were also doing labor. Berkeley Disabled Students was working on it. So, one day, Katie Savin, who I mentioned, she went to the Director of DSP, Karen Neilson, and said, "Hey, is anyone working on this? Like, we really need a cultural center."

So, we kind of all form this task force, and we called it the Disabled Student Leaders Coalition. And it was great. It was just a bunch of awesome women just trying to get our proposal ready. And we presented our proposal. The administration was like, yeah! Like, this is so great, such a good idea. The Chancellor wrote us a letter approving it, saying, "I'm in full support." And then we didn't really hear anything. And yeah, it was just a lot of radio silence and back and forth.

So, it was really difficult because there wasn't a lot of traction. We were going to all of these departments, but they were saying, oh, you can't get academic space because you're not an academic entity. But you can't get a club space because you're not a club. Because we wanted to make it super clear, hey, it's not Alena's coalition that's getting the space. It's not the student government. It's the disability community. And there was not really a policy for that in the UC. So, it made the process a lot more difficult.

And we eventually went to the Space Allocations and Capital Improvements Committee, I believe it's called, the SACI Committee, and submitted a proposal for a space. They're the ones that are in charge of allocating different groups spaces. So, we submitted a proposal, and they denied it because they were like, well, where's your community? We don't see it. Is this a real thing? And I mean, that's just, that was just shocking to me because it's like, well, you're not giving us the ability to congregate and organize.

So, we ended up having like a rally in front of their next meeting, in front of the building, their next meeting. And we were doing lots of chants, "Disabled and proud! What do we want? Disability Cultural Center. When do we want it? Ten years ago!" And just we were all like in a circle sharing stories, and it was just really beautiful. It was like one of the best memories of my life, to be honest. And then they said that day, OK, we believe you now. You were obviously here the whole time. So, here's your space.

And so, that was the OK, you have the space now. Now the question was where? So, then we spent a couple years trying to find the actual space. So, we toured the campus with a task force within that committee, the SACI committee, and it had a couple disabled faculty and a couple other folks as well, Ben Perez, who's the Manager of Physical Access. And so, we all kind of just did that. We are touring spaces: Oh, this isn't super accessible. This is great. This isn't great. And then we submitted a proposal for the space. And then the leader of that task force, he ended up retiring, and he was a powerhouse. And he was Abram, and he had been part of the campus for decades. And when he retired, then there wasn't a lot of accountability within the administration at that point. So, there was a, again, kind of that radio silence situation. So, yeah.

So, then we had to bang on everyone's emails and doors and etc., etc. And what we actually had to do to get a bit more visibility is we decided to actually make our own branch of the student government. And that allowed us to get a bit more of a platform and a bit more, I guess, clout for the administration to listen to us at that point, because there was so much radio silence. And we were able to get some funding from the student government and help fund some of the programs that were cut in the meantime. But that's a whole other story of student advocacy. [chuckles]

So, we eventually did get ahold of the Chancellor and her plan to basically revolutionize all the buildings on campus and house programs' different spaces and etc., etc. And we were able to get our space in Hearst Field Annex, which is a one-story hall on campus. And it's actually great because the Chancellor is planning to house a couple other groups there as well, so Queer Resource Center, and then the Fannie Lou Hamer Black Resource Center

is there, and then Karen Nakamura, who's an amazing Disability Studies professor, her disability lab is also in that hall. So, it's gonna be like a great space. [chuckles]

ALICE: Yeah! I mean, there's gonna be some excellent parties there, I think.

ALENA: Definitely! [laughs]

[bright electronica music break]

Being disabled on campus is more than receiving services

ALICE: It also makes me think about how really, there's a percentage of disabled students who actually request and receive accommodations through the Disabled Student Services. And there's actually far more students, faculty, and staff members that are disabled that never go through the DSP office. So, really, a Disability Cultural Center really is a place that's for the larger community.

ALENA: Oh, definitely. And it really does show, too, because there's hardly any disabled staff or faculty that report having a disability, and they're definitely out there. And because of these messages that are being sent to the community, the retention rate for disabled students, it's very low. So, it's gonna be great because, a, the larger community can meet, but then b, having those relationships with disabled staff and faculty and the wider Berkeley community, just being able to make those connections. And for me, having a conversation with a disabled faculty, it's like, wow. You're so successful in your career. I can do that, too, right? And just being able to meet like that is really great.

And we do also want to be able to have events that foster those conversations so students can feel more comfortable and encouraged to vocalize their access needs in the classroom space and then get resources that maybe go beyond what is super visible at DSP, so we're visible, more visible than what's on campus, right?

What Alena's learned in five years of building up the Disability Cultural Center

ALICE: Yeah. And I love the fact that we're taking the time for this story because we're capturing a moment, right? This is your final year on campus, and I think it takes a lot of persistence and strategy and leadership. And what were some of the things that you think were the big lessons in terms of forming a coalition to really gather enough kind of will, political will, to get this done? I mean, looking back at all of this, the five years that you've been involved on campus, what are some of the most important things that you've learned about yourself and just what you've been through with this process?

ALENA: That's a great question. Because the process was so complex and there were so many barriers, it all was just, it's difficult when you're a student because you're also, you're going to school full-time. And I also work part-time, you're also trying to do internships and other things to help with your long-term career. So, as we were dealing with these hurdles along the way of getting the cultural space, such as the programs that were cut at the same time, the cutting of the No Limits Program, which was a great accessible wellness program at the school gym, you really learn that all of these hurdles are intentional. And you really have to be able to work together as a community to strategize, but also lean on each other because it's draining, right? You juggle so many things as a student, but you're also learning about yourself. Because for me, I started doing all this when I was like 18, so I was still kind of dealing with all the things that come along with being 18. [chuckles] So, I learned to just lean on your community. Interdependence is a wonderful, wonderful thing and helping each other out, learning from folks that came before me. A big mentor of mine is Ben Perez, who I mentioned earlier. Just having other disabled folks such as him and

also Katie just as a wonderful co-leader, I feel like the experience really strengthened my love for the community and made me realize that I wasn't alone in the experience.

And then also, it didn't all have to be on me. I think one thing when I did first start out, because I was dealing a lot with my coalition, my first coalition, the Student Coalition for Disability Rights, we were having so many issues getting members because of the lack of visibility, because we didn't have the cultural center and these resources. And previously, so, when I came in to Berkeley in 2016, the Disabled Students Residence Program had just been cut, and that was a huge resource for the disability community getting accessible housing and other independent living strategies. And so, when that was cut, there was a trend of just lack of attendance for disabled folks. And so, there was a big trend there of all these systems that are trying to boot disabled people out and not have these resources and the isolation because of the system in academia in general. So, for me, when I was trying to try to recruit new members and kind of revamp everything, it was just a lot of pressure. And I did definitely overexert myself, and I was definitely flaring up. My disabilities were like, "What are you doing? You're doing so much right now." So, I really learned to honor my own disability, my own capacity along the way. And that in itself is an act of activism, right?

[bright electronica music break]

Disabled students leave a real mark on university campuses

ALICE: Well, it's really exciting to hear this kinda origin story because students do come and go, and yet for decades, so many students have left an indelible mark on UC Berkeley or just any institution they're part of. And universities are better because of it. And sometimes that a lot of agitation. Sometimes it takes a lot of different kind of means of persuasion. But student voices are so important, and I'm just so grateful to you and just everybody that's involved in this effort right now.

ALENA: Thank you so much. I'm just so happy with how it's going. I mean, it's been a journey, but I'm really happy. And because of this, I've actually been getting emails from people at UCSD and UCLA and UC Davis about setting up a cultural center there. So, really, I think the UC system is in for a surprise because of what our community has done and the fact that we've done it, and we can do it again. And I've been giving my proposals to advocates of those schools saying, "Here, bypass this labor by submitting this and doing this." And I think it's really great.

ALICE: You know, I think the dream is to have every single community college, vocational school, high schools, all of it to have some sort of disability culture component. Wouldn't that be the dream?

ALENA: It really would, yeah! Really, all Katie and I were saying, I was like, man, I wish we had had this when we first came in. Imagine how much more empowered we would've felt from day one and how supported we would've felt from day one and how far we would've gone. So, I really hope that it becomes a bigger thing, and other folks can get those resources and get community, find their home right away so people don't have to feel alone in a space that's so big, you know?

ALICE: Yep. And this is what progress looks like. And it gives me so much hope and joy. So, thank you so much.

ALENA: Thank you! Thank you so much. It's just been a real joy talking to you and just learning from you. So, I'm just very grateful for everything you've done.

ALENA: Thank you so much, Alice. Yeah, it's been such a pleasure talking to you, and thank you for all the work you've done and for this platform.

Wrap-up

[hip hop]

♪ how far will they go (oh yeah yeah)
how far will they go (oh yeah yeah).... ♪

ALICE: This podcast is a production of the Disability Visibility Project, an online community dedicated to creating, sharing, and amplifying disability media and culture. All episodes, including text transcripts, are available at DisabilityVisibilityProject.com/Podcast.

You can also find out more about Alena on my website.

The audio producer for this episode is Geraldine Ah-Sue. Introduction by Lateef McLeod. Theme music by Wheelchair Sports Camp.

Subscribe to our podcast on iTunes, Stitcher, Spotify, Pandora, or Google Podcasts. You can also support our podcast for \$1 a month or more by going to our Patreon page at Patreon.com/DVP. That's p-a-t-r-e-o-n dot com, slash DVP.

Thanks for listening! And see you on the Internets! Bye!!!

♪ rocket to the blast off
stop drop dance off ♪