Disability Visibility Podcast
Episode 54: Disabled Scientists

Guests: Gabi Serrato-Marks and Lisette Torres-Gerald

Host: Alice Wong

Transcript by Cheryl Green

For more information: https://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, friend. Welcome to the Disability Visibility Podcast, conversations on disability politics, culture, and media. I’m your host Alice Wong. Today’s episode is about science with two disabled scientists: Gabi Serrato-Marks, a PhD Candidate in marine biology, freelance science writer, and patient advocate; and Lisette E. Torres, a trained scientist and disabled scholar-activist whose work focuses on addressing racial and gender inequity and disability in science. You’ll hear Gabi and Lisette talk about the training and education of scientists, barriers disabled people face in science, the responsibilities and ethics of scientists, how science can be used as a tool for social change, and the importance of scientists from marginalized communities. Are you ready? Away we go! [electronic beeping]

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

Introduction to Gabi’s interview

ALICE: So, Gabi, thank you so much for being on my podcast today.

GABI: SERRATO-MARKS: Thank you so much for having me. My name is Gabi Serrato-Marks, and I’m a 4th year PhD student in Geology at MIT. So, my day job is looking at past climate change in Southern Mexico. I was recently diagnosed with Ehlers-Danlos Syndrome and have been dealing with chronic pain for about four years.

ALICE: When did you first realize that science is your calling?

GABI: Since I was a little kid, I knew I would be doing something involved in science. When I was in 2nd grade, I did a biography project about Marie Curie, and I ended up dressing up like her for a final presentation wearing a shawl with a little toy microscope. And she was sort of my first STEM role model, which was pretty cool.

Once I got to college, I realized that I wanted to be able to teach people the same way that my professors were teaching me, and I really enjoyed being part of their classes. And so, that’s a big reason why I’m in grad school now. Because I knew that to be in academia, I needed a PhD. I had really dedicated professors who made sure that all their undergrads got research experience and all these skills that a lot of undergrads don’t get.

I’ll give a shout-out to my thesis advisor, Michelle Levine. I took a bunch of classes with her and then did my Honor’s project with her, and she actually had a baby during that whole process.
So, she was a role model for me in terms of balancing her own real life and academic life and her career.

[bright electronica music break]

**It’s Time to Stop Excluding People with Disabilities From Science**

ALICE: So, I really appreciated the article you wrote in 2017 titled *It’s Time to Stop Excluding People with Disabilities From Science*. And what prompted you to write this?

GABI: I started writing with Massive Science, and they had me write an op-ed. And that was something I had never done before. But that fall, I was pursuing treatment and diagnoses for my chronic pain condition, and I was just so frustrated with how many walls I was running into. I was also struck that the whole issue of ableism in academia and in science is something that I previously had the privilege on not being aware of. So, I felt like I was on my own.

Putting writing out into the Internet, you never know exactly what you’re gonna get. I was getting messages from people saying, “Thank you for writing this. I’ve had fibromyalgia,” or, “I’ve had similar problems.” Or, “My sister has this. I know what you mean.” This is something that a lot of people are experiencing, but it’s hard to talk about.

ALICE: What are some of the things that struck you about the way graduate school is organized that really does exclude people with disabilities?

GABI: I think the most frustrating thing is that the work hours is really unlimited. For some advisors, they really expect students to be able to work pretty much 24/7. And for a variety of different disabilities, that just doesn’t work. No one can function 24 hours a day. That kind of burden, I think, is greater on disabled people than it is on non-disabled people.

One thing I’ve tried to do is just not respond to emails that are coming in at a time after I’m working, and that’s my one little piece of resistance. But I think it has to come from higher up where people are aware that that system doesn’t work, that it might’ve worked when the only people in academia were men with wives at home who were taking care of their children or whatever wild system it was. But it just doesn’t work for anyone with a family or with responsibilities or so many different things.

[downtempo electronica music break]

**Self-care and storytelling**

ALICE: You know, if we want people to do well, we have to be able to support everyone. What do you do for self-care? Because clearly, grad school is really stressful.

GABI: I really enjoy writing about things other than my research. So, I do some freelance science writing. And also, building community, so I have a lot of Internet friends who I talk to on Instagram and on Twitter who have similar experiences to me or who understand a little bit about what I’m going through. I have one friend, Susanna Harris, who founded PhDepression, which is an advocacy page, group, site for anyone in graduate school managing mental health conditions. And learning from other disabled activists and asking on Twitter, you know, “How do you ask for a seat on a bus,” and things along those lines has been really valuable. So, I’m very grateful to all the people who’ve come before me and who’ve slowly figured this stuff out.
ALICE: And speaking of community, this past fall, you and your co-partner, Skylar Bayer put out a call for stories from scientists with disabilities. And tell me why you did that and why you think storytelling is important.

GABI: So, Skylar and I both have done stories with The Story Collider. It's a kind of theater-science combination. She and I both have stories about fighting against our bodies to be able to do the science that we really love, and we realized that we were not alone in that. We wanted to make sure that there was a wide variety of stories represented: people who have ended up staying in science, people who have pursued other career paths because of the challenges they've faced, people who've been extremely successful in addition to their disability, all those kind of facets of life we wanted to capture. We thought the best way to do that would be to have people tell their own stories. We're hoping to put the stories together into either a series that'll be published online or potentially even into a book.

ALICE: Wow. That's exciting! I think this will be such a valuable resource for the world.

GABI: Yeah. I appreciate it. I really think so too.

[bright electronica music break]

Annual meetings and conferences and exclusion of disabled people

ALICE: You've also been advocating for improving access at conferences. Can you describe how important annual meetings and professional conferences to you?

GABI: It's a really big deal because it's the one time a year, sometimes only every other year, where everyone in the field gets together to talk about the latest research. And sometimes it’s things that aren’t even published yet. And if you aren’t there, or if you aren’t able to access the information, you’re really missing out. And so, there is a push to do more virtual conferences and to have access to be easier for everyone to not have to fly to a sometimes remote or expensive place, but instead to have this information be more accessible to everyone. But one of the things that has been challenging in the past for a lot of disabled scientists is that these giant meetings, if you do attend, they just aren’t built for us. They aren’t prepared for disabled scientists.

I collected some stories and perspectives from neurodivergent scientists 'cause I was going to make a video about those perspectives, in part because a lot of people wanted to remain anonymous. So, I didn’t wanna tell these stories, but I wanted to highlight them in people’s own words. I was just struck by how powerful these experiences were and how frustrated and left out people really felt in a lot of ways, and especially at conferences that are loud, busy, bright lights, you really don’t get a lot of breaks. That was something that people highlighted as a particularly difficult and really fraught event.

ALICE: Well, you just named my pet peeve at conferences, where they have sessions scheduled from like 8:00 am to 6:00 pm. You know what I mean? It’s just like there’s absolutely no way I would ever be able to go even for a half-day ‘cause that’s just so much back to back.

GABI: Yeah, your brain really gets saturated, I think, after just a few talks. So, doing it all day is kind of wild. For me, the most obvious example of something that could change is the fact that poster sessions where everyone stands next to their poster, and everyone else goes and reads the posters, those so often have alcohol involved, which can be really difficult for a lot of people for a lot of reasons. And they also entail standing at a poster for sometimes four hours. So, those poster sessions, for me, are kind of a nightmare. There’s so many different layers of how
inaccessible they are from actually navigating the poster space, which is often enormous, with sometimes thousands of posters up at the same time, or being able to see and read the poster, or having it at a height that is similar to your eye level, all these different issues. Poster sessions, I think, are some of the most frustrating and difficult spaces, especially for me.

downtempo electronica music break

ALICE: What is lost if disabled people continue to be excluded?

GABI: I think disabled people have a unique level of determination and problem solving that is actually perfect for science. The whole idea of science is trying to discover something new that no one else has discovered before. And sometimes my friends and I say to each other that if research were easy, if these questions that we’re trying to answer were easy, then someone would’ve already answered them. And I think that’s kind of true for a lot of disability experiences as well, that people say, “Oh, I don’t know how you do it.” And the answer is, “Well, you have to, and you just get through it.”

I think science is missing out on a hugely talented pool of people just because of the structural barriers that exist and that disabled people deserve to be there.

ALICE: It takes all of us to do our thing, but I think you’re gonna make an impact on, if not current, right now, people who are thinking about going into science, but just opening the doors, opening the conversation for future scientists. So, thank you for all that you’re doing.

GABI: Well, thank you. I appreciate it.

mellow ambient music break

Introduction to Lisette’s interview

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

LISETTE TORRES-GERALD: Oh, you’re welcome, Alice. Anything for you. My name is Lisette Torres-Gerald. I am a Puerto Rican, a mother, a scholar interested in equity within the sciences and kinda looking at how scientists shape the work that they do. I am currently trying to finish up my dissertation [chuckles] on scientist bloggers of color and how they view their work as public intellectualism. But in terms of my full-time job, I am currently the director of a writing center at a liberal arts college in Nebraska.

ALICE: You have degrees in Earth and Environmental Sciences and Zoology, and I was curious about what led you to study those areas of science.

LISETTE: As a kid, I always loved animals. I thought I was gonna go be a veterinarian. And I took my first Intro to Molecular Biology course, and I just was not a fan of the cellular, molecular stuff. That’s how I kinda wound up in Earth and Environmental Science. And then from there, I met an amazing mentor by the name of Dr. Craig Williamson. I was majoring in Earth and Environmental Science, but I was also majoring in Religion Studies with a focus in Buddhism. I knew there wasn’t many careers that would bring those two together. [laughs] After talking to Craig, he really encouraged me to go to graduate school, which was something that I didn’t even know existed or even considered.
Social transformation through science
ALICE: So, in your university’s bio, you say, “My ultimate goal is to inspire students to learn about themselves and to engage in positive social transformation using science as one of many tools for change.”

LISETTE: That is something that I talk to a lot with my colleagues in Science for the People. In terms of my classroom, making sure that my students know that we’re not coming in and saving people with the tools of science, just making sure my students understand that they should be working with and for the community and not seeing the community through this lens of pity.

And so, what I’ve been pushing at my institution is trying to the darker side of science and kinda showing how science has been used to oppress and then lead them to see how it can transform in positive ways. I’ve been trying to show them the responsibility that they have, like the history, the ethics, and the questionable research that scientists have engaged in, in the name of science. So, I try to teach them about the Tuskegee study and the Guatemala study and talk to them about, especially the women, white women are unaware that they get to use birth control because of the sacrifices of Puerto Rican women and Mexican women who were sterilized with the first trials of birth control, you know. And Henrietta Lack and the use of her cell line and how everyone uses her work, and for the longest time, her and her family received no credit or money.

[mellow ambient music break]

When I talk to a lot of the scientists in my circle anyway, they are surprised or unaware of a lot of these things that have happened, or they assume that those things were far in the past.

ALICE: You and I know this, but eugenics is still alive today.

LISETTE: Yeah.

ALICE: And I think a lot of people in science just deny that because that’s admitting this complicity in perpetuating that. And I think a lot of people in science, sometimes they justify some of the horrific things that’ve been done to people in the name of advancing science.

LISETTE: Mmhmm. Exactly. And they think that it can’t happen again. And I think, like the adage says, we’re doomed to repeat history, right? If you don’t acknowledge that happening, you don’t know that it happened, then the odds of it happening again are pretty high.

I think oftentimes, scientists think they know what’s best for people without actually having conversations with the people they’re claiming that they’re helping. So, working with my students to engage with the communities and to also ask permission. [chuckles] And Indigenous scholars, I’m sure, would tell you this over and over again: most scientists don’t ask permission to be on Indigenous land or to ask particular questions.

ALICE: When we think about how invasive that is to capture animals or take samples of flora or fauna when you’re on lands that are sacred, much less experiment on people.

LISETTE: And related to that, Alice, is I appreciate that, especially climate change, folks and ecologists are reaching out to Indigenous communities. And there’s an acknowledgement of the wisdom of Indigenous communities. [sighs] I always worry also that those communities aren’t necessarily seeing the benefits of that information being, that data being collected and distributed. And so, I want the scientific community to be, I think, a little more reflective and
culturally aware [chuckles] because I think oftentimes, we feel it’s like our right to just collect this information but without talking to the people who it impacts.

And climate change: I think one of the biggest things that I think folks need to understand is that climate change is real, it’s impacting people, and it’s doing so disproportionately. And we’re seeing this impact especially the disabled community and marginalized, poor communities of color. If science is a tool for change and science is liberatory, then we should be talking to and working with those communities to use science to remedy the situation and to make the world a better place.

[chill ambient music break]

**Science for the People and #MarginSci**

**ALICE**: Earlier, you mentioned the publication *Science for the People*. Can you describe what *Science for the People* is and also your involvement with the publication?

**LISETTE**: Sure! Science for the People actually was a group that started in the late, I wanna say late ’60s, and the group was a group of activist-scientists who were anti-military, Marxist, very radical Left, awesome, outspoken group. That very first March of Science was kind of a means by which Science for the People started reaching out to more folks across the country. And we’re just continuing to grow, and actually, we’re relaunching the original *Science for the People* magazine, and that’ll hopefully be relaunched this year.

**ALICE**: And in this first issue, is there a particular theme?

**LISETTE**: Yeah. So, the theme is called *Return to Radical Science*. We’ve been wanting someone to pitch something on disability in STEM ‘cause that’s a gaping hole in our work. There were a few back in ’81 on disability in the sciences, but they were written from able-bodied scientists.

**ALICE**: Oh, wow.

**LISETTE**: So, they’re written by allies, and so it’d be really nice to have disabled scientists come and write stuff [laughs] for us.

[chill ambient music break]

**ALICE**: For people who are unfamiliar with the hashtag #MarginSci, could you talk about what that is and why it’s important?

**LISETTE**: Yeah. I highly suggest following [@OtherSociology]. [@OtherSociology] is Zuleyka Zevallos, and she has an amazing blog. And she provides an overview of the history of the hashtag. The #MarginSci was a tag created by Dr. Stephanie Page. She was involved in some Twitter conversations regarding diversity in the first March for Science. And she kept talking to the coordinators of the march and trying to make them aware of the need for greater representation, and they just weren’t listening to her or to many of the scientists of color and disabled scientists who were kinda telling them, “Hey, for the march, these are the things that we need.” And so, she created the #MarginSci to kind of bring awareness to the lack of representation in the March for Science but also for STEM in general. And she wanted to highlight their refusal to create or include a diversity statement and to engage in conversations around diversity.
I think there are scientists out there, many of whom are scientists of color, who think of science kind of like I do: that there’s a greater purpose than just collecting data and sharing it among a very select group of people. You have a responsibility to translate your findings into accessible language and be intentional about sharing what you’ve collected with the folks around you, especially those who are impacted by the information.

ALICE: Great. Lisette, thank you so much for being on my podcast today! This is delightful.

LISETTE: Aw! Thank you, Alice.

Wrap-up
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 Gabi and Lisette’s work on our website.

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Thanks for listening, and see you on the Internets! Byeee!!

♫ Rock it till the blast off
Stop drop dance off ♫