Disability Visibility Podcast

Episode 3 Assistive Technology

Guests: Lateef McLeod and Jessie Lorenz

Host: Alice Wong

Transcript by Cheryl Green

For more information: https://disabilityvisibilityproject.com/podcast/

Introduction

[atmospheric music]

LATEEF MCLEOD: [typing] Technology...should...be...marketed...to...everyone because everyone can benefit from having an assistive technology in one form or another.

For a human to express oneself is one of the fundamental thing that we do as a human.

JESSIE LORENZ: At the core of it, Independent Living, I think, are those peer relationships, those relationships that kind of validate who we are and our community's way of being in this society, which is not built for us, but is learning how to include us.

[hip-hop music]

ALICE WONG: You just heard from Lateef Mcleod and Jessie Lorenz. Hey everyone, my name is Alice Wong and I'm host of the disability visibility podcast, conversations on disability politics, culture, and media. Today's episode is on assistive technology.

All technology is assistive, and the range of products and services available now for disabled people is pretty amazing. I got a chance to talk with Lateef and Jessie about the tech they use every day, how it impacts their lives, and the current barriers disabled people still face accessing assistive technology. When you heard Lateef earlier, he was using a speech generating app on his iPad called Proloquo2go. It voices what he types.

[electronic bleeping]

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

ALICE: Are you ready? Away we go!

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

Interview with Lateef McLeod

LATEEF: [typing] My...name is...Lateef...McLeod. My name is Lateef McLeod. I am currently a doctoral student in the Anthropology and Social Change program at California Institute for Integral Studies. I plan to concentrate my studies on how people with significant disabilities can acquire more political and social power within this society. More media exposure is part of this acquiring of power. That is why your podcast is important, along with my writing. I am in the process of writing another poetry book and a novel where I will be highlighting more disability issues. I am also busy doing advocacy work at my church, Allen Temple Baptist Church in the

Persons with Disabilities Ministry and with the International Society for Augmentative and Alternative Communication where I am lead Chair.

ALICE: So, Lateef, tell me a little bit about the types of assistive technology that you use and that you can't live without.

LATEEF: [typing] The assistive technologies that I cannot live without are my power wheelchair, because that is how I get around, and the the Proloquo2go and Proloquo4Text apps on my iPad and my iPhone because that is how I communicate.

ALICE: Yep, I'm in a power chair too. And without my computer, without my wheelchair, I would be stuck at home. It's pretty much essential to my life.

[typing]

LATEEF: Yes. Yes, and of course I cannot live without my laptop.

[atmospheric electronica]

Augmentative and Alternative Communication (AAC)

ALICE: So, we're talking about assistive technology and especially ones that assist with communication. What is augmentative and alternative communication, for people who've never heard of that term? It's also known as AAC.

LATEEF: Augmentative and alternative communication is non-verbal communication for people with speech disabilities, using symbols, letters, and words on low-tech and hi-tech devices.

ALICE: And how have you used AAC throughout your life? Was it all throughout your life or only later, as you got a little older?

LATEEF: [typing] I started using AAC when I was six and obtained my first Touch Talker.

ALICE: Obviously, you've seen a lot of changes throughout the years with AAC and other forms of assistive technology. As you grew up, what was it like using all the different kind of devices as time's gone on? What have you observed and experienced?

LATEEF: [typing] The main difference between my iPad and my other AAC devices is the iPad is mass-produced, and as a result, is much more inexpensive than the AAC devices that I had before that was produced specifically for people with complex communication needs. As a result, my other devices were thousands of dollars compared to my iPad, which was hundreds of dollars.

ALICE: Yeah, definitely I think the lean towards universal design has really put the AAC and other forms of assistive technology really in the hands of disabled people, many of whom do not have money, or maybe they might not have insurance to cover devices and technology like this. What do you think can be done to get more iPads and other forms of assistive technology to non-speaking disabled people who really need it?

LATEEF: I think devices need to be more integrated with other devices people normally buy, like phones, tablets, and computers so that the overhead cost will come down.

ALICE: I totally agree with you. There's this rehabilitation-industrial complex where some of these devices you used in the past were designed and created for people with complex disabilities that's medicalized and technology is so much more than that. And for me, the stuff that I used in the past that was designed for us is usually not only, like you said, very expensive, but it's often very ugly and not the easiest to use. And very rarely are these kinds of technology and devices created by disabled people but that's slowly changing.

[upbeat electronica]

Can you tell me about an example of, let's say, before iPads, before iPhones, before Wi-Fi and laptops, a device that you used for AAC that did what you needed to do, but you really kinda didn't like it, or that it really was difficult to use?

LATEEF: One of my first devices was called Touch Talker, and it was a bulky thing with picture icons on it. And I had to remember picture sequences to access instant phrases. But I always would forget the phrases and would just spell everything out.

ALICE: Yeah, I'm imagine that you had to remember a lot of things, depending on the device because they're so limited, and you have limited choices.

So, you mentioned you were six when you first started using AAC. Do you remember what life was like before you started using AAC and other forms of technology like this?

LATEEF: Before I acquired my first AAC device, which was a Touch Talker, my mom made picture boards where I could point to different words. I also could vocalize simple words and could perform rudimentary sign language.

Why is assistive technology important to disability community?

ALICE: What do you think is the importance of AAC and other forms of assistive technology for people with disabilities as you've seen in your own life and with people in the disability community?

LATEEF: [typing] The importance of AAC should be obvious because it allows people who have complex communication needs to express themselves and interact with people in their community.

ALICE: Absolutely. If you had a wish list, or you're in a room with designers and engineers and creators, what improvements would you like with the tech you're using right now? What would you like to see in the future in terms of new forms of AAC or assistive technology?

LATEEF: On the issue of improving the design of AAC is definitely ongoing thing. My first, and the most important, issue that I think needs to be addressed is more availability of AAC devices to those who need them at a more affordable price. I would like to make sure that everyone who needs a device has one.

ALICE: Yeah, I think the lines between technology and assistive technology is really blurry, right? Everybody who has an iPhone can use Siri, and Siri is a form of assistive technology for a lot of people with disabilities. So, I think that the lines are blurry, and when more people think of it as a standard feature, it could only help everyone. Is there anything you would like to see in the future that you would really benefit from but that you haven't seen yet?

LATEEF: I would like to have a vocal ID for my AAC devices because they are advertised to produce a more personalized digital voice that will sound like the particular user.

ALICE: Mm, yeah, that would be nice. It would really nice to have a customized voice to really reflect your personality, 'cause that must be pretty challenging to get the full expression of your emotion and personality from a device that sounds somewhat standardized.

Using AAC to gain more political power, social engagement, and acceptance in society

LATEEF: People who have AAC definitely have a lot of issues beyond acquiring the right AAC so that we can communicate. Some of us have severe mobility disabilities as well. So that further marginalizes us in our community. Because of our challenges with communication, we face more seclusion and isolation than other members of the population.

So, what I am studying now in my graduate program is how people who use AAC can gain the social and political power to be more included and engaged in society. We need more than technology to fix this problem. We need to change the consciousness of society to be more accepting to people who use AAC.

ALICE: I totally agree with you!

Wrap-up

ALICE: So, Lateef, if listeners wanna reach you or talk to you, how can they get in touch?

LATEEF: OK, people can reach me @Kut2smooth on Twitter. That is the letter "k" and the number 2. And also, my website is LateefHMcLeod.com.

ALICE: Great. Thank you, Lateef!

[atmospheric music]

Interview with Jessie Lorenz

Now, let's hear my conversation with Jessie Lorenz about the tech she uses every day and the assistive technology services provided by the Independent Living Resource Center of San Francisco.

JESSIE: I am the Executive Director of the Independent Living Resource Center San Francisco. We are the independent Living Center that serves San Francisco County. We've been around for 40 years now.

Device Lending Library

ALICE: So, tell me a little bit about the services that ILRCSF provides regarding assistive technology.

JESSIE: We have a wonderful service called our Nick Feldman Device Lending Library. We can provide information and referral for assistive technology products, devices, and services. We are part of a network of device lending libraries around the state of California where people can test out technology before the buy it, or sometimes they just need it for temporary reasons. So, we have wheelchair ramps, tablets, computers, support canes. People can borrow them from us or any of the other libraries throughout California.

We also, as part of that library, are beginning a new program with Senior and Disability Action, where we will be offering more classes to people in San Francisco: Classes about what tablet should I buy? My vision is going, and I wanna be able to read things. What options are out there?

ALICE: How do you decide what kind of products are available at your library?

JESSIE: Well, in large part, our choices about the technology that we buy within any given year are based on the needs or the requests that we get from our local San Francisco community. So, for example, small, portable, handheld magnifying devices, people like to try those out before they go and buy. And some of those can be really expensive, especially if you're getting ones that take pictures of things that are far away from you. Wheelchair ramps are another one where people want it because they're coming into town for a short amount of time, but they don't actually wanna buy it. I like to take a look at what the other libraries are carrying and what are some of the hot items. You really can't get enough tablets. There's always new things to try with the tablets. We happen to have a lot of augmentative communication devices because we had somebody who was on our staff who was really into mounting tablets and GoPros on people's wheelchairs. And so, we happen to have a lot of choices for things that can be hooked to wheelchairs!

We actually had some money from the Christopher Reeve Foundation where people, if they participated in a short-term group, they were able to keep that technology.

ALICE: Wow! That's fantastic.

JESSIE: Yeah, and we learned a lot. We learned a lot about the right way to mount things. We did a little how to record your accessibility challenges. A lot of the people in the short-term group were coming out of Laguna Honda Hospital. It all just happened to be men who were folks who had lived in the community for long-term, and we turned them all into photograph-taking, GoPro-using, wheelchair-accessibility-problem-videoing people. It was totally fun!

ALICE: You know, this library, it's so needed. So many products are out there that are fantastic and that could really make a huge difference in the lives of people with disabilities. And yet, for financial reasons and other reasons, it's really out of reach.

AAC's importance and society's barriers to getting technology to disabled people

ALICE: Can you speak to a little bit about, I guess, the importance of assistive technology, and also the financial aspect and other aspects that are barriers to getting the right technology in the hands of disabled people?

JESSIE: It's like the best of times, and it's the worst of times. It's the best of times because there are so many technological options out there for people. And sometimes with some disabilities, those options are really expensive. Sometimes you have to be dependent on agency funding, like Department of Rehab--that's really the one that we work with the most--to fund assistive technology. But then, at the same time, there's a lot of freeware and shareware assistive technologies, like NonVisual Desktop Access, for example, is a screen reader. Anyone can download it from anywhere around the world. Accessibility being built into products, I think, is not so much of an anomaly; it's more of a given with products from both Google and Apple. It is also very true that people who often need technology in their daily lives, that we encounter, can't afford the technologies that they need. So, I mean, I think that the project that we did with the Christopher Reeve Foundation, I'd like to do more programs like that.

ALICE: There's the financial divide and there's also the digital divide.

JESSIE: I think the biggest digital divide has to do with broadband or internet access at home. You know, whether or not people have it or don't have it is a big deal. In San Francisco, they talk about, oh, there's free Wi-Fi all over the city. Sometimes that Wi-Fi doesn't work in some of the more hilly parts of the city. And if you don't have the appropriate equipment to connect in the first place, it doesn't really do a whole lot of good.

So, I think there are some really good conversations going on about how to make sure that seniors and people with disabilities in San Francisco can access Wi-Fi and can access public computer labs. That's part of what we're trying to do with our new project with Senior and Disability Action, is create a space for folks with even the most functional limitations to come in and learn how to use a Mac and do iMovie or learn how to use a spreadsheet on a computer.

There are barriers to access, and I think one of the things that is really unique about what we're trying to do as well is really create a community approach to accessing technology.

By disability community, for disability community

ALICE: Right, especially one that's run by people with disabilities for people with disabilities, which is really kind of a different approach than most other non-profits. And why do you think that's important: From the community, by the community?

JESSIE: I'm a person who was born blind, blind-blind, very blind. Like, I have two fake eyes. And Walter, who runs our Nick Feldman Device Lending Library, is a person who's quadriplegic. Walter and I run our lives using technology. Not because we're geeks, but we are geeks for sure, for sure. But because technology allows us, I think, to hack our disabilities in really and meaningful ways. There really is something to be said for you don't know someone until you you've walked in their shoes, or you don't understand someone until you've walked in their shoes.

ALICE: For so many of us, there's such isolation and fear that it’s incredibly powerful to see other people using technology or just being really creative with their adaptations. And that gives a huge amount of validation and affirmation. I think seeing other peers live their lives the way they want, it's empowering for lack of a better word. People are hungry for that.

[sci-fi music]

Aira smart technology glasses

ALICE: Can you tell me a little bit about these Aira glasses you've been using?

JESSIE: I got these amazing new sunglasses with a small Google camera mounted on the right-hand side. I connect to the Aira service on an app with my phone. Also, the glasses are connected to a portable MiFi that I carry around in addition to carrying my phone. I often wear a little, tiny earpiece and have this person that I contact giving me information about what's going on around me. Within 10 seconds of pushing a button, I can have a sighted person giving me visual interpretation of my environment. This has proved really amazingly helpful in situation like when I got to the airport. I just turn on my glasses, sort of scan my head back and forth, and the lady's like, you know, "Turn to your right. OK, walk about 15 feet. OK, it's to your left. Make a left turn." I turn left. I'm having one of my senses augmented.

You pay for the service, and so it's like $89 for 100 minutes. I'll just say that you can go through minutes really fast [laughs]. And it's sort of an interesting conversation about should one have a

right to visual information, and who should pay for that? And it has changed my life. I used to run before my daughter was born, and then my life got hectic. But now, I've gotten back into running with the glasses. They help me find the trail that I really like. I love to just turn them on and say, "Tell me what's going on around me," in new places or loud places.

ALICE: And is there a lot of interaction between you and the visual interpreter?

JESSIE: They're really helpful for getting Uber because I can just have them call on my account and say, "Hail me an Uber." They will stay with me, looking at the glasses' feed and looking at the Uber feed and be like, "OK, the car just crossed this street. Oh, I see him right there. OK, wave to him. Step in the street." So, there's interaction in that way, but somebody should write a story about this weird relationship that I think does kind of develop.

I went to the National Archives with the glasses, and I walked around all by myself. I intentionally separated from my group, and I just used the glasses, and it was amazing. The guy's name was Drew, who was on the other end of the Aira phone. When I talk about my experience going through the museum, I can't talk about it without talking about Drew because Drew read me all the documents. And I don't know anything about Drew, even Drew's last name. But Drew made my experience at the National Archives absolutely awesome and wonderful.

ALICE: I think a lot about cyborgs because I do think about disabled people who are early adopters of technology and constantly innovating and adapting tech to their bodies and needs. And we all are cyborgs to some extent. Do you imagine tech like Aira becoming a permanent part of your body or another stream of sensory input that might be an option to people one day?

JESSIE: First of all, sign me up to be a cyborg.

ALICE: Cyborg!

[robotic beeping]

JESSIE: [laughs] I think it's gonna take a long time before people adopt this kind of technology. People get upset, like, "Oh, is this gonna replace cane skills or guide dog skills?" No way does it replace it. But I will say for myself, I love having it on when I walk around with just my cane in my neighborhood. I feel my body is more relaxed. I'm physically able to be in space in a different way, and it's not because I'm not a good traveler. I'm a great traveler; I've been doing this all my life. It's not because I don't know how or any of that. It's just it is actually helpful to have some more information about, "Oh yeah, your neighbors left their trash 10 feet in front of you on the sidewalk. Stay to your left."

ALICE: Or, "Watch out. A piece of turd!" [squish]

JESSIE: Yeah, exactly [laughs]! Exactly! Or here's an example: For parenting it was really helpful. When I left Denver airport, I used the glasses to get us out. We had to take the train, and usually I would need to either reach over and make physical contact to make sure she stayed on the train, or I'd make verbal contact just to make sure that she stayed where she needed to be. And the glasses allowed me to confirm, in a non-conspicuous way, what she was doing and that she was doing the right thing.

ALICE: Wow. If it could make such a difference in the lives of people, how do we get it in the hands of more people? We should make it more available, but again, that's capitalism!

[cash register rings up sale]

What assistive technology can you not live without?

ALICE: Are there other types of assistive technology that you use that you can't live without? What are your two favorite things aside from the Aira?

JESSIE: Oh, my life is in the Apple ecosystem. I use my iPhone to manage everything: My life and the lives of others. My iPad is an extension of that. I love my Mac computer.

ALICE: I like the voice memos on my iPhone. I use it a lot. I didn't even realize this feature until a little bit later.

Do you think the term assistive technology is ever gonna be outmoded one day as things become more integrated and mainstreamed?

JESSIE: I think that that term comes out of the Rehab Act, and that programs like this one come from Rehab Act funding. So, I think that that term is outdated, and Universal Design is definitely the way the world is going, not to be nerdy [laughs].

ALICE: Hey, I love nerding out. I love how you think it's outmoded because I do think, in a way, it's another silo. It really creates this idea that there's technology for this group of people that's somewhat separate and special, and non-disabled people have products just for them. Which is not true to life.

JESSIE: Right. I agree.

[soft music]

Wrap-up

JESSIE: I just wanna thank you for all the work that you've done, teaching us about ourselves and our collective history and keeping that conversation going in a way that can be archived forever. It's really, really valuable, and some of the things that we were talking about, affirming one another, your Disability Visibility Project is doing that for our people, and I wanna commend you and thank you.

ALICE: That's really kind of you, Jessie. I do feel like these conversations that we have every day, it's like we're creating history and culture together. And this keeps me going.

It's a delight to do this, and it's a real privilege.

So, Jessie, if people wanna follow you or find you, how can people do that?

JESSIE: My organization website is ILRCSF.org, Independent Living Resource Center San Francisco. I'm on Twitter as @UppityBlindMom, or you can just search for Jessie Lorenz.

Well, thank you, Alice.

ALICE: Thank you, Jessie!

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The audio producer for this episode is Cheryl Green. Introduction by Lateef McLeod. Theme music by Wheelchair Sports Camp.

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Thanks for listening and see ya on the Internets!