

Disability Visibility Podcast

Episode 55: Self Advocacy

Guests: Noor Pervez and Finn Gardiner

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: Howdy, partner! Welcome to the *Disability Visibility Podcast*, conversations on disability politics, culture, and media. I'm your host Alice Wong. So, there are all kinds of advocacy within the disability community. Self advocacy is one unique type that's grounded in a movement, history, and community of people. Today we're going to explore what self advocacy is with two people who identify as self advocates: Noor Pervez and Finn Gardiner. You'll hear Noor and Finn talk about how they first learned about the self advocacy movement and what it meant to them to be self advocates. Are you ready? [electronic beeping] Away we go!

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

ALICE: OK, so, Finn and Noor, I am just so delighted to have you on my podcast today.

FINN GARDINER: Yay. I'm glad to be here too.

NOOR PERVEZ: Yay!

ALICE: Wonderful. So, why don't I have you both introduce yourselves. And Finn, do you wanna go first and then Noor?

FINN: OK. So, hi. My name is Finn Gardiner, and I am a disability advocate and activist and researcher. I currently work for the Autistic Self Advocacy Network as the policy fellow, and I am also a research associate at the Lurie Institute for Disability Policy at The Heller School for Social Policy and Management at Brandeis University. And my work at both ASAN and Lurie focuses on community living for people with disabilities, community inclusion, including issues like inclusive parenting services or accessibility in general or education, etc. So, my work is very much influenced by the importance of making sure that people with disabilities are fully integrated in the community as we deserve to be. Because we are people and deserve to have access to everyone else around us.

ALICE: Absolutely. So, Noor, please go ahead.

NOOR: Sure. Hey, I'm Noor. I am the accessibility director for Masjid Al Rabia, and I am the community engagement coordinate for ASAN. I am a disability rights advocate, a queer Muslim, and very excited to be here. A lot of my work centers around, like Finn, the kind of intersection of community integration and community living but also the intersection of disability, race,

religion, and everything in between. And as a community engagement person, it's really, in my mind, my job to kind of try and build bridges for the various identities within the autistic community that haven't really had their fair space or share of representation.

[funk music break]

ALICE: So, I guess the first question is for both of you, is when did you first hear about the self advocacy movement, and when did you first kinda start identifying as a self advocate?

NOOR: Oh, boy. That's a fun one for me [chuckling] because.... OK. So, I don't know if I've told you this story or not, but I didn't actually get anything resembling a diagnosis until I was well into college, like my sophomore year. So, I didn't really have access to a lot of the language around self advocacy and disability until I was a lot older. But what I didn't realize even until pretty recently, I would say, is that I was, I'd say that if I had the language, I probably would be identifying as a self advocate from a relatively young age, like six or seven years old. Because I was a non-verbal child, and I was a very strongly self-identified like, "I'm a person who does not talk. I do not want to talk. I don't really see the point. I don't like engaging with people. I think that they're not really on my same level. They're not on my page." And I, from a very young age was very firm with my family, like if they tried to push me into speaking, I'd go, I'd just kind of—in whatever manner I could—indicate no, I'm not doing that. I don't want to. Same way with my school. I would indicate. If my teachers were constantly calling on me or trying to push me to socialize with people I didn't want to, no. I don't wanna do that, so I'm not going to.

And it ended up being that pretty much from childhood up until college, I had this constant system of going like, I know what the rules are. I understand what you want me to do. But if their violation of my rights or what makes me feel safe, then I'm going to push back. And I feel like that's not the entirety of what self advocacy is, obviously, but it's definitely a cornerstone. It's knowing where your boundaries are and being willing to kind of push back and find where you fit.

I would say that the first time I actually identified as a self advocate was probably around the start of college. I was one of those kids who always had some form of leadership role or officership from I think age 12 or so. But I never really thought of it as anything more than something that you just kind of had to do until that point. Around college, I got recruited towards the end of my senior year to work with a new LGBT advocacy group on campus, and they were focused on trying to promote better LGBT policy. And I was kind of just like, naaah. I don't really know if I'm up for it. It's this entirely new scenario. I don't know anyone. But you know, I went in, and I ended up really liking it. And I realized fairly quickly when students pushed the administration for things that we specifically knew would benefit our lives or the lives of students that were LGBT, that things could get significantly better. And it was at that point that I was kind of like, OK, so when we advocate for ourselves, we get what we need. And at that point, I think I pretty strongly identified as a self advocate. And then once I ended up going to ACI my, I think, sophomore, junior year of college—

ALICE: Could you say what ACI stands for?

NOOR: Oh yeah. ACI stands for the Autism Campus Initiative. Or, sorry. Finn, can you correct me?

FINN: Autism Campus Inclusion.

NOOR: Inclusion. There we go. Thank you. I always get it mashed up with another program we had on my campus. Thank you. Autism Campus Inclusion Summit. And I ended up going there towards the middle, end-ish of college, and at that point, I learned that self advocacy actually had this entire nuanced history within the disability community. And any doubt that I really had about whether or not I really belonged in the autistic community kind of disability, and I was just like, OK. So, there are people who walk and talk and sound like me. There are people who have similar experiences. OK, cool. I might not have ever seen myself here, but I belong here. [chuckles] And I feel like that was kind of when I totally crystalized and was like, yep. Nope. Self advocate in addition to everything else.

ALICE: Great. Thank you for that, Noor.

FINN: How about you, Finn?

FINN: Well, I didn't really see myself as a self advocate necessarily until my late teens or early 20s, at least not with disability in a strict sense. Though I think I've always had, like Noor, a strong tendency towards wanting to advocate for myself and for civil rights in general. Like I always remember being very justice-minded and focused on fairness and equity. And I would remember seeing, I remember being frustrated, for example, if I saw boys being favored over girls or seeing people making racist comments. I was one of those kids. I remember being 11 and actively reading stuff about [chuckles] depressing social issues like youth in the juvenile justice system or homelessness. And I remember talking to my school counselors and trying to change classes to things that worked better for me, whether it was to give me more of a challenge or to work with teachers who were less rigid and more willing to listen to me. So, I did have a strong tendency towards self advocacy, and I was diagnosed at a young age. I was diagnosed as autistic before starting school, which was really unusual at the time because I'm in my 30s, and it was very rare for, especially Black kids, to be diagnosed at a young age. But I was. And I did not develop a positive attitude towards having a disability or at least a neutral attitude until later on, but I still had, I still did try to advocate for myself in other contexts.

So, I felt more led towards disability self advocacy when I was like 19 and got involved with the online autistic community. A lot of the forums had Asperger in the name, though there were people there who advocated for a more inclusive definition of neurodiversity. I remember coming across sites like Autistics.org, which was still being updated actively at the time. It was run by Mel Baggs and, I think, Laura Tisoncik—or I'm not sure how she pronounces her name, but—and a few other people. But Autistics.org was kind of a revelation for me. There was discussion of the whole range of the autistic spectrum encapsulated on that website, and there was not a focus on functioning labels; here was not this division that I had seen elsewhere in the community. And there were these articles that really resonated with me, and there was also a lot going on, on the LiveJournal, which was you know, very web 1.0 social media before Facebook and Tumblr. But LiveJournal was where a lot of autistic activists were hanging out at the time.

And while a lot of us hung out in the, we were hanging out—Most of us were in this community called Asperger despite many of us not identifying with the Asperger's label because the account called Autism was primarily dominated by parents. But yeah, so despite the name, there's a lot of autistic organization going on. And all of this was before the Autistic Self Advocacy Network was founded. This was like 2005, about a year before it was founded, but that's when I first really got involved in, I guess, the self advocacy movement that was mostly online that I was doing it. And then I got more involved with groups in person in my mid-20s or so. I got involved with the local Boston chapter of ASAN after having moved to Boston from San

Francisco, and I got involved with our chapter. And then I also, like Noor, did ACI, though I was in the 2013 cohort.

[funk music break]

ALICE: I guess I'm kinda curious about a lot of people use the word "self advocate" and "self advocacy," but I was wondering, what does it mean to you personally to be a self advocate in your everyday life.

NOOR: Ooh, boy, yes. I have many feelings about this. [laughs] OK. So, I think we follow each other on Twitter, yeah?

ALICE: Yep, yep.

NOOR: Yeah. So, you've seen the just like incorporeal mass of just like day-to-day anti-ableism tweets that I end up creating on my feed just about the everyday issues I run into with everything from the non-ending stream of airports being terrible at basic accessibility that they're legally required to have to inaccessible restrooms and all of that fun stuff.

FINN: Argh.

NOOR: Yeah, exactly. [chuckling] That's my reaction too.

FINN: Airports are the worst!

NOOR: The worst. I don't think I've actually had a good flight since getting mobility aids unless I haven't brought my mobility aids, and sometimes not even then. To me, self advocacy is not being afraid to, when you see something wrong or when something's going wrong that's harmful to you or that isn't necessarily directly harmful to you immediately but some days could be, or if it's something that is harmful enough to you that you know could hurt other people, it's standing up and saying, "No. This is a thing that shouldn't be happening right now." That's part of why I make it such a big thing every time airports are inaccessible in particular, because there's, I figure, like if you hit a critical mass on people complaining on something, people see it, and people think about it. And when enough people are standing up for themselves individually, I feel like you kind of hit this critical mass where either an algorithm or an individual person or a journalist, someone will start taking notice. And even if that doesn't necessarily change things on its own, if there's a long-standing tradition of it, things move. When you put enough weight behind a boulder, eventually it tumbles. It's just a matter of how long.

FINN: Yeah. I tend to tweet. I tend to tweet every time an airport messes me around in some way.

NOOR: The same, TBH. [laughs] Because they don't care if you DM them. They don't really care if you talk to their help desk. But if you get a few hundred people angry at them, then something's gonna move.

FINN: Oh, and the security line can also be awful.

NOOR: Oh my god, yes. The worst. Even just, I get wheelchair assistance most of the time, but the thing is, they never, like it doesn't matter if I've reserved it in advance or not. They never know that you're coming there with wheelchair assistance. They never actually, somehow, if I bring my chair, know how to use any chair that's not the airport chair. I have a chair that

converts into a roll, that's a transfer chair that converts into a rollator. And to avoid confusing them, I had it in transfer chair mode the entire time I was at the airport, and they still had someone who was saying it was, "illegal for them to move me in any way" because it could, theoretically, at some point be a rollator.

FINN: What?!

NOOR: And it's the exact same format of chair that they have at the airport is the worst part of it. And I'm just like, guys. And the thing that was hilarious too was that they very clearly had never had someone—they either hadn't had or had had and were just very bad at this—had someone bring their own mobility equipment before. The last time I brought my rollator on when I was still using the rollator, and they were just like, "Well, you have to sit on an airport chair." And I was like, "OK. Are you gonna let—OK. Then how are you gonna get my rollator down there?" And they were like, "Uh, you have to check it." And I was like, "No. It's illegal to tell me that I have to check it." And they were just like, "Oh. Well, you have to gate check it." And I was like, "Also illegal." And they were just like, "Well, fine. What do you want us to do?" And I'm like, "Take me down on my transfer chair or else find someone to drag it down with us." And I guess that would count as another instance of self advocacy on a daily level. It's just like the constant need to make space for yourself in a world that is just not built for you.

[funk music break]

ALICE: Both of you have been talking about social media. And I follow both of you on Twitter, and I learn a lot from you both and also so many other people who are self advocates. And the autistic Twitter is incredibly strong. So, I was wondering what both of you think in terms of the role of social media in giving a platform or space for a lot of self advocates to just share their lives and share what it means to be a self advocate.

NOOR: I think it has a lot of power in ways that you would expect, but also in ways that you might now. In ways that I would expect: I would say it's definitely improved things in that a broader range of people are contributing their opinions. You see a lot more autistic people of color, a lot more autistic people with multiple disabilities contributing. I see more autistic people of color there than I will on literally just any autistic just mass media campaign for the most part, I mean other than ours. [laughs]

FINN: Seriously. I see so many more Black and brown and other autistic folks of color there, and that's a revelation because I see, like I feel like the autistic advocacy movement is so white-dominated. And it's depressing because people of color are so under-diagnosed in our community.

NOOR: It's very true. And I would say the thing that makes me happy about that is that it shows that we're there, and if people think to look for it, like if I, in college, had the word "autistic"—and that's a luxury that a lot of us don't have, but if I'd had the word "autistic"—or if I had that word and thought that I might be, and I somehow found autistic Twitter, I feel like I would've been a lot less lonely than I was. But also, you have to have that word to get there.

FINN: Yeah. I knew. I was diagnosed at a young age. Again, I was diagnosed in pre-school, but I still did not have an autistic community until I was an adult. And I found, of course, I was hanging out in LiveJournal and places like that too. But I feel like finding that racial diversity was not a thing that I found, really, until Twitter. Because even on Facebook and Tumblr, I found that a lot of the autistic community there was extremely white.

NOOR: Yeah. I found that too when I was first trying to kind of get my footing. Tumblr, in particular, that surprised me because Tumblr, I feel like I associated with diversity so much, well, at the time, before the great ad-pocalypse. But [laughs] aside from everyone there being extremely LGBT, everyone was white. And it was distressing.

FINN: Yeah. I found it was queer-friendly, but I feel like the discussions about autism and race were not really happening there.

NOOR: Yeah, and they weren't nuanced when they were happening. [chuckles]

FINN: Yeah. I feel like there were only a few people talking about it, and even now, I feel like it's only like a few autistic people of color consistently being amplified on social media.

NOOR: Oh god, yes. OK, that was the other thing I was gonna talk about, the bad thing or the ways that you might not expect social media to get weird around this: the algorithm and the fact that yeah, algorithms, much like people—and there's whole ranges of tech theory that explain this—but the basic concept that if a racist programs a machine, it's gonna come out racist. And I think that has really strong, unintended ramifications here because it's a numbers game, and it's a biases game that are kind of fueled by the algorithm. And that has the potential to kind of raise some voices, namely white voices and cis voices.

[funk music break]

ALICE: So, what do you love about being part of the self advocacy community, and what do you take pride in as a self advocate?

NOOR: So, I would say what I take a lot of pride in is definitely there's a strong sense of heritage in the self advocacy community I feel, particularly with regard to the fact that the self advocacy movement has its roots in people in institutions, and particularly, people with intellectual disabilities standing up and fighting back. And there's this very strong sense of things getting better intentionally through the work that individual people are doing. And I think that there's very much this sense of—there's a tangible sense of—oh, well, 10 years ago, the people who are older than me would have fewer tangible rights to, for example, public transportation or to certain access rules around different parts of life. There's a very strong sense between generations of degrees of freedom in the world, and I feel like there's a very strong sense of respect for that within our community. And there's very much a sense of we know where we've been.

FINN: Well, I think there's a lot of mutual support that I've found from other self advocates, whether they're autistic self advocates or people with other disabilities. I feel that just having that community of people who could empathize with your experiences, who understand that, understand what you've gone through, you realize you're not alone. You realize that hey, I'm not the only person who's had to argue with airlines to have them treat me right. You know, I'm not the only person who's had to deal with overwhelming environments where I just get overloaded and wanna shut down. And that is really vital. I also like the fact that we have started to organize more actively and come together as a community. And there are increased efforts for different self advocacy communities to connect with one another, for example, autistic people and some of the intellectual disability advocacy groups, or people with cerebral palsy, etc., or people with all three or Down syndrome.

I mean I don't think it's perfect, but I do think that we have made a lot of progress in the past couple of years. And that is something I am very proud to see because we used to be more

atomized. We used to be more separate. Especially in the autistic community, there were these people, these Aspie supremacists who would often go, "Oh, we're not like *those* autistic people who have intellectual disabilities and can't work and have high support needs. And of course, that's nonsense. We're all autistic here. We all have disabilities. It does not matter what our support needs are. I mean, obviously, our support needs matter because we need different kinds of help. But I mean our value is not based on our support needs or IQ scores or any of that. Our value comes from being human, and I feel that the autistic advocacy community has become more aware of that. When I got involved years ago, I remember a lot of people going on about oh, well, I'm high functioning, and I don't wanna be lumped in with *those* people! Which is nonsense. We are all in this together.

[funk music break]

ALICE: So, I'm curious about what your vision is for the future of self advocacy. What do you want and hope for future generations of self advocates?

NOOR: What I want and what I hope is that it gets broader and more diverse. I want more voices that are a unique blend of things rather than just oh well, we have one person of color on this board, on this panel, on x, y, or z, so, clearly, we've had enough. We've met our diversity quotient. Like no. I really, my hope is that we recognize that the vision we have currently of self advocacy, by virtue of it being part of larger disability community, is going to be incredibly white, is going to be incredibly cis, is going to be incredibly straight, and that the only way we break free of that is by truly meaningfully platforming as many diverse voices as we can so that both the algorithm itself and the people who are creating it are the people who should've been at the table in the first place, which is to say all of us, and especially those of us who've been left behind.

I think that the way we shape self advocacy and the way that we make it meaningfully available to more people is that. It's by making the voices that we platform, the voices that we pay attention to and listen to, are there and available for more people. And as a result, more voices can be processed and understood, and that ultimately, we can teach more people how to advocate for themselves by teaching them that they exist and that they have a right to the same freedom and availability of just quality of life and existence as every single other disabled person.

ALICE: Thank you for that, Noor.

FINN: So, what is the future of self advocacy? Well, for one, I'd like to see more racial, cultural, etc. diversity. I feel like, as I said before and as Noor said, the disability self advocacy community is incredibly white-dominated. And I feel that for us to make real, substantive change, we need to have people of different racial and ethnic backgrounds. Because you can't just assume that the experiences of say, white people with disabilities, people with I/DD is the same, are the same as those of us who are people of color, who are Black, Latino, Asian, Indigenous, Middle Eastern, etc. I feel like there needs to be space for all different kinds of voices with all different cultural backgrounds. We also need more class diversity. We need more educational diversity. We need to have people with intellectual disabilities at the table. We need to have people with complex support needs at the table. We need to hear from everyone because we are not a monolithic community. We do not all have the same experiences, and our advocacy needs to reflect that.

The last thing I wanted to add about self advocacy is that it doesn't have to be this huge performance if you don't want it to or if you don't have the energy to do that. Self advocacy can

be as simple as talking to your boss to make something, you know, maybe to lower the lighting in your office. Or asking somebody to do an image description. You can do self advocacy as much, anybody can do self advocacy. Self advocacy can be pointing to something that you know is going to make whatever you wanna do more accessible. It's talking to people about your disability. It's any number of things. Of course, if you wanna crawl up the White House steps or the Capitol Hill steps or get arrested in senators' offices, that's another form of self advocacy. There are a lot of different kinds of self advocacy, and there is room for all of us to do it.

[Hip Hop plays]

ALICE: That's excellent. Thank you so much.

FINN: Thank you so much for having us on too.

NOOR: Thank you so much.

♪ How far will they go
Oh yeah, yeah
How far will they go
Oh yeah, yeah.... ♪

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 Finn and Noor's work on our website.

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

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Well, thanks for listening, and see you on the Internets! Byeee!!

♪ Rock it to the blast off
Stop drop dance off ♪