Opening Doors, Season 2, Episode 2

Elsa Sjunesson: Defining Deafblind Intersectionality

Narrator: Welcome to Opening Doors, a podcast about accessibility in arts and civic life. Brought to you by the Seattle Cultural Accessibility Consortium and Jack Straw Cultural Center.

For our second season, we continue to amplify the voices of outstanding individuals with disabilities of all kinds. Here’s your host Elizabeth Ralston, an accessibility consultant and founder of the Seattle Cultural Accessibility Consortium.

Elizabeth Ralston: Hello, we have Elsa Sjunneson here today. Hugo Award and BFA winner editor Elsa Sjunneson is a deafblind hurricane in a vintage dress. Her nonfiction editorial work has appeared at Uncanny Magazine and Fireside Magazine. As an author her work has appeared at CNN opinion, tor.com the Boston Globe and the Nebula nominated Fate Accessibility Toolkit, among numerous other venues.

She also co-authored Marvel’s Jessica Jones, Playing with Fire, which was produced by Serial Box. In addition to editorial and authorial pursuits, she destroys structural ableism in her spare time. Her memoir, Being Seen, will be released in 2021 from Simon and Schuster. Elsa lives in Seattle, Washington, with 2 cats.

And here I am your host, Elizabeth Ralston. I am a white woman with short wavy silver hair wearing some computer glasses and a blue shirt with little half suns on it, and sitting on a brown couch. I’m so excited to be talking to you today Elsa. And you sound like a superhero when you say that you destroy structural ableism.

Can you tell me a little bit more about what that means? And give some examples.

Elsa Sjunneson: Hi I’m Elsa Sjunneson. I am a white woman with brown reddish short hair, purple and gold vintage looking glasses with an occluded cataract on my right side. And I’m wearing pink and gray hearing aids. I’m sitting on a teal couch that matches the cataract. I’m wearing a gray shirt with a gray cardigan.

I do a lot of work that ultimately ends up being about dismantling structures. When I do my writing or I do my editing, it’s sort of the work of theory, but I do actually like to put it in practice.

So, in the last few years, I’ve done things like working with New Jersey 11th for Change, where I was the accessibility coordinator. And we were outside our congressman’s office every Friday from 11am forward to talk to our representatives’ representatives because he wouldn’t have a town hall.

And the only thing that he would do is have telephone town halls, which were inaccessible to deaf constituents because he wouldn’t actually release transcripts. So, I did the work of chasing my congressman out of office.
And was one of the people who’ve sort of been credited for that. So that’s kind of what I mean. Like, in addition to my job, I also volunteer to actually fix things.

ER: That’s awesome and I guess you would have to really point out things like that. And that’s one of the things I’ve been doing is... when you have a video, it’s great to have captions, but if you don’t have a transcript, it’s not going to be accessible to deafblind people. Right?

So, I commend you for calling that out, and sometimes it can be, you know, exhausting work. To try to dismantle all these, I guess, ableism dominated views that we experience every day in life. Right?

EH: It’s exhausting. I mean . . . Hannah Gatsby has a line in her show, Nanette, in which she says, “I identify as tired.”

ER: [laughter]

Yes, I saw that show, that was incredible. And I totally related to her too. Like sometimes at the end of the day I just take my implants off. I just- I have been doing this more and more lately. I don’t know if you do. But umm. I don’t know if it’s my old age or what. But taking them off has been sort of my way of kind of decompressing,

But I want to say that in our earlier conversation you told me that you are a white, deafblind Jewish queer woman. So, what do you - when you think about like intersectionality, you have several identities, right? And some of these are invisible. And some of these are not. So which ones of those feel the most prominent to you as you go out in the world?

ES: You know it’s funny I’ve been working on making some of them more obvious, if that makes sense. For a lot of people, they don’t read me as deaf. And I identify as capital D Deaf. I sign, I have never known a world that was fully hearing. I’m not not hearing—hearing impaired. But because my hearing aids are tiny and they’re not visible, a lot of people don’t read me as deaf. Until I’m like “Sorry I’m deaf, can’t hear you” – like, signing through, you know, the plexiglass at the grocery story. And hoping that someone knows sign language or has a whiteboard.

And so, I’m doing things like working with my audiologist to get brightly colored earmolds instead of the domes so that you can see that I have something in my ears. I’m so excited I’m going to have purple ear molds. It makes me really happy.

ER: [laughter]

ES: We’re going to get this shrink wrap that you can get to go around things that’s hard plastic, to make my hearing aids a brighter color. So, it’s just doing things like that to make my hearing aids more visible.

Because I think most people see me as blind, they see the white cane, they see the glasses, they see the occluded cataract. And they’re like “you’re a blind person.” And I’m like, “no I’m deafblind. That’s a slightly different category.”

And the queerness is invisible to a lot of people. And even more so because as a bisexual woman who’s dating a man, people tend to read us as a straight couple. And I’m definitely not in a straight couple.
ER: [laughter]

ES: That’s not who we are. So, I’m still bi even if I’m dating a man. That doesn’t change.

ER: There’s so many different perspectives and assumptions that people make. It drives me crazy too like I face the same thing when I go to the grocery store and the cashier is talking to me, the mask situation makes it difficult. So, I admire the fact that you would actually make your hearing aids more visible.

I have two kids who have hearing loss. And when they were little, I had brightly colored earmolds for them, so that I could find them, ‘cause they would grab them and throw them on the ground and if they were brightly colored, I could find them.

But for me, growing up, I wanted to be invisible. I didn’t want people to know about my deafness. I wanted to be just like everyone else. So do you find that that changed for you over the years? That maybe when you were younger you wanted to hide it more. But now that you’re older and wiser, and it’s actually more enabling if you make it more visible for people to slow down and stop and communicate with you.

ES: I mean it’s a couple of different things. We’ll get this intersectional space again like, one, I’m blind. I need brightly colored hearing aids so I can find them. Like if they’re on the table I can’t see my hearing aids and I’m like where did my ears go?

Because sometimes I do take my hearing aids out in the middle of the day. Sometimes I don’t want to hear everything. Because my next-door neighbors are doing construction and its loud. So, then I’ll take out my hearing aids.

And then I need to find them again. But also, because I am deafblind, I can’t see people to know if they’re coming. And I can’t hear them well enough to know that they’re there. And it’s a safety issue for me.

I seem to find that it is safer for me when people know that I am deaf because a lot of people think I’m rude and then they start yelling at me because I was ignoring them. Like I literally didn’t know you were there. So, there’s a bunch of different pieces. But I would say as a child it was certainly less safe to have hearing aids. Other children are not kind—

ER: Mm-hm.

ES: and so, I think. Some of it also is like when I was a kid, I didn’t want to wear hearing aids because my classmates would do things like talk to them or scream or whisper or just like whistle into my hearing aids. I had a classmate who would chew gum next to my hearing aids.

ER: Yeah.

ES: so, I just sort of, I have come to use them as a tool that I appreciate. But part of the tool being useful is in people knowing that they’re there.

ER: Yes. And I didn’t think about the safety issue. And that makes so much sense now that you mention it. And it seems like that is part of your a-ha moment that we talked about, you know claiming the identify of being deafblind. So, like this large shift in your perception. And you realize the importance of identity when it comes to access.
And you know I feel the same way, I feel like— if I don’t talk about it, then people are not going to know what’s going on, like they might think I’m rude, like you said. But I’m facing difficulty in having my teenagers, who are both deaf, be more open about that. So do you have any thoughts or suggestions about how to work with young people who just don’t want the world to know that they may seem different in some way?

ES: I think it’s hard being different, especially in high school. Like I remember being a deaf teenager. And I would do just about anything to cope. And for a long time, I did do anything to cope. But I think what I would tell teenagers specifically, and also just adults who are struggling with it, is that being kind to yourself is one of the most important things that we can do as people, not just as disabled people, but as people in general.

But that kindness to yourself includes accepting who you are and what your body is capable of. It’s ok to need hearing aids. Because that kindness to yourself means that you have access to things. If you choose not to wear hearing aids, that’s also fine. It means you need to learn other coping mechanisms.

I know deaf people who don’t want to wear hearing aids, who don’t want to wear cochlear implants. That’s okay. But that means you have to learn sign language potentially. It means you have to cope in a different world, in a different way.

And so just finding the kindest path for yourself is really what I think is what makes you into a disabled adult.

ER: that’s exactly what I would think too, I just didn’t have the words to put into it. So, thank you for telling me that. Because being kind and being compassionate, self-compassion is really important. And I think that is a lifelong process for many people. Especially teenagers, they’re not going to know about being kind. Because that is an age where you are so hard on yourself. And your peers are hard on you.

So, you’re right, coping is actually another key word. If you’re going to stop this, you have to find another way of coping. And so that’s what I’ve been trying to say to them is “Okay, if you don’t want to use amplification in your classroom, what are you going to do? What is your plan?”

ES: Yeah. Because you have to have a plan. You can’t just not use amplification and then not do anything about it. Like I didn’t wear hearing aids throughout high school but that meant that I had to sit in the front row, every single day.

I mean I also had to sit in the front row because I can’t see more than three feet ahead of me at any time. But you know that means that you may not want to sit in the front row every day, maybe you need to look at different options.

ER: Exactly yeah. I want to sit with my friends, right? And that same thing happened to me when we would want to go shows for example. The theater, with my class.

ES: Mm-hm
ER: I would have to be in the front row and everybody else would sit behind me. And that was pretty isolating. But I have to say that as I grew older, I found my community in the deaf community, and the people who are deaf like myself.

As you know I don’t sign. So, I found kinship with other people who were also oral, like myself. Did you find that to be the case as you grew up and found more people with disabilities to be with?

ES: yeah, I mean community has been everything for me. I definitely say my online disability community has been a really important space for me. Disability Twitter is incredibly vibrant and frequently contentious, but it’s all good people.

And it has been interesting. You know, we were talking about my a-ha moment. As I started to sort of accept deafness as an identity. Which is a space that has always been weird for me because when I was growing up, I was looked as, I was too hearing to be part of the deaf community. But my hearing has gotten worse in the last ten years, and with that seems to have come a little bit more community.

And I don’t entirely know how I feel about that. Because I feel like I should have always been here. And the access to that community would have been really positive for me. But having that community now has been really important.

ER: Yes totally, and like you said, the different communities, it’s not just the disabled community. It’s also the queer community, or the arts community, the writing community. So, it’s nice to have different communities that you can rely on.

So, I think an important question I wanted to ask is, in one of the programs that I attended, that featured you as a panelist, you mentioned that you wished people would ask you what it meant to be deafblind. Like people don’t ask you very often what is it like to be in your shoes. And I really feel the same way is, I don’t think anyone understands and they’re too afraid to ask.

So let’s talk about that for a moment. What is it really like for you to be deafblind?

ES: Well, I think to start I have to address the misconception, which is that everybody thinks that deafblind people are like Helen Keller.

ER: [laughter]

ES: And that’s always the comparison that gets made. And so, what people assume is that I’m not going to be oral, that I use tactile sign. That I don’t hear anything, and that I don’t see anything, which are also misconceptions, because Helen Keller had some hearing. But that’s a separate issue.

But, you know, I have bilateral hearing aids. I’m profoundly deaf in one ear, but I have more hearing in the other one. So, I have kind of like a broken speaker on one side of my head.

ER: [laughter]

ES: The other one is okay. It’s not great. I take out my hearing aids and I can’t hear the fire alarm, you know, my phone alarm, my cat,
ES: like all of these things I just don’t hear. But on the other hand, like, that’s not the whole of it. I also don’t see well enough to, say, learn ASL over zoom. I was trying to do that at the beginning of the pandemic and it was impossible. I don’t have depth perception. So, using zoom to learn a language that depends on depth and spatial skills was impossible.

That’s an example of what it’s like to be in my shoes. It’s having to kind of negotiate not between just one disabled identity but two. And figure out that some coping mechanisms that work for blind people don’t work for me because I’m also deaf. Some coping mechanisms that work for deaf people don’t work for me because I’m blind, and living at that intersection means that I actually get left out a lot.

ER: Mm-hmmm

ES: Because adaptive devices aren’t thinking about me or my needs. Communities aren’t necessarily thinking of my needs. Because we just don’t think of overlapping identities. We think of categories.

ER: And that’s why it’s so important, A. to meet the person where they’re at and B. don’t be afraid to ask what someone needs.

And can you go in a little more detail about what you mean by depth perception. I’m thinking about our listeners, and they may be wondering what does that mean, depth perception, using the example of like this platform that we’re on.

ES: So, I’ll use a very simple example that works for everybody. Go and look at a flight of stairs. For a sighted person, when you look at a flight of stairs you can tell that it’s stairs. Because you can see the depth. You can see the rise of each step as you’re going down it. You can tell about how far each step is down.

The only reason why I know how far each step is down is because I’m using a white cane and it tells me because I slide the tip down each step so that I can actually figure out how to go down the stairs.

ER: Wow. Ok so, you have to use your cane to feel your way down the stairs because you don’t know how far down you have to step.

ES: Yeah.

ER: Or how long the stair is, right?

ES: Yeah, pretty much. I mean, I learn stairs. Like I can physically go up and down stairs that are at the front of my apartment without my cane because I’ve learned them at this point. But I don’t like to do that. And I certainly don’t do that in foreign environments.

ER: Right. So, for me, I wish people would ask me what exactly can you hear with your cochlear implants. So, I have a joke that I make, in that “My hearing is actually getting better as I get older because of my implants, where all my friends are getting worse.”

But anyway, I want to be able to explain to people what it’s like because I think there are so many misconceptions about that. And did you see the movie The Sound of Metal?

ES: No, not Yet
Okay, yes. So that movie - I would be interested in chatting with you sometime about that movie. But there were a lot of misconceptions about deafness in that movie. But we’ll have to do a part two to really dive into that.

I want to spend a minute talking about how we both love to travel, right?

You said that you have spent some time in London, and we both have a love of theater. So, from your perspective, what is it like accessing the arts in London? How does it compare to Seattle?

ES: Well, I also lived in New York for ten years, so I’ll actually do the London-New York comparison, because it’s a little bit more damning.

ER: [laughter]

ES: In London, I was able to get a twenty-five pound ticket for a front row seat as a deafblind person. I would just go up to the box office and say “Hi, do you have any disability seats available for the show tonight.” And they would be like “Here have two tickets for twenty-five pounds each. Bring a companion, have a nice show.”

I got to see Daniel Radcliffe in Equus that way. I got to see Wicked that way. I got to see Othello from the Royal Shakespeare company that way, which was incredible.

ER: Mm

ES: so, I got to see all the amazing top of the line theater for nothing. And that’s how it should be, because disabled people have less access to income. We are fundamentally underemployed in this country. And yet in New York, if you want to go see any show on Broadway, you have to pay around 250-300 dollars for your seat at a Broadway show.

ER: Mm-hm.

ES: I saw Hadestown two years ago, and it was an incredible production and I loved getting to see it. But I mean, we had to pay a lot of money to sit in seats I could see from. And you know I basically just stalked the Hamilton lottery for months so I could go see it because I couldn’t afford tickets. And you know, the only spot that I could see from was the first two rows.

I finally got to see Hamilton in Seattle because a friend had an inside track on the accessibility seats, which were much cheaper at the Paramount. So, there’s a difference between the two big theater towns in the world, New York and London. One of them is easy to navigate as a disabled person, and one of them is a nightmare.

ER: You know, I’ve experienced that about London as well. The last time I went there, they were so accommodating about my request to see A Midnight Summer’s Dream. And you know, didn’t have captioning that day, but they said “We will put in a good seat, and we will give you a script,” and I didn’t even have to explain anything.

And I still find that I have to explain and explain even now, but I do think it’s getting a little bit better. I think the arts community here is starting to really think about how to make their spaces more accessible to people of all abilities, and now they’re forced to with the pandemic.
ES: In Seattle my experience has been a little bit different because ACT Theater sort of has like: you buy your ticket and you just pick where you’re sitting. And so, I just always would get there when doors open and scuttle to the front seats and take a seat. I never had a problem. You know, I would always go on the nights where it was very much pick your own seating.

You know, when I went and saw the *Midsummer Night’s Dream* production at 12th Avenue Arts in 2018, that was an ASL production. I had let them know I was deafblind, and they were like “Here you go, front row seats, have a nice time.” But that’s because they were productions that either didn’t have seating rules, or were specifically tailored to the community.

ER: Yeah, I’ve noticed that too, if they have a production that featured disabled actors or some kind of disability, it was easier to go and see. So, I’m hoping that could change as they expand their repertoire to include more regular productions that anybody can go and see.

My last question to you is I really want to ask you about your book, *Being Seen*, and if you can give me a closing statement about *Being Seen*. What are the takeaways from that book that you want your readers to come away with?

ES: So, the book is sort of an odd mish-mash of cultural criticism and memoir. So, what I’m doing is I’m taking a look at how deaf and blind women are represented in media, and how those representations that are false are affecting the way that we view people in real life. What I’m hoping people will see is that it is much more complicated to live a life as a deafblind woman or a deaf woman or a blind woman than it is on TV.

It’s that old joke: I’m not a doctor but I play one on TV. It’s like yeah, how good of a doctor are you when you’re on TV.

But when people look at disability, they sort of swallow the monoliths whole. And they apply them to real living people’s bodies because they can, and that’s when we run into problems.

So, people will say, “O well I watched this TV show and the blind character was completely blind and you can see.” And I’m like “Yes . . . And I’m still blind, isn’t that exciting.”

ER: [Chuckles]

ES: So, I hope people really problematize and nuance their views on disability and disabled bodies. That’s what I’m hoping people do is that they really interrogate what they’re looking at on a TV screen or just on the street, and they start to sort of internalize that a disabled body does not look like what you think it does, in any context.

ER: Elsa, I can’t wait to read your book. I’m definitely getting your book. And I think you should see *The Sound of Metal*, because that’s exactly what happens in that movie. Is that there’s so many misconceptions about cochlear implants that is actually damaging to people who have cochlear implants and the parents who have deaf children and they’re thinking about getting them an implant, and they see this movie and it completely distorts the reality behind it.

So, I’m really glad that you wrote your book and I can’t wait to read it. Thank you so much for your time and speaking with me today.

ES: Thank you so much for having me. It’s been lovely.
Narrator: Opening Doors is produced by the Seattle Cultural Accessibility Consortium and Jack Straw Cultural Center. This podcast was made possible by the Seattle Office of Arts and Culture, the Washington State Arts Commission, the National Endowment for the Arts, and individual donors, with in kind support from Jack Straw Cultural Center, Sound Theater Company, Jennifer Rice Communications, and the Seattle Cultural Accessibility Consortium Steering Committee. Music performed by William Chapman Nyaho, produced through the Jack Straw Artist Support Program

The mission of the Seattle Cultural Accessibility Consortium is to connect arts and cultural organizations with the information and resources to improve accessibility for people of all abilities. SCAC’s fiscal sponsor is Shunpike. To learn more, go to seattlecac.org.

Jack Straw Cultural Center, producer of the Blind Youth Audio Project since 1997, is committed to keeping art, culture, and heritage vital through sound. You can learn more at jackstraw.org.

Join us for our next episode featuring an interview with Vince Medrano, a queer Mexican trans man committed to mental health research and community advocacy.

Vince Medrano: I think social work does a good job in allowing people with lived experiences to be in social work and not stigmatize the fact that they have lived experiences. And it also trains us to be sensitive to things like intersecting identities, to socioeconomic status, to trauma, to all of these things that shape a person into who they are.

Narrator: Hear the whole interview on the next episode of Opening Doors, available at soundcloud.com/openingdoorspod and wherever you get your podcasts.

Thanks for listening.