



How Annie Elainey Is Making the Future Accessible

This popular YouTuber is a bit of a provocateur. “How To Spot a Fake Disability” is among her most viewed and most subversive videos. Annie Elainey, the queer, disabled, intersectional advocate who created #TheFutureIsAccessible, is constantly challenging assumptions about disability and chronic illness.

Clip, Annie Elainey: *There's a saying that goes: you can't be what you can't see. It can kind of shake you when you live in a world where like you just do not see yourself.*

Alicia Menendez: Annie Segarra, or Annie Elainey as she's known online, is an activist who uses platforms like YouTube, Instagram and Tumblr to agitate, educate and share her personal experiences of disability, chronic illness, LGBT+ rights, mental health, and so much more. Her work has earned Annie a loyal following. She has over a million views on YouTube. She's also the mastermind behind The Future is Accessible campaign, a rallying cry for visibility and intersectionality.

Annie, I am so happy to be with you.

Annie Elainey: I am so excited to be here today.

Menendez: Where did you think there was an opportunity for a voice like yours?

Annie Elainey: I still to this moment think that there's, like, such a huge window for disabled people to have their voices heard. There is a strong disability community and chronic illness community online, but a lack of actual visibility in terms of what we're talking about, in terms of using our faces, using our voices.

Menendez: Did you know from the start that you wanted to build something bigger?

Annie Elainey: No. Hell no. The beginning of creating content was literally just self-expression. Eventually, I did slowly start to figure out, “Oh, this is helping other people, this is something that people are kind of hungry for in the same way that I was hungry for it.”

Menendez: Because of the views? Because of comments? What tipped you off?

Annie Elaine: Oh yeah, absolutely. Certain comments, certain messages would say things like, "I've never seen somebody so confident using a wheelchair or using a cane," and see, my response is like, "Really?" Because I struggle a little bit at this point in my life to remember that, yeah, that was me too; that I was once upon a time completely segregated from the disabled community and from having a timeline, a newsfeed that was filled with confident disabled people with very diverse narratives, and very diverse desires, and wants and dreams and jobs and personalities.

So when I read things like that, and people at the very start, people just starting to learn, they're learning about themselves at that point. They're learning like, "Oh, I can also be that confident person who uses a mobility aid." Ooh, I'm like emotional about that. Like, there's a saying that goes: you can't be what you can't see. So for a lot of people, it probably feels like a desert to them. It can kind of shake you when you live in a world where you just do not see yourself.

Menendez: We talk about that a lot in the context of media consumption, and being Latina and not growing up and having a lot of people to look to on television, on radio, but then you add in a whole other identity or myriad of other identities, and then you really, really aren't seeing yourself.

Annie Elaine: Right. Yeah. You feel strange and you feel ugly, and you feel out of place, and those feelings all just bundle up into this incredibly negative self-worth of a human being. And I used to deal with that just in terms of like body image. Like yes, I'm a very like intersectional person: I'm a Brown person, I'm a chubby/plus size person, now I use mobility AIDS--so, aesthetically, something that I don't get to see a lot of in media--adding being LGBT on there as well. There was really nobody to be like, "Hey, you can be all these things and be accepted and be cool--"

Menendez: Desired, loved.

Annie Elaine: "Loved and desired." So I wanted, and I still do--I want to create something, a narrative including queer, disabled people of color, because as bizarre as that sounds to people who are not in the community or very segregated from the community, that is my life and that is my circle of friends.

Menendez: What's your favorite video you've ever made?

Annie Elaine: There are so many.

Menendez: Is there one you've gotten the strongest response to?

Annie Elaine: Yes. It's a video called How to Spot a Fake Disability, which is a clickbait title.

Menendez: Yeah it is.

Annie Elaine: Yeah it is. And it's about how you can't, you cannot spot a fake disability. I found out that people were actually searching for that on Google, because they want to play detective with people's disabilities. And so, when I found out people were searching for it, I was like, "Well, if you're going to search for it, I want you to find

this instead." There's a big issue; people are very upset that they believe that people are faking their need of disability placards for whatever reason, if they walk away from their car, if they're young looking, if they're too fashionable, whatever their reason.

Menendez: Has this happened to you?

Annie Elaine: The funniest one was when I was just starting to use a wheelchair, because my walking limit had decreased to like a couple minutes or so. A woman saw me park my car, get my wheelchair out of the trunk and go into a store. And I guess, because she saw me do that, because she saw me stand up and get my wheelchair out of the trunk, she decided to confront me inside the store, but it was to say, "Honey, did you know if you just lost some weight, you probably wouldn't need to use that wheelchair?" Which sucked. Poor me.

I even tried to explain it to her. I'm like, "Actually it's because I have this condition," and she like interrupted me and was like, "Yeah, yeah, yeah, I know, I know, I know, but really, if you just lost some weight, you wouldn't need to use it anymore." I was like, "Ugh."

Menendez: It's amazing how people feel free to just weigh in.

Annie Elaine: I mean, that's in so many, so many, so many cases. This happens to me with my condition, with Ehlers Danlos Syndrome. too; people are so in a hurry to assume that they have the solution, that they're going to be your hero, right? They're going to tell you how to fix it.

I think I try to explain to Ehlers Danlos Syndrome to people the most basic way. It's a connective tissue disorder. It affects the collagen in my body; the collagen is essentially the glue that holds the body together, so I try to find an analogy for it. I'm like, okay, if a house is put together, it's put together with cement. My house is held together with strawberry jam. It doesn't work.

But they hear the word collagen, so they're like, "Well, have you tried taking collagen supplements?" I'm like, "That's not how this works. My DNA is literally creating defective collagen, so adding more is not going to fix it." It doesn't end.

But then the second part to that is, if I were well enough, I need to use mobility aids, and a lot of places locally are not accessible to me.

Menendez: Meaning, your wheelchair.

Annie Elaine: Right.

Menendez: A cane.

Annie Elaine: Mm-hmm (affirmative). I have specific needs if I'm using a cane. For example, I could probably take a car from home to a restaurant and use my cane, because if the car parks right in the front door of a restaurant, it will take me less than 30 seconds to get from the car to a chair inside the restaurant, and that's what I need, to be on my feet for less than 60 seconds.

Menendez: Let's back it way up. What was your experience of seeking out your diagnosis?

Annie Elaine: Oh, that was long and difficult. I wasn't all that symptomatic when I was younger. And I think around the age of 23, I was in a job where I had to wear heels and I was on my feet for like eight hours a day, and I thought that it was a me problem that I was in so much pain wearing heels at this job. People who work in the service industry go home and they put their feet in hot water because they were on their feet all day, so pain was normalized. I was like-

Menendez: But the pain you were experiencing was very different?

Annie Elaine: Yeah, and I didn't know that because I just thought everybody was feeling the same pain.

Menendez: So when did you say, "There's something about this that is not that"?

Annie Elaine: When my walking limit became like five minutes long. The seven hour mark would hit and I'd be like, "Boss, you got to get me a stool up here in the front, because I can't stand up." And then it just kept declining. I just kept thinking I must be so weak. I need to raise my tolerance for this because everybody else can do it, but I can't do it. I literally was just thinking like it was the shoe thing, it was the standing thing, and-

Menendez: But are you Googling this? I mean, are you trying to find answers?

Annie Elaine: At that point, no. But finally, when I got to the five minute mark, and I was like, "Okay," I was like, "I can't stand up. I need to get a cane, a mobility aid," I did start my process of trying to get diagnosed. So I went to go get a checkup and they did x-rays and they're like, "Uh, nothing's wrong with you."

Menendez: So how do you go from there to actually getting your diagnosis?

Annie Elaine: Through internet research. I brought to them, to the table, I'm like, "I would like to be tested for Ehlers Danlos Syndrome, because I've been researching it." Because doctors over and over and over, for three years, they would say things like, "Yeah, there's nothing wrong with you. It's all in your head," or "Maybe you have some trauma. Maybe it's conversion disorder." They would literally call me crazy.

So I talked to a neurosurgeon who injected me with steroids in the back to try to decrease the pain, but I was undiagnosed Ehlers Danlos Syndrome with a collagen defect, and steroids messes up collagen; so, collagen that already wasn't working, they poked holes in it. So I couldn't get out of bed for like 10 days. I was stuck in a horizontal position because I didn't have enough strength to sit up on my own.

And when I told the doctor that, he laughed and said, "What you're describing is not possible." Then he looks at these scans of my pelvis, because he thinks that the pain in my back is coming from my pelvis, and he sees essentially that I'm walking around on dislocated hips, and he's like, "What the heck, this does not make sense. How could you possibly be walking on dislocated hips?" And I said,

"Okay, well, sir, what you are looking at is actually a symptom of what I'm telling you I think I have and would like to be tested for."

Menendez: So when does someone finally say, "Okay, yes you are correct. Your internet sleuthing is correct"?

Annie Elaine: Not this guy, but it did happen in this office when he kept gaslighting me and dismissing me and telling me that what I was saying was not possible, et cetera. He then suggests and said that he wants to do another operation where he would fuse my hipbones together, and I started freaking out crying because this person was willing to risk me being horizontal in bed for the rest of my life rather than actually listen to me.

And when I started to cry, thankfully, another doctor walked into the office to hand him something, and she sees me crying, and asked him, "Why is this young lady crying in here?" Because I threw a fit. I hit his desk, like I was just full meltdown mode, and he throws his arms up in the air and he goes, "She thinks she has Ehlers Danlos Syndrome," like I'm just the most ridiculous human being on the planet.

She confesses that she's never heard of it before and looks it up on her phone, and looks at my dislocated hips on the screen, and says to him, "She could have this. Why are you being like this?" And I don't know who she was or what kind of power she had over the situation, but his response to her was kind of an eye roll, and he said, "Fine, I'll send her to a geneticist," which is what I'd been asking for at least a year.

At the geneticist, it was as simple as she gave me a blood test, and there it was on paper that my blood type was for classical Ehlers Danlos Syndrome. It was right there in the blood test.

Menendez: When you've pursued a diagnosis for three years, what did it feel like to finally have someone affirm that it was Ehlers Danlos?

Annie Elaine: I feel like, if I'm honest, I was too exhausted to feel anything. To this day, there's diagnoses I'm still trying to get, because Ehlers Danlos syndrome is just the umbrella of a bunch of other stuff that's going on in my body.

Menendez: Many of your symptoms are invisible to others. How does that change your relationship with people in your life?

Annie Elaine: I can only speak for myself. People cannot tell what I'm experiencing when I'm experiencing it. Something as simple as putting a glass of water under the sink to fill it with water: I'm experiencing pain in my hand from just trying to grip it, but from the outside, it just looks like I'm trying to fill a cup. People cannot see when I'm standing up, the longer I'm standing up, the more pain that I'm in, because it's not really going to show on my face. At this point, I'm so accustomed to pain that it's just not going to read.

Menendez: You know how to cover.

Annie Elaine: Yeah. And there's a bunch of discrete things that I'll do. I do a lot of weight shifting from leg to leg, or if there's like a chair or an ottoman, I'll like rest my knee on it. There's a lot of things that people see as rude, but when I'm doing it, I'm doing it to relieve pain.

Menendez: How has your family responded to your diagnosis?

Annie Elaine: So, I have a huge family.

Menendez: Yes.

Annie Elaine: Latino family.

Menendez: You're one of twelve kids, correct?

Annie Elaine: Yeah, because I have a lot of half siblings and step-siblings. Primarily, I'm the oldest of three. I have a bunch of aunts and uncles, and a lot of them were concerned, and I have family who see potential symptoms in their kids, and they're a little freaked out about that because, you know, ableism and thinking that disability means the end of their life and the end of their potential.

And in Latino families, I've come to realize that, you know, their economic potential is extremely important, and disability kind of like is very hindering to that fantasy of economic success.

Menendez: You started the hashtag #TheFutureIsAccessible. What does an accessible future really mean?

Annie Elaine: The Future Is Accessible: to me, it came out of the lack of accessibility and the lack of disability visibility of the first Women's March. So, the word accessible specifically in there is based in the idea of making feminism accessible, making our activism accessible, and thus being more intersectional, because if we don't consider accessibility in these spaces, then you're not including disability within your activism.

But an accessible future overall, outside of the very specific messaging of it, it's going to be so many different things, because what's accessible for one person is not necessarily accessible for another. There's a great example online somewhere about someone might need captions because they are deaf, but then someone who is dyslexic does not really have full use of visual captions, but needs other forms of being able to access the same information. So an accessible future is going to take a lot of consideration and a lot of awareness and a lot of education.

Menendez: What is your advice for other Latinas who want to use YouTube and Instagram as platforms for activism?

Annie Elaine: My advice is do it. Do it even if you're nervous, do it even if you're scared, do it even if you think you don't deserve to take up space. These are all the more reasons to do it, to take up space and to reaffirm yourself, reassure yourself that you are allowed to take up space, that you do deserve to take up space, not just

in existence in the planet but on social media platforms. Because, our presence is so important to ourselves and to other people; because without it, people feel so alone.

And I'm trying to put it into words of how... As much as I feel like putting ourselves out there benefits other people by being representation--by being visible and by quote unquote normalizing our identities, our bodies and our experiences--we can kind of hit the rewind button to talk about the cathartic experience of expressing yourself in that way. Because that builds you up, that allows you to learn about yourself, and the more we learn about ourselves and the more we kind of introspect and self-discover, the better people we can be. And it all just kind of spirals into itself.

You are going to continue to improve yourself and bring the things to yourself, and by doing that, you're going to bring good things to other people.

Menendez: Annie, thank you so much.

Annie Elaine: Thank you so much.

Ad: Thanks as always for joining us. Latina to Latina is executive produced and owned by Juleyka Lantigua-Williams and me. Maria Murriel is our producer. Carlina Rodriguez is our sound engineer. Emma Forbes is our assistant producer.

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CITATION:

Menendez, Alicia, host. "How Annie Elaine Is Making the Future Accessible." *Latina to Latina*, Lantigua Williams & Co., December 2, 2019. LatinaToLatina.com

Produced by

