Disability Visibility Podcast

Episode 31: Disabled Inventors

Guest: Jane Hartman Adamé

Host: Alice Wong

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

Introduction

[hip-hop]

KAYLEN HEFFERNAN: ♪ The inspirational porn star

Oh, my cute wheelchair cost as much as your sports car

Look, we got enough problems

Don't need…. ♪

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

ALICE WONG: Hey, hey! My name is Alice Wong, and welcome to the Disability Visibility Podcast, conversations on disability politics, culture, and media. Disabled people are DAMN creative. We're constantly inventing, adapting, and hacking a world that was never built for us. Today's episode is about disabled inventors, featuring an interview with Jane Hartman Adamé, Co-Founder and Co-Inventor of Keela Cup, a new menstrual cup designed for all types of bodies and abilities. Along with Co-Founder and Co-Inventor Andy Miller, Jane designed Keela Cup using what she calls disability-driven design. You'll hear Jane talk about the origins of Keela Cup, the importance of controlling your own narrative, and how her recent diagnosis of Ehlers Danlos Syndrome, referred to as EDS in this interview, changed the trajectory of Jane's life and career as an entrepreneur. This interview was originally recorded at StoryCorps on February 2nd, 2018 as part of the Disability Visibility Project. Are you ready? Away we go!

[electronic beeping, computerized voice counting down to 5, 4, 3, 2, 1]

ALICE: Welcome, Jane!

JANE HARTMAN ADAMÉ: Thank you so much. I'm so excited.

ALICE: Me too. So I guess, would you mind starting with just a little bit about your background and who you are, just whatever you wanna share about yourself?

JANE: Sure! So I have had a recent big pivot in my life. Prior to this big pivot, I was an entrepreneur. I've had a hair salon in Oakland, California. I've been a hairdresser for the better part of the last decade and owned my salon for the last six years. Last year, after finding that my, what I thought were regular hairdresser aches and pains actually turned out to be an underlying genetic condition. And realizing that I wouldn't be able to do that anymore, I had this major pivot and found myself creating an inclusive menstrual cup and being warmly welcomed into the disability community and the menstrual health community. So I’ve been feeling very supported through all of my big changes.

ALICE: Mmhmm.

JANE: It was just throughout last year when I started having a lot of trouble standing and walking, and I had been fighting so hard to do really well in my Physical Therapy. And I am good at that stuff. I’m really strong, but I was still getting worse. And I brought up EDS to my doctor, and he had me come in the for the clinical tests and said, “Yeah, this seems probable.” And he sent me to a geneticist, and the geneticist said, “Yeah, this seems like what you have.” And the question I had been trying to solve for several years was, I just wanna have one pain-free day: is that something that I could have? And the geneticist basically said, “You know, if you’re an optimist, you should plan for having what you might wanna do with a day like that, but realistically, you’re probably not going to have pain-free days.” And that was a lot to take in. And that also really put into perspective my hair days had been getting shorter and shorter. I just couldn’t stand, and I was having panic attacks before my work day, knowing that my body would be trying to put the brakes on. Like, every time we do this, it doesn’t not turn out well; it hurts us. Let’s stop.

And so it just got to the point where I just knew that that was a transition that I really had to make. But with the diagnosis, you know, realizing that not only was I not lazy and was I not weak, was I not overly-sensitive, that all these things happening to me were real, I also had my hips checked out. And they were like, “Oh, you have hip dysplasia, also! I’m sorry we didn’t catch that earlier.”

ALICE: Mm.

JANE: So that makes sense as to why it’s really hard to walk and stand. And I’m really, I consider myself one of the lucky ones because I’m surrounded by people who believe me, which is not always the case. And that includes my medical care team who takes me very seriously and also has supported me in getting access to mobility aids, which is not always the case.

ALICE: Mmhmm.

JANE: Pain meds, which is certainly not always the case. And my family has been hugely helpful and supportive in helping me through this transition. So I hoped that we get to a point where that can be the story for more people with EDS. And even with it being a great story, it’s still really freaking hard every day.

[electronic experimental pop]

How Jane went about creating Keela Cup and connecting to media through Twitter

ALICE: So I was wondering if we could segue a little bit because I really first learned about you through a Teen Vogue article about the Keela Cup. And I wanna learn all about Keela Cup because you are an entrepreneur. But tell me how you came about creating Keela Cup. But first, describe what it is and how you came about deciding.

JANE: So Keela Cup is a inclusive, new menstrual cup, which is designed to be easier to insert and remove. And it came about from my challenges trying to use conventional cups. With my hypermobility, I’ve injured myself using menstrual cups several times. And it really came about, I was trying to remove one and swearing in my bathroom, and kind of deciding— It was right when I was losing my hairdressing career and right around the time of my diagnosis. And my friend, Andy—this sounds weird—but my friend, Andy's, voice popped into my head because he's a medical device designer, and he was a client of mine. And we would always chit chat about design ideas when he would come get haircuts. And his voice popped into my head saying, "Hey! If there's ever a little plastic thing that you ever wanna make, let me know. We'll make it."

ALICE: Awesome!

JANE: And so I reached out to him, and this was really, it was at a part of my story where I was feeling like I had no control over where my story was going. This is my life story. And I was like, wouldn't this be a cool pivot? Wouldn't this be the better way for it to go?

ALICE: This is your thing.

JANE: Yeah. And so luckily, even though Andy is a cis man, he was not terribly grossed out by the idea of making a menstrual cup. In fact, he was really excited about it, and we spent probably six months making a prototype every four days. And I'm so lucky that he understands all of those sides of things, and we just had a great collaborative process. But the *Teen Vogue* article that you mentioned, that has a funny story because we launched on Kickstarter in the beginning of December. And at that time, it kind of had a slow start, and I was really optimistic. I kind of thought we were gonna make it from the beginning just because we'd had so much positive feedback. But it was starting really slow, and we were like, well, we need press. And I just thought the coolest press we could get would be *Teen Vogue*.

ALICE: Yes!

JANE: Because they're—this will pop up at some point in history—but *Teen Vogue* really made the change from being this sort of teeny bopper magazine to having this much more politically-charged and sort of like woke, I think is the word that everyone was describing it as last year, and like, here's *Teen Vogue* at it again. They were putting out really new, exciting content that was really empowering and, I think, in a time when we really, really needed it. And so I was trying to find the email address of one of the Health and Wellness contributors that looked like it would be a good alignment, Brittney McNamara, I think her name was. And I couldn't find her email address, but I found her on Twitter. And I did not have a Twitter.

ALICE: I love Twitter.

JANE: I know. And we met through Twitter! So Twitter's fantastic, but I did not have one. I made a Twitter in order to direct message the contributor.

ALICE: That's right. That's how you do it!

JANE: And that shouldn't have worked, but it worked.

ALICE: That's what Twitter does.

JANE: Yeah, it does. It breaks down those barriers that—

ALICE: Especially for journalists, I think, because I think it's really done a lot for journalists in terms of really being exposed to much more people, but also giving us readers, non-journalists, a way to push back, a way to sound off, a way to critique, and a way to protest.

JANE: Yes.

ALICE: Yes, I remember following some of the editors of *Teen Vogue*, and they actually included their email addresses in their bios, with like, “Pitch me.” And I’m just like, that is so awesome.

JANE: Well, as I got more into the process of trying to do PR work for Keela, I found that I had been entirely circumventing this apparently really important journalistic process where you do a press release through a specific source, and you pay them to do it. And I didn’t do any of that. But I think you’re right. I think that the changes that we’ve seen happen with publications like *Teen Vogue* and other publications have a lot to do with the feedback that they’re able to get directly from their readers. You don’t have to stop and write a letter and mail it to a PO Box anymore. You can just tweet someone and be like, “That was a messed up thing to say. Please don’t say that again.” And that shapes the way that stories will get told in the future, and that’s amazing.

ALICE: And it’s a way of us controlling our stories.

JANE: Yes.

ALICE: I think that’s what you just said earlier. But I feel like in a way, you’re kind of— Do you identify as a disabled person?

JANE: I do.

ALICE: OK. That’s great. ‘Cause I didn’t wanna like presume that. But I do feel as disabled people, people are always trying to tell our narratives for us.

JANE: Yes.

ALICE: And I think especially without PR, without these kind of gatekeepers, things like Kickstarter, it really allows you to tell your story exactly the way you want and to frame yourself in exactly the way you want.

The *Teen Vogue* experience and disability-driven design

ALICE: So tell me about the *Teen Vogue* story and how that experience turned out for you.

JANE: So the *Teen Vogue* was really pivotal for us. It was an op-ed piece that I wrote that was really, I was asked to just right about periods and disabilities and how those things intersect because you know, it’s one of those things: it’s like how people think that disabled people are non-sexual beings or anything of that nature.

ALICE: Mmhmm.

JANE: And I think it really ties in really strongly with that, that well, you know, you might assume that maybe we don’t menstruate. And I’m sure there are plenty of disabled people who don’t, but there are so few choices for all people who menstruate in the market, in the popular market, in the grocery store. And so you know, I was feeling really limited by choices that were available to me. And I was feeling like my disability was further limiting those choices, which felt like it shouldn’t be happening. And it was really great to have the opportunity to really speak to that piece.

And I had some feedback from my Co-founder, who is an able-bodied cis man, which is, he's a wonderful person. He is so amazing. But there are certain pieces that won't make sense to him until they're explained. And one of those pieces was I kept wanting to use the term "disability-driven design," and he was like, "That makes me nervous because that is a very small market, and that might seem really small to people." And I said to him, "But look what everyone is latching onto with this story. They like that part of it. People want to see and want to embrace and want to participate in that. And it's not a small market, and when we make things, if we inclusively-design things, it really does benefit everybody." So by putting a voice to that—and you're right; it's about taking charge of our own narrative—'cause if this had been applied or ascribed to me from someone else, and I didn't have control over that, maybe it would have been less comfortable to have that facet be so transparent. I think a lot of our marketing stuff we do, we don't necessarily throw me and my disability out front. The whole point is it's an easier product, and you know, if you wanna learn more about why we made an easier product, then I'm here.

ALICE: Yeah, that's right.

JANE: Yeah.

ALICE: I think that lived experience is what's grounded in the design.

JANE: Yeah.

ALICE: And I think that's what it means to be disability-driven design.

[electronic experimental pop]

What Keela Cup is and what needs it fills

JANE: Keela Cup is a lot like a conventional menstrual cup in that it's also made out of medical-grade silicone. It's about the same size and shape overall. The main difference is that where you normally would have a stiff little pokey, irritating stem that most people cut off, we have a soft, flexible stem that actually originates from the top rim of the cup, where it sits up near your cervix. And the purpose of that string running through the middle of the cup is so that when you pull on it, it depresses the side wall of the cup. It sort of collapses the shape in so that you can pull it out as easily as a tampon so that the user doesn't have to reach inside their body and do that reaching, pinching, squeezing, pulling action all at the same time. Which I found really hard for myself, and from surveying lots of people, it seemed like that was the biggest challenge that most people had. Also because as a product, as a user experience, any moment of panic of something being stuck in your body is not a part of the experience that you want to be there. And I, in early research, was seeing lots of Amazon reviews that were pointing to people having ER trips from these things. And to me, you know, we've just been so limited in what we have access to, that that seems like somehow that seemed to be a reasonable choice or you know, risk to take.

ALICE: And menstruation is natural.

JANE: Yeah.

ALICE: It shouldn't be medicalized. I think so much of people who do menstruate, we get medicalized, the whole process. It's just like practicing just like all kinds of things with our bodies.

JANE: Yeah, it would be— You know, it's interesting because as we're sort of marketing it globally, different areas definitely view these things very differently.

ALICE: Mmhmm.

JANE: So like in Canada, menstrual cups are regulated as basically in the same category as surgical devices. They're very heavily regulated. And then in Europe, they're actually not regulated at all. And then here in the US, they're sort of in between. And that's been really helpful for us, actually, to have a framework within the scope of how the FDA wants us to do things to make sure that we are making the safest and best thing to put in your body. But it's true: it's one of those things that's so common and so natural.

And not just about it being medical but about what we've all had to untangle within ourselves because it's imposed on us that it's gross and that it's not something you should interact with. And you know, we all either go through that at different points in our lives or don't. We get people commenting on our Facebook all the time with the, I call it Barf Emoji Bingo, [chuckling] where they just post awful things, and they're just grossed out. But I think we're seeing a big change where there's less of that than I actually thought there would be. And there's more people coming to support and say, you know, "It's no grosser than anything else," you know?

ALICE: And can you tell me a little bit about why menstrual cups over—is it your own personal usage—versus tampons or pads? Because I think in terms of the market, there seems like menstrual cups are still not that widely accepted and not that widely, it's just not thought of as the first thing to use for people who menstruate.

JANE: Yeah. It's not on that tier with tampons and pads yet.

ALICE: Yeah, yeah. So I guess, what are your personal reasons for using menstrual cups, and why do you think they're better? Or do you think they're better?

JANE: That's a really good question. So I think a lot of people would expect that I'm anti-disposable. But the reality is that I'm just pro-choice. I just think we should have, everybody should have access to make the right choice for their own body. What drew me to menstrual cups is being able to wear it for 12 hours. So as someone who lives with a chronic pain condition, changing something twice a day as opposed to three times a day might seem like so small to someone else. But to me, that's a really big difference. And being able to also not have to run to the store and pick up more when you're cramping and feeling horrible. Or I also have agoraphobia. So that can be a really challenging process for me on its own, outside of my physical disabilities. So those were things that I was really excited about in addition to the fact that it's just more eco-friendly to not be throwing disposable products away. And there's been a lot of discussion about well, what's in them? They don't have to actually state what the materials are. And those are all important factors that I think everyone should weigh for themselves. But for me, it was really just about convenience. And so when it tipped the scales from being a convenient option to an inconvenient option was when I sort of felt driven to change that.

ALICE: And it's also, I think, an economic factor too.

JANE: Yeah.

ALICE: Where over a lifetime of a person who menstruates, that's an added cost that people who don't menstruate have to pay for.

JANE: That’s true. And not only that, it’s the taxes that you pay each time you buy the products.

ALICE: That’s right. That’s right.

JANE: Which is just shameful.

ALICE: It all adds up.

JANE: Yeah.

[electronic experimental pop]

Disabled people are experts on design for inclusivity and accessibility

JANE: It’s been really important to me to have presence on social media and answer everyone’s questions. And the greatest thing that’s come out of that is people of all different abilities have been saying, “Well, this thing sucks. Can you fix this?” And I’m like, “Yeah. Maybe. We can certainly look into it.” And people with all sort of different anatomies or structural challenges looking for solutions as well. I had one user who has only two fingers who was wondering if this would work for them.

ALICE: Mmhmm.

JANE: I was like, “I don’t know. I really don’t know. I kind of don’t think it’s gonna be that easy,” but that’s probably how things are when you have two fingers. I’ve just loved those points of connection with all sorts of people and being able to factor that in to how to take it beyond being an awesome cup for Jane and being like an awesome cup for as many people as possible.

ALICE: And I think that’s where user-informed design of the communities that you’re serving is so important.

JANE: Yes.

ALICE: And I feel like this is where disabled inventors, disabled designers, there aren’t that many of you all. And it’s always so exciting to see disabled people intervening and creating much better products, much more accessible. And we can be like so applicable for everybody. So could you talk a little bit about your thoughts on being a designer and what you’d like to see in terms of the future with connecting with other designers, other inventors to really share this idea like, “Hey, you guys should really cultivate, recruit, and really engage with disabled people.” Because many of us are already de factor designers, but we’ll never have products on the market. But there is a wealth of talent out there.

JANE: That’s so true. Yeah. I think it’s interesting because there are some disabled designers in the spaces of mobility aids and things like that, which is great because you know, you’re using the product. You definitely should be the one shaping how that works and what that looks like. I haven’t seen many other, haven’t come across many other designers who are working in these sort of cross-over spaces that also serve the normies too.

ALICE: Those normies. Those normies!

JANE: Those normies. Those darn normies.

ALICE: They’re taking everything!

JANE: [laughs]

ALICE: Damn you, normies! Watch your back. We're coming. We're coming for you!

JANE: But you know, I think as people start to share stories like this and amplify them, I think that companies will start to see that this is a viable way to approach design. And I'm really excited to kind of steer that ship a little bit this year. So I've been trying to hustle for "inclusivity" being a word that is just, I want it to be the word of the year for 2018. I think that there's been a lot of progress and a lot of awareness around that, and I'd like for other people to start latching onto disability-driven design as a term and using that and pushing that forward. Because I think that we, as disabled people, sort of do have a superpower when it comes to designing things, as you were saying, because we've had to creatively figure out how to make things work already for our entire existence. But on top of that, could you think of a more perfect user to demonstrate worst-case scenario how difficult something could be? And there's one really great company that makes kitchen—

ALICE: Is it OXO?

JANE: OXO. Yes. And they actually hire people with different abilities and, I think, a lot of older folks to actually use their equipment and give feedback. And they're all paid, and that's really fantastic. But you know, I realize that a lot of what set me up with this opportunity was just luck of being great friends with someone who knows how to navigate the process of creating a product and creating a medical device in particular. So I'd like to see more people with those sort of skills allow themselves to operate as allies and sort of as a conduit for design from us. Because I don't have any special skillset that should make me be a great designer other than that I live with EDS every day.

ALICE: And that's more than enough.

JANE: [laughs] Yeah.

ALICE: And I think that's what's funny is that, myself included, you know, I think the design world is very exclusive. They really are full of themselves, right? Especially these beautiful products and a lot of aesthetics, and I just, designers have their own language about design and just whatever. There's just a lot of rich, and I think I lot of their industry just purposely distancing themselves because they really do think of themselves as experts better than the everyday consumer. And I feel like that in itself is a really bullshit.

JANE: Absolutely.

ALICE: Because the audience, the customers really know what's needed.

JANE: The customers are the experts. They're the ones who are using the product all the time and engaging with it from this perspective that's actually the most important perspective.

ALICE: And people with disabilities are 1 in 5 in this country.

JANE: Yep.

ALICE: And globally, I mean, we are a market that most people don't even think about really.

JANE: Well, and I've heard people talk about designing for the 90% and that this is sort of a philosophy of just saying, "Well, you know, if we make it work well for the majority of people, then that's a responsible way to do things. That's how we should be designing." And you know, our philosophy has always been well, what if we just included that extra 10%? Then you've grown the market. And then chances are, whatever was a strong barrier for that 10% is also a huge inconvenience to these people in the 90%. 'Cause I remember early on in the process, one of my friends had shared the project, and one of the comments was, "I think this is solving for a problem that doesn't exist." And I thought, wow, that's how most designers think. Because if the problem doesn't exist to them, then it's irrelevant.

ALICE: Mmhmm.

JANE: And that's where disability-driven design is a superpower.

ALICE: That's what the job is because they've never had experience in accessible products and accessible spaces. I mean that's why so much architecture is horrible.

JANE: Yeah.

ALICE: Or the accessibility's added on because—

JANE: As an after-thought.

ALICE: —rather than from the very outset, it should be Universal Design.

Future commercial plans for Keela Cup

ALICE: And do you have plans one day, do you think, as a commercial product where anybody can go to a Walgreens one day and buy their Keela Cup at Target?

JANE: I really hope so. I would love that. I actually think it would be a great introductory cup for most people. And we are starting to see more cups present in those sort of stores, so I really, really do hope that this is the sort of thing that can take off and be a part of mainstream menstrual care. I don't see why it shouldn't.

ALICE: And what do you love about being an entrepreneur?

JANE: Well, I love being able to work from bed when I'm having monster pain days. I did a podcast in my bed yesterday, and it was great. I love being able to be a conduit for everybody's contributions and being able to express that creatively by taking feedback from a zillion different directions and molding it into a physical product. And I love, I've always loved, writing, and it's so fun how much of this job is writing and chatting with people. [chuckles]

ALICE: Mm.

JANE: It's really fun.

Wrap-up

ALICE: Well, thank you, Jane. I am just delighted, and I think it's just like, it just feels good to know that you are in the world, Keela Cup is in the world. I just really appreciate you.

JANE: Well, thank you so much. I'm really happy to have you as an ally. So thank you.

ALICE: I'm a fan!

[hip-hop]

KAYLEN HEFFERNAN: ♪ The inspirational porn star

Oh, my cute wheelchair cost as much as your sports car ♪

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-2.

You can also find links about Jane and Keela Cup on our website.

The audio producer for this episode is me, Alice Wong. Introduction by Lateef McLeod. Theme music by Wheelchair Sports Camp.

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Well, thanks for listening. It's been real. And see you on the Internets! Byyyeeeeee!

♪ Lord knows where I'm headed

It's hard out here for a gimp ♪