Disability Visibility Podcast

Episode 39: Sex Education

Guest: Robin Wilson-Beattie and Julia Bascom

Host: Alice Wong

Transcript by Cheryl Green

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Introduction

[radio, static hip-hop]

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

ALICE WONG: Hello hello hello! Welcome to the *Disability Visibility Podcast*, conversations on disability politics, culture, and media. I'm your host, Alice Wong. Today's episode is about sex education with Julia Bascom and Robin Wilson-Beattie. Both Julia and Robin talk about what inclusive sex education looks like, bodily autonomy, and the right of all disabled people to have pleasure and sexual expression.

Are you ready? [electronic beeping]

Away we go!!! [computerized voice counting down to 5, 4, 3, 2, 1]

Introduction to Julia Bascom's interview

ALICE: OK, so, Julia, thank you so much for being on my podcast today.

JULIA BASCOM: Thank you for having me! I've never been on a podcast before.

ALICE: Yay! One of many.

JULIA: [chuckles]

ALICE: So, Julia, why don't you introduce yourself and just share anything you like about your background or anything you'd like people to know about yourself.

JULIA: Sure. So, my name is Julia Bascom, and I'm the Executive Director for the Autistic Self-Advocacy Network or ASAN. And we're a national self-advocacy organization run by and for autistic adults speaking for ourselves. We represent, obviously, people all across the autism spectrum and that other people with sort of developmental or cognitive disabilities. We focus a lot on policy advocacy and self-advocacy trainings. We take that old disability rights saying very seriously: "Nothing about us without us." And that sort of informs all of our work. Since we're a self-advocacy organization, that means that I'm autistic, people who work for me are autistic, etc., etc. I have some other disabilities. I think that's probably about it.

The Real Talk project

ALICE: Great. Thank you. So, several years ago, ASAN and NICL, which is the National Council on Independent Living partnered on a project called Real Talk, conversations and resources about sexuality for people with disabilities and healthcare providers. Can you tell me a little bit about this project and how it came about?

JULIA: Yeah. So, this ended up being like a pretty simple training for sexual and reproductive healthcare providers. We had a PowerPoint, a fact sheet, and a webinar. And it came about because I think a lot of disabled people have the experience of going to different healthcare providers, especially healthcare providers who don't specialize in your disability, and having them just sort of be completely thrown by your presence, let alone your disability. We were hearing from a lot of young people that this problem was particularly heightened when they were seeking sexual and reproductive healthcare. And I think that makes sense.

Disabled people, especially people with physical disabilities or cognitive disability, are often just sort of routinely desexualized and infantilized, and people don't think that this would be sort of relevant for us. And that compounds the ableism that we already experience in a lot of healthcare contexts, so it's a huge problem. So, we wanted to create a basic resource to educate providers, to try to change that, or bare minimum, to get providers to realize that we exist and will be in their office. And we have a right to competent care, so they better get ready.

[bouncy electronica music break]

Why "Nothing about us without us" is important in educating sexual health providers

ALICE: And speaking of the phrase "Nothing about us without us," the guide developed for this project was grounded in conversations and feedback by actual young disabled people. So, why is that so important, especially when it comes to educating sexual health providers?

JULIA: Yeah, so, "Nothing about us without us" is all about this idea that whenever disability is being discusses, disabled people need to be there leading the conversation. So, we just thought it would be the most effective to talk directly to disabled young people. And that allowed us to sort of number one, capture the experiences that they were having and record what they thought would've helped or should've been different. And ultimately, that made the final resource more effective, but it also gave us real legitimacy. We weren't speaking for anyone. I think a lot of times, especially when we're talking about disability, people like to say, "Oh, you're speaking for those who can't speak for themselves" or something like that. Which is nonsense! Everybody, even if they're not gonna speak in a way that other people understand or would recognize, everyone has their own voice. Our job is to sort of be that microphone. So, we were giving providers a direct window to the experiences and the voices of the people that they serve, and then we tried to sort of get out of the way and let that speak for itself.

ALICE: Was there anything you learned through their conversations in your research, learning from younger disabled people? Was there anything you learned that really surprised you or that really made an impression on you in terms of something unexpected?

JULIA: We tried to go in with as few expectations as possible. There are things we knew that would come up that did, like conversations about assault or about providers talking sort of over our heads and to our support person instead. I think I don't wanna say I was surprised, but I was really impressed. And what really stood out to me was the resilience and the creativity of a lot of the young people, either describing how they made things work or how they were navigating their lives in the absence of healthcare that they needed.

[bouncy electronica music break]

ALICE: Yeah, that's an asset. I think people see us as this vulnerable population when we have such strength and wisdom.

Misconceptions and ableist assumptions around disability

ALICE: What do you think are some of the most kind of misconceptions or just again, kinda ableist assumptions, especially around people with cognitive disabilities?

JULIA: Yeah. God, there are a lot. [chuckles]

ALICE: Yeah, it's tough.

JULIA: I think obviously, there's this idea that we aren't sexual or that no one could be attracted to us or that, if we have a cognitive disability, that must mean we can't give consent or we shouldn't be parents. Often, because of these ideas, people—especially people with intellectual and developmental disabilities—just aren't given any sex education. Or if someone uses a device to communicate basic words for body parts might be removed from that device. And then family members and educators and service providers all exercise a really disproportionate amount of control over our lives, right, especially if you're under guardianship, which means it can be really challenging to find any kind of space to talk about our experiences or our needs or our questions without that surveillance and influence.

There's some state-level self-advocacy groups that are doing really good work on this like—they're my favorite—Green Mountain Self-Advocates in Vermont. But it's really the exception rather than the rule. A lot of the times I think when people think about people with intellectual disabilities and sex, they're thinking in terms of managing behaviors as opposed to think about us as Real People! with the same sort of needs and desires. We aren't really seen as having a right to have sex or to have a relationship with someone. And in a lot of states, if we're under guardianship, we legally don't have that right.

ALICE: Yeah. And also, the idea that we don't have the right to pleasure.

JULIA: No, I think that's really true, and I think that when someone has a disability that means that they rely on other people for support, I think that can also get extra complicated. Like, if we're coming from a baseline reality where people who need assistance with toileting have to restrict their fluids every day, then the idea that we might have some sort of right to pleasure, I think, becomes really, really radical.

ALICE: I think you're right. And I think they're just clutching their pearls at the thought of all these disabled people orgasming.

JULIA: [laughs] The world ends.

[bouncy electronica music break]

Issues with heteronormative, cis representations in sex ed

JULIA: Or even on a really basic level: most social skills trainings assume that everyone is straight and everyone is cis, and they're incredibly gender normative. I remember I worked in a self-contained middle school classroom for kids with intellectual disabilities, and one of the sorting activities that was really common for the students—and to be clear, I don't think this is a good education model for anyone, but it's common—and one of the activities to do was to sort things. And one of the sorting tasks was to sort pictures of people into either the boy category or the girl category based on their hair length and the clothes they wore.

I know trans autistic women who were placed under guardianship when they came out to their families. The family didn't care before. And then this person comes out, and they're immediately like, "Well, OK, we've gotta get guardianship so we can block your transition." It's still really common for gender-affirming care to be denied to trans kids on the basis of their disability. The idea that a, that we might be full people with everything that entails, and b, that we might deviate in any way from the most normative, easy-to-digest, whatever words you wanna say version of this cis, straight, white, able-bodied, etc., etc., etc. version of a human is just really hard for people to grasp. And I think that once you've already deviated so far by being a disabled person, the idea that you could have other differences as well is just like a bridge too far.

And the reality is, there's an extent to which we don't fix any of this until we get rid of guardianship. A lot of states have laws that say people under guardianship have certain rights. Those rights include the right to sex or relationship, etc., etc., etc. But abuse and sort of just like completely ignoring those rules is commonplace, and you wouldn't have to have those rules if that kind of abuse wasn't widespread in the first place.

Presuming competence

ALICE: And can we also talk about presuming competence?

JULIA: Yeah! So, presuming competence is sort of about this idea that everyone learns differently and thinks differently and communicates differently, but everyone has strengths, and everyone can learn and can think and can communicate. And it might be difficult to figure out how someone learns or how someone thinks or how someone communicates, but that doesn't mean we should assume that they don't. And we should act on the assumption that, with the right support, people can learn and develop new skills and make their wishes known and so on and so forth.

[sighs] A, people are terrible about presuming competence and thinking that people can know what they want and can be supported to express those desires and interact with them. But there's also this inverse sorta situation where people with intellectual disabilities are held to a higher standard than their non-disabled peers. So, it's really common for people in group homes or in other kind of supervised living situations or even just people under guardianship to be barred from dating or really doing anything with anyone until we take a class about "healthy relationships."

And a lot of this is framed as being about consent, about unless someone can pass this bar, we can't demonstrate that they can consent to sex. And therefore, we can't allow them to do it. But that's nonsense. I guarantee that the kids hooking up in the back of a car at my high school weren't sitting down and working through all this first, you know? And we have that same right to have fun and to make bad decisions and to mess around. And again, we're operating in the context where people feel comfortable talking about allowing us to do something at all.

[bouncy electronica music break]

What does inclusive sex education mean to you?

ALICE: So, what does inclusive sex education, what does that mean to you? And I guess, if you could create a 2019 version of Real Talk, what would it look like?

JULIA: So, I think there are three meanings of inclusive in this context. So, one is inclusive as in sort of comprehensive: something with the same information, all the information that everybody else gets. And then another meaning is like inclusive as in accessible: so, materials that are written in easy English with pictures and other visual supports and multiple ways of accessing and exploring the information. Or materials not in English, in other languages too. And then the third meaning is inclusive as in equitable or including people from many different backgrounds and communities and sort of representing and speaking to as wide a range of experience as is possible. And I think a good resource would need to have all of that, to have all those different layers of inclusivity.

Real Talk wasn't designed to be a sex ed curriculum; it was supposed to be just like an initial training for providers. But we have talked with NCIL. We're both really interested in potentially actually doing an inclusive sex ed project. It's just a question of when does our capacity line up and when do we find a funder and when does Paul Ryan stop trying to repeal our healthcare for like two seconds so that we can focus on something else? But we would really like to do that.

ALICE: Yeah. That would be fantastic.

JULIA: Yeah. So, hopefully, if things can calm down a little bit for us as a country, we would be able to spend some time working on that.

ALICE: Yeah. All of us have this huge to-do list, I feel like.

JULIA: [laughs] As soon as we can get back to it!

Restraint, behavior modification, and issues of bodily autonomy

ALICE: Yes. Is there anything else you'd like to share with me today about sex ed, sexual health, sexual autonomy?

JULIA: Oh, I had a note to talk about how—I'm trying to find the right words for this—we were talking about misconceptions, and I sort of left off two that I wanted to bring back. One was I think, especially on college campuses, there's this idea that consent is a verbal yes. And well, not for everybody! There are people for whom that's not possible, and that doesn't mean they can't consent. And then the other thing, like some of the sort of differences and nuances that we were talking about, about what it means to be a disabled person and to think about pleasure and sexuality, some of that is really beautiful. And then some of it really isn't. A lot of autistic kids in particular undergo therapies as children that are focused on eliminating any kind of visibly autistic trait to make us appear "indistinguishable from our peers." And that usually boils down to a lot of behavior modification and compliance training, and it's often an intensely traumatic experience.

Restraint is still really common. And we grow up being told that since our perceptions are different from other people, we're always in the wrong, and our bodies and our senses and our instincts can't be trusted. So, then you think about that in the context of a young autistic woman who's facing that 83% assault rate, and how is she supposed to be able to understand that OK, all of her life, she's been held down and handled and hurt by people in her life who have power over her, and everyone said it was fine. Everyone said it was supposed to be good for her. But then, this one time! This one other specific time, that time wasn't OK? I think we really haven't reckoned—when I say "we," I guess I mean this broader community of educators and therapists and everyone—about what that means and what we should be doing in response to it. Which I think is criminal.

ALICE: Wow. Wow. Thank you so much, Julia. I just really appreciate the work that you do, and thank you for spending this time with me.

JULIA: Thank you so much for having me. This was really—I mean except for the end there—this was really fun.

[bouncy electronica music break]

Introduction to Robin Wilson-Beattie interview

ALICE: So, Robin, thank you so much for being on my podcast today. Why don't you introduce yourself.

ROBIN WILSON-BEATTIE: Thank you for having me, Alice. Hi. I'm Robin Wilson-Beattie, and I am a disability and sexuality educator, writer, and activist (sexuality activist) here, based in the Bay Area, and I like to talk about all things related to sexuality and disability.

ALICE: Imagine that. Me too!

ROBIN: [laughs]

ALICE: And today's episode is all about sex education. I'd like to know a little bit more about how you became a sex educator and what led you to go into this profession, and why do you love it, if you do love it.

ROBIN: The thing about— OK, how I became a sex educator: when I started thinking about it, actually it's been a lifelong interest and starting even with high school doing peer education for HIV and AIDS. But as far as becoming a sex educator talking about disability, that grew out of me acquiring my physical disability and learning that I wanted to hear more about sexuality and disability, and I was really frustrated because I wasn't. But also, through a person who became my mentor and one of my best friends, Bethany Stevens, is a sexual health scholar and educator. That was when I was like oh, wait. This is an actual profession? This is something I can do professionally, and I can have this as a career? Huh?! So, I always like to say I am very comfortable talking about things that other people are uncomfortable talking about, and I was always getting in trouble for talking about sexuality in the first place. So, I was like, you know what? Might as well make a career out of it.

[ethereal electronica music break]

Major gaps in current sex ed and services and addressing disabled people's pleasure

ALICE: Most of the curricula is very narrow, very much about the mechanics, the biological facts, what we think of as the birds and the bees. And obviously, that leaves out a lot of different diverse populations. So, what are some of the major gaps that you see in most sex education curricula or programs or services?

ROBIN: I think that a lot of sex education, there's several approaches. If there is sex education where it's scientific, accurate information, it's often presented in a way where it focuses a lot on the negative and the scare tactics. Which, you know, they're all parts of sexuality and things that need to be taught: being taught about STDs and STIs and being taught about sexual assault or being taught about consent and all this. But what I feel like we leave out is the discussion of pleasure, discussion on relationships. When I say relationships, you know, all kinds of different relationships, knowing how they can look different for lots of people. That there's not just this heteronormative model: this is what a relationship is. But not only that, but we especially leave out of sex education, we leave out disability and adaptations.

ALICE: And I think that’s what happens informally when other disabled people find each other, and you learn about how other people do their thing. And that’s how a lot of information is shared, but that often doesn’t show up in actual, within the guise of sex ed. I think in a lot of ways, that’s knowledge that’s hidden, which is really unfortunate. And again, the discussion about desire and about relationships, there’s still a lot of ableism, I think, about the capacity of people with disabilities to have both of those things. So, could you speak to that a little bit in terms of specifically about disabled people and pleasure?

ROBIN: OK, we’re talking about disability and pleasure. One of the things that I also find that people, one of their problems is when we’re talking about pleasure, talking about self-pleasure and teaching people about disabilities about finding ways to discover your body or finding ways to pleasure yourself. So, you’re right. You were talking about it’s either anecdotal advice we share with each other. But what I don’t see—but I’m starting to see because I’ve been asked to contribute towards things, towards the literature—where I do get to talk about hey, this is a kind of, you can find vibrators that can attach to the bed or that you can place different places in order to— ‘Cause not everybody’s able to grasp a vibrator or a sex toy. But there are toys and things that can be placed where you can stimulate yourself if you have needs and some control over it. But I get to talk about specific adaptations.

And I’m seeing where other people are also starting to do that—closing the gap—and trying to make it so people can actually go out there and find it and say, “OK. I know you can make adaptations. I know people talk about it, but what are they?”

Caregivers and attendants assisting for sexual experiences

ALICE: Yeah, and there’s also folks, I think, who’ve also already talked about the usage of attendants to really help set up and help make things, help facilitate sexual activity.

ROBIN: Yeah. It’s like, how do you talk to your attendants and caregivers about assistance? Because as a person with a disability, you own your body, and you should have autonomy over your body. But yeah, there’s the logistics involved a lot of times for many people with disabilities. Because if you rely on somebody for your care to help you up, to get you in bed, to get you in your chair, get you out of your chair, get you dressed, so talking to them about helping sexually, that is something that I’ve talked about, talking with other people and trying to find out, “Hey, so, how do you talk to your caregiver or your attendant about, ‘This is what I would like to do’? On this day, I’m having a partner coming over at this time, and I need some help getting these things set up. But I need you to be able to put me in bed at the time and do that and come back.” So, being able to have those conversations, that’s important.

ALICE: You know, I think a lot of times, the more “professional” the attendants are, the more rules they have in terms of what I can help you with. And that’s very much a medical model of personal assistance. And the ones that are like people that you find that have little to no experience, these are often the ones where because you’re training them, you’re telling them what you expect, they’re much more open-minded, much more willing to do what you want. Which is really the spirit of self-directed care.

ROBIN: Exactly! Yeah, if you have the people who are looking at it purely from this medical model, it’s a mindset of, “Oh, well, I’m here to help them do this thing, just these things. But sex is an extra thing.” And then sometimes, the caregivers have their own ableism that comes into play.

ALICE: So, are you familiar with the term “Activities of Daily Living?”

ROBIN: Yes, yes.

ALICE: So, in a way, I think sex is not seen as an ADL even though it should be, right?

[ethereal electronica music break]

The role of inclusive sex in in preventing sexual violence and abuse and the need for more disabled sex educators

ALICE: And what do you think is the role of inclusive sex ed when it comes to preventing rape culture and sexual violence and sexual abuse? Because I do feel that with the statistics, especially how people with intellectual disabilities, so many of us come so late in life to understanding the agency we have and being able to really say that we own our own bodies, we can make our own decisions. And so much of that is because the people that are all around us are sending really negative messages or not even the basic information that we need. So, what are your thoughts about that?

ROBIN: I think that I feel like we have an obligation to provide sex ed that is accessible in an educational, accessible format for people with intellectual disabilities. I think a lot of plain language and a lot of things like using photographs, pictures, and also we can use things like Pictograms and things like that to illustrate to like, “Hey, this is what molestation is. Or this is what sexual assault and stuff.” Because there are different ways to communicate, and there are different ways that people learn. We need to address the different learning styles.

ALICE: Mmhmm. Do you have any other thoughts about—I think we talked about this earlier—but do you wanna reiterate, I guess, the importance of disabled sex educators and peer mentoring or peer teaching? Because I do think that that’s one of the major problems is that so much of this is about us but not wish us, you know? And you tell me if I’m incorrect, but talk about the sex educators that are present today, I can’t imagine, I’m trying to think about how many disabled sex educators I know. And it seems to me like there aren’t that many. Is that accurate, or am I completely off?

ROBIN: No, that’s pretty accurate. And you know, I am seeing now where people, I see now where more people that have chronic illnesses or people who are sex educators that have a chronic illness. The thing is too, it’s not like this profession pays. The pay is crap. I mean we’re always fucking hustling. You are always like, “OK, yay!” People are like, “Yeah, we want you to speak! We want you to talk. We want you to share. We can give you a free coffee mug.” But that doesn’t pay the light bill. Right now, I am finding that the money that I’m getting paid for is writing or talking to a class, and that pays. And I really like doing that. And I could do workshops. I like it if people come to me. A lot of the things that I’ve done are people have come to me and said, “Hey, I need help with x, y, z to help write this curriculum. Can you contribute towards this?” And I’m like, “Yeah. I can do that. I can help do that.” And so, that’s my particular, that’s where I am. That’s my niche.

ALICE: Great. And so, how can people reach you?

ROBIN: I am most active on Twitter. Twitter handle is @sexabled. But you can also send me a message on @sexabled on Facebook. And my website: sexabledwithrobinwb.com.

ALICE: Great. Well, thank you, Robin, so much for talking with me today. And I think I really do hope that the numbers of disabled sex educators increase and that eventually, that more sex ed will become more inclusive and have better disability representation.

ROBIN: Thank you. And I have a lot more ideas like transition programs! Sex education! But that’s another talk. [laughs] But thank you, Alice, for having me!

Wrap-up

[hip-hop]

♪ How far will they go?
Oh yeah yeah
How far will they go?
Oh yeah yeah…. ♪

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 Julia and Robin on our website.

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Thanks for listening, and see you on the Internets! Byyyeeeeee!

♪ Stop drop dance off ♪