New Insights In Sexual Health Podcast: Sex and Disability

with Katherine McLaughlin, Morrigan Hunter, and Elizabeth Cook and hosted by Catherine Schaefer

Catherine Schaefer (00:00):

Hello, and welcome to the New Insights in Sexual Health podcast. New Insights in Sexual Health is an innovative effort funded by the CDC to enhance STI (sexually transmitted infection) screening and treatment, strengthen partnerships, and build capacity for lasting impact. I'm Catherine Schaefer, a research analyst at Child Trends, a nationwide nonprofit dedicated to research that helps young people thrive. Today we'll be talking about building trust with and promoting sexual health among youth with disabilities. We're specifically thinking about young people ages 18 to 24 who have disabilities. With us today is Katherine McLaughlin, founder, CEO and lead trainer for Elevatus training, and certified Sexuality Educator from the American Association of Sexuality Educators, Counselors and Therapists, also known as AASECT. Katherine is also the primary author of the Sexuality Education for People with Developmental Disabilities Curriculum. She also has experience with disability as a wheelchair user.

Catherine Schaefer (01:00):

We'll also be talking with Morrigan Hunter. Morrigan is an Autistic sexuality educator and researcher who holds a Masters of Arts degree from the University of Oregon and a Master of Social Work degree from Portland State University and brings their experience as a person with a developmental disability. They also have years of professional experience making sexual health curricula better for specific populations. They work for Foundations for Divergent Minds, Kaiser Permanente of Northern California, and Oregon Health and Science University's University Center for Excellence in Developmental Disabilities. And finally, Elizabeth Cook, a research scientist from Child Trends. Elizabeth holds a Masters of Science and Public Health degree from Johns Hopkins with a focus on reproductive, perinatal and women's health. She has been an adolescent sexual health researcher for over 15 years and is currently leading two federally funded randomized control trial evaluations of adolescent sexual health programs. So

let's get started by talking about the wide and varied landscape of disability. I read that about one in four people in the U.S. have a disability, which is over 61 million people. So that's pretty common, and disabilities take a lot of forms. Morrigan, could you maybe start us off by telling us more about what a disability is?

Morrigan Hunter (02:16):

Sure. So I think first it's just important to remember that there are a couple different models of disability, but according to the CDC a disability is any condition of the body or mind or also called an impairment that makes it more difficult for the person with the condition to do certain activities. And this might be referred to as an activity limitation, and it might make it more difficult for them to interact with the world around them. And this might be referred to as participation restrictions. And this is kind of in alignment with the medical model of disability. There's also the social model of disability and then the model that was developed by Sins Invalid and Patty Berne in 2015 that we will be talking a bit more about later on.

Catherine Schaefer (03:06):

Great. That's really helpful information. So now that we know what a disability is and the different ways that people think about them, can you tell me a little bit more about some of the societal messaging around disabilities? And given that this is a podcast about sexual health, what are some of the messages people with disabilities might get from our society specifically around sex?

Katherine McLaughlin (03:27):

Yeah, I mean, many people with disabilities receive harmful messages specifically about sex, and we need to frame our messaging in a more positive way that really supports people with disabilities. For example, we know that people with disabilities have sexual needs and desires just like people without disabilities, and they're just as interested in healthy relationships and they need the same information about health and self-care. But we know that there's many societal messages that suggest the opposite, that people with disabilities don't have sexual lives. And that can result in people who are in charge of programming thinking that they don't need this information, we don't need to worry about this population and giving them the education and skills. And then there's other myths like people with disabilities can't understand sexual relationships or

conversely are oversexed and can't handle information that is sexual. Sometimes people think that people with disabilities are childlike and need protection, and we know that that's just not true.

Katherine McLaughlin (04:37):

And that those ways of thinking result in a lack of agency for the person with the disability. And people have different support and learning needs, but there are ways to make the information and learning accessible to everyone. And the fact that people don't receive this information can really decrease one's sexual health and lead to higher rates of sexually transmitted infections, abuse, higher rates of being charged with a sex crime, unplanned pregnancies and loneliness. And people with disabilities are often taught to comply and listen and do what other people tell them to do rather than speak up for themselves. And this can create a power imbalance. And also people focus on behaviors that someone with a disability might do and see them as problematic rather than seeing them as... helping them have a positive experience about sexuality. Really, people with disabilities deserve to have education and care around sexuality just like others do.

Catherine Schaefer (05:50):

Thank you, Katherine. I can see how all that negative messaging would really affect the way that sexual health education and services are delivered to youth with disabilities. Elizabeth, can you talk a little bit more about that?

Elizabeth Cook (06:02):

Sure. These messages represent underlying societal beliefs that limit people with disabilities' access to optimal sexual health. So for instance, we have many comprehensive sex ed programs that are out there for non-disabled young people, but very few that were designed for young people with disabilities because of the reasons Katherine gave a second ago. And these underlying beliefs contribute to decision makers not investing in the development and use of sex ed programs that are made for people with disabilities, even though these young people need it just as much as anyone else. People with disabilities can benefit from sex ed that was designed for the general classroom, but they aren't adequately served if their specific needs aren't addressed by the curriculum. So I like how an organization called SIECUS puts it, that comprehensive sex ed should provide them with information they need to take care of their sexual health and

then help them acquire skills to make decisions now and in the future. So if they don't get this kind of education, their sexual health is going to be negatively impacted in a multitude of ways.

Catherine Schaefer (07:26):
Thanks, Elizabeth. Now that we've talked a little bit about messaging, I'd like to get to the practicalities of searching for care and for education. So what are some of the experiences that you've heard from people with disabilities that have gotten in the way of finding the care and education that they need?

Katherine McLaughlin (07:43):
Yeah, sure. I mean, some examples are just not even being able to get into a clinic or a health department because the building is not accessible or having access to handouts, but the language is not accessible to them. Or it could look like administrators not making sure that students in the special ed classroom or part of the special ed department, have the same access and exposure to school health clinics, or possibly youth being taken out of a mainstream health class and then having to learn on their own and just lots of other ways that access needs are overlooked or ignored. And just this quote I want to share with you that one person shared, with a cognitive impairment from Illinois, and what she said was, "I learned from the school of hard knocks. I'm still dealing with the trauma of learning the hard way," and people don't need to learn from the school of hard knocks. We can't prevent all negative things from happening, but we can certainly educate and prevent more than what we are doing.

Catherine Schaefer (08:57):
Wow, that sounds really frustrating and unfair, but it also sounds like something that we can actually work on. So what are some of the approaches that you're taking toward changing how sexual education and sexual healthcare is conceptualized and how it's delivered to people with disabilities?

Morrigan Hunter (09:13):
Yeah, so I think earlier I had mentioned that there's a couple different models of disability, and there's one model in particular that was the model that was developed by Sins Invalid and Patty Berne in 2015. And this model of disability is really focused on trying to address the needs of all people with disabilities, which is since we're wanting to serve as many people as possible, that's the model that

we were really inspired by through our work. And so there's a couple different parts of this model, and let's just describe a couple of them here. Leadership of those most impacted is really important because I think as Katherine mentioned, that there's a lot of negative messaging about the sexuality of people with disabilities. And part of that stems from, well, I would say, and I think it's kind of borne out in the literature, is that a lot of people who are doing this work, whether it is researchers, educators, are oftentimes not people with disabilities, but leadership of those most impacted means that people with disabilities should be involved in actually doing this work.

Morrigan Hunter (10:34):
And if you're familiar with the term, "nothing about us, without us," the term that was first used in the disability context by advocates in South Africa in the nineties, that this also sort of ties in with that as well. Another part of the Sins Invalid model is on recognizing wholeness. And this felt really important to us because oftentimes sexuality education for people with disabilities tends to focus largely on preventing bad things from happening. And while that's really important, that's hopefully not the only thing in their life is just all the bad things. Hopefully there are other things in their life. And so we want to think about what are consensual sexual experiences if this person wants to have that, what are ways to support them through that? For instance, one example of that and recognizing wholeness just sort of encourages us to remember that everyone is a complete person and has nuance and complexity and that it's just important to kind of keep that in mind, including in a sexuality education context.

That a person is not just a list of deficits. Another part of this model is understanding the needs of people with disabilities and understanding that there are a variety of disabilities. And so that just means paying a lot of attention to how people might have different, one person might need more time to respond to a question or to a group discussion. Someone else might need something in plain language or in a large print. But just thinking about how there's going to be a variety of different needs, and it's important to make sure as much as possible that everyone could participate.

Catherine Schaefer (12:28):
I want to pause there for a second and talk about something I've been thinking about lately. Of course, accommodation needs are as varied as the disabilities

that people have, but what happens when you have conflicting needs in a group setting?

Morrigan Hunter (12:42):
Yeah, so thank you for bringing that up, Catherine. I think conflicting access needs, as that's sometimes referred to, is pretty common. And so if you're thinking about in a classroom setting, I mean, of course I think there's maybe more limitations there, but I think in a healthcare setting, one of the things could be just having different waiting rooms. For instance, I think a lot of times people talk about having a sensory room. I think it can be really helpful to have a sensory room that's the calm, quiet room, then another sensory room that's the more stimulating room. And so I think thinking about that can be really important, but also it might be kind of like, well, if one person needs quiet and another person needs movement, that that might require some creativity. It may be that means thinking about how to partition a space in the classroom or where should people be seated so that, can the person who needs calm and quiet and the person who needs to get up and move around, maybe they shouldn't be right next to each other when you're thinking about classroom setups. And so it might require some kind of creativity with thinking about arrangement in the classroom. But I think that kind of thing is really common. And so it should probably anticipate there's going to be some conflict as far as what people's needs are. And so thinking about how to make a space that can be modulated to try to meet different people's needs because the reality is that there's no one single thing that's going to fit everyone's needs.

Catherine Schaefer (14:32):
Thanks, Morrigan. Those are all really great ideas. I'm also thinking about all of these concepts we've discussed so far, and I'm wondering, as a researcher, how do those things translate into measurable change?

Elizabeth Cook (14:46):
Yeah, one of the big things I'm trying to change about how sex ed is delivered to young people with disabilities is making sure existing programs that were made for them are strong enough to be rigorously evaluated and ideally added to the evidence base down the road. So a lot of my work focuses on looking at how sex ed programs actually impact young people's sexual behaviors and also the factors that shape those behaviors. Things like knowledge, attitudes, self-efficacy,

those kinds of things. So basically research helps us figure out what works and for whom. And because we know a one size fits all approach doesn't work nearly as well as programs that are tailored to specific groups' needs, we need a variety of them. The problem is that we don't yet have any sex ed programs that are explicitly designed for youth with disabilities that have gone through that kind of rigorous evaluation.

And there are a lot of reasons for that, some of which we've already talked about. What I really want to see is more evaluations happening for programs that are designed for youth with disabilities, and we need to know which ones are effective and which ones young people find affirming and relevant and which ones we can confidently recommend for wider use. So over the past year, Katherine, Morrigan, and I have been working on strengthening Katherine's curriculum. So it is ready for a full-scale evaluation, ideally a randomized control trial if Katherine decides to take that route. And we need more of this kind of formative work happening. It helps programs be as strong as possible before they're tested, which sets them up for the best chance of success. And ultimately that means more high-quality evidence-based sex ed programs reaching young people, which is exactly what we want to see.

Catherine Schaefer (17:01):
Thanks, Elizabeth. That's really helpful. Now Katherine and Morrigan, I'm wondering since we've talked a little bit about changing our perspectives on disability and working to improve education, what are some of the concrete ways that health departments and providers can improve their work to reach and serve people with disabilities?

Katherine McLaughlin (17:19):
Yeah, I think it's really important for providers to get some kind of training on working with youth with disabilities. Both Morrigan and I can provide that kind of training and many educators that already have the sexual health background but don't have the experience or the expertise in working with this population. So we do training on how do you work with people with disabilities around sexual health. One thing that I often say, and I'm not sure if it fits here or not, to educators in particular that have a sexual health background, but they feel less comfortable working with people with disabilities, that they have a lot of the skills already that are needed to work with the population. So I feel like that helps them

feel a little more confident. Like, oh, I don't know how to do this. And so then they don't. So I like to get that out somehow that you already have a lot of these skills around respect and kindness and dignity and just being a sexual health educator or healthcare provider. So it's just tweaking those a little bit.

Morrigan Hunter (18:43):
Thanks, Katherine. And one piece of that is on provider education is to just be aware of assumptions that you might be making about people with disabilities. For example, someone who has a physical disability might be assumed to also have an intellectual disability. This is pretty common. Oftentimes people might have one disability and then people tend to assume correctly or not that they have other disabilities. And so it's just really important to be mindful of that because while it's important to recognize that yes, people might have multiple disabilities, that it's also not very helpful to make assumptions like that. And part of that means that someone's needs can't be assumed. You can't just tell by looking at somebody if they have a guardian or what sorts of needs they might have. You can't tell by looking at them if they're sexually active or what sex might look like for them or their partner or anything like that.

Katherine McLaughlin (19:46):
And I think another tool or concrete way is to really think about the language that we use when we're educating others and to focus on using plain language because plain language is language that really everyone understands, and so it makes the content more accessible to all. We also want to be very concrete in our language too and very specific about what we're talking about. We also want to use their language. And when I first developed the curriculum, I had people with disabilities review the lessons and field test them and things, but they looked at one lesson that was talking about sexual behavior and they said, “We don't like the word behavior.” It just has too many negative connotations to them. And so we changed it to sexual acts, so we use language that felt more comfortable to them and didn't have these negative connotations. And then I think lastly, like Morrigan said, nothing about us without us; talk to people with disabilities and ask them the best way to reach them.

Elizabeth Cook (20:57):
And one of the ways to get that feedback is putting together an advisory board that's made up of people with different disabilities that will help guide the

planning and decision making of say, a health department. So these advisors should be paid for providing their expertise on what people with disabilities need from their healthcare providers. But that is a good way to bring people to the table who have different perspectives, but experience with these kinds of systems and can give you specific insights that you wouldn't be able to get otherwise.

Morrigan Hunter (21:36):
Thanks, Elizabeth. And one thing I would say about that is that when we're creating advisory boards, as someone who's been on things like that, I think it's really important that you make sure that you're actually listening to what people are saying and that they're not just there to rubber stamp stuff; but are they actually having a meaningful impact on anything? And so I think that's really important to make sure that there's actual... if they're saying you shouldn't do this, that there's actual weight behind what they're saying.

Catherine Schaefer (22:12):
Those are really helpful suggestions. So calling back to some of the issues we discussed earlier, we discussed access to care and education, and those are pretty much at the individual level, but I'm also thinking about barriers at the systemic level. What can we do to address those larger issues?

Elizabeth Cook (22:30):
That's such an important question because real change happens when we strengthen entire systems and not just rely on small one-off efforts that depend on one really passionate or dynamic person. That's so common in these kinds of situations where one person's really driving it and then if they leave, then it's not sustained. One big step is for health departments and school districts to work together to identify and offer high quality sex ed programs that are specifically designed for young people with disabilities. And that last part is key. We want them to be designed for them, not just adapted like after the fact. Because right now what often happens is that a sex ed program made for the general population gets handed to a special ed teacher and they're asked to modify it for their classroom. And that puts a lot of pressure on the teacher and often will likely lead to programs that don't really meet students' needs.

So health departments can play a big role in changing that. They can recommend programs that are a better fit and really help schools put those programs into

place. Another system level opportunity is with school-based health centers. And those are clinics or doctor's offices that are located inside or near schools. It's not the school nurse, it's an actual clinic. And there are thousands of them across the country, often in under-resourced areas. And school-based health centers are in a great position to reach young people with disabilities because they're already part of the school community. But here's the challenge. Most school-based health centers don't have a clear plan for supporting the sexual health and education of students with disabilities. And it's just such a missed opportunity. And I really think that health departments can step in here too by providing training and resources and bringing in guest speakers and sharing best practices with the healthcare providers who work in those centers, those school-based health centers. So when we strengthen those kinds of partnerships between health departments, schools, and these health centers, these school-based health centers, we really make it easier for young people with disabilities to get the sexual health education and health care that they deserve.

Catherine Schaefer (25:08):
So speaking of education settings, I know that you all are working on a curriculum that's specifically for youth with disabilities. Can you tell me a little bit more about that curriculum and that process?

Katherine McLaughlin (25:19):
Yeah, so the curriculum was originally created by myself and a group of people with intellectual and developmental disabilities. They reviewed lessons. I also worked with Green Mountain Self Advocates, which is a group of people with disabilities in Vermont. And they field tested the lessons, they gave input and we made revisions. It's designed to be team taught between a person with IDD (Intellectual and Developmental Disabilities) and a professional as the training team, and now we're refined. So that was the base, and now we're refining it and we're talking to youth with IDD and getting their input. We're talking to people who have used the curriculum over the years as well, and we also have our own experience of working together, working with people with disabilities and also having disabilities ourselves.

Morrigan Hunter (26:17):
Thank you, Katherine. And I want to talk a little bit about the messaging that I think that we mentioned earlier that people receive about sexuality. And so we

decide that an important part of this would be addressing messaging about the sexual health needs of people with disabilities, and particularly those around their self-worth. We decided that this was important to really focus on addressing the negative messages about disability and sexuality in order to help disabled people unlearn those things and hopefully have a more positive view of themselves.

Katherine McLaughlin (26:56):

And I think self-worth is such an important piece. And then we also added more around one's sexual rights and responsibilities. So for example, we talk about the right to have your own boundaries, but also what's the responsibility in that as well is respecting others' boundaries too around sexuality. We've also expanded on the term sexual self-advocacy. There's a whole self-advocacy movement in the United States around speaking up for what you want in your life. And so really taking that term sexual self-advocacy or relationship self-advocacy and really adding more of what are the beliefs and knowledge and skills that are needed to be a strong sexual self-advocate. Adding that into the curriculum as well. And for this population, being a sexual self-advocate is really two parts to it. First, it's speaking up for your right to be in relationships. Like we mentioned earlier, many people don't see them as sexual beings or wanting relationships at all. So speaking up for your right to be in relationships and date and learn about this topic as well as speaking up for your right within relationships as well.

Morrigan Hunter (28:16):

Another thing that we did is we conducted interviews with youth with disabilities, and it was really helpful to hear directly from young people. And these interviews helped us to better understand their needs and their priorities. For instance, the young people who we interviewed were generally quite interested in receiving sexual health education even if they hadn't really gotten to learn about it before. And we also learned that they were interested in learning about preventing sexually transmitted infections through a broad range of barrier methods. So not just one type of thing, not just condoms, but they told us that they wanted to learn how to use both internal and external condoms as well as dental dams, dental dam underwear, and gloves. If we didn't interview them, we might not know that oh, actually young people with disabilities are interested in a wide range of things, so we shouldn't make assumptions about what we do or don't teach to them.

Katherine McLaughlin (29:16):
I think also there's some great new materials out there that have been helpful too for people with IDD to learn about sexuality and one is yoursexualhealthtoolkit.org, and it's a website specifically designed for youth with IDD to learn about this topic.

Catherine Schaefer (29:38):
Thank you. Finally, I want to focus on actionable changes health departments and providers can make to improve their service provision for youth with disabilities, what are some parting thoughts you'd like to share? So what's one thing that a health department can do today to get started on changing its service provision for the better and making it more accessible?

Elizabeth Cook (30:00):
Well, one thing that you can do is start asking questions about the services that people with disabilities are receiving at health department sponsored like clinics and school-based health centers, like I mentioned earlier, and what sex ed is being even provided to youth with disabilities in schools in your community. So just gathering that information so you have a sense of what's going on. You could also look at what trainings you're offering your providers, if any of them have anything to do with disability or if that seems to be a real gap in the trainings that you're offering. Also, if you collect data from these clinics or these schools as part of your sponsoring of them, you could see if you can collect some information about what they're offering people with disabilities or if they're even collecting, if they're even looking at how well they're serving people with disabilities. There are guides that exist on ways to best serve people with disabilities in health clinics. One in particular that was just released recently is from the National Coalition for Sexual Health, and it's called the Clinician's Guide to Disability Informed Care. And I would strongly recommend looking at that. And there are sex ed curricula that are designed for young people with disabilities. So familiarizing yourself with the options and seeing if you can encourage schools in your area to utilize those kinds of curricula for young people with disabilities. So just collecting information about what's happening in your clinics and in your community is a good first step.

Morrigan Hunter (31:41):
Thanks, Elizabeth. And to add to that, I would say that part of the data that you can collect could be doing focus groups or interviews with youth with disabilities

in your community, whether in a school setting or in a healthcare setting, really ask people and to ask youth what their priorities are around the health care that they're receiving or around the sex ed that they're receiving. I think just like we found that we couldn't anticipate what people would tell us necessarily. And so I think it's important to really hear from young people as far as what sorts of problems they're seeing come up in their lives. What are the topics that they're really feeling like they need to learn about? What are some of the challenges that they're experiencing? Do they feel like they're not being taught certain topics that they're having to learn from the school of hard knocks as Katherine had mentioned? Or what are some of the barriers that they're receiving that they're experiencing if they're trying to get healthcare for their sexual health needs? So those are some of the things that can be really invaluable insights that you might not be able to figure out any other way other than getting the qualitative data from young people with disabilities themselves.

Katherine McLaughlin (33:16):

Those are both great ideas, and I think we can also just reflect personally and ask ourselves, why might I be forgetting students with disabilities regarding sexual health? And we've all grown up with these messages that people with disabilities are not sexual beings, and so it makes sense that we might have forgotten or have these beliefs that they don't need this information. But I don't know where this quote came from, but once we know better, we can do better. I'm not sure who said it, but I think it's true. Once we know better, we can do better, and you can please reach out to any one of us if you have any questions about your next steps and how you might do better at serving this population with sexual health information and care.

Catherine Schaefer (34:10):

Awesome. I really appreciate you all sharing your strategies and expertise for providing sexual health information to youth with disabilities. This team has also put together a brief on creating a conceptual model for STI Prevention in Disabled populations titled Leveraging Conceptual Models to Refine a Sexual Health Curriculum for Young Adults with Intellectual Disabilities. Look for that on the Child Trends website. We'll also be creating a short tip sheet based on this conversation and posting more related resources to our webpage. So look out for those. Thanks everyone.

Resources

- Your Sexual Health Toolkit by Project SHINE
- Our Lives, Our Choices, Our Rights! by the Rainbow Support Group
- Clinician's Guide to Disability-Informed Care by the National Coalition for Sexual Health
- Refining a Sex Education Curriculum for Young Adults with Intellectual Disabilities by Child Trends
- Sexuality and Developmental Disabilities Workshops by Elevatus Training
- The Arc: For people with intellectual and developmental disabilities by the Arc

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Contact

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