

That's Inclusive!

Episode 7 Transcript

Episode title: Parent advocate, Carrie Duran and NHCDD Executive Director, Isadora Rodriguez-Legendre, talk about helping disabled young people navigate learning about sex and relationships.

Welcome to That's Inclusive! Where we talk about disability and what it means to live a full life, engaging in our communities.

What does that look like? And how can we work together to make our world a more inclusive place?

Hi everybody and welcome to our podcast - That's Inclusive! Conversations with the New Hampshire DD Council. My name is Isadora Rodriguez-Legendre and I serve as the Executive Director at the NH Council on Developmental Disabilities. And with me here today is Carrie Duran, who is a Council member and I'll let her introduce herself a little bit more. And today we're going to be talking about sexuality and relationships for people with disabilities.

[Music] That was quite an introduction.

So do you want to tell our good listeners who you are and what brings you here today?

Sure. It's a pleasure to be here today. My name is Carrie Duran as Isadora said. I am a proud Council member – have been since 2018. I have a 12 year old daughter, Katie, who experiences Down Syndrome. I'm excited to be here today to explore all the ways that I can potentially support her in her development and her sexuality.

So, when you and I were talking about putting this episode together, we had a lot of good conversation about what we see as some of the potential barriers and issues in our system, especially for people with disabilities to access health education, sex education – to understand healthy relationships and all of the things that really we don't talk about- we don't talk about these things. They're kind of taboo subjects. We're here to kind of lift the veil a little bit and try to be a

little bit uncomfortable in making sure that we have tools and resources for people with disabilities. And especially since kids are kids. They're going to talk about things and they're gonna talk about things with their peers in school about things that are happening. About how their bodies are changing and how their hormones are flaring and who's cute –

According to my daughter everybody's cute.

I think I was one of those girls also!

She wants to date everybody. One of the things we were talking about was, if we look generationally, from when our mothers, our parents, to when we grew up and now my kids, every generation has access to more and more information at an earlier age. So, my daughters have been able to access things on the internet and social media that I didn't see until I was much older.

Right. Right. I think I told you when we talked, I used to hide out in the section of the library that had the books about the things because my mom was not bringing me any books. And so I used to sneak peek it at encyclopedias and books about the human body because I didn't get that. But I heard other people talking about it. So that was the access to the information I had at the time.

I think for me it was Judy Blume. I can't wait to bring my girls to see the new movie—we're not here to plug a new movie – but there is a new Judy Blume movie out. But I can't wait to bring my girls. But those books were really important. And talking about books like my first introduction into learning about my body and my development as a young girl was through a book. My mom was like, hey, you might be getting your period soon, here's a book about it. Let me know if you have any questions. And I was like, what! What is this?!

Yah, talk about an introduction. So it's really fascinating to me that in New Hampshire there is no statewide sex education curriculum. And we talked about that a little bit and I think you're the one that brought that up to me because you found out through your girls' school, right?

Sure. Sure, well, Katie's 12 and she sees her classmates and her typically developing friends have boyfriends and they all have cell phones. She doesn't

have a cell phone yet. They have Instagram. She does not have Instagram. And they're all relating on a certain level. And so then Katie comes to school and she's trying to relate at their level. But she also doesn't quite have the developmental understanding of the nuances of a boyfriend/girlfriend, or flirting or just friends. Or what's the difference between a friendship with girlfriend. What's the difference with a friendship with a boyfriend. It's all the same to her—love is love. And she wants love and affection from her friends. She wants love and affection from boys. But she wants to get married and have kids and she wants everything that we all want. But her level of understanding is much younger than her peers. And I'm finding that at school, especially because we are a household of all girls – I have two older daughters who are teenagers – I'm a single mom, so there are four girls in the house—we're not around a lot of boys. So, I can't say "look at how she's speaking to a boy" or interacting with a boy because we're not in situations where I see her do that. It's happening at school. And unfortunately, it's her team and her teachers feel like sometimes she's not reacting appropriately. Whether it's "Hey, I want you to be my boyfriend" and the boy might be uncomfortable and not know what to say. But for Katie, she's not trying to make someone feel uncomfortable, she just see's oh well they have a boyfriend and, they have a girlfriend, I want one, too.

Like, she's exploring relationships.

Yes. Yes.

Trying to form connections which is so important when you're a young person going to school.

It is. And, as a parent, I don't want those experiences for Katie for her to feel punitive. That she's wrong in her understanding at her level. She's not wrong. She's a whole human being whether she has a disability or not. And she deserves the same happiness that her peers have in relationships. But, how do we bridge that gap for her? And how do we as parents assist the schools in bridging that gap for her?

I think that that's a really important point. And I was surprised to learn that New Hampshire has an opt out law so even if there is health class or some sort of educational programming at school, parents can say, no, I don't want my child or

my young adult to participate in that lesson. Which was a little bit shocking to me because an assumption I have is that probably most of those lessons are about abstinence. And so why wouldn't you want your kids to learn about abstinence and safe sex and also the changes in their bodies and the hormones and all of the things that are impacting us when we're young and we don't know what's going on. There's a lot of changes happening and you would want to learn. I think you would want your student, your son or daughter, to learn about what is important - just the physics of it, right? The physical changes. So that they don't feel like wow, they're living in an alien body now.

And, my daughter Katie, when they first started to have health class, she's in the 6th grade now, it was about wearing deodorant and you need to shower every day. And when you have a child who has sensitivities and doesn't enjoy having her hair brushed let alone her hair washed, you've got to make sure to take a shower, you've got to wear deodorant, you've got to brush your teeth. These are all sensory things. And I did thankfully with my school district, I did ask the health teacher at the time—can you break down these lessons a little bit more and give me some support materials so I can back it up at home? And thankfully, they did. But I had to, as a parent, seek that out because there wasn't anything available. It was certainly extra work for the health teacher to do that and I'm so thankful that she did. But now moving on to the next level where Katie is exploring those relationships, she does want to have a relationship, there isn't any material available to break down for her level of understanding. So, we're kind of at a crossroads right now. As a parent, it's already, as we talked about earlier, it's already so hard to have those conversations with your kids. Whether you have a son or daughter, it is so difficult. And you don't want to embarrass them and you don't want to say too much. But you want them to be empowered and have the facts. And, so that when they are exposed to something on the internet or social media or on the playground or with their friends, they already know the facts.

Right. It's like you started saying, they have access to way more information than we had access to when we were their age. I can't imagine what my parent's parents did for educating their sons and daughters about sexuality and relationships and how to be safe and all those other things. Because we live in a culture of just, what I see is, people have blinders on still. And a lot of times, it was the truth in my family, if you don't talk about it, it doesn't exist, right? And so we forget that this very real place where we're at – where information is

everywhere, everywhere. And, even when you have parental controls, you were talking about that earlier. You can't know whether everything is safe that they're watching or listening to or engaging with in some way.

I just remembered a moment that broke my heart. Kind of on a different topic but it was when my younger girls learned there was no Santa Claus. They were on the playground and they were 2nd grade and it was someone's older brother told them and they came home crying and I was like "Oh my gosh! What do I do?" They were decimated. They were like "Is this true? Is this true? Is it really you who gets the presents?" And I said, "You know Santa Claus", I totally lied, I felt terrible because I didn't know what to do. You don't want to lie to your children but you want to keep that wonder, you want to keep that innocence that is a balance of what we're talking about, facts and keeping them safe. What I came up with was Santa comes to your house as long as you still believe in him. And when you get to a certain age, and you're older and you don't believe in him anymore, your parents take over.

That's pretty good!

They bought that for a few more years!

It's kind of like their first ushering into adulthood, right? All of a sudden it's like, oh man, everything I know is questionable now.

And then you had mentioned that their bodies start changing and there's all of these things happening and they're nervous, they don't have all the information. I want to make sure they always have the facts so that they can always make the right decisions for themselves. And, after that whole incident with Santa Claus, I said "if any of your friends ever share something with you and you have questions about that, you can come to me and I will always tell you the truth. It might be really uncomfortable, but I will always tell you the truth". For Katie, my 12 year old daughter with a developmental disability, I can't always tell her the exact truth. I want to be able to.

All of the gory details.

Correct.

I have to make sure, is it at her developmental level? But how do I balance that, here's my question, so to all of the listeners, all of the parents who have been through this before, how do I balance being cognizant of her developmental age, what she's learning who she is, with being respectful of who she is as a human being and respecting that "so what that she has a developmental disability?". She deserves to know about having her period. She deserves to know about having a boyfriend. How do you start a relationship? How do you end a relationship? As we talked about earlier, and how are you safe in a relationship? How do you show affection? I don't know how to do that—I admit it! I don't know everything.

I think one of the questions that you had was kind of what resources are available because the schools don't have the resources. They don't take the extra time, like that teacher did, to see what's out there and to really break it down in appropriate chunks of information that are not only digestible and easy to understand, but then you can go back and talk with your family about. And, for a lot of families, they're involved in decision making. We talk about decision making being one of the things that we need to really educate young people about like—what is a decision? How do you get there? How do you weigh pros and cons? What happens if you make one choice over another and can you change your mind about that? All those things that no one was talking to us about, but that we recognize now, looking back, as this is the foundation of the choices that we make in life. We need to be able to understand what the consequences of our decisions are and what the potential benefits are of those decisions, too. And that's like a big focus in a lot of the sexuality trainings. I've taken the Train the Trainer for a sexuality education for people with intellectual and developmental disabilities, and I know that those are the key pieces of the early education for folks, or later because didn't get it when they were a young girl, like -- how do I find friendships? How do I go from being a friend to a romantic partner? How do I go from a being a romantic partner to being in a partnership around marriage or living together? Living together is a whole next level thing. And then, if it's not working for me, how do I, in a very healthy way, end that relationship? And how that is ok too. And you're able to be ok with that happening, because it's a part of life. So all of those things I agree that it takes extra effort to find those resources and to really be person centered about how we break that down for people with lived experience with disabilities and whatever their disability is. I think that I'm a fan of integration and inclusion and I

think when people learn together, everybody learns the best, right? And so I wonder about how we can be more consciously bringing resources and tools and strategies for school districts, for parents, for school social workers, for school based support teams to really be able to address the needs of students with disabilities and not feel like weird or that it is extra or so careful and tiptoe around these topics. They're going to learn about it, right? At some point, Katie's going to have a cell phone. She'll be able to look stuff up, right? Look up what she thinks is the hottest guy. She has to be prepared. She has to be prepared to understand how to make choices that are healthy and choices that are in her best interest, right?

Another question perhaps I have for you and also for our listeners – how do you educate the people around her, her fellow students and her teachers and the community, that just because she has a disability, does not mean that she's not wanting that acceptance, wanting that connection. And how do we help Katie be safe with those interactions? God forbid, down the line, we don't want her to be taken advantage of because she really is seeking out that connection? But how do we help her peers to understand that she is deserving still of having a boyfriend. Just because she has a disability doesn't mean she's not a whole human. I keep going back to that. I think we have a tendency in our society to treat people with intellectual disabilities as if they stay childlike forever and that they never grow up. They have a Peter Pan syndrome and, that is not the case.

That's one of the other foundations of sexuality education is that you may feel as though the individual isn't at the cognitive level to understand certain things. But, guess what? Their body is still changing like their non-disabled peers and they're having the same urges and the same feelings. And, it's really important that we provide them with information that this is typical for people at your age, go back to the age, to go through these things. And then temper the cognitive part of that of how we can make healthy choices, how we can deal with our urges, how we can—because you know, I won't get gross, but we're all going to at some point, whether you have a disability or not, have questions that are uncomfortable for other people to answer. It's not necessarily that the person with the disability is going to be uncomfortable, it's that who ever they're asking will be uncomfortable and not know how to handle it. We have to be prepared and we have to be brave. And we have to really talk about the biological development, because that's an important piece of what impacts our social and emotional

development. But then talk about those differences those social pieces and how you make friends and how you can go from being friends to being romantic partners and all the things that come with that. And then the emotional piece of “What does it mean to be in love?” and “How does that feel like?” and “What happens when you’re not in love anymore?”. That’s a huge thing for me. We don’t teach people, we don’t teach young people, one, that it’s ok to break up. It’s not the end of the world even though it feels like it when you’re 12, right? It’s a part of the experience and that it’s perfectly alright to change your mind and to not get stuck in a relationship where you don’t either feel valued or you just don’t feel like it has that same fire anymore. And that’s important.

And I think that whoever is the adult, or guardian, or friend or sibling or whoever it is, like when Katie grows up, I want those around her to trust her as an adult to make those decisions for herself. But be there to guide if needed. But that the goals for herself is that she wants to as I said get married, have kids, she wants to live on her own, she wants to go to college, she wants to drive a car. She also wants to be a doctor, dentist, stylist, astronaut – all those things. She’s gonna be busy. She’s a whole, whole person. I know we don’t have all the time in the world today and maybe this is where we come back, is where does the LGBTQ+ community fit into this conversation? Because Katie’s 12 and she already has questions. When she sees someone—she’s say is that a boy or a girl? She already asks those questions. So, we’re talking about where do we find resources to help a 12 year old girl with Down Syndrome understand her sexuality and relationships? But where do we find resources to understand where the LGBTQ+ community comes into those questions and help her with that?

And, that’s definitely part of that exploration as young people like we explore. Whether we learn from our parents or not about the choices and the options out there. We live in a society, thankfully, that really is embracing folks who are non-binary, folks who are trans, and we really need to be able to present those. If somebody with a disability is having those feelings and they aren’t exposed to that at home or at school, it’s just so alienating, right? To be the only one or to not to have people you can talk to about that. I think it’s super important, especially for people with intellectual/developmental disabilities, to also have the ability and the freedom to explore. What do they like? What do they not like? What are they attracted to? What are they not attracted to? How do they want to dress? How do they want to present outwardly? It’s all so much the fit we kind of

take for granted as part of the teenagers' development of their identity. Because they're exposed to a lot more today than they were before. But if people are sheltering their individual with a disability, the potential there is, and we hear about it all the time, now you have increased rates of suicide for individuals with disabilities who identify as LGBTQ just like you have increased rates of suicide for people without disabilities that identify as LGBTQ. And that parental acceptance is a huge piece of that. And we need to be open and honest with people, whether or not we identify in the same way. Again, it's one of those really taboo topics. To your point, kids have access to all this information, all of these resources, all of this social media. We can touch briefly on the social media piece before we kind of wrap up because that is a huge impact that we didn't have to deal with when we were kids.

I had those ABC Afterschool Specials—that's how I learned about teen drinking and all that kind of stuff. But we didn't even talk a lot about that with our friends. It was just "Oh, you'll learn about that when you're older" and then when you're older, you don't have the tools to handle these things that come up. I want to create that safe space for my daughter, Katie. So that if she comes to me one day and is like "I want to get married, or hey, I just want to live with a person, or I just want to go to the movies with them, but I want to kiss them-I don't want to kiss them-I don't know if I want to kiss them. Should I ask them? Whether that is a boy, whether this is a girl, whether that's a trans person, a non-binary person. I want her to just feel safe to just be the person she wants to be and I want to provide an outlet – a safe place as her mom to have those conversations or not have those conversations. But at least she knows she can come to me. It might be really uncomfortable for me to have those conversations as her mom, but at least she'll know there's a space for her to do that.

And that you're always going to support her true authentic self, whatever that is.

As a doctor, dentist, stylist, astronaut—whoever her true authentic self turns out to be. The sky's the limit.

That's fantastic. The hope for me is that's the best we can do. We can strive to be better than the previous generation at just supporting people and embracing this person-centered and self-determination in our society for people with or without disabilities to be whoever they want to be. I think it's so important

especially with social media because there's a lot of pressure. There's always a lot of pressure in the media with body types and what should be the model of a relationship—two and a half kids and a dog and a picket fence and all those things...

I'm a little older than you but we're about the same age. I was telling the girls when I was their age, my older two, they're 16 almost 17 now, and I said when I was their age, yes, I wanted to go to college but really my big goal was, I wanted to get married and have kids and have a house and have a car and like to me, that was the ideal. I didn't even think past that. And I got married at a pretty young age. Now I have three beautiful kids and I'm very blessed but I shared with them – don't feel pressured that you have to be in a relationship, that you have to get married and you have to have kids. I tried to let them know if you do, that's great I'll be the best grandma ever, and I will be so happy – but wait ten years please. But if you just have fur babies, you just have fur babies, too like – there's no pressure from me. As a woman, there are other pressures that things you have to live up to in a societal fashion. And I keep trying to tell all my girls, you don't have to live up to anybody's expectations except the for ones you have for yourself. When you have a child with a disability, how do I remind her that every single day that the only expectations that matter are the ones she has of herself and just by continually letting her that I love her, I'm proud of her, and home is always a safe space to have those conversations. There's no magic sauce unfortunately—I wish there were! – but again, if we go back to resources...it's great that you and I can sit here and have this conversation and bring awareness but if somebody listens to this and then decides "Hey, I want to find a resource", I'm going to ask you a question, Isadora. Where would you recommend that they go?

It really depends on the topic and it depends on the audience I want to say. There are some resources available for adults with intellectual and developmental disabilities to kind of learn more. We talked about sexuality education being out there and available. I would say different resources for school districts talking about how do we bring more positive messages, even just about identify, into schools. It doesn't have to be about sex, it doesn't have to be about all the things that make people uncomfortable. But, really about being your true authentic self. What is consent? What are healthy boundaries? What are healthy choices? I think a lot of times people get hung up on the sex part, right? It's really like relationships are a lot more than sex, right? And it's really important to have all

those tools to help inform that latter part. I think we're moving towards that, moving toward having more resources available. We're kind of in that paradigm shift I think where people are becoming more aware that this is a major issue, especially in a society where there are still huge divides in gender expectations. And, in not accepting of people who have differences. We're moving toward a world where that's more typical. What we're talking about here is moving the needle in bits and pieces and making sure that we're giving people information about just that they are valued and they are important and that they matter and their opinions matter and their thoughts matter. Supporting that in some way. It's so nice to hear how welcoming and how transparent you are as a parent. Understanding that this is challenging but let's talk about it anyway. And I want you to know that I'm there to talk about it, even though it's uncomfortable for me and probably for you, but I'm always going to support you and who you are and help you overcome obstacles in your life. That's the best we can hope for.

Absolutely. Unfortunately, no one said parenting was easy.

You didn't get the book?

No, I didn't get the book. I think there are a few books – I should have read them. Being a teenager, being a young person today is way more difficult certainly than it was when I was growing up, when you were growing up.

And we all just do the best we can. 'Each one teach one' is one of my mottos. I learned something I want to share it with other people because it's worth them knowing it, too. So that we're not all just walking around in the dark.

And was it Maya Angelou that said, "When you know better, you do better"?

Yes, that's right. You do better. So, I want to thank you for coming on the show and for exploring this topic.

You're so welcome.

It's such an important issue. And, I think that if I can just share that there are rainbow support groups out there which are specifically for individuals with intellectual and developmental disabilities who identify as LGBTQ+. Your people

are out there and you can be supported and you should be supported in all of the ways that make you who you are. We will be working, the DD Council will be working, on exploring and supporting that community as well. Because it's so important that people with disabilities to have a place where they feel safe.

And I would also recommend that if there are conferences out there that perhaps Isadora is doing a training at, or another organization there are wonderful trainings out there. I think it's been since before Covid you had a chance. But hopefully we'll see you out there. It's a wonderful class—I've had the opportunity to take it myself and Isadora is a wonderful trainer so I encourage everyone....

I get around. Usually it's people like you who are volunteering me for things.

Well, we wouldn't do it if you weren't amazing. So it's just been such a pleasure to be here and bring my personal experience of what I'm going through with my 12 year old, vivacious 12 year old, and just get some different perspective on it. I can't wait to hear if there's other parents and folks who have any advice for me.

Feel free to reach out to the DD Council if you want to learn more about anything we talking about on today's episode or if you want to share information with us also. We're always open and we are welcoming of diverse perspectives and want to make sure that people have an outlet to really share those perspectives.

Absolutely. Well, thank you again Isadora, so much.

Have a good one.

This was a production of the New Hampshire Council on Developmental Disabilities produced by Isadora Rodriguez, Legendre, and Vanessa Blais with many thanks to Josh Hardy and rest of the crew here at Concord TV. We love to have guests with differing perspectives. These are personal, and do not necessarily represent those of the DD Council.