

Vanessa:

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?

Welcome to That's Inclusive! with Isadora Rodriguez-Legendre, the executive director of the New Hampshire Council on Developmental Disabilities.

Isadora:

Hi, Vanessa!

Vanessa:

Hi Isadora! How's it going it's going?

Isadora:

It's going pretty good.

Vanessa:

Great! I'm glad to have you here. Thanks for coming.

Isadora:

Glad to be here.

Vanessa:

So, tell us what is the New Hampshire Council on Developmental Disabilities, and why should I care about it?

Isadora:

That's a great question. So, the New Hampshire Council on Developmental Disabilities is a federally funded state agency that was created by a Federal law known as the DD Act.

It's actually called the Developmental Disabilities Assistance and Bill of Rights Act.

And that act created DD Councils, as we refer to the Council as. In every state and territory to really help identify the needs and help address those needs on the ground in the state where it's situated.

So, in New Hampshire, what we do is we do a lot of what we call data collection. We do surveys and feedback sessions, and we really poll our community to find out what the most pressing issues are.

And then we create a 5 Year State Plan to help address those needs.

The Council's mission is that we're dedicated to dignity full rights of citizenship, cultural diversity, equal opportunities, and full participation for all New Hampshire citizens with developmental disabilities.

So, we carry out our mission through education, advocacy, and funding innovative projects that really make a difference in people's lives in New Hampshire, who experience developmental disabilities.

But I like to say that we mostly work with other people.

So, we collaborate with other organizations and groups that have similar visions of community inclusion and integration for individuals with intellectual and developmental disabilities in New Hampshire.

And that's why you should care. Because it affects us all. To be able to have inclusive communities, we all have to be a part of that, and we all have to pitch in and and really advocate for accessibility, because when something is accessible for a person with a disability, it's accessible for everyone, whether it's an older adult or you know, a mom, with kids we have similar barriers, sometimes, to community access and so we're working to reduce the barriers in that way.

Vanessa:

Can you tell me a little bit about some of your key partners?

Isadora:

Yeah. So, I'll talk a little bit about membership, and then I'll lead right in.

So, our federal law actually states that at least 60% of our council must be individual with lived experience of intellectual or developmental disability and or parents of kiddos who have developmental disabilities or guardians of adults who have intellectual or developmental disabilities that may not be able to advocate for themselves. So, the other 40% of our Council as temporary of what we call community partners or agency states.

So, we have represented things like vocational rehabilitation, education for people who need supports and services.

We have the Bureau of Developmental Services in New Hampshire.

We have our DD act Federal partners, which include the Institute on Disability at UNH, and the Disability Rights Center, New Hampshire, and then we have a private provider network.

We have organization called New Hampshire Family Voices, which really focuses on advocacy and information for parents of children who are currently receiving supports in the school system.

We have a number of different organizations that we work with.

So, we partner with them on a lot of different things, like trainings and conferences and different activities. And we also partner with what we call adjacent organizations.

So, these are organizations and groups that are working on different priorities that actually impact the disability community but not it's not a disability group.

So, for example, groups working on housing access, right? So, for our community, housing access is a big issue.

But it's not a disability housing group that we belong to.

We actually go to different housing groups around the state, and we talk about how it's important to remember that to create, not just housing that is accessible for people with disabilities physically, but also kind of universally designed in a way that is more acceptable for anyone who might the lower light switches or wider door frames, or things like that, and then we also advocate for affordable housing, so that the people that support people with disabilities can also afford to live in the community and be part of providing kind of this community integration, that we talk about for people with disabilities.

Vanessa:

That's great. So, what are some other initiatives that the DD Council works on?

Isadora:

So, we work on a lot of different things.

And so, our 5 Year Plan currently has 2 really, really broad goals.

And that really enables us to focus on a larger rate of issues by essentially lumping them into a category called quality of life.

So basically, anything that improves community access or quality of life, including quality services or people with disabilities included under that goal.

And that way we can support a number of different programs and agencies in the work that they are doing to make things more inclusive and more accessible for people with disabilities, and we mostly do that through small grants to different projects so for example, when we would support something like an accessible trail, or a universally designed playground for kids, so that the ideas that people with and without disabilities, or you know, anyone who might have a difference that needs to access the community in some way, we're we're kind of breaking down barriers and creating opportunities for people to participate in their community.

So, we like to say to live, work, and play right? So, recreation is a big part of what we think is important to have a robust community-based life for people with disabilities and community.

Vanessa:

So, what is something that you're especially focused on in the upcoming year?

Isadora:

So, I would say so. The other goal that's currently on our Five-year Plan has to do with advocacy and training.

So, we support a lot of different initiatives that are really about building awareness about the needs of the disability community, how people with disabilities can contribute to their communities, how actually having inclusive settings it, it creates a more cohesive workplace, for example, a more cohesive classroom, because you have people working together with and without disabilities and so part of what we include as part of our admission and training. It's really we want more people with disabilities, who are of culturally and linguistically diverse backgrounds to get more involved.

We've seen at the DD Council that a lot of our members because they're it's a volunteer position, right?

You have to have the time you have to have the ability to really attend meetings and get involved in projects and a lot of people who are involved are kind of, you know, middle class families who, where maybe one parent had some time to to

really invest in advocacy and working towards improving the system in some way, and so what I have seen while I'm at the Council is that there there aren't really a lot of people who are first generation immigrants who may have a language barrier, or you know who who English is not their first language.

A lot of folks in this situation are not at the table, and so you know, when I first moved to New Hampshire, I heard someone say, if you're not at the table, then you're on the menu right, and that really struck a chord with me because it's true. Unless you're there to lend your voice, people are making decisions for you, without you.

And so the disability community has a great slogan call, and that's that's nothing about us without us.

And I think that it's it's especially important in this day and age where diversity, equity, inclusion, is kind of at the forefront of a lot of our conversations that we have, you know, a diversity expressed in our membership, in our resource availability that we are translating documents, that we're making that extra warm invitation to folks that haven't traditionally been at the table and say hey?

What you think is important to us. We need to know what your issues are.

We need to know what your barriers are, because otherwise we're only, you know, we're only looking at half the picture, and you know, traditionally decisions are made by those who are in power and and who are of the majority.

And so for me, it's especially important to think about how the Council can be more inclusive and more diverse in its membership, and bring those voices to all of these different meetings, all of these different decision makers, policy makers.

We need to really be intentional, and how we address the barriers for communities of color and communities with diverse culture and linguistic backgrounds, because if we don't do it, you know who is?

Vanessa:

That's a heavy lift, because you not only have families who are already having to like deal with so many challenges, raising kids or having spouses or family members who needs supports. And then you kind of like, bring in that some people are new Americans, a lot of like immigration and and refugee settlement, especially in Manchester, and they are already having to navigate those challenges, and then I mean, New Hampshire is not a very diverse place. Right? It's pretty white, so that's a big challenge.

How, how do you think that the Council can address those challenges?

Isadora:

Yeah, I mean, that's a great question. It's kind of a question we've been asking ourselves.

So, you know, especially the last couple of years, when there have been some threats to how we talk about race and culture and inclusion, and you know the the good thing that's come out of that is there has been this kind of very intentional movement around diversity, equity and inclusion, and you know part of how we're getting people involved or or getting the message out.

There is by getting people involved with those groups. A lot of folks are focused on, you know race and ethnicity as they talk about diversity, and we're there at the table saying, Hey, don't forget disability. It's part of diversity, you know, just like you know, LGBTQ as part of diversity, just like, you know, don't forget about people with invisible disabilities, like mental health conditions that also need supports to be included in these conversations.

And so, we've made a commitment to kind of be more again intentional about how we outreach to different groups and organizations, working with people who might be new Americans who might be of, you know, have a where English is not their first language we're translating a lot of our materials into Spanish and trying to message that we are able, you know, to get things translated into any language that's someone might need it.

We have the funds available to be able to get things like interpreters for people who would want to get involved, or who, you know maybe they want to testify on a bill and we would want to support them in whatever way they would need to be supported in order for their voice to be heard.

But a big way, you know, is really just getting getting the message out there.

So, getting involved with initiatives like 603 Diversity, which has a magazine that talks about diversity and inclusion, and I wrote an article there to talk about disability, and how important it is to include disability in those conversations.

We're really trying to be intentional about inviting people to become members of the DD Council and of other groups like, if the council is not your jam, then there's another group that you could certainly join that is going to be working on, you know, quality services and supports for individuals who need supports and and also just you know again making sure that that the the

perspectives of people who represent diverse backgrounds are considered and valued and taken into consideration when decisions are made about policy changes or about initiatives that are meant to improve the lived experiences of people.

Again, you know, because we don't know what we don't know, and sometimes there can be unintended consequences with moving forward on a project and not getting input from all of the communities that it might impact.

Vanessa:

So, when you are also trying to get buy in from the council members themselves, how do you go about doing that?

Isadora:

Yeah, I I mean, I love our council. I think it. We have a very broad array of people represented so different disabilities, different groups and organizations.

We have parents, we have different regions represented, and I think at the end of the day what I have seen time and time again is, even if people don't agree on something like we're all there for the same reason.

Everyone's mission is more inclusion, more integration, more supports and services that can help people live authentic community-based lives in and in wherever they want to live. Right?

However, they wanna live. And so creating opportunities for authentic relationships and opportunities for leadership development is especially important to us.

We really want to give people with disabilities and family members the opportunities to access different trainings and advocacy platforms that they might not have been exposed to previously.

But you, you know, I think again, as a community, I think that we're stronger together, and that people know that.

And people come together at the end of the day. Whatever their differences are.

If there's a bill that needs support, or a topic that really needs to be addressed or something going down in the in, in the service system that could impact families like people come together, and they rally around that that cause.

Vanessa:

So, if you if someone is of a more diverse background. Or maybe English is not their first language, and they become interested in the council but they're not really sure if it's their place a place for them.

What would you want them to know about the council, to let them know that there is a place for them there?

Isadora:

Yeah, I I think so. My message to those folks, or to anyone really, who wants more information is like, there's no there's no charge for for learning more right? You can learn as much or as little as you want without committing yourself, right?

We, our meetings are public, we are open about sharing our goals and our priorities.

We ask for volunteers, even if you're not a council member, and you, wanna, you know, support us by being at an information table at a pride event, or at a parade or some any activity that we're located at that I think we could use volunteers, and we could use people and their voices to really champion the work that we're doing.

But I I would I would, you know, say that again, we want to make it as easy as possible for people they want people to get involved.

And so if someone has the barrier has the concern or has an issue like, just let us know, and like we'll do our best to try and eliminate that barrier, or if provide some sort of opportunity for you to lend your voice, so some of what we've done in the past includes like, if someone can't be physically somewhere, we would still want to collect their you know, whatever their story is, whether it's through a podcast or Youtube, video, or you know, a Zoom video or, one of our members is doing like little interviews, I think it's important to collect

those stories and to share them with other people who, you know, may have different perspectives on things, and so bringing that awareness to light and and reminding people that just their personal experience is their personal experience, and nothing more and nothing less, right?



There are lots of people out there with different experiences and that we need to be considerate, as considerate as we would want someone to be of our experience.

We need to value and champion other people's experiences.

So, I would say that I would say that it costs nothing to get involved, and you can do as much or as little as you can you know, as your time and availability allows, but having more information, never hurt anybody.

Vanessa:

And so, speaking of personal stories, I know the Council has started doing some more intentional story collecting.

And so if someone wanted to tell their story, how would they go about doing that?

Isadora:

Yeah, I mean they. There's a number of different ways, right?

So, if you have a topic that you would, it's you think it might be worthy of a podcast, we can invite you on the show, and you can do a podcast, you just want to do a zoom recording and so we could put that on Youtube. We can do it that way.

Some people write their stories down, especially if, for example, a lot of what we do is monitor bills and legislation, and so, if there's a particular bill or a potential piece of legislation that it's gonna impact somebody in a significant way, we would want to collect their story and share it with policymakers and really share it with decision makers so that they have a full picture of what the consequences might be of law that they pass, and so that's another way that people can share their stories through testimony or through just, you know, and and again, we want to eliminate barriers. So, if someone can't write in English, or you know, doesn't use words to communicate like we will, we will work with you to get that story collected in some way, and then share it with decision makers so that your voice can be heard.

Vanessa:

So, speaking of the legislature. Can you talk a little bit about what the council's relationship is as far as the legislature and other policymakers?

Isadora:

Sure, I mean, we're we're in an interesting position because we're a state agency so we are not allowed to lobby also, because we receive Federal funds.

However, we do impact and influence decision makers through story collection and through sharing of member experiences.

So that's why it's so important to collect as many different types of stories from the disability community as we can.

Because you again you never know how your story is going to really impact somebody's decision.

And how they see the world, and and if you can get them to kind of see the world through your lens for even just a split second, sometimes it's enough to really make a huge change, a huge impact, and and how they vote, or how they speak with their colleagues about an issue, or how they, you know, really support other constituents around an issue, and so we build relationships with legislators, especially those who you know have a demonstrated interest in disability issues. And then you know others who maybe don't and need a little more information about why it's important to really understand the the needs of the disability community and how those needs can be supported through policy that's that's a big part of what we do. Right?

We we through our sharing of stories, we help people under this whole other community, that they may maybe didn't know about or didn't understand the significance of what some idea they had, how that's gonna impact their lived experience on the ground.

And so, yeah, our policy work is really, really important

Vanessa:

And policymakers aren't expected, you know, like the legislature has, you know, hundreds of bills that they have to, yeah, vote on. And they're not really, you can't expect them to know everything about everything.

So, it's important for people to be there to give them the information so that they can make better decisions for the whole community.

Isadora:

I mean, a lot of people don't even realize that that's how a lot of the bills even get written as somebody goes to their local legislator in the New Hampshire.

You know they could be your neighbor. They could look down the road, or you could meet them at the supermarket cause.

There's so many of them that they're so accessible.

And and typically someone will come to a state rep or senator and say, Hey, you know I have this issue, or I have this concern, or you know, what do you think about this? This is this is something that's important to me and my family, and I know it's important to other families, too.

Let me tell you about this problem, right? And then legislators, they're doing their job right.

They're responding to the needs of their constituents and the community by saying, Hey, you know I think I'm gonna take that idea or that issue and make a put in a bill that can help address that.

So that you know my constituents and people in my community no longer have this difference in access or this concern, or whatever the thing is right and and then that's how typically I'm bills get put in.

So, anyone can put in a bill. Any legislature can put it in a bill that's that's basically based on a conversation that they had with somebody who lives in their districts.

And so, it's important for people to know that and to know that like, that's their job is to listen to you and to really take into consideration what your needs are, and to think about ways that those needs can be addressed.

And and fortunately, you know, we also have. We have other states that we can look at and say, Oh, wow!

They're doing a really good job at this thing. Maybe we want to put in a bill that's like, gonna make New Hampshire do that thing, too.

So that was the case with supported decision making which passed last year, and that's an alternative to guardianship.

So that's an example of a bill that was really a great idea that other states were already doing.

And you know we got a legislator to put in a bill.

And and now it's a law. And and so anytime schools are talking about guardianship with parents, they're they're also responsible for telling them about

supported decision making as an alternative which really is more person-centered and it puts the individual in the driver seat rather than you know, stripping some rights away and having parents or guardians make all of the decisions for for them, they get to choose who their trusted supporters are that are going to help them make decisions for themselves

Vanessa:

And that bill is very exciting, very exciting, and so how is the council helping to move forward? I mean, cause you can, you can have the law, and then you have to live out the law.

Yeah, and so, how is the council a part of unfolding this new way of thinking about guardianship and thinking about people's lives of self-determination?

Isadora:

Yeah, so that is a really exciting part of what we are able to do.

So, when there's something big like that, I mean, this is the huge.

This is the game changer for our system, right, when there's something big like that.

I'm also that have like it's a best practice, right?

It's like I I I don't know if it's evidence-based, or what it or whatever.

But I think that like this is an ideal for how we would want to approach the the self-determination of individuals with lived experience of intellectual and developmental disabilities moving forward is to really have them be able to make the decision that they can with you know someone helping them understand the the pros and cons of something.

So, we were able to, because it's such a big deal we were able to put out an RFP, a request for proposals, to to really fund some education and training around this new law cuz this is a new law so, not only to parents and individuals and families need to learn more about it, but so do attorneys and judges who are granting guardianship or supported decision making and other organizations that are really responsible for in essence ensuring that an individual's rights are are are not being, and that so?

I, at any rate so we put out an RFP and we funded a training and education project that's being led by the Disability Rights Center of New Hampshire and

we're happy to see we just extended that because there's still a lot of work to be done.

But it's really been amazing to see kind of presentations around this topic. And then how people are really kind of, you know, taking note and and and doing something different, or thinking differently about how an individual can be supported to make decisions.

And I want, I want to say that a lot of the guardianship situations before this was a law were in essence supported decision making and that now we have, I know the legal way to change the guardianship to a way of supporting individuals that is really more person-centered and self-determined.

Vanessa:

Yeah, it's, it's like the next step after you know, New Hampshire, closed its institutions. You had to convince you, had to have a complete cultural shift yeah, you had to complete you had to convince people that this was a vision that can be a reality.

And then there's supported decision making, which is kind of the next step is being able to convince people that you don't have to have complete control over someone's life.

They, they are capable of making decisions.

So, what do you think if you had a magic wand, what would your next step in that cultural shift be?

Isadora:

Oh, so many things I mean, I think a lot of our a lot of our barriers come from just I I wanna say, like institutional barriers that just have been around forever like you were saying it, a cultural shift.

Not only does it take time, and it takes like really intentional, meaningful effort and resources.

And so my magic wand would be that we would have all of the resources that we would need to really make communities more accessible to to build affordable accessible housing and workforce housing for people with disabilities and the people that support them, to ensure that we have broadband access throughout the states so that people with disabilities can be connected to folks through Wi-fi and through cell phones and through zoom meetings and all of the things that in

this virtual world that we are living in and we take for granted having wifi access and and transportation right? If we had the resources to really develop and maintain and accessible transportation for people, then, like sky, is the limit. Right? Access is key.

And so when you can't get to work, cause you don't drive, and there's no bus, and there's no train, then you can't get to work right.

You can't work and that's a huge, huge barrier.

There's lots of people that wanna work, but they're aren't the supports and services or the resources available to really get them.

What they need to live the life that they want for themselves.

And so my magic, wand?. My wish list is that we would just have all the resources that people need, whatever they need.

That's what that's what I want.

Vanessa:

So, to wrap up. is there anything else that you want to add about the council?

Isadora:

Hey, I mean, I just wanna take this opportunity to like, you know give a call to action. I really, I really want people to get involved.

I want people to know that like your voice is important to us, that we really need you at the table.

We want to make sure that your needs are being met. But if we don't know what those needs are, then there's no way for us to even know what to ask for.

And so, I want people to to think about that, to think about getting involved.

And if it again, if it's not at the DD Council get involved with your local school support system, get involved with your local, you know, legislators, or get involved with different community groups that are involved in making parks more accessible or bringing more inclusive recreational opportunities to your area.

So, I wanna say that it's it's this is again, I think I said it at the beginning, but it's it's all of our responsibility to make more inclusive communities.

And and so we need to know what people need in order to make sure that we're building the best, most accessible communities for people with and without disabilities.

Vanessa:

Perfectly said.

Thank you for joining us today. I'm Vanessa Blais.

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.