

That's Inclusive!

Episode 18 Transcript

Episode title: Stop Special with the DD Partner Directors

Vanessa Blais (VB): 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?

Isadora

Hi everyone, and welcome to that's inclusive conversations with the New Hampshire Council on Developmental Disabilities. Today we're going to be talking with Stephanie Patrick from the Disability Rights Center in New Hampshire and Kelly Nye Lindemann from the Institute on Disability at U and H. And we're going to be talking about something called the Stop Special campaign. So first of all, I'm Isadora Rodriguez Legendre.

I work at the New Hampshire Council on Developmental Disabilities, and I'd love to do some brief interactive introductions with you ladies.

Stephanie

Great. Thank you so much for having me, Isadora. I'm so excited to be here. So, I'm Stephanie Patrick, the director of Disability Rights Center, New Hampshire, and we're New Hampshire's protection and advocacy agency. We provide legal advocacy for people with all kinds of disabilities across the state. And we're really excited to partner with you all for this special campaign.

Isadora

Great, Kelly.

Kelly

Hi, Isadore and Stephanie, this is Kelly. And again, I serve as the director of the Institute on Disability at the University of New Hampshire and the IOD. The Institute on Disability is New Hampshire's designated. You said our University Center for Excellence in developmental disabilities. And we work together with the DRC in the Council as the Developmental Disabilities Act partners here in New Hampshire.

And our role is unique because as a university center, we are really charged with conducting research and evaluation, community service dissemination and outreach and training and technical assistance and sort of all things related to disability policy and services. And so, we've been in existence at UNH since 1987.

Isadora

Wow. That's a long time. So together, our three DD partner network agencies work on a number of different collaboratives, work groups and projects. One of those projects is Stop Special. Would someone like to tell us a little bit about what that project is?

Kelly

Yeah, I will start us off here. So, Stop Special is a campaign that audience members will be able to see very soon if they're not already looking at it already. And this was an initiative that came, out of the idea of as we listened to our constituents, as DD act partners, we heard more and more people with disabilities and family members and allies talking about how certain words were very disrespectful, very triggering, very outdated.

And that term that we heard a lot and very consistently was the term special. And special is used as a euphemism a lot in our industry and in the work that we do. And as we really pause and sort of reflected, it was like this was a word that didn't feel respectful or representative or inclusive. And so, we came together with our

colleagues, some community members and each other to say, how do we actually contribute to changing the conversation and helping educate people both about the word special and just advancing inclusive language?

Isadora

Yeah. And we've talked a lot about how language is really important and how important it is for the community itself to determine what words, and terms are appropriate for describing them and themselves. And so, this seems to be a very grassroots driven, movement. Right? We're hoping a movement, to really, listen to what people have to say and use words that are not going to set them apart in some way or make them excluded in some way.

Do you have anything to add Stephanie?

Stephanie

Yeah, I think that's true. I mean, I think if we look back on the history of language, you know, it is always changing and shifting. So, language is not a static thing. The words that we're commonplace to be used when I was a kid are some of them we don't use anymore because people have clearly said, I don't want to use that.

And I think, you know most clearly about the R word and the use of the R word and how that's really changed in our culture now. And people understand that that is not a term that people with disabilities want, that anyone wants to use to describe people with disabilities. And I think this is just a new opportunity to look critically at the languages we use now and listen to people with disabilities about what they want and need.

Isadora

Great. So how do we hope to accomplish that?

Stephanie

Well, we're going to start out by starting a campaign. And that's why I'm glad we're able to highlight it today. We have a website that hopefully will be out by the time the podcast comes out. And what's that? Kelly.

Kelly

It's www.stopspecial.org.

Isadora

That's amazing.

Stephanie

Yeah. And so, we'll be asking people to actually pledge to stop using the word special whenever they can. We recognize I think that this is going to be a long-term long-term change. You know, disability rights. And in particular we recognize that special is used throughout the law. It's used to describe programs and systems and grants.

And it's going to we're going to really have to think critically about when we use it and when we don't. But make a concerted, direct effort not to use it unless we have to, and to call it out and say, this is not what people with disabilities once we don't want to use special education, we don't want to use special needs. We want to we want to use other terms that are more that people with disabilities want.

Isadora

Yeah, I think for me, I've definitely found myself getting and it's a habit. It's a practice. Right. Like anything else. just getting in the habit of instead of saying special education, saying something like educational supports and services for students with IEPs or students with disabilities. You know if it's if you're referring to people with disabilities don't use a euphemism.

They know they have a disability, and they want the respect and the dignity for you to recognize that they may just need a little bit of support to be able to do the same things that you and I do.

Kelly

I think I would add to that too, is a really central focus of this campaign, is also really educating people and creating space to have conversations because, as you both pointed out, so many of these words are embedded in everyday language of how we talk. They're in our laws, they're in our programmatic language. And so, it's really hard to extract.

And so, part of having a campaign like this is just getting people to have these individual conversations, these group conversations organizationally, and for people to also feel empowered to say other people have been thinking that this word doesn't fit, doesn't represent me for a long time. And sort of giving, giving space to have both opportunity and voice to share of like there's a different way.

And I think all of us agree that we don't have the perfect direct answer because there is not a one size fits all answer to this conversation, but that we as partners really want to take the opportunity to build conversation and community around the use of inclusive language.

Isadora

Yeah, one of the things I really love most about this campaign is that we are kind of stepping back and elevating the voices of people with disabilities. And on the website, there are different videos where you can hear from people with lived experience about what the word special or being called special has meant for them and to them, and how they really find it disempowering in a lot of ways.

And so that's one way that we really, we expect to hear from people with disabilities and have heard from people with disabilities about what this means to them. And it's not something we are doing for people because we think it's in their best interest. It's the community itself that's driving this.

Stephanie

Yeah. And I think that's really important. And I would just put a plug in that if people are listening and they're interested and they want to talk about this, either they're a video, they're really short and pretty easy to record or through just a statement and a picture or either of those. We would welcome more of that because we really we want to be the way for people with disabilities to speak their own words, make their own communications in whatever way works for them about how they feel about this.

Kelly

And I think the other piece that's both exciting at a local level here in the state of New Hampshire, but also even thinking broader is, you know, each one of us as partners has national associations and groups and colleagues that exist in every state and territory around the United States. Is that, well, this sort of birthed here in New Hampshire, are we? We were trying to create space to have these conversations and do this education and outreach that it isn't just about New Hampshire, like, this is actually bigger than all of us.

I think first and foremost, these are the communities we care about most in our own state. But we really want this, and we believe this to resonate with so many other places because we have colleagues and partners and people with disabilities nationwide that have been sharing this.

It's just sort of interesting that even at this day and age, there hasn't. We as a group have not found any other sort of collective action around this yet. And so, the fact that it's coming from New Hampshire and our community is, is exciting.

Isadora

So, what else is important to know about this initiative? I would ask the group here.

Kelly

I think one of the things that I think about a lot, and I think this is we've had conversations about this, we're going to have more conversations about this, is that this campaign is not about shaming people, making people feel bad, trying to rewrite history. We I think all of us recognize. And just as Stephanie mentioned, about the history of languages, that we're on this interesting continuum, you know, and that when we know better, we do better, and that there are still people and groups and organizations that are going to use and have special as part of their identity, it doesn't make them individually bad.

Or, again, we this campaign is not about that sort of public shame or repudiation. It really is about educating and calm and having conversation. So, I think that's one thing that I would really want to convey to our colleagues and partners and community members is to say we're trying to facilitate conversations, to move our language and our inclusion forward.

Stephanie

Yeah, I think that that's really that is very true and important. I think another thing that we're really looking for is for people to pledge not to pledge to be perfect, because I still say it and I catch myself and sometimes I don't even catch myself, but I still say it. But to pledge to be really thoughtful about using the word special and to try to make that difference and so there's also another thing on our website, will be an opportunity for individuals to pledge to make that difference and to help to spread the word about this to other places and organizations.

And so, we're really looking for people, organizations, groups, advocates to come and join us and say, I am want to make this commitment to be able to make this change. And I'm willing to take that pledge and then to say, stay with us, with you as we send email alerts. And we have social media planned out as we try to make this happen over the course of the next five years, ten years, the R-word has been around for a long time.

It was a long time before it really got to be part of the regular day vernacular, but it did. And we're I'm really excited and confident that we'll get there too.

Isadora

Yeah, I love that. I think it's so important to recognize that change happens really slowly. Right. And that it's one person's experience. One person's story sometimes is that catalyst to really starting people talking about things and then taking action around something. And so, we are also interested in having other groups and organizations take action around this and really become part of that conversation and part of that what I would refer to as, that gentle nudge in the direction of listening to people with disabilities about what they want and what they want and see language that to be that's supportive and also that recognizes their value, their dignity, and their strengths.

Kelly

And I think the tricky thing about that, and what I would add to that, is that just as we're on this sort of long historical trajectory about language, there's also this continuum about how people want or can use the campaign. You know, you use that you phrase that is a door, the gentle nudge. I think there are many of our colleagues, people with lived experience, our friends, our communities, they're like, no, we don't need a gentle nudge.

We need a hard push to be like, this should change. You know, this is how I want to be referred to reference. This is this is the way I'm using words and language, and I want you to do the same. Yeah. and so I think it's sort of a booth and, and I think again, it's a the our, our community has is very diverse and broad, but our, our goal and our hope and kind of design of this is also not only meeting people where they're at, but then again creating some tools and opportunities so you can do the gentle nudge or you can do the hard like, hey, we're going this way now.

And we recognize, I think there's going to be lots of different people's group groups and communities that are going to be in different places, but it's kind of designed in a way of like wherever you're at right now, we'll meet you there.

Isadora

Yeah. And I definitely think that in in my experience, certainly there have been individuals that that don't see an issue with that word. And it's important to recognize that for those individuals that maybe this movement doesn't resonate. I think it, it would be important to say to those folks that there are people for whom this word really, is disempowering and really, kind of works to continue segregation and social isolation in a way that not everyone with a disability is going to experience.

Right. And so, a lot of the folks that, we work with have intellectual or developmental disabilities and, and they have seen how this word is used, like, almost like a good buddy or, way to go, champ. Right? And, and really kind of to belittle and, infantilized people with disabilities in a way that we know today is not appropriate because adults are adults, and they are capable of making their own choices and living their own life and following their own dreams and goals.

They just need the supports to be able to do that.

Stephanie

But everybody needs a set of supports. That's the thing. It's not like I didn't need those supports when I turned 18 and I had no idea how to, you know, wash my clothes or like, keep change the oil in my car or even where to go to have someone do that. Like everyone needs supports in different parts of their lives and making people with disabilities feel different because of that is not helpful to them or to anyone.

Kelly

I think the other thing too, that I think about as we're having this conversation here too, is that sometimes with things that we want to see changed, whether it's about policy or practices or experiences, is that one of the things we have the most control over is the words that we use. and yet it can be one of the most powerful things, because the words that we use, impact of how we think, the impact how we feel, they impact our decisions, they impact the other people around us.

And so again, it I hope we hope that people also walk away from this feeling empowered in the sense of that we this is something we can do something about at a very individual level, and that we can do something about it at broader levels too. But it often starts with who we are and how we use language as people.

Stephanie

You know, the other thing that I think has been interesting is that some people haven't really had an opportunity to think about this, as we've been talking about this with some advocates to say, what do you think? Do you want to be a part of this? Do you want to help us with our videos and testimonials? I think that some I've heard from some people I don't I don't know really.

And that's okay too, right? This is an opportunity for you to think about it and decide what you think. And if you want to support something like this or you don't, it's those are all okay. Choices are fine choices for anyone to make. but we do want to encourage people to be thinking about it.

Isadora

Yeah, that's a great point that there's not really, one size fits all or a right answer. Get on board or get off the train. We're really interested in just moving the conversation along and having people think about something that maybe they haven't really had an opportunity, to do before and figure out what works for them.

Kelly

I think a little bit about, you know, we were talking earlier about how deeply the word special is embedded in our in the work that we do in the communities that we, we operate in. I also think about the use of the term as an identity for groups of professionals. So, when we think about again, I'm going to use the term special educators.

They, they have worked in a career in an industry, you know, dedicated and focused on improving the life and the quality of educational services for students with disabilities like that is very professional, honorable, noble, and an essential ingredient in community and society. And so, I think two this challenges the way that we think about that.

And as I was talking about earlier of not wanting to, you know, create divisiveness, bias or cancel culture or things like that, but recognizing that there are groups of professionals that have that also embedded in our title. But this conversation is for them to and again, a handful of the folks that we've continued to kind of talk and, and, and shop these ideas with also say that they as an industry and as, as educators, as educators, you know, are thinking about these things too.

I think that'll be an interesting thing to watch as that also sort of moves forward in the next three, five, ten, 15 years. Because even if we think about the kind of journey with the R word, the last thing to change was the federal legislation with Rosa's law. You know, we had made decisions as individuals, community and society well before, you know, the federal government and legislation, you know, caught up to that.

And so we I do I think many of us do hope that a similar trajectory will happen with the use of this word, too, recognizing that it's a long game, it's deeply embedded, but that there are things that we can do as individual members, professionals, you know, to again, think critically about how that is representative of us today or no longer representative of us today.

Isadora

Yeah, sometimes. Sometimes it's those professionals, right. That can be the strongest allies to in helping move legislation and policy. And, you know, when I think about educational policy, or even civil rights policy that uses euphemism names or words that are intentionally portraying people as different, less than needing help or support, to be able to essentially justify services or funding or things like that.

It really does sometimes become those folks who are most in, in those leadership roles, in those decision-making positions that are able to be the catalyst, be the impact on that change. And so hopefully we can we can get some people to really understand, how, you know, the Stop Special campaign really aligns with, the vision of the world we want to see.

Stephanie

Right? I mean, I think it's important to that changing how you describe yourself, if you're a special educator or a special needs parent, doesn't mean that you're not valuable or that your contributions are not important and you're not doing really good work, it doesn't mean to undermine that at all. I think sometimes when people think about how they how they describe themselves, it's hard to think about changing that because it's been part of a narrative for a very long time.

But it doesn't. I just want people to recognize that. It doesn't mean that your work isn't good, that your thing isn't invaluable, or that you were making bad choices before. This means that now we've learned some lessons about how we're going to do things moving forward, and we hope that people will be able to join us, to be able to really say, I've done this for a long time. I recognize that this is not what I want the future to be for my for myself or my profession, for the people that I'm working with.

Isadora

Yeah. And then take action, right? Either sign the sign, the pledge or, you know, talk to other people in your fields or in your family or in your community about, this topic and, and just have those conversations and, you know, encourage people to tell their stories. We talk about how advocacy is really the harnessing of people's stories to be able to impact change and be and be, influencing how people see things that don't personally impact their lives.

Kelly

And I think one of the great things kind of, again, circle coming full circle to, to our different roles as part of the network that is really kind of at the heart of what we try to do is, is blend education, advocacy together for the most powerful, impactful messages that sometimes stories are the most important and most important.

Sometimes education or data is the most important. But when you can find a topic, an issue where you really can pull those things together, that can that can lead to some of the greatest change. And again, I think we're talking a lot here about the hope of sort of what comes next with this campaign. And I think it I think it really remains to be seen, because part of this is sort of reflecting back to the communities that we're a part of to say, where's it going to go next?

Like we've used some of our expertise and resources to create a sort of a framework based on the lived experience feedback that we've received. But where it goes next is, is kind of up to all of the rest of us.

Isadora

Right. And kind of putting it back in the hands of the people the most impacted. Right. And those voices, those disability voices that have something to say about this.

Stephanie

So maybe we want to remind people of the website

Kelly

Because that's the where we people should go read stopspecial.org. That's where you can go and read some stories, get a little bit more background, take the pledge. There's some additional language resources on there as well. and again, we hope to continue to build out the website, some social media presence. and we really want to also welcome and encourage other people to applied in the ways that's most meaningful to them.

So again, yes, we created in New Hampshire. Yes, we're the DD act partners, but it doesn't preclude anybody from another state, another community, another organization, another person someplace else in the country or the world that says this. I want to carry this message forward. I want to put this on my media. I want to embed this in my newsletter, tell my story.

That's what we want to happen is to sort of say, yes, take it into the universe and make it have impact in meaning for you.

Isadora

Yeah. That's great. So, thank you, ladies for coming. talk to talking with us on our podcast. we hope you check out the website and, keep listening.

Stephanie

Do you want to, like, spell out the website, you know, for accessibility? You might want to like insert that in somewhere.

Yeah. Yeah. So, it's stock special.org.

Kelly

S t o p s p e c i a l . o r g .

Isadora

Great. Thank you. And that'll be available in the transcript as well. So, check it out and thanks for joining us today.

Kelly

Thanks so much. This was enjoyable.

Vanessa Blais (VB): Thank you for joining us today. I'm Vanessa Blais and 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.