

# Podcast Episode 4 Transcript

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?

Hey everybody, this is Vanessa Blais. I serve as the director of policy and planning at the NH Council on Developmental Disabilities. And I am here today with two guests, Patricia Vincent-Piet, who is our DD council member and also a fellow podcaster and her daughter, Katelin Garland. She is an investigator for the public defender's office.

And they're here today to talk about Katelin's experience growing up with 2 parents who experience disabilities.

Hey, Katelin!

Hey, Mom!

Hey, Hey, Hey! So, well I guess we will get right into it. I was just going to ask generally what was it like growing up with parents with disabilities, but I thought well that's a little too general.

That's a lot to say in that. Yeah.

So, we will start with what was some of the, while you were growing up, were some misconceptions people had about you because you had parents with disabilities?

Yeah, a lot of, my main one was why don't you also have a disability? That was the main misconception. Everyone thought that oh, physical, they didn't understand the difference between physical disability and one that could be passed along through genetics or ones that were you know, you know, not that. I think that that was the general misconception. So I was often explaining no, ya know, it's not anything that I was born with or that not worked out that way. And it was fine. I don't mind explaining its like people see people that are different then them and they get curious, and want to know why they experience life the

way they do, and I don't mind explaining. I think it's helpful in the grand scheme of things.

You don't now, but I remember as a kid you did find it a little tedious.

Yeah, because I was asked all the time. And like constantly having to explain yourself as a kid is kind of annoying.

Yeah, Yeah. I know the feeling.

It's way worse for you and dad, probably, because it is just a constant issue that you deal with, but...

Yeah, I don't know. I don't know if it was worse but...so what has your experience been with people who use terms that demean Dad and me.

Yeah, that was harder because that was not a general curiosity anymore. That was people being malicious on purpose. Or, that I definitely struggled with that a lot. I think I told you this story but when I was younger. I can't remember what grade; I was definitely in middle school. I was definitely in Manchester at the time. We were living in Manchester. And this kid in my class, he used the C word to describe his injury he had recently had, he's like...

I'll just verify, she means crippled, for people who don't know. We are trying not to use the word, but I want to make sure people know. What you are referring to.

Yeah, yeah, and the R word was thrown around a lot as well. But, I feel in that situation specifically he was referencing to an injury that he had gotten and he said that in front of the entire class. And this is a memory that I have so it's kind of like a vague memory, I can't remember everything but, I do remember standing up to him and saying you shouldn't say that. My dad's in a wheelchair and you are not experiencing that and I explained that it was a; I am sure that I did not explain it well because I was only like 11, or I, I was young at the time. But, the teacher, I remember what made it worse was the teacher was like oh, he's not talking about your dad. And like trying to almost justify the child's actions, which was really weird. So, I think that like watching an adult like that made it even worse. And like, shutting it down and making me feel like I was the one that was in the wrong in that situation was bad. So, after that it kind of got more difficult for me to confront people on situations. I think that's, that's, kind of like the

starting point because before then I was very vocal about when people would use derogatory language against people with disabilities. I would often speak out and and be like you shouldn't say that that's not or often even if it wasn't meant to be at someone with a disability, if they were just saying it because people often use the R word all the time, I feel like still even though its obviously not a word that should be used. But as I got older it became harder to confront people about it. I think it had a lot to do with that particular situation being shut down by someone who I feel like in that situation should have used it as a teaching moment, you know what I mean.

Someone in authority that you thought had your back and didn't.

Right.

So, like as an adult now, like, we've moved into a place where we talk about ableism. We talk about those things. We have a little bit better language around that. Do you think that is what makes it easier for people to be able to be more outspoken about it? Because people can actually name what they are doing?

I think so. I think also when the R word kind of like left, it was no longer used as a medical term, and people really started advocating for the fact that it should not be used in a derogatory way or just in general it shouldn't be used because it is seen as a derogatory word. Yeah, I think that impacted it a lot. I think that having the language to tell people why and explain hey this is why you shouldn't say this. And but doing it in like a respectful way and saying hey I know that your intentions weren't to, you know. It's like the same when people are swearing or using any other sort of word that can be seen as derogatory if it upsets someone just, just don't use it, obviously. But, yeah, I think that explaining and having the language to use is definitely helpful. As you get older, because as a kid, I definitely didn't have those tools, for sure.

Well, I don't think anybody did.

And when you were young, I don't think if you used the word ableism, I don't think anyone would know what you are talking about.

Right.

Ableism was not understood, really.

Yeah. I don't even think disability was commonly used. I think handicapped was still.

When you were a kid?

Maybe?

People still use that word.

Yeah, but I think it was not as commonly used as it is now. From my memory, but.

Yeah, things change. So when you were growing up is there anything you felt like you missed out on because you had parents. Because I can think of lots of things that I thought that you missed out on .

Really? I guess I just don't look at it that way. I don't think about it in retrospect a lot. I just, I did have time to reflect on it recently when I had there was a trend going around on Tik Tok a while ago. I made a whole Facebook post about it because I was very upset. And I talked about my entire history basically like growing up with both you and dad. And in that post I said I didn't see, I just saw that I had parents. I didn't really ever think of you as different. I knew obviously that you had disabilities and that was apparent, it just didn't feel like I was lacking something because of that. If that makes sense. And I was able to do a lot of things that everykid, like, I went to school. I went to public school. I went to Concord High School. And I also did theater, which is like, I didn't do, I did sports like vaguely. But, I just didn't personally like them.

She tried one year, and you were like, no, not for me.

Not for me, yeah, I tried track and then soccer and soccer was all right. I thought you know, you were both were very supportive. I was able to make decisions about what I wanted to do when it came to extracurricular. When it came to, I had normal friendships like Jenna. And my friends never really like, I know Jenna asked I think when we first started as friends what was the situation? But after that it was never brought up again and she treated you guys the same exact way she treats her own parents; I feel. She's basically like my sister so, and I think that she is also more aware of the way people with disabilities are treated because if that, so yeah. I don't know. Yeah, I don't think I've lacked anything for sure.

Well, that's nice to hear because as a parent with a disability when you watch what other people can do for their kids. Like when it was time for you to learn how to ride a bike, I can't ride a bike. I can't show you how to ride a bike. So like going on vacation. We couldn't really do that because it really was...so it's nice to hear that you remember it better than I do. And maybe it's because I was an adult so I was aware, maybe?

Yeah, and I feel like we had a lot of support, like familial support from other people in the family. So, I don't think that. Like, I went on vacations with Grammy and Grampy. I mean I went to Disney that one time with my cousins. And I think I went on other smaller vacations here and there with like friends and stuff. And you know, but personally even now as an adult I don't find vacations to be like, I like traveling. I like the thought of it, but it's so exhausting when you're doing it. Like when we went to Universal last February. That was really fun. But I was so tired, and it was not even because of you and dad at all. Because you and Dad were doing your own thing, basically. It's just that Brandon and I were walking around a ton, and I was exhausted. So, when you're on vacations, it's almost like yes, it's a fun experience, but sometimes it doesn't really feel like a vacation.

You know what I mean. I am much more of a homebody.

You need a vacation after your vacation?

Exactly. That's why I always take a few extra days after.

And sometimes it's like the memory is more meaningful than the actual time.

Speak for yourselves. I happen to love vacation.

I know, you and your traveling.

Not to say that I don't enjoy time off from work. Because I definitely do. Traveling can become, when you have to plan everything, you know. You have to decide where to go.

She's an ace. I mean this woman. That's part of the reason I have the traveling bug is because of her stories. So many cool stories.

I want to ask you when you talk about your friendships, did you ever see or experience any of your friend's parents reacting to the fact that both of your parents have disabilities?

That's a good question. I don't think so. I am trying to remember what parents met my parents. Out of my friends. I know Jenna's has and Ann and Greg are great. I don't think they ever really, Ann is also a nurse, so, her background may have like she doesn't really find that, a family nurse too. I think that she worked for a family doctor. Not like, I know hospitals and stuff that can be a little grey when it comes to, because I know you haven't had the best experiences with hospitals, necessarily when it comes to Dad's care.

Yeah, they have no idea.

Yeah, but, I, yeah, I am trying to think of any other. Yeah, when they would come, when you and dad would come to see shows. Like when I was doing theater. I feel like maybe we got the odd look now and then, but I don't think it was, no one would have the guts I feel to come up and directly address us and be like, you know, asking me questions about my family. When I, it's mainly the kids, I feel like, because they're generally curious and its never with like, malicious intent was always how I saw it as a kid. Well now in retrospect I am sure that when I was a kid, I was irritated by it. But, yeah, I, yeah, the parents were always respectful.

When you were a kid at the theater, I remember like some of the parents, some of the parents were just a cliky as their children were, so I would end up sitting all by myself. But I don't think that had anything to do with me having a disability. It they were just.

That was kind of the theater culture.

The theater culture is very high school-ish, at least it was at that time.

And also, the theater that I was involved with was like you are going to go professional, you what I mean. That kind of like. Not competitive. It was pretty competitive. But now, it's a lot more like, now that I do community-based theater, I enjoy it a lot more. I think it's definitely more about the community and like building a community together versus...

Yeah, like you're not all in competition for...

Exactly.

We all lift each other up. It's been a lot more of a positive experience. Now that I am not doing theatre, as like, or pursuing theatre as a career.

Can you think of any way that having parents with disabilities, do you think, sorry the question, can you think of any way that it has benefitted you.

Benefitted me? That's a good question.

Yeah, I was thinking that it made you, it made you a lot more open minded. Like, you wouldn't jump to conclusions about people.

Yeah. I was definitely more aware of the fact that there are communities of people that look and sound different from me. I think that I wasn't quick to judge people with disabilities, too. I never assumed someone's disability, or I never assumed that they, um, oh, they must have a physical disability or a cognitive disability, you know what I mean. I never automatically assumed that about people with disabilities. I guess that also plays into just your everyday kind of life. Like when it comes to just anyone who doesn't look like you. Not making any assumptions. Being genuinely curious about people's backgrounds and where they come from. Because I know that coming from a specific background, I kind of, I think I talked to you about his too. I kind of relate myself to CODA kids a little bit. Not that I would say that we are anything alike really. But you know they grew up with two parents who are deaf and have that sort of background and that sort of understanding of their own community. I feel like I have that kind of with a with your community and growing up in that for sure.

Because you had a lot of exposure to the disability community in general.

From a very young age, yeah.

You would hang out a GSIL with me and all sorts of things. And I'm thinking that in your current line of work, you aren't inclined to judge people.

Oh, for sure, especial in my current job for sure. I think, now that you say that I am very big on, yeah we have had DEI trainings at work and things of that nature and it was always important for me to go to them and make sure that I kept up to date with certain terms and what was being used in any sort of community. And you know, being an investigator for the public defenders, seeing the

disproportioned effect, seeing the way the justice system disproportionately effects people who do not have a lot of money, who are indigent. That's part of our job essentially. You definitely have to have a more open mind for that kind of work, and I am of the mind that everyone deserves representation. So that is why I do what I do. Sometimes people are sometimes judgmental of that, but everyone has their own opinions on that. That is definitely a whole other topic of.

How has the lack of paid caregivers in the state affected our family, do you think?

Oh, God, greatly. Well, this has been an issue since I was a kid, I feel like. I mean Tracey, we had Tracey for a long time luckily, who was a caregiver with my dad for a while. And that was great because she knew Dad really well and she knew like what he needs, and it was almost like getting into that routine was easy because she already knew what to do. Every time you have to hire a new person, they have to learn the routine, they have to get into it, they have to you know, be comfortable with everything and it's a lot to teach someone over and over and over again. Especially with such high turnover that you are experiencing, and I see. It also affected us recently because you are Dad's primary caregiver essentially at the moment especially when it comes to aides' and what not. And when you broke your wrist, you couldn't help him get up anymore, so I had to like to come for a few weeks and help you out with that, which was totally fine. And I knew that the day would come, you know, what I mean. Because I know that the state unfortunately does not pay people enough to keep people in those jobs. And even if you are with a different program that's not through the state, and they pay people a little more, but they don't have great benefits.

It is through the state. It is the same funding stream it is just a different middleman. So, they don't provide the same supports, but they can pay people more but.

They don't have health insurance. Is that a thing?

No. None of them do. With these guys I have to find the people myself. Do all the advertising myself.

Right and just even not having any health insurance for any of them is so like, you are never going to keep someone long term in those positions.

We could have a podcast just on that topic.



No, I...

For sure. I want to ask you because you said I knew that day would come, or I knew that time would come. So, can you like expand on that a little bit? In the past there was an awareness that there was a time when you were going to have to be part of the caretaking.

Yeah, I didn't think about it as much when I was a kid. It definitely was a more recent...I remember when Dad had his first heart attack. I think that was when I like kind of, I knew that you know Tracey was not going to be around forever. And then I knew that so with the difficulties that they face in hiring caregiver or aides, I just knew that I was probably going to have to step up and help. And it never really bothered me because I just knew that it was something that they might need, and I didn't want them to feel like it was a burden ever because I don't know. There is a lot of stigmatism. That's not the right word. A lot of stigma around. Sorry, I misspeak so often, so I am going to use the wrong word.

Join my club.

There's a lot of stigma around caring for the elderly I feel and add people with disabilities on top of that I think it just becomes a whole wild concept to America for some reason because we really don't care for our elderly as well as like other countries do for example. But I want to be there for my parents because I knew from a young age that that would probably have to be the case and it never, it never negatively impacted me. I think it will only like bring us closer as we get older. If that makes sense.

And so, like I believe you have a partner.

Yes.

And so, I am curious. Have you had conversations with your partner about you know, as my parents age that they're probably going to need more care. Is that ever a conversation that goes on between you?

It is. Well, yeah, you know, when you want to potentially marry someone you always have to discuss those sorts of things.

But he's very supportive of me taking care of my parents. That's what I if I want to do or need to do. Nursing homes are not. They're just not what I would like for

my parents, you know what I mean? Like I know that that may have to potentially have to be a part of the conversation in the way, way future. I think that I would prefer to help as much as I can, personally. And when it comes to Brandon, you know his parents have a very different outlook on that sort of idea of ending up in a nursing home and all that. And I won't share their opinions here, but we definitely do have some sort of differentiations, but he also has two brothers. And I'm an only child. So, we definitely grew up in very different families and very different backgrounds. So, it's interesting to see how those affect our conversations about how we approach things as our parents get older and what we are going to do. But, yeah, I, he's very respectful and knows that I am going to do what I want either way.

Well, that's a good step.

I am pretty stubborn. But we compromise on a lot of things but that was one thing I won't compromise on for sure.

That's good.

It really is.

So, you have answered my next questions. Some have suggested. Some have suggested.

Some have.

That an answer to the caregiver crisis is to create more congregate housing. Where people, and you know what I mean by congregate housing?

That's basically putting people in assisted living essentially, right?

Not necessarily. It could be like remember where Dad lived when we met him?

Yes, yes.

That would be considered congregate housing. Or it can be like a group home.

Right.

Anytime that you have just people with disabilities living in a certain space. Some have suggested creating, and I think this person had in mind like group homes

more that that would be a good solution for the caregiver crisis. Do you have any thoughts on that?

That's such a weird take. Let's put everyone together so its more convenient for me, is how it reads. Versus like, it just doesn't make any sense to me. It's just taking away people's independence to live on their own and like set their own paths. Like, you're basically forcing people into a living situation that they may not want for the convenience of care and that just, I don't know. That just sounds like a really bad take.

And say Dad would be like living in a group home. I mean what are the odds that we would have met him. And like how do you get married and have a family if you are living, even where he lived before.

The one-bedroom apartment basically.

We couldn't have moved in with him.

No, we couldn't have, yeah.

And so, we were just fortunate enough that we both had the income that we could find another, and it was a brand new apartment building. And we had to move into a really expensive apartment.

I remember it was a nice apartment, but.

It was brand new. But to, only buildings build since 19...I don't even think it was even 90 because 90 was when the ADA passed. So, it was like 91. Had to have accessible units.

Right.

And there are just not a lot of buildings like that, so.

So, it's almost like you have to have money in order to live an independent lifestyle, which is crazy. Our capitalist society for you unfortunately.

Oh, boy another conversation we can have.

Yeah, another conversation we can have.

There're so many things that we can branch off here.

But it is interesting to think about that about that you send if Jim were living in a group home, you guys wouldn't be a family.

No, right.

And so that is such a real-world view that people really need to understand. That people who have disabilities and experience disabilities have a right to have a family and be a family.

Exactly, yeah.

And that's kind of something that I think needs to be pushed into the narrative when people are talking about the benefits of group homes or the benefits of segregated housing. Especially for parents who have younger children who are becoming adults and they are afraid for them; you know that's one of the things behind them leaning towards congregate settings because they'll be safe there. They'll be taken care of. But, I think it's really important to push that narrative of well don't you want your son or daughter to, you know, be able to experience having a family, and falling in love and doing all of the wonderful things that we able-bodied people don't even think about.

Yeah, because once you are in those situations, you really don't tend to get out. People, there aren't many people living in group homes and then move to a less segregated setting. It's pretty rare.

Yeah, it's very difficult to reverse that situation. I mean I remember too when I don't know if you ever read the article that I wrote on your mom and Jim. About how the met.

Yes, I did.

And they were getting married. It was a few years ago.

I think I remember it was at my office! Yes, it goes to the public defenders. This was before I became an investigator, and I was handing out the mail. And it came in the mail. And I put it in all of the attorney's boxes and I was like, it's my mom and dad!

That's so awesome! That's so great! But I remember someone had read it and they have two very young children who both experience disability. And they said

to me how meaningful it was to read about people with disability who went on and you know, she said sometimes I wonder what, what's their life going to be like? And she said being able to hear about people who fell in love and got married and had a family, she said it just gave me a lot of hope and made me see their future in a different way. So, I think it's important to kind of keep that conversation going with people who rightfully fear for, you know, their children and what their future holds.

Yeah, I definitely agree. I feel like that's why becoming more involved in the community definitely helps because you can get all sorts of different perspectives and how it can work out for anyone.

Yeah, and your perspective is really valuable.

Yours's too.

Oh, thank you.

Do you have any advice for people with disabilities who might be thinking about having children?

Oh, my God, do it. If you want to have a child, you should. I don't think anyone should be limited to...I know even right now the financial state of the world is pretty bad, so I understand that there's a lot to consider when you are having a kid. But I feel like everyone should have the right to have children, no matter what they experience. In any way, shape, or form.

So, what you are saying is we didn't mess you up too badly.

No, no, you didn't. You really didn't. I think I turned out pretty good, mom.

That was loud.

Oops.

Yeah, mean I'm biased, so.

I think every parent worries about how much they'll mess up their children.

Oh, yeah, that's not exclusionary. Exclusionary is not a word, but then again, I am misspeaking, is not exclusive to any sort of community. I feel like everyone

worries about that for sure. Me, contemplating having kids, you know is a part of that too.

Right, especially since you are at that age. Not having kids, but where a lot of people around you are having...

Yeah, and are dead set on having children, too. I am like, how can you, how could you, I don't know. I have always been back and forth, like, I do really love kids. I think it would be great and then I am like so much money and time. It's definitely worth it. I can see that it's worth it. It is just going to take longer for me. I am so decisive as a person in general.

Once it happens, it happens.

I know, there's no going back from there, for sure.

You get real decisive, real quick.

Yeah, right.

Just to wrap things up, is there anything that you'd like to add? I like to give people a little bit of time at the end, just to say anything that they feel like they wanted to have a chance to say.

Yeah, I mean thank you for having me. It's been really fun. I don't get to talk about this a lot. I feel like it's kind of part of who I am. And it's so hard to put into words to describe my experiences and when it's just the way I have lived my whole life. So, I apologize if anything was not really eloquent because it's me kind of... I mean my mom did send me the questions beforehand, but I didn't want to prepare anything to written because I wanted it to come from the heart, if you will. But I appreciate you highlighting people who have different experiences. And it's definitely valuable to people who are like me or who have family members with disabilities and understand that it's just, you know, it's just another way of living. Another way of growing up and experiencing life. So, thank you so much for having me.

Yeah, it was so great having you.

Thank you for coming. It was great Katelin.

It's definitely a perspective that a lot of people don't get to hear about. There's a lot of conversation around what it's like to be a parent with a child with a disability. But we don't really get to hear a lot about being a child of parents with a disability. We really appreciate you coming.

Yeah, I don't know if I've ever, I know people have written about it because I have been asked a few times in the past, but I don't think I've ever seen someone well, I am sure it's happened. I am definitely not the first. But thank you so much, I appreciate it.

Do you have anything you want to say?

I just want you to let you know how much I appreciate you coming in, Katelin. And thank you for helping out, Vanessa. It's been great. I even learned some new things that I haven't thought about before, so it's been cool.

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.