

That's Inclusive!

Episode 15 Transcript

Episode title: Advocacy Through Media

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?

VB: Hi everyone and welcome back to That's Inclusive! And today we have a very exciting episode. Today we are talking to Pat Piet, our fellow podcast host and producer. And we're going to be talking about her experience of advocating through her different media channels. Pat, would you like to introduce yourself?

PP: Sure, and anyone who's listened knows who I am. I'm a council member and an advocate. I run a YouTube channel with my husband, Jim Piet, focusing on ableism and inclusion. I've written some articles and recently spoke at the Winter Awards Ceremony which was a lot more fun than I anticipated!

VB: You looked like you were having fun. And I think other people were having fun listening to you.

PP: Once I got going I was ok. But like, the night before, I had this moment of, oh man, what did I agree to. It went really good sharing stories. It's a lot of fun to share your own story. It's a lot of fun to hear other people's stories.

VB: So, that's one of the things that I wanted to talk to you about was the way that you've been using different media channels to share your story and your Jim, your husband's story, and the story of your family. I was interested in the project you were doing at the Caregivers Conference, where you were recording other people telling their stories. Can you talk a little bit about that?

PP: Yah, that was great. I had people come into a room. I had my video equipment and I just asked them to tell me about caregiving. Tell me really anything they wanted to share about caregiving. Right, about caregiving itself or if they wanted to share a specific story they think got to the heart of the importance of caregiving. The importance of family caregiving. Especially since we don't tend to value family caregivers. And so hearing people's stories about, especially, caring for a spouse since they've gotten older and dealing with those changes – how do you do that. People just have the funniest stories. One woman was telling me about the first time her husband failed to recognize her. And how meaningful that story was. And how it affected her emotionally and how she learned to navigate being married to someone who was different.

VB: I remember I was at the DD Council table and we were telling people about the project you were doing and inviting them to be part of it and signing up for people to go ahead and tell their stories to you. And there was one person who was kind of like – I don't really know if I have a story to tell—and then within twenty seconds was telling me a story and I was like, I'm pretty sure you have a story, you should go and tell it. And you could tell the recognition in her eyes, that she was like, oh yah, maybe I do have something to say that people might want to hear. And that's obviously the power of storytelling. You never know who's out there that is going to be impacted by what you have to say. I think we're starting to really recognize what storytelling can do for advocacy and the way that there are so many different media channels that we can use now to get our stories out there. And how people can access this information and these experiences through these media channels especially the power of YouTube. I'm just always amazed at what you can find on YouTube and just how easy it is for someone to upload anything they want to say. So I want to hear from you about how you started your YouTube channel. What motivated you to do that and how did you feel about first putting your content out there?

PP: So, what motivated me was I didn't see a lot of content in the local NH media that really told any positive story. There were people using images of people with disabilities. There were people who didn't have disabilities who were putting stories about disabilities out there without having any concept of disability. Specifically, disability as a culture. Absolutely no understanding when you're

putting someone with a disability in the public eye, it's not just that individual. That individual represents an entire culture of people and you have to be very cautious about how – If you're telling your own story, you tell your own story the way you want to tell your own story. But when you're telling someone else's story or helping them to tell their own story, you need to be very cautious and you need to be aware of 60 or 70 years worth of history of the disability rights movement. The few stories that we were being told, were being told without any context. And so I wanted to give disability stories context especially locally in New Hampshire. There are several disabled YouTubers, but I had to go look for them. I had to put in like top ten disabled YouTubers and find out who they were Because you don't--

VB: It's not like it falls in your algorithm like other things do.

PP: I thought maybe if Jim and I started doing YouTube videos, local New Hampshire people would watch if they watched our videos then these our videos would start coming in that algorithm. I'm still trying to figure out how that all works.

VB: That's a great strategy that if people only look it up once, then it highlights a lot of other content.

PP: I do try to connect to other YouTube videos about disabilities, whose content I really like so that people here in New Hampshire will find out about them. So just telling the story about disability in New Hampshire from the perspective of a person with a disability and not just to each other. Trying to make it accessible to more than just the disability community in New Hampshire.

VB: One of the things I really like about your YouTube channel, is that it's you and Jim, out in the community, doing fun things. There's one that I watched where you were on the Marginal Way in Ogunquit, which is a place that I really love. Or like you're just out in the community enjoying recreation and it's just about how easy it is for you to find places to that you can do the things that other people are doing without it being a special event. It's a day of recreation for Jim and Pat.

PP: One thing I'm always keenly aware of is that oftentimes were the only people with disabilities in a given space. And I'm not sure why that I know that the regions are far reaching and complex. A lot of it is not getting the support needed to get out there. But I also wonder if it's just not knowing what's available. Or a lot of people would not be able to see themselves doing it. So if you see someone like you doing it, OK, maybe that would work for me.

VB: Yah, I can see that. I can see like having a vision is a lot about the spaces that you think you can access and not access.

PP: I'm fortunate in that Jim says let's just try to go do it! And I'm like -What if this happens, what if that happens? If worse comes to worse we'll just end up in a fast food joint. We go to all sorts of restaurants. We also have had quite a bit of luck too.

VB: Like I bumped into you at the Mt. Washington Hotel.

PP: That was so funny. That was a gorgeous day. Like I said we were the only people with disabilities there. Certain places we go there are more people with disabilities, but I feel we stand out like sore thumbs. But that's not the reason why. People can look at us anyway. Walking around with a camera with me because--

VB: It's not like you're attracting more attention than you would otherwise. One of the other things you do a lot of advocating for through media is the discussion around inspiration porn and ableism. I want to hear about how you've been using your talents to bring more awareness to those things.

PP: I wrote one article that I'm sure some people are aware of criticizing some famous New Hampshire people and it got a lot of attention. It's funny, I had a few people tell me how brave it was and I said I was just pissed off. I think for me, I was just so tired of every time something came on the television, Jim and I would grunt and groan and throw things at the television until finally, you know what? I'm going to grunt and groan at the entire state. It ended up all over the internet. My daughter found out about it from someone I don't even know who found out about it from a person who worked with them. I found out that a lot of people

feel the same way I do. It's not just within our community. It ended up being getting a lot of attention. I think that's what frustrates me a lot in New Hampshire. We have our little circles and we talk to our circles. And I get that it's hard to talk to someone who might not understand where you're coming from. And I get that it's hard to put something out there that might be considered really controversial. But things don't change unless you do—I wanted people to know that not all people with disabilities were ok with this.

VB: That's true. Because that was the impression.

PP: The impression was that people with disabilities love these people! And, ah, no!

VB: I remember when we first started talking about it and talking about you writing something about it, how I think you felt a little bit alone in that place where you were just so frustrated by it. And once we started to spread the article around, how many people were saying, I feel this way too. Or thanks for helping me put the words to what I was feeling about this and more and more and more and after awhile it was just like this whole group of people who actually are not ok with this. Which again, is the power of one person saying I feel this way about this and I'm just going to put it out there and see what happens.

PP: And I think that's a good point. If you see a problem, other people are seeing it too. You feel like you're the only one and maybe no one is talking about it. You're not the only one. Somebody just needs to hear the words to make it make sense to them. And by telling it in a story, like when I spoke at the Winter Awards Ceremony, telling our personal story of experiences where people were ableists that was the part of the presentation that will stick in people's memory. Them being able to make the connection between the images of inspiration porn and someone with a disability actually experiencing a very intrusive, uncomfortable situation. Because the damages are out there. Telling your story as a person with a disability. At one time it's very unique and very personal and it needs to be told because it is so unique. But it's also universal at the same time. And people seem to be able to connect it to themselves in some way. And it will make what maybe didn't make sense, make sense to them. We feel so alone. At the Winter Awards Ceremony, one of our winners was telling a story about someone that she used to care for who had a physical disability. And this person, when they were

infantilized by a stranger, didn't say or do anything. And maybe part of the reason they didn't was because they felt alone. They just got so tired of feeling like they had to stand up for themselves by themselves. No one else was experiencing this. And so if we have to use whatever the sway is, or something painful or awkward, somebody out there who had that happen and felt very alone, will go – they will suddenly feel empowered and they will tell their story.

VB: And there's so many ways to be able to do that now.

PP: If you have a smart phone, all you have to do is record and hold it up to your face and talk. You can easily put it on tons of platforms. If you don't know how to do it, just google it or have someone else google how do I post to whatever platform I want to post it. I think sometimes we don't do it because we fear backlash. But there are so many people posting. Odds are that it's going to take a while for anyone to know you-- what got me started was these people saying just hit record and do it and do it and do it. Only friends and family are going to see it at first. Once you overcome that fear of that first post or that first article, it becomes easier and easier and easier.

VB: Yes, that's great advice. I remember when we were just talking about doing a podcast and both of us being like, ok, how do you do a podcast? And then you found out about how Concord Community TV had a program and we came down here and Josh did an awesome job training us – which actually doesn't take a lot of training. And now we can access the studio, we're not professionals- but we are now, professional podcasters. But it just took you and I being like, ok, let's figure out how to do this.

PP: And that's how it was with the YouTube channel. The first video, I didn't have any equipment. I had my old phone and I actually put a chair on the bed and leaned the phone up against the back of the chair with the books to hold it at just the right height and just recorded myself talking about why I thought it was important to get a story out there. Just a recording, just start telling your story, however you can. If you don't have a smart phone, somebody in your circle has one. Having them just hold the phone while you tell your story. You can get really deep in the weeds. Specifics I've learned - I've learned a lot of tech stuff, graphics because to me, that's just a lot of fun, I'm just kind of a geek that way. But, you don't have to do any of that. I'm just here to tell the world how it makes

me feel, what this experience meant to me. Those are actually the ones I love to hear.

VB: And I should let everyone know that if they want to tell their story, and they're not really sure how to do it, they should contact the Council. We have an open invitation to people who want to come on the podcast and talk about stuff that they want to talk about. We have Pat here who can come down and record people's stories if they want. And maybe even just talk to them about how you got started and give a little tech advice or anything that they need. So the Council is definitely a resource and we're here to support people in the ways that they want to be able to talk about their life experiences. So they should definitely give us a call. Our number is 603-271-7040 and obviously you can find us on line.

PP: Your story is important. It has power. If only changes one person's mind or gives one person hope or purpose, it is worth telling. There is no one who doesn't have a story. Everyone has a story that's worth telling.

VB: Yes, that's very, very true. And we probably are going to have a lot more opportunities for people to tell their stories at different conferences that we'll be attending, definitely at the Family Support Conference that is coming up in August. We're going to have a place where people can come and tell their stories. But also it's just an opportunity to just watch people in action. Even if you just want to watch it happening.

PP: It's funny- people will tell me they're uncomfortable but they start talking and then they take off. We have so much to say. We've been holding it in.

VB: Like you said earlier, you might think you're alone in your experience, but chances are there's someone out there that is also experiencing some of that. And that, being able to connect with that person and be able to connect with those ideas and not feel alone can be a turning point for people. When it comes to being more engaged socially or with the community or; like with caregivers, we talk about caregivers being an invisible part of society. And just being able to say things that other people might say, "Oh, I feel that way, too" or "what's gonna happen in the future? Maybe this is gonna happen and I need to know I can talk to somebody about that". It's very powerful and you are such a great role model for someone who just put themselves out there who said I'm going to take this on, I'm going to do these things. I think that's a tremendous value for the

disability community to have someone like you who isn't just talking at people but you're just kind of like advocating for inclusive living. But, I think that you really do fully embrace the idea of living fully inclusively in the community- I think that's so valuable to people to be able to see someone doing that and living it. And then going out and talking about it, there needs to be more of that in New Hampshire.

PP: Yes. Thank you. And that's one thing that I wanted to do with all of my work. It's not just a problem within the disability community. People with disabilities have not been good at cultivating the next generation and compelling--you usually learn your culture from your parents. I must say the LGBTQ community has been much better at this and supporting young people who are part of that community. Whereas the disability community, we've had such meaningful heros, that as they've passed away, there's been no one to fill their shoes. One thing I wanted to do with this was to help to raise up the next generation in any way that I could.

VB: Definitely needed. And a topic that could take up a whole other podcast. We'll have to bring that back around. But, definitely soon. I think that's a great discussion to have. Thank you for coming and can't wait to get back out there and watch you tell more stories.

PP: Yah, I've got to get my computer working.

VB: Is that a technical issue? Isn't that what we were discussing?

PP: Yah, sometimes you just have to be patient.

VB: With tech. Well, thank you for coming and in closing, just want to say since this is dropping in January, we hope that everybody had a safe and happy holiday season and that you were able to get some relaxation time in there because these days everybody needs a little extra relaxation. Thanks a lot Pat.

PP: Thank you for having me.

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.