

The Think Inclusive Podcast

Season 9, Episode 2

Genia Stephen | Good Things In Life Podcast

Tim Villegas (00:01):

Genia Stephen, host of the podcast the Good Things In Life, wants you to know why podcasting is her medium of choice to get her message across.

Genia Stephen (00:09):

You know, my goal really was to bring the voices and the conversations of disability thought leaders to families. And so podcasting really made sense. I wanted to provide a really accessible, easy way for people to be able to connect with my network and to connect with people who would really be able to help parents to think through devaluation, think through unconsciousness, think about how we frame our expectations for people with disabilities, and then how we can move really towards thinking about people with disabilities building rich lives full of the good things in life.

Tim Villegas (00:54):

And why the differences between the United States and Canada regarding inclusive education may not be as large as you think.

Genia Stephen (01:01):

I can speak to Ontario where I live in particular, where, similar to the states, we have a tiered system. So people can go into general education be placed in general education, but they can also be placed in segregated classrooms or segregated schools depending on the community you live in.

Tim Villegas (01:25):

Hey, y'all. My name is Tim Villegas, and you are listening to the Think Inclusive podcast presented by MCIE. This podcast exists to build bridges between families, educators, and disability rights advocates to create a shared understanding of inclusive education and what inclusion looks like in the real world. To find out more about who we are and what we do check us out at <u>thinkinclusive.us</u> or on the socials, Facebook, Instagram, or Twitter. Today on the podcast, we interview Genia Stephen about why she started the Good Things In Life podcast, what some of the differences and similarities are with the educational systems in the United States and Canada, and if there is such a thing as perfect inclusion. Thank you so much for listening. And now our interview with Genia Stephen.

Tim Villegas (02:19):

So today on the podcast, I'd like to welcome Genia Stephen, who helps kids with intellectual disabilities build inclusive lives at home, at school, and in the community. She is the founder and host of the Good Things In Life podcast and manages a community of parents of children with disabilities. Welcome to the podcast, Genia.

Genia Stephen (02:53):

Thank you so much for having me, Tim. It's truly an honor. I'm excited to be here.

Tim Villegas (02:57):

Fantastic. So will you tell us a little bit about yourself and your advocacy work?

Genia Stephen (03:05):

Absolutely. So I had the great benefit of having a younger sister with an intellectual disability and a mom who went from never having known anybody with a disability and really being quite freaked out when my sister received a diagnosis of having a disability to surrounding herself with thought leaders and mentors in the field of disability. And so I was raised at the feet of giants as far as the thought leadership and really grew up in a disability positive community. And then 15 years ago I had my second child and my son has disabilities and medical complexities as well. And it was, you know, striking to me at the time how lucky I was that I was starting my parenting journey at such a different place than my mother had started her parenting journey. And that I already had a community of people who got it, you know, around me and supporting me.

Genia Stephen (04:14):

And I'm also a midwife and I've been a midwife for more than 10 years. So I've supported, you know, well over a thousand families during their time of welcoming a new person into their family and had lots of opportunity to be supporting families who either are having a child with a disability or who suspect they might be having a child with a disability. And it just really became very apparent and very distressing to me that most of those parents were starting their parenting journey at the same place that my mom did. And nowhere close to where I had started my parenting journey. So I started the Good Things In Life to close that gap, to provide other families with the world-class disability education that I benefited from by running the podcast and having guests such as yourself on the podcast and also offering events, learning opportunities courses, and memberships.

Tim Villegas (05:19):

What about podcasting? You know, why podcasting? Why is that the medium that you chose to kind of disseminate your message?

Genia Stephen (05:28):

Well, besides the fact that I can show up and not have my image you know, I can show up in my pajamas and have laid back conversations with people without anybody seeing into my disheveled world is one benefit. But primarily, you know, my goal really was to bring the voices and the conversations of disability thought leaders to families. And so podcasting really made sense, you know, that that was what I wanted to capture specifically. So that's why, you know, is I wanted to provide a really accessible, easy way for people to be able to connect with my network and to connect with people who would really be able to help parents to think through devaluation, think through unconsciousness, think about how we frame our expectations for people with disabilities, and then how we can move really towards thinking about people with disabilities building rich lives full of the good things in life. So a podcast just seemed like the, you know, the best fit for that.

Tim Villegas (06:43):

Has there been anything surprising that you've learned from interviewing your guests over the last, you know, since you started the podcast?

Genia Stephen (06:54):

That's an interesting question. There's a couple of things. The low hanging fruit is it's remarkable how small this community is. The other thing that has really surprised me and made me sad is that the broader my conversations are geographically, the more I realize that the world is still, while there's been some tremendous improvements since I was a young child and a lot more opportunities for people with disabilities compared to when I was a young child. And just for context, my sister and I were going to school in the early years of our education at the time when people with disabilities, students with disabilities were just first starting to come into general education classrooms. So that's our generation. But it's so sad as I, as I speak with people all over the world that so many kids are still in segregated programming, segregated separate schools, classrooms, and that lots and lots of people really have never had the opportunity to think about a different way. And I didn't expect that. I thought, I guess my, because I know all kinds of people who are living inclusive lives and, you know, that's been the way and their families have been thinking about this for decades. And I'm connected with all of these leaders in the field of inclusion. I think I thought that it spread a little farther than it has, and I'm very sad that that doesn't seem to be the case.

Tim Villegas (08:41):

Let's talk a little bit about for those, for our listeners who are maybe not versed in how education works in Canada. So, you know, what do you think is the biggest difference about how people with disabilities are educated in Canada versus, you know, your understanding of how they are in the United States?

Genia Stephen (09:08):

Well, Canada's a big country and there's a lot of variety across the country. So we have you know, in the province of New Brunswick, there is a universal policy of inclusion in general education. So with a couple of very, very small outliers, there is no segregated classrooms. There are no segregated schools, special schools, everybody is educated together. And then we have other areas. I can speak to Ontario, where I live in particular, where similar to the states, we have a tiered system. So people can go into general education be placed in general education, but they can also be placed in segregated classrooms or segregated schools, depending on the community you live in. There's also a large variety. And I know this is actually a similarity in the, in the states as well. You know, low resource areas, you know where there are small populations of students living in rural areas, for example, there may just not be enough money to fund special programming. And so you know, you find greater concentrations of inclusive policies just because there's no alternative for where the kids might be.

Genia Stephen (10:26):

I think one of the things that is a little bit different is that in Canada, I think that, you know, I'm always learning so I'm a little hesitant to say this like it's a fact because I just could be mistaken about this. But it's my impression that in Canada, we have a longer history of advocating for and succeeding with inclusive education in general. And so there was in the seventies and eighties, for example quite a lot of advocacy for inclusion. And there were some very significant changes made that I think influenced most areas of the country. And what we've seen in the last little while is what I perceive to be almost like a turning of the tides where parents have really been convinced that special means specialist and means, you know, some sort of higher quality education for their children.

Genia Stephen (11:30):

And there doesn't seem to be the same opportunity. I don't know if parents are not connected to the same organizations or I'm not really sure what's going on, but it seems like there's, there's this turning of the tides. And we're seeing increases in some areas of the country in separate and segregated education. And my impression from speaking to American colleagues and friends is that there's not a turning of the tide in the states, we never had that critical mass change towards general education in the first place. So but I think that, you know, much like Canada, the US is a huge country, and it's very different depending on where you are in the US so I'm not, as I said, confident that any of that is factual.

Tim Villegas (12:27):

Do you have some really great examples of inclusive education where you are, or maybe ones that you've heard of?

Genia Stephen (12:34):

Yeah. Well, I think one of the important things to know is that even when inclusion is not done perfectly, which is everywhere, always because it's, you know, perfect inclusion is kind of aspirational. Even when it's not done particularly well, it still results in better outcomes for people than segregated, special education. So when I'm thinking about it, I'm thinking about all the people that I grew up with, who you know, experienced less than ideal inclusion, inclusive policies, inclusive classrooms, you know, where teachers were really just stumbling around trying to figure it out. You know. She's passed away now, but I had a friend. Her name was Becky Till, and Becky was one of the first people my age and I'm 45, I think Becky was a year older than me. She was one of the first children with significant disabilities to enter a general education classroom in her community. Her parents had to go through legal battles to make it happen.

Genia Stephen (13:47):

And at that time the teachers had notes and things like universal design for learning, or, you know, backwards design or any of the things that we talk about around you know, good classroom design, none of that was available to teachers at the time. And yet just the good intention of having Becky included in the classrooms that she was included in meant that she ended up with lifelong friendships, that she had tremendous opportunities that her language and communication flourished in a way that it wouldn't have otherwise, and that she was cared for and known in her community. I can say the same for my sister. You know, my sister's 41. So around the same time, and then, you know, we fast forward a few decades and I can talk about my son's education.

Genia Stephen (14:48):

So when my older son was at the age where he was entering school, we actually didn't think that he was going to, we're going to send them. We thought we were going to homeschool him. And then he decided that at the wise old age of four, he's decided, no, I want to go to kindergarten. So we supported that and I went to interview schools. And in our community, we have a French language school that's part of a board that actually is massive geographically because they encompass all of those French language schools, you know, but there's not that many of them in the surrounding communities and the outlier communities and our town is one of them. And I went to I went and I spoke to the principal and I

said, I'm, you know, I'm looking for a school for my older son, but I'm also thinking about my, my second child.

Genia Stephen (15:41):

And I'm a little bit nervous, you know, that the school it's French, they speak French, you know, all of the time. We don't speak French at home, you know, is this going to be too much for my son? And she said, well, you know, it's really only in the Western world that people are expected to only speak one language, you know. Pretty much in the rest of the world, people speak two or more languages. And, you know, there are people with disabilities all over the world and they seem to manage that just fine. And I can't imagine that your son would be any different. Yuu know, it's like, oh, I just got totally put in my place, you know, totally put in my place and had my expectations really checked there. And so we enrolled him in the daycare that was attached to that school when he was two.

Genia Stephen (16:33):

And he could only go for two hours twice a week because just from a health perspective, that was as much as he could handle. And we did everything that we could to make sure that he was known by the, you know, attached school. And he's been there ever since. He's in grade nine this year. And it hasn't always been easy. It hasn't always been positive. He's had some years with some teachers who really just weren't sure what to do. We've had years where it feels like we're, you know, taking steps in one direction and then we hit a wall. And as a, as a school team, we're turning around and going in a different direction and trying to figure it out. But we've had consistent effort by the school team to make sure that my son is a member of the school, a member of the classroom that he has access to the curriculum that he's being taught the curriculum. And overall it's been a really, really, very positive experience for him, despite the fact that it's imperfect.

Tim Villegas (17:47):

What is your dream, when you think about education in the future, what would you love for it to look like?

Genia Stephen (17:57):

I think the short and sweet answer is that I would, I would like it to look like all kids being educated together. I would, you know, making that a little bit longer, not just being placed together, but with real attention to all of the isms, you know, to real attention paid to ableism and racism and all of the other isms, so that kids aren't just placed in a physical space together, but are truly educated together as a community.

Tim Villegas (18:39):

What about for your podcast? So like, you know, you started this podcast, you've been doing it for awhile. Like where do you want to see it go? Like if you project a few years down in the future, what would you love to see happen?

Genia Stephen (18:58):

Yeah. Well, part of the reason why, you know, I've already talked about why I decided to do this, but an additional reason was that it made me so, so sad that I really very often had parents of older kids, you know, teenagers aging out of the school system, for example, and they would hear me speak or , you know, we get connected in some way. And they would say, "Why didn't nobody tell me this 20 years

ago? Like, why am I just hearing about this? My son or my daughter is graduating from high school and there's nothing. They have no life. You know, we're just, all we're being offered is you know, residential programming and day programming, but no real life." And so my goal has always been to try and get the podcast and, you know, not me particularly, but the people that I have on the podcast, into the hearts and minds or available to the hearts and minds of parents early on in their parenting journey. Because supporting somebody with a disability to build a positive and inclusive life is in some ways simple, but it's not easy.

Genia Stephen (20:22):

It's actually really hard because we still live in a society where people with disabilities are still profoundly devalued and underestimated. And so, you know, I often say that supporting people to build a good positive life is a little bit like pushing a boulder up hill, but starting when the person is 20 or older is like pushing a boulder uphill during a landslide, it just gets that much harder. So my goal for the podcast has always been that when people start thinking about decisions around things like education and friendships and recreation, when their children are very young, that the podcast, the Good Things In Life Podcast will be a place to start as opposed to something they find later on, perhaps when they become disillusioned with a medical model approach to disability or a therapeutic approach to disability. So that's my goal is that you know, somewhere amidst the, you know, here are all the early interventions that you should think about and here's all the special talk and all the rest of it, that the podcast will be there as an alternative way to think about parenting a child with a disability.

Tim Villegas (21:44):

Well, if you are listening to this, make sure that you subscribe to the Good Things In Life podcast and share it with people that you know. Share with people that are at the beginning of their journey, like Genia says, because you know, we want to support you in the goal for the podcast. Let's see, what else I want to ask you here? I felt like I had a question then it just POOF went away.

Genia Stephen (22:17):

That happens to me all the time.

Tim Villegas (22:17):

Oh, you know what. Okay so, when I was on your podcast, I think that you're the one who did this. So you asked me, is there anything else, is there anything that you wished I would've asked you? Right, was that you?

Genia Stephen (22:27):

Yeah.

Tim Villegas (22:29):

So I'm going to turn that back on you. Is there anything that you wish I would have asked you?

Genia Stephen (22:38):

I need to stop doing this to people, this really puts people on the spot.

Tim Villegas (22:41):

Now you know how it feels.

Genia Stephen (22:44):

Yeah. I definitely need to give people a heads up about that. I don't know that I wish that you had asked me this, but I think people who listen to your podcast, Tim, already know this. That there is an alternative to special. And so, you know, I'm not saying anything that people don't already know. But I guess the thing that I most want people to know and to think about is that you know, if what you want for your child is the typical, good things in life. You know, relationships, the opportunity to make a contribution personal growth, a feeling of belonging. That if that's what you want, is those typical, good things in life, then the path you need to follow is the typical path to getting those things. And it's never special. It's never specialist. It's really about living your life at the heart of community in the same way that everybody else does. And that pathway just by virtue of walking, the path creates opportunity for all kinds of good things to happen. And that's true even when it's not perfect. But there's no alternative to that. That works.

Tim Villegas (24:19):

See, it is a good question.

Genia Stephen (24:21):

It is a good question.

Tim Villegas (24:23):

It is because it's like, oh, I have to like, you know, like the most important thing on top of your brain go.

Genia Stephen (24:33):

Yeah, that's true.

Tim Villegas (24:33):

It is a good question. Very, very good. Where can you give us all of the details where people can find you, where they can listen to the podcast any sort of thing that you want to plug? I think you have some online courses, whatever it is, just go ahead and tell us.

Genia Stephen (24:51):

Sure. So people can find me, the easiest place to find me is <u>goodthingsinlife.org</u> and all the other links are somewhere at goodthingsinlife.org. One of the things that we just started doing is inclusionary podcast parties. And so we're you'll receive your invitation soon if you haven't already Tim, we are having guests of my podcast join into a Zoom party and inviting all listeners to join as well so that we can work on increasing the community and people's direct connection and network to those thought leaders that I'm so blessed to have on my podcast. And so if people are interested in attending inclusionary podcast parties, they can go to <u>goodthingsinlife.org/party</u>. And all the links to our monthly membership inclusion academy are also available at goodthingsinlife.org. So it's a good one-stop place to go.

Tim Villegas (25:52):

Okay. So thank you so much Genia Stephen for being on the Think Inclusive podcast, we appreciate your time.

Genia Stephen (25:59):

Thank you so much for having me. It's been fun.

Tim Villegas (26:13):

That will do it for this episode of the Think Inclusive podcast. Subscribe to the Think Inclusive podcast via Apple podcast, the Anchor app, Spotify, or wherever you listen to podcasts. Have a question or comment? Email us at <u>podcast@thinkinclusive.us</u>. We love to know that you're listening. Thank you patrons Pamela P, Veronica E, Kathleen T, Mark C, Sarah C, Kathy B, and Sonya A for their continued support of the podcast. When you become a patron, your contribution helps us with the cost of audio production, transcription, and promotion of the Think Inclusive podcast. And you could even get a shout out like the fine people we just mentioned. Go to <u>patreon.com/thinkinclusivepodcast</u> to become a patron today and get access to all of our unedited interviews, including our conversation with Genia Stephen. Thank you for helping us equip more people to promote and sustain inclusive education. This podcast is a production of MCIE, where we envision a society where neighborhood schools welcome all learners and create the foundation for inclusive communities. Learn more at <u>mcie.org</u>. We will be back in a couple of weeks to talk with Emily Ladau, Think Inclusive alum and author of "Demystifying Disability."

Emily Ladau (27:44):

I think the most important thing to understand is that ally is not a title that we can just bestow upon ourselves. Allyship is very much an action. Ally is a verb. It's not a noun, despite what actual grammar rules may tell you. To me, it's all about the actions that you take. And it's not about taking actions and then looking for a pat on the back for taking those actions. It's about incorporating them into everything you do in your daily life.

Tim Villegas (28:14):

Thanks for your time and attention. Until next time. Remember: inclusion always works.

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