

Interview with Tonia Christle with host Ellen Stumbo on the topic of, "Growing Up With a Disability."

Ellen Stumbo: Hi, this is Ellen Stumbo from ellenstumbo dot com: Hope and Encouragement for Parents of Kids with Disabilities, and today I have with me, Tonia Christle from toniasays dot blogspot dot com. Tonia, thank you so much for being here!

Tonia Christle: Yeah, no problem!

ES: Tonia recently did a series called Growing Up with a Disability, where she addressed what it was like to grow up with a disability, and they were fantastic. I'm so glad that she did that. I know, personally, I learned a lot and I thought it would be a great idea to talk to her about her posts and growing up with a disability and also answer the questions that came through the posts. So, Tonia, let's just get right to it. Let's start with The Early Years.

TC: Okay.

ES: So, you had a quote in there that said "Comments about our differences will stick in our heads long after they leave yours."

TC: Yes.

ES: So, I think that's a very powerful thing for a parent to hear. You and I have talked about this before, but sometimes I don't think about everything that I say in front of my kids.

TC: Right.

ES: Now, having that in mind, I think: "Huh." You know, like the comments about the wheelchair with Nina.

TC: Mmm-hmm.

ES: You know, when I asked her, "What do you think I feel about your wheelchair and what do you think I feel about your disability? I was shocked that some of those comments had affected her.

TC: Yeah.

ES: Maybe you can share a little bit more about growing up hearing those things, and what that is like. Share a little bit about what you wrote in your blog posts.

TC: Okay. Let's see... I think the main thing that was in the post was the part about being photographed and the way I was photographed. It was actually my great-grandparents. They were well-meaning and they *loved* me and I love them. It was just the fact that my sister and I actually lived with them when we were, like, five, for just a little bit. And so, we were there all the time and my grandpa always had the video camera and the regular camera, and he was always like, "Hey! Come and get your picture taken!" He would stand us side by side and then the walker would just end up being wherever it was and he tended to say, "It's better like this, isn't it?"

ES: Hm.

TC: I wonder how much of it was related to us being twins, and wanting the cute little twins that looked the same or was it a comment on me being more obviously physically disabled? And again, I know, they totally meant well. We were just cute little kids and they wanted the cute little picture of us standing side by side but I have a whole photo album that Grandma put together that, I don't know how many... Well, there's some! Some pictures. But the ones that are *in* great grandparents' house, they're all up against a wall holding onto a chair or up against some cupboards, holding onto whatever's behind me. As opposed to being photographed my whole body. I'm not saying that that never happened because it *did*. It just... it's the stuff that I heard when I was really, really little. It kind of stuck with me!

ES: Mm-hmm.

TC: I think by the time I was nine, which is kind of getting into later, but I remember because it was on video that my grandpa was going in for a close up with the video camera and he said: "Oh, there's just the top part of you! And no—" he called my crutches my sticks— he said, "No sticks, or anything!" He said, "That's better that way, isn't it?" and it was the first time that I remember - because it was on the tape - that I said: "Not to me."

ES: Wow.

TC: He didn't say anything back because then my sister was like, "Oh! You didn't give *me* a close up!"

ES: Mm-hmm.

TC: It went on from there. But that was one of the first times that I really spoke back about it. It was very soft. I was very uncomfortable. He never said anything.

ES: Yeah. That's very interesting that you finally spoke up. I think, yesterday at church was the first time that Nina actually spoke up to a peer. A little girl had come to say, "I'm going to go get your walker." And she turned and she said, "I can do it on my own."

TC: Mm-hmm.

ES: And she said, "No, no, no...I'm going to go get it, and [Nina] did turn and she said: "No. I can get it on my own."

TC: Mm-hmm.

ES: I did tell her I was very proud of her for speaking up for herself.

TC: Yeah! That's good! That's awesome!

ES: Just your comment that you *did* say something to your grandpa, that you said, "Well, not to me." That, for you, the sticks were good!

TC: Yeah! And it wasn't about being disrespectful. Do you know what I mean? And I *know* that they loved us. And the did a *ton* that was right. But, as we're speaking about this other side of it...

ES: I think that's true that, as parents sometimes, especially when we first receive a diagnosis...as we start dealing with the diagnosis I think kids can see us being sad or maybe crying or maybe saying things in the moment because we have so many emotions. We do say those things out loud. Part of your advice really was, "It's okay for you to feel the way you feel. Just be careful when you're saying it and who you're saying it to."

TC: Right.

ES: That does make sense.

TC: Mm-hmm. Also, I think it's important to know that everybody makes mistakes. We make mistakes. Parents make mistakes. Everybody makes mistakes, it's just, what are you going to do going forward?

ES: Right.

TC: If a parent accidentally makes a comment, or... Like you said, you can't think about everything you say every moment of every day. If you realize: "Oh! I said something in front of whoever. I think they might have had their feelings hurt."

Just go to them and be like, "You know what? That was about me. You didn't do anything wrong." You know what I mean? They might not have cared, or heard or even noticed, but it would probably mean a lot.

ES: Yeah. That's a good point. It's about me. I'm struggling. It has nothing to do with you.

TC: Mm-hmm.

ES: I like that. Okay, so, The Elementary Years.. Now that was my favorite post!

TC: I know!

ES: Because you talked about ableism and to be honest, I don't think that I was even aware of what it was in the subtle ways, you know, when it comes across as niceness?

TC: Right. How it *can* look.

ES: Yes. So, that was pretty actually convicting to me as a parent because I thought: "Oh! I've done that before to my kids."

TC: Mm-hmm.

ES: And again, not wanting to be *mean*...

TC: Right!

ES: And so I really, really liked that post a lot! But then you told the experiences that happened at school where it's really also, I mean, as parents, we don't have any control over.

TC: Right.

ES: And our kids might not even know how to communicate that it's happening.

TC: Right! For me, it was like, "What do I say?" I think that my parents were aware, to an extent, but then maybe, like... They didn't go to school with me every day. You know what I mean?

ES: Right.

TC: They weren't by my side every single day. I feel like if they were, perhaps, the teacher's actions would have been different.

ES: So, when you were in fourth grade, that lady came to do a report.

TC: Mm-hmm.

ES: And in that report you were disrespectful and you did not thank your peers...

TC: Yup!

ES: You were defiant.

TC: I don't remember this, but luckily there is this report that has come along and followed me through the years and I found it while I was writing these posts and I was like, "This is gold."

ES: Yes. Because I really liked what you said. You said, this woman, who actually wasn't your teacher, she just came that one day...

TC: She just came to observe me.

ES: Okay. So she's filling that out, and again, she says all of that about you, but I really liked what you said: "This is what she did *not* see."

TC: Right! That was all true! I was behaving very badly!

ES: [laughs]

TC: But, I mean, there was more to it. Do you know what I mean? Often, other people - nondisabled people - will maybe observe a disabled person and be like "Oh, they're so angry!" or "They're so disrespectful!" You know what I mean? What's going on to cause that? What's going on behind...in the moments when you're not here, random lady...

ES: Right. But I really liked how you explained that! You said, "This is what she *didn't* see."

TC: Mm-hmm.

ES: So, you had a teacher who would call you a *princess*!

TC: Mm-hmm!

ES: In fourth grade!

TC: Yes. "Make way for the princess!"

ES: My oldest is in fourth grade and I think she would feel *babied* if her teacher said something like that!

TC: Yes! Right!

ES: And then, she actually had other kids from your class even go to the bathroom with you.

TC: Mm-hmm! Not to veer it off, but I think we did get another question about that and about the teacher and what made my teacher so *mean*?

ES: Oh yeah! Yeah!

TC: And I wanted to speak to that. I don't think her intentions were mean. I think she was inexperienced. She was very experienced as an educator. She was very *inexperienced* as an educator of anybody who was different. It was 1990, and I don't know how much you know about civil rights and the disabled community but the ADA passed in July of 1990 and my school year started that year, in September. So, I feel like it wouldn't be too far of a stretch to say, perhaps, I was the first student with a physical disability that she had ever taught.

ES: That's true. That's possible.

TC: I don't know. But even in that report that I had quoted, there's a piece near the end, where she - this lady - had spoken to the teacher and talked to her about: "You're doing a lot of... Kind of hovering a lot..." and the teacher said that she was afraid. That she was very fearful that I would get hurt.

ES: Mm-hmm.

TC: And I think that, perhaps, drove a lot of her actions. She meant well, and she was probably terrified.

ES: Right. Which, and I think that's the reality for people who are not familiar with disability, there is a lot of fear.

TC: Mm-hmm.

ES: I think, at least for me, as a parent, when my daughter was born with Down Syndrome, a lot of the feelings that I had were really based on fear because-

TC: You didn't know.

ES: I didn't know. Which also goes to ignorance. I was just very ignorant about disability at the time. And I'm sure there

are still many ways in which I am ignorant to disability because my kids are younger-

TC: Me too!

ES: [laughs]

TC: It's true for everybody. Until you know. Even disabled people grow up with these ideas in our heads because of society and the way that society actually is. It's built for able-bodied people. It's not built for us. So then we kind of have that internalized: "Well...if I wasn't [disabled]...things would be a lot better."

ES: That's true. And that brings up a good point, because some of the comments that I got and maybe that you got too, were not public.

TC: Hmm...

ES: I found it very interesting that it was other adults with disabilities that did respond to your posts saying, "I felt that way, too." "That happened to me, too."

TC: Right.

ES: And even comments of, "Because of the messages from home, and from school, I did grow up feeling a little bit" one person even used the word "worthless, with little value, because of a disability."

TC: Yeah. I could see that.

ES: That breaks my heart. I have two kids with disabilities and I don't want them to ever grow up feeling that way.

TC: Right.

ES: And just trying to encourage them. I want to support them. Which is another question: How do you push your kids, and encourage them, without making them feel like their disability is bad? How do you push them to do better, to try harder, without them feeling like, "Oh, you just wish that I didn't have a disability."

TC: "You just wish that I could walk." Or, "You just wish that I could do this better." I think that is a very fine line to walk, as a parent, and I don't envy you [laughs] at all!

ES: So what can parents do to encourage their kids, but at the

same time, not make them feel like they wish that they were different? Or that you don't like their disability?

TC: Right. Okay. So I would definitely say that it's... I would probably just start with, "Everybody has things that they need to work on." It's not specific to—I mean, it *is* specific to disability, but it's *not*! Everybody has areas of themselves, educationally or whatever that they need to improve on. And you could give examples for your own self if you're talking to your kids, or whatever, and just say, "Oh, I really struggle with..." I don't know. Whatever you struggle with.

ES: [whispers] Math!

TC: Math! Yes! "I really struggle with math and I really need to work harder on that." And then, to really be aware, to not make it the be all and end all. To know that a lot of times, this progress happens slowly, and over a long time. So, what you read about me in the early years? I could do so much less then, than I can do now. I've really made improvements over the years and it was due to a lot of things, but it didn't happen overnight. And so, to know, and to frame it that way, "You just do a little bit at a time and hopefully, it will help." I was going to also add, to encourage your kid or your family member or whoever it is in the things they already do well.

ES: Mmm. Yeah.

TC: So that they're... It's not like, "You *just* need to focus on strengthening your legs." Or, "You *just* need to focus on stretching or speech therapy or whatever it is. If they're creative, if they like dressing up, if they're *kind*. Make a big point to say, "You're *really* good at this!"

ES: Yeah.

TC: Build them up in those senses, too, so it's not like, "Well, I don't have any..." Like you were saying about those people that responded privately. They said they didn't feel like they had any value. And that's because, *maybe*, I can't speak for them, but if you're only getting *one* message.

ES: Yeah.

TC: They're only getting: "You need to work harder at this."

ES: Right.

TC: And then there's the thing where, you need to praise your kid ten times more than you correct them for it to kind of

balance out.

ES: Right. I think because you talked about telling your kids that "It's gonna take time. It's not gonna happen really quickly." But I think, as a parents, that's a *very good thing* to be reminded of. I feel like, "I know she can do it. She just needs to try a little bit more, and try a little bit more!" And I need to remember, "It will happen when it will happen."

TC: Mm-hmm.

ES: And it takes time. It's a gradual process to get there. So that's a good thing to remember. Okay, so then, we're going to move onto The Middle School Years.

TC: Oh boy...

ES: I love that post because you were very open and very vulnerable. And most people don't like middle school because it's really hard.

TC: I didn't. [laughs] I know you couldn't tell at all!

ES: I think that there's a lot of struggles and I feel like even in the area of development for most people, you're not a kid anymore. You're not going to go talk to your parents about everything that's happening.

TC: Right!

ES: That's when you don't wanna talk about a lot of things! So, as parents, we need to be proactive, asking questions and maybe looking at behavior.

TC: Mm-hmm.

ES: You did mention, one of your quotes was: "If your child is dealing with bullying, self harm, other abuse, depression or anxiety, make it clear that counseling is available and that there is no shame in it."

TC: Mm-hmm.

ES: I really liked that. Because you did talk about some issues there, like bullying...and I will tell you, I think, as parents, that is one of our biggest fears: that our kids with disabilities will encounter a bully or two or three.

TC: Yeah! And it wasn't super prevalent for me, but when it did

happen, it was in middle school. And a little bit in high school.

ES: So, as parents, what can we *do* to be aware if we don't have a kid coming up to say, "Hey, So-And-So is picking on me?"

TC: Right. That is awesome, if your kid is able to do that. If they're in the place where they feel they can share that. Sometimes, it doesn't have anything to do with you as a parent. It's just where that kid is.

ES: Right.

TC: Emotionally, it's demoralizing. When you're bullied, and it's because of an issue like being disabled in a way that people can see? Even if that's not the reason why they're picking on you? That's the reason why they're picking on you.

ES: Right.

TC: What can you do as parents? I would say, have conversations. Bring it up. And not in the way that, "Well, you know, if someone's picking on you..." I think media is really powerful. So, if there are any shows that your child likes to watch, watch with them. If there's a storyline about bullying, listen to how they talk about it.

ES: Mm-hmm.

TC: What's their reaction? What questions are they asking? We used to read a lot with our little brother. We have a really a lot younger brother. And we used to read a lot with him. And when he was in middle school, we were reading this book. And it didn't have anything to do with being bullied at *all*. But it had this other storyline. It was actually about adoption. This main character was actually realizing that he was adopted. And our little brother closed the book, looked at my sister and I, and said, "Am I adopted?"

ES: Hm.

TC: Whoa! But that question would have never come up. Or if it did, he would have never felt... But *because* we were reading out loud together, which is something that we do with each other—

ES: Mm-hmm.

TC: --He felt like he could ask us. We said, "Nope. You're not. We remember when you were born, and we remember Mom being

pregnant with you.”

ES: Yes.

TC: It’s nothing that he should be concerned about. But that was right in that age. He was twelve.

ES: Mm-hmm.

TC: And it’s not the same thing, but I feel like it’s—

ES: It’s a good example.

TC: It was something that he was concerned about, and something that he had been wondering about and had an insecurity around. And that we could address it. To pay attention to—What are they reading? What are they watching? Do they have questions about it?

ES: That’s true.

TC: That’s probably one of the—not a surefire way, but it’s probably a really good way to reach out to your kid. In a way that doesn’t make them feel like you’re—

ES: On the spot.

TC: --Sitting down and pointing your finger and like... Thinking that they *should* be bullied. Or “Well, naturally, they would pick on you...” When you’re eleven, everything is very personal. Even if you don’t mean it that way.

ES: That’s true.

TC: And so, you can talk about something else. “Oh, what’s happening with this character?” And you can maybe have a different conversation.

ES: Right. Those are good thoughts. And hopefully, as parents we do have open communication with our kids.

TC: Mm-hmm. That’s very important.

ES: That they know they can talk to us about anything that’s happening. Especially in regards to their disability. And I think that if they know that we’re a safe place where they know that we don’t dislike their disability. And we recognize that it’s part of who they are...

TC: Right.

ES: And we love them completely, that hopefully even those conversations become not weird conversations.

TC: Not weird, and not off-limits.

ES: Right. Yeah, that's a good point. Not off-limits. In some of the comments that were left, it seemed like for some of them, that disability was an off-limits topic.

TC: Mm.

ES: You know, "We're going to treat you like you're 'normal.'"

TC: Mm-hmm.

ES: And then, that made disability as something that you don't talk about.

TC: Right.

ES: Like someone expressed, almost shameful. When it's not.

TC: Right.

ES: It shouldn't be.

TC: But it's all about how it's framed and how you internalize that stuff when you're little. And wherever your parents are in their journey.

ES: Right. That's true. So, now High School Years.

TC: Yay!

ES: Your quote from The High School Years was, "Being disabled is not a free pass to be coddled or excused from responsibilities that are within our ability to maintain." And I really like that. I like that you told the story that because of your sister's illness and that she ended up in the hospital, you stepped up.

TC: Yeah...I guess you could say that. I would say that I just did what I had to do. It's not like stepping up, it's just like "Okay, I have to do this." And that's a family trait, I think. I see that in my mom.

ES: Uh-huh.

TC: She has that as well. Whenever the situation is like, "Okay, you need to do this," and she just steps up and does it.

I have found that to be true for me.

ES: Yeah.

TC: If the pressure is on, you can be as scared as you want, but still do it.

ES: Yeah, I like that. I like that you said that it's not really stepping up, it's doing what you have to do.

TC: It's doing what you have to do in the moment.

ES: Yeah. I do wonder sometimes even now with my girls. And they're younger, but it's funny that I go out to the school, and I talk to people, and I say "I want you to have big expectations for my kids."

TC: Mm-hmm.

ES: Sometimes, at home, I do kind of baby them in some ways.

TC: Mm-hmm.

ES: It's almost like, "Well, I don't know if they can do it or not, so maybe *I* can do it *for* them."

TC: Mm-hmm.

ES: And I think in your High School Years post... You have a disability, but guess what? You still have responsibilities.

TC: Yeah.

ES: Expectations.

TC: I still had schoolwork to do.

ES: Yes.

TC: Papers to write.

ES: Yes. And you need to fulfill those.

TC: Right.

ES: That's your place in your family. And I think maybe it depends on the disability, and being aware of that.

TC: Because it is different depending on what you are dealing with. Some expectations are too high. If it's a different kid

in the same situation, maybe they're not going to be able to do everything.

ES: Right.

TC: And that's totally fine.

ES: Yes. So, this reminds me. There was a question that came in about a woman who was standing in line at JoAnn Fabrics, and a lady in a wheelchair was behind her. She made a comment, "Oh, there used to be a line for disabled people. It's not there anymore." And the lady felt like, "Well, am I supposed to let her go first? Am I not supposed to let her go first?" What do you do in a situation like that?

TC: Was she giving telepathic signals? "Actually, you should let me go first."

ES: Yes.

TC: I would say that obviously I can't speak for every disabled person. However, I saw the question as well. And I thought that I could totally see myself making that same remark. Not in sending the message that "I should go first," but it would be my way of making conversation.

ES: Mm-hmm.

TC: It's a long line. You're just standing there, waiting. Or sitting there, waiting. And that's what comes to your mind—"I remember when things were quicker." And chances are, she wasn't upset. She wasn't trying to tell you, "Actually, let me go first." Obviously, I don't know for sure.

ES: Mm-hmm.

TC: I also think it's important to say that a lot of times... If you're speaking to someone with a disability, and it's something that [they've] grown up with [their] whole lives, we grow up learning to ask for what we need. So, if she *needed* to go ahead of you in line, I feel like she would have said [so]. "Actually, can I get ahead of you? I'm in a rush." She would've been more explicit. That's my take on it, anyway.

ES: I've heard from other friends that I have that have disabilities that sometimes people are trying to be nice and saying, "Oh, you can go first!" or whatever.

TC: Mm-hmm. Right!

ES: And some of them feel like, "Don't treat me different just because I'm disabled!" I have a friend that said, "Why would I go first? I'm sitting in a chair!" [laughs]

TC: [laughs] Right!

ES: "I'm not the one *standing!*"

TC: I've got it easier here. I'm not the one dealing with my legs being tired. I think that that person was very... They were like, "I didn't want that person to think that I was babying them." And I thought that was very smart that they were aware of that. If you were ahead of a lady in line who was standing behind you, would you be like...? If she talked about the express lane, would you be like, "Oh! Does she want to go ahead of me?"

ES: Yes.

TC: Maybe that's not...that wouldn't maybe be your first thought.

ES: Right. It also reminds me... We talk about, treat people how you want to be treated. Sometimes I do say to other people who are not disabled - I make a point to say - I don't mean treat others how you would like to be treated *if you had a disability.*

TC: Right!

ES: Because you have a certain perception of what it would be like to have a disability so forget that aspect. How would you want to be treated right now? In your situation? As an able-bodied person? That's exactly how you should treat people with disabilities.

TC: Right, because being able-bodied is just as much their norm as being disabled is *my* norm. I've grown up my whole life like this. I'm reminded of this quote by Ali Stroker, who I actually had one of her quotes in one of my blog posts and I can't remember which one it was, but she said: "A trauma when you're young doesn't feel like a trauma. It just feels normal."

ES: Hmm...

TC: That's kind of how I feel. If something happens to you later in life, even if you're a parent and you have a child with Down Syndrome, or whatever, that's a huge thing, and it takes some adjusting. Because your previous experience - *for you* - was to have a typical child and you don't have any experience with this. Having a baby with health problems. And so it took

some time for you to adjust.

ES: Mm-hmm..

TC: For me, there was no adjustment. It was *always* my reality.

ES: Right.

TC: And so it's not anything that I had to be like, "Oh! That's really sad for me!" Like, why? [laughs]

ES: Right! You know, that's a great point! I hope everybody, if they remember *anything*, they remember this right here. That it's your normal. I think about both my girls. Nichole has Down Syndrome. She's always had Down Syndrome. She doesn't know life without Down Syndrome. Nina has Cerebral Palsy. She does not know life without Cerebral Palsy. It's their normal for both of them. That's a great thought, so thank you for that.

TC: Yeah!

ES: The other quote that you have for The High School Years, you talk about, you know, fitting in. So you said, "Being in choir gave me a place to fit in. It gave me an identity outside of the girl in the wheelchair. I was okay being that, but I wanted my peers to understand I was more than one-dimensional." I think the fitting in is something that all of us - deep down we all need to fit in. But I really liked what you said, for your peers to know you [as] more than one-dimensional. Is that something that you feel happens a lot to you? That people say, "Oh. The girl in the wheelchair." And all of a sudden that's *all* that people see?

TC: I will say it's the *first* thing people see.

ES: Mm-hmm.

TC: It's the very first thing. Even before people see that I'm a woman, because I wear my hair short, so sometimes there's confusion about that. But this is the first thing they see. I come down the sidewalk in a wheelchair and that's what they see, and then there's judgment. Right or wrong. Some people are great and they don't care, and they're just like, "Hey!" and they keep going. And some people look at you, and they go, "Oh my gosh! You're doing such a great job!" Like, "Why? I'm going to the store!" [laughs]

ES: [laughs] Yes, and you and I have had lots of conversations

about some of the things that people say.

TC: Mm-hmm.

ES: And how *inspirational* people with disabilities can be for going to the grocery store, just like everybody else.

TC: Yeah! Right, and so yeah, I would say, it is the *first* thing that people see, and so, as such, there's judgement made based upon that. Now, there's also invisible disabilities, which people can't see.

ES: True.

TC: That's a whole other perspective and experience that I don't know anything about because this is all I know. People seeing it and judging it. For good or bad.

ES: Yes, that is true. I see that. As an outsider, I see that with my girls sometimes, too. You know that, when people see either one of my girls, because they both have very obvious physical disabilities. I feel like that's all they see. They see the disability. They don't see the person. And I would say that disability is very much a part of who they are, but it is not the only thing that defines them.

TC: Right. Like the quote. You want people to know that your girls are more than one-dimensional. Like, that is one dimension of them. There's also all these other ones.

ES: Right. That's good for all of us to keep in mind. Unfortunately, people that don't have any connection with disability, or they don't know anything about disability, it's hard to make people see them. When they don't have that experience.

TC: Right.

ES: Anyway, moving onto The Adult Years.

TC: Oh...

ES: Which, that was great. And you did share about some of your plans and moving out and going to college. And that doesn't work out and how do you deal with those emotions?

TC: Right.

ES: You did go back to live with your parents. You lived with your aunt and uncle for a while.

TC: Mm-hmm.

ES: And eventually you and your sister moved to an *awesome* apartment! Because we have been there! It's really awesome! Fully accessible!

TC: Yay!

ES: But you live independently and you have pretty full, busy lives. But I really liked your quote. You said that 'The level of independence will be awesome for people, regardless of what [that] level of independence is.'

TC: Right.

ES: Now, for me, having a child with Down Syndrome, I do wonder what that level of independence is going to be.

TC: Mm-hmm.

ES: And so, the day she's born, I'm thinking, "Oh no! Is she going to live with us forever?" And now I think, "Oh! I *want* her to live with us forever!"

TC: [laughs]

ES: But I think part of it is the fear that *I have*.

TC: Right.

ES: I think I'm speaking as a protective parent because I do have to protect her and advocate for her.

TC: Right!

ES: And I do so much for her. But at the same time, I do think that the healthy thing is to pursue the highest level of independence that she can have.

TC: Mm-hmm.

ES: If that means that she lives at home, then she lives at home. But maybe there are other options. Which will make me so sad! [laughs] With Nichole!

TC: You can still stay in touch! I'm sure. I'm sure she would want to.

ES: Yes. But I mean, is there any way that you would encourage parents not to be afraid to pursue that independence for their

kids?

TC: Hmm. That's a good question!

ES: Because you're in a very different position in that you're fully capable, and you have a physical disability but it's not going to affect necessarily where you live. Or maybe it would. I don't know.

TC: Yeah. I would say that it does.

ES: Okay.

TC: It affects a lot of different aspects in my life *including* where I live. Because now that I'm older, I don't have the stamina that I had, even in my 20s. And so now I just use the wheelchair a lot more. And I do wonder if I use the wheelchair more now because I'm where it's accessible and so then I *can*, or, if it's vice versa.

ES: Hmm.

TC: I'm not really sure. Also, there are things that I can't do. There are household chores, for example, that I can't do. It's just about finding a balance. Like I said in the post. Everybody needs help.

ES: That's true.

TC: Everybody needs help! We have cable people, and electricians and all those people that help us do those things that we don't know how to do. Or we just don't have the skill level.

ES: That's a great perspective.

TC: There's no shame in that. Maybe that would be my advice is to frame it like that. Even as parents, and as adults, you're all grown up, maybe you're married, whatever. Do you do every single thing by yourself all the time?

ES: No. [laughs]

TC: No. You need help. You need help from your spouse. You need help from outside people who know how to do other things better than you. That's true for everybody, I think. And I think it would be helpful to come at it from that angle, as opposed to, either, "Oh, my poor baby. What are they gonna do? Are they gonna be able to reach any level of independence?" Or, "No, you need to be *completely* independent!" Do you know what I

mean?

ES: Right.

TC: Because nobody's completely independent, and I think that there's a lot of stigma around needing help.

ES: Yeah, I think you're right.

TC: I have a couple of friends who do have CP and theirs is more involved, and they do require - I don't know if it's called a PCA or, like a one-to-one - to help with different activities of daily living. And that's just reality. Just because I can do certain things, doesn't mean... They still make it work for themselves. It just means that their day is a little different. And that's not to diminish the impact of disability on everybody's life because it's obviously there. But yeah, that's probably what I would say. Everybody needs help and it's not a bad thing to need help. So, just to kind of take that in, and then figure out, as your kid's growing up, "What can she do?" "What can he do?" "What do they probably need some more help with?"

ES: Yes. That's a good point. I'm so glad that you're the one speaking on that, because we're not there yet. My kids are so young. I just have a lot to learn when it comes to those older years, and the independence and all of that. So, there's a questions, and one of the questions [was] "How can you help kids with disabilities who feel left out?" So what are things that as parents, maybe, we can do?

TC: Okay, yeah. So, this is one that I-I thought about it overnight and I remembered a really good example from my life growing up. I was eleven or twelve - which was a *great* time in my life, as we know, from the middle school post... Not the greatest! So, my little brothers had grown up playing baseball. They played on teams. Then, when we were in sixth grade, my sister joined a softball team. So every single one of my siblings played a sport, and they played similar sports. I was fine when my brothers played, I was like, "Hey! I'll go cheer them on!" When my sister joined the softball team - which, I don't know how much of it was because she wanted to play and how much of it was because our best friend was on the team...

ES: [laughs]

TC: But I was like, "Ohhh, I feel so left out! I really want to be able to do this!" I knew I couldn't.

ES: Mm-hmm.

TC: There were just some things it was just not realistic to do!

ES: Right!

TC: So, it wasn't like I was in denial, but it was just like, "Oh, I really want to do this..." And I remember that my dad actually got me a glove.

ES: Mmm.

TC: And it wasn't like... He knew I wasn't going to be able to use it to *play*. I mean, I could barely *catch*! If you'd throw me a ball, I'd be like, "Where is it?"

ES: [laughs]

TC: Hand-eye coordination? Not really there. Not the point. He did that, and that made me feel like I was a *part* of things. And it wasn't a pity-glove, you know? It was just, "Here. Everybody else is getting gloves. I'll get you a glove." And knowing that I was always wanting to go to my sister's practices, and just, wear the glove and be out off to the side and kind of watch things.

ES: Mm-hmm.

TC: And wish I was out there, and knowing that I couldn't be, but at least I had the glove. [laughs] You know what I mean?

ES: [laughs] Yes.

TC: So it was kind of a small thing, but it meant something.

ES: Yeah. It's almost like the glove was a symbol from your family saying, "You're not out. You're in. Your part of us."

TC: Right. "You're part of us. Here, you have a glove like everyone else has a glove...even though you can't play on the team." You know, I was very involved and I came to everybody's games and I watched everything and it was still enjoyable, and I would also say *that*. How do you help your child from feeling left out? There's that example, and then there's emphasizing what can be really positive about supporting your family members. You know what I mean?

ES: Yes.

TC: Not 'from the sidelines.' Just supporting them. Even as an adult. My sister and I, we're really into dance. We're big dance fans. Obviously not big dancers. But we're big dance fans! [And] one of our cousins dances. And there was this dance workshop recently - a couple of years ago - and we asked if we could go and observe.

ES: Mm-hmm.

TC: And we got told, "Yup, you can come and observe!" So, Tara and I came, and sat the whole day by the wall, and we brought our cousin. And we got to watch him be awesome!

ES: [smiling] Mm-hmm.

TC: Like, *so good!* And be singled out in a positive way: "Let the boy do it! Let the boy be the example!"

ES: Uh-huh!

TC: We were so proud of him! And we wouldn't be able to be proud of somebody else if we were busy sitting by the wall, like: "[sigh] I really wish *I* could do that!" You know what I mean?

ES: That's true! That's true. You know how they say that the secret to happiness is not to focus on you, but to focus on others?

TC: Mm-hmm.

ES: And I think maybe that's a little of the not feeling left out? When you can focus on someone else and celebrate something for someone else and be there for them.

TC: Right.

ES: That you don't have to get up and dance with him, but you can be on the sidelines supporting him.

TC: And at the same time, like knowing, like we talked about earlier: There are things that your child is good at. There are positive skills that your kid has. Maybe they are really good at writing. Maybe they're really good at drawing. Maybe they are really funny!

ES: Right, right!

TC: And those things - if you can frame them as having just as much weight and significance... You know, like, sports are huge.

ES: Right.

TC: Especially in America. They're probably huge all over the world. It's easy to say, "I'm not a football player! I could never be that! I can never have that level of impact!" Well, yes you can! Because, guess what? The world needs people who know how to write books. And the world needs people that are kind and are gonna help people. And the world needs people who are funny, when we're having bad days!

ES: Yes, that's a great point!

TC: So, yeah, I think it's a multi-faceted answer. Where it's the glove. It's feeling validated or affirmed by your family: "I see you. I know you wanna be a part of this. You are a part of us." It's teaching them to be supportive in the right way. "Everybody supports everybody else in this family. We all went to see so-and-so's dance recital *and* we also went to see you perform with your class at your Christmas concert."

ES: Those are great. Great points to keep in mind. So, another question is about friendship. How did you form long-lasting friendships? Now, you have a twin sister!

TC: I do!

ES: And you and her are the best of friends!

TC: Yes, we are!

ES: And you have always been! So you always had the unique situation where your best friend lived with you.

TC: Mm-hmm!

ES: And you went to school together!

TC: Yup!

ES: So, I don't know if for any reason, there were problems with other friends or if you were not making other friends, you always had each other. *However*, I am sure that you had friends outside of just the two of you!

TC: I think that's an interesting conversation because I think, growing up, we often had the same friends. Either one of us met a friend and then they became the other one's friend. If there [were] friends exclusive to one of us, it's kind of rare. We

usually end up sharing friends, and it's fine!

ES: Like me! [laughs]

TC: And we love that! Like you! Yes! We *totally* share you and it's *awesome!* We both *love it!* But I think to speak on the long-lasting friendships. Did we make long-lasting friendships? I don't think so. Save about...I think we tried to count this morning...maybe two or three?

ES: Wow.

TC: And I think the exceptions were... There was a little girl in the fifth grade, and if she watches this, she's gonna know who she is. In the fifth grade, Tara and I both had really intense surgery. I had it on both my legs and Tara had it on one of hers. We were out of school for a long time. The recovery was pretty intense. We got taught at home. Our teachers came to our house, after they taught a whole day, they came over and taught us, because they were awesome! But this girl would send us get well cards. And the classes were: "Oh yeah! We're gonna make get well cards for the girls!" And it's a fun little activity for all the kids to do, to teach them compassion, or whatever. This girl went above and beyond. She's like, sending a card every week. "How are you doing?" and like, writing a full-on, "This is what we're learning in science class: we are learning about pathogens and germs. They are *everywhere!* You would not believe..."

ES: [laughs]

TC: Just like, *the sweetest.* And Tara just mentioned this this morning, that this little girl had mentioned to *her* that she had had walking pneumonia one of the previous years. So she had an insight into what it was like...

ES: Yeah!

TC: ...to be out of school for an extended period of time, and to be away from your peers. Our other friendship which is a little bit longer, coming up on ten years... She's also experiencing having surgeries from being injured, and having to go through that recovery. And so, we connect based on that.

ES: Yeah.

TC: The only exception to that was this really young friend. Really awesome, great friend, we met through church. And she was just very open. At church, there was always the calls at the end, "Everybody come up if you want some healing!"

ES: Mm-hmm!

TC: And there's quite a few years between us. So she was I think eleven or twelve years old, to my 19 or 20. She saw me, and she leaned over to who was sitting next to her, which happened to be one of my friends: "Why doesn't she go up to get some healing?" and my friend said: "She believes that she's fine the way she is and she doesn't believe that she needs to be healed. Does that make sense?" "Oh yeah, that makes sense!" And then, fast forward a few years. We became friends. We both sang. We both were singers. And there was this instance where we were going to the State Fair together. We had packed my chair into the car, but then we had stopped at church, to run in and go to the bathroom. And I was like [frustrated face.] Of course I didn't think to bring my crutches as well, because I didn't think I would need them. Well, are we gonna take the chair out of the car, put it together, find the door to get in-

ES: Oh, yes!

TC: --find the door to get out, and then take it apart again? Just to run in for five minutes? So I'm sitting in the front seat going, "Great. This is awesome." And all of a sudden, my friend comes around the car, opens the door: "Do you need to use the ladies room?" She was seventeen. And I was a little bit older, I think there's about eight years between us. Just floored [me.] And she just offered me her arm, walked in with me, into the bathroom, to the stall door, and then to the sink, and then back out. That's the best kind of help! If you actually need it, and then if somebody can give it to you in a way that's natural and that makes sense. And it's not "Oh, I feel so bad for you! Can I help?" [Instead] it's like, "I see that there's a need, and actually, I can help you with that, if you want."

ES: Right.

TC: So, those are the three friendships, and I feel like they're very particular, which is probably the reason why they've lasted. Because it is difficult, I think, for people with disabilities to *maintain* friendships. There's a lot of spontaneity in friendships, I feel...

ES: Hm.. Mm-hmm.

TC: Just from observing. I don't actually know. It's something that we can't actually participate in as much, the spontaneous things, because being disabled means you plan for everything. Can I get in?

ES: Right.

TC: Once I'm in, can I get everywhere I need to go inside? Can I get out? Is there parking that's close enough? You have to think about every single thing.

ES: Right.

TC: So you can't be spontaneous in the same way that other people can, and it's not a pity thing, it's just reality. So, I think a lot of the friendships that have dissolved and not worked out is because they wanna do all that spontaneous stuff, and we can't. And so, we're kind of the downer friends, and it's just kind of the way it is. Like, "I'm sorry but I can't!"

ES: Right, and I wouldn't say you're downer friends, it's just a reality for you.

TC: Right.

ES: Because, I think, our family experiences a little bit of that, too. There are times that we know that it just doesn't work for our family. And I think that touches a little bit on the feelings of isolation. I hear that, naturally, people with disabilities can be a lot more isolated than the average person.

TC: ...Probably true. I don't have anything to compare it to.

ES: Right. That's a good point. But I would say that as I look at my family, that sometimes we do have a little bit more of that isolation because we can't participate in activities that other families can participate in.

TC: Right, and you would have something to compare that to. You'd be able to look back and go... "There was, maybe, a time!"

ES: Or even for *me* growing up! You know, it was different! Because there was no disability in my family as I was growing up. And I know from a parent's perspective, that is a really big thing. That even as parents, when we parent kids with disabilities, sometimes, some of the friendships that we had before, those do kind of fade away. And I think that's what it is! You can't be spontaneous like that anymore! You don't have as much time! You can't just go and do something like you did before because maybe your child has certain needs or medical issues or whatever it is.

TC: Right!

ES: Or even when you talk to people - and you and I have talked about this - when you talk to people and you feel like your life is just so completely different that you don't have things in common anymore...

TC: Right. Yeah! And that's a huge thing with my friendships, too! How much work it takes to maintain those other friendships? Like, "Hey! I'm coming over to hang out at your house! So, what's going on? What's new in your life?" And you feel like, "What can I say? What can I say that you'll actually get? Well...not much..." So, I'm left with: "Hey, did you see that episode of Grey's Anatomy?"

ES: [laughs] Yeah! That's true and that's a big issue. And maybe it's a reflection that we get so focused on the *doing* and forget about the *being* and just being together with a friend.

TC: Right!

ES: But anyway, those are good points! Well, I think maybe we're gonna wrap this up. And thank you so much for doing this interview!

TC: Thank *you*!

ES: Yes! And if you did not get a chance to read Tonia's posts, they are all on the blog: ellenstumbo.com. And she has five posts from The Early Years, Elementary Years, Middle School Years, High School Years, and then College and Adult Years. And you can stop by her blog: toniasays.blogspot.com. I will have the links available for everybody! And, Tonia, thank you so much, and hopefully we can do this again!

TC: Yeah!

ES: Yes, and just talk about more issues from the parent perspective and the adult with a disability's perspective.

TC: I would be down for that.

ES: Yeah. So, thank you so much!

TC: Yeah! You're welcome!