Voices of ABLE2 Episode 7: Navigating FASD- A Parent's Journey of Advocacy, Love, and Support featuring Teresa Ethier

EMELOU

[00:00:00] Welcome to Voices of ABLE2, where we share real conversations about disability, inclusion, and community. I'm Emelou Porquez, and today's episode is called Navigating FASD: A Parent's Journey of Advocacy, Love, and Support.

Today I'm joined by Theresa Ethier, a devoted grandparent raising three young adults living with fetal alcohol spectrum disorder, or FASD.

FASD is a lifelong condition caused by prenatal alcohol exposure that can affect brain development, learning, behavior, and daily functioning. It looks different for every individual, with each person having their own strengths and challenges. With the right supports, people with FASD can grow, learn, and lead meaningful lives [00:01:00] As you'll hear, each of her grandchildren has their own unique strengths, challenges, and a way of understanding the world.

Their diagnosis came later in the teenage years after years of unanswered questions, and that journey has shaped not only their lives, but Teresa's as well. In this episode, Teresa shares the emotional realities of receiving a diagnosis later in life, the frustration of navigating systems and wait lists, and the strength it takes to keep advocating when the answers aren't easy to find.

Let's begin.

Thank you again so much for joining us today, Teresa. Tell us about your family, and take us back to the time when you learned that your grandchildren were confirmed to have Fetal Alcohol Spectrum Disorder.

TERESA

All three of them have just been diagnosed in the last two years. Well, the oldest one didn't find [00:02:00] out until he was almost 17, which played a really hard part with him because he always struggled with learning and couldn't figure out why.

So it was, it was very hard on him, and it built up a lot of anger with him because sometimes people don't wanna tell the truth. Mm-hmm. Or some people don't know- Yeah ... the effect that it had on the children. So he struggles. He's struggled for many years, and when he found out, it felt like his whole world crashed So it made it really hard trying to get him to understand he's still the same person.

Mm-hmm. It's only a title. It's not, it's not him. Yes. And he still struggles today, you know, because he couldn't figure out why people couldn't be truthful with him. Mm. And maybe things would've been different for him as he grew up. So it made it very [00:03:00] hard for him. Um, the youngest one, uh, was diagnosed with it, uh, a year ago.

Mm-hmm. Um, he had a global development growing up. How they determined of with a- all his... Well, they call him kind of mentally challenged sometimes in his paperwork. Mm-hmm. And he's a young lad that just, he's 17 now. He's a young lad that is like, "So what do I do now?" Like he's that mellow kid there. Yeah.

Like mellow. And it's like, "Oh, okay." But he, he, he accepted it differently. Mm-hmm. And then the third one, uh, he was diagnosed a month ago. Yeah. So it took a while for them to get on the list, but with COVID and everything that happened- Yeah ... it didn't help everything either. Yeah. [00:04:00]

EMELOU

Yeah, yeah. And COVID certainly slowed down a lot of processes, especially for diagnosis.

And then given that, you know, your kids now are older, what was it like, um, for you as a grandparent on the receiving end of that diagnosis? Like, how did you feel when you officially confirmed?

TERESA

I think I felt the same way that each one of them felt, because like I said, the oldest one has always tried to find why he couldn't do what he did, could do.

Mm-hmm. And he, he always felt there was something wrong with him. Mm-hmm. But he could never figure out what. So I see his anger because maybe he is right, it could have been different for him. Mm-hmm. Or maybe it would, might have been not, I don't know. It's, it, it builds a lot of anger. Trying to find people to help him 'Cause now he's at that adult stage [00:05:00] pretty much.

Mm-hmm. So it, it made it harder to find the help for him than it did when, well, when he was younger. And then that was my biggest challenge is trying to help him get the, the, the help he needs, to know that he's still him. Yeah. Because he, he did a lot. He played football. Whoa. He won awards, and when, it felt like when they told him this, his whole world just crashed.

Aw. Like, in his eyes to the, to this day, he feels they could have helped. Hmm.

EMELOU

Yeah. And, and if you could share a little bit about why, um, you know, just for, uh, people's understanding about the diagnosis or the process of it, like, why did you, why did they just get diagnosed later in their, you know, adulthood or youth, not earlier in the years?

TERESA

The mother wasn't [00:06:00] open to it. Okay. And she was young herself. Yeah. You know? Like, I, I guess today they don't believe what can happen. Mm-hmm. You know? Do I blame her? She was a kid herself. Yeah. Yeah. You know? Nobody knows what the outcome's gonna be. Mm-hmm. You know? A- and it's, it's sad. You know? Like, it's maybe she didn't understand it at all herself.

Yeah. And there was really never kind of a connection 'cause of the way the courts put it. There was, like, no contact, no nothing. So it made it very hard to, uh, get the help from her also. So I think a lot of it, you can't put the blame on anybody. Mm-hmm. You know? There, there's no blame. Um, it's just a, it's a sad situation all around.

Mm-hmm.

Well, I, it's like, like do I blame [00:07:00] the mom? I don't. Do I knock her down? No, I don't. Just like I said to them, she, the, their ages nows was when she had them. I said, "Would you be able to make choice, the right choices yourself?" You know, do, do you really understand the, the, um, impact that it had, had- Mm-hmm

happened to you, you know? Mm-hmm. Unfortunately, it happened. Mm. And now, uh, they have to live with it, and they have to figure out where to go.

EMELOU

Yeah. Yeah. And I, I guess moving forward, the focus is supporting and, you know, empowering your grandchildren to live the lives that they truly want and thrive in wherever they choose to be.

TERESA

And they are. Like, they, they are, and they just don't see it, you [00:08:00] know? They, they can do anything they wanna do. Mm-hmm. But they just have to let go of that word, so that it's not who they are. It's just something they have, you know? It doesn't stop you from living.

EMELOU

When you first heard the term fetal alcohol spectrum disorder, FASD, what did you actually know about it back then?

TERESA

Actually nothing. Well, I didn't know anything really. I had to learn myself. Like, once the, the diagnosis was there, I took some ... I looked into a lot of stuff to try and figure out how, what it is about, what I can do for them. I kind of had to just learn how to help them- Yeah ... because I didn't know anything about it.

I heard of it. Don't, don't get me wrong. I've heard of it, but I didn't know anything about it.

EMELOU

Yeah. A- and, and you talked about the mother of the children who sort of felt, [00:09:00] mm, maybe ashamed of getting a diagnosis because maybe there were feelings of not wanting to confirm anything. Or because she really didn't

Like, the way the court sets it up, yeah, she didn't really get to know her children. Mm. Like, she really doesn't get that kind of information. If they're struggling, she's not allowed to talk about it, and that's the sad part because I find maybe if she was able to know what was going on more about her children- Mm-hmm

maybe things would be different. Mm-hmm. Like, like I said, I don't want the mom down whatsoever. I don't have- Yeah ... any meanness towards her. Mm-hmm. You know? It ... And like I said to my grandson, it, it takes two. Yeah. You know? Sure. You know, you have to look at the whole picture of what was going on in her life also.

Like, she was, had her own struggles, but [00:10:00] I ca- I, I really don't know everything about her except for the time that she was, when I knew her, you know?

EMELOU

And, and we see that a lot with, you know, the, the parents and caregivers that care for children and youth with FASD, is that they carry a lot of shame.

There's stigma around FASD. Um, have you personally experienced this as the, you know, primary caregiver of your grandchildren? Um, and what's that like for you as a caregiver?

TERESA

Well, they're each, they each have it, but they each have their own individual. Like, I have one who's very vocal. Um, he gets very angry very fast.

I have one that's like, "Oh well, it is what it is." And then I have one that's, "So, what do I do now?" Mm-hmm. So they, each of them are, they've all [00:11:00] been diagnosed with pretty much the same, but each, each of them are very different on the approaches. Like, um, the middle one, they said he's a very unique child with FASD.

Um, he, he does a lot where he wouldn't be able to do. Mm-hmm. He, he can do a lot of stuff where they said that he's unique. And then I have the oldest one who struggles with a lot of learning and trying to figure out things. And then I have the youngest one is just, "Oh, I'm just gonna live life. Thanks for letting me know."

So they're, they're, they're all different. Yeah. You know? But you know, it, I'm, I'm kinda glad I kinda know now more. Yes. Because now I know where I need to help them with. Yeah. You know, like I've done everything I could with them in the past, but now I need to set them up for the future. Like, I'll need [00:12:00] to know what they're capable of doing for themselves.

And I'm pretty sure they can do a lot for themselves. They just have to see it, and that's where the biggest support comes in. Yeah. And, you know, like, talk to people, um, uh, to get the understanding that you're not alone. You're not, uh, you're not unable to do things in life. You can achieve a lot in life.

Yeah. And you can. You know? Like, like I said, they all, they all played football, but the oldest one has a, a trophy, and, and he struggled back then, but the, the, the football team that he played on were amazing because they don't judge, and they help each individual to achieve. So they make- That, that's amazing

a big difference. Yeah. It's an amazing football team. Yeah. That's, that's amazing, and it's very empowering for, for him to be a part of that. That's great. Yeah. [00:13:00]

EMELOU

Yeah, and, and that's what we find too with many, you know, individuals with FASD, is that they have these different strengths, and that the condition doesn't really, does not define them fully. They are able to achieve many things. It's just a matter of finding the right supports and resources in place to bring them to their fullest potential.

TERESA

Well, I tell my grandkids everybody learns differently. Mm-hmm. There's no, no two people alike. Yeah.

Yes. They, they... Everybody learns differently. I struggled myself in, when I was young, but I didn't stop myself. Like, everybody, everybody has... I said, "Everybody has to make a goal in life." Yeah. And sometimes it takes longer to get the goal, and sometimes people can do it fast. I really encourage them.

EMELOU

Yeah, and they're very fortunate to have you on their team.

TERESA

Oh, I have an amazing team. I've always had a beautiful team for these kids. Aw. That's good. Like, from the time I got them and, [00:14:00] and to this day, I thank everybody that has helped me with them. Like, without that team behind me, I'd probably be lost myself. Yeah. Yeah. A lot.

EMELOU

And I, I can't imagine navigating through FASD on your own, so it's great to hear that you actually have a very supportive community, a team behind you.

What were the, you know, major challenges throughout the years in caring for your grandchildren, navigating with FASD, and what's kept you going through all those challenges?

TERESA

They're my grandkids. Mm-hmm. They're my grandkids. Yeah. And I'm, I'm very fortunate to have them in my life, and I'm, I'm proud of each, each, uh, time they achieve something, and I let them know about it, you know, whether it's small or big.

Um, I think it... You can't give up. Mm-hmm. Like, once you start giving up, I think they'll start giving up. And I think that the biggest part is [00:15:00] being there for them- And I help them with each challenge because they can, they can do it. They just have to see it. Yeah. And that's the biggest part is seeing what, what they can do.

Yeah. Yeah. I think, I think my biggest goal is To see them achieve. Like, I, they're all gr- they've all ... Well, the oldest graduated. I have one that's graduating out of grade 12 this year, and then I have the last one will be in grade 12 next year.

EMELOU

Congratulations.

TERESA

So they've, they've done well. They have done well.

Yeah. But I said, "You, you just can't give up on yourself." But I think the biggest challenge is, like I said, just getting the help, you know, because there's so many restrictions and there's so many waiting lists. I, I have a hard time accepting no. Is- I can't accept no. Yeah. Because I know there is an answer [00:16:00] out there.

Mm-hmm. Yeah. That if you just start ta- like accepting the nos, then your battle's over.

EMELOU

And that's, that's very admirable of you, you know, pulling through all of the hurdles and barriers and the waiting lists that-

TERESA

I, I'm very fortunate to make the connection with Courtney, though. She's amazing. Oh. Um, she's not afraid to answer the questions. She's a, a very good counselor for them.

EMELOU

That's truly amazing to hear. So just so our listeners know, Courtney is, uh, your FASD worker from ABLE2. Uh, how else has Courtney helped you or worked with you with your grandchildren?

TERESA

I think that she's helped me with a lot. Yeah. To, like, understand more. Mm-hmm. Like every step I get to understand them a little more.

So that's helps a lot. And then she's helped me, like, you have to look at teenagers. [00:17:00] Teenagers do crazy things. A bit. And you have to kind of break it down. You know, is it the learning disability, or is it the teenager, or is this the rebellion stage? So you kind of have to figure each step out without judgment.

EMELOU

Yes. Absolutely. Yeah. Um, I, I also wanted to talk about, and actually you a- you sort of answered it already, but, like, how did you reach out to ABLE2 and seek support? How did that all start?

TERESA

I heard about the program, and I, at first I had a hard time trying to connect with you guys. It was on the challenge side.

Yeah. Um, but once all the paperwork and everything kind of fell in place, uh, I, that's when they gave me Courtney as the counselor. Met up with her, and we had a chit-chat on what, what I, what I need to learn about FASD. Mm-hmm. [00:18:00] And where do I go with it, and how do I get the help for it. Um, she was able to answer a lot of my questions.

But like I said, at the beginning it was a Up and down with it. And then I, I forget who I talked to, one of the man- uh, one of the office managers, I guess. Um, he, he kind of apologized for the runaround, but- Uh-huh. Yeah ... it all fell into place. Yeah. I guess, and it was coming out of, like, the COVID part, and it was coming- Yes

out of everybody's trying. I am very proud to be part of the ABLE2. I'm very proud that they're able to give me my answers and work with me. Mm-hmm. And help my, my grandkids move forward, and helping them understand that it's okay to be, have that title in your line- Mm-hmm ... but it doesn't make you y- who you are.

Yeah. Yeah. And really showing that to my grandkids. It's, it's a word It's only a word.

EMELOU

Thank you for your kind [00:19:00] words for ABLE2. But it's amazing to see the kind of confidence that you also have as a parent in supporting your grandchildren moving forward, navigating FASD with the support of ABLE2's FASD worker, Courtney.

TERESA

Well, I think everybody, like, I think it takes a team. It is a team. Mm-hmm. It's a teamwork, you know? And a- as they always say, it takes a village, uh, no matter what age they are. It always seems to, like, just take a whole village to care for these children. Well, like I said, I got through ABLE2, and then I found out there's other programs through ABLE2 that can help them.

And then, you know, it's a, a progress- Mm-hmm ... in place. Yeah. And you get to learn all the different places where you can get the help. ABLE2 was very good for that, for me. Um, yeah. But I think we made a very good [00:20:00] connection. Uh, like, not, not every worker is that you connect with, and then there's some people you can't, and there's some people who you can.

Yeah. And I think I had a very good connection with Courtney- Mm-hmm ... from the start. Yeah. Which made it very nice. I'm very thankful to have you guys in my life- Aah ... and helping with them. And I'm hoping that, you know, they keep moving forward every day- Mm-hmm ... to help them.

EMELOU

Yeah. That's, that's incredible. Um, if you were to talk to a parent who also just got a diagnosis of FASD or another disability, um, someone, you know, in those very early overwhelming months, what would you tell them?

TERESA

I've talked to a couple of people that I, I've talked about ABLE2 with them, and I've shared a lot of the, um, information that I was given. And I tell [00:21:00] them, "Get in contact with you guys," because once the door's open, it, it helps you. Not only them, but it helps you to understand it.

EMELOU

Yeah. Yeah. Absolutely. So, uh, anything else that you want to share about your whole experience, uh, as a parent, uh, for children with disabilities?

TERESA

Just never give up hope. There's always somebody out there that can help you. Yeah. 'Cause there's somebody that will actually listen to you.

EMELOU

Perfect. That, that's a great way to end it. Thank you so much, Teresa- Yeah ... for your very wonderful insights on this, and we appreciate you taking the time to chat with me today.

EMELOU

Teresa's story is a powerful reminder that behind every diagnosis is a person, a family, a journey that deserves understanding and support. Her honesty about the challenges, the late [00:22:00] diagnoses, navigating systems, and finding the right supports highlight just how important it is to build communities where no one feels alone.

As Teresa shared, there is always someone out there who will listen, who will help, and who will walk alongside you. And just as important, a diagnosis does not define you as a person. With the right supports, individuals living with FASD can achieve, grow, and live meaningful and fulfilling lives

If you'd like to learn more about ABLE2 and the supports available for individuals and families navigating FASD, please visit able2.org. We would like to thank our presenting sponsor, Sequence Marketing. As one of ABLE2's most trusted partners, Sequence Marketing has played a vital role in amplifying ABLE2's mission, connecting with communities and sharing stories that matter.

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