

Kelly Cervantes: 00:10 My guests today are Stacey Pigott and Shalee Cunneen. These two talented women and mothers have some amazing perspective to share with us about individualized education plans. Stacey Pigott is the mother of Evan, Henry, and Eva, very apropos to our conversation. She has a Bachelor's in Education and an MA in Liberal Studies from Northwestern University. Additionally, Stacey has been a volunteer with CURE, Citizens United for Research in Epilepsy, for the past 10 years. She is now the Chair-Elect for the CURE board as well. Shalee Cunneen is the mother of Ella and Sean. She has a Bachelor's in Business from the University of Washington and an MBA from the University of Chicago. She has been a volunteer and fundraiser for CURE for the past five years. Thank you, ladies, so much for joining me today.

Shalee Cunneen: 00:58 Thanks for having us.

Stacey Pigott: 00:59 Thanks for having us.

Kelly Cervantes: 01:00 Let's start things off super simple, what is an IEP?

Stacey Pigott: 01:05 An IEP is an individualized education plan. It is a legal document from the school. But please keep in mind that we're moms. We're not lawyers, we're not school administrators, we're not advocates. This is very much a mom perspective of the IEP or our view of it...

Kelly Cervantes: 01:27 Absolutely, yes.

Stacey Pigott: 01:27 ...but, an IEP is a plan for educating your child. It has goals and accommodations for every child's learning that is individual to each student and their individual diagnosis or diagnoses.

Kelly Cervantes: 01:43 Brilliant, so I would love to hear about both of your children for whom you have had to create IEPs.

Shalee Cunneen: 01:52 My daughter Ella is nine years old, and she has severe epilepsy. That's why I'm here today.

Kelly Cervantes: 01:57 She's absolutely adorable.

Shalee Cunneen: 01:59 She's a sweetheart. We're very lucky in that respect, but she has a lot of learning delays pretty much across the board.

Shalee Cunneen: 02:05 She functions at a three-to-four-year-old level, and it's very hard, but the school and the IEP are great. Her plan includes goals for academics, as well as speech therapy. She gets two

hours of speech therapy every week within the school setting, which is wonderful. We also do some outside work with speech therapists as well as occupational therapy and physical therapy.

- Shalee Cunneen: 02:26 There are all kinds of things that go into the IEP, which is great because, a lot of these services and accommodations are things she needs help her get through the day. She also has a one-on-one nurse with her at all times because she could have a seizure at school. She has a whole team, and everyone on the team knows what to do in the event of a seizure at school. There are also things such as just going up and down the stairs by herself or going outside by herself. Ella functions like a three-to-four-year-old, and she'll take off running. There's always someone there with her, which makes us, as parents, feel good knowing she's safe at school.
- Shalee Cunneen: 02:59 Other than that, it's all about the academics, her goals, and the therapies she gets at school. It's pretty great.
- Stacey Pigott: 03:05 My son, Evan, is 17. He's had an IEP since he was in kindergarten. Through elementary school he had a one-to-one aide. There was a safety component for him obviously with that, but it really ensures he has equal access to the curriculum like all the other students in the classroom to nurture his learning. I think the interesting thing for epilepsy moms is it's not just looking at the safety and security. It's not just looking at the learning impacts of epilepsy, but also the impact medication has on a student's ability to access the curriculum.
- Kelly Cervantes: 03:52 I think one of the hardest pieces is just to know what accommodations you can ask for and what options you have. What are some of the accommodations that you've asked for your children or that you know have been asked for other kiddos with epilepsy that have been really beneficial?
- Stacey Pigott: 04:16 Depending on how frequently they're seizing, what kind of seizures they have, and the medication they take, a child could look very different to the teacher any given day in the classroom or even from morning to afternoon. Your accommodations need to fit all kinds of scenarios, so it's a pretty fluid list. For instance, my son's accommodations deal with cognitive processing speed to make sure there's no timed work and he has extended time on tests. Additionally, it always takes my son so much longer to do every single assignment. He was struggling just to make it through the school day. It's so hard. Then he has to come home and do a homework

assignment that maybe should last an hour, but it could take him four hours.

- Stacey Pigott: 05:14 That just didn't seem fair. The school board has a policy that says for every grade that your child is in, they get a certain number of minutes of homework. For example, first grade cannot no more than 10 minutes. Second grade cannot no more than 20 minutes. For each grade, what I basically said is, "He is doing 20 minutes of homework. Period. Whatever he can do in that time period is what's going to come back to school." That is really easy to do at the elementary years. It gets a little dicier at the junior high years, but we stuck to that. Often if the team was not sending back accommodated homework with him each day, I would mark it up. I would say, "You know what? He doesn't need to do these 50 math problems, he can show you he knows it in these five."
- Stacey Pigott: 06:04 I would circle the problems, and that's what he would do, so that's an accommodation we would adhere to for cognitive processing speed.
- Stacey Pigott: 06:13 Preferred seating, frequent breaks, getting drinks of water, things like that are really helpful. Resetting kids because they are struggling throughout the day. A lot of our kids have executive function issues.
- Kelly Cervantes: 06:29 What does that mean, executive function?
- Stacey Pigott: 06:30 They have a lot of trouble planning, sequencing, problem-solving. For example, frontal lobe issues make it really difficult to know what their homework is each day, organize a notebook, take classroom notes and have it organized in one place. Kids with executive function issues need a lot of help staying organized. You have no chance of doing your homework if you don't know what your homework is. Many schools now use online apps like Schoology and Canvas. These apps are lifesavers and are really helpful. Some kind of organizational system or executive functions system is really important as well to teach them the skills to try to get organized.
- Shalee Cunneen: 07:22 We have had some interesting accommodations. For example, when Ella was potty training, she needed to be near a bathroom. That's an accommodation you could have, or if your kid is in a preschool class or kindergarten class, there needs to be a bathroom nearby. Also, kids with epilepsy can get really tired throughout the day. My daughter was still taking a nap in kindergarten (which was a full day), so we had an

accommodation that she would go up to the nurse's office. They had a mat, and she would lay down and rest, and that was one of my big holdups for full-day kindergarten, but I know that she needed that time. She needed a longer day, and that's another example of an accommodation. We provided a seizure monitor because she has to be watched when she sleeps. It's all a fluid process, but I think that was an important accommodation that I didn't even know that they could do. But then, we asked for it, and they did it. Don't be scared to ask for accommodations you think your child needs.

Stacey Pigott: 08:14 I think a great example for us is that when Evan was five, he was on such high doses of Depakote his hands were always shaking. They're teaching you how to write when you're five, and he couldn't write. His hands were shaking constantly, so his handwriting, as a result, is horrible. He can't read it. Teachers can't read it. We needed to have an accommodation that he has access to keyboarding in any class he wants. It's something that holds through as kids gets older, even into things, such as ACTs and SATs. Those IEP documents can be used in other ways as well to provide accommodations for students.

Shalee Cunneen: 08:58 Yeah. Another example of an accommodation is that my daughter needs to take frequent breaks. Her accommodation is they take her around the hall. She gets to catch, play ball, or run around for five minutes and then go back to sit at the table and work. They have the accommodations at all different levels for the kids that are really important for their learning.

Kelly Cervantes: 09:13 That's incredible. In my situation, Adelaide just turned three, and we decided to keep her at home for the time being and to not put her in the school system even though the school does have to take her. The public school system does have to take her, which is really important for all parents to know. For us, the risk-benefit of having her in school with a compromised immune system at this point with her cognition so low just wasn't worth it to us. But, at some point, it might be, I'm just so overwhelmed. How do you even get the process started?

Shalee Cunneen: 09:54 The first thing you do once you're done with early intervention at age three is contact your school. They will set up an evaluation. The district will probably send you a bunch of questionnaires to answer and gather some data on your child. Then, they will set up a full evaluation and meet with you and determine what they think is the next best step for setting up their therapies and services at that age.

Stacey Pigott: 10:14 The school has a full team: psychologist, occupational therapist, and physical therapist. They will all do an evaluation on your child, and there's an opportunity for families who have done private therapy and private evaluations to bring those evaluations in as well and to try to make it a joint decision. There's also increasingly number of hospitals who have someone on-staff who will help you with your child's IEP, at least for kids with epilepsy. Sometimes, bringing them along as an advocate during the process is really helpful.

Shalee Cunneen: 10:53 Yeah. I think getting advocates on your side is very important, especially at first because you're new to the whole process. For us, we didn't know what to expect. It was a little bit overwhelming because people are giving you advice on your child and saying what they think you need. You obviously know your child best, so you have to be willing to speak up and say if you agree with something or don't agree with something. You're the person who knows your kid best. You need to do everything you can for them because you're the one that's gonna fight the hardest. I think everyone has your kid's best interest at heart, but there's limited resources. Getting whoever, you can to these meetings, especially at first, is going to help you. We took in my daughter's speech therapist and we brought in her OT, and said, "Hey, can you come to this meeting with us just to help out?"

Shalee Cunneen: 11:42 A lot of outside therapists have been to a lot of these and so, they offer assistance as to what you need to ask for.

Shalee Cunneen: 11:49 I think that's important.

Kelly Cervantes: 11:50 I feel like both of you have had positive experiences in creating these IEPs, but I imagine that there have also been obstacles along the way. What are some obstacles parents should be on the lookout for?

Stacey Pigott: 12:05 IEPs are expensive for school districts, and it can be very challenging for school districts. They don't hand them out like candy. The school district will really protect and safeguard them because IEPs should only be used for the correct students. Some school districts have, what I would almost liken to, a gatekeeper effect where they might deny certain services. Just because they deny someone, doesn't mean that you are not entitled to get them. Sometimes, you have to take the no and turn it into a yes, and that's where parental advocacy is critical to. We know our kids best. We know what they need. We know what they're struggling with in school and medically. It's just very important

to advocate for your child and continue as respectfully as possible fight these obstacles. Some districts are lovely and really bend over backwards to provide support and services. It's varies widely depending upon what school district you're in.

Shalee Cunneen: 13:21 Yeah, I agree. I think, for the most part, we've had a pretty good experience, but we have had an experience at a prior district that wasn't so great. It's very disheartening; I'm not an aggressive person. Luckily, my husband knows what to say and knows what to do, and is like, "No, this is unacceptable. We need to do more for her. She needs more than this, and this is why." You have your facts, you have people that know her, you can have your doctor write letters. Like I said, have other people that know your child and know their disabilities come with you to the IEP meetings. I think that really helps. Because, if you state the facts, there are things the district has to do. But, like Stacey said, "for the most part, everyone's there to help. Everyone wants to see your child succeed. It's just there are limited resources."

Stacey Pigott: 14:04 What separates us with epilepsy from other special needs is if you have a child, for example, who is on the spectrum, there's a pretty clear protocol and a therapy program that a lot of people adhere to. It's accepted within the parent groups, and it's accepted at school. With epilepsy, it's so variable, depending upon the child. It's so variable upon how they're cognitively impacted, or upon the medications they take. We beg and borrow from other disabilities to work through a therapeutic program, but we don't have a clear set of identified issues that we can all work through. For example, for my son, cognitive processing speed is the most debilitating part of his epilepsy. The more I talk to other parents and doctors treating kids with epilepsy, it seems to be a pretty common theme.

Stacey Pigott: 15:14 For example, with Evan's accommodations, I have to look at the IEP to make sure, my son never has any kind of timed work whatsoever. My son has been in a classroom where a teacher has been snapping. No, no, no, no. They can't handle that. Anything that's going to add that time pressure is really going to hurt a child; a teacher may have been doing it, keeping pace, and whatnot. There can be a very good educational reason for it, but you have to advocate, "No, I'm sorry. This is not gonna work for my child, this is actually going to have the opposite effect." Finding a group of other parents is difficult, but it's really needed.

Shalee Cunneen: 15:58 Yeah. When we moved from the city to the suburbs, we didn't really know anyone. My daughter goes to an outside therapy place. I asked them, "Are there any parents you could put me in touch with who have kids who are in this district, so I can ask them questions?" I think that was great.

Stacey Pigott: 16:14 That's a great idea.

Shalee Cunneen: 16:15 I was talking to other people who've gone through the process there. Granted, they might have a different diagnosis. One of the big things for IEP that I forgot to mention earlier is communication. I think you need to lay out on the line right away that we need strong communications back and forth, especially with kids with epilepsy because each day is different. For example, Ella had a seizure this morning. I had to let her team know that, "Look, she had a very long seizure last night. She might not be herself today." They can also start to see patterns that will direct her learning because she might need a lot more breaks today. Maybe she will have an amazing day and not need as many, but they need to know what to be on the lookout for. I think that was one thing we left out originally in her first IEP.

Shalee Cunneen: 16:58 Now, we know communication is huge for these kids. We need to know what's going on day-to-day. Was there a medication increase? Are we weaning off a medication? All of that affects their day and some kids with different diagnoses don't have that variability in their day-to-day activity. I think that's huge.

Kelly Cervantes: 17:18 How does it work when ... you have this team at one school, and you figured out all the kinks. You figured out what you need. Now, your child is going to middle school, high school, or college, which is in your very near future, Stacey. How do you make those transitions? Is that just an accrued knowledge when you go into the next meeting?

Stacey Pigott: 17:46 There are transition teams from the school where they handle transitions from school to school, even from elementary to high school. The IEP can read a little differently depending upon the level of academics at that school and where your child is at that particular time. It is more than just the IEP document and following it.
The kids themselves struggle with the transitions a lot.

Shalee Cunneen: 18:17 They do.

Stacey Pigott: 18:17 A lot of times, you think you've got something set, you have your transition plan, and you get them into the new school. They regress, that's pretty standard. I think that's pretty common.

Shalee Cunneen: 18:31 It is. We have run into that. My daughter's been in a few different schools. This year is her first year at the same school, same complete team, and a little bit different IEP. Obviously, we make tweaks every year, but she hit the ground running, and that was amazing. Am I nervous about the next transition? Very much so, but you just take everything that you've learned over the process and try to make it as seamless as possible. But, it's not easy.

Kelly Cervantes: 18:58 While all of this is going on and you are tweaking and fine-tuning, there is an emotional component that is, I'm sure, playing out very strongly for you both as parents, as well as for your children. Can you explain what that's like and what to be on the lookout for in terms of how that plays out emotionally?

Shalee Cunneen: 19:26 I think it's always an emotional experience. People are in there talking about your child. Let's face it, they're not exactly talking about all the great things your child does. They're talking about all the things you need help with and/or he or she needs help with. It's hard. I've left multiple meetings crying, just because you're hearing it all. You might not disagree with it, but it's just like, "Oh, my gosh." Then, I've also left a meeting crying because I was happy because it was a good meeting. Everyone was there to help her, and it's an emotional experience. I get emotional just thinking about it right now because it is a very emotional experience. But, when you feel like the people are invested in your child and that things are going so well, it's overwhelming in a good way. You just have to get ready for that because I don't think I knew walking in the first time what it was really going to be like.

Shalee Cunneen: 20:12 My daughter had other evaluations for early intervention, but this is a whole team. Now, we're starting to talk about her life in school, and it can be hard to see the numbers they give you and where your child compares to typical kids. You know in your heart where your child is, but it's not fun to hear that. At the same time, the school is there to help you. You have to remember this is all to help your child succeed in school and keep them safe. I think you just need to be ready for it to be a somewhat emotional experience.

Stacey Pigott:	20:44	Also, if you have to advocate for your child that puts you in a position where you have to repeatedly point out where they're falling short, how they're not succeeding, or what certain problems they face. It's not a pleasant place to be, and yet you have to spend a lot of time there. I think my biggest recommendation to people, is to just always adhere to the 24-hour rule. It's so easy to respond when a child comes home, and they have had a bad day. Obviously, this doesn't apply if a kid had a seizure during the school day or there's an emergent need to talk to a teacher. A lot of times there's a thought that maybe an accommodation hasn't been followed. You wanna just so badly rattle off that email and say, "No, this was in the IEP," or, "This is an accommodation." Wait 24 hours because we are super protective.
Stacey Pigott:	21:40	We're mama bears who will do anything to try to protect our kids' experiences. Unfortunately, a lot of school districts have with over-enrolled classes. The teacher load is massive. Within each class, one-third of that class could have IEPs. We're not talking about just one or two children, so there is a time and place to recognize what their experience is and what they go through.
Shalee Cunneen:	22:17	Yeah.
Kelly Cervantes:	22:18	Where can you find help to navigate this? Is there help to navigate it?
Stacey Pigott:	22:23	The school district has the legal responsibility to provide the support and all the evaluations and all the therapy that a student should require allowing them to access the curriculum in the least restrictive environment. But, if a school is not doing that, there are advocates that are out there that usually function in legal offices. You might have an IEP or a special-ed lawyer and a less expensive way from getting services from that law office is to work with one of their advocates, but that costs money. That, still, is a cost that a lot of people don't have. Some hospitals are starting to bring in IEP advocates who can help parents tremendously. Then, there are some places like Toronto's SickKids Hospital that have schools in their epilepsy center.
Kelly Cervantes:	23:18	Oh, my gosh.
Stacey Pigott:	23:18	They're amazing.
Shalee Cunneen:	23:20	Amazing.

Stacey Pigott:	23:20	If a child with epilepsy is really struggling in school, the parents can pull them out of the public school. They can enroll them into the epilepsy classroom, and they're there for one calendar year, and they will work with that student to get them caught up to grade level. Then, when they send them back to their original school, they will help retrain the staff on what accommodations to offer.
Kelly Cervantes:	23:44	Wow, that's amazing.
Stacey Pigott:	23:44	It's an amazing model.
Kelly Cervantes:	23:47	Yes, we definitely need that here.
Shalee Cunneen:	23:48	How do we get that in the US?
Kelly Cervantes:	23:52	Exactly. Well, thank you, ladies, so, so much for letting us pick your brains and for sharing your experiences. I think it is incredibly helpful to so many other families out there who are either just starting on the IEP journey or are well into the thick of it. I know it helps me. Thank you, guys, so much.
Shalee Cunneen:	24:13	Thank you.
Stacey Pigott:	24:13	Thanks a bunch.
Shalee Cunneen:	24:14	Thank you.
Kelly Cervantes:	24:16	I wanna thank Stacey and Shalee for their insights into how IEPs work for children with epilepsy. It was so interesting to see how parents participate in the IEP process. If you are watching this episode and know a parent who can benefit from the information we shared today, then please share this episode with them. Also, if you can, then we'd be grateful if you can share this episode with your social network on Facebook or Instagram. Thanks so much.