Navigating Special Education: I don’t know what I don’t know

*In this episode, we hear again from Christian Davis, a parent in Southwest Ohio, and Amy Welly, a parent in Northwest Ohio, as they share their experiences navigating the special education system with their child. They open up about the good and the not-so-good experiences they had working with their schools to ensure that their children receive the quality education they deserve. We will also hear from Dr. Kenyona Walker, a Senior Project Manager and a Licensed School Psychologist, as she provides her perspective as a special education professional.*

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# Episode Transcript

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**Christian Davis:** Every parent, regardless of their race or ethnicity, their financial background, we all want the same thing, which is to make sure that our kids have the best educational experience as possible.

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**Thomas Capretta:** Welcome to Family-to-Family. This is a podcast for families by families on topics and questions about the education system in Ohio. I am your host, Tom Capretta, coming to you from the Ohio Statewide Family Engagement Center in the Center on Education and Training for Employment at THE Ohio State University. Now let’s get to sharing Family-to-Family.

[Music]

**Thomas Capretta:** Hi, Fara

**Fara Allen**: Hi, Tom. Are you ready for another episode of Family-to-Family?

**Thomas Capretta:** I sure am. I am actually super excited for today’s episode because it centers on a topic near and dear to my heart, families navigating special education.

**Fara Allen:** Oh, I agree. It can be such a daunting, scary, anxiety inducing process and families really rely on their schools to provide them with accurate and unbiased information.

**Thomas Capretta:** Exactly. To make sure that students and families have the information they need, access to additional resources, and have input in the process requires strong planning, communication, and partnership between schools and families.

**Fara Allen:** Whew! There’s a lot to unpack here and we know every family and child’s story is unique. Are you ready to jump in and hear a couple of these family experiences?

**Thomas Capretta:** I sure am. Let’s get sharing family-to-family.

**Amy Welly**: My name is Amy Welly; you can call me Amy.

**Thomas Capretta:** Amy is a parent from Northwest Ohio.

**Amy Welly:** I am a mom of six. My second child, when he was about 18 months old, we had started him with early intervention. After early intervention when he started preschool, we're like okay now he'll do good in preschool, which I mean he did, but we had some behavioral issues and some more concerns.

**Thomas Capretta:** It can be scary for any parent to begin recognizing concerns in their child’s behavior. Here, Amy shares just how scary and confusing addressing these concerns can be.

**Amy Welly**: So, his pediatrician had actually sent him down to Nationwide Behavioral Developmental Center. We did the autism evaluation, not once but twice, because the first time that we did it the doctor that did it said that if she was a betting person, she was only 50% positive that my son was autistic. And obviously 50% didn't sit right with me because I mean that's way too much like you know 50% but there's so much that can happen. So, we did the evaluation twice, and the second time that we did it she gathered information from his teacher, which was at Lincoln it was his very first full year at Lincoln and my first full year meeting Michelle, so this is where Michelle being a godsend actually comes in.

**Thomas Capretta:** Finding your champion, a partner in your child’s school can make all the difference for making sure a child receives what they need to be successful.

**Amy Welly:** Nationwide had told me my child was not capable of learning and not only that he was not capable of learning. That he would hinder the learning of other students in this classroom and their recommendation was for me to take him out of the preschool that he was in which was Lincoln elementary and put him in the Center for autism and dyslexia. So, I went to Michelle first and his teacher like I got a meeting between both of them, and I explained what nationwide had told me. Michelle’s response was you leave that baby alone. You leave him here. So, we did.

[Music]

**Christian Davis:** My name is Christian Davis.

**Thomas Capretta:** Christian Davis is a mother from Southwest Ohio.

**Christian Davis:** So, I have nine children altogether I don't think I mentioned that, but I have nine children altogether. I have two sets of twins; four of my children are grown. I have three children that were on educational IEPs. And I knew nothing about the IEP process right. I felt like I was getting kind of nowhere with the school. I felt like they were using a lot of the jargon or large vocabulary that, at that point, I wasn't really familiar with, nor were they really taking the time to sit down to work with me to understand that process. So, manifestation hearing, that's a term that's heavily used within IEPs that the average parent or even myself 10 years ago had no idea what that meant. But I went above and just kind of like looked, googled, I’m like what is the minute-based manifestation hearing, or who can help me understand that process.

**Thomas Capretta:** Jargon is a common barrier to effective school-home communication and there is no area is this more true than special education. While Amy found a partner in her child’s school, let’s hear about how Christian looked for a partner in the community.

**Christian Davis:** So, then, I reached out to our legal aid. So, I encourage parents who have children that may require educational or behavioral IEP to reach out to their local legal aid, because their local legal aid does have an educational department that will help you and represent you for free during like manifestation hearing. But again, the school districts didn’t say, hey we see that you're a parent that's struggling through the IEP process or you don't even know how to advocate for IEP. Why don't you go ahead and reach out to legal aid, and they can help you. That's free information that's a free program everyone is entitled to that service. But my school district, they knew of it, but they were not helping me through it, if that makes sense. So, I had to go out outside of the school community to find help to help me access a school program or a school resource. And then I started to also look to see what resources were available at the state level, because I realized that certain resources were only available by zip code or school district. But then I wanted to know well if I live in the state of Ohio and, you know, you now have the Ohio Department of Education what other resources are available to my children, regardless of what school districts they’re in, like are there resources that are state driven and state accessible?

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**Thomas Capretta:** We know families receive much of the information about what’s going on at school from other families. It’s actually one of the reasons we started this podcast. Check out how Christian took her journey even further by connecting with other families.

**Christian Davis:** As soon as I found something out, I would literally go back out and just share it with the masses because I’m like I can't be the only person or the only parents experiencing this. So, as I was finding out information to better help my children, I started having conversations with parents who had similar stories. And then that's how my support network was being shaped. Because now, I have a mom that, you know, we’re connected just because our kid has an IEP, or our kid has behavior issues or medical issues. Or, you know, I have a nephew that has autism. I had no idea, I didn't know anything about autism, but now I have a whole support network of parents that have children with autism. So, I’m learning. As I’m educating my network, they're also educated me.

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**Amy Welly:** His teacher, from that point on, like with the IEP we made modifications to his IEP but without modifications his teacher made adaptions in the classroom for him that would help him learn without having to change his whole structure and routine and his entire plan. So, they made the adaptions in the classroom where, you know, he couldn't tolerate sitting on the carpet. So, they let him sit in a chair on the carpet during carpet time when he couldn't focus. They have the little beanbag weighted lap pads. They put these lap pads on him that, for whatever miracle purpose, it grounded him out and it by him sit there. They gave him stress balls so when he started getting overstimulated or overwhelmed, they gave him the stress ball and he was able to squeeze the stress ball. And, like I said, that was his first full year there. He was there for three years. The next few years of being there, anything that we needed for him, they were there. All I had to do is say, you know, hey this is what's going on, and they're like, they were there, like, how can we help, what do we need to do, what do we need to do for him to succeed.

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**Thomas Capretta:** Amy’s experience provides a great example of a responsive and positive home-school partnership. Her appreciation and respect for the teachers who proactively engaged and supported her child shines through here.

**Amy Welly:** If every school ever operated the same way Lincoln preschool does because they set the parents up, for like, your child is going to succeed in this world, your child is special, your child is loved, your child is our goal. So, they give the parents this sense of hope for their kids. And if every school could operate the way Lincoln does, there would be no issues in the educational system.

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**Christian Davis:** I think that the biggest benefit, at least for my children, is that now my perspective has shifted. There's a thing, where you know, when you know better, you do better, and I literally honestly believe that. I think, as a parent, I became super frustrated with one child. In particular, my youngest, he's nine now, but he was having a lot of trouble with the school that he was at. He was having a lot of trouble adapting. And I think, as a parent, you know, I was so fixated like oh my God, this is a good school. I want my kids to go to a good school. They have to go to a good school, best education. Every parent, regardless of their race or ethnicity, their financial background, like we all want the same thing, which is to make sure that our kids have the best educational experience as possible.

**Thomas Capretta:** Christian makes a good point about wanting kids to have the best educational experience as possible. Here, she emphasizes supporting your child’s learning and ensuring their school is the right fit.

**Christian Davis:** But with that being said, it may not be a good fit for your child. And the more I started to realize and educate myself on, you know, your child's learning styles or your child's temperament or, you know, however your child can adapt. Then I was able to understand my child a lot better. And once I began to understand my child as an individual and focus on what their educational needs were, then, their experience became just a whole lot better.

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**Amy Welly:** So, once we get to kindergarten our world crashed with him. Because it was, you know, he was in a different building, different teachers, different staff.

**Thomas Capretta:** Here Amy discusses that even after establishing great partnerships with teachers and staff at a child’s school, transitions to a new grade or building are inevitable. Ensuring the continuity of services and establishing new relationships takes a lot of communication.

**Amy Welly:** So, for the first nine weeks it was pretty rough. It was trial and error, it was me advocating for my child like no like don't let him do this. He would they would let him sleep his entire school day I’m like no he's going to fall behind, like everything that he's learned he's going to lose. So, we finally got it to where, I’m like, no, you need to get him up, to where they realized, no, this is a behavioral thing. That child shouldn’t be sleeping the whole day. To the principal literally had to go in the classroom. I’m like, get him up, make him stand up beside his desk. And then she did realize he's not sleeping, he's acting like he is, because he grabbed the corner of his desk and picked his desk up with him. So again, like I said in the beginning, the doctor that initially diagnosed with autism said he was not capable of learning, and he was going to hinder the learning of other students. You know, my first grader is in the end of a third grade reading level, my first grader is one of the top spellers in his classroom, my first grader is one of the top math students in his classroom. Through the biggest struggles and everything you know with the teachers, with trying to get you know what he needed. This year, I had his intervention specialist look at me and asked me are the goals on this IEP accurate, because this is not the child that I see. Like are the goals accurate? And you know, he did that, like as a parent, I’m proud. But he did that. He did that, because he has teachers at the school and a parent that's going to be like no this isn't working, we're going to do what we need to do for him to succeed.

[Music]

**Thomas Capretta:** Christian wraps up our family conversations with a call to action.

**Christian Davis:** Continue to seek answers and never take no or never take I don't know as an answer just continue to seek answers. You know, if you're not getting heard at your local level or within your school district, you know go to your board. If you're not being heard at the board level, you know, go to the state. If you're not being heard at your state level, you know, look to see what other resources are available in other states and advocate for those resources to become available in your own State. And then, you know, and not to get like political because I’m not a political person, but what I will say is that, you know, we elect board members, we elect, you know, mayors and we elect City Hall members for a reason. And a lot of times what I found out is sometimes they are completely clueless about real issues that are affecting everyday communities. And so, you have to share your story whenever there's a platform for you to be able to share your story. Please do that, so that it can be heard.

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**Thomas Capretta:** We now welcome Dr. Kenyona Walker. Dr. Walker is a colleague at the Center on Education and Training for Employment here at Ohio State and frequent collaborator with the Ohio Statewide Family Engagement Center. I will let Dr. Walker introduce herself and her work.

**Kenyona Walker:** My name is Dr. Walker. I'm a nationally certified school psychologist, but I’m also licensed to practice in the state of Ohio. I’m clinically trained to provide psycho-educational mental health behavioral and social emotional supports and surfaces to students. I'm Also trained in working to build systems and also working to address systems that impacts students, educational experiences. I have a past experience with partnering with both families and educators. I'm also a skilled researcher and consultant as well, and currently, I'm. The Director of Oversight and Professional development for the Ohio parent mentor project, which pretty much means. I have extensive experience working with early learners, students with disabilities, and students who are identified as being minoritized.

**Kenyona Walker:** I really enjoyed the podcast because I believe that it was a realistic depiction of family experiences with our education system more specifically with special education. We have times where families will have wonderful experiences. They share those experiences, and then we have times where families don't have great experiences. I appreciated it kind of both of those perspectives that were shared by the parents and caregivers. I was not surprised to hear the mention of maybe a first evaluation of a student being about fifty percent accurate. One thing I'm often told parents, is when I evaluate your kiddos or caregivers, I should say it's a snapshot of many conditions of that day. So that would be, how does the student look in the classroom? So then, we need an educator perspective as well. But we also need a parent perspective. And so that first evaluation that was mentioned did not have all of those perspectives. But it's not surprising. The second one was a bit more accurate, because it had information from a caregiver from an educator, and also just some observations about the student. That was external. What I can appreciate is that the podcast allows us to see that each student is different, and so that means that when we consider each student and their individual assets and their individual needs. When we take that approach, when schools takes that that approach and even caregivers, it allows us to identify realistic expectations and goals, but it also allows us to kind of center around that shared understanding of that student and that student's needs and the expectations that we can set for that. And so that requires everyone to be on the same page and are able to identify and agree upon what each student's strengths are where they have areas of opportunity for growth, because we all do, regardless of whether or not we need specialized services. That then allows us to really accurately assess kind of what we need to do in order to prepare that student for their success in their future, regardless of wherever they're transitioning to.

**Kenyona Walker:** There were many things that struck me. I’ll highlight one. So, we have a parent who has at least three children who are identified with disabilities. We have to look at each student individually. Cookie Cutter approaches to evaluation. Cookie Cutter approaches to interventions. Number one are not really legal, based on the law, but they're not best practice. And so, to hear a mom really articulate that, in a way, that may be lost on other folks, I think, is very helpful. This is a parent who really highlighted what it looks and feels like to get lost in the sauce with special education, not really understanding the process. Acronyms that were just not, you know, reachable really created barriers just for her to be any engaged. We don't want parents, Googling.

**Kenyona Walker:** What we know, what research tells us is that parents create informal networks out of need and necessity. And what I heard that parent saying is what I learned, I'll share with everybody. So, not only did the parents share that negative experience, but the parent was able to then share all of the information that she found with other parents, and research tells us that parents who form social networks form them because they have a shared interest, they have a shared experience, but they also want to make sure that other parents have access to the information that they have, which I think is absolutely phenomenal.

**Kenyona Walker:** So, transitions in general, in general education, are difficult, amplified many times for our students who have disabilities, and they can be very difficult. Particularly because the research tells us that we don't plan well for transitions. We don't have a lot of plans, and that goes back to the fact that we don't spend a lot of time really understanding each student individually to understand. Again, where are their strengths? Where are the areas of opportunities? What are their current goals? What experiences do we need to expose them to in school, so that they can transition successfully? But we also have to be realistic, being realistic doesn't mean that we lower standards being realistic means that educators, parents, and caregivers really understand what is the capacity of this student? And how can we continue to expand that capacity? But how can we also understand what are their options? And those are conversations that can happen really early on, as we're meeting for our annual IEP meetings. We are not required to wait until the quote unquote transition time to discuss transitions. But if we have a more realistic picture of our student, their strengths, and assets, what they want to do, and sometimes we can do that by including them the actual meetings. And then what the caregivers and parents want to do. We could have a much better, robust, accurate transition plan in place. But we really should be mindful of the fact that we want them to be best positioned when they leave high school, whether it’s at 18 or even 21 because we know some of them can stay a little longer.

**Kenyona Walker:** The special education jargon - alphabet suit. Most people don't know that even folks that are that only work in like general education. Sometimes don't understand the acronyms that we use for special education, let alone some of the terms that we use, because some of the terms that we use are so specific to small amounts of student populations, and we throw them around as if they are as common as the word the, and they're not. I think that if we could put ourselves in a parent or for caregivers’ position, we would really understand the small tweaks that we need to make in order to make these conversations accessible. Sometimes providing families with just a brief kind of one or two-page dictionary of the terms that we use related to special education Research says, is extremely helpful. If we come to that table those tables with a shared understanding of the language that we are using. Imagine the game changer that would be for families because I will tell you, research tells us that an empowered parent is an engaged parent, and if we create a culture of shared language and collaboration, we are not only going to empower parents. Research tells us that educators themselves are empowered. They are more deeply invested, and their expectations tends to adjust when parents and students are at the table, speaking the same language.

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**Thomas Capretta:** Thank you Christian, Amy, and Dr. Walker for sharing with us today. While the special education remains a complex and confusing journey for many families, today we heard the approaches of two families who partnered with others and worked hard to ensure that their children had what they needed to be successful. I know that it can be difficult when we don’t know what we don’t know, but by expecting and engaging in on-going communication with teachers and school staff and continuing to seek answers to stay informed and involved in the process, students with disabilities can get the quality education to which they are entitled.

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