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JEN BAVRY: Welcome to *From My Perspective*. This is OCALI's family and community outreach center podcast. In these podcasts, you will hear from people with disabilities, their families, friends, co-workers, and neighbors. You'll hear about everyday life-- their passions, their interest, their opinions.

You'll be inspired. You might laugh or cry. But most importantly, you will better understand what life is like from our perspective. I am your host, Jen Bavry, program director of the OCALI family and community outreach center. Joining me for this episode is Katawi, a mother of a nine-year-old son on the autism spectrum.

Katawi shares her journey as a parent and advocate for her son, and how this journey took many paths in finding the diagnosis the services programs and resources to best support her son with living his best life. One where he is welcomed, he is heard, he is accepted, and he is loved.

Over the years, many factors and experiences influenced this journey. Her interview includes many programs mentioned by name. Please note that this is not an endorsement of any of the programs mentioned, but more so how these experiences and interactions influenced and guided this family's journey. So let's begin.

Welcome to OCALI's *From My Perspective*.

KATAWI: Thank you so much. Thank you so much for this resource.

JEN BAVRY: It's so great to have you here. I really enjoy talking with families and hearing their stories. And why don't you start by sharing with us just a little bit more about your family and son?

KATAWI: Oh, absolutely. So I am a single mom to an amazing nine-year-old son, Isaiah. He was recently diagnosed with autism, July of 2020. But it's been a long journey. We do have joint custody, Isaiah's father and I, so there's another challenge with having to transition between two homes, and the styles of parenting are very different. So that's been a huge hurdle to jump through all these years of really trying to find answers for Isaiah.

JEN BAVRY: And like you mentioned here, he's just recently diagnosed. But can you tell us a little bit more about how this journey began? When did things start that took you down this path prior to receiving the diagnosis?

KATAWI: I can remember when Isaiah was two years old, he would have these extreme explosive bouts of anger, and it was more than a tantrum. And I just remember being really confused and concerned because these meltdowns would last 25, 35 minutes. And it seemed like you know you snap your fingers and he would be just back to normal.

So I think it was around that time that I heard someone say he might be on the spectrum. And I can remember being really offended when that person mentioned autism because back then I did not know as much as I know now. But I thought, you know what? He's only two, let's just let him grow, and maybe it's just a coincidence.

But as he got older, the anger and the aggression really intensified. And he had a very, very hard time transitioning back and forth between homes. So it would be just explosive going from my house to his dad's, or my house to his grandma's.

Once he got to preschool around age four or five, that's when the red flags really became obvious. With just peer interactions, he was very physical in other people's personal space a lot. We noticed that very early on that those personal boundaries and social cues were being missed.

And you think, OK, well, he's only four or five, but those are the things that we take for granted. Those intuitive, social skills that kids just have, a neurotypical child just has. So when it stands out like it did for Isaiah, it's a cause for concern.

So he was diagnosed with ADHD first. And this was when he was age six. So going into kindergarten, he was diagnosed with ADHD. And because Isaiah was so talkative and had decent eye contact, I can remember autism was ruled out during his ADHD diagnosis. And there was never an efficient test done. It was just like an observation. Like, OK, well, he's looking at me right now, so we're just going to rule that out.

So at six, I thought he just had primarily behavioral problems associated with ADHD. He was super hyper, still having the meltdowns that lasted anywhere from 30 to 45 minutes. As he got older and we move into kindergarten. Now he's in a huge school with 25 other kids and the problems, they continued.

There was a lot of aggression, just he wanted things a certain way in class. They would take pictures in the classroom, he wanted to stay in the same spot every single picture. And if he didn't get to stand there, there was this explosive reaction.

So I requested a multi-factored evaluation, probably the second month of kindergarten. And that was my first experience with the school district. So this was my first ride with having to request services and trying to figure out what is his category.

And again, during the MFE, autism was highly likely based on the scoring that I did, his father did, and his kindergarten teacher. It was ruled highly likely however the district ruled it out, again, because of his verbal skills and eye contact. So his special education category was emotional disturbance. And I can't remember having such a hard time with that because it just sounds so negative.

But at the time, there really was no other category to give him so that he could've received the services and accommodations that he needed in class. I thought, well, there's the magic pill. We've got the answers. But we didn't. The behaviors continued, the aggression continued, and I had a genetic test done for him to figure out which ADHD medication would he respond the best to. I really try to give him time without medicine to see if just some of the behavioral supports and intervention strategies would stick, and maybe that was it. But the doctor made me comfortable with the idea of introducing his medication for him.

So after the genetic test, I put him on medication and his behavior did start to improve, but there were still issues with his fine motor development, a lot of sensory issues. He was certain fabrics he couldn't wear jeans. Buttons, he would have just extreme reactions. So there were still these like outliers that really couldn't be categorized under ADHD to me.

So this is when I started to feel like I think there's something else going on. But I think having a co-parenting relationship with someone that doesn't really see the needs and the concerns like I do, that prolonged getting more answers. First, let me go back, kindergarten, in the summer of kindergarten. This is so fun for me because I'm like, I'm going to put him in all kinds of summer camps, he's going to be so cool to see what he loves, and he's going to meet new kids.

I think I picked five camps just for him to explore so we could see what he really, really liked. And there were problems out of all five. So I had to scramble to figure out, OK, where are we going to go? Who's going to have space right now? And I ended up calling Haugland.

And I knew to do that because Isaiah's cousin who's about 25 now, he has Asperger's. And I know we don't even use that terminology anymore, but back when he was Isaiah's age, that's what he was diagnosed with. So he went to Haugland and just really excelled once he got to that school.

So I called to see maybe they have a summer program. And I talked to someone. He let me know the summer options were really just for the kids that were already enrolled but he educated me on those MFEs that are done in the district and how sometimes the autism category may not come, but it doesn't mean the autism isn't there. He told me about the Franklin County Board of Developmental Disabilities. So he really just opened my eyes up to all of these different resources that Isaiah was eligible for even with an ADHD diagnosis.

So after I spoke with Haugland, that's when I learned about Bridgeway and I learned about all these other programs and organizations that really advocate for children that have special needs. I put Isaiah on the waiting list at Bridgeway Academy. This was 2017-ish. Let's see from there. We go into first grade.

As I said, as Isaiah gets older, the aggression intensifies and the verbal aggression was giving a little more mature and just really inappropriate honestly. And I remember telling the district, I think he needs more of a specialized school. Knowing what I know now, there's a process. You can't just jump from A to Z, the district has to really exhaust all the possibilities before there's a placement like that.

So our next option was to put Isaiah in a behavioral learning center. So he was still be in a Gen-ED classroom, but whenever he needed that supported intervention, there was another room or a few rooms that he could go to for sensory needs, breaks, anything that he needed to calm himself down after an escalation. That's what was built into the school.

So we tried that. The anxiety really started to become obvious. A lot of disruptions in class, which led to redirection, which led to escalation. So now he's being secluded he's being restrained on a daily basis.

And after first grade is done, that summer going into second grade, we really didn't have any options for him. He did do a few days a week at We Rock the Spectrum. But what I noticed at that point was, the kids that he was grouped with, they were higher on the needs level than Isaiah was.

So there was that imbalance. And I'm new to the world, I didn't really know how to articulate what I was observing. Isaiah doesn't understand. So we're just trial and error at this point. We go into second grade. And we made the mistake of taking Isaiah off of his ADHD medicine the summer before second grade. And when he got to second grade, I mean, it was just chaos.

Day 10 of second grade, the district said we're going to have to give you an alternative placement. They couldn't handle him. And they're worried about the safety of the other kids because again, aggression with staff and peers was just at an all time high. And of course as a mother, I'm devastated because I don't want my child to feel ostracized.

And he felt like, I'm a bad kid. That's how he internalized all the school changes. And having to be pulled out of the class, and he just felt like he was different. He's on medicine. So there's all these negative messages that he's internalizing. So that was the toughest part to watch.

He was placed at St. Vincent. Nothing against that program at all, but I knew in my heart that that was not the place for him. Most of the staff and administrators, they thought Isaiah just had a behavioral problem. But I knew there has to be something else going on. He's not just going to school wanting to fight and disrupt the class. No child just wants to do that.

He doesn't have the skills to really communicate what's going on, what he's feeling, But I knew that a school that was that strict was not going to be healthy for him. And some of the strictness I'm referring to is, he could not take a backpack to school for safety reasons, couldn't bring a lunch, so he never really ate at school because he didn't like the food, but he wasn't really able to bring anything from the outside. And he still had major behavioral issues.

He did make some progress because he did have a counselor that he worked with, that they could pull in whenever they needed to help de-escalate or redirect when necessary. But in terms of great progress, based on his IEP goals, he was not progressing at all.

So COVID was a blessing in disguise because I started the intake process with Franklin County Board of Developmental Disabilities January of 2019. December of 2019 I got a benefits coordinator. And based on his ADHD, the county was going to provide five hours of behavioral support every month.

So they gave me a list of agencies that I could choose from. I found one and we went in January 2020 to do the intake interview. COVID hadn't quite started yet, but we go in and we're doing this intake interview. It's about an hour long and it's just Isaiah and myself. And she's asking us questions, and the office has several therapy dogs just running around.

And I noticed how Isaiah's demeanor just changed. I mean, he was so calm and the dogs really just made him feel so comfortable in that moment. And I asked, how do I get him a therapy dog? And the lady that's interviewing us, she said, well, honestly, after my observation here and after some of the things that you shared with me, she said, I really think he might be on the spectrum. And I wanted to cry not because I was upset or sad, because I was validated in that moment.

I knew there was something else I thought it could be autism, but I didn't have the support from other family to be able to really pursue this. So when she said that it was such a blessing. COVID is around the corner at this point, but I was able to get all of the components of this psychological evaluation done prior to the lockdown.

And it took a while because of COVID to finally get the evaluation report. So that's why January to July is a long time to wait, but finally I got the diagnosis of autism spectrum disorder. And there were areas that I didn't even know he was challenged in.

Here I am thinking, OK, yeah he's going to be high functioning. I know it's autism but he's high functioning. And there were areas where actually he wasn't. So it was such an eye opener and a learning experience to see exactly how he is affected and how much the spectrum, how wide it is. The fine motor to social skills, to cognitive processing. I mean, it's just a large gamut of things that are considered when making this diagnosis.

So that was a blessing. Now I told you back in 2017-ish, I put Isaiah on the waiting list for Bridgeway. When I got this diagnosis, the first thing I did was I called Bridgeway and I said, hey, I just want to update you on Isaiah's diagnosis. He's been on the waiting list for a couple of years now, and I let them know he's on the spectrum.

And the admissions person that I worked with, she said, "What grade is he going into?" I said, he's going into third. And she said, "Well, wait a minute. I just got confirmation. We've got a room in our third grade class." And I'm like, are you kidding me? And she said, "Yeah. She said, so let me go ahead and schedule a virtual tour with you because of COVID, we can't do all the in-person stuff."

So I do the tour over Zoom, and I talk to the directors. And within a few days, they offered Isaiah enrollment. Yeah. And it's just like divine intervention.

And with COVID, he still enrolled at St. Vincent at this point. Now St. Vincent's program is not designed for children that are on the spectrum. So receiving that diagnosis meant, OK, he's going to have to be placed somewhere else, first of all. Second of all, St. Vincent was never a long-term placement anyway. Kids go there six to 12 months, and then they return to their home school.

Because of just the chaos and just not really knowing what was what during this time, principal said, you've got two options. You can waive Isaiah's IEP so that he can come back to St. Vincent. The other option was, you can go back to the district, you can ask them for another placement.

So I did that. I went to the district I said, hey, he's had this full evaluation, he's got a new diagnosis. Can we just place him at Bridgeway? No, we can't. Because at this point, he's due for his three year renewal anyway. So they wanted to do another evaluation to really determine if autism was the correct category they have similar to the behavior learning center that we already experienced.

This center would cater to the kids that were on the spectrum. So he would be Gen-Ed. When he needed a break or some sensory stimulation, he would be removed, go down to this other wing of the school, and then come back to be with 25 other kids. And I said, no, I don't want to do that. We've already gone down that road, it did not work. I know at this point he cannot be with 25 other kids. That's way too much stimulation.

They didn't want to acknowledge my feelings, so I hired an advocate. And we did like an emergency meeting, IEP team meeting, and helped me get the district to adopt the psychological evaluation that was already done, adopt that and use that for the records review.

And they did give him the category of autism. They also gave him other health impaired, I think that's what it is. And he kept the emotional disturbance category. And usually during that IEP process the team has to agree on whether they think this is sufficient. Two of the teachers did not agree with the category of autism for Isaiah.

And these two teachers had only been around Isaiah maybe three to four months. So they had no clue as to what I dealt with from age two on. What Isaiah has experienced from two on. They thought, oh he just has anxiety. It's not autism. When you have staff or personnel that disagree with the outcome of the IEP, you can write a response to their disagreement. And I did. I wrote it and it's included in his final IEP.

But I just wanted to address those two teachers professionally, of course, respectfully, but to remind them autism does not have a look, you can't look at somebody and say, yeah, they have it or no they don't. You have to dig deeper. And I've done that for years and years and years.

So despite having to write that response and deal with the naysayers, I got Isaiah into Bridgeway. I got his autism scholarship. And when I tell you he did almost a 180, this is the first school that he is accepted. He is understood. They are patient with him.

The challenges aren't just going to magically go away. It requires a completely different teaching model. It requires a completely different mode of just being, I feel like a special person has to really understand the hearts of these kids. and they do. He's got friends. He has a best friend. We do sleepovers with his best friend.

These things that a lot of parents might take for granted, they weren't happening for Isaiah. He didn't have best friends, he didn't have friends. He had really he had a hard time with peer relationships. So now to see him thrive in this environment where he's not the only one, it's a dream come true.

And he said, Mommy, I love this school, I love the teachers. There's at least 10 people on his support team. And his therapies there every day, they're right on site. There's not this pulling him out and doing this. And it's an individual thing, just him doing it.

No, it's everybody. It's all inclusive, and he got student of the month in January. And I cried like a baby because I didn't see the light at the end of the tunnel. I was being met with just wall after wall. Naysayer. Judgment. You name it.

And now my son is student of the month, and his behavior. He's learned how to use the functional communication skills of saying, I'm mad because I'm hungry. I'm mad because, I'm hot. You know what I mean. Those things, again, we take for granted all the time.

He didn't know how to do that prior to Bridgeway. And he's only been there since September of 2020. And look at the progress already. I can't sing their praises enough, for really believing in Isaiah. And they're so creative with the tools that they introduced to him. For example, they just randomly started using a phone. Isaiah loves technology, loves devices.

So when he's escalated, they'll get a phone out and text, and say, how can we help you? And when he doesn't want to talk because in that moment he just can't, he can grab that phone and text, I need a break. They're just amazing.

So even now, I've share this, I'm fighting for my son. I'm his biggest advocate whether it's against family, or at school personnel. I'm fighting so that he can have what he deserves. He sees that. He sees my tenacity. And I teach him. I don't hide from anything. I let him know, yes, this is what you were diagnosed with.

We read books about autism. Cory stories. I have a bunch of social skill books that have interactive activities and games for us to work on. But he understands he has a disability. These are some of the limitations that he's working through. But this is how God made him. He's not bad, there's nothing wrong with him. He just learns differently.

So that is the narrative that I'm constantly feeding him. And he is empowered because of that. There are still the explosive escalated moments, but not nearly as much as they have been in the past. And this is how OCALI has really been instrumental for me.

There is a guide that you published regarding how to deal with dangerous behaviors in children. And I follow that to a T. Staying calm. I can remember reaching out to his dad. Isaiah was very escalated, we were at a trampoline park. And I called his dad just so we could have another voice, supportive voice to know that in that moment he's supported.

There's also the autism certification center with a ton of videos, stories from other families. It matters because so many times I felt like I'm on an island. Nobody understands me, there's no one else going through this. But the resources on OCALI's website have really comforted me.

And have really guided me to continue the fight, continue the journey, and to understand that there are answers, there are people that get it, there are resources, abundant resources. It's just being patient enough with myself as a mother to learn, learn, and learn more. It's a continual educational process.

As he gets older, new challenges present themselves. And I have to be prepared. The only way to be prepared is to continuously educate myself about autism, about aggression, and why it's there. And it's really been a blessing, honestly.

So we're nowhere near where I know we're going to end up because he's only nine. But we've come so far. I'm so proud of him. He's proud of himself. And I've got an amazing group of people behind me, and they're so excited about the trajectory of his life.

JEN BAVRY:

I'm tearing up. Just listening to how much where he is now and where he was before, and just being in a place now where he's understood, being in a place now where he feels accepted, being in a place now where people are really, they're really looking at him. But what you have gone through, I know is really going to help others. In their experiences, they're going through and understanding that they're not alone.

And I really appreciate the fact that you've been able to access resources. And I know that the ones you mentioned from OCALI definitely were designed to help support families and making sure that they have things that they can access and learn. And things that they can access and use with others.

So, what's based on your experience, what are things that you would want to make sure that they're thinking about, or just words of encouragement especially in those low moments?

KATAWI:

Absolutely. I would definitely say, don't blame yourself. You didn't do anything wrong. You're not doing anything wrong. As long as you are fighting and keeping your child's needs at the forefront of what you do, you can never do anything wrong. For so long, I've heard blame, it's your fault that he's acting this way or maybe you're not parenting him right, or so much, really work hard to negate everything that you're hearing.

Follow your heart. I knew something else was going on with my son. As a mother, you have that instinct, your gut is there for a reason. When you have that gut feeling that you need to do a little bit more research, get a second opinion, go with that. That is going to save your life. That is going to save your child's life.

Listen to your child. So I found that when playing with him, he opens up and he communicates a lot when he's playing his game. So use those little moments to just get to know your child. And they'll tell you what they need in their own way.

JEN BAVRY: So beautiful. Thank you again for joining me and sharing this story. It's a very powerful one, and one I know that will benefit many in hearing this path that you have been on. Is there any other final thoughts or comments that you'd like to share?

KATAWI: I just want to thank my church, Vista Community Church, for loving us. Thank you OCALI for everything that you produce. Yeah. And thank you Isaiah for choosing me to be your mom.

JEN BAVRY: That is the perfect way to end this. Thank you again.

KATAWI: Thank you so much.

JEN BAVRY: I'm glad we could do this.

KATAWI: Me too .

JEN: Thank you for listening to this episode of *From My Perspective*. If you would like to learn more about OCALI and its resources, including those mentioned during this episode. Please visit ocali.org. That's O-C-A-L-I. O-R-G.

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