FASD Video Series Transcript: Jen

Narrator: Lived Experiences with Fetal Alcohol Spectrum Disorders. Jen.

Jen: I am Jen, and I am an incredibly fierce advocate. When you hear about Mama Bear, that is me, and I very proudly wear the title of 'that mom' when it comes to doing what needs to be done for my kiddos.

I have a son, Jay, and he is nine years old. He is an amazing kid. He's so funny. He is the comedian. When he gets out of the car during drop-off line, he always has a joke for whoever's helping to open up the door for him. We finalized his adoption right before his first birthday. I was wheeled out of the hospital with him, so I'm the only mom he's ever had contact with.

So, we knew going home from the hospital that he had alcohol, tobacco, and meth exposure. He had spent 15 days in the NICU. We had no idea that the alcohol exposure was a factor. He has lots of behavior struggles. He is smart as a whip, but his impulse control definitely is a thing, and that impacts the way that he is able to function in everyday life. Wasn't until he was five that a friend of mine who happens to work in child welfare, she says, "You know, Jen, I really think that you need to look into this FASD piece." And so, me, being the mom that I am, I'm like, "Done." I go home that night, I start googling FASD Florida, which is where we are, and I came up with our diagnostic clinic that we happen to have. But other than that, I didn't even know to be looking for something prior to having that conversation with her. I even made an appointment with our pediatrician when we're in the middle of big struggles and I just said, "I need help." And I was told I wasn't stern enough as a parent, and I was told to go read a book. I left that appointment in tears.

The center is able to offer diagnostic evaluations for kiddos who have confirmed alcohol exposure for free. But the moment that they told me he had fetal alcohol syndrome, [Jen cries] it was a kick to the gut because I knew that that meant he was gonna have lifelong challenges. But it was also very validating because I knew there was something off. I just couldn't pinpoint what it was. So, again, I didn't know what I didn't know, but I knew something was off and I just really wanted to be able to help him. So, as hard as it was to get his diagnosis, it was also very freeing because then we had a direction. They came with a plan in the form of their reports that we got from the assessment team. It is a wonderful, very thorough, "This is the information that we found, here's our observations from the day, and then here's what you can do for going forward." So, a wonderful list of recommendations of books, of different providers to reach out to, of ways that we can start supporting his needs.

So, one of the things that was really supportive for Jay that I learned about was occupational therapy in sensory needs. I didn't know what I didn't know about sensory and all of these behavioral symptoms that I was seeing. So, that was one of the supports that we were able to get pointed in the right direction of. I was able to shift my thinking.

Before we had his diagnosis, his trajectory was very unknown. I didn't know if we were looking at significant behavior needs, I didn't know if he would be able to be successful in a classroom.

Once we got his diagnosis, we were able to kinda flip the script on that. We were able to put him in a place where he could be successful. I call it 'name it to tame it.' So, I can label and identify what his needs are, then I can help tame those behaviors.

If I were talking to another caregiver who either knew or suspected that their kiddo has FASD, I would tell them that it's tough in the beginning because we don't know. It's tough because we may be sad about what we envision for our children might not be possible, but our children are going to show us how amazing they are, our children are gonna show us how successful they can be, and when we find those other caregivers, when we know, we don't have to do it alone, we can truly accomplish anything.

Some of the things that Jay has been able to progress through are when he went from a non-supportive school environment to an environment where his needs are being met, he went from having struggles every day to not having struggles, being his version of successful. He then graduated from those needs to have less supports and continues to just knock it out of the ballpark. He is going from the EBD school (a school serving students with Emotional/Behavioral Disorders) that he was in initially, to transfer over into a self-contained classroom, and every time we up the bar for him, he meets it. He meets it and says, "I got you, Mom." Jay is able to be in a regular classroom, in a school that is meeting his needs. Jay is able to learn. He is an A honor roll student, and he has gone from a place where you could see how hard it was for him and how he was internalizing so much of his struggle to a flourishing, happy kid.

What keeps me positive is knowing that there are others on this journey with me, and we will not stop. In the future, I see my son proud of himself, reaching his potential, and being the amazing kiddo that I know he is.

Narrator: For more information, visit www.cdc.gov/fasd.