

The Story of Iyal

[Donnie Kanter Winokur] We started seeing a lot of hyperactivity and emotionality so we started getting a little concerned. When we first saw the developmental pediatrician, he suspected that there was an underlying syndrome due to fetal alcohol exposure. A diagnosis gives you some validation. We can say this is a disability that is a result of a birth defect.

Living with a child with fetal alcohol syndrome is like living with a constant anticipation of a hurricane. Over time you understand, on so many different levels, how this impacts not only your child, but your family.

It's very hard to be a sibling of a child with fetal alcohol spectrum disorders. It's hard as a parent not to put this burden on your typical kid because it's like you want to say, "You're the easy one, don't act out."

We know there is no magic bullet; there is no one thing that is going to change everything. Having some OT and speech and physical therapy certainly helped. And you want to try to teach social skills to your child.

But I think the intervention that I am most excited about is that we obtained a service dog. Iyal has an unconditional companion. One of the things we've learned as parents is that you want to try to create external supports for your child so that they can feel successful in any environment possible.

The earlier you have a diagnosis you can start intervention. If you see some behaviors in your kids that might look like what I'm describing, you certainly would want to make sure that you have a pediatrician examine your child, and if you're not hearing things that feel intuitively like they're answering your questions or your concerns, that you go to some sort of specialist, either a child neurologist or developmental pediatrician.

You have to look at this in the face so that you can help your child. I think it's important to tell the truth, to talk about what this is, and not to be ashamed because if you're going to teach your child to be an advocate for themselves, you have to say, This is my kid; part of my kid is that he has a disability, a profound disability."

Every parent wants their child to be happy and certainly that's what we want for Iyal. I think finding happiness within the context of this disability is going to depend a lot on Iyal feeling safe. Because he's so vulnerable it is going to be our lifelong job to keep him protected and safe.

There are ports in the storm. You just have to look for them.