

## AMBASSADOR INSIGHTS



How do you initiate a conversation about autism and neurodiversity with a family whose child may be neurodivergent?

### When the parent brings it up to you

I acknowledge the concern of the parent. I am honest about any observations that support the parent's concern. I typically state that the behavior, play, or learning style can be consistent with people who have been diagnosed with Autism. I encourage the parents to write down their concerns and discuss them with their child's provider. I also reassure parents that a diagnosis can help the adults understand the child and potentially change the support. However, the child is supported through services based on their need and the root cause of a delay or atypical development, not a diagnosis.

I usually like to start by asking a parent what they've observed that has led them to wonder about it. We would share information on Autism and possibly signs that may be a concern, maybe use an M-Chat. I think we can rely on our data (PG, M-Chat, etc.) to help a family discuss if testing is something they'd like to pursue. It's important to share with a family what their options are and how our services would continue to support the child/family.

If a parent talks to you about worries regarding their child's neurodiversity, it's important to listen carefully and be understanding. Let them know you're there to help and suggest resources like information on autism and neurodiversity. Encourage them to get professional help if needed and remind them that neurodiversity is normal.

I ask them what they are seeing that makes them wonder about this. We will talk together about things that I might be seeing that may or may not indicate autism. I share that I am not able to diagnose and that they need further testing if it is something they are interested in pursuing. I may or may not provide suggestions of places they can go to get overall development assessed. I also tell them that the strategies we have been discussing and using with their child will continue with or without a diagnosis, but that now we have a different lens to look through to see how we approach strategies.

I start by thanking the family for sharing their concerns and for asking courageous questions. I also share it's a good topic to discuss with everyone, no matter a child's diagnosis, to help improve general understanding of Autism. Then we discuss general

## AMBASSADOR INSIGHTS



How do you initiate a conversation about autism and neurodiversity with a family whose child may be neurodivergent?

Autistic traits and the child's traits that may indicate a need for an Autism evaluation. We also discuss where to schedule an evaluation. While the family is waiting for the evaluation, I provide information on the social model vs. medical model of autism (in family friendly terms) and ALL possible treatment options (It seems most families are only informed about ABA options after the diagnosis). I also empower families to make decisions that feel good for them (vs. my opinion or MD's).

Autism Navigator has great resources to go through, especially for younger children. We will often go through the Lookbooks together. They have 16 early signs of autism by 16 months. They also have 16 gestures by 16 months and 16 actions by 16 months. It is a nice way to have a conversation about concerns.

### When you see signs and are thinking of discussing them with caregivers

I had a parent who insisted their child had ADHD. During conversations about his functioning, I would make sure to bring up comments about seeming to be in his own world, not seeming to recognize when he was being spoken to or his name said, rigidity in play, stimming-type behavior (I didn't say stim, I would just mention the behavior itself), etc. Every single time she said it was ADHD as it ran in the family. Seemed defensive of it. I asked if the Dr ever mentioned any concerns about his development. Finally, I had to rip the bandaid off, and at his last session before turning three, I brought it up and said, "Has anyone ever brought up that some of these behaviors are also some of the red flags of Autism?" (I usually take this method, but don't wait *quite* as long to say something.....)

Sometimes I call the doctor and have a talk with them, to make sure we are on the same page before bringing it up.

Parents have a right to our honesty about observations and we have a professional responsibility. I will point out atypical behavior at the initial evaluation if observed immediately. I don't usually use the label Autism right away. However, I will describe what is atypical in development and ask the parents if this is consistent in how their child engages. I give parents ideas to watch for and let them know that we will be monitoring and having further conversations. I have also contacted the provider to discuss if they have concerns or had a conversation with parents.

## AMBASSADOR INSIGHTS



How do you initiate a conversation about autism and neurodiversity with a family whose child may be neurodivergent?

If you notice things that make you think a child might be neurodivergent, it's best to talk to their caregivers gently. Focus on what you've seen, not on labeling the child. Offer to help and share info on neurodiversity calmly. Always respect the caregivers' choices and privacy, and let them know you're there to support them.

I will often start with a behavior that I might believe is indicating possible autism and discuss this. If they use the word autism, the door has been opened. If not, I ask if they have heard of autism and if autism is something they have considered. Nine of ten times, they have. I then address it like I would above.

I find it's easiest to bring up observations at the evaluation if there are any observed traits. In the evaluation report, I recommended talking to the child's PCP about a general developmental evaluation (and I list Autism as a possible outcome of the evaluation). I then identify the observed traits that prompted the recommendation. For me, it is more difficult to bring up Autism/Neurodivergent traits during coaching visits...indicating the traits are not as apparently Autistic (e.g., general executive dysfunction vs. ADHD vs. Autism). Given there are big gaps in understanding of Neurodiversity it can be hard to have these nuanced conversations with families. It would be really helpful to have approved Autism screeners for Birth to 3 providers to provide more objectivity to the conversations. Currently it seems to be based on provider opinion/understanding of Autism which varies greatly. (Colleen Woyach)