



Tips for talking to caregivers when Autism is first expected

P.R.E.P

- If you are concerned about a child’s social skill development or autism, it’s important to discuss your observations with the caregiver early and intentionally.
 - Keep in mind, the goal is not to diagnosis, but rather to acknowledge and address red flags, support the family, and refer as appropriate.
 - During these conversations, balancing your response to the parents’ perspective with your message about delayed skills or behaviors is critical. This balance can be challenging, so here are some tips to manage the conversation.
 - Consider your emotional reaction to the conversation. If you seem nervous or negative, parents will sense and respond to your emotion.
 - “This is a very hopeful period. We are learning more and more about the different outcomes about a diagnosis and about the strengths people with autism.”
- ◇ **Prepare**-Invest time in how you’re going to frame and discuss your concerns
- Use a checklist or screener so the information is not solely based on your feelings, but also on an objective measure. Rely on “absolute indicators” and supplement with your observations.
 - MCHAT, Navigator
 - It’s important to assess where a parent is related to understanding their child’s development before sharing your concerns. Listen to caregivers.
 - Ask the caregiver to reflect on their child’s development. This will help you to predict and be supportive of the parent’s response to the conversation.
 - Caregivers may not use words that map clearly to red flags. Ex. Video
 - He doesn’t look at me when he nurses
 - Our favorite routine is watching the motor of my truck
 - His first word was car, not mama
 - Be open and available.
 - Consider the language you will use ahead of time. Avoid technical jargon.
 - Plan the timing. Try to minimize interruptions so the parent can engage in the conversation.
- ◇ **Recommend**-Provide next steps. Based on caregivers’ response to the conversation, determine how many next steps to provide.
- Have a list of recommendations prepared that includes referrals for ASD evaluation, Regional Autism Network, and other community-specific resources.
 - Introduce ASD specific interventions and coach the caregiver through a few.
 - Actions help counteract feelings of helplessness and fear by empowering parents.
 - See resources at end of document.
 - Think about conceptual vs actionable recommendations.
- ◇ **Encourage**-Early identification of autism is key to long term success. Use this fact to emphasize the importance of early detection.

- Highlight the child's strengths to keep the conversation positive.
 - Name the milestones the child is meeting and skills that are emerging.
 - Though these conversations can be difficult, you may be providing language to a parent's concerns or fears that they have been unable to express.
- ◇ **Pursue**-Parents need time to process and interpret the initial conversation. Pursue the conversation through follow up and check ins.
- Re-open the conversation during your next visit. Parents may or may not initiate the follow up.
 - They may have done their own research, spoken to other professionals, and consulted family members. You may need to help them navigate an abundance of autism information.
 - Be prepared for them to ask you about alternative treatments.

Example: *I'd love to talk with you about Max's development and social skills since reviewing his developmental checklists and observing him here at home. Max is such a playful child. He likes a variety of toys and is labeling so many of them! Based on the developmental screener we completed together, he is showing delays in his social skills. Specifically, he is not initiating interaction and is not communicating for social purposes such as playing peek a boo or looking at you when asking for something he wants. Not initiating early social interaction and not communicating for social purposes are early red flags for autism. This does not mean that Max has autism, but I'd like to refer you to a specialist to rule it out. In the meantime, I can teach you specific strategies to help Max improve his social skills at home. How does that sound?*

Assure the family that whether or not the child has autism, you will continue to focus on the caregiver's priorities and IFSP outcomes within the family's daily routines.

If parents disagree with you about their child's behavior or abilities, be supportive and non-judgmental.

I'm only able to share my observations and results of Max's developmental checklists, of course you spend more time with Max and know him best. I want what's best for Max, that's why it's important for me to share my concerns with you. I want Max and your family to have as many resources as possible as early as possible.

Adapted from CDC Learn the Signs, Act Early; POAC, First Signs

Resources:

- Autism Speaks 100 Day Toolkit for Newly Diagnosed Families
<https://www.autismspeaks.org/tool-kit-excerpt/caring-caregiver>

The 100 Day Kit is divided into the following sections:

- About Autism, Diagnosis, Causes and Symptoms
- You, Your Family and Autism
- Getting Your Child Services
- How is Autism Treated?
- Making It Happen
- A Week by Week Plan for the Next 100 Days
- Useful Forms
- Glossary and Resources
- CDC: How to speak to Talk to the Doctor
- CDC: Tips for talking with Parents about Developmental Concerns (Box file)

Discussion:

1. What ASD signs are most observable and therefore easiest for to discuss?
2. Which ASD signs are less observable and more challenging to discuss?
3. Think of a time you have shared your concerns about autism with parents. What went well? Is there anything you wish you had done or said differently?
4. What steps can you take to continue to support parents after you have encouraged them to talk with their child's doctor about their child's development?