

Sharing Your Concerns with Families

(Credits to Judy Ledman, Tanya Baker McCue, Mareth Williams)

Who should talk with a family about difficult information?

Anyone who works with children and has basic knowledge of child development might encounter a situation in which they could consider bringing up the possibility of developmental problems with a child's parents.

If you are part of a team providing services to a family, you will want to be aware of what other team members have told a family so you can coordinate the information you share with the family.

Why bring up the possibility of a developmental concern early with a family?

- ❖ Lessen fear of the unknown and help prepare the family for appropriate intervention decisions
- ❖ Help prepare family for the idea of a diagnostic evaluation
- ❖ Increase the likelihood of an earlier diagnosis (and earlier intervention)
- ❖ Find out if the family is already thinking about possible developmental delay
- ❖ Be prepared if family asks you a direct question about a sensitive topic

Common concerns about bringing up the possibility of developmental delay or difference:

- ❖ *Unwilling/unable to make a diagnosis*—state your concerns and acknowledge your limitations. Identify resources for further assessment.
- ❖ *Fear of being wrong*—Be familiar with typical development and red flags for concern.
- ❖ *Fear of upsetting the family*—Express concern, but don't insist; if the family needs protection from the idea, they will protect themselves. It is ok if the family rejects the idea or refuses further evaluation.
- ❖ *Cultural or language differences* - Consider cultural implications and the possibility of a language barrier in how you bring up concerns, and which team member initiates conversation.

Preparing to talk to the family

- ❖ Talk with others working with the child or family. Are others concerned?
- ❖ Choose a person who knows the child and has a good relationship with the family. Sometimes, it works well to have two people talk to the family together.
- ❖ Those who plan to discuss this type of information with families should be prepared for a variety of responses from families (e.g. disbelief, distress, anger, or even relief). It may take several approaches.

- ❖ Prepare by exploring your personal feelings about being involved in this type of situation (e.g. sadness, guilt, identification, feeling of failure).
- ❖ Explore your personal values about the types of situations you will address.
- ❖ Reflect with a colleague or supervisor.

How to start the conversation

- ❖ Discuss your concerns with the family using your own observations:

“I am concerned about your child’s ability to communicate his needs using gestures (or learn from watching other, or engage in turn-taking activities, etc.. Be specific.) Does this sound like what you see?”

“When I play with your child, I wonder about his ability to start a game with me, or to keep it going. Is this something you have noticed?”

“When I see these behaviors, I wonder about the possibility of autism. Is this something you have heard of, or thought about, for your child?”

- ❖ Listen to the family’s concerns and bridge their concerns to your concerns:

“When you describe your child’s development/behavior, I wonder about the possibility of autism. Have you thought about that possibility for your child?”

“This behavior reminds me of some of the characteristics of children with autism. Is that something you have thought of?”

- ❖ If the family asks directly about a diagnosis:

“That is something I have wondered about too. Let’s figure out how we can get more information.”

- ❖ Bring up the possibility of an extended evaluation:

“I would like some help and clarification on these specific aspects of your child’s development or behavior”

“I would like to get some new ideas for working with ____”

“An ECEP evaluation can help sort out the possible reasons for a child’s developmental pattern (or behaviors) and this can help us know how best to help your child.”

“Many things can contribute to a delay in speech development such as hearing problems, difficulty coordinating the muscles of the mouth, autism, or a different learning style. The ECEP evaluation will consider all these possibilities in order to help us decide which are important in understanding your child.”

- ❖ Discuss the possibility of a specific diagnosis in the context of preparing for an evaluation:

“The evaluation will look at the possible reasons for your child’s difficulty using his left hand. Some children who show this pattern of development have cerebral palsy. Is that something you have heard of or thought about?”

“During the ECEP evaluation, all children are screened for autism. Is that something you have heard of or thought about for your child?”

- ❖ Reassure families that they will always be able to accompany their child throughout the evaluation process and that we will be mindful of whether the behavior and skills during the evaluation are typical of their child.

During the conversation:

- ❖ Take plenty of time. Of course, in person is best.
- ❖ Be direct and honest, and at the same time, supportive and hopeful.
- ❖ Use language the family can understand.
- ❖ Avoid censoring what you think the family is prepared to hear. Use techniques for sharing (rather than delivering) difficult news such as Ask-Tell-Ask, Tell me more...., Respond to emotions and accept feelings.
- ❖ Be concerned and caring.
- ❖ Appreciate the child as a person. Point out the child’s strengths.
- ❖ Listen to the family and feedback what you hear. They are the expert on their child.
- ❖ If there is disagreement, confrontation will not help. This is a process.
- ❖ Be willing to say “I don’t know.”
- ❖ Be sensitive to feelings. Try not to interrupt a family’s feelings; tears are ok, silence is ok.

Helping the family cope with the stress of the diagnostic evaluation

- ❖ Support the family after they are given difficult information. If appropriate, help them process the information, allow them to share feelings.
- ❖ Provide information, help find resources, provide some simple positive steps the family can take to support their child's progress at home, connect the family to other families who have had similar experiences.
- ❖ Communicate with other providers, especially the one who shared the information if there is confusion or questions.



Revealing an ASD Diagnosis: Showing, Not Telling, a Caregiver

Resource Article: Roberts, Megan, PhD, CCC-SLP, "Seeing Autism Signs? Speak Up and Guide Parents to See Them Too," *The ASHA Leader*, 1 Apr, 2019)
<https://doi.org/10.1044/leader.FTR1.24042019.46>

My goal is to help caregivers see signs of ASD on their own—and to understand how an evaluation might help them learn more. To do this, I:

Provide help-giving behaviors, building on caregivers' strengths.

- "You always know what Simone wants! Tell me about how you know what Simone wants for breakfast."
- "Would you like to brainstorm ideas about how to help Simone use words to make breakfast choices?"

Call attention to potential developmental issues with the phrase "I wonder":

- "I wonder why Simone takes your hand to the fridge instead of pointing at the fridge."
- "I wonder if using your hand to get things she wants might be affecting her ability to learn new words."

Acknowledge caregivers' own observations and feelings when talking about ASD signs:

- "Yes, I see how she loves hugs, too. That is a great example of social interaction! And we have also both noticed that sometimes she doesn't always make eye contact when she tells us things, which is a potential sign of autism."

—Megan Roberts