

Tips for Early Intervention Providers to Talk about Autism Spectrum Disorder (ASD) Concerns with Families of Young Children

Lauriann King, MA; Debra Sugar, MSW, LCSW
Autism and Other Developmental Disabilities Division

Early intervention (EI) providers are often the first professionals to spend time with the families of children with developmental differences. If you are an EI provider, you are a witness to many aspects of the first three years of development. This puts you in a unique position to notice early signs of possible ASD and refer families for additional screening and assessment.

The diagnostic criteria for ASD include **social communication differences and restricted repetitive behaviors**. As you observe/work with some young children, you may notice that they do not look at people in the same way that other young children do. They may not respond when their names are called or imitate simple gestures/games that other young children enjoy. They may appear to not enjoy being held or cuddled. They may not pay attention to you as you do things that might not interest them and they don't engage you to see what you might say or do next.

Some children may be slower in using gestures such as pointing, waving bye-bye, etc. Their non-verbal communication (the way they use gestures, body posture and facial expressions) may

not fit what is going on or what they might say. When they do speak they might sound odd—robotic or flat, high pitched, very soft or loud. They may not play in the same way that others do. Something that is frequently noticed is that children may line things up or stack them up over and over. They may spin the wheels on a toy car rather than pretend to send it down the road. They may not be interested in exploring toys but go back to the same ones over and over. They may become very upset if they don't get a specific toy or book. You may also notice repetitive behaviors as you watch them use their bodies. They may spin, flap their arms and/or hold their fingers or hands in odd positions. Many young children do some of these things, but children who may have ASD do it more intensely and more often. They may also react differently to noises, smells, movement or touch. Some children seem to “over-react” to everything—loud noises, different foods, textures or touch. Others seem to be unaware of the very same things. Some may even appear to be deaf or have a very high tolerance for pain. What can also be confusing is that the same child may sometimes over-react and sometimes under-react.



Typical Concerns from Parents

What you might hear from the parents of a young child is that they are concerned that the child is not yet talking or using language. They may be noticing the same things you are: The child is not interested in others or does not enter into play; child has odd ways of playing alone and using his/her body. They may be wondering why the child responds to sensory stimuli in unusual ways. These worries are likely to be especially noticeable if there are siblings, young relatives or friends that are developing in a more typical way.

Starting the Conversation

While bringing up your concerns with a family might not be easy, it is important that you share them. The research about early intervention is clear—it makes a big difference! In order to get autism-specific intervention, the child must first be identified. Sharing your concerns may give the family an opportunity to talk about their concerns and get an understanding about why some behaviors are not considered “typical.” You may also be able to help them with their feelings regarding their own parenting skills/style and you may be able to support them through the evaluation process.

Obviously, this is a topic to be thoughtfully and carefully approached. Good and trusting relationships with families are extremely important for early interventionists and fears of being wrong, damaging the relationship or upsetting the family may prevent you from expressing concerns. Sometimes a “wait & see” approach that avoids “labeling” seems wise. It is, however, important to keep in mind that ASD currently is very much in the public eye. Others may have expressed the same concerns or the family themselves may have questions. Waiting wastes precious time as specific early intervention can have a tremendous impact on a developing young brain! Your responsibility is to honestly and objectively express developmental concerns.

The Potential benefit outweighs the risk!

Referral & Evaluation

Your support during the referral and evaluation process will be very important. You can walk through this together with the family. They may need your support in knowing what to expect, completing necessary forms and documentation, and understanding their very important role in the evaluation process. They may need reminders that, by starting the process, they are supporting their child’s development and doing what is best for the child.

You will help the family and evaluators by talking about strengths that you hear about and observe in both child and family, and by describing behaviors you have observed over time and in other settings. You can also be key in helping the families understand and follow-up on recommendations and resources in your community.

Be prepared to deal with the emotions that may come to the surface during the evaluation or after.

- ⇒Grief—Families may be grieving the loss of the child they had in their thoughts/dreams.
- ⇒Self blame/Guilt—Families may wonder what they may have done wrong.
- ⇒Fear—Families may fear what this will mean for their child and their family in the future.
- ⇒Overwhelm—Families may feel overwhelmed with the information and suggestions.
- ⇒Defense—The family may feel the need to review and express all the reasons this shouldn’t have happened or does not make sense.
- ⇒Relief—The family may have had questions and, following the evaluation, may be relieved to have some answers.

Understanding and Supporting the Family

In general, life can be very challenging for the family of a child with ASD and may include any or all of the following:

Exhaustion: Lack of sleep

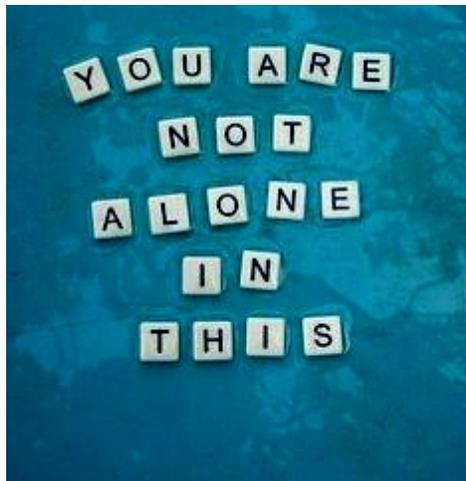
Distress: Want to do the right thing; right now!

Overwhelm: What is the right thing?

Out of Time: How can I help this child and still take care of me and my family?

As families hear the results of the evaluation, it will be important for you to understand that processing information takes time. Be patient and follow their timing. It will take time for them to “hear” everything that was said or explained and time for them to understand the impact on the child and the family. Now is the time to remind families about the child’s strengths and successes as well as their own and to remember that families and individuals have different ways of coping. While it is our nature to think about what we might do in the same situation, try not to make judgments.

As you support the family, be thoughtful and supportive about all aspects of family life, such as understanding that the diagnosis impacts the child, parents, siblings and extended family members, such as grandparents. Help them to figure out ways to participate in and be successful in their communities. Be generous in sharing information and resources with family, friends and extended family.



The Family and Provider Resources at the Autism Programs

A state-wide information line for families, individuals with ASD, and providers seeking autism specific resources. For more information about this resource call

(505)272-1852, Toll free (800) 270-1861

www.cdd.unm.edu/autism

About the Author (s):

Debra Sugar, LCSW, MSW, is a Clinical Social Worker at the University of New Mexico, Center for Development and Disability, Autism Programs.

Lauriann King works as Senior Program Therapist at the University of New Mexico, Center for Development and Disability, Autism Programs

Tips for Success:

Ideas of what to Say to Parents

- ◆ “It is not your fault.”
- ◆ “This will give us information about how she learns best. It doesn’t change who he is or what she is capable of.”
- ◆ “You know your child best and autism doesn’t define who your child is.”
- ◆ “Let’s take this one step at a time.”
- ◆ “What are YOUR priorities?”

Talking About Concerns:

Do...

- ◇ Create a safe time and place
- ◇ Be direct and honest
- ◇ Communicate concern and support
- ◇ Describe what you see and ask questions
- ◇ Listen to what parents say and build on it
- ◇ Use language the family can understand
- ◇ Be sensitive to cultural factors
- ◇ Be willing to say “I don’t know”
- ◇ Get comfortable using the words (practice!)
- ◇ Acknowledge strengths and progress
- ◇ Let parents know that no one is to blame
- ◇ Discuss concerns over time

Don’t...

- ◇ Compare to other children; with or without autism
- ◇ Make predictions about future potential, even if parents ask
- ◇ Make the diagnosis, even if you think you are right
- ◇ Use jargon
- ◇ Pass the buck

The Word “Autism”

This should **not** be your *starting* point

- ◇ Keep in mind that this may already be a concern
- ◇ Say “Some of these characteristics are seen in children on the autism spectrum”
- ◇ Better to hear the word for the first time from someone who is familiar and trusted

Talking About Concerns: How?

Be Specific...

- ◇ “What have you noticed...?”
- ◇ “What you’re saying makes me wonder...”
- ◇ “You mentioned that you’ve been concerned about...”
- ◇ “I’ve noticed...”
- ◇ “I’m concerned about...”

Reference or Comment on:

- ◇ Observable behaviors
- ◇ Developmental checklists
- ◇ Red flags
- ◇ Resources where families can learn more
- ◇ The importance of early identification and intervention
- ◇ The value of a rule out diagnosis

Resources:

- Autism and other Developmental Disabilities Programs Division (AODD) (505)272-1852, (800) 270-1861, <http://www.cdd.unm.edu/Autism/index.html>
- Autism Speaks: <http://www.autismspeaks.org/>
- Early Childhood Evaluation Program (ECEP): <http://www.cdd.unm.edu/ecep/index.html>
- <http://www.firstsigns.org/index.html> www.cdc.gov/actearly

