Date: May 26-27, 2010

Topic: How to Talk with Families about a Diagnosis of Autism

Hosts: Jen Brown & Mary Zaremba – Early Childhood Learning Network

Guest Facilitators: Judy Ledman, MD, and Mareth Williams, MD

# of Participants: 10

Introduction to the discussion:

The May audio conference calls were facilitated by Judy Ledman, MD, and Mareth Williams, MD, experienced developmental pediatricians with the CDD Early Childhood Evaluation Program (ECEP). The focus of our discussion was on; when and how to talk with families about the possibility of a diagnosis of autism and, exploring what families may already be thinking about that diagnosis for their child.

Introduction to the topic

The potential diagnosis of autism is a difficult and painful one to face with families. We know that early diagnosis is important to begin to support the family and child through meaningful interventions. Yet, the average age of identification of autism in children is 4 years. Meanwhile, families maybe wondering and worrying about the possibility of their child having autism, but we may be hesitant or unsure whether to raise the topic with them. While early intervention teams are usually not in a position to make a diagnosis of autism there is a lot we can do to support and prepare the family for that outcome.

We might find ourselves asking if I bring this up to the family, “Will I make it worse? or “is the family ready?” We need to trust that families do have ways to protect themselves. If families are not “ready” they will let us know in their way. If we don’t raise the issue families may not have the opportunity to share what their unspoken worries might be and we won’t be able to affirm those thoughts and feelings.

A story was shared about an almost three year old child referred to ECEP at the time of the child’s transition from early intervention. While the early intervention team felt that the child showed some behaviors associated with autism, autism was not discussed with the child’s mom. Prior to the ECEP evaluation, one of the ECEP pediatricians called mom to learn more about her child. After mom described some of her child’s behaviors, the pediatrician commented that these behaviors sounded like those associated with autism. Mom then shared that she had taken a class in her community a year earlier. The instructor of the class took her aside and wondered if the child was autistic. Mom did not share this with her EI team.

This story illustrates how parents will either suspect themselves or receive information from some other source about the possibility of autism. The following comments and ideas were shared about ways to communicate with parents/caregivers who may be facing a diagnosis of autism:
* It’s ok to say, “I don’t know.”
* Use your own personal observations of the child’s behaviors to share with the family, for example, “He doesn’t seem to make eye contact,” “Is this typical?” “What are some other ways he plays with the spoon?”
* State that autism may be one possible explanation for the child’s behavior.
* “When I see these behaviors (state what you have specifically seen) I think about autism.”
* Suggest an ECEP evaluation as a means to gain more information for both the team and the family.
* Use of Modified Checklist of Autism in Toddlers (MCHAT) can be a great opening to discuss family concerns.
* Use ECEP pre-referral form (listed in resources) attached.
* Call one of the ECEP pediatricians with your questions and concerns: Judy Ledman, 505-272-5894, or Mareth Williams, 505-272-2943

Judy and Mareth have developed a handout related to this topic as a resource for all of us on pages 3, 4 and 5 of this Journal.

For a certificate or if you have any questions about the information included in this Journal summary, please contact:

ecntraining@salud.unm.edu
Why should EI teams bring up the possibility of autism?

- Help prepare family for the most appropriate intervention
- Help prepare family for the idea of a diagnostic evaluation
- Increase the likelihood of an earlier diagnosis
- Find out if the family is already thinking about the possibility of autism
- Help the family cope with the diagnostic evaluation and process the information—Families hearing bad news for the first time may have a temporary “learning disability”

Concerns about bringing up the possibility of autism

- Unwilling to make a diagnosis—state your concerns and acknowledge that you do not diagnose autism
- Fear of being wrong—Be familiar with the red flags for autism. Talk with others on the child’s team; are they concerned?
- Fear of upsetting the family—Be concerned; 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 a diagnostic evaluation.

Who should talk to the family?

- Talk with all members of the EI team. Are others concerned?
- Choose a person who knows the child and has a good rapport with the family.
- It may work best to have two people talk to the family together.

How to start the conversation

- 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 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 slower 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 autism in the context of preparing for an evaluation -

“The evaluation will look at the possible reasons for your child’s speech delay. Some children who are slow to talk may have autism. Is that something you have heard of or thought about with regard to your child?”

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

“The ECEP team will ask for your questions about your child. Would you like to brainstorm some questions that might help us understand your child and how to help him? One thing I have wondered about is the possibility of autism. Is that something you have thought about for your child?”

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 or maintain an interaction with others. Is this sometime 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 families concerns and bridge their concerns to the possibility of autism

“When you describe your child’s development/behavior, I wonder about the possibility of autism. Have 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 autism:

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

**During the conversation:**

Be concerned and caring.

Listen to the family and feedback what you hear.

If there is disagreement, confrontation will not help. Allow more time.

Be willing to say “I don’t know.”

Be sensitive to feelings.

Be direct and honest.

Use language the family can understand.

**Helping the family cope with the stress of the diagnostic evaluation**

Describe the evaluation process in detail (wait list, scheduling, travel, length of the evaluation, report)

Support the best logistical plan (travel the night before, housing, presence of both parents or other family members, EI team presence or availability)

Support the family after the evaluation (help process the information, provide information about autism, help find resources, help the family understand the report)

Call us if concerned. We appreciate feedback

Call us if you want to talk about bringing up these issues with a specific family. The pre-referral form could also be used to raise these issues without identifying the family.

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