

Autism Spectrum Disorders in Very Young Children: Providing Screening and Support

In the Meantime . . .

While Head Start staff refer children as soon as possible for early intervention services, it can take months and even years to get a full diagnostic evaluation. Understanding the importance of early intervention, what can staff do to support children who they suspect may have an ASD?

Remember the importance of relationships: Young children need the support of responsive adults. Continue to work closely with families and share observations over time. Pay attention to the way a child's behaviors affect parents and you. Get support if you need it to continue to reach out to the child and family.

Partner with early intervention: Even as children wait for formal diagnostic evaluation, early intervention programs provide developmental evaluation and services. Work with families to refer children as soon as possible. Become full partners in the delivery of those services and learn how you can help.

Individualize: ASDs are expressed differently in different children. Remember that what works for one child with ASDs may not work for another.

Continue to observe: As you work with the child, continue to observe and record his or her responses, interactions and behaviors. Talk with families, and, together, identify strategies about what works well - and what does not.

Keep communicating with children: Talk in simple sentences. Get down on the child's level and try to get eye contact. When appropriate, use hand gestures as well as words to communicate.

Provide help with transitions: Many children with ASDs have a hard time adjusting to change. Give warning signs that a new activity is going to happen to decrease transition problems. Use songs, timers, and visual aids to prepare children for changes to come.

Pay attention to cues: Children with ASDs, like all children, will try to communicate their needs, whether they are hungry, tired or in need of a diaper change. However, for children for whom communication is challenging, it is particularly important to attend to these sometimes subtle cues.

Be consistent: Like all children, children with ASDs need consistent limits to help them self-regulate and control their behaviors. If a child is exhibiting an unwanted behavior, use redirection whenever possible.

Adapted from Peacock, G., & Perez, A. (in press). Autism Spectrum Disorders in very young children: What you need to know and how you can help. *Children and Families*

The Early Head Start National Resource Center @ ZERO TO THREE



Note: These slides are adapted from *Autism Spectrum Disorders: Perspectives on Surveillance, Research and Early Identification*, an audioconference featuring Catherine Rice and Georgina Peacock from the Centers for Disease Control and Prevention held on May 21, 2007. While this audioconference does not include a slide presentation, we thought these slides would be helpful to your participation and understanding of the topic.

Slide 1

What is Autism?

- **Developmental Disability**
not identifiable at birth
- **Neurological Disorder**
complex genetic interaction + ???
- **Complex Disorder**
affecting social skills, communication and behavior
- **Wide Range of Impairment**
mild to severe across areas



Slide 2

What's in a Number?

1 in 10,000

4-5 in 10,000

1 in 1,000

1 in 500

1 in 200

1 in 166

1 in 150



Slide 3

The Autism and Developmental Disabilities Monitoring (ADDM) Network

- In 1994, the 14 sites in the ADDM reported about 10% of the births in the United States.
- In 2002, 2,685 of those eight-year-olds were identified with an ASD.
- The average prevalence across all 14 sites was 6.6 per 1,000 (about 1 in 150).



Slide 4

Early warning signs of ASDs
Refer to a developmental specialist immediately!

- No big smiles or other warm, joyful expressions by 6 months or thereafter
- No back-and-forth sharing of sounds, smiles, or other facial expressions by 9 months or thereafter
- No babbling by 12 months

Greenspan, S.I. (1999) *Building Healthy Minds*, Perseus Books; Filipek, P.A., et al. Practice parameter: Screening and Diagnosis of autism. *Neurology* 2000, 55: 468-79



Slide 5

Early warning signs of ASDs (cont'd)

- No back-and-forth gestures (e.g., pointing, showing, or waving) by 12 months
- No words by 16 months
- No two-word meaningful phrases (without imitating or repeating) by 24 months
- Any loss of speech or babbling or social skills at any age

Greenspan, S.I. (1999) *Building Healthy Minds*, Perseus Books; Filipek, P.A., et al. Practice parameter: Screening and Diagnosis of autism. *Neurology* 2000, 55: 468-79





Slide 6

Parent Struggle for Answers

- Early signs may be subtle
- Lack of physical signs
- Inconsistent skills - strengths and weaknesses
- Regression in some children
- Parents often suspect their child
 - has a hearing loss
 - was “too” good as a baby
 - has language delays
- Pediatricians often first line of professional help



Slide 7



Parental Concerns

(Wiggins, Baio, Rice, 2006)

Recent study by CDC indicated most children with an ASD diagnosis had signs of a developmental problem before the age of 3, but average age of diagnosis was 5 years.



Slide 8

Impact of ASD on Family

- Emotional and financial costs
- Lack of support from family and community
- Navigating system to get help –
 - Just getting recognition of a problem is often a challenge
 - Hard to get intense intervention
 - Long waits for diagnosis



Slide 9

Impact of ASD on Family (cont'd).

- Significant stress on parents and entire family
- Siblings may also have difficulties, or must act as “caretaker”
- Intense and complicated needs of child
- Bombarded by options of interventions



Slide 10

Learn the Signs. Act Early.

www.cdc.gov/actearly



Opening the Conversation with Families

Staff may be the first to talk with a family about concerns regarding their child's development. Other times, families come to EHS with concerns about their child's development and/or their child already has a diagnosis. Individual parents and extended family members can respond very differently at any point in this process. With time, as families learn more and their children grow and develop, feelings change. Parents will sometimes go through the stages of grief, responding initially with denial, disbelief and/or anger. Some parents feel a tremendous sense of guilt, a sense that the condition is their fault. Other parents might move quickly to acceptance. Often, families will express relief that they are getting help that they wanted. In some communities, families might see the ASD affecting their child as a good spirit or an evil demon. Staff can support families by giving them opportunities to express their feelings and beliefs, validating what they are saying, offering information, and connecting them with resources. It can be hard to open these different conversations with families. As you do so, remember your role. **Without special expertise, program staff are not in a position to diagnose or even suggest autism or autism spectrum disorders to parents.** Talk about your observations, a child's behaviors and skills, and available resources. Here are some questions to help:

As Part of a Screening Process:

Tell me about your child.

What do you love about him or her?

What do you see as his or her special strengths?

What has challenged you?

Do you have any concerns?

After A Diagnosis:

What have you heard about autism/autism spectrum disorders?

What does this diagnosis mean for you?

What does this diagnosis mean in your family/community/tribe?

What are other people saying to you about this diagnosis?

Tell me about what you see in your child's future. Has that changed? How?

Understanding and learning about a disability and how it impacts your child can be a lifelong process. How are you doing today?

What questions do you have at this time?

How can I help?

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