

Talking with Parents about Autism Spectrum Disorders

Resources to Support the PowerPoint Presentation

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Talking With Parents About Autism Spectrum Disorders: A Guide for Professionals in Early Intervention And Early Childhood Special Education

Rationale

Autism Spectrum Disorder (ASD) is a complex disorder that can sometimes involve other health, developmental, neurological, and genetic conditions. This is reason enough for you to share your concerns with parents when you see possible “red flags” for an autism spectrum disorder. Additional support for early identification of ASD comes from a growing body of evidence suggesting improved outcomes for *most* and dramatic response to intervention for *some* children with characteristics of autism. A third rationale for talking with parents about your concerns is that it demonstrates your knowledge of ASD, which will make it more likely parents will turn to you for guidance and support in the future. Finally, there are some resources and services that are *only available* to children diagnosed with an autism spectrum disorder. Your open communication with parents at this critical time can be the first step toward building a relationship of mutual trust and respect. This document is intended to provide you with information and resources to guide you in carrying out this critically important responsibility in an effective and sensitive manner.

Where to Begin

This information is intended to compliment the *Talking to Parents About Autism Action Kit* developed by Autism Speaks:

http://www.autismspeaks.org/whatisit/talking_to_parents_action_kit.php

Step 1: Go to the website to view the video (for you) and download the *Early Childhood Milestones Map* brochure (for family members). A copy of the DVD and brochures has been included in the hard copy version of this packet.

Step 2: If you or your team need additional resources on early identification of ASD in young children, the following websites are a good place to begin. Along with print resources, each site offers video clips to help professionals and parents learn to identify possible signs of ASD in young children.

Learn the Signs. Act Early. www.cdc.gov/ncbddd/autism/actearly/

Autism Speaks. www.autismspeaks.org/video/glossary.php

First Words Project. <http://firstwords.fsu.edu/>

What Families Really Need to Know and Why

The Autism Speaks training materials primarily target childcare providers and early childhood teachers in community settings. This flyer with its supporting materials is intended for practitioners in early intervention (Part C) and early childhood special education (Part B/619) programs that observe “red flags” for a possible autism spectrum disorder during the course of an evaluation. Evaluation and eligibility determination for Part C or Part B/619 services for *this* child will proceed as it would for any other. As with any child, you will be identifying and describing the strengths *and* needs of the child with characteristics of ASD. Parents need to know that early intervention and early childhood special education services are *always* individualized for a child and provided according to

eligibility and need, not prescribed by diagnosis. This is consistent with federal law and state statutes governing Part C and Part B/619 services. Parents also need to know that they made the right decision when they decided to trust you to evaluate their child. They need to know if your team sees possible signs of an ASD. They need your help in making fully informed decisions about next steps for their child and family.

Be Prepared

Step 3. You should provide parents with a list of resources: national, state and local. The *Autism Speaks Early Childhood Milestone Map* brochure recommends several websites for families. You should have additional resources available to share with families, depending on the level of information they might need. Here are sample sources of information for families at 3 levels:

- Brief and concise (6 pages)
<http://www.nichey.org/InformationResources/Documents/NICHCY%20PUBS/fs1.pdf>
- More detail, including treatment options & research (41 pages)
<http://www.nimh.nih.gov/health/publications/autism/complete-index.shtml>
- Comprehensive video course, *My next steps: A parent's guide to understanding autism*, in 2 parts. The first part explains *What is Autism?* Part 2 takes parents through next steps following a diagnosis. The video can be viewed in segments online, downloaded, or ordered from the website <http://depts.washington.edu/uwautism/video/video.html>

Practice

Your message to families could include these key “talking points”:

- 1) Some of the characteristics described in their child’s initial evaluation are consistent with characteristics of children with an autism spectrum disorder. It’s your responsibility to make families aware of your team’s concerns. Find out if they see what you see.
- 2) You have information on ASDs to share, now or later, as they choose. Find out what they already know about ASDs.
- 3) Some children with ASDs are more likely to have certain medical problems. A medical doctor can *rule out* ASD along with any associated conditions. For example, according to the NIMH website above, children with ASD need a formal audiological evaluation (to rule out hearing loss). Some may need lead screening (for children who put things in their mouths), genetic testing (to rule out conditions such as Fragile X Syndrome), laboratory tests (for metabolic problems), or a neurological evaluation (1 in 4 may have a form of seizures).
- 4) If the family wants to pursue a medical consultation, offer to share the results of your team’s evaluation. Be willing to speak with their child’s pediatrician or family physician. If the family wants a referral for a specialist, be sure you have information regarding developmental pediatricians and specialty clinics in your area of the state. If the family wants to pursue a medical consultation but does not have the resources, you will help them find the support they need (remember, any of these activities requires a signed consent for release of information).
- 5) There are some resources and services in addition to those offered by Part C or Part B/619 programs that are *only available* to children diagnosed with an autism

spectrum disorder, such as the Kansas Autism Waiver program
<http://www.kansasearlyautism.org/>

- 6) The best outcomes for children with ASDs are associated with early and intensive intervention to address medical, educational, and behavioral concerns.
- 7) Their child is eligible for services from their local Part C or Part B/619 program based on identified need, *regardless of diagnosis*. If eligible, an effective IFSP or IEP can be developed without delay.
- 8) Set a date to follow up on referrals and any requests for additional information or assistance.

Final Thoughts

Sharing sensitive news with parents is never easy, but planning ahead helps. Role-play with a co-worker or friend (preferably one who is also a parent). If you are a Part C or Part B/619 provider who needs more information or support on this topic you can contact:

Kansas Inservice Training System (KITS), 1-800-362-0390 ext. 1618 or kskits@ku.edu
Kansas Instructional Support Network (KISN) 1-913-588-5943 or shoffmeier@kumc.edu

On the following page is a “Talking Points” handout that you might leave with parents.



Kansas Inservice Training System & Kansas Instructional Support Network. (2009, April).
Talking with parents about autism spectrum disorders: A guide for professionals in early intervention and early childhood special education. Parsons, KS: University of Kansas Life Span Institute at Parsons.

Talking With Parents About Autism Spectrum Disorders: Professional “Talking Points”

- Early intervention/early childhood special education services are individualized for every child and provided according to eligibility and need, not prescribed by diagnosis. Your child is eligible for early intervention/special education services through the IFSP/IEP developed by your child’s team (including you). Your child’s individualized program plan will build on his or her strengths to address the needs we have identified together.
- Some of the characteristics observed in your child’s initial evaluation are characteristics we see in young children with an autism spectrum disorder (ASD). Autism used to be considered a rare disorder. Now it’s not. As many as 1 child in 91 can be considered to have an autism spectrum disorder, with characteristics and symptoms ranging from very mild to severe. Only a medical doctor or licensed psychologist or psychiatrist can diagnose *or rule out* autism spectrum disorders.
- Some children with ASDs are more likely to have certain medical problems. A medical doctor can *rule out* ASD along with any associated conditions. For example, children with ASD need an audiological evaluation (to rule out hearing loss). Some will need
 - lead screening (primarily for children who put things in their mouths)
 - genetic testing (to rule out other conditions with symptoms of ASD)
 - other laboratory tests (to rule out possible metabolic or immune system problems)
 - a neurological evaluation (to rule out possible seizure activity).
- If you like, your early intervention/early childhood special education program will help you talk with your child’s physician and share the results of their evaluation. However, they can only share confidential information about your child or family with your signed consent.
- If you do not have the resources to pursue a medical evaluation for your child, and you wish to do so, your early intervention/early childhood special education program will assist you in obtaining the support you need.



- There are some resources and services in addition to those offered by your child's early intervention/early childhood special education program that are *only* available to children diagnosed with an autism spectrum disorder, such as the new Kansas autism waiver program.
- The best outcomes for children with ASDs are associated with early and intensive intervention to address medical, educational, and behavioral concerns.
- Review the resources you received from your child's team. Talk with your spouse and others you trust. Make a list of your questions or concerns. Then schedule a time to meet again with a representative of your child's early intervention or early childhood special education team to discuss your questions or concerns and what you want to happen next.



Kansas Inservice Training System & Kansas Instructional Support Network. (2009, January). *Talking with parents about autism spectrum disorders: Professional "talking points"*. Parsons, KS: University of Kansas Life Span Institute at Parsons.

Talking with Parents about Autism



Talk over what you plan to say with a co-worker:

- ◆ Put yourself in the parent's place.
- ◆ Talk over potential questions.



Set the stage for a successful conversation:

- ◆ Talk in a comfortable, private place.
- ◆ Avoid talking in crowded hallways or over the phone.
- ◆ Sit close to the parent in order to best attend to emotional cues.



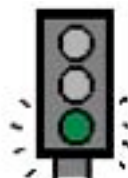
Allow plenty of time:

- ◆ For asking questions.
- ◆ For expressing emotions.



Be prepared:

- ◆ To explain your observations with facts.
- ◆ To give the parent written information and trusted internet resources.



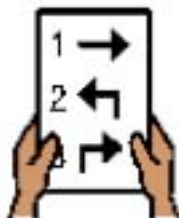
Start the conversation with the parent's observations and concerns:

- ◆ Explore what the family already knows about autism.
- ◆ Ask how they feel about their own child's development.
- ◆ LISTEN, LISTEN, LISTEN to the parent.



State your observations:

- ◆ Get to the point quickly.
- ◆ Share observations in a neutral manner.
- ◆ Be sincere and caring.
- ◆ No jargon.



Don't leave the parent's side without a plan:

- ◆ Even if the plan is to do nothing.
- ◆ Make sure the plan is clear to all involved.

Stressful Myths and Autism

Myth Autism is caused by immunization of vulnerable children.

Reality Children not immunized with rubella, measles, mumps, hemophilic influenza, pneumococcal, and pertussis vaccines have high rates of developmental disabilities, including deafness, blindness, cerebral palsy, epilepsy, and autistic spectrum disorders.

Myth Autism is a mental illness.

Reality Autism is a developmental disability impacting on understanding and use of language, complex learning, and social communication.

Myth Autism is caused by problems during labor and delivery.

Reality Prematurity and neonatal complications have not been scientifically linked to autism. Major known etiologies associated with autism include phenylketonuria, tuberous sclerosis, congenital rubella, fragile X syndrome, chromosomal disorders, and severe retinopathy of prematurity.

Myth Children with autism cannot learn.

Reality Children with autism have strengths in motor skills, fine motor manipulative skills, nonverbal intelligence, and basic adaptive skills. There is a range of communicative, cognitive, and complex adaptive abilities. All children with autism learn.

Myth Autism is caused by poor parenting.

Reality Autism is a neurobiological disorder whereby brain systems integrating language, complex learning, and social communication are underdeveloped.

Myth Experimental alternative medical treatments involving specialized diets, megavitamins, and natural therapies can cure autism.

Reality Autism is not caused by food, allergies, or malabsorption. The best treatments for autism are special education programs that build on a child's strengths, provide family supports, and comprehensively address communicative, learning, and behavior challenges. Children with autism with gastrointestinal concerns should receive competent pediatric care.

Myth There is no role for pediatric medicine for children with autism.

Reality All children require a medical home that monitors growth and development, identifies sensory, neurological, and health concerns that can interfere with progress, helps set comprehensive goals that optimize adaptive functioning, and advocates for proactive community programs that provide quality family supports.

Gray, L.A., Msall, E.R., & Msall, M.E. (2008). Communicating about autism: Decreasing fears and stresses through parent-professional partnerships. *Infants and Young Children*, 21(4), 258. Reproduced with permission.

**Talking With Parents About ASDs:
Early Intervention Services
Role-Play Scenario**

Dante’s parents, Rashida and Tyrone, were referred to Parents As Teachers (PAT) by their pediatrician shortly after Dante’s first birthday. Dante, their first child, was an irritable baby who had difficulty sleeping most of his first year of life. By 18 months, parents and parent educator were beginning to be concerned about Dante’s lack of babbling, fleeting eye contact, and inconsistent responses to social initiations (i.e., not responding to his name, or looking up when someone came into the room). Results of the routine ASQ and ASQ-SE administered by the parent educator at 24 months suggested a considerable discrepancy between Dante’s personal-social and communication skills in comparison with his motor and problem-solving skills. Parents indicated a number of concerns, especially on the ASQ-SE.

Results of the PAT screening were shared with Dante’s pediatrician at his 2-year check-up. The M.D. suggested that Dante might benefit from being around other children more, and advised Rashida and Tyrone that developmental milestones can vary widely among young children. Still, the M.D. was unable to get a hearing screening in the office, so he suggested parents contact their local infant-toddler network to request an evaluation, just for reassurance.

Members of your early intervention team have completed an initial evaluation that confirms while Dante’s audiological evaluation was within normal limits, he is significantly delayed in social-communication and adaptive behavior compared to other 2-year-olds. He is eligible for early intervention services through development of an IFSP. In addition, your team has identified multiple “red flags” consistent with what you know about autism spectrum disorders. You have reviewed the outcome of the evaluation with the parents. Now you need to make them aware of the possible significance of your team’s findings with regard to the need to rule out an autism spectrum disorder.



Talking With Parents About ASDs: ECSE Services Role-Play Scenario

Scott is a 4 year-old who had been kicked out of 2 community childcare settings and was about to be asked to leave his current family daycare home when his parents brought him to your district developmental screening clinic. “What are we doing wrong?” they asked. “He’s so smart, and so good when he’s at home, by himself. Then he gets around other children and goes ballistic! At first we blamed the daycare, but now we’re really worried it’s us, and maybe we give in to him too much at home. Or maybe he’s spoiled by being the only child...”

Scott’s DIAL-3 screening was essentially within normal limits except for the need for frequent redirection and some “quirky” behaviors noted by the examiner. A follow-up observation in the family childcare setting confirmed that Scott was exhibiting some serious ‘out-of-bounds” behaviors there. With parent consent, an evaluation was initiated, including a functional assessment of behavior in the childcare setting, along with repeated observations of Scott during daily activities and routines at home and in childcare. The evaluation also included a standardized communication test conducted by the speech-language pathologist, and a curriculum based assessment completed by the team, including the childcare provider and parents. You have finished going over the results of the evaluation with parents prior to the upcoming IEP meeting. You have confirmed Scott’s many strengths in cognition, visual-motor construction tasks, expressive vocabulary (around restricted areas of interest) and self-help skills. You have described the problem behaviors noted in his childcare setting, most notably transitioning from preferred activities, as well as Scott’s promising response to the positive behavior supports that have been put into place. The team will be recommending an IEP that includes a positive behavior support plan, at the same time establishing goals for developing “replacement skills/behaviors” in social communication and social interaction with peers. You are also recommending a goal to address a significant delay in prewriting skills. Parents are in agreement with the strengths and needs you have described, and want to know what you think is going on with Scott. They ask if you think he will outgrow his quirky behaviors.

