

Autism: The Importance of Talking with Parents

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Agenda

- I. What Children Should We be Concerned About?
 - Autism Spectrum Disorder
 - Early signs and real life characteristics
 - Screening
- II. Conversations with Parents about Our Concerns
 - What's stopping us?
 - Where to go for training & support
 - Practice: Role Play Scenarios
 - Resources for families

Objectives

- What Children should we be Concerned About?
 1. Learn to recognize possible signs and characteristics of ASD in toddlers and preschoolers.
 2. Identify resources on ASD appropriate to share with all staff and families.
- Conversations with Parents about our Concerns
 1. Identify rationale and reasons for sharing professional concerns when possible signs or characteristics of ASD are observed.
 2. Remember talking points to use when sharing concerns with coworkers or family members.
 3. Identify resources on characteristics of ASD, options for community referrals, and the most reliable websites for family members seeking information on ASD.

Autism Spectrum Disorder

Which Children should we be concerned about?

- Children who show delays in social communication and social interaction:
 - Lack of appropriate eye gaze
 - Lack of warm, joyful expressions
 - Lack of sharing interest or enjoyment
 - Lack of response to name
 - Lack of showing gestures
 - Lack of coordination of nonverbal communication
 - Lack of back and forth conversation
 - Lack of sharing imaginative play or making friends

DSM-V, 2013

Which children should we be concerned about?

- Children who show possible restrictive, repetitive patterns of behavior, interests, or activities:
 - Repetitive motor movements, use of objects, or speech
 - Insistence on sameness
 - Highly restricted, fixated interests
 - Hyper or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment

DSM-V, 2013

Autism Spectrum Disorder (ASD)

- A developmental disability and the result of a neurological disorder that affects the normal functioning of the brain, impacting development in the areas of social communication and social interaction, and restricted, repetitive patterns of behavior, interests, or activities.

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Prevalence

Total number of cases in a population diagnosed at a given time

Or

Total number of cases in the population divided by the number of individuals in the population

<http://en.wikipedia.org/wiki/Prevalence>

Prevalence*

- 1 in every 88 children is diagnosed with ASD in U.S. (2008)*
- Four times more likely to occur in boys than girls (1 out of 54 boys diagnosed with ASD vs. 1 of 252 girls)*
- 1.5 million individual Americans and tens of millions worldwide are affected
- Increases documented across gender and race
- More than half of children meeting criteria for ASD at age 8 had documented developmental concerns by age 3

*Centers for Disease Control and Prevention (CDC). Prevalence of Autism Spectrum Disorders—Autism and Developmental Disabilities Monitoring Network, United States, 2008. MMWR Surveill Summ 2012/61(SS03):1-19.

Why the Increase in ASD?

May be a true increase in the incidence of ASD, or the result of:

- Heightened public awareness
- Physicians actively screening for and more willing to diagnose ASD
- Improved access to services/treatments for ASD
- Children now diagnosed with ASD who might have received different diagnosis in the past
- Children with mild symptoms who might not have been diagnosed with any disability in the past now diagnosed with ASD
- Earlier diagnosis, leading to higher total prevalence at any one point in time

AAP (2009) *The Prevalence of Autism Spectrum Disorders. (Parent handout)*
<http://www.medicalhomeinfo.org/health/Autism%20downloads/AutismOct5parenthandout.pdf>

Impact of Changes to Diagnostic Criteria for ASD in DSM-5?

In Brief

Susan Sweedo, MD, member of DSM-5 workgroup
<http://www.psychiatry.org/practice/dsm/dsm5/dsm-5-video-series-impact-of-changes-to-autism-spectrum-disorder>

A More Detailed Description

- Susan Hyman (2013) New DSM-5 includes changes to autism criteria. *AAP News*. The American Academy of Pediatrics. Downloaded from
- <http://aapnews.aappublications.org/content/early/2013/06/04/aapnews.20130604-1>

History

- In use for about 100 years
- In 1911, Swiss psychiatrist Eugen Bleuler was the first person to use the term autism
 - Referred to one group of symptoms for schizophrenia
- In the 1940's in the United States, researchers began to use the term autism to describe children with emotional or social problems
 - Leo Kanner, a researcher at Johns Hopkins University
 - Hans Asperger, a scientist in Germany
- Autism & Schizophrenia remained linked until the 1960's

Cause

- The cause is unknown
- Multiple causes due to varying levels of severity and symptoms
- Research points to a combination of genetic components, environmental factors, and timing
- Autism is a biological disorder

Child Development

Normal Developmental Milestones

- Holds head up (6 weeks)
 - Smiles (2 months)
- Babbles (3 - 4 months)
- Rolls over (4 months)
- Reaches for object (4 - 7 months)
- Sits without support (6 - 7 months)
 - Crawls (6 - 7 months)
- Drink from cup (6 - 9 months)
- Stands alone (11 - 12 months)
- First word 'mama' and/or 'dada' (12 months)
 - Walks alone (12 - 18 months)
- Uses two-word phrases (18 months - 2 years)
 - First tooth (6 months - 1 year)
 - Toilet trained (24 - 42 months)

Early Signs of ASD

- **6 to 9 months:**
 - Infrequently looks to others' faces
 - Gaze aversion
 - Poor eye contact
 - Decreased social smiling
 - Absent facial expression
 - Poor emotional modulation
 - Delayed babbling
 - Infrequent vocalizations
 - Abnormal pattern of focus and attention

Early Signs of ASD

- **9 to 12 months:**
 - Decreased orienting to name
 - Seems to hear environmental sounds better than human voice
 - Decreased monitoring of other's gaze
 - Inability to follow a point
 - Abnormalities in arousal to stimuli
 - Infrequent babbling

Early Signs of ASD

- **12 to 15 months:**
 - Lack of or rare pointing
 - Lack of or rare showing
 - Delayed speech
 - Repetitive or preservative play with objects
 - Does not wave bye bye
- **15 to 18 months:**
 - Limited or scripted pretend play
 - Lack of imitation
 - Reduced variety of play acts
 - Early signs of developmental regression

Real Life Characteristics of Autism

Characteristics	What you see in the child
Insistence on sameness; resistance to change	Takes all the cans out of the cabinets and lines them up; there's just one route you can drive to any destination; his/her toys must be always in the same place
Difficulty in expressing needs	Will take your hand and lead you to the object or food and place your hand on it
Acts as if they are deaf	Will continue to play with an object or continue to engage in an activity while you are calling them, with no acknowledgement. Then you open the cookie jar, and the child is right next to you
Shows distress that is not apparent to others	Will start to laugh uncontrollably while sitting alone, then will begin to cry
No real fear of dangers	Will run out into the road or out of the house when they get a burst of energy; not hesitant around fire or with heights

Ball, J. Early intervention and autism: Real-life questions, real-life answers. Future Horizons, Inc.: Arlington, Texas, 2008.

Screening

- **National AAP (American Academy of Pediatrics) Recommendations:**
 - Developmental surveillance at all well child visits
 - Elicit parent concerns
 - Developmental screening at 9, 18, and 30 (or 24) months well child visit
 - Use structured development assessment
 - Screening for autism at 18 and 30 (or 24) months well child visit

AAP (2006) Identifying Infants and Young Children With Developmental Disorders in the Medical Home: An Algorithm for Developmental Surveillance and Screening. Pediatrics, 118 (1): 405-420 <http://pediatrics.aappublications.org/cgi/content/full/pediatrics;118/1/405>
AAP (2007) Identification and evaluation of children with Autism Spectrum Disorders. Pediatrics, 120(5), 1183-1215 <http://aappublications.org/cgi/content/abstract/pediatrics.120/5/1183>

Comprehensive Developmental Screenings

- **ASQ-3 (Ages & Stages Questionnaire, Third Edition)**
 - 4 months to 60 months
 - Assesses 5 domains
 - 19 questionnaires, each 30 questions
 - 10-15 minutes to complete
 - 2-3 minutes to score
 - Available in English, Spanish, French, Korean, Norwegian
- **ASQ-SE (Ages & Stages Questionnaire- Social/Emotional)**
 - 6 months to 60 months
 - Assesses personal social
 - Self-regulation, compliance, communication, adaptive functioning, autonomy, affect, and interaction with people
 - 8 questionnaires, each 30 questions
 - Available in English and Spanish

Comprehensive Developmental Screenings

- **PEDS (Parents Evaluation of Developmental Status)**
 - 0 to 8 years
 - Elicits parents concerns
 - Sorts children into high, moderate, or low risk for developmental or behavioral problems
 - Scored in 2 minutes
 - Available in English, Spanish, Vietnamese, Somali, Chinese
- **M-CHAT (Modified Checklist for Autism in Toddlers)**
 - 16 to 30 months
 - 23 Yes/No questions
 - Follow-up interview
 - Scored in 2 minutes
 - Available in English, Spanish, Arabic, Dutch, Bangla, French, German, Greek, Gujarati, Icelandic, Japanese, Kurdish, Portuguese, Sinhala, Somalian, Tamil, Turkish, Vietnamese

Conversation with Parents about Concerns

- What's stopping us?
- Where to go for training & support
 - Autism Speaks video
 - Talking points handouts
- Practice: Role Play Scenarios
 - Toddler
 - Preschooler
- Resources for families

What stops us from having the talk? (A reality check about our fears.)

- "I don't really know enough about Autism to be sure."- You are not giving a diagnosis. You are stating observations. With the current rate of statistics, we need to know something about autism. Do some research and talk to someone who does know. Use your screening tool as a point of reference when talking with the parent.
- "What if I'm wrong?"- Being wrong is a good thing. You will not lose the parent's respect if they are part of the whole process.
- "I don't think the parents are ready."- No one is ever ready to hear this kind of news. Our job as professionals is to state what we have observed. The parent will decide what happens next.

Autism Speaks, CDC and the Ad Council Present
Talking to Parents About Autism

Action Kit

• **Talking to Parents About Autism Training DVD**

A documentary-style resource with examples of how to broach the topic of a potential developmental delay with parents. It contains real-life situations, strategies and success stories.

• **Early Childhood Milestone Map** Take-home flier to share with parents to help them follow their child's developmental path. The flier offers important ideas and suggestions for parents who have questions or want to learn more.

<http://www.autismspeaks.org/what-autism/learn-signs/talking-parents-about-autism-action-kit>

Reactions to Talking With Parents DVD

- What did you like about it?
- What did you learn from it?
- What did you hear that you might question?
- What information was missing for teachers working with your population?

Talking with Parents About Autism

TA Packet Contents

- ◆ TWP Power Point
- ◆ ASD Screening Tools 0-5 Years
- ◆ Resources to Support TWP PPT
- ◆ ASD Website Resources
- ◆ Local Resources Worksheet
- ◆ TWP Implementation Checklist
- ◆ TWP Resources

http://www.kskits.org/ta/Packets/talking_with_parents/talking_with_parents.shtml

Additional Information and Resources

For Early Childhood/Disability Professionals:

- Delivering Hard News Well
www.pent.ca.gov/beh/dis/deliverhardnewsello8.pdf
- Delivering Difficult News
<http://www2.aap.org/sections/dbpeds/pdf/Delivering%20Difficult%20News.pdf>
- Delivering Concerning Screening Results to Families (Video webcast)
http://www.waisman.wisc.edu/connections/webcast/view/Sharing_Concerning_Results/player.html

For Primary Care Physicians:

- 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)*, 256-271.

From *Delivering Difficult News*

Respect the rights of the family:

- To know you care about their child and recognize and appreciate his or her unique qualities
- To receive the news in private
- To hear your message in a way that is comprehensible to them, not buried in jargon
- To be overwhelmed by the message, and to react openly and honestly with a range of emotions
- To a compassionate, professional (not defensive) response to their reaction
- To have time—now or at a time of their choosing—to ask any question they might have

Talking with Parents About Autism Spectrum Disorders: A Guide for Professionals in EI and ECSE

Reasons to Share Concerns with Families

1. ASDs can sometimes involve other health, developmental, neurological, and genetic conditions
2. Growing body of evidence suggesting improved outcomes for *most* and dramatic response to intervention for *some* children with characteristics of autism
3. Demonstrates your knowledge of ASD, making it more likely parents will turn to you for guidance and support in the future
4. Some resources and services are *only available* to children diagnosed with ASD

Where to Begin?

Step 1: Go to the website to view the video (for you) and download the *Early Childhood Milestones Map* brochure in English and/or Spanish (for family members).

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.

Early Identification of ASD Module.

<http://autismpdc.fpg.unc.edu/content/early-identification-module-menu>
Know the Signs. Act Early. <http://www.cdc.gov/ncbddd/autism/actearly/>
Autism Speaks. <http://www.autismspeaks.org/video/glossary.php>
First Words Project. <http://firstwords.fsu.edu/>

Be Prepared

Step 3: Provide parents with a list of resources: national, state and local. The Autism Speaks *Early Childhood Milestone Map* brochure recommends several websites for families. 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.nichcy.org/InformationResources/Documents/NICHCY_PUBS/fs1.pdf

•More detail, including treatment options & research (27 pages)

<http://www.nimh.nih.gov/health/publications/a-parents-guide-to-autism-spectrum-disorder/index.shtml>

•Comprehensive video course, *My next steps: A parent's guide to understanding autism*, in 2 parts.

<http://depts.washington.edu/uwautism/video/video.html>

Practice Resources

Talking with Parents about ASD: Professional "Talking Points"

- Major points for professionals who have observed and/or evaluated the child
- Provides outline for developing your own "script"

Sample Talking Points

- Some of the behaviors we talked about are characteristics we see in children with an autism spectrum disorder.
- Autism used to be rare, but now it's not. Symptoms range from mild to severe.
- Some children with autism are more likely to have certain medical problems.
- Only a medical doctor or licensed psychologist or psychiatrist can **rule out** autism or other associated conditions.

Practice Resources

Talking with Parents About Autism: Reminders

- Graphic representation of strategies to remember
- Based on advice from parents and professionals

Talking With Parents About Autism



Talk over what you plan to say with a co-worker – Put your self in the parent's place. Talk over questions the parents might have and ways you can support the parents through this process.




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- Time for asking questions Time for expressing emotions

Talking With Parents About Autism




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.

Talking With Parents About Autism



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 it is clear to all involved.

Practice Resources

Be Prepared to Counter Myths with Facts

Myth: Autism is caused by immunization of vulnerable children.

*Fact: 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.*

(Gray, et al., 2008)

Practice Resources

Be Prepared to Counter Myths with Facts

Myth: Autism is a mental illness.

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

(Gray, et al., 2008)

Practice Resources

Be Prepared to Counter Myths with Facts

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.

(Gray, et al., 2008)

Practice Resources

Be Prepared to Counter Myths with Facts

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.

(Gray, et al., 2008)

Practice Resources

Be Prepared to Counter Myths with Facts

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.

(Gray, et al., 2008)

Practice Resources

Be Prepared to Counter Myths with Facts

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.

(Gray, et al., 2008)

Practice Resources

Be Prepared to Counter Myths with Facts

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 conditions 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, et al., 2008)

New skills take practice!

Activity

In pairs, select 1 of the family scenarios to role play. Decide who will be the parent and who will be the professional. Remember tips from the video, and use your “talking points” handout.

Reflection on Role-Play Experience

- Parents: What did you appreciate hearing?
- Professionals: What was most difficult to say? What would you say or do differently next time?

What a few parents wanted you to know:

It is not “too soon” to talk about autism.

- Don't give us false reassurance when there is a problem.
- If we don't seem ready to you, it is still your job as a professional to discuss your concerns.
- If our child had a physical illness would you tell us?
- Waiting may cheat us out of time that we can use to get help for our child.

What a few parents wanted you to know:

Listen to our concerns.

- Acknowledge our parent's intuition and take time to talk about the differences we are seeing. Respect that we know our child best.

Give us written information.

- We may not remember everything you said when we get home. We need information to share with family.

What a few parents wanted you to know:

Be open to scheduling a time to talk again.

- We will have questions and may want to include family.

Help us find resources.

- We may need resources for information, resources for services for our child, and resources for our family

What a few parents wanted you to know:

- Tell us what happens next.
- Tell us, "It is not about poor parenting".
- Tell us, "You are not alone, your child matters, you matter".
- Make us part of your team and we will be fearless and tireless. The success of our children is up to us as parents.

Resources for Families

◆ *Selected* Web-based Resources on Autism Spectrum Disorders

- Primarily .org, .gov, and .edu sources
- International-National-Kansas

Resources for Families

◆ Worksheet for Identifying and Describing Local Resources For Families of Young Children

With Disabilities, Including ASD

- Using state websites combined with local expertise and experience to "build-your-own" family resource directory

Questions? Comments?

We'd love to hear from you! For an electronic copy of this PowerPoint presentation with notes, please contact Phoebe Rinkel, M.S. prinkel@ku.edu

Thanks to TASN Autism & Tertiary Behavior Supports team members who helped develop this presentation:

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Kansas Inservice Training System

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