Southern Indiana Physicians

Children with Autism Spectrum Disorders In Primary Care

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Children with Autism Spectrum Disorders
In Primary Care

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Financial Disclosures

• Dr. Naomi Pickholtz - none
• Dr. Dorota Szczepaniak - none
Objectives

1. Review current prevalence and tools for screening for ASD in pediatric PC;

2. Discuss most common medical problems that affect children with autism and role of the family in diagnostic and management process;

3. Present tips for promotion of healthy social and emotional development;

4. Review NDBC services at Bloomington and Indianapolis campuses.
Patient Centered Medical Home

- **The medical home** is the model for 21st century primary care, with the goal of addressing and integrating high quality health promotion, acute care and chronic condition management in a planned, coordinated, and family-centered manner.

  - AAP 2011
ASD Prevalence

- All racial, ethnic, and socioeconomic groups.
- 5 x boys (1 in 54) than girls (1 in 252).
- Asia, Europe, and North America prevalence about 1%.
- South Korea reported a prevalence of 2.6%.

Screening for Autism in PC

• Early Autism Detection: Routine Screening, AAP 2007
• Parents raise concerns.
• Special education services Individuals With Disabilities Education Act (IDEA) in 1990.
• The medical home is an important setting for surveillance and screening to detect ASDs and other developmental disorders. AAP 2007
• Average age of ASD dx in Indiana 64 mo (personal communication ISHD)
• Learning collaborative: MH and ASQ dev. screening.
**Autism is prevalent**
- 1 out of 6 children are identified with a developmental disorder and/or behavioral problem
- Approximately 1 in 88 children are diagnosed with an autism spectrum disorder
- Developmental disorders have subtle signs and may be easily missed

**Listen to parents**
- Early signs of autism are often present before 18 months
- Parents usually DO have concerns that something is wrong
- Parents generally DO give accurate and quality information
- When parents do not spontaneously raise concerns, ask if they have any

**Act early**
- Make screening and surveillance an important part of your practice (as endorsed by the AAP)
- Know the subtle differences between typical and atypical development
- Learn to recognize red flags
- Use validated screening tools and identify problems early
- Improve the quality of life for children and their families through early and appropriate intervention

**Refer**
- To Early Intervention or a local school program (do not wait for a diagnosis)
- To an autism specialist, or team of specialists, immediately for a definitive diagnosis
- To audiology and rule out a hearing impairment
- To local community resources for help and family support

**Monitor**
- Schedule a follow-up appointment to discuss concerns more thoroughly
- Look for other conditions known to be associated with autism (eg, seizures, GI, sleep, behavior)
- Educate parents and provide them with up-to-date information
- Advocate for families with local early intervention programs, schools, respite care agencies, and insurance companies
- Continue surveillance and watch for additional or late signs of autism and/or other developmental disorders
- Continue to provide a medical home


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**Is Your One-Year-Old Communicating With You?**

*Ta-da! *“Ma-ma,” *“Ha-ba!” What will your baby’s first word be? Whatever the word is, when you hear it, it’s an exciting moment in your child’s language development.

However, language skills begin long before the first spoken words. Your child starts to communicate with you during the first year of life. She may respond to you and the world around her with eye gaze, smiles, gestures, or sounds. Later on, you’ll notice more obvious “speech” skills or milestones. Read more to learn about early language and social milestones and possible signs of language delay.

If you have any concerns about your baby’s development, share them with your pediatrician—the sooner the better.

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**About developmental language delay**

Delays in language are the most common types of developmental delay. One in 5 children will show a developmental delay in the speech or language area. Some children will also show behavioral challenges because they are frustrated when they can’t express everyday needs, desires, or intentions.

Simple speech delays are sometimes temporary. They may resolve on their own or with a little extra help from family. Sometimes formal speech therapy is needed.

It’s important to encourage your baby to *“talk”* to you with gestures and/or sounds before filling a need. In some cases, your baby will need more help from a trained professional.

Sometimes delays may be a warning sign of another serious disorder that could include a hearing loss, global developmental delay, or autism. Delays could also be a sign of a possible learning problem you may not notice until the school years. It’s important to have your child evaluated if you are concerned about your child’s language development.

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**Milestones**

Remember, children develop at different rates, but they usually are able to do certain things at certain ages. The following developmental milestones are guidelines:

- **My 12 months** your baby should:
  - Look for and be able to find the source of sounds.
  - Respond to his name most of the time when you call it.
  - When prompted.
  - Look when you point when you say *“Look at the ______.”*
  - Change from monotone babble to babble with inflection as if telling a story in a foreign language.
  - Take turns *“talking”* with you—listen to you when you speak and then resumes babbling when you stop.
  - Say *“da-da”* to dad and *“ma-ma”* to mom.
  - Say at least 1 or more words.
  - Point to items he wants that are out of reach or make sounds while playing.

Between 12 and 24 months your baby should:
- Follow simple commands with, and then later without, gestures.
- Get objects from another room when asked.
- Point to a few body parts when asked.
- Point to interesting objects or events to get you to look at them too.
- Bring things to you to *“show you.”*
- Point to objects so you will name them.
- Name a few common objects and pictures when asked.
- Enjoy pretending (for example, has a tea party). She will use gestures and words with you or a stuffed animal.
- Learn about 1 new word per week as she approaches her 2nd birthday.

By 24 months your toddler should:
- Point to many body parts and common objects.
- Point to some pictures in books.
- Follow 2-step commands.
- Say about 50 to 100 words.
- Say several 2-word phrases like *“daddy go,”* *“doll mine,”* and *“all gone.”*
- May say a few 3-word sentences like *“I want juice” or *“Me go bye-bye.”*
- Be understood about 50% of the time.

**Not typical behaviors**

Sometimes language delays are associated with behaviors that may concern you, like your baby:
- Doesn’t talk like other babies.
- Doesn’t return a happy smile back to you.
- Doesn’t even notice if you are in the room.
- Doesn’t seem to notice certain noises (for example, seems to hear a car horn or a car’s mew but not when you call his name).
- Acts as if he is in his own world.
- Refers to play alone seems to *“does others out.”*
- Doesn’t seem interested in or play with toys but likes to play with objects in the house.
- Shows a strange attachment to hard objects (would rather carry around a flashlight or ballpoint pen than a stuffed animal or blanket).
- Can say the ABCs, numbers, or words to TV (singles but can’t ask for things he wants).
- Doesn’t seem to have any fear.
Screening for ASD

- Family hx.: Siblings at 10X higher risk
- Parental concerns
- Red Flags – young children
  - 12 mo no babbling, pointing, gestures;
  - 16 mo no single words;
  - 24 mo no 2-word spontaneous (not echolalia) phrases;
  - Loss of language or social skills at any age.
- Older children: problems with interaction with peers, nonliteral communication, obsessions, difficulty understanding other people perspective or humor.
Screening tools for Autism - MCHAT

- 23 questions
- Follow-up questions
- Very sensitive but not specific – needs follow up
- STAT – play based interactive testing
PCP role in identification of Children with ASD

- Surveillance at every Well Child Check.
- Listen, watch out for sibs and red flags!
- Screen at 18 + 24 mo WCC, and if concerned.
- Refer to early evaluation clinic if concerned.
- Act on a positive screening result – Do not take a “wait-and-see” approach.
- Refer for all 3:
  - comprehensive ASD evaluation;
  - early intervention/early childhood education service;
  - audiologic evaluation.

AAP Guideline 2007
Communicating the Diagnosis?  
How do Families Want to be told?

- Who should communicate the diagnosis?
- Different stages – denial, grief, acceptance;
- Families may not hear you the first time;
- Web resources, printed materials: 100 Day Kit

- Follow up visits and follow up on referrals...“Did you have a chance to call First Steps?”
Other Tips from Families

• Avoid medical jargon
• Pictures or graphs can be good
• Avoid phrases that may be perceived as threatening
Autism Speaks 100 Day Kit

- Autism Diagnosis, Causes and Symptoms;
- Family Tips: Sharing, Caring and the Future
- Early Intervention and Education Rights
- Information on Therapies and Treatment
- Assembling and Managing Your Team
- 10 Things Your Child Wishes You Knew
- Resources by Topic
- Action Plan for the Next 100 Days
- Safety Tips
- Useful Forms

www.autismspeaks.org
Nutrition and deficiencies

- Iron Status in Children With Autism Spectrum Disorder  
  Reynolds 2012

- Food aversion and habitual eating behaviors
- Obesity in <5 yo
- Underweight 6-12 yo
- Insufficient intake of calcium, fiber, zinc, and vitamins A, D, and K
- Restrictive diets

S Hyman et al, *PEDIATRICS* Vol. 130 November 1, 2012
Psychotropic Medications use in ASD

**Table 1** Medication Use by Age (N = 2843)

<table>
<thead>
<tr>
<th>Age group (n)</th>
<th>Any medication, n (%)</th>
<th>2 medications, n (%)</th>
<th>≥3 medications, n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;3 y (367)</td>
<td>2 (1)</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>3–5 y (1147)</td>
<td>119 (10)</td>
<td>23 (2)</td>
<td>10 (1)</td>
</tr>
<tr>
<td>6–11 y (951)</td>
<td>422 (44)</td>
<td>119 (13)</td>
<td>60 (6)</td>
</tr>
<tr>
<td>12–17 y (276)</td>
<td>176 (64)</td>
<td>55 (20)</td>
<td>31 (11)</td>
</tr>
<tr>
<td>Total</td>
<td>760 (27)</td>
<td>208 (7)</td>
<td>130 (5)</td>
</tr>
</tbody>
</table>

Daniel L. Coury et al., *Pediatrics* 2012;130;

- Stimulants 33%
- Alpha Agonist 14%
- SSRIs 32%
- Atypical Antipsychotics 23%

- 15% of children with no MH dx,
- Systematic Reviews of current literature – marked lack of data,
- No medications specifically address the core sx of ASD.

Gerhard T et al. 2009
Complementary and Alternative Medicine Use

• Remember to ask!

• 20% to 40% of children using some CAM, but >50% with ASD >> than DD

• Special diets >50%,

• Vit Supplements >50%

• Digestive enzymes >15%

• Children with psychotropic medication use had significantly lower use of special diets

• More use with GI symptoms, seizure disorders, and behavior problems

Kemper K et al, *Pediatrics* 2008

Most Common Medical Problems

“You can safely presume that majority of children with Autism have the following problems:

- Constipation
- Feeding problem
- Sleep problems
- Behavior problems”

– Dr. M Ciccarelli, 2011
Patient Centered Medical Home – Making the Visit Easier

- Every child is different
- Nursing staff familiar with CSHCN
- Appointments – first in am or afternoon
- Use picture charts
  http://www.do2learn.com/, MAS;
  http://www.freeprintablebehaviorcharts.com/
- Do not relay on verbal communication
- Relaxation techniques (counting, ABCs)
- Sometimes benzodiazepines:
  - Diazepam and Lorazepam
Life Stage Issues

Under 5 years old
  • Disruptive behaviors, toileting, sleep, diet

5 years through puberty
  • Anxiety, academics

Puberty through adolescence
  • Hygiene, making friends, romantic interests, realizing they’re different

Young adulthood
  • Independent living, employment, companionship
Treatment Options: Early Intervention

• Developmental, speech, and occupational therapies
  • Early intervention is associated with higher cognitive functioning and more positive outcomes than those children who do not receive early intervention services (Eaves & Ho, 2004).
Goals of early intervention when working with a child with autism

• Increase socialization
  • Eye contact
  • Pretend play
  • Spontaneous interactions with others

• Increase Communication

• Focus on building on the skills the child has already begun to develop.
Treatment Options

Behavior therapies
- Play therapy
  - Modeling/teaching *how* to play
  - Meeting the child where they are at
- ABA
- Discrete trial training (Lovaas)

Social Skills training
- Groups
- Individual therapy
- School interventions (social skills group, interaction with typically developing peers)
Pushing our own social norms on a child who is not interested in socializing

- Do we force a child who doesn't want friends to learn how to make friends?
- Does the desire to relate to others continue to require external motivation?
What parents can do

- Often, things that work for typically developing children need to be amped up for children with autism
  - Routine, schedule*, PREDICTABILITY
  - One-on-one time
  - Healthy sleep habits, diet, and exercise**
  - Feeling understood, appreciated, praised
What parents can do

• Adjust expectations

• Meet child where s/he is at
  • play with Thomas trains (talk to adolescent about subway maps) but encourage interaction/reciprocation, elaborate

• Consider what works for the particular family (schedule, siblings, extended family interactions)
Psychology referrals: When to refer? And who to refer to?

Behavior problems

- When parents cannot cope
- When behaviors are impacting learning/school, family relationships, social relationships, legal trouble

Refer to behavioral therapists (ABA clinics, community mental health, private practitioners who specialize in ASD)
Psychology referrals: When to refer? And who to refer to?

Mood and Anxiety concerns

• If parents notice a change in their child’s mood and/or behavior
• Increased irritability (in children this is a key sign of depression)

Psychotherapy

• “Talk therapy”
  • Psychodynamic, cognitive-behavioral, interpersonal, humanistic, etc...
  • Rapport is key indicator of successful outcomes
Working with parents

Regardless of the type of therapy/presenting problem, it is CRUCIAL to involve parents

- Provide tools and support to help parents manage their child’s emotional difficulties
What happens in the therapy room?

- Build rapport/provide support
- Set goals
- Identify problem behaviors
- Develop strategies
- Parent guidance
ASDs and mental health

Comorbid psychiatric diagnoses:

“95% of the youth with ASD had three or more comorbid psychiatric disorders and 74% had five or more comorbid disorders.” (Joshi et al., 2010)

Anxiety Disorders:

• OCD: 25%
• Social phobia: 28%
• Panic disorder: 6%
• Agoraphobia: 35%
• Separation anxiety: 37%
• GAD: 35%
Comorbid psychiatric diagnoses

Disruptive Behavior Disorders
- ADHD: 83%
- Conduct disorder: 22%
- ODD: 73%

Mood Disorders
- Major depression: 56%
- Bipolar I disorder: 31%

Psychosis: 20%

Intellectual disabilities
- Mild (42%), Moderate (34%), Severe (24%)*
- Math (22%), Reading (13%), Writing (64%)**
Other issues

Sensory Processing difficulties

“Unusual sensory responses... have been reported in 42 to 88% of older children with autism in various studies” Baranek, 2002

- Can often be mistaken for defiance
- Can manifest as anxiety
  - Attempts to avoid certain situations due to sensory overload
- Occupational therapy can help
Tools You Can Use

• Care Plans

• School Communication

• Community Based Resources and Organizations
3-Way Communication

COMMUNITY

PATIENT + FAMILY

MEDICAL MANAGEMENT TEAM

SCHOOL
Neurodevelopmental and Behavioral Center

To improve care for children with neurodevelopmental and behavioral disorders and make services more accessible

- Dept. of Pediatrics,
- Dept. of Neurology, at IUSM
- Dept. of Psychiatry,

IUH Riley Hospital

Developing regional pilot sites to better serve children with disorders such as Autism, Developmental Delays, and ADHD.
NDBC Mission

To provide accessible, seamless, evidence based, and family-centered services through innovative care, training, research, education and support for Indiana families, community partners and health care providers in order to improve the health outcomes, cost effectiveness and quality of life for children, youth and young adults with neurodevelopmental and behavioral disorders.
Online Resources

- **IN*Source**
  - 866.644.2454

- **First Steps**

- **Hands in Autism**

- **Autism Speaks**
  - 317.944.8162 option “0”

- **Indiana Resource Center for Autism**
  - 800.825.4733