Autism and the Medical Home: Before, During, and After the Diagnosis

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Accreditation

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Please note:

- This webinar is being recorded. Recording and slides will be made available to participants.

- CME evaluation link will be sent following the conclusion of the webinar.

- Q&A will be held at the end of the presentation. Please enter questions into the Q&A function located at the top or bottom of your screen.
Objectives:

1) review the recommendations for autism screening in primary care
2) discuss the diagnostic process for Autism Spectrum Disorder (ASD)
3) recognize important issues for children with ASD within the medical home
4) learn about the NJ AAP Early Identification and Referral for Autism (EIRA) Project ECHO
Disclosures

I have no financial disclosures.

I will be discussing meds using generic and brand names

I will be discussing some non-FDA-approved alternative treatments
Autism Facts

They Say 1 in 88
I Say 1 of a kind
Autism Awareness - Pass it On

And in NJ- 1 in 34
A Snapshot of Autism Spectrum Disorder in New Jersey

Findings from the New Jersey Autism Study (NJAS) help us to understand more about the scope of autism spectrum disorder (ASD) in children, describe the expression of ASD in those children, and identify disparities in the prevalence or detection of ASD.

3.0% is higher than the average percentage identified with ASD in 2014
1.7% in all ADDM sites

1 in 34 8-year-old children were identified with ASD by NJAS in 2014
Fewer than half (42%) of children with ASD received a developmental evaluation by 3 years of age.

19% of children with ASD received developmental evaluations between 3 and 4 years of age.

39% of children with ASD received developmental evaluations after 4 years of age.
Why do we all need to know about ASD?

Because it is relatively common

You will see children in your practice with ASD

If not yet diagnosed- you can make a **huge** difference- REFER

**Medical Home** is especially needed for children with complex chronic conditions
What is an Autism Spectrum Disorder? DSM IV

A neurodevelopmental disorder characterized, in varying degrees, by difficulties in social interaction, verbal and nonverbal communication and repetitive behaviors.
The so-called ‘*triad of impairment*’ summarises the difficulties of the autistic child but the actual manifestation of these can vary.

(Prior to 2013)
What is an Autism Spectrum Disorder?

DSM IV= A neurodevelopmental disorder characterized, in varying degrees, by difficulties in social interaction, verbal and nonverbal communication and repetitive behaviors.

DSM 5= A group of complex neurodevelopmental disorders characterized by repetitive and characteristic patterns of behavior and difficulties with social communication and interaction. The symptoms are present from early childhood and affect daily functioning.
Diagnostic criteria for autism (DSM 5)

A
Impairment in social communication and interaction

B
Restrictive repetitive patterns of behaviour

ASD
Development

- Gross motor Development
- Fine motor Development
- Personal/Social and Adaptive Skills
- Expressive and Receptive Language
Early Development

Babies start communicating and relating to other people at birth

Continued social-emotional development is key to forming strong relationships and continued learning
By the end of 3 months

Begin to develop a social smile

Enjoy playing with other people and may cry when playing stops

Become more expressive and communicate more with face and body

Imitate some movements and facial expressions
Surveillance and Screening in Primary Care

**Surveillance** for Social and Communication skills (using developmental milestones) at all visits

**Screen** at 18 and 24 months with specific screening test - M-CHAT

**Reassess** at well child visits and if concerns arise
- Later age at diagnosis for children with high functioning ASD
By the end of 12 months

Use simple gestures
Imitate actions in their play
Respond when told “no”

Red Flags
- No back-and-forth gestures, such as pointing, showing, reaching, or waving bye
- Not answering to one’s name when called
- No babbling – mama, dada, baba
By the end of 18 months

Do simple pretend play
Point to interesting objects
Use several single words unprompted

Red Flags
• No single words by 18 months
• No simple pretend play
• No pointing
By the end of 2 years (24 months)

Use 2- to 4-word phrases
Follow simple instructions
Become more interested in other children
Point to object or picture when named

Red Flags

• No two-word meaningful phrases (without imitating or repeating)
• Lack of interest in other children
General Red Flags

- Avoids eye contact
- Delayed speech and language
- Repeats words and phrases (echolalia)
- Gets upset by minor changes
- Has obsessive, atypical interests
- Makes repetitive movements such as rocking, spinning, hand flapping
- Unusual reactions to sensations- over- or under- reacts to sound, smell, taste, touch, sight
- Has trouble understanding others feelings or discussing their own feelings
- Doesn’t share interests- lack of joint attention
Red Flag: Any loss of speech or babbling or social skills

Regression at any age is cause for immediate referral
ASD Screening in Primary Care:

**Children at Higher Risk:**
- Siblings of children with ASD: 10 x increased risk
- Premature Infants
- Comorbid Genetic Syndromes: e.g. Fragile X syndrome, Tuberous Sclerosis
- Prenatal Exposures e.g. Valproic acid

**Regression in Milestones:** 25-30%
- 15-24 months of age
- Change in language, social awareness or behavior
M-CHAT: Does your child...

- Like to be swung?
- **Take interest in other children?**
- Like climbing?
- Enjoy peek-a-boo?
- Ever pretend to talk on the phone?
- **Ever use index finger to point to ask? To indicate interest?**
- Play properly with small toys?
- **Bring objects to show?**
- Look you in the eye?
- Seem oversensitive to noise?
- Smile in response to you?
- **Imitate you?**
- Respond to name?
- **If you point, does he look?**
- Walk?
- Look at things you are?
- Make unusual finger movements near face?
- Act as if deaf?
- Understand what people say?
- Stare at nothing?
- Look at your face to check reaction?

Robins et al, 1999

http://www2.gsu.edu/~psydlr/Diana_L_Robins_Ph.D_files/M-CHATInterview.pdf
AAP Developmental Screening Guidelines

The American Academy of Pediatrics recommends developmental screening at well-child visits

- All children screened to assess their general development at 9, 18 and 24 or 30 months
- All children screened for ASD at 18 & 24 months

1 in 6 children has a developmental disability

Learn the Signs. Act Early.

www.cdc.gov/ActEarly
Board Certified Pediatricians in U.S. = 120,000

U.S. Peds Subspecialists:

Peds Cardiology = 3,218
Peds Heme-Onc = 3,027
Peds Endocrinology = 1,781
Peds Gastroenterology = 1,649
Peds Pulmonology = 1,205
Peds Nephrology = 932

Developmental/Behavioral = 775
Neurodevelopmental Disabilities=255
(Not mutually exclusive, Many double boarded so estimate 900 U.S. total)

(Data from AAP, ABP, CDC)
Diagnostic Evaluation:

Medical History
- Developmental milestones
- Behavioral History
- Family History: Genetic risk factors

Physical
- General exam
- Neurodevelopmental assessment

Application of DSM V Criteria:
- History
- Observational Measures

Assessment of Parental Understanding, coping skills and resources
Best Practice for ASD Assessment

Early assessment and intervention are crucial to progress

WHO?
- Trained professionals (Field less important than expertise)
  - Neurodevelopmental Pediatricians, Neurologists, Pediatricians, Psychiatrists, Psychologists
- Interdisciplinary is best

WHAT?
- Developmental history, observations, direct interaction, parent interview, evaluation of social, communication, sensory, emotional, cognitive and adaptive behavior.

WHERE?
- Multiple settings

WHEN? As early as possible
DSM 5  (ALL must be present)

A) Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive):

1) Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.

2) Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.

3) Deficits in developing, maintaining, and understand relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.
B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive):

1) Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypes, lining up toys or flipping objects, echolalia, idiosyncratic phrases).

2) Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day).

3) Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).

4) Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment (e.g. apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).
Medical Work Up- (may include)

<table>
<thead>
<tr>
<th>Genetic Testing</th>
<th>Karyotype- 5% yield</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Microarray- 6-27%</td>
</tr>
<tr>
<td></td>
<td>Fragile X-1-2%</td>
</tr>
<tr>
<td>Metabolic Testing</td>
<td>Amino Acids-&lt;1%</td>
</tr>
<tr>
<td></td>
<td>Organic Acids&lt;1%</td>
</tr>
<tr>
<td></td>
<td>Only if indicated</td>
</tr>
<tr>
<td>Neuroimaging</td>
<td>MRI, any lesion-up to</td>
</tr>
<tr>
<td></td>
<td>48%</td>
</tr>
<tr>
<td></td>
<td>Only if indicated</td>
</tr>
<tr>
<td>EEG</td>
<td>Any abnormality-16-68%</td>
</tr>
<tr>
<td></td>
<td>Seizures- 25% lifetime</td>
</tr>
<tr>
<td></td>
<td>Only if indicated</td>
</tr>
<tr>
<td>Other</td>
<td>Lead- low</td>
</tr>
</tbody>
</table>
A broader conceptualisation of ASD

- Motor difficulties
- Feeding difficulties
- Communication
- Repetitive interests, activities and behaviours
- Sleep problems
- Sensory issues

Underlying impairment
The autism ‘disease entity’
Specific aspects of medical history to target in children with ASDs:

**GI concerns:**
- Diarrhea/constipation/bloating/pain

**Sleep problems:**
- Night waking, delayed sleep onset

**Feeding behaviors:**
- Aversions based on taste/texture/appearance
- Monitor growth and nutrition
Treatment

• Goals
  • Minimize core features and associated deficits
  • Maximize functional independence and QOL
  • Alleviate family stress

• Educational intervention

• Developmental Therapies
  • Communication
  • Sensory, fine motor, gross motor

• Behaviorally Based treatments
  • Core and associated symptoms
  • Social skills

• Medical or biologic treatments

• Support family in home and community
Evaluation and Intervention Services

- Birth to 3 years: Early Intervention
- 3-5 Years: School district
- 5-21 Years: School district
- Transition age planning and young adult service referrals

Assessment includes: IQ, Speech and Language, Adaptive, Motor, Social and Emotional, and Hearing
Educational Interventions:

1- **Applied Behavioral Analysis (ABA):** works to systematically change behavior based on principles of learning derived from behavioral psychology and encourages positive behavior as well teaching new skills.

2- **Speech Therapy:** with a licensed speech-language pathologist is important in helping to improve a person’s communication skills, allowing better expression. Some individuals with ASD are nonverbal, so the use of gestures and sign language are useful.
Educational Interventions:

3- **Occupational Therapy (OT):** used as a treatment for the sensory integration issues associated with ASDs. Improves the individual’s quality of life and ability to participate fully in daily activities.

4- **Physical Therapy (PT):** to improve gross motor skills and handle sensory integration issues, particularly those involving the individual’s ability to feel and be aware of his body in space.

5- **Social Skills Training**
<table>
<thead>
<tr>
<th>Symptoms/ Disorders</th>
<th>Freq</th>
<th>Treatments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attentional, impulsivity, hyperactivity</td>
<td>59%</td>
<td>Behavioral intervention&lt;br&gt;Psychopharmacotherapy – stimulants, atomoxetine, alpha agonists, anti-anxiety</td>
</tr>
<tr>
<td>Anxiety</td>
<td>43-84%</td>
<td>Behavioral treatment – relaxation, cognitive&lt;br&gt;Psychopharmacotherapy – SSRI, alpha agonist</td>
</tr>
<tr>
<td>Depression</td>
<td>2-30%</td>
<td>Psychotherapy&lt;br&gt;Medication – anti-depressants</td>
</tr>
<tr>
<td>Obsessive compulsive symptoms</td>
<td>37%</td>
<td>Behavioral treatment, supportive counseling; Medication – SSRI, others</td>
</tr>
<tr>
<td>Disruptive, irritable or aggressive behavior</td>
<td>8-32%</td>
<td>Behavioral intervention&lt;br&gt;Medication – atypical neuroleptics (risperidone, arapiprazole (Abilify), others)</td>
</tr>
<tr>
<td>Self-injurious behavior</td>
<td>34%</td>
<td>Behavioral intervention&lt;br&gt;Medication (e.g., naltrexone, risperidone, others)</td>
</tr>
<tr>
<td>Tics</td>
<td>8-10%</td>
<td>Medications; Alpha agonist (clonidine, guanfacine), others</td>
</tr>
<tr>
<td>Sleep disruption</td>
<td>52-73%</td>
<td>Sleep diary; sleep hygiene; behavioral supports; investigate possible medical comorbidity/ies as cause(s)</td>
</tr>
</tbody>
</table>
Biologically Based CAM

Supplements
- B6/Magnesium, B12
- DMG/ TMG
- Vitamin A, Vitamin C
- Folate
- Omega 3 Fatty Acids

Elimination Diets
- Casein/ gluten free

Off-label medications
- Secretin

Immune
- Antifungal therapy
- Immunotherapy, steroids
- Antibiotics/Antivirals
- Stem cell transplantation

Immunization-related
- Withhold immunization
- Chelation

Hyperbaric oxygen therapy (HBOT)

Always others coming along...
Wandering / Elopement

Prevalence

- **29% to 49%** of children with autism have parent-reported wandering

US surveys; 526-2077 families; 2012-2019
Outcomes by Age Group, 2011 to 2016

Children 5 to 9 had the highest number of deaths. Children under 5 faced the highest lethal risk with cases ending in death nearly 60% of the time.
Lethal Outcomes by Cause, 2011 to 2016

The vast majority of deaths were caused by **accidental drowning**, followed by traffic and train injury.

Of drowning deaths, 76% occurred in a natural body of water, or drainage water.
Elopement Patterns: Situations

Avoidant/Anxious Situations
- Escape anxious situation (43%)
- Stressful environment (39%)
- Conflict-laden environment (24%)

Sensory
- Noisy (38%); Uncomfortable sensory experience (34%)

Goal-Directed
- Pursue special interest (27%); Reach play he/she enjoys (18%); Reach favorite food (11%)

Impulsive
- Under-stimulated (27%): “Boring” environment (27%)

Andersen, Law, Marvin, and Lipkin, J Autism Dev Disord. 2020
Keeping Kids with Autism Safe from Wandering: Tips from the AAP (HealthyChildren.org; Hyman & McIlwain)

- Know wandering triggers
- Secure your home (regardless of age)
- Reinforce water and swimming safety
- Work on communication and behavior strategies
- Set expectations with the child when going out
- Consider monitoring technology and identification
- Rest (child and parent)
- Family wandering emergency plan
The AWAARE Collaboration  Working to prevent wandering incidents and deaths within the autism community

*Three digital safety toolkits*
- Caregiver Toolkit
- First Responder Toolkit
- Teacher Toolkit

http://awaare.nationalautismassociation.org/

https://nationalautismassociation.org/big-red-safety-box/

This program is supported by grant 2020-J1-BX-0009 provided by the Office of Justice Programs (OJP), U.S. Department of Justice (DOJ)

WHAT TO DO IF SOMEONE WANDERS
- Stay Calm
- Call 911
- Search Nearby Water First
- Implement your Family Wandering Emergency Plan (FWEP)
**Family Wandering Emergency Plan**

Make sure your family has a plan in case of a wandering emergency. Before an emergency happens, sit down together and decide how you will get in contact with each other, where you will go and what you will do in an emergency. Keep a copy of this plan in your emergency supply kit or another safe place where you can access it in the event your child is missing.

### Critical Information

**Child's Name:**

**Child's Transmitter Tracking Number (if applicable):**

**Child's Official Diagnosis:**

**Child's Identifying Marks, Medications & Medical Needs:**

### Emergency Steps:

- **Always Call 911 Immediately if Your Loved One is Missing from Your Home.**
- Clearly state your child's name.
- State that they have a cognitive impairment, provide the diagnosis, state they are endangered and have no sense of danger.
- Provide your child's radio frequency tracking number (if applicable).
- Provide your child's date of birth, height, weight, and any other unique identifiers such as eyeglasses and braces.
- Tell them when you noticed that your child was missing and what clothing he or she was wearing.
- Request an AMBER Alert be issued (if your child is a minor) or a Silver Alert be issued (if your child is an adult)
- Request that your child's name and identifying information be entered immediately into the National Crime Information Center (NCIC) Missing Person File.
- Search known areas your child would likely be, or attracted to. If you have an emergency point person assigned to contact neighbors, pick up your other children from school, watch your children, etc. alert them while searching known areas your child would likely be, if you have other small children, never leave them unattended.

### TIPs:

- Create an emergency point person who can contact neighbors, fax your alert form to local law enforcement, and assist in making arrangements for your other children.
- Should your child go missing, make sure this contact has a cell phone. Knows what your child is wearing, any identifying features, where your child was last seen, how long your child may have been gone, any medical needs or allergies your child may have, your child's likes and dislikes and main attractions. Ideally, the emergency contact will be a relative or close friend. Provide your emergency contact with a copy of this plan and ask them to keep it in a safe, accessible place.

---

**Emergency Contact Name:**

**Emergency Contact Number:**
The Only GPS Tracker *Designed for Kids With Autism*

Keep Your Child Safe From Wandering, Bullying & Mistreatment with **AngelSense**

**Monitoring Plan Includes:**
- Unlimited Notifications & Email Alerts
- Unlimited Users
- Unlimited Location Updates
- Real-time Tracking App: iOS, Android, Web
- Listen-in with a Single Click (60 minutes/mo)
- Expert and Caring Support
Important Roles of Primary Care Physicians and the Medical Home

Early recognition
- Knowledge of signs and symptoms
- Developmental surveillance and screening

Guiding families to diagnostic resources and intervention services (simultaneously)

Being part of the medical evaluation

Providing ongoing health care including anticipatory guidance

Supporting and educating families
From the American Academy of Pediatrics:
Clinical Report
Identification, Evaluation, and Management of Children With Autism Spectrum Disorder
Susan L. Hyman, Susan E. Levy, Scott M. Myers and COUNCIL ON CHILDREN WITH DISABILITIES, SECTION ON DEVELOPMENTAL AND BEHAVIORAL PEDIATRICS
Pediatrics January 2020, 145 (1) e20193447; DOI: https://doi.org/10.1542/peds.2019-3447

NJ Department of Human Services- A Family Guide to Navigating the NJ Service System for Individuals with Autism Spectrum Disorder and other Developmental Disabilities. www.state.nj.us.humanservices/ddd/home/ooa


SPAN- Statewide Parent Advocacy Network www.spanadvocacy.org

Autism Speaks – 100 Day Kit. www.Autismspeaks.org
Questions?

Please type questions in the Q&A function located on the control bar at the top or bottom of your screen.
Early Identification and Referral for Autism (EIRA)  
Project ECHO

Goal to advance recommended Autism specific screening at 18 and 24 months and link families to resources and services.
Early Identification and Referral for Autism (EIRA) Project ECHO

- Collaboration with Cognoa, Inc.
- Partnership with SPAN
- ABP approved MOC Part 4 QI program utilizing the Project ECHO® model
- Now recruiting up to 12 pediatric practices to participate!
- March-October on 3rd Thursday 12-1 pm
- 5 targeted at-risk communities: Camden, Cumberland, Essex, Middlesex and Passaic
EIRA Project ECHO

Aims to improve screening and referral for ASD and strengthen the pediatric medical home in care coordination for children with ASD by:

- Enhancing knowledge of recommended screening guidelines
- Improving utilization of MCHAT and other screening tools
- Increasing confidence in performing screening and identification of at risk individuals
- Improving communication with families about findings
- Growing knowledge of referral networks for ASD
Interested in signing up?

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- Sharleen van Vlijmen, Program Manager
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