Autism Spectrum Disorder in Primary Care
Supporting Children and Families

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Disclosures

• None
Learner Objectives

1. Define Autism Spectrum Disorder (ASD) in DSM-5

2. Describe 2 strategies used in the early detection of ASD and list 3 ASD screening tools

3. Appreciate the importance of the life course approach in ASD and

4. Name 3 examples of how to support children and families
Agenda

Part 1
• ASD defined in DSM-5
• Prevalence and trends in ASD diagnosis

Part 2
• ASD screening tools
• Observing: “training the eye”

Part 3
• ASD and the medical home
Part 1
Definition and trends
Suggestions Regarding Respectful Autism Language

<table>
<thead>
<tr>
<th>Traditional terms, concepts, ideas</th>
<th>Suggested alternatives</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disorder</td>
<td>Disability</td>
</tr>
<tr>
<td>Autism Spectrum Disorder</td>
<td>Autism, Autism Spectrum Disability</td>
</tr>
<tr>
<td>Deficits</td>
<td>Area of challenge, difficulty</td>
</tr>
<tr>
<td>Autism symptoms</td>
<td>Autism features, characteristics, traits</td>
</tr>
<tr>
<td>Red flags</td>
<td>Signs or indicators of possible Autism</td>
</tr>
<tr>
<td>Restricted interests</td>
<td>Focused, intense interests</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>First person language</th>
<th>Identity first language</th>
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<tbody>
<tr>
<td>Person with Autism</td>
<td>Autistic person</td>
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Dwyer MA, 2022
Medical versus Social Model of Disability

**Medical**

The disability is part of YOU, and the solution to the disability is to fix YOU

**Social**

This disability is a function of SOCIETY, and the solution is to fix SOCIETY
DSM-5 ASD Criteria

Grzadzinski R, 2013
A: Social Communication

Persistent deficits in social communication and social interaction across multiple contexts

Evidenced by deficits in the following, currently or by history as manifested **by all of the following**:

1. **Social-emotional reciprocity** (e.g., back-and-forth conversation)
2. **Nonverbal communicative behaviors** used for social interaction (e.g., eye contact, facial expressions, body language, gestures)
3. **Developing, maintaining, and understanding relationships** (e.g., modifying behavior to context, engaging in pretend play, showing interest in peers)

B: Restricted, Repetitive Behaviors

Restricted, repetitive patterns of behavior, interests or activities

Evidenced by **two or more** of the following, currently or by history:

1. **Stereotyped/repetitive movements, use of objects, or speech** (e.g., lining up toys, flipping objects, echolalia)

2. **Insistence on sameness, inflexible adherence to routines, ritualized patterns of verbal or nonverbal behavior** (e.g., need to take same route or follow same schedule every day)

3. **Highly restricted, fixated interests – abnormal in intensity/focus** (e.g., preoccupation with unusual objects)

4. **Hyper-or hyposensitivity to sensory input or unusual interest in sensory aspects of the environment** (e.g., adverse response to specific sounds or textures)
ASD DSM-5 levels of support

LEVEL 1: Requiring Support

LEVEL 2: Requiring Substantial Support

LEVEL 3: Requiring Very Substantial Support

American Psychiatric Association: DSM-5, 2013
ASD prevalence data and trends

<table>
<thead>
<tr>
<th>2018</th>
<th>4-year-olds</th>
<th>8-year-olds</th>
</tr>
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<tbody>
<tr>
<td>Prevalence</td>
<td>1:59</td>
<td>1:44</td>
</tr>
<tr>
<td>Sex</td>
<td>3.4 to 1</td>
<td>4.1 to 1</td>
</tr>
<tr>
<td>Age of children with ASD who had first developmental evaluation completed by 36 months</td>
<td>72%</td>
<td>47%</td>
</tr>
</tbody>
</table>

Maenner 2021, Shaw 2021
ASD prevalence and trends

https://www.cdc.gov/ncbddd/autism/data/index.html
2018 ASD and Intellectual Disability: Racial Discrepancies

* IQ score ≤70 or examiner statement of intellectual disability in a comprehensive evaluation

Maenner, 2021; Shaw, 2021
ASD Prevalence and Trends

Cumulative incidence of autism spectrum disorder diagnosis or eligibility per 1,000 children aged 4 or 8 years, by State

Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2018

Shaw 2021
Part 2

ASD in primary care- surveillance, screening and training the eye
Assessing ASD in Primary Care

1. Developmental **Surveillance**

2. Developmental **Screening**: 18 months and 24 month screening for ASD

3. “Train the eye” for signs of ASD: **Observation**
Surveillance in ASD

By 9 months
- Does not respond to name
- Does not show facial expressions like happy, sad, angry and surprised
- No sharing of vocal sounds, smiles, or other nonverbal communication

By 12 months
- Does not play simple interactive games like pat-a-cake
- Uses few or no gestures by 12 months (e.g., does not wave goodbye)

By 15 months
- Does not share interest with others (e.g., shows you an object they like)

By 18 months
- Does not point or look at what you point to

By 24 months
- Does not notice when others are sad or hurt

By 30 months
- Does not pretend play (e.g., does not pretend to feed a doll)

Adapted from https://www.cdc.gov/ncbddd/autism/signs.html
## Surveillance in ASD

<table>
<thead>
<tr>
<th>Possible signs of ASD</th>
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<tbody>
<tr>
<td>Loss of previously acquired speech, babbling, or social skills</td>
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<tr>
<td>Avoids or does not keep eye contact</td>
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<tr>
<td>Trouble understanding people’s feelings or talking about their own feelings</td>
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<tr>
<td>Shows little interest in peers</td>
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<tr>
<td>Does not play games with turn taking</td>
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<tr>
<td>Repeats words and phrases over and over (echolalia)</td>
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<tr>
<td>Gives unrelated answers to questions</td>
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<tr>
<td>Gets upset by minor changes</td>
</tr>
<tr>
<td>Has obsessive interests</td>
</tr>
<tr>
<td>Makes repetitive movements, e.g. hand flapping, rocking, spinning in circles</td>
</tr>
<tr>
<td>Unusual response to sounds, smell, taste, look or feel</td>
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</tbody>
</table>

Adapted from https://www.cdc.gov/ncbddd/autism/signs.html
## Screening ASD tools

<table>
<thead>
<tr>
<th>Autism Screening</th>
<th>Ages</th>
<th>No. Items</th>
<th>Parent Completion Time (min)</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>M-CHAT R/F</strong> Modified Checklist for Autism in Toddlers Revised-Follow-up</td>
<td>16-30 months</td>
<td>20</td>
<td>5-10</td>
<td>No</td>
</tr>
<tr>
<td><strong>SCQ</strong> Social Communication Questionnaire</td>
<td>≥ 4 years (mental age &gt;2 years)</td>
<td>40</td>
<td>10</td>
<td>Yes</td>
</tr>
<tr>
<td><strong>POSI-SWYC</strong> Parent’s Observations of Social Interaction Survey of Wellbeing in Young Children</td>
<td>16-35 months</td>
<td>7</td>
<td>&lt; 5</td>
<td>No</td>
</tr>
</tbody>
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https://screeningtime.org/star-center/#/screening-tools
Joint Attention

Joint Attention

Part 3

ASD in the medical home
ASD in primary care (no diagnosis but concerns)

• Listen to parental concerns (always)…

• Use surveillance, screening and clinical skills

➢ When MCHAT-R/F positive (fail)
  ❑ child may/may not have ASD but further evaluation is indicated: refer for evaluation
  ❑ refer to Early Intervention
  ❑ if comfortable diagnosis of ASD/long wait list, offer diagnosis (provisional)

➢ When MCHAT-R/F is negative - continued vigilance is warranted
  ❑ MCHAT- R/F is designed for screening 16-30 months
  ❑ since not all children captured early, continue surveillance
ASD in primary care (after ASD diagnosis)

Accommodations

➢ Prepare for visits to doctor’s office (pictures, social story)

➢ Time of appointment if flexibility exists

➢ Use of visual supports

➢ Bring preferred toys

➢ Limit transitions

➢ Address co-occurring conditions (look for something you can treat)
Co-occurring conditions in ASD

ASD

Motor Difficulties
Intellectual Disability
Communication Disorder
Learning Difficulties
Immune Dysfunction
GI Dysfunction
Seizures
Genetic Syndromes
Sleep Problems
Mood Disorders
Self-injury
ADHD
Anxiety
Irritability
Psychosis
Sleep Problems
}

Seizures
Mood Disorders
Self-injury
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Sleep Problems
Motor Difficulties
Intellectual Disability
Communication Disorder
Learning Difficulties
Immune Dysfunction
GI Dysfunction
Seizures
Genetic Syndromes
Sleep Problems

Center for Autism and Related Disorders at Kennedy Krieger Institute
Challenges (examples)

- Family stress, waitlists
- Challenging behavior, school?
- Difficulty getting medication
- Disorganized paperwork
- Limited family support
- Home modifications, no time
- Limited progress on speech, summer camp, no sleep
- Limited finances, pica
- Toilet training, fun? Allergy, future planning, recreation
Example working plan for concern (sleep)

Main Concern

Related Clinical Information

Current plans/Intervention

People responsible

Date Completed

NO SLEEP

• Rule out Iron deficiency and underlying neurological concerns.
• Behavioral Psychology

• Begin Behavioral Psychology
• Attend parent education session
• Consult with outpatient OT and school staff.

• Will call Pathfinders to find new Behavior Psych provider
• Contact Jane Doe OT and School team for tips.

• Pathfinders call completed
• Phone conference w/school and outpatient OT scheduled 12/01/14

Slide: courtesy Ellie Sollins LCSW-CARD
ASD in primary care (after ASD diagnosis)

- Ask family to bring information they would like to process
- What is your understanding of the information you were given?
- Address safety (wandering, self injurious behaviors) and scary
- Family impact: e.g. siblings, work, finances, mental health, long term planning
- Screen siblings

- Identify STRENGHTS
Shared Decision Making in ASD

• Topics of shared decision making
  ➢ Therapeutic interventions
  ➢ School placement
  ➢ Complementary and integrated medicines
  ➢ Psychopharmacological interventions

• Tools to aid shared decision conversations
  ➢ Checklists (behavioral, transition, planning)
  ➢ Tool kits
  ➢ Knowledge about complementary and integrated medicine
Life course ASD

Preschool age (before the age of 6 years)

School age (between the ages of 6 and 11 years)

Adolescence (between the ages of 12 and 17 years)

Adults (18 years and older)

Adapted from Lord, 2022
The drawing she kept: road map
Looking Into the Future for a Child With Autism

As my son’s limitations became clearer, I found it harder every year to write a vision statement for his I.E.P. Then he showed us how.

By CARRIE MCDONNELL AUC. 30, 2017

Ethan’s vision statement

Not simply because Ethan had articulated his own entirely reasonable vision statement, but because it incorporated every aspect of his present life that brings him joy. After years of fabricating visions for a future we never honestly thought possible, Ethan was offering one that was both optimistic and breathtakingly simple: *I want my life to keep looking the way it does now.*

I wish I could tell other parents at the start of their journey what it’s taken me two decades to learn. First, that your child may continue to grow and change and, even at the age of 21, may surprise you by doing things you never thought possible. Second, that in the end, success won’t be measured by academic performance or job placement. It will have more to do with accumulating small pleasures and filling your life with those. I don’t know why it never occurred to me: Your future should look like the best parts of your present.
Pearls

• Identification of ASD requires surveillance, screening and clinical evaluation before and beyond current recommended screening ages at 18 and 24 months

• Medical and mental health co-occurring conditions in ASD are common and often identified and treated in the medical home

• Shared decision making is often an effective approach to discussing therapies and interventions in ASD
References

- https://www.cdc.gov/ncbddd/autism/signs.html
- https://screeningtime.org/star-center/#/screening-tools
Questions, comments, feedback
Billy has 32 pieces of bacon. He eats 28. What does he have now? Happiness.
Billy has happiness.
Tools and Resources

• Pathfinders for Autism- lifespan checklists
Milestones Matter
Track your child’s developmental milestones and try brain building tips to add learning to everyday moments!

Track Your Child’s Development
Track how your child plays, learns, speaks, acts, and moves with CDC’s Milestone Tracker app—read share all progress and any concerns with their doctor during well-child visits.

www.cdc.gov/MilestoneTracker

BY 2 MONTHS:
Smiles at you

BY 6 MONTHS:
Laughs with you

BY 12 MONTHS:
Plays games with you, like “peek-a-boo”

BY 18 MONTHS:
Points to show you something interesting

Brain Building Tip:
Suggested Age: 6-2 years
We’re surrounded by words that are ready for reading. Try reading signs aloud to your child and talk to them about what they mean.
It doesn’t matter if it’s a book, magazine, or billboard—it all counts! Reading to your child, anywhere and everywhere, helps them develop a rich, diverse vocabulary. Find more tips at vroom.org.

Do you have concerns about how your child plays, learns, speaks, acts or moves?
Visit www.cdc.gov/concerned and talk with your child’s doctor.

CDC does not endorse private products, services, or enterprises. Vroom Tips are not a diagnostic test.
April is Autism Acceptance Month; AAP Has Online Course on Caring for Children With ASD:

Pediatric clinicians play a critical role in the screening and diagnosis of children with autism and other developmental delays. The AAP provides detailed information on the clinical signs, surveillance, and screening of autism spectrum disorder.

The AAP offers a free self-paced online PediaLink course Identifying and Caring for Children with Autism Spectrum Disorder:

A Course for Pediatric Clinicians. Find the course at Identifying and Caring for Children with Autism Spectrum Disorder: A Course for Pediatric Clinicians - AAP. It is available until Sunday, April 19, 2023.
Extra slides on the WHO model
WHO International Classification of Functioning Disability and Health

[Diagram showing the relationship between Health Condition, Activity, Participation, Body Functions and Structure, Environmental Factors, Personal Factors, and Contextual Factors.]
The WHO model - children
### Integrative model of Disability adapted for children

<table>
<thead>
<tr>
<th>F</th>
<th>Meaning</th>
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| **Function** | What people do “how” things are done is not what is important.  
Role-job-task: for children play and school is their work |
| **Family** | Family represents the essential “environment” of all children |
| **Fitness** | How children stay physically active, include exercise and recreational activities |
| **Fun** | Activities children are involved in or enjoy participating in |
| **Friends** | Social development is an essential part of childhood |
| **Future** | Refers to parents and children’s expectations and dreams for their future |