Early Identification of Children with Developmental Delays and Disabilities: A Public Health Perspective

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Learning Objectives

- Why is it important to identify children with developmental delays and disabilities early?
- How does CDC promote developmental monitoring of all children?
- What are some findings from CDC’s work on screening for autism spectrum disorder (ASD)?
- How does ASD surveillance help us understand early identification of children with ASD?
Did you know?

About 1 in 4 children younger than 5 years are at risk for behavioral, developmental, or learning delay.¹

About 1 in 6 children aged 3-17 has a developmental disability (DD).²

About 1 in 59 children has ASD; however, diagnosis is often not until after age 4 years.³

Why is it important to identify children with DD early?

Early identification can lead to early intervention\(^1\) that:

- **Improves developmental skills and intellectual functioning;**\(^2-4\)
- **Reduces challenging behaviors such as aggression;**\(^4\) and
- **Empowers families to advocate for services and help their child learn and grow.**\(^4,5\)

EARLY IDENTIFICATION

- Monitoring
- Screening
- Diagnosing
- Referring
- Serving
How do developmental monitoring and screening compliment one another?

**SURVEILLANCE/MONITORING**
- Informal process
  - Milestone checklists
- Conducted at every well-child visit

**SCREENING**
- Formal process
  - Standardized tools
- Conducted at 9, 18, and 30-month well-child visits

Refer to achievement of milestones to guide decision-making
How does CDC promote developmental monitoring of all children?
Are there recommendations on how and when developmental monitoring should be conducted?

The American Academy of Pediatrics (AAP) recommends that developmental surveillance, or what we call monitoring, be conducted at every well child visit.¹

According to the National Survey of Children’s Health:

- Only 37% of parents of young children reported that their healthcare provider asked if they had concerns about their child’s development;² and
- Providers are more likely to elicit concerns among white parents compared to black and Latino parents.³

What is “Learn the Signs. Act Early.”?

The goal of “Learn the Signs. Act Early.” is to improve early identification of developmental concerns so children and their families can get the services and support they need as early as possible.
How does CDC help families and providers “Learn the Signs.” and “Act Early.”?

**Learn the Signs:**
- Resources for monitoring **key developmental milestones** and “red flags” that may indicate concern

**Act Early:**
- Discuss concerns
- Provide positive parenting tips
- Encourage developmental screening
- Refer for evaluation and services
- Find resources for early intervention and family support
What are some “Learn the Signs. Act Early.” materials?
How can providers conduct developmental monitoring on the social delays associated with ASD?

In addition to using a checklist, providers can observe the child and ask parents about delays in social-emotional milestones, such as problems with:

- Social-emotional reciprocity, such as **inconsistently responding to own name**;

- Nonverbal communication, such as **poorly modulated eye contact**; and

- Developing, maintaining, and understanding relationships, such as **diminished interest in same-aged peers**.
How can providers conduct developmental monitoring on behaviors associated with ASD?

In addition to using a checklist, providers can observe the child and ask parents about the presence of odd or unusual behaviors:

- Repetitive movements, use of objects, or speech, such as flapping hands or repeating words;

- Insistence on routines or rituals, such as showing distress over small changes;

- Highly restricted interests, such as having an intense or unusual preoccupation with specific toys; and

- Unusual response to sensory input, such as being bothered by sounds not distressing to other people.
What are some other important points to remember when monitoring for ASD?

- Developmental monitoring is recommended at every well-child visit.

- Tools are available to help guide the surveillance process (e.g., milestone checklists).

- ASD affects multiple areas of development.

- There is significant variability in symptom presentation.

- ASD is associated with other common conditions.

- More than half of school-aged children with ASD have average or above average intellectual ability.
When should a provider move beyond routine monitoring and administer a screening tool?

Do not wait and see if the child progresses at the next visit. Administer a DD or ASD screen if:

- The child is not meeting developmental milestones;
- The child is showing odd or unusual behaviors associated with ASD;
- A healthcare provider is concerned about the child’s development;
- A parent or educator is concerned about the child’s development; or
- During a routine 18- and 30-month well-child visit.
What are some findings from CDC’s work on screening for autism spectrum disorder (ASD)?
Are there recommendations on how and when developmental screening should be conducted?

<table>
<thead>
<tr>
<th>9 months</th>
<th>18 months</th>
<th>30 months</th>
<th>3-5 years</th>
</tr>
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<tbody>
<tr>
<td>General Developmental</td>
<td>General Developmental</td>
<td>General Developmental</td>
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<td>Screening</td>
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<tr>
<td>Screening</td>
<td>Screening</td>
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<td>as needed</td>
<td>as needed</td>
<td>as needed</td>
<td>as needed</td>
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</tbody>
</table>

- Healthcare providers can also screen a child **any time** a parent has a concern.

- The AAP recommends the use of **standardized screening tools** for both general developmental and ASD-specific screening.¹

According to the National Survey of Children’s Health, only 30% of parents of young children reported that they completed a questionnaire on developmental milestones in the past 12 months.\(^1\)

Only 40% of children on Medicaid were screened for behavioral, developmental, or social delays using a standardized tool in fiscal year 2017.\(^2\)

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Provider reports of developmental screening vary from a low of 16% among early childcare providers who responded to a web-based survey in 2016 to 82% of general pediatricians who responded to an AAP survey.¹,²

Provider reports of ASD-specific screening has improved from a low of 8% among general pediatricians who responded to an AAP survey in 2004 to 81% of general pediatricians who responded to an AAP survey in 2016.³,⁴

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How can we improve rates of developmental screening?

Both practice change and policy levers are employed in states and communities to improve rates of monitoring and screening.

- Quality improvement projects\(^1\)
- Statewide adoption of developmental screening during well-child visits\(^2\)

How do I find the right screening tool?

First consider:

- Age
- Time
- Cost
- Training
- Languages
- Culture
- Purpose
- Alignment with local service agencies
What are some general developmental screening tools?

Birth to 5: Watch Me Thrive!
A Compendium of Screening Measures for Young Children

www.hhs.gov/WatchMeThrive
What are some screening tools reviewed in the Birth to 5: Watch Me Thrive! Compendium?

- Ages and Stages Questionnaire – 3rd Edition (ASQ) (1-66 months)
- Ages and Stages Questionnaire – Social-emotional (ASQ-SE) (6-60 months)
- Brigance Screens (birth through end of first grade)
- Developmental Assessment of Young Children – 2nd Edition (DAYC) (birth through 60 months)
- Parents’ Evaluation of Developmental Status (PEDS) (birth through 7 years)
- Parents Evaluation of Developmental Status – Developmental Milestones (PEDS-DM) (birth through 7 years)
What are some ASD-specific screening tools?

AAP recommended screening tools with established evidence base:
- Modified Checklist for Autism in Toddlers (M-CHAT) (16-30 months)
- Screening Tool for Autism in Toddlers (STAT) (24-35 months)
- Social Communication Questionnaire (SCQ) (48+ months)

Other screening tools that are building an evidence base:
- The Infant Toddler Checklist (ITC) (6-24 months)
- First Year Inventory (FYI) (12 months)
- Early Screening for Autism and Communication Disorders (ESAC) (12-36 months)
- Rapid Interactive Screening Test for Autism in Toddlers (RITA-T) (12-36 months)
- Parents Observations of Social Interactions (POSI) (16-35 months)
Screening for Autism with the SRS and SCQ: Variations across Demographic, Developmental and Behavioral Factors in Preschool Children

Eric J. Moody¹ · Nuri Reyes¹ · Caroline Ledbetter² · Lisa Wiggins³ · Carolyn DiGuiseppi² · Amira Alexander⁴ · Shardel Jackson⁴ · Li-Ching Lee⁵ · Susan E. Levy⁶ · Steven A. Rosenberg¹
Why are children not referred for evaluation if they fail a developmental screen?

- About **60% of children who failed a developmental screen are referred** for follow-up care.¹,²

- Providers report that they:
  - Are more likely to refer if developmental screening indicates delays in physical skills or multiple skills, followed by delays in language skills;
  - Are **less likely to refer if screening indicates delays in social skills**; and
  - Struggle to track referrals after well-child visits and/or that many families did not complete the recommended referral steps.

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What are some important points to remember when screening for DD and ASD?

- Many general developmental and autism-specific screens take only 5-10 minutes to administer.

- Many screens are parent-questionnaires that can be completed in the waiting area.

- Most are written at a 5th grade level or less.

- Some are in Spanish and other languages.

- Regardless, some parents may need help answering questions. Providers should therefore consider having a protocol for oral administration.

- Providers may be reimbursed for screening with CPT code 96110.
How does public health surveillance help us understand early identification of children with ASD?
What is public health surveillance?

A way to conduct ongoing systematic tracking of children with DD in an effort to:

- Estimate prevalence;
- Monitor trends over time;
- Highlight patterns of occurrence; and
- Describe the population of children surveilled.

Public health surveillance informs policy, public health, and research.
What is prevalence?

- The total number of people
  + with a condition
  + in a given population
  + at a specific time.

\[
\text{Number of 8-year-olds with CP} \div \text{Total number of 8-year-olds} = \text{PREVALENCE}
\]
Autism and Developmental Disabilities Monitoring (ADDM) Network Sites, Surveillance Years 2018 and 2020

Tracking Autism among 4- and 8-year-olds

Tracking Autism among 4- and 8-year-olds AND Follow-up of 16-year-olds
What makes CDC surveillance unique from other tracking systems?

- Verifies ASD cases from information contained in education and health records
- Reflects diagnostic and education service practices in multiple geographic areas
- Has the largest denominator of any surveillance system in the United States
- Conducts education and outreach activities in specific communities
- Collects information on age of first evaluation, age of first ASD diagnosis, cognitive functioning, and co-occurring conditions
- Provides an opportunity to follow children into adolescence and adulthood
What is the estimated ASD prevalence among 8-year old children from CDC surveillance?

<table>
<thead>
<tr>
<th>Surveillance Year</th>
<th>Birth Year</th>
<th>Number of Sites</th>
<th>Average Prevalence per 1,000 Children (Range)</th>
<th>This is about 1 in X children</th>
</tr>
</thead>
<tbody>
<tr>
<td>2000</td>
<td>1992</td>
<td>6</td>
<td>6.7 (4.5-9.9)</td>
<td>1 in 150</td>
</tr>
<tr>
<td>2002</td>
<td>1994</td>
<td>14</td>
<td>6.6 (3.3-10.6)</td>
<td>1 in 150</td>
</tr>
<tr>
<td>2004</td>
<td>1996</td>
<td>8</td>
<td>8.0 (4.6-9.8)</td>
<td>1 in 125</td>
</tr>
<tr>
<td>2006</td>
<td>1998</td>
<td>11</td>
<td>9.0 (4.2-12.1)</td>
<td>1 in 110</td>
</tr>
<tr>
<td>2008</td>
<td>2000</td>
<td>14</td>
<td>11.3 (4.8-21.2)</td>
<td>1 in 88</td>
</tr>
<tr>
<td>2010</td>
<td>2002</td>
<td>11</td>
<td>14.7 (5.7-21.9)</td>
<td>1 in 68</td>
</tr>
<tr>
<td>2012</td>
<td>2004</td>
<td>11</td>
<td>14.5 (8.2-24.6)</td>
<td>1 in 69</td>
</tr>
<tr>
<td>2014</td>
<td>2006</td>
<td>11</td>
<td>16.8 (13.1-29.3)</td>
<td>1 in 59</td>
</tr>
</tbody>
</table>
What is the average age of first ASD diagnosis for children born in 2006?

- Although ASD can be reliably diagnosed by 24 months, the average age of first ASD diagnosis is **52 months**.¹

- Concerns by age 36 months were documented for 85% of children with ASD, yet **only 42% had a comprehensive evaluation by 36 months**.¹

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What are some factors associated with early age of ASD diagnosis?¹

- Male sex
- Intellectual disability
- Loss of developmental skills
- Non-Hispanic ethnicity

How can we build a more effective workforce trained in the early identification of DD and ASD?

CDC “Learn the Signs. Act Early.” materials for parents and providers: www.cdc.gov/ActEarly


AAP resources for pediatric practices to implement quality improvement projects on developmental surveillance and screening: https://www.aap.org/en-us/professional-resources/quality-improvement/Pages/Developmental-Surveillance-Screening-and-Referral.asp

The Autism Navigator professional development courses in ASD: www.autismnavigator.com
What happens after my child receives an ASD diagnosis?

Autism Speaks 100-day toolkit:

- General information about ASD
- How to access services and supports
- Description of evidence-based treatments
  - Delivered in the first 36 months and involve a behavioral component
- Sample week-by-week plan for next 100 days
How can I learn more about services and supports in my state?

- Find and learn more about your state early intervention program:
  - [https://www.cdc.gov/ncbddd/actearly/parents/states.html](https://www.cdc.gov/ncbddd/actearly/parents/states.html)

- Locate a pediatrician or Medicaid provider for your child and family:
  - [State Medicaid Provider Directory](https://www.medicaid.gov)
  - [Healthychildren.org “Find a Pediatrician”](https://www.healthychildren.org)

- Find other services and supports specific to ASD:
  - [Autism Speaks: Find Services and Supports](https://www.autism.org)

- Identify your Learn the Signs Act Early (LTSAE) Ambassador:
  - [https://www.cdc.gov/ncbddd/actearly/ambassadors-list.html](https://www.cdc.gov/ncbddd/actearly/ambassadors-list.html)
EARLY IDENTIFICATION

Monitoring
Serving
Screening
Diagnosing
Referring
What else is CDC doing to learn more about ASD?

ASD is a *developmental* condition that can change with age and impact many stages of life:

- The “Learn the Signs. Act Early.” program: [www.cdc.gov/ActEarly](http://www.cdc.gov/ActEarly)
  - Tracks 4- and 8- year old children with ASD, and will begin a 16-year old follow-up
- The Study to Explore Early Development: [www.cdc.gov/SEED](http://www.cdc.gov/SEED)
  - Researches factors associated with ASD in preschool children, and behaviors and health conditions that impact children and families
  - Follows the same preschool children in adolescent years
THANK YOU

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For more information, contact CDC
1-800-CDC-INFO (232-4636)

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.