

# Developmental Surveillance and Screening: Where We Were, Where We Are, and Where We Are Going

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# Disclosures

- I am a member of the CDC “Learn the Signs. Act Early” (LTSAE) Developmental Milestones revision committee.
- I am an author of the American Academy of Pediatrics (AAP) Developmental Surveillance Pedialink Module.
- These activities have not resulted in any financial disclosures.

# Presentation Objectives

- Recognize many children with developmental delays and disabilities are not identified early.
- Understand developmental screening and surveillance programs and trends in U.S. pediatric practices.
- Improve awareness of systems for early identification of developmental delays and disabilities.
- Discuss policy options to optimize outcomes for children who would benefit from early detection of developmental disorders.
- Review AAP, CDC and other partner initiatives and resources available to assist with implementation of developmental screening, referral, and follow-up.

CLINICAL REPORT Guidance for the Clinician in Rendering Pediatric Care

American Academy  
of Pediatrics




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# Promoting Optimal Development: Identifying Infants and Young Children With Developmental Disorders Through Developmental Surveillance and Screening

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SPECIAL ARTICLES | FEBRUARY 08 2022

## Evidence-Informed Milestones for Developmental Surveillance Tools

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# Why Monitor Development?

- Developmental disabilities are common and often not identified before school age.
  - Up to **1 in 4** ( $\leq 5$  yrs. of age) are at moderate to high risk for developmental, behavioral, or social-emotional delays<sup>1</sup>
  - **1 in 6** (3–17 yrs. of age) has a developmental disability<sup>2</sup>
  - **1 in 44** (8 yr. olds) are estimated to have autism spectrum disorder<sup>3</sup>
  - At-risk due to psychosocial disadvantage: additional (10% - 12%)

1. *National Survey of Children's Health, 2011-12*
2. *Zablotsky, B, et al, Pediatrics 2019*
3. *CDC, MMWR Surveillance Summary 12/2021*



# Earlier Intervention is Better

- Evidence shows that starting supports as early as possible is best
- The earlier a child is identified, the sooner targeted intervention and family supports can start
  - It is never “too late” to start services and supports
- Intervention can improve skills, abilities, future school performance, long-term self-care skills, and quality of life
- Other benefits of early identification & intervention
  - Families understand their child’s strengths, and areas they may need support
  - Family wellness



# Why Screen?

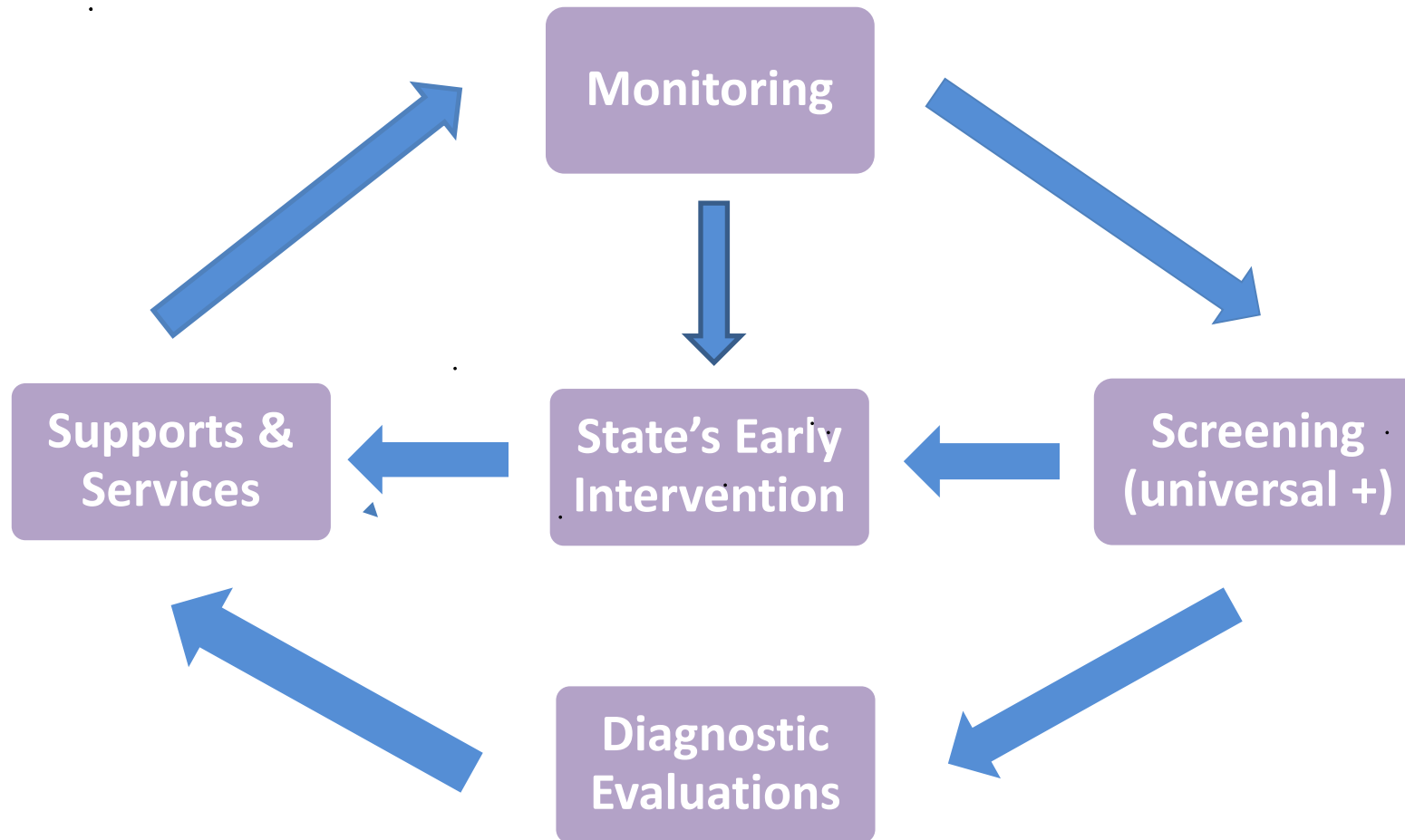
- Current Detection Issues
  - Only 2 ½ - 3% of children 0-5 served in early intervention
  - Enrollment rates in early intervention (EI) should be closer to 8%<sup>1</sup>
  - Only about 30% of children with substantial delays and disabilities are detected by their health care provider
  - Many of those detected are not referred

***Thus most children do not receive the benefits of early intervention that can prevent school failure, high school drop out, etc.***

<sup>1</sup>CDC, [www.cdc.gov](http://www.cdc.gov)



# Early Identification & Intervention



# Developmental Monitoring vs Screening

## Monitoring/Surveillance

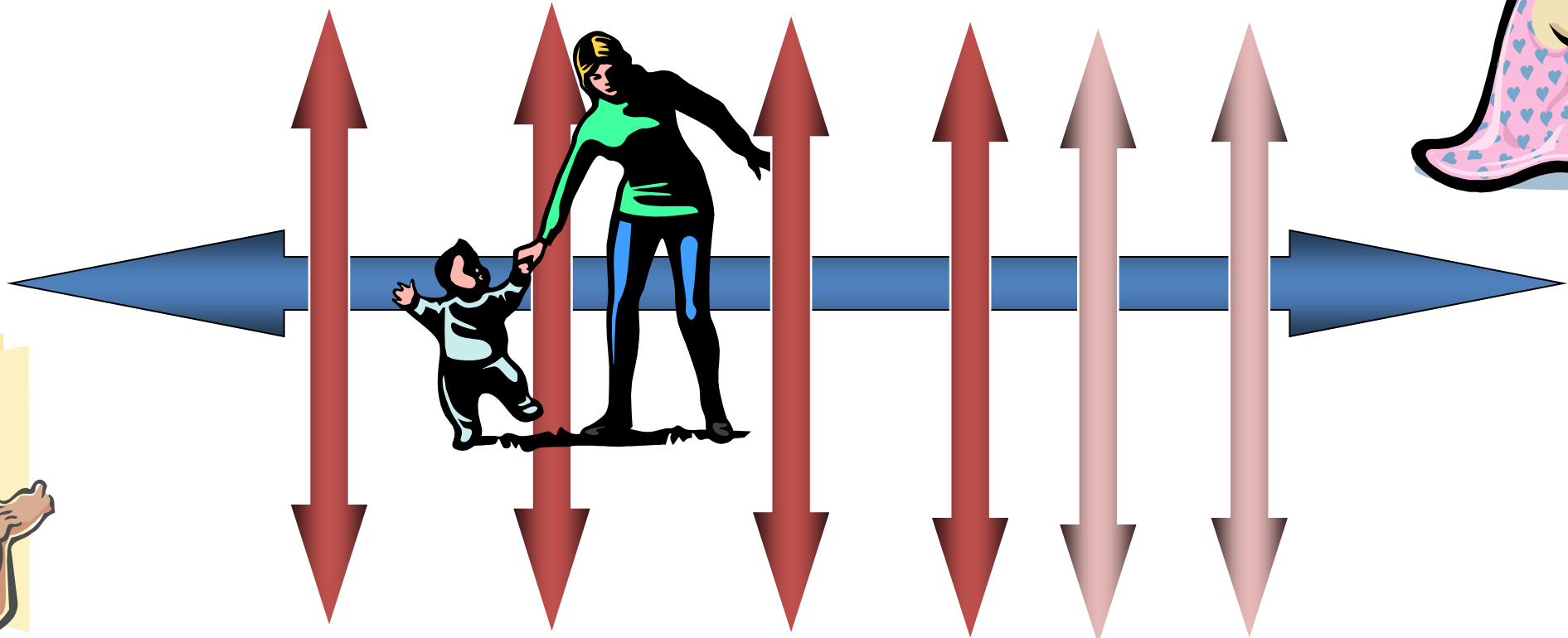
- Also called developmental surveillance
- Occurs at each well child visit
- Uses developmental milestones and much more
- Ongoing and longitudinal
- No scores, no risk categorization
- Can support the need for any additional developmental screening

## Screening

- Administered by early childhood professionals
- Recommended at specific ages and whenever concerns arise
- Uses validated developmental screening tools
- Provides a risk categorization, not a diagnosis
- Helps determine if additional diagnostic evaluations are needed
- May be used to qualify for state early intervention programs



# Developmental Surveillance



9 m\* 18 m\*\* 24m+ 30m\* 4 yr 5+ yr

Developmental\* & Autism+ Screening

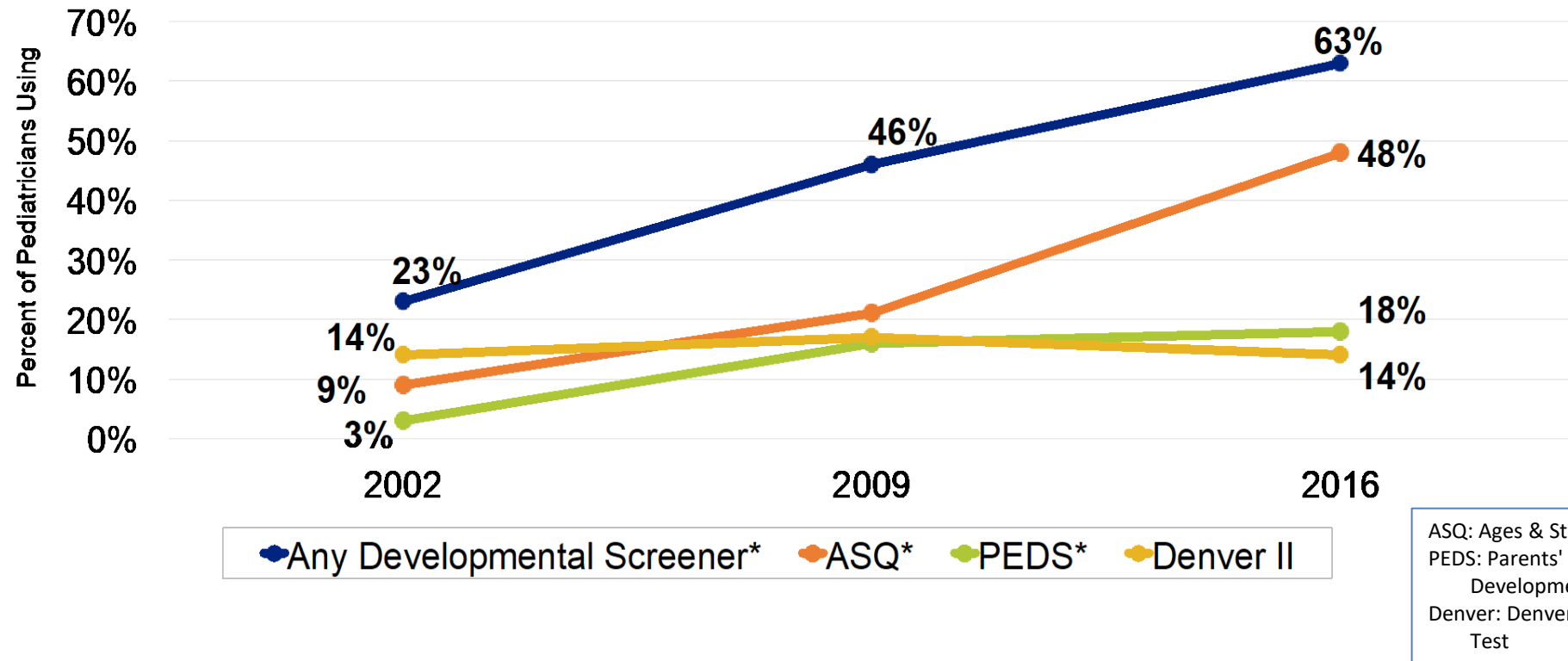
# What is AAP Early Detection Policy?

- Eliciting and addressing parents' concerns at each visit.
- Viewing milestones at each visit.
- Identifying and addressing psychosocial risk and resilience factors.
- Sharing and obtaining opinions and findings with other professionals.
- Using a general screen that is validated and accurate at 9, 18, 24 – 30 m, (4y+) *and whenever surveillance yields concerns about delayed development.*
- Using an autism-specific screen at 18 and 24 months.



# Trends in Standardized Developmental Screening: Results from National Surveys of Pediatricians, 2002-2016

Fig. 1: Rates of Developmental Screening Tool Use among Pediatricians, 2002-2016



Data from Lipkin PH, Macias MM, Baer-Chen B, et al. Trends in pediatricians' developmental screening: 2002-2016. *Pediatrics*. 2020;145(4):e20190851.

# Learn the Signs. Act Early

Mission: To improve early identification of developmental delays and disabilities by promoting developmental monitoring and screening so children and their families can get the services and support they need.



# Recent Milestone Revision

- Incorporate feedback from over 15 years of use
  - Where are 15- and 30-month checklists?
  - Vague (“may”, “begins”)
  - “How many milestones can be missing without being concerned?”
  - Are only the “warning signs” important?
  - Are these milestones MOST children do by this age?
- Revisions were completed in 2019
- Publication of the process and results in Feb. 2022



Zubler J, et al, *Pediatrics* 2022



# Implementation: Screening and Continued Care

- Early return visits for continued close surveillance with ongoing concerns.
- Refer when results are concerning:
  - Early intervention and early childhood programs
  - Medical workup as indicated (Primary care provider vs. Consultant)
  - Developmental evaluation to identify a specific developmental disorder
- Initiate a program of chronic condition management.
- Family support services (e.g., Family Voices, Parent to Parent USA, and state-based Family-to-Family Health Information Centers)



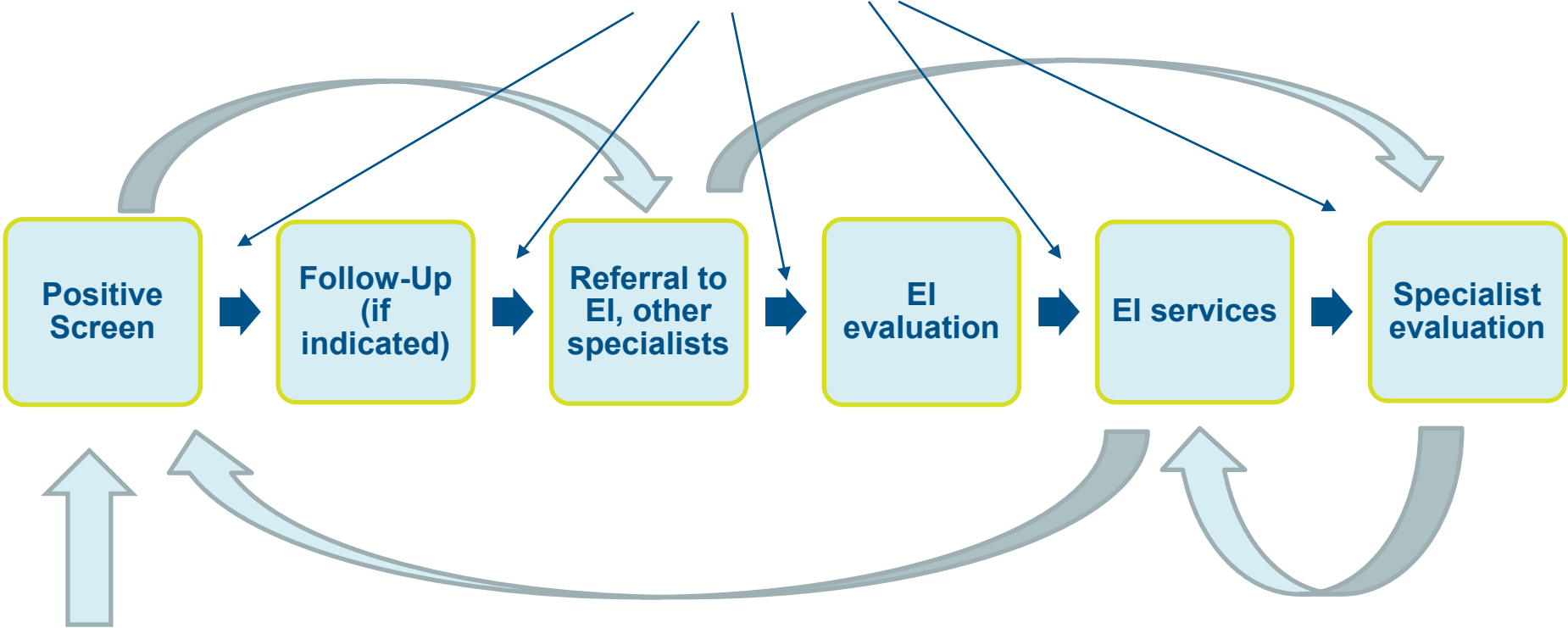
# Ongoing Challenges to Referral

- High rates of non-referral (~40%)
- High rates of incomplete referrals and evaluations
  - Consider parental health literacy.
  - Rates improved by strategies that closely connect the medical home with early intervention (EI) such as electronic transmission of referrals.
- Barriers
  - Lack of feedback from EI program about the child's progress and outcomes.
  - Time limitations
  - Payment (surveillance, follow-up, counseling; chronic management)
  - Professional and staff education/Office workflow
  - Integration and coordination of screening, referrals, and care by health care, education, and social service professionals



# Screening to Services

## Barriers



EI = Early Intervention

# ADMINISTRATION FOR CHILDREN & FAMILIES

- Coordinated federal effort to encourage universal developmental and behavioral screening and support families and providers who care for them.
- Informed by the Child Care and Development Block Grant (CCDBG) Act of 2014

<https://www.acf.hhs.gov/archive/ecd/child-health-development/watch-me-thrive>

BIRTH TO 5:  
**WATCH ME THRIVE!**



DEVELOPMENTAL SCREENING PASSPORT FOR:

U.S. Department of Health and Human Services  
U.S. Department of Education



ASSOCIATION OF MATERNAL & CHILD HEALTH PROGRAMS

SPHARC

State Public Health Autism Resource Center

is a comprehensive web-based resource center for state programs, including Title V.



OUR AIM



is to help increase state capacity to implement systems of care for children and youth with ASD/DD.

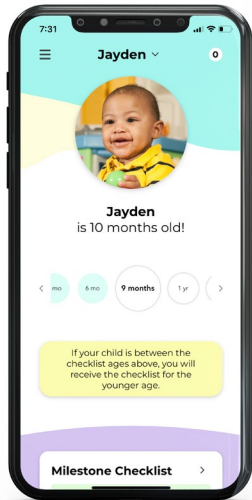
<https://amchp.org/cyshcn-current-initiatives/#>

Learn the Signs. Act Early.

# CDC's Developmental Milestones

[Español \(Spanish\)](#)

The STAR Center offers information and resources, including screening recommendations, practice tools, and individualized assistance, to help pediatric health care providers implement effective screening, referral, and follow-up for developmental milestones, maternal depression, and social determinants of health.



**Your child at 15 months**

Child's Name: \_\_\_\_\_ Child's Age: \_\_\_\_\_ Today's Date: \_\_\_\_\_

Milestones matter! How your child plays, learns, speaks, acts, and moves offers important clues about his or her development. Check the milestones your child has reached by 15 months. Take this with you and talk with your child's doctor at every well-child visit about the milestones your child has reached and what to expect next.

**What most children do by this age:**

**Social/Emotional Milestones**

- Copies other children while playing, like taking toys out of a container when another child does
- Shows you an object she likes
- Claps when excited
- Hugs stuffed doll or other toy
- Shows you affection (hugs, cuddles, or kisses you)

**Language/Communication Milestones**

- Tries to say one or two words besides "mama" or "dada," like "ba" for ball or "da" for dog
- Looks at a familiar object when you name it
- Follows directions given with both a gesture and words. For example, he gives you a toy when you hold out your hand and say, "Give me the toy."
- Points to ask for something or to get help

**Cognitive Milestones (learning, thinking, problem-solving)**

- Tries to use things the right way, like a phone, cup, or book
- Glazes at least two small objects, like blocks

**Movement/Physical Development Milestones**

- Takes a few steps on his own
- Uses fingers to feed herself some food

**Other important things to share with the doctor...**

- What are some things you and your child do together?
- What are some things your child likes to do?
- Is there anything your child does or does not do that concerns you?
- Has your child lost any skills he/she once had?
- Does your child have any special healthcare needs or was he/she born prematurely?

**You know your child best.** Don't wait. If your child is not meeting one or more milestones, has lost skills he or she once had, or you have other concerns, act early. Talk with your child's doctor, share your concerns, and ask about developmental screening. If you or the doctor are still concerned:

1. Ask for a referral to a specialist who can evaluate your child more, and
2. Call your state or territory's early intervention program to find out if your child can get services to help. Learn more and find the number at [cdc.gov/FindEI](http://cdc.gov/FindEI).

For more on how to help your child, visit [cdc.gov/Concerned](http://cdc.gov/Concerned).

Don't wait. Acting early can make a real difference!

**Milestone Moments**

**Milestones Matter!**

Look inside for milestones to watch for in your child and tips for how you can help your child learn and grow from birth to age 5.

Screening Recommendations



Screening Tools



Interactive Training



Screening Process Resources



Practice Success Stories



Questions? We Can Help.



[www.aap.org/screening](http://www.aap.org/screening)

[www.cdc.gov/ActEarly/Materials](http://www.cdc.gov/ActEarly/Materials)

[cdc.gov/ActEarly/Ambassadors](http://cdc.gov/ActEarly/Ambassadors)



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# Developmental Surveillance and Screening in 2023: Next Steps

- Continue current unified national efforts toward early universal screening and increasing detection rates across health care, education, and social service sectors.
- Additional efforts to enhance referral systems, improve early intervention (EI) programs, and provide better tracking of child outcomes.
- Improve access to evaluation and treatment options for children with concerning screen results needed.
- Utilize effective and evidence-based interventions across EI and treatment programs.
- Improve communication between pediatric providers and local EI professionals.

# Take Home Messages

- Developmental delays and disabilities are common.
- Earlier is better for identification of developmental delays and disabilities.
- Developmental monitoring/surveillance and developmental screening are complementary but different.
- Universal developmental screening at recommended ages AND whenever there are concerns.
- National and state efforts together can improve early detection.
  - Connect with state Title V systems, EI (“Part C”), state AAP chapters on existing initiatives.
  - Help spread awareness to work toward universal developmental screening access, including in child care settings.

# Additional Developmental Screening Resources

- **Early Childhood Technical Assistance Center (ECTA)** [www.ectacenter.org](http://www.ectacenter.org)  
Provides practice improvement tools, contact information for state Part C coordinators, and other early childhood resources.
- **Center for Parent Information & Resources**  
[www.parentcenterhub.org/resourcelibrary](http://www.parentcenterhub.org/resourcelibrary)  
Provides information on disabilities, IDEA, and effective educational practices (English and Spanish).
- **National Academy for State Health Policy (NASHP)** Healthy Child Development State Resource Center: [healthychild.nashp.org](http://healthychild.nashp.org)  
One stop shop for state and national tools related to healthy child development policies and practices.

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