



Promoting Early Identification of Developmental Delay and Disability: An Overview of Developmental Surveillance, Screening, and CDC's Developmental Milestones

[Insert presenters' info here]

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





Disclosures

- [Insert financial disclosures here]
- [Include other disclosures here]



Presentation Objectives

- Recognize that many children with developmental delays and disabilities are not identified as early as they could be.
- Understand the difference between developmental surveillance and developmental screening.
- Identify how surveillance and screening together improve early identification of developmental delays.
- Learn to use evidence-informed CDC *Learn the Signs. Act Early.* (LTSAE) developmental milestones and/or other resources to support surveillance and screening in the medical home.
- Understand the supporting evidence for the revised milestones released in 2022.



Why Monitor Development?

Developmental disabilities are common and often not identified before school age¹

- **1 in 6** (3–17 years of age) has a developmental disability²
- **1 in 36** (8-year-olds) is estimated to have autism spectrum disorder¹
- Developmental disabilities are even more common among children from low-income households, with **1 in 5 children** experiencing a developmental disability²

1. Maenner, MJ, et al. CDC, MMWR Surveillance Summary 03/2023
2. Zablotsky, B, et al, Pediatrics 2019





Developmental Surveillance, Screening, and Early Identification



Developmental Surveillance vs. Screening

Surveillance

- Ongoing/longitudinal at each well-child visit
- No scores/risk categories
- Can support screening
- Six components
 - Elicit concerns
 - Obtain developmental history
 - Assess strengths, risks
 - Observe the child
 - Document findings
 - Obtain and share results

Screening

- Recommended at:
 - 9, 18, 30 months for general development
 - 18 and 24 months for autism
 - Also perform if there are concerns at other times or missed visits
- *Validated* screening tools
- Provides scores/risk categories
- Not diagnostic, but helps determine if evaluation needed
- May be used to qualify for some state early intervention programs

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Pediatrics January 2020



Detailed information on American Academy of Pediatrics (AAP) recommendations can be found in the Clinical Report

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

(Lipkin and Macias)

<https://doi.org/10.1542/peds.2019-3449>

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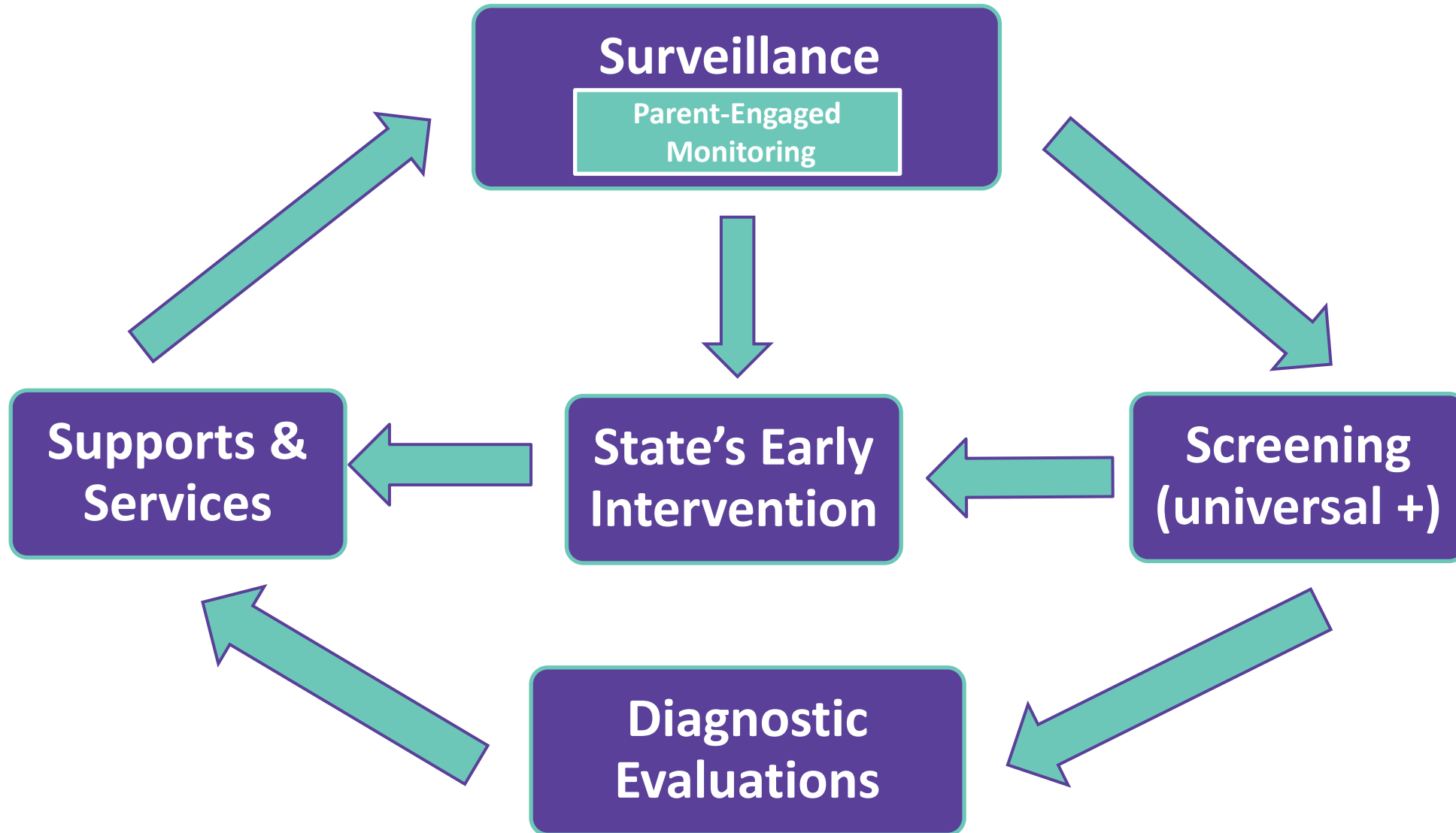


Earlier Intervention is Better

- Evidence shows that the earlier a child is identified to have a developmental disability or delay, the sooner interventions 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
- Other benefits of early identification & intervention
 - Families understand their child’s strengths, and areas in which they may need support



Early Identification & Intervention





Introduction to *Learn the Signs. Act Early.*



Learn the Signs. Act Early. (LTSAE)

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.

Materials



Strategy



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CDC's Milestone Materials

Health Communication Tools for Developmental Surveillance



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)

Cognitive Milestones (learning, thinking, problem-solving)

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

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

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.

For more on how to help your child, visit 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.



www.cdc.gov/ActEarly/Materials

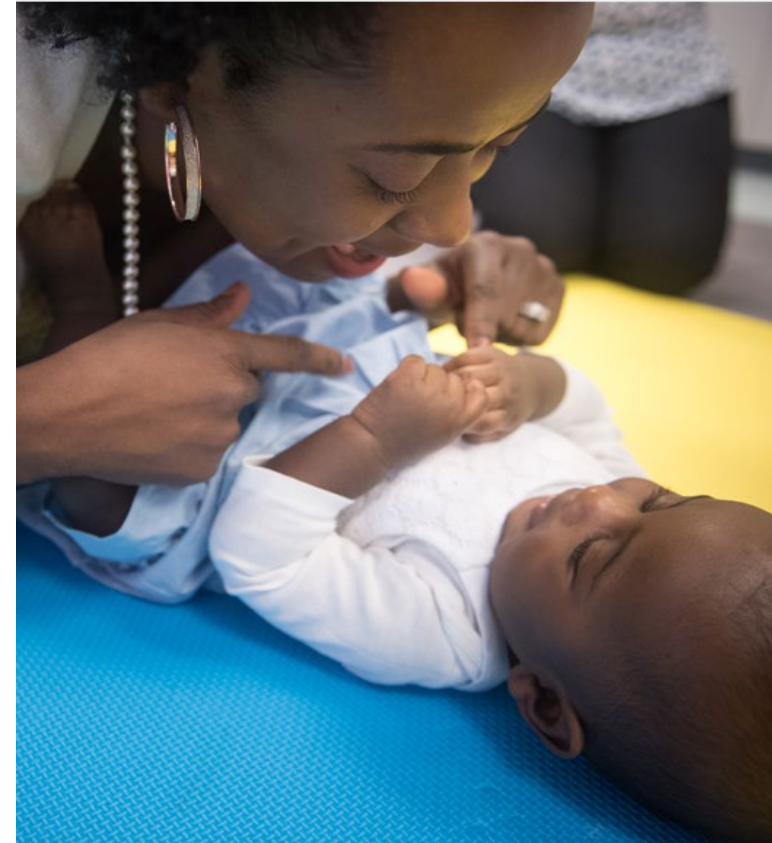
Program Benefits

- Is evidence-informed
- Includes milestones **MOST** ($\geq 75\%$) children are expected to achieve by given ages
 - Any missed milestone is cause for discussion or action
 - Approach allows for
 - Discussions on milestones **most** children meet
 - In-depth/targeted surveillance when missing milestones
 - Discussion of concerns not captured by milestones (open-ended questions)
- Avoids the “wait and see” approach, and encourages screening as a possible next step
- Meets the needs of parents and professionals related to developmental monitoring



Additional Checklist Features

- Open-ended questions (*new*)
- Guidance for what to do when there is a developmental concern
- Early intervention information
- Tips and activities for developmental promotion and early relational health (*revised/expanded*)
- Reminders about well visits and developmental screening ages
- Anticipatory guidance on what to expect by the next age checklist





Milestone Revisions



Why Were the Milestones Revised?

To incorporate feedback from more than 15 years of use

Revised milestones

- Include new 15- and 30-month checklists
- Eliminated vague language (example: “may,” “begins”)
- No longer include warning signs

Revisions will help avoid common questions like

- “How many milestones can be missing without being concerned?”
- “Are only the ‘warning signs’ important?”

Revised milestones are based on what MOST children do by specific age, making missed milestones more actionable

- Avoids a “wait and see” approach
- Avoids unnecessary worry



Revision Process

- Established 11 criteria (including “most” $\geq 75\%$ of children)

- Searched literature for milestones with normative data

- Reviewed existing CDC milestones for evidence-base and age placement using literature review, common screening/evaluation tools, published clinical opinion

- Eliminated milestones without evidence or expert agreement from CDC's surveillance checklists

- Added milestones with evidence and expert agreement to CDC's surveillance checklists

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“Evidence-Informed”

TABLE 3 Social Emotional Milestones With Supporting Normative Data, Evaluation Tools, and Published Clinical Opinion References

Social Emotional Milestones	Age	CDC or New	Normative Data ^a	Developmental Screening and Evaluation Tools ^b	Published Clinical Opinion ^c
Calms down when spoken to or picked up*	2mo.	New	Ertem et.al ⁵² ,2018		ASHA ²⁸ ; Bright Futures ⁵⁴ ; Dosman et.al ⁷ ,2012; Sharp et.al, ⁵³ ,2008
Looks at your face	2mo.	CDC	Ertem et.al ⁵² ,2018; Sheldrick,R.C and Perrin, E. C. ¹³ ,2013		Bright Futures ⁵⁴ ; Dosman et.al ⁷ ,2012; Scharf et.al ³⁵ ,2016
Seems happy to see you when you walk up to her	2mo.	New	Ertem et.al ⁵² ,2018; Sheldrick,R.C and Perrin, E. C. ¹³ ,2013; Thalagala et.al ⁵⁵ ,2015		
Smiles when you talk to or smile at her	2mo.	CDC	Bhave et.al ⁵⁶ ,2010; Ertem et.al ⁵² ,2018; Lejarraga et.al ⁵⁷ ,2010; Thalagala et.al ⁵⁵ ,2015	ASQ-3 ³⁹ ; PEDS-DM ⁴²	ASHA ²⁸
Smiles on his own to get your attention	4mo.	CDC	Ertem et.al ⁵² ,2018	ASQ-3 ³⁹ ; PEDS-DM ⁴²	Bright Futures ⁵⁴
Chuckles (not yet a full laugh) when you try to make her laugh	4mo.	New	Accardo P. and Capute A. ⁴⁷ ,2005; Bhave et.al ⁵⁶ ,2010; Ertem et.al ⁵² ,2018; Sheldrick, R.C and Perrin, E. C. ¹³ ,2013	ASQ-3 ³⁹ ; PEDS-DM ⁴²	ASHA ²⁸ ;Bellman et.al ¹⁷ ,2013; Bright Futures ⁵⁴
Looks at you, moves, or makes sounds to get or keep your attention	4mo.	New	Ertem et.al ⁵² ,2018	PEDS-DM ⁴²	

Zubler JM, Wiggins LD, Macias MM, et al. Evidence-Informed Milestones for Developmental Surveillance Tools. *Pediatrics*. 2022;149(3):e2021052138. Reproduced with permission from *Pediatrics*, Vol. 149, Page 4, Copyright © 2022 by the AAP.

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Process for Updating Parent Tips and Activities

CDC Subject Matter Experts

- Reviewed parenting tips from trusted organizations
- Consulted CDC communication experts, early childhood educators, pediatricians, and speech language pathologists
- Looked for areas for improvement/expansion
- Reworded for clarity and added more examples
- Included social emotional, relational health, responsive parenting, feeding, self-care, and screen time tips

Updated tips were reviewed by CDC nutrition, injury prevention, LTSAE, and other CDC groups



Developmental Expertise on Evidence Review Team

- Developmental-behavioral pediatricians
- Neurodevelopmental pediatricians
- General pediatricians
- Speech-language pathologists
- Child and developmental psychologists
- Professors of special education and early intervention
- Developers of developmental screening tools
- Editor of *Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents 4th Edition*
- Authors of AAP's 2020 clinical report *Promoting Optimal Development: Identifying Infants and Young Children with Developmental Disorders Through Developmental Surveillance and Screening*
- Parent representatives/disability navigators
- CDC *Learn the Signs. Act Early.* Ambassadors



Biggest Challenges



- Normative data was difficult to find
 - References for typical developmental milestone tables are not usually cited or cite each other
- Screeners/psychometric tests are often based on unpublished normative data
- Even when normative data exists, milestones don't easily "fit" into well-visit ages

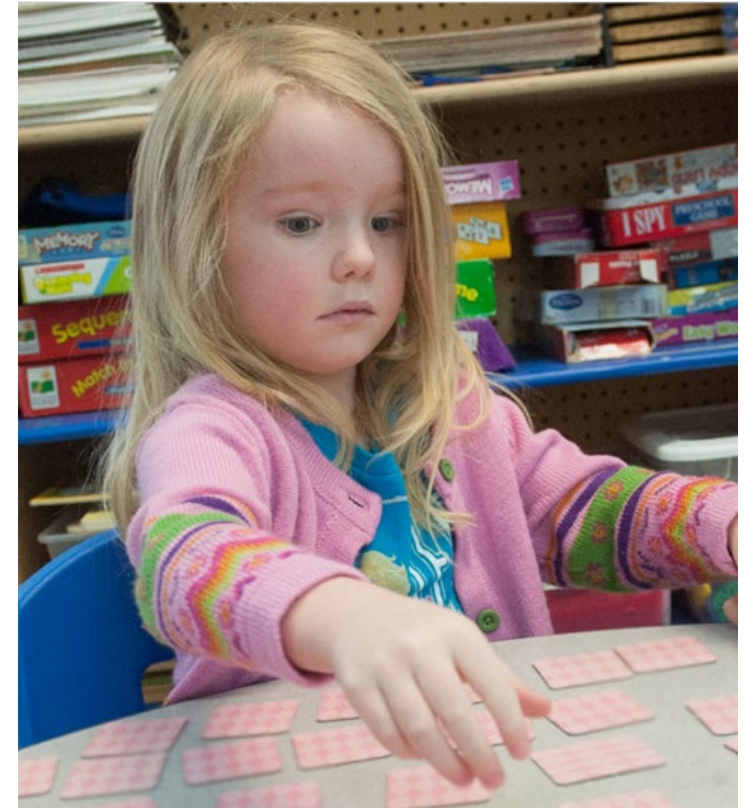
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Results of the Process

- 26% reduction in total milestones
 - 216 to 159 milestones
 - 25 duplicates removed
 - Average milestones/checklist reduced from 23 to 13
- 60% of milestones were retained from original
 - 94 retained and 65 new
- Majority of retained milestones stayed at the same age
- 80% of the final milestones had normative data from at least 1 source
- Evidence for social-emotional and cognitive milestones was particularly hard to find



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Support from Leaders in the Field

Dr. Paul Dworkin, Help Me Grow National Center

[Strengthening Developmental Surveillance to Enhance Developmental Promotion and Early Detection | Help Me Grow National Center](#)

- “Simply a reflection of the intent to more clearly identify children who are lagging behind the majority of their peers and to encourage a closer look at children, through such methods as screening, when they are not meeting age expectations.”
- “For those who understand the intent and purposes of this revision, the new CDC developmental checklists should be a welcome addition to our developmental monitoring and early detection strategies.”

Zero to Three

[Leading Early Childhood Development Nonprofit Applauds New Pediatric Milestones • ZERO TO THREE](#)

- “By moving ... specific milestones from 50% to 75%, we will be able to move away from ‘wait and see’ to a more direct and targeted approach. When we know what our children are facing, we can move toward earlier intervention and, ultimately, better outcomes.”

Dr. Barbara Howard, Johns Hopkins University, creator of CHADIS

[What Can Be New About Developmental Milestones? \(medscape.com\)](#)

- “As primary care providers, we not only need to detect children at risk for developmental problems but also promote and celebrate developmental progress. I hope that changing the threshold for concern to 75% will allow for a more positive review with the family ...”
- “The recommended “use of validated screening tools” when the new milestones are not met give us an objective tool to share with parents, more confidence in when referral is warranted ... and baseline documentation from which we can “track” referrals, progress, and, hopefully, better outcomes.”

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Pediatrics March 2022

Detailed information on CDC's developmental milestones and the 2022 revisions can be found in

*Evidence-Informed Milestones for Developmental Surveillance Tools.
Pediatrics.2022;149(3):e2021052138.*

<https://doi.org/10.1542/peds.2021-052138>



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More than Milestones

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Open-Ended Questions

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 they once had?
- Was your child born prematurely?
- Does your child have any special healthcare needs?






Reminders for Visits & Screenings

- The checklists align with well-child check-up (health supervision visits)
- Informs families
 - ✓ about developmental surveillance at **each** visit
 - ✓ when general developmental (9, 18, and 30 months) and autism screenings (18 and 24 months) are due
- The *Milestone Tracker* app reminds families of upcoming recommended well-visits, to schedule an appointment, and to complete the checklist

Your child at 30 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 30 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

- Plays next to other children and sometimes plays with them
- Shows you what she can do by saying, "Look at me!"
- Follows simple routines when told, like helping to pick up toys when you say, "It's clean-up time."

Language/Communication Milestones

- Says about 50 words
- Says two or more words, with one action word, like "Doggie run"
- Names things in a book when you point and ask, "What is this?"
- Says words like "I," "me," or "we"

Cognitive Milestones (learning, thinking, problem-solving)

- Uses things to pretend, like feeding a block to a doll as if it were food

Movement/Physical Development Milestones

- Shows simple problem-solving skills, like standing on a small stool to reach something
- Follows two-step instructions like "Put the toy down and close the door."
- Shows he knows at least one color, like pointing to a red crayon when you ask, "Which one is red?"
- Uses hands to twist things, like turning doorknobs or unscrewing lids
- Takes some clothes off by himself, like loose pants or an open jacket
- Jumps off the ground with both feet
- Turns book pages, one at a time, when you read to her

*** It's time for developmental screening!**
At 30 months, your child is due for general developmental screening as recommended for all children by the American Academy of Pediatrics. Ask the doctor about your child's developmental screening.

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?

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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.

For more on how to help your child, visit cdc.gov/Concerned.

Relatable and Accessible



- Family-friendly language at a 5th–7th grade reading level
- Milestones observable in natural settings
- Cognitive testing of the milestones done with families
- Available in [multiple languages](#)
- Free and accessible

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When to Act Early?

- “When to act early” milestones are no longer on a separate list, though 77% are still represented in the revised checklists.
- Many of the eliminated “when to act early” milestones were subjective or physical exam findings and not actual milestones.
- On the new checklists, since the milestones represent those that **MOST** (at least 75% of children) would be expected to achieve, missing any milestone could warrant formal screening.
- Open-ended questions can help identify concerns as well
 - “Is there anything your child is doing or is not doing that concerns you?”
 - “Has your child lost any skills they once had?”



Checklist Limitations

- CDC surveillance tools are **not** developmental screeners
- Not validated (*screening tools are validated*)
- Do not change developmental screening or evaluation tools
 - Should not be used to qualify for or discontinue services
- Not inclusive of all potential milestones

Remember, surveillance is more than milestones!



Tips from Healthcare Professionals

- Discuss results of surveillance and screening tools even if not concerning
 - Builds trusting relationships
- Take a strength-based approach
 - Then discuss any concerns
- Partner with family through “shared decision-making”
- Materials can support family engagement
 - CDC milestone checklists
 - Family-friendly referral guide
- “Close the loop” after referrals have been made
 - Track developmental referrals and support families while navigating referral process



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[Add Local Information Slides]

- Presenter insert [How to make an EI referral, part B and Part C] here
- Presenter insert [Resources for diagnostic evaluations] here
- [Click icon to the right to add an accompanying image and then DELETE this bullet point]



CDC's Act Early Ambassadors

- 59 Ambassadors: representing 48 states; Washington, DC; and 3 territories
- Champions for CDC's *Learn the Signs. Act Early.*
- Individuals passionate about early identification and professionally connected
- Work to advance integration of developmental monitoring into programs across their state/territory
- Learn more and get connected here: cdc.gov/ActEarly/Ambassadors



Future Research Possibilities

- What are the best practices for developmental surveillance?
 - Use of milestones/surveillance tools
 - Conversations with families regarding their child's development
 - To support developmental screening and early identification
- How to work across early childhood systems for early identification?
- How to support families in navigating referrals for early intervention and diagnostic evaluations?



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Practice Change

- Review current processes for
 - Surveillance
 - Screening
 - Discussion
 - Referral
- Consider resources to support your practice and families
- Know the features, strengths, and limitations of resources to use them optimally



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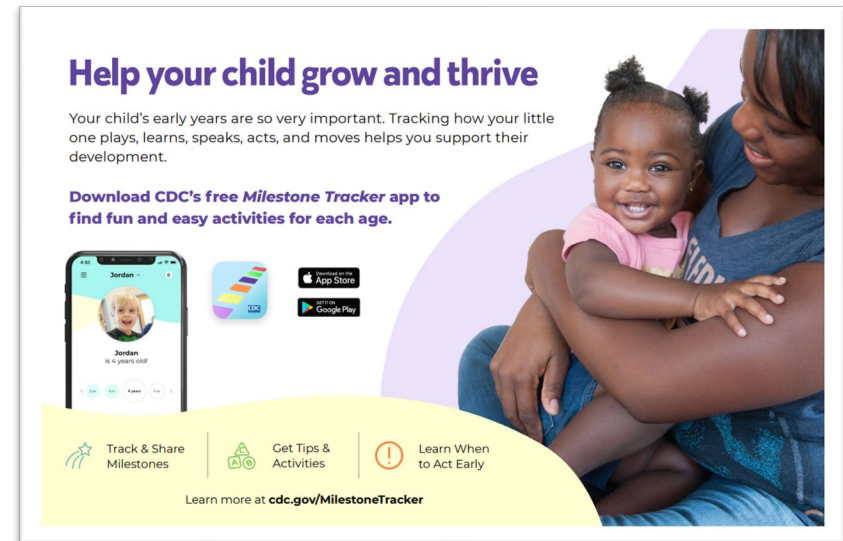


What Can I Do Today?

- Download *CDC's Milestone Tracker* app
- [Order](#) *Milestone Moment* booklets and *Milestone Tracker* app flyers
- Register/take an *AAP Pedialink* course
- [Email](#) your Act Early Ambassador
- Share a [social media](#) message
(Find under videos, social media, and web buttons)

Baby's first smile is just as important as the first step. Learn when to expect these and other milestones www.cdc.gov/Milestones

Check out @CDCgov's tips on how to talk to your doctor about #developmental #concerns: www.cdc.gov/Concerned



Help your child grow and thrive

Your child's early years are so very important. Tracking how your little one plays, learns, speaks, acts, and moves helps you support their development.

Download CDC's free *Milestone Tracker* app to find fun and easy activities for each age.

Track & Share Milestones | Get Tips & Activities | Learn When to Act Early

Learn more at cdc.gov/MilestoneTracker

The flyer features a photograph of a woman holding a young child. On the left, there is a smartphone displaying the app's interface for a child named Jordan, who is 4 years old. The app interface includes a profile picture, name, age, and several icons for tracking milestones, getting tips, and learning when to act early. The flyer also includes the App Store and Google Play logos.






Resources and Trainings



Free Resources From AAP and CDC

Family-friendly Guide to Next Steps

Developmental Concern? Next Steps for Families and Caregivers



Your child has many strengths and a supportive family. Together, we want your child to have what he/she/they need to learn and grow. Today our office is referring your child to see if services might help their learning and development and/or see if your child may have developmental delays.

<3 YEARS If your child is under 3 years of age, one of the places our office may refer you to is _____ (Name) _____ your state's early intervention program. If referred to early intervention, the program will evaluate your child at no cost and provide early intervention services, if they qualify, for minimal to no cost.


3+ YEARS If your child is over 3 years of age, our office may ask you to call your local public elementary school _____ (Name) _____. When you call the school you can say, "I have concerns about my child's development and I would like to have my child evaluated through the school system for preschool special education services." If the person who answers is unfamiliar with preschool special education, ask to speak with the school or district's special education director.

Along with referring your child to your state's early intervention, preschool special education, or Head Start program, our office may refer them to see one or more early childhood professionals, or programs, including:

- Physical Therapist** (addresses delays in head control, sitting, walking, running, jumping, kicking, or climbing).
- Occupational Therapist** (addresses sensory issues and delays in reaching, using hands together, self-feeding, undressing/dressing).
- Speech and Language Pathologist** (addresses delays in understanding and making speech sounds, words, having conversations, feeding problems, stuttering).
- Behavioral Therapist or Social worker** (addresses trouble engaging socially, paying attention to others, or having behavioral challenges).
- Early Childhood Care and Education**, eg. Head Start (provides early childhood education, health, nutrition, and family engagement services to children and families/caregivers).
- Other:** _____

Final Steps:

- Keep your follow up appointments at our office.
- Contact our office if you are having trouble making the referral appointments.
- Let our office know what the professional/specialist said and any next steps they recommend by:
 - Making an appointment at our office to discuss.
 - Contacting _____.
 - Other _____.
- Start any early intervention services your child qualifies for, even if you are waiting for other appointments to find out if there is a cause/diagnosis for any delays.

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Clinician Tip Sheet

Identifying Risks, Strengths, and Protective Factors for Children and Families: A Resource for Clinicians Conducting Developmental Surveillance



www.aap.org

[Developmental Surveillance and
Screening Patient Care \(aap.org\)](http://www.aap.org)

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Free *PediaLink* Courses

ONLINE COURSE

**Milestones Matter:
Don't Underestimate
Developmental Surveillance**


PediaLink
The AAP Online Learning Center



ONLINE COURSE

**Innovative Strategies for
Improving Developmental
Surveillance and Screening**

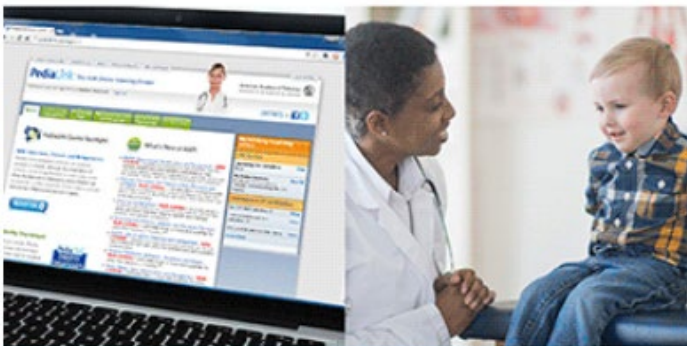
PediaLink
The AAP Online Learning Center



ONLINE COURSE

**Identifying and Caring for Children
with Autism Spectrum Disorder:
A Course for Pediatric Clinicians**

PediaLink
The AAP Online Learning Center



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Brief Team Training

Facilitated Mini Training – Developmental Surveillance

This course was supported by funds from the Centers for Disease Control and Prevention (Cooperative Agreement Number #6 NU38OT00282-01-01). Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention or the Department of Health and Human Services.

The format for the following training was inspired by the Spark trainings developed by the Adolescent Health Initiative at the University of Michigan. Their trainings can be found on their website at: http://bit.ly/AHI_Spark.

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- Team-based approach to surveillance and screening
- Brief 15–20 minutes
- Presenter slides
- Speaker notes
- Case-based learning

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Questions?



[Insert speaker' contact information here]

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Sources





AAP Resource Links

“Milestones Matter: Don’t Underestimate Developmental Surveillance”

<https://shop.aap.org/milestones-matter-dont-underestimate-developmental-surveillance/>

“Innovative Strategies for Improving Developmental Surveillance and Screening”

<https://shop.aap.org/innovative-strategies-for-improving-developmental-surveillance-and-screening/>

“Identifying and Caring for Children with Autism Spectrum Disorder: A Course for Pediatric Clinicians”

<https://shop.aap.org/identifying-and-caring-for-children-with-autism-spectrum-disorder-a-course-for-pediatric-clinicians/>

Family-friendly Referral Guide to Next Steps

“Developmental Concern? Next Steps for Families and Caregivers”

https://downloads.aap.org/AAP/PDF/LTSAE_FamilyFriendlyGuide_form%20updated%2010-22.pdf

Clinician Tip Sheet

“Identifying Risks, Strengths, and Protective Factors for Children and Families a Resource for Clinicians Conducting Developmental Surveillance”

https://downloads.aap.org/AAP/PDF/LTSAE_PediatriciansResourceGuide.pdf

Additional AAP resources

<https://www.aap.org/dss-patient-care>

Brief Team Training:

https://downloads.aap.org/AAP/PDF/Developmental_Surveillance_Spark_Training_Presentation_FINAL_10.2020.pdf

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CDC Resource Links

Download the *Milestone Tracker* app:

<https://www.cdc.gov/ncbddd/actearly/milestones-app.html>

Order Milestone Moment Booklets, *Milestone Tracker* App flyers, milestone brochures, and books:

<https://www.cdc.gov/ActEarly/Orders/>

Download and print milestone checklists and other resources:

<https://www.cdc.gov/ActEarly/Materials>

Email your LTSAE Ambassador:

<https://www.cdc.gov/ncbddd/actearly/ambassadors-list.html>

