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

CDC Learn the Signs. Act Early Illinois Ambassadors
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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

We are the CDC Learn the Signs. Act Early. Co-Ambassadors for the state of Illinois.

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Presentation Objectives

• Support **early identification** of children with developmental disabilities in your practice
• Understand CDC’s *Learn the Signs. Act Early.* program revisions and how they relates to early identification processes
• Understand how **parent education & engagement** in developmental monitoring/surveillance, combined with developmental monitoring, improves early identification
• Improve **awareness of systems for early identification** of developmental delays and disabilities
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.
1 in 6 Kids

Has a Developmental Delay
1 in 36 Kids

8-year-old children living in ADDM Network sites* were identified with ASD in 2020

* 11 U.S. Communities

Autism Diagnosis is very reliable at 24 months & can be done as early as 18 months
CDC’s Learn The Signs. Act Early
Four Steps of Early Identification

- Parent-Engaged Developmental Monitoring
- General Developmental and Autism Screening
- Referral for Services
- Receipt of Early Intervention
Milestones = Family Tool

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Parent / Family Engaged Developmental Monitoring
Developmental 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 that provide scores/risk categories

• Not diagnostic, but helps determine if evaluation needed
CDC’s Learn The Signs. Act Early Four Steps of Early Identification

- Parent-Engaged Developmental Monitoring
- General Developmental and Autism Screening
- Referral for Services
- Receipt of Early Intervention
Milestone Media for Parents

www.cdc.gov/ActEarly/Materials
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
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
Learn More about Your Child’s Development:

Developmental Monitoring and Screening

Taking a first step, waving “bye-bye,” and pointing to something interesting are all developmental milestones, or things most children can do by a certain age. Children reach many milestones in how they play, learn, speak, act, and move. Developmental monitoring and screening are ways to look for your child's developmental milestones.

**Developmental Monitoring**

- **WHO:** You — parents, grandparents, other caregivers
- **WHAT:** Look for developmental milestones
- **WHEN:** From birth to 5 years
- **WHY:** To help you:
  - Celebrate your child's development
  - Talk about your child's progress with doctors and child care providers
  - Learn what to expect next
  - Identify any concerns early
- **HOW:** With easy, free checklists – get yours at [www.cdc.gov/Milestones](http://www.cdc.gov/Milestones)

**Developmental Screening**

- **WHO:** Healthcare provider, early childhood teacher, or other trained provider
- **WHAT:** Look for developmental milestones
- **WHEN:** At 9, 18, and 24 or 30 months, or whenever there is a concern
- **WHY:** To find out:
  - If your child needs more help with development, because it is not always obvious to doctors, child care providers, or parents
  - If a developmental evaluation is recommended
- **HOW:** With a formal, validated screening tool – learn more at [www.hhs.gov/WatchMeThrive](http://www.hhs.gov/WatchMeThrive)
Learn the Signs. Act Early. Milestones
CDC Milestones...

Are communication tools for family developmental monitoring

• Evidence Based
• Not screening tools
• Not standards or CDC guidance
Detailed information on CDC’s developmental milestones and the 2022 revisions can be found in


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

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

Revisions will help avoid common questions like
- “How many milestones can be missing without being concerned?”
- “Are only the ‘warning signs’ important?”

Learn the Signs. Act Early.
Biggest Change

New Milestone
Ages Reflect When 75% or more of Children Reach Each Milestone

75% +
Previous Milestones

May Begin...

On Average...

Starts to...
Well Child Visit Aligned

New Milestone Ages Reflect When 75% or more of Children Reach Each Milestone & Well Child Visit Age Aligned
Improved Clarity

Clarified Language to Better Assess Quality of Skills
Parent Tested

Cognitive Testing Completed with Families of Different Backgrounds
Additional Checklist Features

- Open-ended questions (new)
- Act early messaging
- Early intervention information
- Tips and activities for developmental promotion and early relational health (revised/expanded)
- Reminders about developmental screening
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
Controversies – Masking Covid?
Pre Covid Data Used

• Used pre-pandemic data
• Revisions were completed in 2019
• Family Testing in 2020
• Publication of the process and results in February 2022
• Goal was to find MORE kids earlier
Controversies - Crawling

• Not clear normative data to match the well child visit ages
• Quality and “type” of crawling is very variable, some children skip all together
• Omission is not to negate importance but simply did not fit the parameters of the “tool” – 75% at well child age
Talking – When to Refer?

LTSAS revised milestones: 50 words at 30 months

VS.

ASHA maintains traditional age of 50 words at 24 months

Data review correlated with the 75% or more at 30 months

Refer if you are concerned at 24 months – Do Not Wait!-
Learn The Signs Act Early
In Your Practice
Spread The Word
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.

Learn more at cdc.gov/MilestoneTracker
Help Identify Other Needed Supports

2 Year Milestone Checklist

- Notices when others are hurt or upset, like pausing or looking sad when someone is crying

Help his learning and brain development. Try these simple tips and activities in a safe way. Talk with your child’s doctor and teachers if you have questions or for more ideas on how to help your child’s development.

- Use positive words when your child is being a good helper. Let him help with simple chores, such as putting toys or laundry in a basket.
- Watch your child closely during playdates. Children this age play next to each other, but do not know how to share and solve problems. Show your child how to deal with conflicts by helping him share, take turns, and use words when possible.

Reviewing Milestones Facilitates Discussions of Concerns & Parent Coaching
Community Supports

Connect Families to Other Needed Resources

If your child is between the checklist ages above, you will receive the checklist for the younger age.

Milestone Checklist
13/13 Milestones Answered

Appointments
+ Add Appointment

Helpful Resources For Families

Click here for more information on programs in Illinois for families.

Click the buttons below to learn more about other programs available for families in your state/territory that can help support your child's development. Your child's healthcare provider, teacher, or others may be able to connect you with these programs.

Early Intervention
WIC
Early Head Start/Head Start
Child Care Programs
Home Visiting Programs
Parent Information from CDC
Free Books & Checklists

Your baby at 9 months

What most babies do by this age:

Social/Emotional Milestones:
- Smiles at anyone who talks to her
- Points at others
- Looks around
- Dances
- Jegels
- Squeezes things

Cognitive Milestones:
- Looks for objects when dropped out of sight
- Holds two things together

Motor/Physical Development Milestones:
- Sits in a sitting position by herself
- Moves things from one hand to her other hand
- Taps to music
- Holds a cup without support

Language/Communication Milestones:
- Makes different noises
- Likes to share
- Samples

Other important things to share with the doctor:
- What are some things you and your baby do together?
- What are some things your baby likes to do?
- Do you have any concerns about your baby's development?
- Do you have any other concerns about your baby?
- How do you feel about your baby's development?

You know your baby best. Don't wait. If your baby is not meeting one or more milestones, talk to your doctor. If you have other concerns, talk to your doctor. If you are still concerned, talk to a specialist who can evaluate your baby more closely.

Baby’s Busy Day

Being one is so much fun!
Free Toddler Tools

Grow Up Healthy!

WHERE IS BEAR?
A Terrific Tale for 2-Year-Olds
Written by Libby Martinez
Illustrated by Allison Valentine
Free Posters & Brochures

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—and 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 Ages: 0-2 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 www.VKOM.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.
Developmental Surveillance Resources for Healthcare Providers

CDC's milestones and parent tips have been updated and new checklist ages have been added (15 and 30 months). For more information about the recent updates to CDC's developmental milestones, please review the Pediatrics journal article and these important key points.

In addition to early childhood screenings, the American Academy of Pediatrics also recommends developmental surveillance, a flexible, longitudinal, continuous, and cumulative process, at each health supervision visit to help identify children with developmental concerns. CDC's “Learn the Signs, Act Early” program has FREE parent-friendly milestone...
Concerned about Development?
How to Get Help for Your Child

Talking to the doctor is the first step toward getting help for your child if you are concerned about his or her development (how your child plays, learns, speaks, acts, or moves). Don’t wait. Acting early can make a real difference!

1. Make an appointment with your child’s doctor
   - When you schedule the appointment, tell the doctor’s staff you have concerns about your child’s development that you would like to discuss with the doctor.

2. Complete a milestone checklist
   - Before the appointment, complete a milestone checklist by downloading CDC’s free Milestone Tracker mobile app from the App Store or Google Play or printing a paper checklist from www.cdc.gov/Milestones.
   - Write down your questions and concerns; take these with you to the doctor’s appointment.

3. During the doctor’s appointment
   - Show the completed milestone checklist to the doctor
     > If your child is missing milestones, point them out, and share any other concerns that you have.

You Know Your Child Best

If your child’s doctor has told you to “wait and see,” but you feel uneasy about that advice:

Talk with another doctor to get a second opinion

AND

Call for a free evaluation to find out if your child can get free or low-cost services that can help.

If your child is under age 3:
Call your state’s early intervention
Consider using a smartphrase to direct parents to the CDC Tracker App and Website in your AVS:

Learn more about your child’s expected development with the CDC’s **Milestone Tracker App**, available at the Apple App Store or Google Play Store. See the website for more: [https://www.cdc.gov/ncbd/dd/actearly/index.html](https://www.cdc.gov/ncbd/dd/actearly/index.html)
CDC’s Learn The Signs. Act Early
Four Steps of Early Identification

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Referring for Intervention
Supports and Services
Early Intervention

Early Intervention in Illinois is a statewide program that provides supports and services for families to help their children under age 3 meet developmental milestones. The Illinois Chapter’s Early Childhood Committee identified Early Intervention (EI) referral processes as a top priority for pediatrician engagement. The Committee is actively working to collaborate with state agencies to improve and streamline the EI process for pediatricians.

Scroll through this page to find ICAAP member recommendations for navigating Early Intervention in your practice!

- ICAAP Member Survey 2022 Results
- Make an EI Referral
- Early Intervention Toolkit

Early Intervention Referral Form and Release of Information
Referring for MDX Visit

• Autism can be identified as early as 18 months and reliably diagnosed at 24 months

• Efforts are made to ensure children receive medical diagnostics before 36 months; The more time to receive targeted therapies in early intervention the better

• Reasons for a referral: a child is not responding to interventions as you expect; you have questions about development; or you wonder if there may be a medical reason for delays
Referring for Help

Look What I Can Do
Early Intervention For Young Children With Developmental Delays

1-800-323-GROW
Voice and TTY

The Sooner We Start, The Farther They’ll Go!
Search for the local Child & Family Connections Office to start the Early Intervention evaluation process.
Early Intervention

- Developmental Therapy
- Speech Therapy
- Occupational Therapy
- Physical Therapy
- Social Work
- Preschool Transition
- Can Come to Day Care
Getting Started

- Early Intervention Delays
- Speech
- OT/PT
- Other Medical Concerns: Sleep, GI, Picky Eating, Genetics
- Refer to Early Childhood Home Visiting Program
- Swim Classes
- Assess for Safety Concerns
Referring for Help

Supporting the Process

Parent Navigators
Local Interagency Councils
EI Illinois Clearinghouse
3-5 Yr Olds – School

Child Find or Special Education Evaluation
3-5 Yr Olds - School

School District Services are 3 hours of services a day

Children do not need to be toilet trained to attend school with an IEP

School district is responsible for transportation for children with an IEP can take kids to daycares
3-5 Yr Olds – School

Family Resource Center on Disabilities
frcd.org

Family Matters Parent Training & Info Center
fmptic.org

Star Net
Starnet.org

Equip For Equality
EquipforEquality.org

Family Support Resources
Other Resources
Questions?

ActEarly@cdc.gov
Cari Roestel - Caroline.Roestel@aah.org
Jean Davis – Jean.Davis@Illinois.gov
Learn the Signs. Act Early
Website: https://www.cdc.gov/ncbddd/actearly/index.html

Early Intervention:
CFC Locator: https://www.childfind-idea-il.us/Default.aspx
El Clearing House: https://eiclearinghouse.org/
Provider Referral Form with Communication Consent: https://www2.illinois.gov/hfs/SiteCollectionDocuments/hfs650.pdf
ICAAP Early Intervention Website: https://illinoisaap.org/early-intervention/

Chicago Public Schools – Child Find:

Other Child Find: Call school district and request special education evaluation specifically

School District Services – Family Support:
Equip For Equality Special Education Helpline/Clinic: https://www.equipforequality.org/issues/special-education/
Family Resource Center on Disability (Chicago area): frcd.org
Family Matters Parent Training and Information Center (covers the state of Illinois outside of the Chicago area:
https://www.fmptic.org/
Star Net: https://starnet.org/home/

Home Visiting Programs: igrowillinois.org

Other supports:
Illinois Cares for Kids: https://www.illinoiscaresforkids.org/
The Arc of Illinois Family to Family: https://www.thearcofil.org/
The Big Red Safety Toolkit: https://nationalautismassociation.org/big-red-safety-box/
Reading

Learn The Signs, Act Early Official Website:
https://www.cdc.gov/ncbddd/actearly/index.html

Pediatrics Article:
“Evidence-Informed Milestones for Developmental Surveillance Tools”
https://doi.org/10.1542/peds.2021-052138

Physical Therapy: Learn the Signs. Act Early.”: Updates and Implications for... :
Pediatric Physical Therapy (lww.com)

ASHA Fact Page on LTSAE Milestones:
https://www.asha.org/practice/Frequently-Asked-Questions-CDC-and-
AAP-Developmental-Milestones/

AOTA Fact Page on LTSAE Milestones:

Help Me Grow Blog Post: new blog post
Additional Information
Revision Process

- Established 11 criteria (including “most” ≥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
<table>
<thead>
<tr>
<th>Social Emotional Milestones</th>
<th>Age</th>
<th>CDC or New</th>
<th>Normative Data$^a$</th>
<th>Developmental Screening and Evaluation Tools$^b$</th>
<th>Published Clinical Opinion$^c$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Calms down when spoken to or picked up*</td>
<td>2mo.</td>
<td>New</td>
<td>Ertem et al$^{52,2018}$</td>
<td></td>
<td>ASHA$^{28}$; Bright Futures$^{54}$; Dosman et al$^{5,2012}$; Sharp et al$^{53,2008}$</td>
</tr>
<tr>
<td>Looks at your face</td>
<td>2mo.</td>
<td>CDC</td>
<td>Ertem et al$^{52,2018}$; Sheldrick, R.C and Perrin, E. C.$^{13,2013}$</td>
<td></td>
<td>Bright Futures $^{54}$; Dosman et al$^{5,2012}$; Scharf et al$^{53,2016}$</td>
</tr>
<tr>
<td>Seem happy to see you when you walk up to her</td>
<td>2mo.</td>
<td>New</td>
<td>Ertem et al$^{52,2018}$; Sheldrick, R.C and Perrin, E. C.$^{13,2013}$; Thalagala et al$^{55,2015}$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Smiles when you talk to or smile at her</td>
<td>2mo.</td>
<td>CDC</td>
<td>Bhave et al$^{56,2010}$; Ertem et al$^{52,2018}$; Lejarraga et al$^{57,2010}$; Thalagala et al$^{55,2015}$</td>
<td>ASQ-$^{59}$; PEDS-DM$^{42}$</td>
<td>ASHA$^{28}$</td>
</tr>
<tr>
<td>Smiles on his own to get your attention</td>
<td>4mo.</td>
<td>CDC</td>
<td>Ertem et al$^{52,2018}$</td>
<td>ASQ-$^{59}$; PEDS-DM$^{42}$</td>
<td>Bright Futures $^{54}$</td>
</tr>
<tr>
<td>Chuckles (not yet a full laugh) when you try to make her laugh</td>
<td>4mo.</td>
<td>New</td>
<td>Accardo P, and Capute A.$^{47,2005}$; Bhave et al$^{56,2010}$; Ertem et al$^{52,2018}$; Sheldrick, R.C and Perrin, E. C.$^{13,2013}$</td>
<td>ASQ-$^{59}$; PEDS-DM$^{42}$</td>
<td>ASHA$^{28}$; Bellman et al$^{17,2013}$; Bright Futures $^{54}$</td>
</tr>
<tr>
<td>Looks at you, moves, or makes sounds to get or keep your attention</td>
<td>4mo.</td>
<td>New</td>
<td>Ertem et al$^{52,2018}$</td>
<td>PEDS-DM$^{42}$</td>
<td></td>
</tr>
</tbody>
</table>

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
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
Support from Leaders in the Field

**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. 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.”

**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.”