

Parent-Engaged Developmental Monitoring Using CDC's Developmental Milestone Checklists

An Overview of Revisions and Updates

Fran Goldfarb, MA, MCHES, CPSP

Learn the Signs. Act Early Ambassador to California



Presentation Objectives

- Recognize many children with developmental delays and disabilities are not identified early
- Improve awareness of systems for early identification of developmental delays and disabilities
- Understand CDC's *Learn the Signs. Act Early.* program's revisions to free resources for families to monitor and discuss their child's development
- Promote parent-engaged developmental monitoring/surveillance



Why Monitor Development?

- Developmental disabilities are common and often not identified before school age
 - Up to **1 in 4** (≤ 5 yrs. of age) are at moderate to high risk for developmental, behavioral, or social-emotional delays¹
 - **1 in 6** (3–17 yrs. of age) has a developmental disability²
 - **1 in 44** (8 yr. olds) are estimated to have autism spectrum disorder³

1. *National Survey of Children's Health, 2011-12*

2. *Zablotsky, B, et al, Pediatrics 2019*

3. *CDC, MMWR Surveillance Summary 12/2021*



Why Monitor Development (Cont.)

2018 CA Children's Report Card

Developmental Screenings

GRADE: C -

The American Academy of Pediatrics recommends that all children under the age of three be screened routinely to monitor their development and identify potential delays. Screening is the first step to connecting children with the supports they need for healthy development.



CA's rank has dropped 13 places for the rate of young children who received screenings:^{3,4}

Ranking in 2012

#30

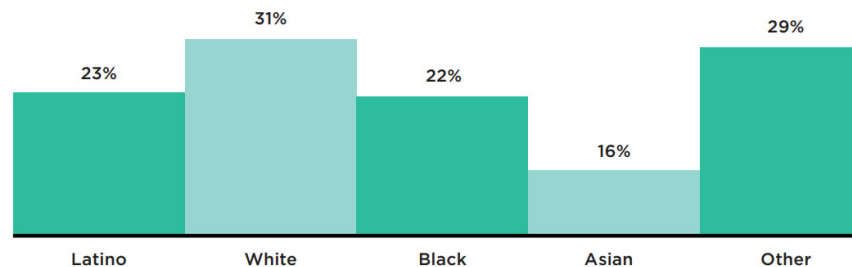


Ranking in 2016

#43



Rate of Parent-Completed Developmental Screenings⁵



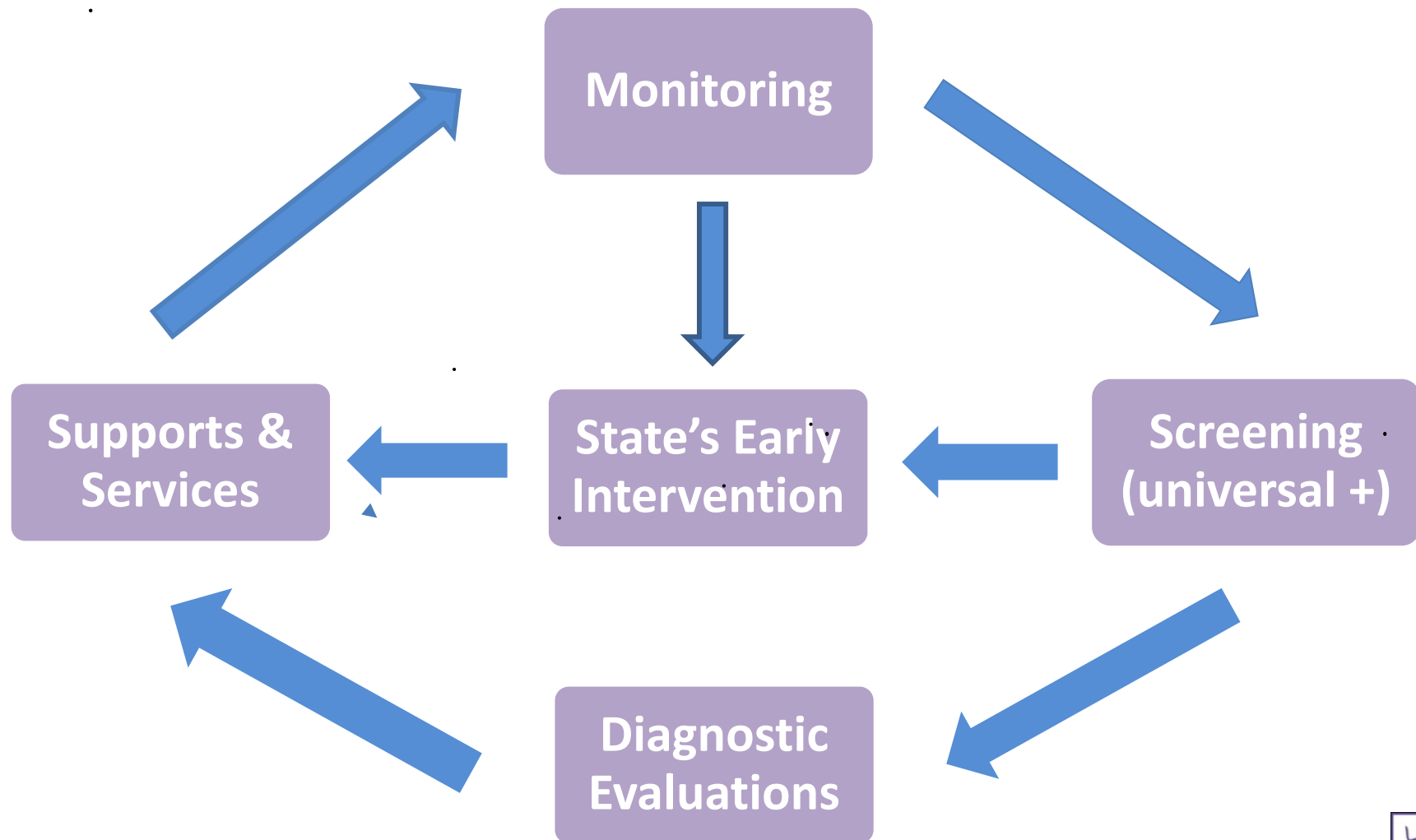
Children Now (2019)

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



Early Identification & Intervention



Developmental Monitoring vs Screening

Monitoring/Surveillance

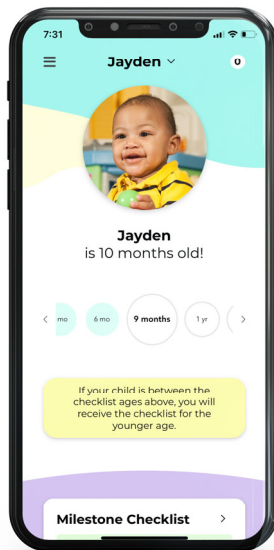
- Also called developmental surveillance
- Occurs at each well child visit
- Uses developmental milestones and much more
- Families and early childhood professionals also monitor development (team approach)
- Ongoing and longitudinal
- No scores, no risk categorization
- Can support the need for any additional developmental screening

Screening

- Administered by early childhood professionals
- Recommended at specific ages
- Also recommended if there are concerns when monitoring or other times
- Uses validated developmental screening tools with milestones
- Provides a risk categorization/scores
- Not diagnostic
- Helps determine if additional diagnostic evaluations are needed
- May be used to qualify for state early intervention programs



CDC's Milestone Checklists



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
- ☐ Stacks 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...

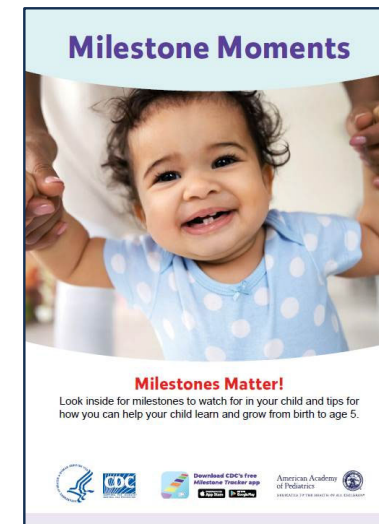
- What are some things you and your child do together?
- What are some things your child likes to do?
- Is there anything your child does or does not do that concerns you?
- Has your child lost any skills he/she once had?
- Does your child have any special healthcare needs or was he/she born prematurely?

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.

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

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



www.cdc.gov/ActEarly/Materials



Developmental Monitoring

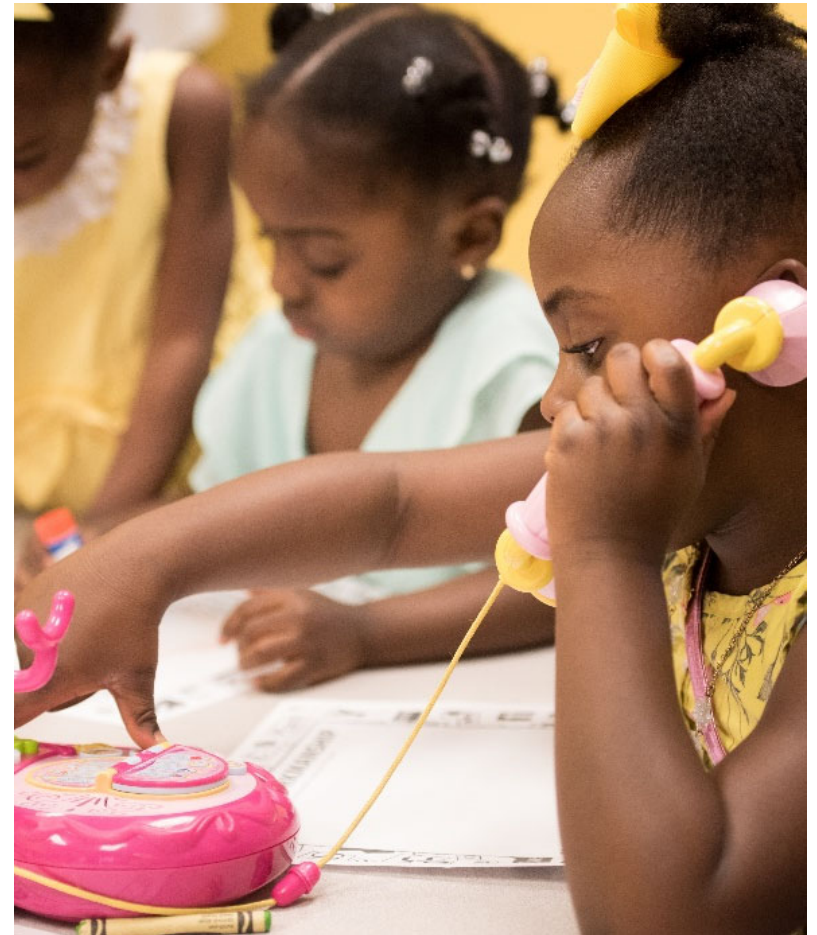


- Helps with early identification
- Adds different information than screening alone
 - Longitudinal
 - More than milestones
- Education/protective
 - i.e., Strengthening Families
- Developmental promotion
- Family engagement- trusting relationships



You May Have Heard...

- CDC milestone checklists:
 - Are communication tools for developmental monitoring
 - Not screening tools
 - Do not replace screening
 - Not standards or CDC guidance
- Revisions were completed in 2019
 - publication of the process and results in Feb. 2022



Why Revise?

- 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?



Developmental Expertise

- Developmental-behavioral pediatricians
- Neurodevelopmental pediatrician
- General pediatrician
- Speech language pathologist
- Child and developmental psychologists
- Professor of special education and early intervention
- Developer 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 representative/ disability navigator
- CDC *Learn the Signs. Act Early.* Ambassador



Developed 11 Criteria

1. Age most ($\geq 75\%$) children would be expected to demonstrate the milestone
2. Eliminate “warning signs”
3. Easy for families of different social, cultural, and ethnic backgrounds to observe
4. Able to be answered with yes/not yet/not sure
5. Use plain language; avoiding vague terms like may, can, and begins
6. Organize in developmental domains
7. Show progression of skills with age, when possible
8. No repetition across checklists
9. Include open-ended questions
10. Include information for developmental promotion
11. Include information on how to act early if there are concerns



Why “Most” ($\geq 75\%$)?

- Traditionally, milestone lists use 50th percentile or average age milestones
 - Half of children not expected to exhibit the milestone yet
- What if a child is missing 50th percentile milestones?
 - May cause unnecessary parental concern
 - May result in “wait and see” approach by professionals
- $\geq 75^{\text{th}}$ percentile milestones may better support validated screening as next step for children missing milestones.



Evaluating “Most”

- Literature search to find individual milestones with normative data
 - 34 articles found
 - 24 had normative data
 - 10 published clinical opinion
- First reviewed existing milestones for evidence-base and age placement using:
 - Literature review data
 - Common screening and evaluation tools
 - Common published clinical opinion
- Original milestones without an evidence-base and expert agreement were eliminated
- New milestones with evidence and expert agreement were added



Additional Sources

TABLE 2 Additional Developmental Resources Reviewed

Parent Resources	Educational/Training Resources	Developmental Screening Tools	Diagnostic Evaluation Tools ^a
AAP Bright Futures Previsit Questionnaires ¹⁰	AAP Bright Futures guidelines (4th ed) ⁹	Ages & Stages Questionnaires (3rd ed) ²²	Bayley Scales of Infant and Toddler Development (3rd ed) ²⁷
American Speech-Language-Hearing Association development charts ¹¹	AAP <i>Pediatrics in Review</i> articles ^{15–21}	Ages & Stages Questionnaires: Social-Emotional ²³	Beery-Buktenica Developmental Test of Visual-Motor Integration (6th ed) ²⁸
AAP brochure “Is Your One-Year-Old Communicating With You?” ¹²		Modified Checklist for Autism in Toddlers, Revised ²⁴	BRIGANCE Early Childhood Screens III ²⁹
CDC <i>Learn the Signs. Act Early.</i> checklists ¹³		Parents’ Evaluation of Developmental Status With Developmental Milestones ²⁵	The Capute Scales: Cognitive Adaptive Test/Clinical Linguistic and Auditory Milestone Scale ³⁰
FIRST WORDS Project 16 × 16 ¹⁴		Survey of Well-Being in Young Children ²⁶	MacArthur-Bates Communicative Development Inventories (2nd ed) ³¹
			Mullen Scales of Early Learning ³²
			Peabody Developmental Motor Scales (2nd ed) ³³
			Preschool Language Scale-5 ³⁴

^a Diagnostic evaluation tools were cross referenced when there was lack of agreement supporting a milestone or age of a milestone across other data sources. Not all milestones were cross referenced with diagnostic resources.

Learn the Signs.
Act Early.



Biggest Challenges



- Normative data difficult to find
 - Typical developmental milestone tables
 - Resources used for such tables are not usually cited
 - Cite each other
- Screeners/psychometric tests - based on unpublished normative data
- Even when normative data exists milestones don't "fit" nicely into health supervision visit ages



“Evidence-Informed”

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	



Remaining Criteria



- Reviewed using remaining criteria
- LTSAE team also reviewed for:
 - Family friendly
 - 5-7th grade reading level
- Cognitive testing with English and Spanish-speaking parents, mothers and fathers from different
 - Racial groups
 - Educational levels
 - Income levels



Results of the Process

- 26% reduction in total milestones
 - 216 to 159 milestones
 - 25 duplicates removed
 - Average number of milestones/checklist was reduced from 23 to 13
- 40% milestone replacement
 - 94 retained and 65 new
- 1/3 of retained milestones were moved to a different age
 - 2/3 moved to older age
- 80% of the final milestones had normative data from ≥ 1 source
- Social-emotional and cognitive milestones were the most difficult to find



Pediatrics



More information about the revision process can be found in the article

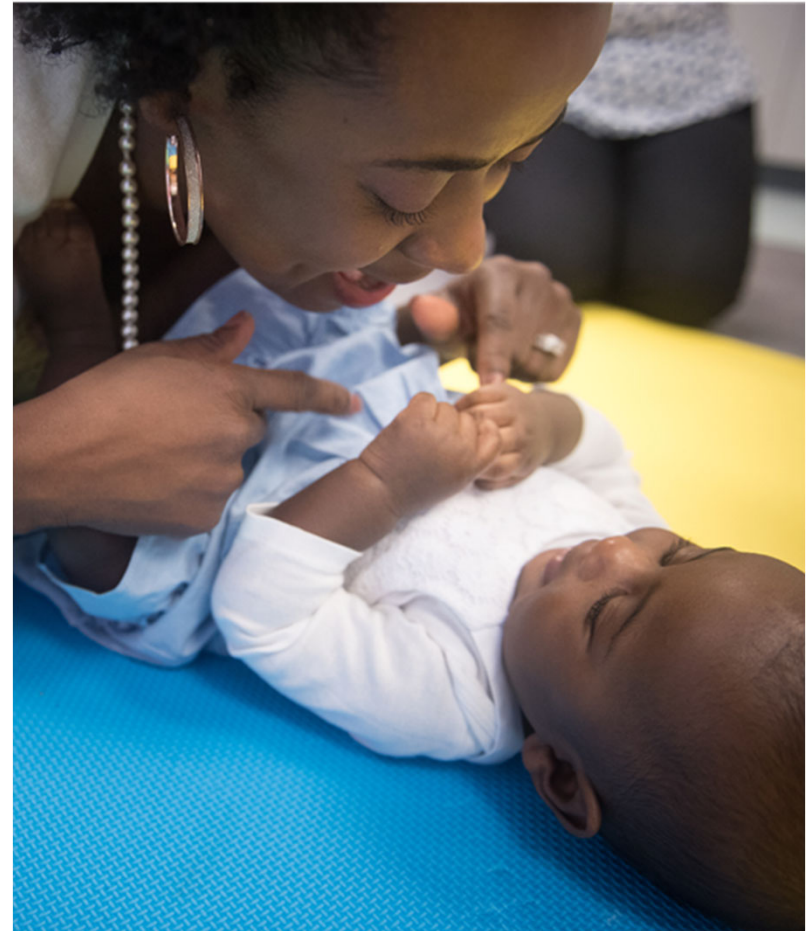
“Evidence-Informed Milestones for Developmental Surveillance Tools”

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



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



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 he/she once had?
- Does your child have any special healthcare needs or was he/she born prematurely?



Where are the “Red Flags”?

- “When to act early” milestones served as “red flags”
- 77% of these milestones are still represented in the revised checklists
- Missing any milestone that 75% or more of children are expected to exhibit could warrant screening
- What about the ones that were deleted?
 - Physical exam findings / subjective
- Open ended questions: *“Is there anything your child is doing or is not doing that concerns you?”*, *“Has your child lost any skills he/she once had?”*



Developmental Screening Reminders

Your child at 18 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 18 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

- ☐ Moves away from you, but looks to make sure you are close by
- ☐ Points to show you something interesting
- ☐ Puts hands out for you to wash them
- ☐ Looks at a few pages in a book with you
- ☐ Helps you dress him by pushing arm through sleeve or lifting up foot

Language/Communication Milestones

- ☐ Tries to say three or more words besides "mama" or "dada"
- ☐ Follows one-step directions without any gestures, like giving you the toy when you say, "Give it to me."

Movement/Physical Development Milestones

- ☐ Walks without holding on to anyone or anything
- ☐ Scribbles
- ☐ Drinks from a cup without a lid and may spill sometimes
- ☐ Feeds herself with her fingers
- ☐ Tries to use a spoon
- ☐ Climbs on and off a couch or chair without help

* It's time for developmental screening!

At 18 months, your child is due for general developmental screening and an autism screening, as recommended for all children by the American Academy of Pediatrics. Ask the doctor about your child's developmental screening.

Parent Tips and Activities

- Used CDC's positive parenting tips as foundation
 - www.cdc.gov/ncbddd/childdevelopment/positiveparenting/
- Reviewed parenting tips from trusted organizations
- CDC communication expert, early childhood educator, pediatrician, speech language pathologist
- CDC nutrition, injury prevention, LTSAE and other CDC groups reviewed and made recommendations
- Looked for areas for improvement/expansion
- Reworded for clarity and added more examples
- Included social emotional, relational health, responsive parenting & feeding, self-care, screen time



Strengths

Tools to support conversations that may:

- Improve clarity
- Improve sharing concerns
- Improve sharing concerns when there is no corresponding milestone
- Decrease “Wait and See”/ support trusting relationships
- Support screening as a next step
- Additional tips/activities for developmental promotion



Learn the Signs.
Act Early.



Relatable



- International normative data used to determine milestones
- Reviewed by 2 native Spanish speaking pediatricians
- Milestones are those that can be observed in natural settings
- Written at 5th-7th grade reading level, using family-friendly language
- Cognitively tested milestone descriptions with a diverse group of parents



Checklist Limitations

- CDC surveillance tools are not developmental screeners or “pre-screeners”
- Not validated (screening tools are validated, not surveillance tools)
- Not inclusive of all potential milestones
- Surveillance is more than milestones/checklists
- Have not been tested to see if they:
 - Improve conversations
 - Support developmental surveillance
 - Support developmental screening as next step

ActEarly@cdc.gov



The Larger Landscape



- Social emotional development
- Infant and early childhood mental health
- Safe stable nurturing relationships
- Resiliency/ACEs
- Developmental promotion
- Social determinants (drivers) of health and health equity
- Family-centered care



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
- CDC's milestone checklists can support parent-engaged developmental monitoring/surveillance
- Universal developmental screening at recommended ages AND when ever there are concerns
- Know the strengths and limitations of surveillance and screening tools you use when considering next steps



LTSAE: More Than Materials

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



Learn the Signs.
Act Early.



CDC's Act Early Ambassadors

- 59 Ambassadors: all 50 states, Washington, D.C., and 3 territories
- Champions for *Learn the Signs. Act Early.*
- Professionals passionate about early identification and professionally connected
- Work to advance integration of developmental monitoring into programs across their state/territory
- cdc.gov/ActEarly/Ambassadors



AAP Partnership

Clinician Tip Sheet

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



Free Online 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



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.



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.



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:

1. Keep your follow up appointments at our office.
2. Contact our office if you are having trouble making the referral appointments.
3. 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 _____.
4. 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.

American Academy of Pediatrics
DEDICATED TO THE HEALTH OF ALL CHILDREN®



Learn the Signs.
Act Early.



www.aap.org

Additional Resources

- Learn the Signs. Act Early
<https://www.cdc.gov/ncbddd/actearly/>
- Evidence-Informed Milestones for Developmental Surveillance Tools
<https://publications.aap.org/pediatrics/article/149/3/e2021052138/184748/Evidence-Informed-Milestones-for-Developmental>
- Salon (2022) No, the CDC didn't "lower standards" for childhood development because of the pandemic
- <file:///G:/BIGGER/UCEDD/LTSAE/revised%20milestones/No,%20the%20CDC%20didn't%20lower%20standards%20for%20childhood%20development%20because%20of%20the%20pandemic%20%20Salon.com.html>
- She Knows (2022) There Are New Developmental Milestone Guidelines — And They Could Help Identify Delays Sooner
<file:///G:/BIGGER/UCEDD/LTSAE/revised%20milestones/There%20Are%20New%20Developmental%20Milestone%20Guidelines%20for%20Young%20Kids%20%E2%80%93%20SheKnows.html>

Contact

Any Questions?



Fran Goldfarb, MA, MCHES, CPSP

fgoldfarb@chla.usc.edu

323 361-3831

Michele Rogers, PhD

micheler@earlylearninginstitute.com