Developmental Surveillance and Screening and the AAP: Where We Were, Where We Are, and Where We Are Going





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Learning Objectives

- Understand developmental screening and surveillance trends in US pediatric practice
- Summarize the changes and recommended steps in this practice for effective identification of children with developmental problems
- Explain the system of pediatric care from surveillance and screening, to diagnosis, and referral
- Identify components of developmental surveillance, including communication with early childhood and medical professionals outside of the medical home
- Review AAP partner initiatives and resources available to assist with implementation of developmental screening, referral, and follow-up in the medical home

"Pediatricians' Reported Practices Regarding Developmental Screening: Do Guidelines Work? Do They Help?"

TABLE 2. Methods Reported by Pediatricians to Identify Children at Risk for Developmental Problems

Method/Instrument	n	Proportion Who Reported Using Method or Instrument Always or Almost Always, %
Clinical assessment (ie, history and physical examination without screening instrument or checklist)	569	71
Clinical assessment guided by standardized instrument	562	33
Informal checklist completed by physician or office staff members	548	37
Informal checklist completed by parents	539	15
Standardized screening instrument	565	23
Bayley neurodevelopmental screen	509	2
Denver II	549	14
Ages and Stages	509	7
Parents' Evaluation of Developmental Status	504	3
Other	41	49

The *n* values for the survey items vary because of missing data. The use of the listed screening techniques is not mutually exclusive; therefore, proportions do not add up to 100%. Periodic Survey of AAP Fellows #53 (2002); N Sand, et al., *Pediatrics* 2005

TABLE 5. Reported Barriers to Conducting Standardized Developmental Screening for Children 0 to 3 Years of Age

	Proportion of Pediatricians Reporting Factor as Barrier to Screening, %
Time limitations in current practice	83
Lack of medical office staff to perform screening	49
Inadequate reimbursement for conducting formal screening	46
Language barriers (ie, physician or staff members cannot speak language of family)	19
Lack of confidence in ability to screen	10
Lack of treatment options for positive screening results	9
Lack of knowledge regarding referral options for positive screening results	8
Lack of confidence in validity of screening instruments	8
Belief that formal screening is not an appropriate role for pediatricians	8

Periodic Survey of AAP Fellows #53 (2002); N Sand, et al., Pediatrics 2005

POLICY STATEMENT

Identifying Infants and Young Children With Developmental Disorders in the Medical Home: An Algorithm for Developmental Surveillance and Screening

Council on Children With Disabilities
Section on Developmental Behavioral Pediatrics
Bright Futures Steering Committee
Medical Home Initiatives for Children With Special Needs Project Advisory Committee

Pediatrics 2006; 118: 405-420



Definitions (AAP 2006)

Developmental surveillance

 "A flexible, longitudinal, continuous, and cumulative process whereby ... identify children who may have developmental problems"

Developmental screening

- "The administration of a brief standardized tool aiding the identification of children at risk of a developmental disorder"
- Periodic
- Not Diagnostic!

Developmental evaluation

 "Aimed at identifying the specific developmental disorder or disorders affecting the child"

AAP 2006 Developmental Screening Recommendations

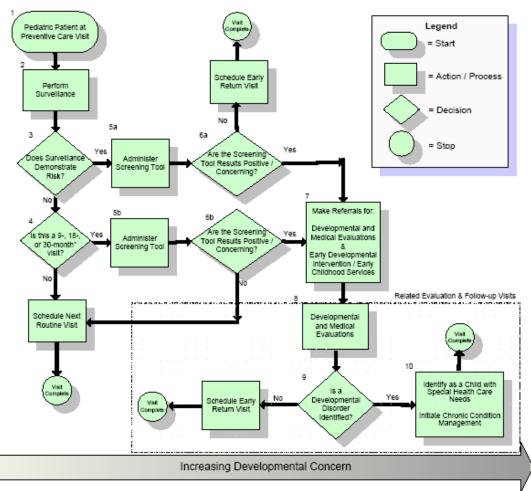
- Developmental surveillance
 - Every well-child visit
- Developmental screening using a standardized screening tool
 - > 9, 18, and 30 months
 - When concern is expressed
- Autism screening
 - > 18 and 24 months



Algorithm:

Surveillance
to
Screening
to
Referral

Developmental Surveillance and Screening Algorithm Within a Pediatric Preventive Care Visit

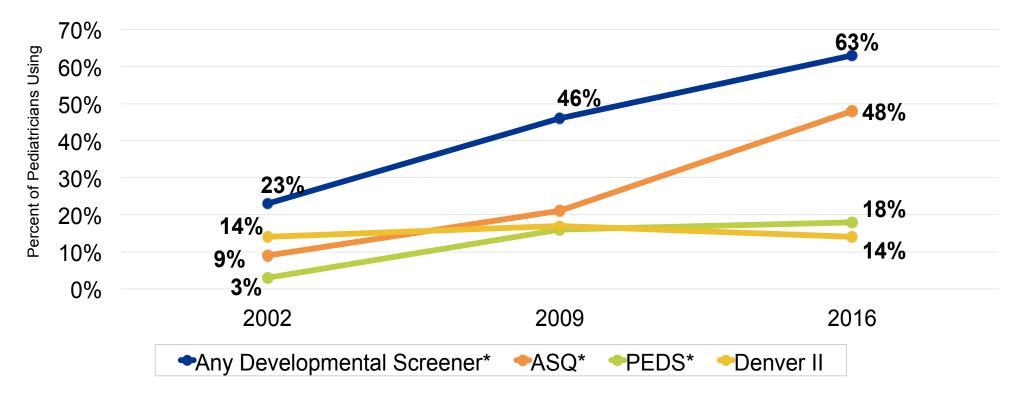


"Because the 30-month visit is not yet a part of the preventive care system and is often not reimbursable by third-party payers at this time, developmental screening can be performed at 24 months of age.



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.

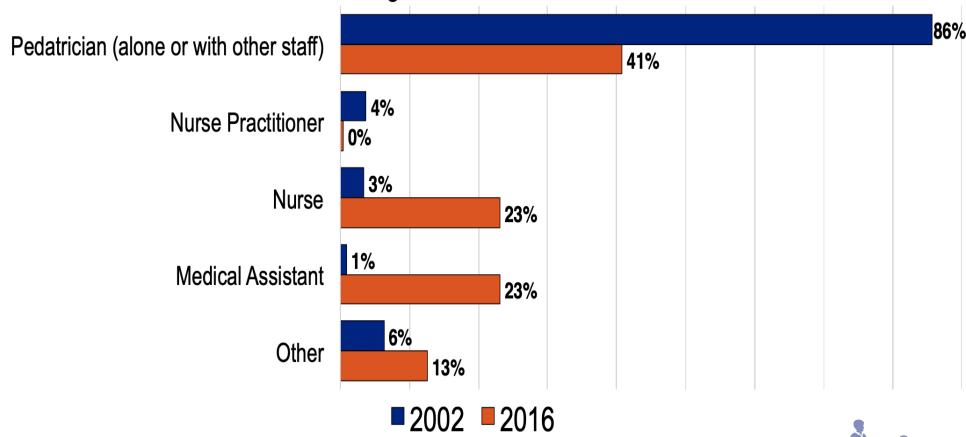




Trends: Screening Test Administration

Fig. 2: Who Administers Formal Screening in Pediatricians' Practices?

Changes from 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.





Trends: Screening and Referral

Screening Barriers

- Time limitations
- Inadequate reimbursement
- Lack of office staff to perform screenings

Referrals

 Increase from 41% in 2002 to 59% of at-risk patients to Early Intervention (EI)

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



CLINICAL REPORT Guidance for the Clinician in Rendering Pediatric Care

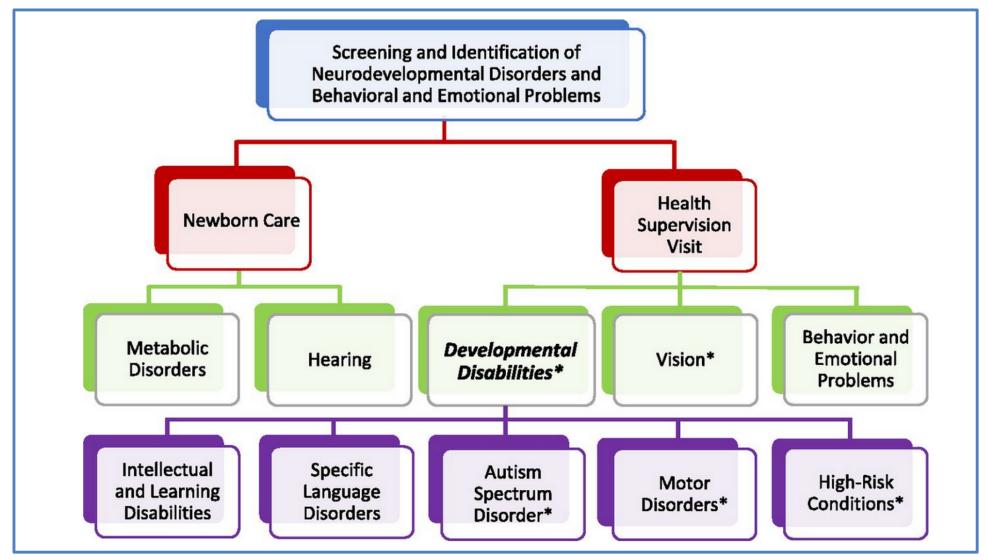


Promoting Optimal Development: Identifying Infants and Young Children With Developmental Disorders Through Developmental Surveillance and Screening

Paul H. Lipkin, MD, FAAP, Michelle M. Macias, MD, FAAP, COUNCIL ON CHILDREN WITH DISABILITIES, SECTION ON DEVELOPMENTAL AND BEHAVIORAL PEDIATRICS

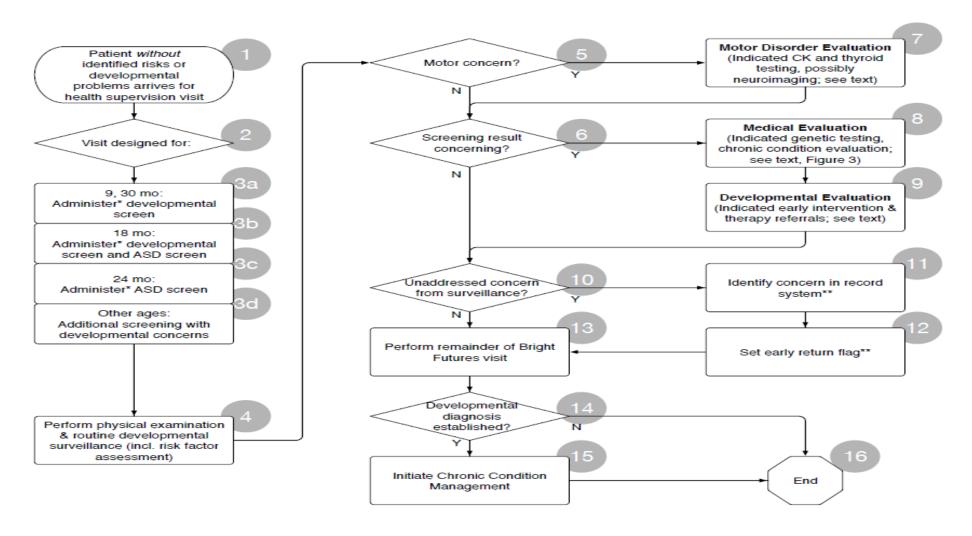
Lipkin PH, Macias MM, AAP Council on Children With Disabilities, and Section on Developmental and Behavioral Pediatrics. Promoting optimal development: identifying infants and young children with developmental disorders through developmental surveillance and screening. *Pediatrics*. 2020;145(1):e20193449.

Screening and Identification of Developmental Disabilities and Behavioral and Emotional Problems



Lipkin PH, Macias MM, AAP Council on Children With Disabilities, and Section on Developmental and Behavioral Pediatrics. Promoting optimal development: identifying infants and young children with developmental disorders through developmental surveillance and screening. *Pediatrics*. 2020;145(1):e20193449.

Algorithm for Screening a Patient Without Identified Risks for Developmental Problems at a Health Supervision Visit



- *Screening instruments may be administered through a pre-visit process initiated by the practice or by the family.
- **Providers should create methods in their record system (paper or electronic) to ensure that these facts are visible to clinicians in future visits and in the appointment scheduling process.

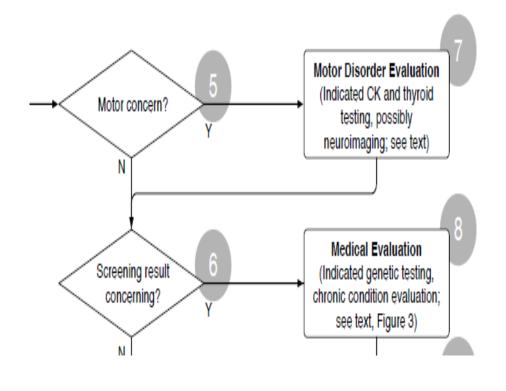
Lipkin PH, Macias MM, AAP Council on Children With Disabilities, and Section on Developmental and Behavioral Pediatrics. Promoting optimal development: identifying infants and young children with developmental disorders through developmental surveillance and screening. *Pediatrics*. 2020;145(1):e20193449.

Uniting Developmental Screening

General and Autism Paths

Patient without identified risks or developmental problems arrives for Bright Futures visit Visit designed for: 9, 30 mo: Administer* developmental screen 18 mo: Administer* developmental screen and ASD screen 24 mo: Administer* ASD screen Other ages: Additional screening with developmental concerns

Motor Path



Lipkin PH, Macias MM, AAP Council on Children With Disabilities, and Section on Developmental and Behavioral Pediatrics. Promoting optimal development: Identifying infants and young children with developmental disorders through developmental surveillance and screening. *Pediatrics*. 2020;145(1):e20193449.



Surveillance and Screening: Modifications

- Screening
 - Integration of general developmental screening with autism screening, motor screening, other
 - Ages of screening unchanged (9, 18, 24 [ASD], 30 months)
- Surveillance: refined definition
 - Screening by childcare and early childhood professionals: Incorporation by the pediatrician into surveillance at every health supervision visit
 - Review with family
 - Associated actions?
 - Discussion with screening professional
 - Repeat screening?
- Heightened attention to surveillance at the 4- to 5-year visit



Implementation: Surveillance 2020

Parent-Clinician Discussion at Every Health Supervision Visit

- 1. Eliciting and attending to the parents' concerns about their child's development;
- 2. Obtaining, documenting, and maintaining a developmental history;
- 3. Making accurate and informed observations of the child;
- 4. Identifying risk and strengths and protective factors;
- Maintaining an accurate record of documenting the process and findings;
- 6. Sharing and <u>obtaining</u> opinions and findings with other professionals (childcare providers, home visitors, preschool teachers, and developmental therapists), especially when concerns arise

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Implementation: Surveillance 2020

- Developmental surveillance at every health supervision visit
 - Includes sharing and obtaining opinions and findings
- Establish relationships with local childcare professionals, therapists, and educators for ongoing developmental surveillance and discussion of screening results.
- Consider direct referral to El/early childhood education, for developmental and medical evaluations without screening, when the child is determined to be at increased risk.





Implementation: Screening 2020

- Standardized screening test for all children at 9, 18, and 30 months, <u>and</u> for those whose surveillance yields concerns about delayed or disordered development.
 - Heightened attention through surveillance at the 4- and 5-year visits
- Standardized ASD screening test at the 18- and 24month visits and at any time for those whose surveillance yields concerns about delayed or disordered social development.

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Supplemental Table 1 Developmental Screening Tests

	Description	Age Range	No. Items	Administration Time	Forms Available EHR Compatible
Ages and Stages Questionnaires — 3	Parent-completed questionnaire. Series of 21 questions screening communication, gross motor, fine motor, problem- solving, and personal adaptive skills. Results in pass, monitor, or fail score for domains	2–60 mo	30	10-15 min	Electronic format that can be adapted for an EH
PEDS	Parent interview form. Designed to screen for developmental and behavioral problems needing further evaluation. Single response form used for all ages. May be useful as a surveillance tool	0—8 у	10	2-5 min	Electronic format that can be adapted for an EHR
PEDS: Developmental Milestones Screening Version	Parent interview form. Designed to screen for developmental and social-emotional problems	0—8 у	6–8 items at each age level	4–6 min	Electronic format that can be adapted for an EHR
SWYC: milestones	12 age-specific forms, keyed to pediatric periodicity schedule. Includes cognitive, language, and motor skills	1–65 mo	10	∼5 min	Available through Patient Tools, Epic, and CHADIS Available for free download as PDFs from www.theswyc. org

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Ages and Stages Questionnaire (ASQ)- 3rd edition: 1 months to 5½ years

- Caregiver questionnaires: Ages 2 to 60 mos., including 9, 18, 24, and 30
- 30 items per form describing skills
- Domains: Communication, Gross Motor, Fine Motor, Problem Solving, Personal-Social
- Time: Parent completion 10-15 mins, Scoring 2-3 mins.
- Scoring: 'On schedule'; Monitor; Further Assessment
- Languages: English, Spanish
- Can be photocopied
- ASQ-Social-Emotional works similarly and measures behavior, temperament, etc.
- http://www.brookespublishing.com/tools/as q/index.htm

de	n the following pages are questions about activities scribed here, and there may be some your baby h tes whether your baby is doing the activity regularly	as not begun doing yet.	For each iter			
ı	mportant Points to Remember:	Notes:				
9	1 Try each activity with your baby before marking a	a response.				
9	Make completing this questionnaire a game that you and your child.	is fun for				
9	Make sure your child is rested and fed.					
6	Please return this questionnaire by					
child	nis age, many toddlers may not be cooperative whe if more than one time. If possible, try the activities we "yes" for the item.					
1.	Does your child point to, pat, or try to pick up pictu	res in a book?		0	0	1
	Does your child say four or more words in addition	to "Mama" and	V	0	0	1
	"Dada"?					1
3.	When your child wants something, does she tell you	u by pointing to it?		0	0	1
	When you ask your child to, does he go into anothe miliar toy or object? (You might ask, "Where is your "Bring me your coat," or "Go get your blanket.")		•	0	0	
	Does your child imitate a two-word sentence? For e say a two-word phrase, such as "Mama eat," "Dade home," or "What's this?" does your child say both v (Mark "yes" even if her words are difficult to unders	dy play," "Go words back to you?	•	0	0	1
	Does your child say eight or more words in addition	to "Mama" and	0	•	0	-
			(COMMUNICATIO	ON TOTAL	7
GR	OSS MOTOR		YES	SOMETIMES	NOTYET	
	Does your child stand up in the middle of the floor several steps forward?	by himself and take	•	0	0	1
	Does your child climb onto furniture or other large clarge climbing blocks?	objects, such as	0	•	0	-
	Does your child bend over or squat to pick up an ol and then stand up again without any support?	bject from the floor	•	0	0	1

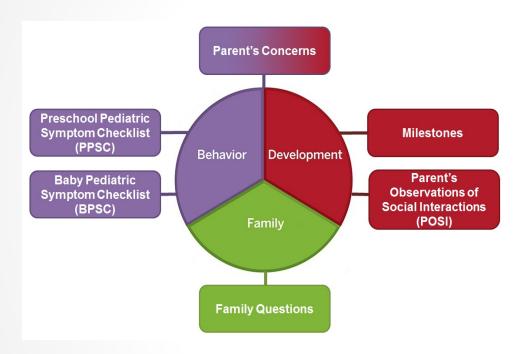
PEDS: Parents' Evaluation of Developmental Status



- For children 0 to 8 years
- Many languages
- Takes 2 to 10 minutes
- Elicits parents' concerns (surveillance?)
- Sorts children into high, moderate, or low risk
- 4th 5th grade reading level
- Score/Interpretation form used longitudinally
- http://pedstest.com/ind ex.php

	PEDS	RESPONSE FO	ORM	Paragon Provider			
Child's Name _Rus	sell Ríchards	Parent's Name Mr. a	ınd Mrs. Rích	ards			
Child's Birthday	3/21/04	Child's Age 30 monthsT	Today's Date <u>9/2</u>	3/2006			
Please list any co	ncerns about your ch	aild's learning, development, and b	oehavior.				
	Mostly his behavior. He doesn't mind me or seem to listen at all. Tantrums all the time						
Do you have any Circle one: No		your child talks and makes speed COMMENTS:	ch sounds?				
Do you have any	concerns about how	your child understands what you	say?				
Circle one: No	Yes (A little	COMMENTS:					
		your child uses his or her hands	and fingers to	do things?			
Circle one: No	Yes A little	COMMENTS:					
Do you have any		your child uses his or her arms a	nd legs?				
Circle one: No	Yes A little	COMMENTS:					
		your child behaves?					
Circle one: No		COMMENTS:					
This may	just be the terribl	e twos but it is really <u>terrible</u>	<u> </u>				
Do you have any	concerns about how	your child gets along with others	?				
Ctrcle one: No	Yes A little	COMMENTS:					
Do you have any	concerns about how	your child is learning to do thing	s for himself/h	erself?			
Ctrcle one: No	Yes A little	COMMENTS:					
He tries to be	He tries to be too independent						
Do you have any	concerns about how	your child is learning preschool of	or school skills	•			
Circle one: No		COMMENTS:					
I	thínk he's too you	ing for that sort of stuff					
Please list any other concerns.							
Nothing other than behavior and listening.							
		er Press, LLC, 1013 Austin Court, Nolensville, TN 37 ic applications contact support@forepath.org, 770%					

The Survey of Well-being of Young Children



- 12 age-specific forms keyed to periodicity schedule
- Development: 1-65 mos (10 items)
- Autism: 16-35 mos (7 items)
- Time: <5 minutes
- Free (public domain)
- www.thesywc.org





Screening Results

- Low risk
 - Review result, highlighting strengths
 - Inform when next screening will occur
- High risk
 - Review responses to items
 - Provide clinical interpretation
 - Discuss next steps (Referral, Follow-up)





Implementation: Screening & Continued Care

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



Implementation: Screening and Medical Testing

Medical diagnostic evaluation to identify an underlying etiology and to provide related counseling and treatment.

- Hearing and vision screening
- Motor delay: detailed neurologic examination
 - ↑ tone → consider brain imaging
 - normal or ↓ tone → creatine kinase (CK) and TSH should be obtained
- Global delay, intellectual disability, or autism, consider chromosome microarray, Fragile X testing
 - Consider metabolic testing depending on H&P





Follow-through is ESSENTIAL!



Screening



Referral



Follow-Up



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 EI such as electronic transmission of referrals.
- Barriers
 - Lack of feedback from El program about the child's progress and outcomes.
 - Increased concern with quality of services.

Jimenez ME, Fiks AG, Shah LR, et al. Factors associated with early intervention referral and evaluation: a mixed methods analysis. *Acad Pediatr.* 2014;14(3):315–323; Jimenez, ME, Barg FK, Guevara JP, et al. The impact of parental health literacy on the early intervention referral process. *J Health Care Poor Underserved.* 2013;24(3);1053–1062; and Lipkin PH, Macias MM, Baer-Chen B, et al. Trends in pediatricians' developmental screening: 2002-2016. *Pediatrics.* 2020;145(4):e20190851.



Developmental Surveillance and Screening in 2020: Next Steps

- Work toward early universal developmental screening of all children for earliest identification of developmental disorders, with identification of barriers limiting this practice.
- Additional efforts needed to enhance referral systems, improve El programs, and provide better tracking of child outcomes.
- Improved access to evaluation and treatment options for children with concerning screen results needed.
- Continue advocating for effective and evidence-based interventions across El and treatment programs.
- Need for improved communication between pediatricians and local El professionals.

CLINICAL REPORT Guidance for the Clinician in Rendering Pediatric Care



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

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Screening Technical Assistance & Resource Center

CHILD DEVELOPMENT

🌟 MATERNAL DEPRESSION 🌟 SOCIAL DETERMINANTS OF HEALTH 🕏

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.



www.aap.org/screening



Bright Futures...

prevention and health promotion for infants, children, adolescents, and their families™

BrightFutures.aap.org



Learn the Signs. Act Early.

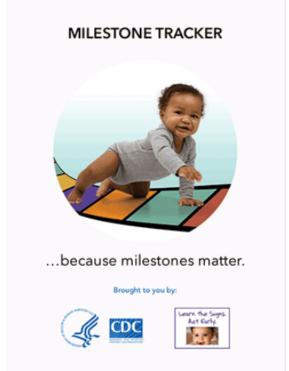
CDC's Developmental Milestones

Español (Spanish)

CDC's Milestone Tracker App

Español (Spanish)

Download it free today on iOS and Android devices in English and Spanish



ONLINE COURSE

Milestones Matter:
Don't Underestimate
Developmental Surveillance





Milestones Matter: Don't Underestimate Developmental Surveillance

MOC

AVAILABLE:

01/07/2020 - 01/06/2023

DESCRIPTION & LEARNING OBJECTIVES | CREDIT INFORMATION | REGISTRATION FEES COURSE DETAILS | TECHNICAL REQUIREMENTS

FORMAT:

Online Course

— Price **\$0.00**

Member Price **\$0.00**

ONLINE COURSE

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





Birth to 5: Watch Me Thrive!

 Coordinated federal effort to encourage healthy child development, universal developmental and behavioral screening for children, and support for the families and providers who care for them.

www.acf.hhs.gov/programs/ecd/watch-me-thrive

- Birth to 5: Watch Me Thrive! seeks to:
 - Celebrate milestones.
 - Promote universal screening.
 - Identify possible delays and concerns early.
 - Enhance developmental supports.
- Provides:
 - Compendium of research-based screening tools
 - "User's Guides" for multiple audiences
 - Electronic package of resources for follow-up and support
 - Screening passport available!



DEVELOPMENTAL SCREENING PASSPORT FO

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



Developmental Surveillance and Screening During the Pandemic

- Continue to follow recommendations from the AAP developmental surveillance and screening clinical report
- Consistent with AAP guidance on well-care during the COVID-19 pandemic, continue in-person well-care whenever possible.
 - Incorporate strategies such as scheduling well-care at different times of day than sick visits.
- Continue to utilize available resources and communicate with community partners and EI, discussing any changes during this time.





Developmental Screening Resources

- Early Childhood Technical Assistance Center (ECTA)

 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
 Provides information on disabilities, IDEA, and effective educational practices (English and Spanish).
- Learn the Signs. Act Early. www.cdc.gov/ncbddd/autism/actearly Provides parent, provider, and childcare educational resources on developmental milestones and developmental disabilities. Milestones Matter Encourage Parents to Track Their Child's Development.

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Developmental Screening Resources cont.

- CDC's free Milestone Tracker App helps parents monitor their children's development from age 2 m–5 yrs. Interactive checklists with photos and videos make tracking milestones easy and fun. Generates a personalized summary to help you perform developmental surveillance as recommended by the AAP and offers parents tips for developmental promotion and information about what to do if there is a developmental concern. Visit www.cdc.gov/MilestoneTracker to print a free poster about the app to hang in your exam room.
- Birth to 5: Watch Me Thrive! Website and Screening Passport
 <u>www.acf.hhs.gov/programs/ecd/watch-me-thrive</u> and
 <u>www.acf.hhs.gov/sites/default/files/ecd/birth_to_5_watch_me_thrive_screening_pass_port_desktop_printing.pdf</u>
- National Academy for State Health Policy (NASHP) Healthy Child Development State Resource Center: <u>healthychild.nashp.org</u>

One stop shop for state and national tools related to healthy child development policies and practices.

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