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

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

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

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

- Any Developmental Screener
- ASQ
- PEDS
- Denver II

Trends: Screening Test Administration

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

Changes from 2002-2016*

- **Pediatrician (alone or with other staff)**: 86% in 2016 (41% in 2002)
- **Nurse Practitioner**: 4% in 2016 (0% in 2002)
- **Nurse**: 3% in 2016 (23% in 2002)
- **Medical Assistant**: 23% in 2016 (1% in 2002)
- **Other**: 6% in 2016 (13% in 2002)

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)

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

Screening and Identification of Developmental Disabilities and Behavioral and Emotional Problems

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.*
Uniting Developmental Screening

General and Autism Paths

Motor Path

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;
5. Maintaining an accurate record of documenting the process and findings;
6. *Sharing and obtaining opinions and findings with other professionals (childcare providers, home visitors, preschool teachers, and developmental therapists), especially when concerns arise.*
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 EI/early childhood education, for developmental and medical evaluations *without screening*, when the child is determined to be at increased risk.
• Standardized screening test for all children at 9, 18, and 30 months, and 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 24-month visits and at any time for those whose surveillance yields concerns about delayed or disordered social development.
Supplemental Table 1 Developmental Screening Tests

<table>
<thead>
<tr>
<th>Description</th>
<th>Age Range</th>
<th>No. Items</th>
<th>Administration Time</th>
<th>Forms Available</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ages and Stages Questionnaires – 3</td>
<td>2–60 mo</td>
<td>30</td>
<td>10–15 min</td>
<td>Electronic format that can be adapted for an EHR</td>
</tr>
<tr>
<td></td>
<td>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</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PEDS</td>
<td>0–8 y</td>
<td>10</td>
<td>2–5 min</td>
<td>Electronic format that can be adapted for an EHR</td>
</tr>
<tr>
<td></td>
<td>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</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PEDS: Developmental Milestones Screening Version</td>
<td>0–8 y</td>
<td>6–8 items at each age level</td>
<td>4–6 min</td>
<td>Electronic format that can be adapted for an EHR</td>
</tr>
<tr>
<td></td>
<td>Parent interview form. Designed to screen for developmental and social-emotional problems</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SWYC: milestones</td>
<td>1–65 mo</td>
<td>10</td>
<td>~5 min</td>
<td>Available through Patient Tools, Epic, and CHADIS. Available for free download as PDFs from <a href="http://www.theswyc.org">www.theswyc.org</a></td>
</tr>
<tr>
<td></td>
<td>12 age-specific forms, keyed to pediatric periodicity schedule. Includes cognitive, language, and motor skills</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
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.
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

PEDS Response Form

- Child’s Name: Russell Richards
- Parent’s Name: Mr. and Mrs. Richards
- Child’s Birthday: 3/21/04
- Child’s Age: 30 months
- Today’s Date: 9/23/2006

Please list any concerns about your child’s learning, development, and behavior.

- Mostly his behavior. He doesn’t mind me or seem to listen at all. Tantrums all the time.

Do you have any concerns about how your child talks and makes speech sounds?

Circle one: Yes A little COMMENTS:

Do you have any concerns about how your child understands what you say?

Circle one: Yes A little COMMENTS:

Do you have any concerns about how your child uses his or her hands and fingers to do things?

Circle one: Yes A little COMMENTS:

Do you have any concerns about how your child uses his or her arms and legs?

Circle one: Yes A little COMMENTS:

Do you have any concerns about how your child behaves?

Circle one: Yes A little COMMENTS:

This may just be the terrible twos but it is really terrible.

Do you have any concerns about how your child gets along with others?

Circle one: Yes A little COMMENTS:

Do you have any concerns about how your child is learning to do things for himself/herself?

Circle one: Yes A little COMMENTS:

He tries to be too independent.

Do you have any concerns about how your child is learning preschool or school skills?

Circle one: Yes A little COMMENTS:

I think he’s too young for that sort of stuff.

Please list any other concerns.

Nothing other than behavior and listening.

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)
• 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)
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 EI program about the child’s progress and outcomes.
  - Increased concern with quality of services.

• 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 EI 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 EI and treatment programs.
• Need for improved communication between pediatricians and local EI professionals.
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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.

<table>
<thead>
<tr>
<th>Screening Recommendations</th>
<th>Screening Tools</th>
<th>Interactive Training</th>
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</thead>
<tbody>
<tr>
<td><img src="image1" alt="Screening Recommendation" /></td>
<td><img src="image2" alt="Screening Tool" /></td>
<td><img src="image3" alt="Interactive Training" /></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Screening Process Resources</th>
<th>Practice Success Stories</th>
<th>Questions? We Can Help.</th>
</tr>
</thead>
<tbody>
<tr>
<td><img src="image4" alt="Screening Process Resource" /></td>
<td><img src="image5" alt="Practice Success Story" /></td>
<td><img src="image6" alt="Questions We Can Help" /></td>
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</tbody>
</table>

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

[BrightFutures.aap.org](http://BrightFutures.aap.org)
Learn the Signs. Act Early.

CDC’s Developmental Milestones

CDC’s Milestone Tracker App

Download it free today on iOS and Android devices in English and Spanish.
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 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](http://www.ectacenter.org) Provides practice improvement tools, contact information for state Part C coordinators, and other early childhood resources.

- Center for Parent Information & Resources  
  [www.parentcenterhub.org/resourcelibrary](http://www.parentcenterhub.org/resourcelibrary) Provides information on disabilities, IDEA, and effective educational practices (English and Spanish).

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](http://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 [www.acf.hhs.gov/programs/ecd/watch-me-thrive](http://www.acf.hhs.gov/programs/ecd/watch-me-thrive) and [www.acf.hhs.gov/sites/default/files/ecd/birth_to_5_watch_me_thrive_screening_passport_desktop_printing.pdf](http://www.acf.hhs.gov/sites/default/files/ecd/birth_to_5_watch_me_thrive_screening_passport_desktop_printing.pdf)

- National Academy for State Health Policy (NASHP) Healthy Child Development State Resource Center: [healthychild.nashp.org](http://healthychild.nashp.org)

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


