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

Michelle M. Macias, MD, FAAP
Professor of Pediatrics
Chief, Division of Developmental-Behavioral Pediatrics
Medical University of South Carolina
Who Are We Detecting?

- Those with significant delays and disabilities (16% – 18% of 0-18 y/o). Of this group, common problems are:
  1. language impairment (~45%)
  2. learning disabilities (~30%)
  3. intellectual disabilities (~20%)
  4. autism, motor disorders, brain injury, etc. (~5%)
- At-risk due to psychosocial disadvantage: additional (10% - 12%)

TOTAL = ~ 30%
Why Screen?

- Early Intervention (EI) Benefits*
  - Parent satisfaction
  - Better outcomes for participants:
    - Successful treatment before school entrance
    - More likely to complete high school, become employed, avoid criminality and teen pregnancy.
- For every $1 spent on EI, society saves $13-17.

*Includes Individuals with Disabilities Educational Act (IDEA) and Head Start programs
Who Are We Detecting?

- 4% of 0 - 2 year olds
- 8% of 0 - 3 year olds
- 12% of 0 - 4 year olds
- 16%+ of 0 - 8 year olds
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


ASQ: Ages & Stages Questionnaire
PEDS: Parents’ Evaluation of Developmental Status
Denver: Denver Developmental Screening Test
Detection/Referral Issues

- Only about 30% of children with substantial delays and disabilities are detected by their health care provider.
- Many of those detected are not referred.
- Only 2½ - 3% of children 0 - 5 served in early intervention.
- Enrollment rates in EI should be closer to 8%.

*Thus most children do not receive the benefits of early intervention that can prevent school failure, high school dropout, etc.*
Definitions (AAP 2020)

- **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”
What Is Early Detection Policy?

▸ Eliciting and addressing parents’ concerns at each visit
▸ Viewing milestones at each visit
▸ Identifying and addressing psychosocial risk and resilience factors
▸ Sharing and obtaining opinions and findings with other professionals
▸ Using a general screen that is validated and accurate at 9, 18, 24 - 30 m, 4 yr+ and whenever surveillance yields concerns about delayed or disordered development
▸ Using an autism-specific screen at 18 and 24 months
The Ideal Screening Tools

- Addresses all developmental domains
  - Motor skills
  - Language/communication
  - Problem solving/adaptive behavior
  - Social-emotional skills
- Screens for Autism Spectrum Disorder
- Elicits and addresses parents’ concerns
- Culturally and linguistically sensitive
- Reliable, standardized, validated and accurate
Trends: Clinical Challenges

- Perceived Barriers
  - Time limitations
  - Payment (surveillance, follow-up, counseling, chronic management)
  - Professional and staff education/Office workflow
  - Integration and coordination of screening, referrals, and care by health care, education, and social service professionals

Ongoing Challenges to Referral

- High rates of non-referral (~40%)

- High rates of incomplete referrals and evaluations
  - 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

Follow-through is ESSENTIAL!
National Initiatives

DHHS Administration for Children & Families
www.acf.hhs.gov/programs/ecd/watch-me-thrive

AAP STAR Center
www.aap.org/screening

CDC’s Developmental Milestones
www.cdc.gov/ncbddd/autism/actearly
Developmental Surveillance and Screening in 2020: Next Steps

▸ Continue current unified national efforts toward early universal screening and increasing detection rates across health care, education, and social service sectors.
▸ Identify and address barriers limiting this practice.
▸ Enhance referral systems, improve EI programs, and provide better tracking of child outcomes.
▸ Improve access to evaluation and treatment options.
▸ Support effective and evidence-based interventions across EI, early childhood education, and treatment programs.
Additional 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).

- **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.
References


