

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

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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.

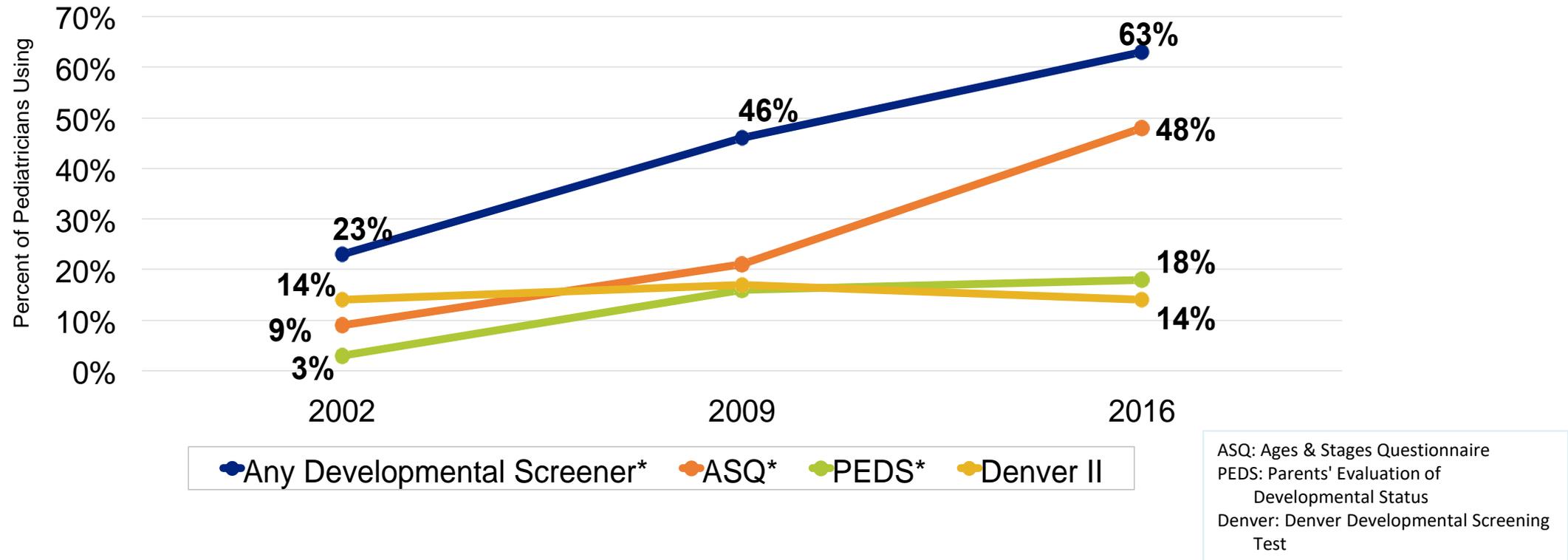
**Includes Individuals with Disabilities Educational Act (IDEA) and Head Start programs*

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



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

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 drop out, 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



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

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

4. FIGURES 1 AND 2: REFERRALS TO EARLY INTERVENTION

Fig. 1. Percent of Pediatricians that Directly Refer At-Risk Patients to EI

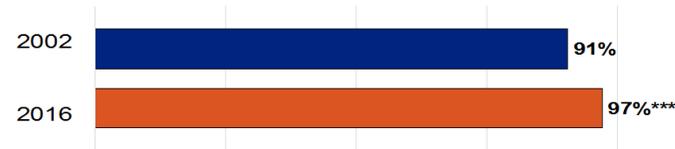
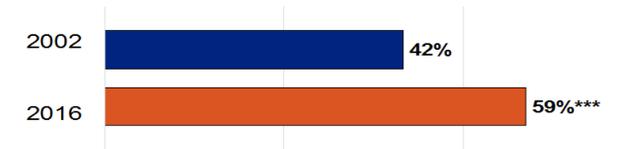
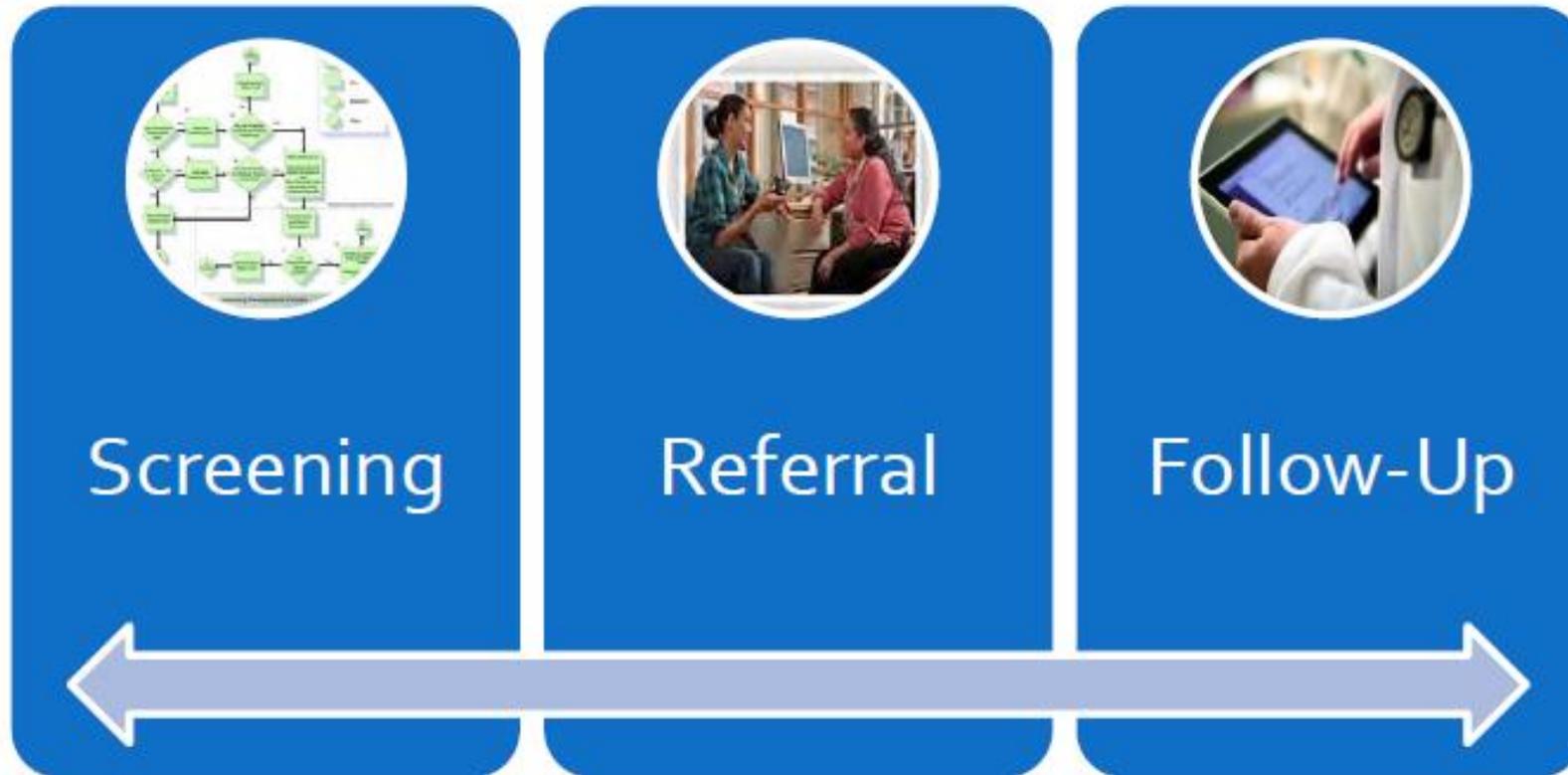


Fig. 2: Percent of At-Risk Patients that Pediatricians Directly Refer to EI

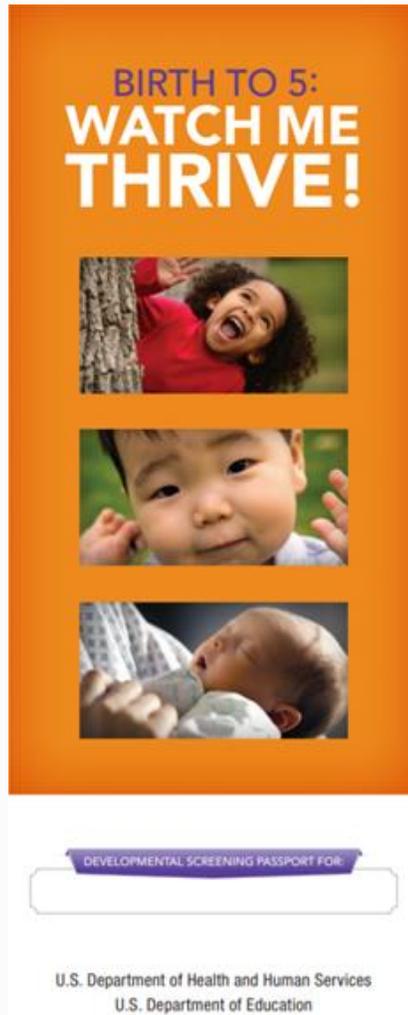


Jimenez ME, Fiks AG, Shah LR, et al. Factors associated with early intervention referral and evaluation: a mixed methods analysis. *Acad Pediatr.* 2014;14(3):315–323; Jimenez, ME, Barg FK, Guevara JP, et al. The impact of parental health literacy on the early intervention referral process. *J Health 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.

Follow-through is ESSENTIAL!



National Initiatives



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

AAP STAR Center



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



Learn the Signs. Act Early.

CDC's Developmental Milestones

[Español \(Spanish\)](#) 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
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).
- **National Academy for State Health Policy (NASHP) Healthy Child Development State Resource Center:** healthychild.nashp.org
One-stop shop for state and national tools related to healthy child development policies and practices.

References

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- ▶ Jimenez ME, Fiks AG, Shah LR, Gerdes M, Ni AY, Pati S, Guevara JP. 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, Gerdes M, Fiks AG. The impact of parental health literacy on the early intervention referral process. *J Health Care Poor Underserved*. 2013;24(3):1053–1062.