Implementing Developmental Screening Tools in the Patient Centered Medical Home

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Outline

- Definitions and guidelines
- Why follow the guidelines?
- What happens after children are identified with developmental concerns?
- Making this work in your practice

Developmental Surveillance

"A flexible, longitudinal, continuous, and cumulative process whereby knowledgeable health care professionals identify children who may have developmental problems"

- Eliciting and attending to parent concerns
- Maintaining developmental history
- Making accurate and informed observations
- Identifying risk and protective factors
- Documenting process and findings

Source: Council on Children With Disabilities. Identifying infants and young children with developmental disorders in the medical home: an algorithm for developmental surveillance and screening. Pediatrics. 2006 Jul; 118(1): 405–20.

Developmental Screening

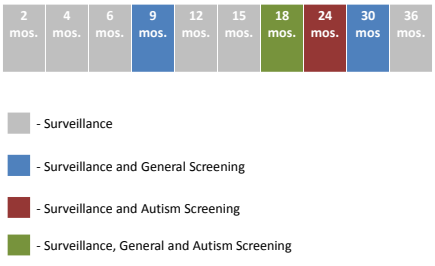
- Using a validated, structured tool at designated intervals to help identify children with developmental delay
  - General developmental screening
  - Disorder specific

AAP Recommendations for Birth to 3

- Developmental surveillance at all well visits
- General Developmental Screening
  - 9, 18 and 24 or 30 month visit
  - Any visit where a concern is identified
- Autism Specific Screen
  - 18 and 24 month visit
  - Any visit where a concern is identified

Source: Hagan JF, Shaw JS, Duncan PM. Bright futures : guidelines for health supervision of infants, children, and adolescents (3rd edition). Elk Grove Village, IL: American Academy of Pediatrics, 2008.

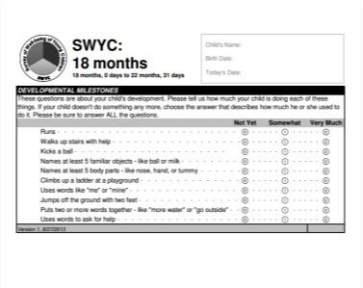
Scheduled Well Visits



* Screen whenever a developmental risk is identified or elicited

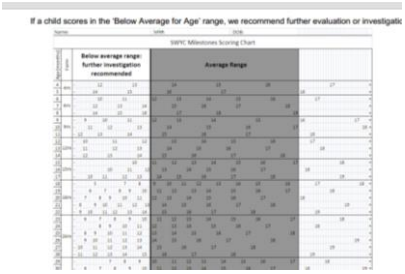
Commonly Used General Developmental Screening Tools

	ASQ-3	PEDS	SWYC
Ages	2 months- 5.5 years	Birth – 8 years	2 months – 5 years
Sensitivity	0.7- 0.91	0.75- 0.79	0.78-0.81
Specificity	0.79- 0.86	0.8	0.73-0.76
Reading level	4th-6th grade	4th – 5th grade	2.7 grade



Available at: https://sites.google.com/site/swycscreen/home

Scoring



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Scoring

- Score each item
  - Not yet= 0
  - Sometimes = 1
  - Very much = 2
- Add items 1-10
- Match age in far left column
- "Below average" requires further evaluation

Available at: https://sites.google.com/site/swycscreen/home

Autism Specific Screeners

- Modified Checklist for Autism in Toddlers
  - Parent report
  - Assesses for symptoms of autism spectrum disorder

Sensitivity and Specificity

	Condition	No Condition
Positive Test	True Positive	False Positive
Negative Test	False Negative	True Negative

Sensitivity= True Positive/ (True Positive + False Negative)

Specificity= True Negative/ (True Negative + False Positive)

Too Many False Positives?

	Dev. Delay	No Dev. Delay	Total
Positive Test	91	**183**	274
Negative Test	39	687	726
Total	130	870	1000

- You decide to screen 1000 infants and toddlers in your practice
- Assume sensitivity of 0.7, specificity 0.79, and prevalence of developmental delays- 13%
- Expect 183 false positives! ?

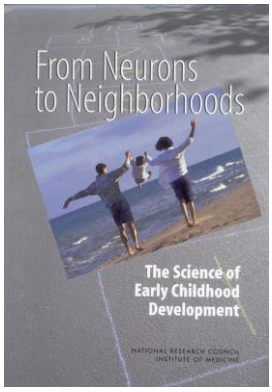
Even "False Positives" Can Benefit from Early Detection

Table 4. Comparison of Children's Performance on Diagnostic Measures Across Screening Outcomes

Characteristics of Children	Screening Outcomes*				
	True Negative	False Positive	False Negative	True Positive	F†
Adaptive behavior quotient	103 (18.3)	93 (15.0)	90 (10.1)	83 (12.6)	30.78
Language quotient	105 (19.0)	96 (15.2)	74 (15.4)	72 (14.0)	85.23
Intelligence quotient	113 (15.8)	99 (15.2)	95 (17.8)	92 (15.2)	50.08
Achievement quotient	103 (11.0)	94 (10.9)	95 (10.9)	89 (9.8)	32.46

*Data are given as median (SD). Outcomes are defined in the first footnote of Table 3.
†P<.001 for all.

Source: Glascoe, *Archives Pediatr Adolesc Med. 2001; 155:54-59*



Part C of the Individuals with Disabilities Education Act

- Federal program administered at the state level
- Participating states are required to identify and provide early intervention services to infants and toddlers with developmental delay
- Goals
  - Enhance the development of infants and toddlers with disabilities
  - Enhance the capacity of families to meet their infants needs

Early Intervention Helps Families

- 82% of parents felt their families were better off because of early intervention
- 96% of parents felt they were able to work with professionals and advocate for services
- 96% of parents felt they knew how to help their child develop and learn

Source: Bailey, *Pediatrics 2005;116;1346*

Early Intervention Helps Children

- Programs like Part C Early Intervention
  - Improve developmental outcomes
  - Improve behavioral outcomes

Sources: Nordhov *Pediatrics 2012;129;e9;* Nordhov Pediatrics DOI: 10.1542/peds.2010-0778; Shonkoff *Pediatrics 1987;80;650-658*

Potential Barriers to Developmental Screening

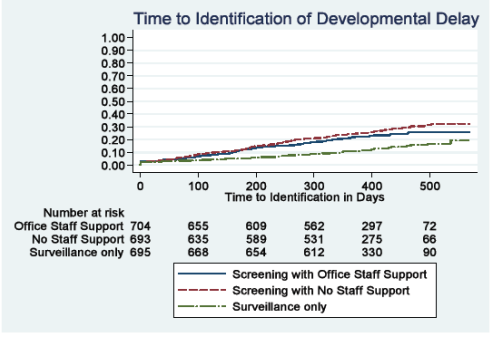
- Time
- Cost
- Literacy burden
- Parental confusion
- False positives
- Lack training
- Disrupts work flow
- EMR compatibility

Why not just do surveillance?

Translating Evidence Based Developmental Screening into Primary Care

- Randomized controlled trial evaluating 3 arms:
  1. Developmental screening with office staff support
  2. Developmental screening without office staff support
  3. Surveillance alone
- Conducted at 4 urban pediatric practices which served as continuity clinic training sites
- Eligibility: <30 months old, born ≥ 36 weeks EGA, without congenital malformations or genetic syndromes, not currently enrolled in EI

Source: Guevara *Pediatrics.* Jan 2013;131(1):30-37



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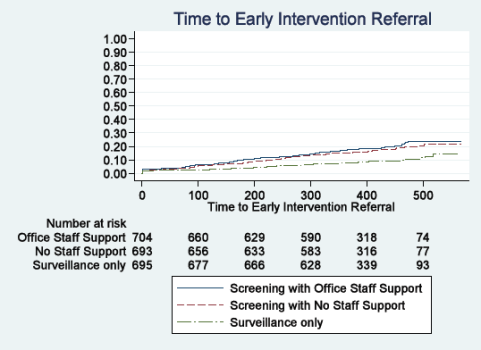

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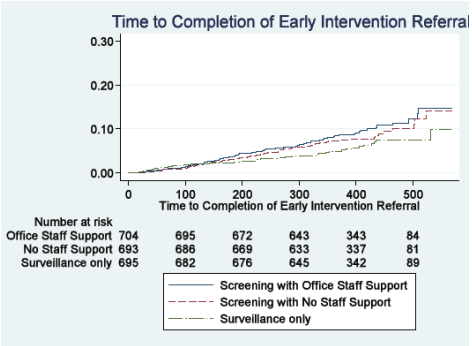

Source: Guevara *Pediatrics.* Jan 2013;131(1):30-37

What Happens After Children are Identified with a Developmental Concern

Source: Guevara et al *Pediatrics.* Jan 2013;131(1):30-37
Jimenez et al *Academic Pediatrics.* May –June 2014; 14(3):315-323

Factors Associated with Referral

- Increased odds of EI referral
  - Special health care needs odds of referral
  - Concerns involving 2 or more developmental domains

Jimenez et al *Academic Pediatrics.* May –June 2014; 14(3):315-323

Families Influence Decision to Refer

" 'Ok, we won't refer today, but let's come back in a month', so I shorten the time to next visit and I make a plan… if he's doing 'x' by then, great, if he's still not doing 'y' then let's refer, and they usually are on board with that. So that's when I tend not to refer…."

Pediatrician

Jimenez et al *Academic Pediatrics.* May –June 2014; 14(3):315-323

Problems with Screening Tools

- "I think [the questions] are written well for the most part, but I definitely absolutely have families who are at a low enough cognitive level that they don't understand."

Pediatrician

Jimenez et al *Academic Pediatrics.* May –June 2014; 14(3):315-323

Factors Associated with Completed Evaluation

- Two or more developmental domains
- Faxed referral form versus just handing parents a phone number

Jimenez et al *Academic Pediatrics.* May –June 2014; 14(3):315-323

Just the Fax

- 58% of children referred by fax completed an evaluation
- 33% of children whose parents were only given the EI phone number completed an evaluation

Jimenez et al *Academic Pediatrics.* May –June 2014; 14(3):315-323

"I think before we relied on the parents to make the first contact, that wasn't working because the parents would either forget or [EI] was so busy they would tell them to call back… but now that we fax our forms, it's much better."

Pediatrician

Jimenez et al *Academic Pediatrics.* May –June 2014; 14(3):315-323

Family Perspectives on the EI Referral Process

Themes

- Miscommunication
- Parents Want to be Heard
- Wait and See
- Practical barriers
- Skepticism

Source: Jimenez et al. *Academic Pediatrics.* Nov 2012;12(6):551-557.

Miscommunication

"I was voicing my concerns...she agreed with them but didn't seem overly concerned, so that kind of brought me down a few notches and so my urgency was already dropping at that point. So I didn't realize that maybe that [EI referral] was something I should definitely do."

Not evaluated

Source: Jimenez et al. *Academic Pediatrics.* Nov 2012;12(6):551-557.

Parents Want to be Heard

"I spend all my time with her, so I know her habits and I know her speech."

Not evaluated

"I thought it was my choice, it was my responsibility… to contact [EI] if I felt that he needed services or not."

Evaluated

Source: Jimenez et al. *Academic Pediatrics.* Nov 2012;12(6):551-557.

Wait and See

"We were like, no, we'll just work with him, at first. So we tried to work with him. Then at the next appointment he didn't make too much progress and they were like, yeah we recommend [EI]. So we called the number."

Evaluated

Source: Jimenez et al. *Academic Pediatrics.* Nov 2012;12(6):551-557.

Practical Barriers: Time constraints

"I did put it in my pile of to-dos, which is a mountain. And it got lost in the mountain."

Not Evaluated

Source: Jimenez et al. *Academic Pediatrics.* Nov 2012;12(6):551-557.

Practical Barriers: Not Understanding the Referral Process

"I didn't have a number to call. I wasn't really sure why the process was going on and I was also in school. So I just focused on school and didn't really pay it any mind"

- Not evaluated

Source: Jimenez et al. *Academic Pediatrics.* Nov 2012;12(6):551-557.

Skepticism

"Some people they already have other issues going on. They might feel insecure about their home environment. It might not look the way other people think it should look. That's their standard of living. Because it's in the home, it's not like you're coming to a location, they might feel insecure, like okay I know I'm not the best parent or they might judge me when they come in here, or they might take my kids"

EI Employee

Source: Jimenez et al. *Academic Pediatrics.* Nov 2012;12(6):551-557.

Parental Health Literacy

	Evaluated (n=20)	Not evaluated (n=20)
Possibly Limited	3 (13.6%)	9 (40.9%)
Unlikely Limited	17 (77.3%)	11 (50%)

Source: Jimenez et al. *Journal of health care for the poor and underserved* 24(3): 1053-62, 2013.

Differences by Health Literacy

	Possible Limited literacy (n=12)	Unlikely limited literacy (n=28)
Confusion about EI process	6 (50 %)	9 (32%)
Issues contacting EI	4(33.3%)	3 (10.7%)
Physician does not explain EI	4 (33.3%)	5 (17.8%)
No established pediatrician	7 (58.3%)	8 (28.6%)

Source: Jimenez et al. *Journal of health care for the poor and underserved* 24(3): 1053-62, 2013.

Making this work in your practice

Surveillance and Screening

- One does not replace the other
- Always begin by attending to parent concerns
  - "Do you have any specific concerns about your child's development, learning or behavior?"
- Screening at regular intervals improves detection of developmental concerns

Communicating results

- Attend to parent concerns
- Clear communication
- Communicate concerns in the context of specific strengths
- Delineate clear action steps
- Provide ongoing support

Next steps

- Plan for borderline results
- Link families to resources
  - Community resource (e.g. early intervention)
  - Medical specialist
- Do not wait for medical specialist before referring to community resource

SERIES

- Screening
- Early identification
- Referral
- Intake
- Evaluation
- Services

Source: Kavanagh, et al. An integrated approach to supporting child development. Policy Lab Evidence to Action Brief, Children's Hospital of Philadelphia PolicyLab

Considerations for Implementation

- Set a goal
- Choose a screening tool
- Assess your work flow including EMR if applicable
- Identify roles for team members
- Set up a plan for tracking
- Get to know community providers

Resources

- **American Academy of Pediatrics National Center for Medical Home Implementation- Developmental Screening** http://www.medicalhomeinfo.org/how/clinical_care/developmental_screening/implementing/
- **Early Childhood Developmental Screening: A Compendium of Measures for Children Ages Birth to Five. Available at:** http://www.acf.hhs.gov/programs/opre/resource/early-childhood-developmental-screening-a-compendium-of-measures-for-children-ages-birth-to-five

Take Away Messages

- Developmental screening is effective
- Children at risk for developmental problems benefit from services
- Identification does not guarantee intervention

Take Away Messages

- Educate and partner with families to help link them to services
- Simplify the referral process for families when you can
- Be aware of families with low health literacy
- Create a work flow for your practice

NJ 0 to 3 EI

- Regional Intake Line 1-888-653-4463
- Service coordinator helps arrange evaluation
- Assessment and Evaluation occur at no cost for family (sliding scale for services)

NJ 0 to 3 Early Intervention

- Eligibility
  - under the age 3
  - scores on a standardized instrument at least 2.0 standard deviations below the mean in one functional developmental area or at least 1.5 standard deviations below the mean in two or more developmental areas.
  - Developmental areas include gross motor, fine motor, sensory (vision and hearing), cognitive, communication, social- emotional, adaptive.

Contact Information

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Questions?