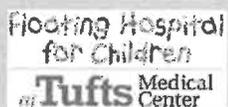


## The Survey of Wellbeing of Young Children (SWYC)

[www.theSWYC.org](http://www.theSWYC.org)

Ellen C. Perrin, M.D.



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## What's the problem?

- 15 - 20% of children have emotional and/or developmental disabilities
- Higher among children
  - born prematurely
  - in poverty
  - with a chronic health condition
- Few are treated

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## Recent trends:

- Reported prevalence is increasing
- Increasing awareness
  - ADHD
  - Autism
  - Depression, anxiety
  - Social risk factors
- Growing evidence that early interventions help



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## Increased Focus on Children's Development & Mental Health

- Centers for Disease Control (CDC)
- American Academy of Pediatrics (AAP)
  - Task Force on the Family
  - Mental Health Task Force
  - Screening Guidelines 2001, 2006, 2015
  - Practice Guidelines (ADHD, Autism)
  - Bright Futures
- American Academy of Child and Adolescent Psychiatry (AACAP)
- Many state initiatives for screening

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## Concerns about Instruments: "Behavior" and "Development"

- Screening instruments have been disconnected
  - Cognitive, language, motor development
  - Social/emotional wellbeing
  - Psychosocial challenges
  - Parental depression
- Evidence of 'development' is 'behavior'
- Inextricably interconnected



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## Other Concerns about Screening Instruments

- Most are proprietary
  - Cost
  - Adaptability
  - Electronic format
- Concerns about
  - Feasibility
  - Validity
- Not tested for longitudinal use
- Many require props, follow-up
- Not comprehensive



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## SWYC goals

- To maximize the amount of information that can be elicited from parents of young children before a visit.
- Comprehensive
  - Behavioral symptoms
  - Developmental milestones
  - Autism symptoms
  - Family risk
- Feasible
  - Brief
  - Easy to administer and score
  - Amenable to electronic administration
  - Free
- Valid across gender, race/ethnicity, SES

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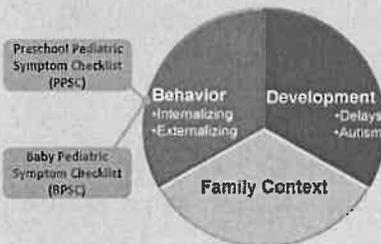
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Academic Pediatrics, 2012  
Academic Pediatrics, 2013

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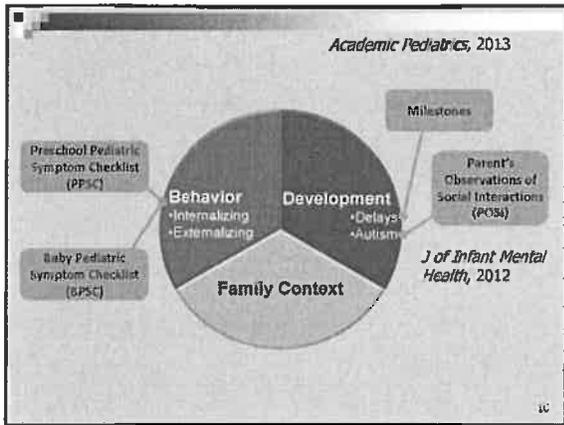
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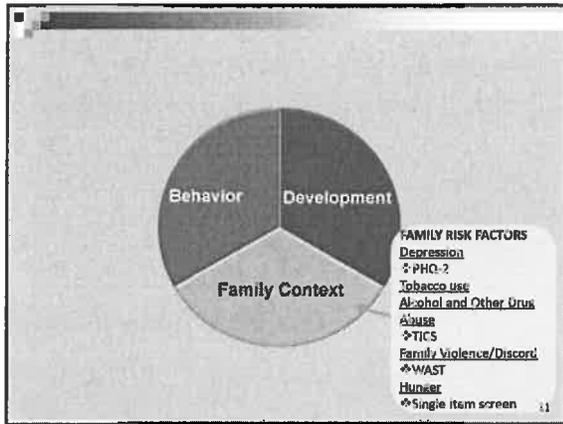
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SWYC forms

Visit on periodicity schedule

2	4	6	9	12	15	18	24	30	36	48	60

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### SWYC forms

	Visit on periodicity schedule											
	2	4	3	9	12	15	18	24	30	36	48	60
Social-emotional functioning	●	●	●	●	●	●	●	●	●	●	●	●
Developmental milestones	●	●	●	●	●	●	●	●	●	●	●	●
ASD symptoms							●	●	●			
Family risk	●	●	●	●	●	●	●	●	●	●	●	●

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### SWYC forms

	Visit on periodicity schedule											
	2	4	3	9	12	15	18	24	30	36	48	60
Social-emotional functioning	BPSC			●	●	●	●	●	●	●	●	●
Developmental milestones	●	●	●	●	●	●	●	●	●	●	●	●
ASD symptoms							●	●	●			
Family risk	●	●	●	●	●	●	●	●	●	●	●	●

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### SWYC forms

	Visit on periodicity schedule											
	2	4	6	9	12	15	18	24	30	36	48	60
Social-emotional functioning	BPSC			PPSC								
Developmental milestones	●	●	●	●	●	●	●	●	●	●	●	●
ASD symptoms							●	●	●			
Family risk	●	●	●	●	●	●	●	●	●	●	●	●

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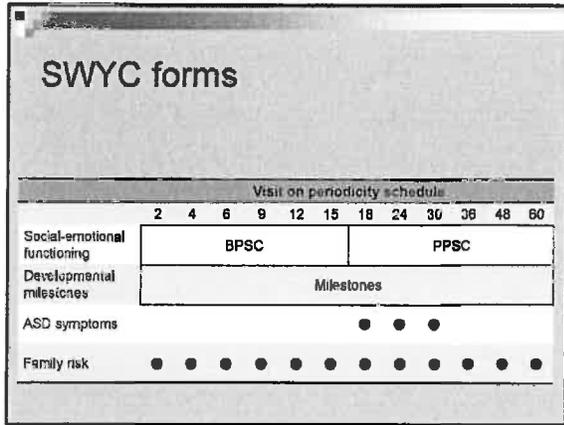
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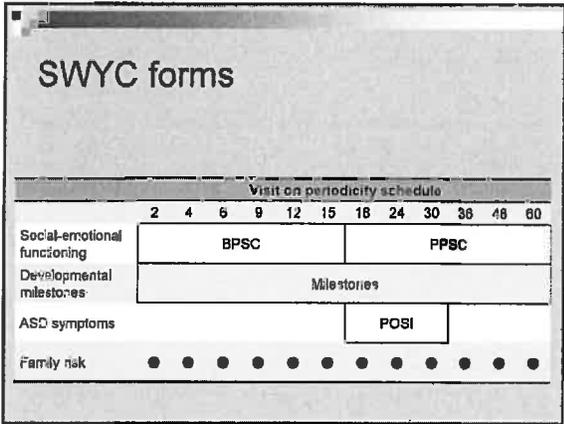
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### Development & initial validation

- Wrote >300 questions based on previously validated screening tests and expert opinion
- Obtained responses from > 1500 parents of children 2 months to 5 years old
- Chose best questions based on statistical analyses of responses
- Borrowed Family Risk items from previously validated screening questionnaires

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**Example SWYC Forms**

SWYC Milestones: cognitive, language, motor development

10 items each form  
 Response options: not yet, somewhat, very much  
 Different at each age  
 1 score  
 Match score to normative data chart  
 Creates longitudinal "growth curve"

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**Example SWYC Forms**

12-Month                      24-Month

Social-Emotional/Behavior

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**Example SWYC Forms**

Baby Pediatric Symptom Checklist (BPSC)  
 <18 months  
 12 questions  
 3 subscale scores,  $\geq 3$  is positive

BPSC <18 months

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### Example SWYC Forms

**Preschool Pediatric Symptom Checklist (PPSC)**  
 18-30 months  
 18 questions  
 1 score, ≥9 is positive

**PPSC**  
 18 months - 5 years

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### Back of SWYC Forms

#### 12-Month

#### 24-Month

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### Back of SWYC Forms

**Autism: Parent's Observations of Social Interactions (POSI)**

- 18 to 30 months
- 6 "critical items" based on MCHAT + 1 additional item
- 5 response options
- 3 responses in 3 right columns is positive

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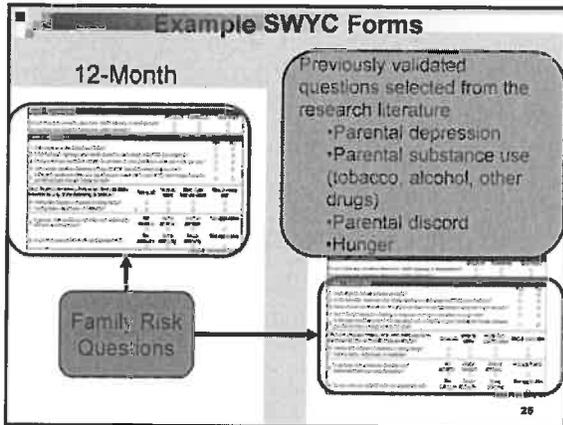
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### Development & initial validation

Initial research on each SWYC domain:

- Is published in a peer-reviewed journal
- Includes findings from 2 independent samples
- Compared accuracy against accepted screeners

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### Ongoing work

- Manual in process
- Electronic format in process
- Discussions re EMR integration
- Comparative accuracy study funded by NICHD
  - PEDS + MCHAT
  - ASQ + ASQ-SE + MCHAT
  - SWYC
- Translation and replication in Spanish
- Qualitative study by Tribal Early Childhood Research Center
- International interest

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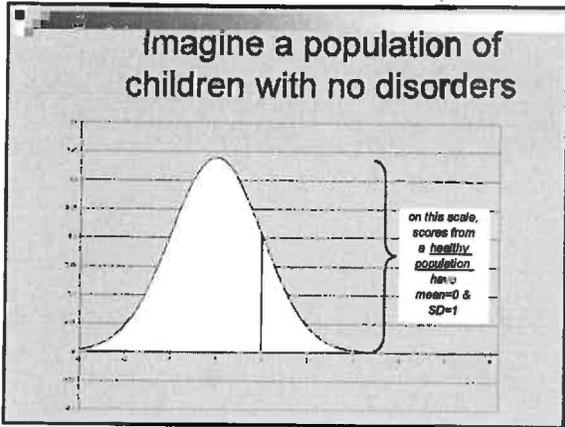
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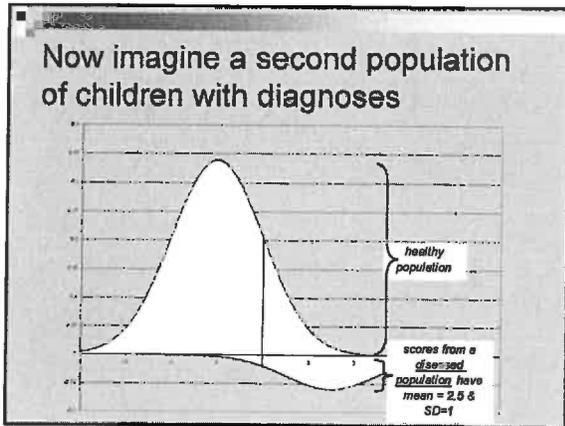
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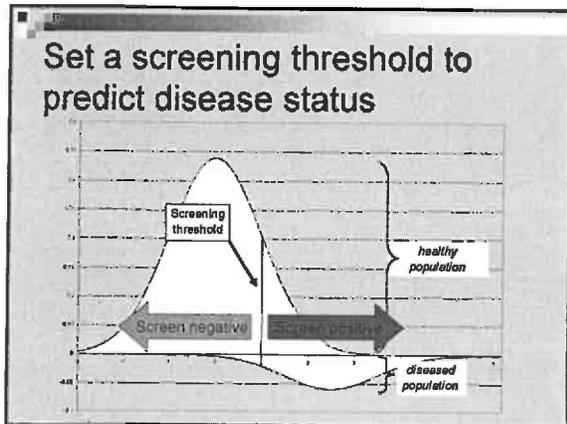
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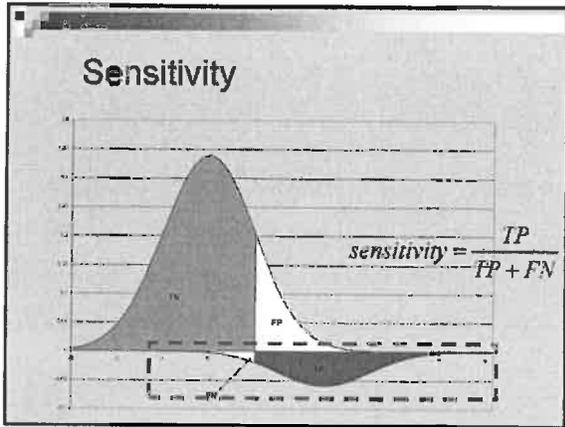
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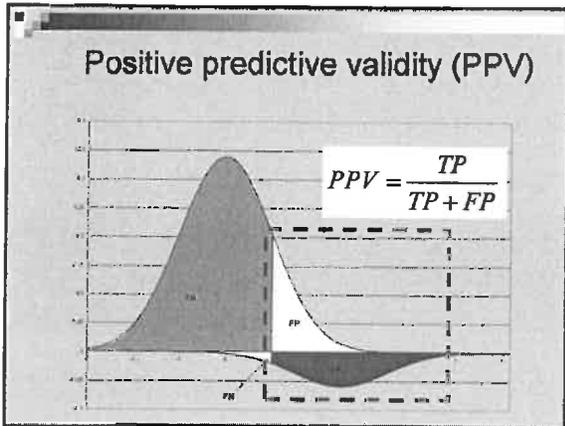
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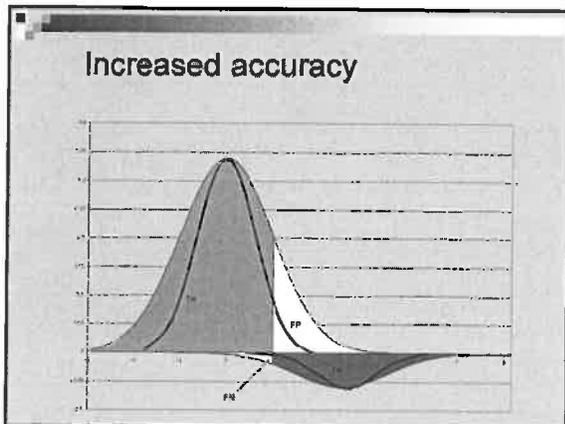
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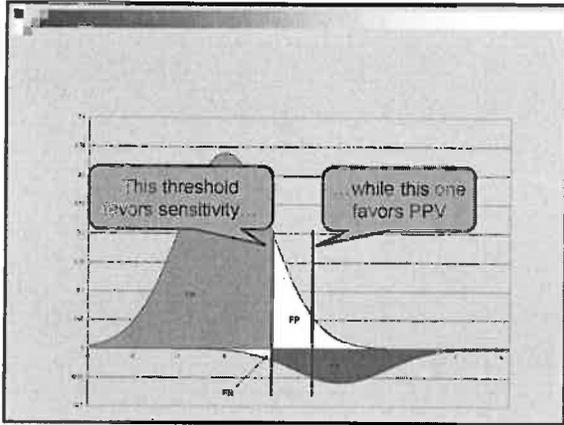
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**Summary: SWYC**

- Brief surveillance (~ 10 minutes)
- Accuracy (sensitivity and specificity) comparable to longer screening instruments
- Comprehensive (cognitive, motor, language and social-emotional development, risk factors)
- Amenable to electronic format
- Freely available in English & Spanish
- Approved for use by MA Medicaid/CBHI
- [www.theSWYC.org](http://www.theSWYC.org)

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