The Survey of Wellbeing of Young Children (SWYC)

www.theSWYC.org

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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

Recent trends:

- Reported prevalence is increasing
- Increasing awareness
  - ADHD
  - Autism
  - Depression, anxiety
  - Social risk factors
- Growing evidence that early interventions help
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
  - Practice Guidelines (ADHD, Autism)
  - Bright Futures
- American Academy of Child and Adolescent Psychiatry (AACAP)
- Many state initiatives for screening

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

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
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
### SWYC forms

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SWYC forms

Visit on periodicity schedule:

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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
Example SWYC Forms

SWYC Milestones: cognitive, language, motor development.

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

Example SWYC Forms

12-Month 24-Month

Social-Emotional Behavior

Example SWYC Forms

Baby Pediatric Symptom Checklist (BPSC)
<18 months
12 questions
3 subscale scores: ≥ 3 is positive

BPSC <18 months
Example SWYC Forms

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

PPSC: 18 months – 5 years

Back of SWYC Forms

12-Month

24-Month

Back of SWYC Forms

Autism: Parent's Observations of Social Interaction (POSI)

- 24-24 months
- 3 items
- 1 item based on "CHAT + 1 additional item"
- 9 response options
- 3 responses in 3 right column is positive
Example SWYC Forms

12-Month

Previously validated questions selected from the research literature:
- Parental depression
- Parental substance use (tobacco, alcohol, other drugs)
- Parental discord
- Hunger

Family Risk Questions

Development & initial validation

Initial research on each SWYC domain:
- Published in a peer-reviewed journal
- Includes findings from 2 independent samples
- Compared accuracy against accepted screeners

Ongoing work

- Manual in process
- Electronic format in process
- Discussions re EMR integration
- Comparative accuracy study funded by NICHHD
  - PEDS + MCHAT
  - ASQ + ASQ-SE + MCHAT
  - SWYC
- Translation and replication in Spanish
- Qualitative study by Tribal Early Childhood Research Center
- International interest
Imagine a population of children with no disorders

Now imagine a second population of children with diagnoses

Set a screening threshold to predict disease status
Sensitivity

\[ sensitivity = \frac{TP}{TP + FN} \]

Positive predictive validity (PPV)

\[ PPV = \frac{TP}{TP + FP} \]

Increased accuracy
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/CBHII
- www.theSWYC.org