

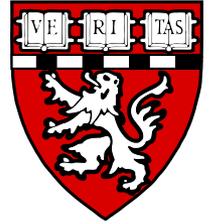


**Boston  
Children's  
Hospital**

Until every child is well™



**Boston Children's Hospital  
Autism Spectrum Center**



**Harvard  
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# **Development of the Autism Spectrum Disorder Parent Report for Outcome Monitoring (ASD-PROM)**

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# Introduction

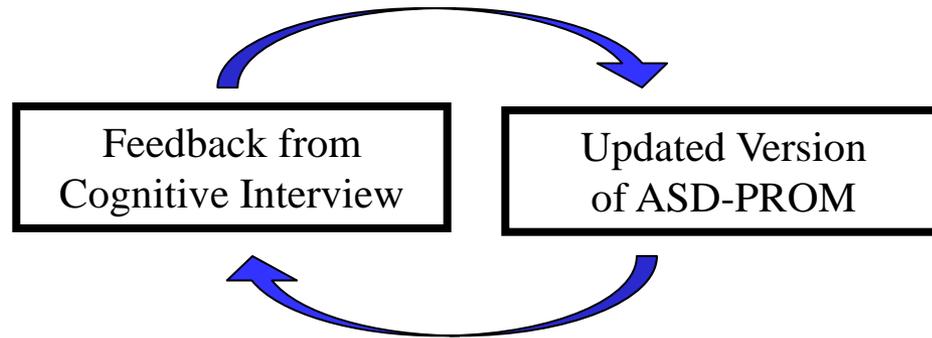
- Children with Autism Spectrum Disorder (ASD) face multiple challenges & comorbidities
- Monitoring developmental progress and behavioral functioning is critical to
  - Assess effectiveness of services
  - Improve quality of care for children with ASD
- No currently available tool to assess progress and measure outcomes across all domains of functioning
- Goal: develop an ASD-specific parent report measure focused on family centered outcomes
  - capture skills across the full range of developmental function
  - address developmental outcomes and behavioral concerns
  - measure change over time
  - ultimately available in an electronic format

# Methods: ASD-PROM Development

1. Create draft with inputs from a multidisciplinary group of experts
  - 127 Likert type questions
  - Assess key domains of clinically relevant developmental and behavioral functioning
  - Assess change over time
2. Pilot the ASD-PROM using cognitive interview to assess clarity and relevance to families

| <b>Communication and Social Skills</b>  |       |        |           |       |        |
|---|-------|--------|-----------|-------|--------|
| Please answer these questions based on your child's primary form of communication. How often does he or she do the following without prompting: |       |        |           |       |        |
|   | Never | Rarely | Sometimes | Often | Always |
| 18. Understands one-step directions (e.g., "Go get your shoes.")  | ①     | ②      | ③         | ④     | ⑤      |
| 19. Understands two-step directions<br>(e.g., "Put the toy away, then go get your shoes.")  | ①     | ②      | ③         | ④     | ⑤      |
| 32. Recognizes the emotions of other people   | ①     | ②      | ③         | ④     | ⑤      |
| <b>Behavioral Functioning</b>   |       |        |           |       |        |
| To what extent does your child do each of the following:  |       |        |           |       |        |
| 56. Has repetitive movements (e.g., hand flapping, finger wiggling, jumping)  | ①     | ②      | ③         | ④     | ⑤      |
| 79. Runs away (e.g., bolts, wanders)  | ①     | ②      | ③         | ④     | ⑤      |

# Results: Iterative Process for Updating ASD-PROM Based on Pilot Feedback



“Filling this out was very emotional. I don’t usually have to think about all the things my child can’t do all at once, especially since she is not verbal and acts like a baby even though she is five.” – Participant #1

“My child has outgrown some of the questions. For example, I didn’t know how to answer the question about how often he engages in simple pretend play, because he is too old for that.” – Participant #4

“When you ask about her peers, do you mean kids she knows or just other kids her age?” – Participant #7

Use branching logic to eliminate questions beyond a child’s developmental level. For example, if a child “Never” understands one-step directions, questions about two-step and if-then directions are skipped.

Once a family responds that a child has mastered a skill, the question about that skill is removed from future questionnaires for that child (unless parents report regression between visits).

Changed wording of questions about “peers” to “classmates or other familiar children.”

# Discussion

- Participants provided positive feedback for ASD-PROM

“This helps me see where we were before and how far we’ve come.” – Participant 2

“This addressed every part of what you would see in autism, across the spectrum.” – Participant 6

- Potential strengths of ASD-PROM
  - Monitoring outcomes for children with ASD
  - Sensitivity to change over time
  - Applicability to children with ASD at variable levels of functioning
  - Utility in clinical and research settings
  - Free availability for use by clinicians and researchers

# Conclusion and Next Steps

1. Administer the ASD-PROM electronically via a web-based information sharing system

## **Integrated Clinical Information Sharing System (ICISS)**

### Features:

- Automated emails and online links to questionnaires
- HIPAA-compliant data storage, behind a hospital firewall
- Clinicians receive notification emails
- Graphing shows change over time
- Results are in a natural language which can be used as narrative for clinical notes



# Conclusion and Next Steps

2. Pilot in the electronic system with additional parent and clinician surveys to assess ease of use and clinical relevance
3. Evaluate test re-test reliability
4. Compare performance to standardized assessment tools
5. Examine ability to measure change over time
6. Use item response theory to identify the most relevant subset of questions