

## Introduction

- Children with autism spectrum disorder (ASD) face multiple challenges & comorbidities<sup>1-7</sup>

• Social skills	• Safety awareness
• Communication	• Independence
• Repetitive behaviors	• Feeding
• Sleep	• Toileting
• Aggression	• Psychiatric comorbidities

- Monitoring progress in these areas critical to

- Assess effectiveness of services
- Improve quality of care for children with ASD<sup>8</sup>

- Potential benefits of an ASD monitoring tool include

- Focus visits on areas of primary concern for children and families
- Screen for common comorbidities of ASD
- Standardize routine ASD follow-up care across clinicians and departments
- Assess developmental progress across key domains of functioning
- Measure response to clinical and research interventions
- Assess impact of interventions

- No currently available tool to assess developmental progress and measure outcomes across all areas of functioning described above<sup>9</sup>

- Goal: develop the ASD Parent Report for Outcome Monitoring (ASD-PROM)

## Sample Questions from ASD-PROM

Please answer all questions as they apply to your child OVER THE LAST 6 MONTHS.

All children function differently from very early skills to more complex skills. If there is a skill listed that your child has already mastered independently **without prompting or reminders**, please mark as **Always**. If there is skill listed beyond your child's developmental level, please mark **Never**. Please fill this form out to the best of your ability and discuss any additional concerns with your physician.

### Communication and Social Skills

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 (e.g., "Put the toy away, then go get your shoes.")	1	2	3	4	5
20. Understands if-then directions (e.g., "If you eat the broccoli, then you can have a cookie.")	1	2	3	4	5
32. Recognizes the emotions of other people	1	2	3	4	5

### Adaptive Skills

To what extent does your child do each of the following:

	1	2	3	4	5
51. Is potty trained during the day	1	2	3	4	5
53. Is able to dress independently	1	2	3	4	5

### Behavioral Functioning

To what extent does your child do each of the following:

	1	2	3	4	5
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
92. Is easily distracted; has difficulty paying attention.	1	2	3	4	5

### Behavioral Functioning

To what extent does your child do each of the following:

	1	2	3	4	5
107. Has trouble falling asleep	1	2	3	4	5
110. Wakes too early in the morning	1	2	3	4	5

## Discussion

- Feedback from families piloting the ASD-PROM thus far has been positive.

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

"This helps me see where we were before and how far we've come." – Participant 2

- Plans for clinical implementation in ICISS are now underway.

- Ultimate goals for the ASD-PROM are the following:
  - Monitor outcomes for children with ASD
  - Feasibility for use in a clinical setting
  - 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
    - In the Autism Spectrum Center at BCH
    - Across the globe

## References

- American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition*. (American Psychiatric Publishing, Inc., 2013).
- Jeste, S. S. The neurology of autism spectrum disorders. *Curr. Opin. Neurol.* 24, 132–9 (2011).
- Maskey, M., Warnell, F., Parr, J. R., Le Couteur, A. & McConachie, H. Emotional and Behavioural Problems in Children with Autism Spectrum Disorder. *J. Autism Dev. Disord.* (2012). doi:10.1007/s10803-012-1622-9
- Jawaid, a *et al.* "Too withdrawn" or "too friendly": considering social vulnerability in two neuro-developmental disorders. *J. Intellect. Disabil. Res.* 56, 335–50 (2012).
- Hume, K., Loftin, R. & Lantz, J. Increasing independence in autism spectrum disorders: a review of three focused interventions. *J. Autism Dev. Disord.* 39, 1329–38 (2009).
- Joshi, G. *et al.* The heavy burden of psychiatric comorbidity in youth with autism spectrum disorders: a large comparative study of a psychiatrically referred population. *J. Autism Dev. Disord.* 40, 1361–70 (2010).
- Johnson, C. P. & Myers, S. M. Identification and evaluation of children with autism spectrum disorders. *Pediatrics* 120, 1183–215 (2007).
- Reichow, B., Volkmar, F. R. & Cicchetti, D. V. Development of the evaluative method for evaluating and determining evidence-based practices in autism. *J. Autism Dev. Disord.* 38, 1311–9 (2008).
- Magiati, I., Moss, J., Yates, R., Charman, T. & Howlin, P. Is the Autism Treatment Evaluation Checklist a useful tool for monitoring progress in children with autism spectrum disorders? *J. Intellect. Disabil. Res.* 55, 302–12 (2011).
- Cohen, I. L., Schmidt-Lackner, S., Romanczyk, R. & Sudhalter, V. The PDD Behavior Inventory: a rating scale for assessing response to intervention in children with pervasive developmental disorder. *J. Autism Dev. Disord.* 33, 31–45 (2003).
- Rimland, B. & Edelson, S. M. Autism Treatment Evaluation Checklist (ATEC). at <www.autism.com/ari>
- Kanne, S. M. *et al.* The Autism Impact Measure (AIM): initial development of a new tool for treatment outcome measurement. *J. Autism Dev. Disord.* 44, 168–79 (2014).

## Methods: Stages of ASD-PROM Development

### Step 1: Draft initial version of ASD-PROM

- Collaboration among a diverse interdisciplinary team of expert clinicians at BCH:
  - Neurology
  - Developmental Medicine
  - Psychiatry
  - Speech and Language Pathology
  - Sleep
- Review of tools currently available to assess outcomes in ASD<sup>9-12</sup>

### Step 2: Pilot ASD-PROM

- Assess clarity and relevance to families
- 8 families (9 total parents) completed the ASD-PROM
  - Average time to complete ASD-PROM: 15 minutes
- Each family provided feedback through a cognitive interview
- The ASD-PROM was updated iteratively based on this feedback

### Step 3: Clinical Implementation in ICISS

- ICISS is the Integrated Clinical Information Sharing System
- Core features include:
  - Automated emails to parents, with secure links to online questionnaires
  - Data storage in a HIPAA-compliant database, behind the hospital firewall
  - Result notification emails to clinicians
  - Natural language summary of results that can be inserted into clinical notes
- Assess clinical impact through parent and clinician surveys

### Step 4: Validation

- Test-Retest Reliability
- Compare performance with respect to other assessment tools
- Examine ability to measure change over time

### Step 5: Create a "Short Form"

- Using item response theory, we will determine the subset of individual questions that provide the greatest information regarding a child's progress over time.

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

Feedback from Cognitive Interview

Updated Version of ASD-PROM

"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

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.

"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

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).

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

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

## Acknowledgements

- BCH Program for Patient Safety and Quality
- Harvard Catalyst Clinical Research Center
- Many providers from multiple departments at BCH who provided suggestions in creating the initial pilot version of the ASD-PROM
- The families who have participated in the study

We thank the BCH Autism Spectrum Center for identifying the need for this tool, and for providing outstanding clinical care to children and families living with ASD.