Developing the Pediatric Evaluation of Disability Inventory-Patient Reported Outcome (PEDI-PRO)

Youth and Young Adults Empowerment, Leadership, and Learning Lab
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Why is the PEDI-PRO important?

- The PEDI-PRO supports youths’ rights to be involved in decisions about their healthcare and education and ensures comprehensive documentation of youths’ needs and outcomes.
- The PEDI-PRO is important because research demonstrates that youth and parents have different perspectives about youths’ performance.

What is the PEDI-PRO?

- The PEDI-PRO is based on a gold-standard parent-report called the Pediatric Evaluation of Disability Inventory-Computer Adapted Test (PEDI-CAT).
- In the PEDI-PRO, Daily Activities, Social/Cognitive, and Mobility items are linked to 11 “everyday life situations.” Everyday life situations are areas of participation important to youth, such as: working at a job, sports and fitness, going to a restaurant, getting ready in the morning, etc.

What does the PEDI-PRO look like?

The PEDI-PRO user interface includes accessibility features to ensure standardized, independent administration.
What is the PEDI-PRO’s measurement conceptual framework?

Our research suggests that youth better recall and reflect on their performance in the context of everyday life situations. Our conceptual framework assesses discrete tasks in the context of familiar everyday life situations.

What is participatory action research?

Participatory action research is a research approach in which stakeholders are involved in the entire process as co-researchers. Since November 2013, we have collaborated with a team of 8 youth to develop and study the PEDI-PRO. This collaboration has led to:

- **Unique conceptual framework**: assessment of functional tasks in the context of everyday life situations.
- **Generation of 36 new functional tasks** not assessed in any currently available patient-reported outcome measure.
- **Revision of parent-report PEDI-CAT items** to ensure appropriateness and relevance for youth and young adults with DD.

The PEDI-PRO youth team thinks we need the PEDI-PRO because...

- To help us advocate for ourselves later on in life.
- To ask young people what they want to accomplish.
- To help young people understand what they can do to help themselves.
Focus groups
Focus groups were conducted with youth with developmental disabilities (n = 67) and professionals who work with youth with developmental disabilities (n = 26).
- Youth participants: average age: 18.6 (range: 9.5-22.2), 55% female, 19% non-white, 51% had a diagnosis of intellectual disability
  - Youth identified valued everyday activities that are included in PEDI-PRO items and everyday life situations.
- Professional participants: 46% occupational therapist, 27% physical therapist, 16% psychology/social work, 12% other profession
  - Professional focus groups confirmed the content validity of the PEDI-PRO functional domains and items.

Cognitive Testing
We asked youth with developmental disabilities (n = 37) to describe their thinking as they responded to PEDI-PRO items. Cognitive interviews helped us find out if youth with DD understand the PEDI-PRO items.
- Youth participants: average age: 19.0 (range: 8.5-21.7), 65% female, 24% non-white, 68% had a diagnosis of intellectual disability
- Across all domains, approximately 85% of items were interpreted as intended by youth.
- Most of the time (96%), youth selected a response category that matched their self-evaluation of functional performance.

Pilot testing
We administered a subset of PEDI-PRO items to youth with developmental disabilities (n = 51). We used Rasch analysis to make sure items from each domain work together to measure a common concept
- Youth participants: average age: 17.7 (range 9.9-21.7), 47% female, 29% non-white, 77% had a diagnosis of intellectual disability
- Initial evidence suggests that when items are administered in the context of everyday life situations, unidimensionality of the functional domains (Social/Cognitive, Daily Activities, Mobility) are maintained. This is an indicator of construct validity.
Who have you been telling about the PEDI-PRO?

We presented our findings at the following professional organizations’ conferences:
• American Occupational Therapy Association (April 2016)
• Occupational Therapy Research Summit (May 2016)
• American Academy on Intellectual and Developmental Disabilities (June 2016)
• American Academy for Cerebral Palsy and Developmental Medicine (September 2016)
• American Congress of Rehabilitation Medicine (November 2016)
• Massachusetts Association for Occupational Therapy (November 2016)

Read more about our work: https://sites.bu.edu/yell

What’s next?

We have applied for funding to continue to develop the PEDI-PRO items and software. We hope that after additional research, the PEDI-PRO will be available for use in schools, clinics, and hospitals to help youth share their perspective and to increase their involvement in healthcare and school evaluation and planning.

Please contact us if you would like to be involved in our research and help us collect data for the PEDI-PRO.