

Testing an electronic option to empower family-centered early intervention services

Why we did this research:

Beginning in early childhood, participation in daily activities supports children's development and wellbeing. Children who experience developmental delays, or are at risk, tend to have more difficulties participating in everyday activities as compared to their typically developing peers (1). Everyday activities take place at home (e.g., personal care management), daycare or preschool (e.g., socializing with friends), and in the community (e.g., shopping and errands) (2). Young children with, or at risk for, developmental delays benefit from services like early intervention. These services, however, only have one option (i.e., face-to-face) for gathering parent expertise about which everyday activities are most challenging and why. Our lab creates and optimizes electronic tools that can be used to expand options for families engaged in Early Intervention (EI) services (3).

What we did:

One electronic tool we work with is the Young Children's Participation and Environment Measure (YC-PEM) (2). Since 2008, we have conducted multiple studies of the YC-PEM to develop and test its validity, reliability, feasibility, and acceptability as an electronic patient-reported outcome. EI providers and parents whose children accessed EI services enrolled in these studies and provided valuable input to our interdisciplinary research team, so that we could optimize its content and layout and its implementation (1,4–6).

What we learned:

We have been finding the YC-PEM to be feasible, reliable, valid, and acceptable (1,6). Based on provider and family input, we took the following steps to support its implementation within a routine clinical workflow: 1) we created an animated introductory video and activity illustrations to help families complete the YC-PEM; 2) we created an optimized the report structure and provider guide to facilitate the integration of YC-PEM results when co-designing the service plan; and 3) we worked with the community engagement core of our Center for Clinical and Translational Science (CCTS) to build a research group to effectively partner with EI

providers when building evidence about the value of implementing the YC-PEM into their workflows (6–8).

The Parent-Reported Outcomes for Strengthening Partnership within the Early Intervention Care Team (PROSPECT) is our latest trial underway to test the effectiveness of the YC-PEM option when it is implemented into the clinical workflow of one EI program, and to identify salient strengths and barriers to its broader adoption from the perspectives of diverse EI stakeholders (i.e., parents, service providers, and program leadership). We are including a control group for comparison to strengthen the evidence of its effectiveness, as well as collecting diverse stakeholder perspectives to strengthen evidence about its scalability. This evidence will help us best understand ways to maximize stakeholder benefit across multiple EI programs within the broader early intervention service system (9).

Why this is important:

Our ultimate goal is to co-create evidence with EI programs so that they can make smart decisions about how they deliver on their promise of family-centered and participation-focused services. EI families have expertise about their child’s participation needs that are critical to designing meaningful service plans but have only one option for sharing this expertise (9). The YC-PEM is an evidence-based tool to expand options for collecting family expertise to drive service design. Our project will yield new evidence about the effectiveness and scalability of the YC-PEM as an electronic second option for families to share their expertise and co-design the EI service plan.

References

1. Khetani MA, Graham JE, Davies PL, Law MC, Simeonsson RJ. Psychometric properties of the young children's participation and environment measure. *Arch Phys Med Rehabil* [Internet]. 2015 Feb;96(2):307–16. Available from: <https://linkinghub.elsevier.com/retrieve/pii/S0003999314011551>
2. Khetani M, Coster W, Law M, Bedell G. Young Children's Participation and Environment Measure (YC-PEM) [Internet]. Available from: <https://canchild.ca/en/shop/23-yc-pem-young-children-s-participation-and-environment-measure>
3. Children's Participation and Environment Research Lab. Advancing client-centered care and outcomes in pediatric re/habilitation [Internet]. Available from: <https://cperl.ahs.uic.edu/>
4. Albrecht EC, Kaelin VC, Rigau BL, Dooling-Litfin JK, Scully EA, Murphy NJ, et al. Pilot implementation of an electronic patient-reported outcome measure for planning and monitoring participation-focused care in early intervention. *BMC Med Inform Decis Mak* [Internet]. 2020 Dec 24;20(1):199. Available from: <https://bmcmmedinformdecismak.biomedcentral.com/articles/10.1186/s12911-020-01189-9>
5. Khetani MA, Cohn ES, Orsmond GI, Law MC, Coster WJ. Parent Perspectives of Participation in Home and Community Activities When Receiving Part C Early Intervention Services. *Topics Early Child Spec Educ* [Internet]. 2013 Feb 18;32(4):234–45. Available from: <http://journals.sagepub.com/doi/10.1177/0271121411418004>
6. Khetani MA, McManus BM, Arestad K, Richardson Z, Charlifue-Smith R, Rosenberg C, et al. Technology-based functional assessment in early childhood intervention: a pilot study. *Pilot Feasibility Stud* [Internet]. 2018 Dec 21;4(1):65. Available from: <https://pilotfeasibilitystudies.biomedcentral.com/articles/10.1186/s40814-018-0260-1>
7. Rigau BL, Dooling-Litfin J, Scully E, Killian C, Fisher G, Mcmanus B, et al. Building organizational capacity for research in early intervention. *ZERO TO THREE J* [Internet]. 2019;39(6):54–61. Available from:

www.zerotothree.org/p-5

8. Rigau BL, Scully EA, Dooling-Litfin JK, Murphy NJ, McManus BM, Khetani MA. Community engagement to pilot electronic patient-reported outcomes (e-PROs) in early intervention: Lessons learned. *J Clin Transl Sci* [Internet]. 2018 Feb 6;2(1):20–6. Available from: https://www.cambridge.org/core/product/identifier/S2059866118000158/type/journal_article
9. Kaelin V, Villegas V, Chen Y, Murphy N, Papautsky E, Litfin J, et al. Implementing an electronic patient-reported outcome measure and decision support tool for family-centered and participation-focused early intervention: PROSPECT trial protocol. Under Review.