**Title**: A mixed-method evaluation of the acceptability of a novel parent-mediated intervention for young children with Down syndrome in the US

**Authors**: Madison M. Walsh1,2, Miranda E. Pinks1,2, Sara Colaianni3, Sara Onnivello3, Susan Hepburn1, Nathanial R. Riggs1,2, Kaylyn Van Deusen1,2, Chiara Marcolin3, Lisa A. Daunhauer1, Silvia Lanfranchi3, & Deborah J. Fidler1,2

**Introduction**: Parent-mediated intervention (PMI) is becoming an increasingly favored approach to strengthening early foundations in children with neurodevelopmental conditions (Lanfranchi et al., 2024). PMIs reduce barriers associated with traditional clinic-based services, including a shortage of trained professionals, limited financial resources, challenges with transportation, and geographic isolation (Stahmer & Pellecchia, 2015). “EXPO: EXecutive function Play Opportunities,” is a novel PMI designed to target the development of executive function (EF) skills for preschool-aged children with Down syndrome (DS). Throughout this 12-week intervention, caregivers implement play-based activities with their children for 10 to 15 minutes a day, 3 to 4 days a week. Activities target skills related to EF, including working memory, inhibition, flexibility, and planning. EXPO was developed through a community-based participatory research approach that sought input from caregivers on intervention structure and priorities (Walsh et al., 2024). The present study used a mixed-methods approach to evaluate the acceptability of EXPO by examining caregiver appraisals of the intervention and their implementation experiences. Examining the acceptability of this newly developed PMI is critical for understanding how well the intervention components meet the needs of its end users and for determining families’ ability to engage with the program, both of which are essential for program effectiveness.

**Method**: Participants were 15 primary caregivers of a child with DS between 3 and 7 years of age (*M* = 5.22, *SD* = 1.13) in the US. Caregivers implemented the full 12-week EXPO intervention with their child. Caregivers were provided with materials, including a caregiver guidebook, detailed activity instructions, demonstration videos, and a smartphone application to record attempted and completed activities. Caregivers also received weekly support from the research team via telehealth coaching sessions. Within two weeks of completing the intervention, caregivers completed an intervention feedback survey. Individual qualitative interviews were also conducted with caregivers via a secure video-conferencing platform. Interview questions and survey questions were developed by the research team and aimed to elicit appraisals of different components of the intervention. Using ATLAS.ti 23.2.1 for Windows, thematic analysis was conducted to identify themes and patterns related to caregiver feedback. A codebook was developed by the first author through an iterative process of listening to interview recordings, reading transcripts, identifying themes, and refining codes (Saldaña, 2021). Two research assistants independently coded the transcripts; inter-rater reliability was assessed using Krippendoff’s alpha and agreement was reached (*α* = 0.83). Descriptive statistics, including frequencies and means, were computed to analyze quantitative survey data.

**Results**: Qualitative themes related to *intervention usability*, *positive intervention aspects*, *areas of improvement*, and *barriers to participation* were identified from interview transcripts. Caregivers reported that EXPO was easy to use, the activities were enjoyable for children and caregivers, and that coaching sessions were an important mechanism of support. Caregivers also reported that busy schedules were a barrier to participation at times, and they described a preference for improved activity tracking in the smartphone application. Still, caregivers reported many perceived benefits for themselves and for their children, including learning about new ways to play with their child and learning more about aspects of cognitive regulatory skills. Quantitative findings from the survey results corroborated findings from the rich qualitative interview data. In the post-intervention survey, caregivers rated the intervention materials and intervention structure favorably. Most caregivers (*n* = 11, 73.3%) rated the activity instruction cards as “very helpful”. All caregivers reported using the website and the demonstration videos less frequently than the physical materials. All caregivers rated the weekly telehealth coaching sessions as “very helpful” and eight caregivers (53.3%) rated the sessions as “more helpful than anticipated”. Some caregivers (*n* = 4, 26.7%) reported difficulty attending the telehealth coaching sessions, but the majority of caregivers (*n* = 9, 60%) reported that they experienced minimal or no difficulty attending the coaching sessions.

**Discussion:** This study used a mixed-methods approach to evaluate the degree to which the community-informed intervention design of EXPO was acceptable and usable for families in the US. Caregivers reported positive appraisals regarding EXPO design, including the flexibility built into the program activities, the utility of the physical materials, and the support provided by the coaches throughout the intervention. They also reported numerous perceived benefits for themselves and for their children. Caregivers reported concerns related to the time commitment required by the program and the usability of the smartphone application, which should inform the iterative intervention development process for the next version of EXPO ahead of larger randomized controlled trials. Overall, findings suggest that leveraging community partnerships in the design and formulation of EXPO led to an acceptable and usable PMI that removes barriers to participation for families of young children with DS.

**References:**

Lanfranchi, S., Onnivello, S., Walsh, M.M., Colaianni, S., Pinks, M.E., Marcolin, C., Van Deusen K., Ceci B., Riggs N.R., Rossi E., Daunhauer L., & Fidler, D. J. (2024). Considerations for developing syndrome-informed early interventions for children with neurogenetic conditions.

Saldaña, J. (2021). The Coding Manual for Qualitative Researchers (4th ed.). SAGE Publications, Inc.

Stahmer, A. C., & Pellecchia, M. (2015). Moving towards a more ecologically valid model of parent-implemented interventions in autism. Autism: The International Journal of Research and Practice, 19(3), 259–261. <https://doi.org/10.1177/1362361314566739>

Walsh, M.M., Van Deusen, K., Pinks, M.E., Ceci, B., Hepburn, S., Riggs, N.R., Pulina, F., Marcolin, C., Onnivello, S., Colaianni, S., Gray, B., Daunhauer, L.A., Lanfranchi, S. & Fidler, D.J. (2024), Parent Perspectives on Parent-Mediated Intervention for Young Children With Down Syndrome. Journal of Applied Research on Intellectual Disability, 37: e13307. <https://doi.org/10.1111/jar.13307>

 Colorado State University, Fort Collins, Colorado, United States

2 Prevention Research Center, Colorado State University, Fort Collins, Colorado, United States

3 University of Padua, Padua, Italy