Title: Implementation Fidelity of PANDA, a Parent-Facilitated Telehealth Assessment for Children with Neurogenetic Syndromes

Authors: Taylor Halligan¹, Nicole Witthuhn², Bridgette Tonnsen³

³Purdue University

Introduction: Infant screening tools often fail to capture the complexity of symptoms and trajectories indicative of ASD in intellectual disabilities (IDs) (Adamson, Deckner, & Bakeman, 2010). Further, very few studies have characterized early ASD-related features in neurogenetic groups due to the high cost and travel burden associated with accessing children with low-incidence disorders. We have begun to address these needs through Parent-Administered Neurodevelopmental Assessment (PANDA), a remotely-administered, parent driven platform and assessment battery for assessing ASD risk via telehealth. The PANDA battery includes a series of activities that parents administer while an examiner provides real-time remote support via a teleconferencing and support platform. The goal of the present study was to assess preliminary feasibility of PANDA in mother-child dyads, both with and without children with Down syndrome (DS), who completed the battery. Specifically, we examined the quality of parent-administered prompts during a simulated remote assessment.

Method: Data have been collected from 14 infants ages 3- to 24-months old (12 low risk (LR) controls; 2 infants with DS; anticipated sample 20 LR, 20 DS). Per standard PANDA protocol, infants and their mothers were alone in the laboratory and the examiner relayed instructions, prompts, and task materials via phone and remote access of a research computer. Mothers facilitated several tasks including positioning heart rate monitors, two visual attention tasks, autism-specific presses (e.g. response to name, peek-a-boo), a temperament assessment, and a storybook task. Three independent raters behaviorally coded tasks for the mothers’ implementation fidelity, i.e. compliance with instructions and prompts. Here, we focused on the percentage of tasks that were completed with “high fidelity” per behavioral ratings. We hypothesized that across tasks, mothers would generally exhibit high fidelity, i.e. >90% of tasks implemented with very few deviations, when implementing the PANDA protocol. We also hypothesized that implementation fidelity would differ across tasks, with tasks requiring less instruction having higher fidelity.

Result: Agreement between coders was greater than 85% across all tasks. Preliminary results in a subset of the tasks (visual attention, temperament assessment, storybook) suggest that 93% of tasks were implemented as directed with very few deviations. In the subsample of DS infants, 100% of tasks were implemented with very few deviations. Further, 90% of mothers implemented with very few deviations within the visual attention, temperament assessment, and storybook tasks. Final analyses will examine how fidelity varies by task, as well as how child’s age predicts implementation fidelity.

Discussion: Preliminary results suggest the PANDA protocol can be implemented with high fidelity by mothers naive to the protocol. These results indicate the PANDA battery is generally appropriate for parent administration. Contrary to our hypothesis that fidelity would differ across tasks, this initial subset of tasks indicates high fidelity regardless of the task. Expanding analyses to the full battery of tasks will further assess these findings. Results support the continuation of remote assessments with adaptations for at-home administration based on both qualitative and quantitative data. The impact of this work may provide lower-cost, remote access of early ASD risk detection for geographically dispersed or otherwise underserved populations.

References/Citations: