Symposium Title: Using Technology Advances in Interventions for Children with Intellectual and Developmental Disabilities

Chair: MaryAnn Romski\textsuperscript{1}, Rose A. Sevcik\textsuperscript{1}

Discussant: Nancy Brady\textsuperscript{2}

Overview: Rapid technology advances have occurred over the last few years including tablet computers, APPs, and web-based tools to name a few. Many aspects of society have employed these technologies to advance their development. Telehealth and Mobile Health Technologies (MHT) have the potential to positively impact the delivery of intervention services for children with intellectual and developmental disabilities. Systematic development and assessment of these technologies is needed. This symposium presents findings from four lines of research that address incorporating technology advances into interventions for children with intellectual and developmental disabilities. The first presentation describes the results of a unique telehealth intervention study for children with Prader-Willi Syndrome. Presentation 2 describes the acquisition of caregiver behaviors taught during coaching sessions delivered via telehealth. The third presentation highlights focus group data about the use of APPs to enhance the delivery of communication interventions for children with developmental disabilities in rural South Africa. The fourth and final presentation describes the use of a coaching platform, which included interactive lessons, video analysis, and implementation planning management, to facilitate the child’s use of AAC across communication partners. The symposium concludes with our discussant contextualizing these advances within service delivery.

Paper 1 of 4

Paper Title: Telehealth in Children with Prader-Willi Syndrome: Understanding the Unique Benefits and Challenges of Remote Intervention

Authors: Anastasia Dimitropoulos\textsuperscript{3}, Olena Zyga\textsuperscript{3}, Ellen Doernberg\textsuperscript{3}, & Sandra Russ\textsuperscript{3}

Introduction: Individuals with Prader-Willi Syndrome (PWS) express deficits in social responsivity and competence, and high externalizing behaviors surrounding rigidity (Dimitropoulos, Ho, & Feldman, 2013). Preliminary research has also found that children with PWS have impaired pretend play abilities that are similar to children with ASD (Zyga et al., 2015). Given that these deficits emerge early in development, targeting skill building through play in children with PWS may strengthen adaptive skills, social-communication, socioemotional understanding, and the ability to appropriately interact in social situations. However, given the low prevalence of PWS in the general population (approximately 1 in 12,000 live births), developing behavioral interventions for individuals with PWS is faced with the significant challenge of enrolling enough participants for local studies where multiple visits per week are indicated for effective intervention. Telehealth may reduce barriers in implementing interventions for individuals with PWS. To date, few telehealth intervention studies have been reported on directly working with a child with a developmental disorder via an online format. Further, no previous study has used telehealth as a means of delivering services to the PWS community.

Method: The current study delivered a 6-week play-based behavioral intervention directly to children with PWS, ages 6-12 years, twice a week, for 15-20 minute sessions. This presentation will report on (1) the feasibility of using telehealth directly with a child with PWS, (2) parents’ reports regarding the acceptability of the program, and (3) specific technological and behavioral challenges that may be unique to delivering remote intervention to this population. Findings to date include a sample of 10 children with PWS (7 males; 3 females) and their parents. Participants were recruited nationally (mean distance from study site: 844.4 miles). Enrolled participants partook in in-person baseline and post-intervention visits. During the intervention period, participants completed 12 sessions via videoconferencing software, which were recorded for subsequent analysis. Parents of

\textsuperscript{1} Georgia State University
\textsuperscript{2} University of Kansas
\textsuperscript{3}Case Western Reserve University
participants were asked to complete a Behavioral Intervention Rating Scale (BIRs) after the post-intervention visit (5-point Likert scales [1 = strongly disagree; 5 = strongly agree]).

Results: Of the 10 children enrolled, 8 completed the intervention program [mean number of sessions completed =11.875(0.33)]. BIRS findings indicated that caregivers rated the program highly with an overall rating of 5.54/6.00 for the program’s acceptability, 5.06/6.00 program effectiveness, and 4.86/6.00 for the program’s usability. Overall satisfaction was also high (4.14/5.00) and parental attitudes towards telehealth as a modality through which treatment can be delivered was rated positively (4.71/5.00). With regard to technological issues, 15% of all sessions conducted had some type of technological difficulty, however, only 8% had to be rescheduled. Participant factors that impacted successful completion of sessions, such as technological issues, meal timing, fatigue, and problem behaviors will be discussed.

Discussion: Preliminary results suggest that telehealth is a feasible modality through which to deliver intervention directly to a child with PWS. Specifically, this study found that the majority of children were able to engage in the intervention sessions independently and complete the entire program with minimal behavioral or technological difficulty.

References/Citations:


Title: Maternal Response to Coaching in the Context of a Language Intervention Delivered Via Telehealth

Authors: Amy Banasik, Sarah Nelson, Lauren Bullard, Andrea McDuffie, Leonard Abbeduto

Introduction: Correlational studies have shown that enriched language input from caregivers plays an important role in scaffolding the language skills of children with neurodevelopmental disorders. In this distance-delivered language intervention, mothers of school-aged and adolescent boys with fragile X syndrome (FXS), the leading inherited cause of intellectual disability, were taught to use three evidence-based strategies to support their children’s spoken language development. Speech/language pathologists used clinician coaching (including guided practice, feedback, and joint problem solving) to build each caregiver’s capacity to use the targeted strategies with her child. Coaching sessions were delivered into each family’s home by means of distance video-teleconferencing technology. The goal of the current presentation is to provide a description of patterns of acquisition of caregiver behaviors targeted in the intervention. Research Questions: 1) To what proportion of clinician prompts do mothers respond during coaching sessions? 2) What is the profile of maternal spontaneous and prompted use of targeted intervention strategies?

Method: Participants were the biological mothers of ten boys with FXS who had been randomly assigned to the treatment group of a parent-implemented spoken language intervention. Boys had a mean age of 13.9 years and ranged in age from 10 to 18 years. Boys had a mean nonverbal IQ of 41.8 and a mean ADOS severity score of 6.00 indicating a moderate degree of autism symptoms. All boys used spoken language as their primary means of communication. Mothers had a mean age of 44.2 years (range 36-53), had completed an average of 15.3 years of school, and had a mean IQ of 109 (range 86-133). The intervention was delivered into each family’s home by a speech/language clinician using distance video-teleconferencing software (i.e., SKYPE). Mothers were taught to use three language facilitation strategies (open-ended questions, expanding, and intonation prompts) to support their child’s spoken language within the context of a shared storytelling interaction. Dyads received 12 weeks of the

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4 The Mind Institute, University of California, Davis
Results: We examined how often the mothers responded to guidance from the clinician during coaching sessions across early (1-4 weeks), middle (5-8 weeks), and late (9-12 weeks) stages of intervention. Maternal response to coaching across the three language support strategies was 80% during the early stage of intervention, 81% during the middle stage, and 92% during the late stage. Maternal prompted use of strategies remained relatively stable across the duration of the intervention. Specifically, the average frequency of prompted use of wh-questions was 19.00 during the early and middle stages of intervention and 17.98 during the late stage. The average frequency of prompted use of expansions was 5.10 during the early stage of intervention, 4.20 during the middle stage, and 4.43 during the late stage of intervention. The average frequency of prompted use of intonation prompts was 4.85 during the early stage, 4.88 during the middle stage, and 4.33 during the late stage. Maternal spontaneous use of strategies, however, increased over the course of treatment. Specifically, the average frequency of spontaneous use of wh-questions was 20.65 during the early stage of intervention, 23.83 during the middle stage, and 25.28 during the late stage. The average frequency of spontaneous use of expansions was 27.13 during the early stage of intervention, 34.50 during the middle stage, and 39.40 during the late stage. The average frequency of spontaneous use of intonation prompts was 12.95 during the early stage of intervention, 15.43 during the middle stage, and 15.83 during the late stage of intervention.

Discussion: On average, mothers responded to a high proportion of the clinician prompts during coaching indicating that mothers were frequently practicing the use of the targeted language facilitation strategies within the coaching sessions. In addition, mothers increased their spontaneous use of the targeted strategies during the intervention suggesting that they were able to use the strategies more independently as the intervention progressed. These results support the promise of a parent-implemented, distance-delivered intervention approach for targeting spoken language in children with a low incidence neurodevelopmental disorder. Future analyses will examine the relationship between maternal strategy use and child intervention gains.


Paper Title: Mobile Health Technology to Optimize Communication Outcomes for South African Children with Neuro-Developmental Disorders

Authors: MaryAnn Romski1, Juan Bornman5 Rose A. Sevcik1, Vuledzani Madima5, Marika King1

Introduction: Children with neuro-developmental disorders (NDD), such as intellectual disability, autism spectrum disorder, cerebral palsy and other genetic disorders, that affect development and functioning, are at extremely high risk for developing speech and language disorders secondary to their primary condition. Speech and language disorders result in great difficulty communicating with others including primary caregivers, families, peers, and health care providers. These disorders and resulting communication difficulties negatively impact the child’s growth, quality of life, long-term development, and later employment reducing the child’s ability to contribute to society (Beukelman & Mirenda, 2013; Yeargin-Allsopp & Boyle, 2002). Critical barriers to progress in intervention to remediate these difficulties, in low and middle income countries, such as South Africa, are that (1) children with NDD and their families often live far from secondary and tertiary hospitals where speech and language intervention services are provided, (2) the families have diverse linguistic backgrounds and (3) health care providers have overwhelmingly large caseloads that result in reduced access to interventions. Mobile Health Technology (MHT), through the use of readily available cell phones in the country, has great potential to enhance service delivery to children with NDD and their families in rural areas of South Africa. This presentation describes the first phase of a project that focuses on the development and assessment of a new MHT application that integrates regular primary caregiver implemented beginning communication activities.

5 University of Pretoria, South Africa
between monthly visits to the SLP. We will characterize the outcomes of two focus groups with two distinct stakeholder groups (primary caregivers of children with NDD and SLPs) from the same rural area in northern South Africa.

Methods: Focus groups identified the possible advantages as well as expected challenges of using MHT in this context. They also provided suggestions for content that should be included in such an app. Participants were 10 primary caregivers of children with NDD about service delivery using APPs on a mobile phone. 80% were mothers and 10% each were grandmothers or aunts. The ages of the primary caregivers were between 25 and 70 years, with 30% between the ages of 21-30yrs; 20% between 31-40yrs; 40% between 41-50yrs and 10% above 60yrs. 20% of the caregivers had no formal schooling, 20% had less than Grade 10, 20% had Grade 12 and 40% had some form of formal schooling (30% had between grade 10 and 11 and 10% post-school education). 50% of caregivers were unemployed, 40% employed part-time and 10% employed full-time.

Results: Ninety percent of participants owned a smartphone despite the fact that only 10% were employed full-time. Eighty percent had good internet coverage. None of them had APPs on their mobile devices related to intervention though they did have other features such as a camera (90%); sms (90%); WhatsApp (70%); internet (70%); and gaming (40%). Main limitations of using smartphone: very expensive (70%); only good for limited use (20%); internet connection and coverage is poor (10%). The participants viewed the benefits of using APPs with their children to include: frequently get ideas of new activities; helping other family members (e.g. fathers) to do therapy at home when mom is not there; saving on transport costs; empowering mothers; complimenting mother’s existing knowledge; enabling on-the-spot problem solving; and increasing knowledge and skills of mothers. Features that should be incorporated into the APP will be presented.

Discussion: Caregivers had a very positive and supportive response about the use of MHT to assist them in communicating with their children. Additional focus groups with SLPs about the use of an APP will also be presented. We will describe how we integrated the focus group information into the components of the MHT APP and present the protocol for the actual APP. Phase One will provide the basis for a randomized control trial comparing the effects of the communication app intervention to the standard treatment children with NDD currently receive in South Africa.

References/Citations:

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Paper 4 of 4

Paper Title: Coaching Insights from the Personalized Service and Care Platform

Authors: Samuel Sennott

Introduction: There are hundreds of thousands of US school age children with complex communication needs who cannot speak or communicate to meet their full daily communication needs (CCN), making school and their connection to their families and communities difficult (Beukelman & Mirenda, 2013). Augmentative and alternative communication (AAC) supports have positively impacted these children’s expressive communication abilities. AAC tools have come in a range of forms, from the most simple gestural or paper based systems to new technologies, including tablet computers such as the iPad. However, for families, teachers, and therapists, a large gap still exists in the successful use of AAC systems to improve communication for children with CCN. The gap in knowledge, skill, and coordination of care is substantial. The purpose of this study is to share insights from our systematic way to improve the knowledge, skill, and coordination of care in the area of assistive technology for people with complex communication needs. This is important because coaching communication partners to better performance can serve thousands of children without the opportunity to adequately communicate to loved ones, friends, and in the wider community.

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*Portland State University
Methods: This presentation is based on a study whose purpose was to coach the communication partners of a six year old beginning communicator with Down Syndrome inside of the first year of our larger 3T (Teaching, Technology, and Theory) Accessibility Project. The study utilized a single-case design, specifically a multiple baseline across communication partners design (Kratochwill et al., 2010). IES-recommended guidelines for meeting evidence standards with reservations in single-case design were employed: (a) the researcher systematically manipulated the independent variable; (b) each outcome variable will be measured over time by more than one observer and inter-observer agreement was collected for at least 30% of the data points in each phase of the study per participant and met minimum thresholds; (c) three demonstrations of an intervention effect occurred at three different points in time; and (d) three or more data points were collected in each phase of the study per participant (Kratochwill et al., 2010). The study’s methods were a systematic replication of Sennott & Mason (2016), with the primary dependent variable being frequency and modality of communication turns and a secondary variable being challenging behavior. The intervention consisted of using a package intervention that included a combination of person centered planning, elements of our coaching platform, the MODELER (Model, Encourage, and Respond) AAC modeling strategy, and face-to-face in session coaching. The study worked across three communication partners.

Results: At baseline, the child was making few communication attempts and was experiencing frequent instances of challenging behavior in the form of not following directions, calling out, and pushing teachers. The child worked with two educational assistants throughout her school day, but neither of them had any training/coaching in AAC intervention. They were becoming increasingly uncomfortable working with the child whose challenging behavior was escalating. The communication partners in the across partners design included the mother and two educational assistants. The research team was able to use our person centered planning process to focus the team and set objectives and a course for intervention. To train and coach each of the partners, we were able to use elements of our coaching platform, which included interactive lessons, video analysis, and implementation planning management. The communication partners learned to use the MODELER AAC strategy to criterion, with large level increases in the number of AAC models provided to the child. The child made large, immediate level increases in communication turns, primarily using AAC on and iPad. The child also experienced an immediate level reduction in challenging behavior. The child results were replicated across the three partners.

Discussion: Despite work demonstrating the tremendous potential that assistive technologies hold for people with speech disabilities, and many individual success stories, the field has failed to turn these possibilities into large scale probable outcomes, both here in Oregon where this child lives and nationally. This study is a sample of broad need and demonstrates some unique insights about the change process that must happen in an individual child’s systems of supports in order for her to experience increased performance in her communication ability.

References/Citations: