Symposium Title: Development and Evaluation of Virtual Adaptations of Evidence Based Interventions for Autism Spectrum Disorder and Fragile X Syndrome

Chair: Rebecca Shaffer¹,²
Discussant: Judy Reaven³

Overview: In the field of developmental disabilities, there is a critical need for easily accessible treatment programs to address a wide range of concerns, including emotion dysregulation, social skills, and language delays. This need has only been further exacerbated by the COVID-19 pandemic which left many children without access to needed services. Virtual telehealth interventions are an innovative solution to this pressing concern, but many in person interventions have yet to be adapted or thoroughly researched in telehealth modalities. We report the outcomes of four interventions, designed to be completed in person but adapted to virtual formats. We will share a range of results including initial measures of feasibility and satisfaction of virtual adaptations, as well as, preliminary child and parental predictors, and intervention outcomes. The first presentation will use quantitative data and qualitative interviews to examine an individual, CBT intervention for autistic children with emotion dysregulation challenges. The second presentation will describe family factors influencing outcomes of a virtual, parent training language intervention for fragile X Syndrome. The third presentation will examine the efficacy of PEERS for Teens via telehealth delivery and compare telehealth treatment outcomes with in-person groups. Finally, the last presentation will describe development and results of synchronous and asynchronous versions of an established emotion regulation group intervention for autism spectrum disorder. Collectively, these presentations present early support for virtual interventions for both the ASD and fragile X populations and lay the groundwork for future trials. The potential of telehealth interventions adapted from evidence-based treatments offers exciting opportunities for those without access due to location or resources.

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Title: Adapting the Secret Agent Society: Operation Regulation Intervention to Remote Delivery in Response to COVID-19

Authors: Vivian Lee¹, Flora Roudbarani¹, Ava Pouyandeh¹, Paula Tablon Modica¹, and Jonathan A. Weiss¹

Introduction: Emotional regulation and mental health problems are concerns that impact autistic children’s wellbeing, and support often involves in-person evidence-based skill building programs. Outside of the COVID-19 pandemic, between 40-70% are estimated to have clinically significant levels of emotional problems, such as anxiety, depression, or anger; difficulties which are highly interrelated (Simonoff et al., 2008). As a result of the COVID-19 state of emergency, mental health vulnerabilities are more prevalent than before the pandemic (Torales et al., 2020). Distancing requirements have halted all in-person social, education, and therapeutic programs (e.g., interventions, day programs, schools, adapted recreation and leisure, etc.). Autistic children with mental health problems will struggle even more than usual to access evidence-based care, and their parents will be further forced to manage without effective external support. Policies have inadvertently exacerbated the difficulties experienced by autistic children and further exposed them to vulnerabilities that will impact their mental health. Prior to COVID-19, our research team was evaluating the efficacy of an in-person, spy-themed, manualized cognitive behaviour therapy (CBT) program for autistic children; the Secret Agent Society: Operation Regulation (SAS-OR; Beaumont, 2013). SAS-OR is a modified version of the evidence-based social and emotion skills program (Beaumont et al., 2015). The 10-session program targets emotion regulation skills and is provided as individualized CBT. The child, their parent and a therapist are present for each session. In response to COVID-19 physical distancing measures, in-person sessions were postponed, and we worked promptly to adapt the SAS-OR program for online remote delivery. The current study describes our adaptation process, explores changes from pre- and post-intervention quantitative data about the child’s mental health and wellbeing, and synthesizes the key themes from qualitative interviews with parents and therapists about their experience of using the remote, online option during the pandemic.
Method: Fourteen families were originally enrolled in the in-person CBT program, which was halted in March 2020. Of these, 2 discontinued participation because virtual delivery was not preferred, one dropped out of the study for family reasons, and one is still in progress of completing the SAS-OR program. All remaining children (n = 10, 30% females; M_age = 9.40 years, SD_age = 1.07; M_age = 103.40, SD_age = 14.92) and their primary caregivers (80% females; M_age = 44.20; SD_age = 6.76) participated in in-person screening sessions where family demographics, parent and child mental health, IQ, emotional regulation and social skills (ERSSQ; Beaumont & Sofronoff, 2008) and other direct behavioural assessments were completed. All children met study inclusionary criteria, including having a confirmed autism diagnosis from a regulated health care professional and parent reports of clinically significant internalizing or externalizing symptoms (BASC-3; Reynolds & Kamphaus, 2015). Of these families, 4 started in-person therapy sessions prior to March (M_sessions = 4.3; Range 1-6) and the rest were waiting to start therapy. During the suspended period, our therapist team (6 graduate students and 1 clinical supervisor; 85% females) received training from the SAS-OR development team to adapt the program including the use of physical materials and activities, to a virtual platform (i.e., Zoom) and team discussions prepared them for online delivery. All families received an orientation session to Zoom with their therapists prior to their first virtual therapy session. Families who had already started therapy waited on average 21.6 days between their last in-person session and their first virtual session. On average, families received 8.7 virtual SAS-OR sessions (SD_sessions = 2.5; Range: 4-10). Parents completed post-intervention surveys online. Parents and therapists completed an implementation acceptability scale after their last session (Sekhon et al., 2017). A preliminary qualitative analysis was performed using interpretative description to summarize general themes from post-intervention interview transcripts with 10 parents and 7 therapists.

Results: Paired samples t-tests showed no significant difference from pre-COVID and intervention to post-intervention in parent-reported externalizing behaviours (t(9) = -0.70, p = 0.51, d = 0.13) and in internalizing behaviours (t(9) = 1.41, p = 0.19, d = 0.28) on the BASC-3 in their child, but did indicate a significant increase in parent-reported child emotional regulation and social skills (t(9) = -2.64, p = 0.03, d = 0.84). Overall, parents reported feeling positive about the program (90%) and agreed or strongly agreed that the amount of effort required to do this program was acceptable (90%), aligned with their values (80%), that they understood the program and how it worked (80%), and that it was effective in achieving their goals (70%). Therapists reported feeling positive about the program (85%) and agreed strongly or above that the program required an acceptable amount of effort (85%), and they felt strongly about their ability to lead the program (100%). Qualitative interviews revealed that both groups reported difficulties in the online format, including challenges with using technology, screen fatigue and difficulties with managing challenging child behaviours (e.g., inattention, aggression, or lack of engagement). These challenges were mitigated by the preparatory support therapists received during the transition training period and the orientation session parents received from therapists (e.g., how to use cameras, organizing physical spaces). Parents and therapists highly valued the orientation sessions as it allowed them to communicate with each other and the research team about potential technology and behavioural concerns. Both therapists and parents highlighted the importance of consistent communication, flexibility in program delivery, and the ability to develop and maintain rapport with the child as key elements to program success. Therapists and parents were encouraged to see that rapport, trust, and behavioural redirections were possible with the child, even though the program was delivered online. Therapists appreciated the ability to modify program components to fit the families’ needs and highlighted the importance of incorporating child-specific interests to keep them engaged. Therapists reported the importance of modifications to the program to fit the remote environment, including making several modifications to support family engagement. For example, shortening session lengths, changing the order of therapeutic activities, and increasing parental involvement as a “co-therapist” during in-session activities. Parents noted specific therapeutic outcomes after completing the program, such as the benefits of in-session activities (e.g., deep breathing, body scans) that they found most helpful and continue to practice.

Discussion: The social distancing policies put in place to limit the spread of COVID-19 have resulted in service disruptions to families and children on the spectrum and posed unique challenges to therapists who wanted to continue providing mental health support during this time. In this pilot group, we observed no changes in child internalizing or externalizing symptoms, but parents reported improvements in child emotion regulation. Despite adaptations made to the SAS-OR program as a result of moving to an online platform, there may continue to be therapeutic benefits to the children and parents who participated in the program. Preparatory sessions for both parents and therapists seemed to result in satisfactory assessments of the transition to remote delivery. These findings suggest that remote delivery of manualized CBT for autistic children is possible, and according to parents and therapists, the program continues to have utility and therapeutic benefits. Further investigation of the efficacy of remote, online CBT is warranted. Generally, the lessons learned from the transition from in-person delivery to a remote option can inform future online clinical training programs.
References/Citations:


Paper 2 of 4

Paper Title: Family and Caregiver Characteristics Contribute to Caregiver Uptake of Strategies and Growth in Child Spoken Language in a Remote Delivered Parent-Implemented Language Intervention in Fragile X Syndrome

Authors: Amy Banasik¹, Lauren Bullard¹, Sarah Nelson¹,², Robyn Tempero Feigles¹, Vivian Nguyen¹, Angela John Thurman¹, Andrea McDuffie¹, Randi Hagerman¹, Leonard Abbeduto¹

Introduction: Fragile X syndrome (FXS) is the leading inherited cause of intellectual disability (Hagerman et al., 2017) and is often characterized by significant delays across multiple domains of language (Abbeduto, Brady, & Kover, 2007). Therefore, there is a need for interventions focused on optimizing child language outcomes. One way to provide meaningful and prolonged treatment for these individuals is through parent-implemented interventions in which parents take on the role of a clinician. Distance teleconferencing can be utilized to deliver parent-implemented interventions, which increases the frequency and ease of training for parents without adding the burden of travel. Maximizing the efficacy of such interventions, however, may require additional support for parents to address factors such as parenting stress (Stahmer & Pellecchia, 2015). Further, biological mothers of individuals with FXS are at a higher risk of experiencing psychiatric disorders such as anxiety and depression compared to the general population (Bourgeois et al., 2011), suggesting an even greater need to consider maternal needs in intervention delivery in this population. Therefore, the present study focused on how family factors might relate to caregiver uptake of strategies and ultimately child growth in spoken language over the course of a parent-implemented language intervention (PILI) delivered remotely across four different treatment conditions. Such data are needed to develop comprehensive family system-focused interventions.

Method: A total of 47 parent-child dyads participated in two different studies looking at the benefits of a distance-delivered PILI in children with FXS between the ages of 10 and 17 years. The first study involved 19 parent-child dyads with 9 dyads randomly assigned to a treatment-as-usual group and 10 to the PILI group (described in McDuffie et al., 2018). For the second study, 28 parent-child dyads participated in a small-scale randomized controlled clinical trial during which all the parent-child dyads received PILI in addition to either a placebo pill (N=16) or the pharmaceutical, lovastatin (N=12). In both studies, PILI involved the parent and child telling the story from a wordless picture book while the parent was trained to use three primary strategies: (1)
Results: All children who received PILI showed significant gains in their lexical diversity when compared to those who did not. Further, children who received PILI only or PILI + lovastatin, increased their overall story-related talking when compared to children who did not receive PILI, whereas children who received PILI + placebo were only marginally higher than those who did not receive PILI. With regard to parental uptake of strategies, all parents who received PILI showed significant increases in all of the targeted intervention strategies as well as in their overall story-related talking (i.e., total strategy use plus story-related comments) when compared to parents who did not receive PILI. Further, parents in the PILI only group had significantly greater improvements in their use of expansions when compared to parents who received PILI + placebo.

Next, we looked at potential barriers to treatment gains in this population by examining correlations between caregiver well-being and parenting stress prior to starting the intervention, and the change in both the use of parent strategies and child spoken language over the course of the treatment period. First, looking at change in parent strategy use, for the non-PILI group, parent use of open-ended questions was related to the difficult child rating as well as total parenting stress, whereas overall strategy use was related to the difficult child rating. For the PILI only group, parent use of intonation prompts was related to parent self-report of depression, parental distress, and total parenting stress and parent use of expansions and total strategies were related to parenting sense of competence. For the PILI + placebo group, parent-child dysfunctional interaction was related to parental use of intonation prompts, total strategy use, and story-related talking, with total parenting stress also relating to total strategy use. Interestingly, for this latter group, relationships indicated that the higher the level of parent-child dysfunctional interaction and total parenting stress, the more the parent used the intervention strategies. Lastly, for the PILI + lovastatin group, parent story related talking and total strategy use were correlated with parent self-report of depression. With regards to change in child performance, for the non-PILI group, changes in child story-related talking and linguistic diversity were related to the difficult child scores of the PSI with child story-related talking also relating to total parenting stress. For the PILI only group, parent self-report of depression, parental distress, and overall sense of parenting competence were significantly correlated with changes in child lexical diversity, with depression also relating to child story-related talking. Different patterns emerged for the PILI + placebo and PILI + lovastatin groups with no significant correlations for the former and difficult child ratings being significantly related to child grammatical complexity in the latter group.

Discussion: Our findings suggest that family factors, in particular parenting stress, influence the outcomes of parent-implemented interventions, affecting not only the uptake of the targeted parenting strategies, but also aspects of child treatment gains. More work is needed to further differentiate what family factors might be most critical to the efficacy of parent-implemented interventions and ultimately, how those factors should be addressed within the interventions.

References:

Paper Title: PEERS® for Adolescents via Telehealth Delivery: Thumbs Up or Thumbs Down?

Authors: Jasper A. Estabillo\textsuperscript{1}, Laura Adery\textsuperscript{1}, Christine T. Moody\textsuperscript{1}, Solene Poulhazan\textsuperscript{1}, Elizabeth Denluck\textsuperscript{1}, & Elizabeth Laugeson\textsuperscript{1}

Introduction: PEERS® for Adolescents is the only publicly available, evidence-based social skills program for teens with autism spectrum disorder (ASD) and other social challenges. It is widely accessible, translated into over 12 languages and is currently in use in over 75 countries worldwide. The efficacy and effectiveness of the PEERS® curriculum have been well established for improving overall social skills, frequency of social engagement, and social skills knowledge, while decreasing autism symptoms and mannerisms\textsuperscript{5,6}; however, limited data exist on the use of PEERS® via telehealth delivery. Results from a small pilot study on PEERS® telehealth indicated similar treatment outcomes to in-person delivery in some areas of social skills, social responsiveness, and decreased problem behaviors, suggesting that remote delivery of PEERS® can improve outcomes in adolescents with ASD\textsuperscript{7}. Given a strong established evidence base for PEERS®, a need for duty of care in times of crisis such as the COVID-19 pandemic, and in conjunction with promising pilot findings using PEERS® via telehealth, research on the use of PEERS® utilizing remote delivery is of high need. The present study aims to: (1) examine the efficacy of PEERS® for Adolescents via telehealth delivery and (2) compare outcomes between in-person and telehealth groups to determine potential differences in intervention efficacy.

Methods: The study sample was comprised of five adolescents diagnosed with ASD ($M = 14.6, SD = 1.67$; 100% male) who received telehealth delivery of PEERS® for Adolescents, a 16-week empirically supported caregiver-assisted group social skills intervention for adolescents with ASD and other social challenges. Sessions were modified for delivery via a telehealth format; groups were conducted remotely utilizing HIPAA-compliant Zoom with procedures and PEERS® content (e.g., lessons, cognitive and behavioral rehearsals, homework) modified as relevant to virtual social interactions. The in-person comparison group included 137 adolescents ($M = 14.07, SD = 1.95$; 73.7% male). Primary treatment outcome measures included the Quality of Socialization Questionnaire (QSQ; self and caregiver report\textsuperscript{2}, Test of Adolescent Social Skills Knowledge (TASSK)\textsuperscript{4}, Social Responsiveness Scale, second edition (SRS-2)\textsuperscript{1}, and Social Skills Improvement System (SSIS)\textsuperscript{3}, each completed at baseline and post-intervention. To address Aim 1, treatment outcomes were examined by conducting a series of paired sample t-tests with total scores on each treatment measure as the dependent variable. For Aim 2, outcome measures were converted to difference scores (DS) to examine improvements pre-test to post-test. DS were then compared between telehealth and in-person delivery methods by conducting a series of independent samples t-tests.

Results: As measured by the QSQ, caregivers indicated significant improvements on adolescent social engagement, including total get-togethers, $t(3) = -4.38, p < .05$, and in particular, the number of hosted get-togethers, $t(3) = -3.87, p < .05$. Caregivers did not report significant improvements in the number of invited get-togethers ($p > .05$). While teen self-reports in the telehealth group did not indicate significant improvements in the number of total, hosted, or invited get-togethers on the QSQ ($p > .05$), they demonstrated significantly increased social skills knowledge as measured by the TASSK, $t(3) = -5.14, p < .05$. Scores measuring autism symptoms on the SRS-2, social skills on the SSIS, and problem behaviors on the SSIS were not found to significantly improve ($p > .05$) in this pilot. Teens completing in-person delivery of groups did demonstrate significant improvement on the QSQ, TASSK, SRS-2, and SSIS ($p < .05$), however no significant differences were found between telehealth and in-person groups on DS post-pre on any outcome measure ($p > .05$).

Discussion: Findings from the present study demonstrate that PEERS® for Adolescents via telehealth delivery results in significant improvements in social engagement and social skills knowledge for adolescents with ASD that are relatively equivalent to in-person delivery outcomes. Given the physical distancing requirements associated with COVID-19 and the subsequent impacts of limited accessibility to peer groups and social activities, improvements on social engagement are of particular interest. Caregivers indicated significantly higher number of hosted get-togethers following intervention, highlighting the importance of caregiver support to facilitate social engagement (i.e., get-togethers) for adolescents, especially during the current period of physical distancing. Social skills knowledge results indicate that telehealth delivery is comparable to in-person groups in improving
understanding of social skills taught within PEERS® for Adolescents; thus, content knowledge is maintained when modifying
groups for remote learning. These results indicate that PEERS® for Adolescents via telehealth delivery is a promising method to
teach adolescents with ASD social skills, extending accessibility and providing necessary support during challenging social times
for individuals on the spectrum and their families.

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1 UCLA

2021 Gatlinburg Conference Symposium Submission

Paper 4 of 4

Title: Virtual Emotion Regulation Treatment for Children with ASD: An Intensive, Group, Parent-Assisted Program Pilot

Authors: Rebecca Shaffer¹ ², Marika Coffman³, Lauren Schmitt¹ ², Debra Reisinger⁴, Shelley Randall¹

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Background: Regulating Together is an evidence-based intervention for youth with ASD and co-occurring emotion dysregulation (ASD+ED). Youth with ASD+ED have higher rates of psychiatric hospitalizations, school disciplinary action, rejection by peers, failed transitions to college and employment, and use of psychotropic medications compared to their typical peers. Due to the severity of concerns associated with ASD+ED (i.e., physical aggression), traditional school- and outpatient-based programs are often not equipped to deal with this population and specialized services outside of university medical centers are often unavailable or have extensive waitlists. There is a pressing need for interventions that can be widely and easily accessed for individuals with ASD given the relative lack of resources in many rural and underprivileged areas. This need was further exacerbated by the COVID-19 pandemic, forcing many providers to quickly pivot to telehealth or virtual treatment models. In response to the pandemic, we adapted a trial for ASD+ED to include a virtual, telehealth modality.

Methods: Pilot data was collected for two virtual versions of the program. The first version included synchronous caregiver groups and synchronous 13-18-year-old groups (Teen Group, N=5, additional 6 expected to complete). The second version was created for 8-12-year-old children with synchronous caregiver groups and caregiver facilitated child videos with children joining briefly at the end of the synchronous caregiver group (Child Group, n=12). Synchronous sessions occurred via a Zoom platform. We completed a within-subjects trial of each format with a 5-week baseline period, 5-week intervention period, and 5- and 10-week follow up. Adaptations were made to the curriculum and delivery based on family feedback and expert consultation. For example, treatment session time was decreased from the 90 minute in person sessions to one hour to accommodate attention spans. Additional visuals were provided and included a shared slide deck that was presented the material being taught, and all participants received workbooks before the start of the group with paper materials. Child group videos were created teaching the material with guided pauses for caregivers to discuss the material covered and complete activities. Reward plans were adapted for the virtual format. The videos were presented in PlayPosit, a learning platform that tracked completion and time spent viewing each video. In addition, data was collected at the end of each child video and teen group regarding amount learned and emotion level. Feasibility was assessed with enrollment and attendance rates. Acceptability was assessed with caregiver satisfaction surveys and youth ratings of learning at the end of each session. Initial efficacy was assessed with the Aberrant Behavior Checklist-Community (ABC), Emotion Dysregulation Inventory (EDI), Emotion Regulation Skills Test (ERST), Flexibility Scale (FS) and clinician rated CGI-I.

Results: At the time of this submission, two groups have been completed, one is nearing completion, and one has started (anticipated n=23). The dataset will be complete at the time of the conference. Of enrolled participants, the mean age was 11.4 years and 72.2% were males. Caregiver education included: 17.6% some high school, 11.8% some college, 41.2% college graduate, and 29.4% advanced graduate degree. Annual household income included: 5.6% $20,000-40,000, 27.8% $40,001-60,000, 33.3% $60,001-90,000, and 33.3% over $90,000. CGI-I was rated by the lead clinician. During the baseline period, 57% of the children had no change, 28.6% Minimally Worse, and 14.3% Much Worse. At the completion of treatment, 33.3% were Much Improved and 66.7% were Minimally Improved. In the small number of children who have completed to the first follow up period, 40% were Much Improved and 60% were Minimally Improved. Paired samples t tests demonstrated no significant changes during baseline period for any measures (EDI-Reactivity: t(16)=0.19, p=0.985; ED-Dysphoria: t(16)=-0.054, p=0.958; Flexibility Scale Total: t(16)=-1.22, p=0.239) and there was significant improvement for post treatment (EDI-Reactivity: t(9)=2.134, p=0.062, Cohen’s d=0.68, trending; ED-Dysphoria: t(9)=2.608, p=0.028, d=0.83; Flexibility Scale Total: t(9)=4.154, p=0.002, d=1.314). Parents provided overwhelmingly positive feedback in regard to the program as a whole with 80% very satisfied and 20% satisfied. There was a 100% retention rate of youth who started the program and a 92% attendance rate suggesting overall feasibility. Challenges arose with caregiver attention, talkativeness, and internet connectivity, providing needed direction for future versions of the intervention.

Discussion: We created a virtual version of an established intervention for emotion dysregulation. Satisfaction by caregivers was similar to in person groups and the retention rate was 15% improved for virtual versus in person. Participants demonstrated improved reactivity, dysphoria, and flexibility, very similarly to our in-person treatment results. Despite very promising preliminary findings, our initial sample only included 23 (12 8-12, 11 13-18) ASD participants which limits our ability to determine treatment efficacy. In addition, all data was collected during the COVID-19 pandemic which likely impacted participants’ stress response and emotion dysregulation in general. Adaptations have been made to the virtual program based on clinician and parental feedback.


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