

Efficacy of a Telehealth-Based Parent Training Intervention for Children with
Autism Spectrum Disorder: Rural versus Urban Areas

Angela Dahiya-Singh

Thesis submitted to the faculty of the Virginia Polytechnic Institute and State University
in fulfillment of the requirements for the degree of Master of Science in Psychology
in the Department of Psychology

Angela Scarpa, Ph.D. (Committee Chair)
Russell Jones, Ph.D.
Richard Winett, Ph.D.

May 5th, 2019

Blacksburg, VA

Keywords: autism spectrum disorder; parent training; telehealth; rural communities

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Abstract

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder that presents many challenges for parents and service providers. Unfortunately, there are limited examples of parent-mediated interventions for parents of children with ASD that can help manage behavioral problems, especially those that can be implemented in both urban and rural communities. COMPASS for Hope (C-HOPE) is an 8-week parent-mediated intervention that enhances parent knowledge, behavior management skills, and supportive strategies. Telehealth-based interventions can be especially effective for rural communities due to its ability to address common barriers of geographic location and lack of resources. When implementing this intervention, the ability to decrease child problem behaviors as well as increase parental activation, self-management, perceived competence, and knowledge are essential to determine the efficacy of this treatment. The purpose of the current study is to evaluate these outcomes in the implementation of C-HOPE via telehealth in rural versus urban communities. 20 parents with children from 3-12 years of age with a diagnosis of ASD were sampled from two rural sites and two urban sites in Kentucky. Few differences were noted between the participants in the rural versus urban group at pre-treatment. Following C-HOPE, in the urban area, there were significant treatment effects in parent knowledge outcomes. In the rural areas, a significant effect was found in change of parent self-management skills of toileting issues. Future directions for telehealth treatments for this population are discussed.

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General Audience Abstract

ASD is a developmental disorder that presents many challenges for parents and providers. Unfortunately, there are limited behavioral treatment options for parents of children with ASD, especially those that can be utilized in both urban and rural communities. COMPASS for Hope (C-HOPE) is a parent intervention that improves parent knowledge, management, and supportive strategies. Technology-based interventions can be especially effective for rural communities due to its ability to address barriers of geographic location and lack of resources. In this intervention, the ability to decrease child problem behaviors as well as increase parental activation, self-management, competence, and knowledge are essential for this treatment to be effective. The current study evaluates these outcomes in C-HOPE using technology in rural versus urban communities. 20 parents with children with ASD, ranging from 3-12 years of age, were sampled from rural and urban areas in Kentucky. Few differences were noted between the participants in the rural versus urban group before treatment. After treatment, in the urban area, there were significant effects in parent knowledge outcomes. In the rural areas, a significant effect was found in change of parent self-management skills. Future directions for technology treatments for this population are discussed.

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Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder which is comprised chiefly of deficits in communication and social skills and the presence of restricted interests and repetitive behaviors. According to the Centers for Disease Control, it is estimated to impact about 1 in 59 children in the United States (Baio et al., 2018), affecting the individual's developmental trajectory in communication, social competence, and adaptive behavior. Early identification and intervention can improve functional outcomes for children with ASD (National Research Council, 2001), but access to such services is not equal across all demographic groups. Rural communities face significant challenges regarding the availability and adequacy of services for children with ASD due to barriers such as financial challenges, geographic location, fewer resources, and general apprehension or the mental health stigma and hesitation towards outside professionals. These barriers greatly affect the ability to utilize services in rural areas (Antezana et al., 2017), making it crucial to implement efficient and cost-effective ways to deliver ASD services to rural communities.

Previous research has examined technology as a means to deliver services for children with ASD. Specifically, telehealth, which is the delivery of services through the use of information and communication technology, has been shown to be proficient in administering assessment and intervention in a cost-effective way (Ashburner et al., 2016). As such, telehealth-based approaches may be efficient prospects for improving the delivery of ASD services in rural communities.

Parent Training

Research shows that parents can effectively learn behavioral strategies for ASD that have a positive impact on child development (Brookman-Frazee and Koegel, 2004; Rocha, Schreibman, & Stahmer, 2007). Parent training programs for parents of children with ASD have

indicated positive language and behavioral outcomes in children (Bearss et al., 2015) as well as increased parental skills, confidence, and knowledge of appropriate evidence-based strategies (McConachie and Diggle, 2007, Hassenfelt, Lorenzi, & Scarpa, 2015, Hardan et al. 2015, Symon, 2005). For example, Pivotal Response Treatment (PRT), which often focuses on parent education as the core framework of service delivery, capitalizes on training parents to work on pivotal skills in natural environments, leading to widespread improvements in children (Koegel, Koegel, & Brookman, 2005). Studies have also shown that PRT parent training leads to increases in positive parent-child interactions, decreased parental stress, and increased parental positive affect (Koegel, Bimbela, & Schreibman, 1996). Another approach to treatment, known as COMPASS for Hope (C-HOPE: Collaborative Model for Promoting Competence and Success for Students with ASD; Ruble et al. 2012), utilizes an 8-week parent-mediated intervention consisting of individual and group sessions. The focus of the C-HOPE treatment approach is to include activities to enhance caregiver knowledge and skill in behavior management and supportive strategies, specifically for children diagnosed with ASD.

C-HOPE is adapted from COMPASS, which is an evidence-based school consultation model. The goal of COMPASS is to decrease child problem behavior and increase parent competence and knowledge by utilizing child preferences and strengths, parent and family resources, and evidence-based practices. COMPASS uses information about assessment and development from caregivers of children with ASD as well teachers who work with children with ASD in order to measure outcomes in social, communication, and learning skills. In a randomized controlled trial (RCT), Ruble et al. (2010) found that children enrolled in COMPASS were able to reach educational goals at a significantly higher level than children enrolled in treatment as usual ($d = 1.5$). A second RCT implemented a telehealth delivery of

COMPASS (Ruble et al. 2013), which also demonstrated efficacy compared to treatment as usual ($d = 1.1$). Based on these findings, C-HOPE was developed as a model for caregivers with children with ASD to promote positive parent and child outcomes, using caregivers as the primary target for treatment, as the clinician provides direct training to parents and helps create a parent-implemented behavioral plan. In addition to the skills taught in COMPASS, C-HOPE targets behavioral skills and parent stress management.

Technology-Based Parent Training

Because telehealth may be a service delivery model that can reach across long-distances, several technology-based interventions are being developed for ASD parent training. The Online and Applied System for Intervention Skills (OASIS; Buzhardt & Heitzman-Powell, 2005) training program, for example, combines online instruction with hands-on practice of evidence-based behavioral techniques for service providers working with children with ASD. Heitzman-Powell, Buzhardt, Rusinko, & Miller (2014) examined the modification of OASIS in order to train these skills in parents of children with ASD in remote areas. These changes included the integration of online tutorials with “parent-friendly” language and web-based video calls for in-vivo coaching. The study required parents to complete the full training program, which included eight modules of instruction on ASD and Applied Behavior Analysis (ABA) techniques, as well as take part in live online coaching sessions. Results indicated that the OASIS parent-training program was effective in training parents and caregivers without the need of outside providers. Post-intervention results indicated an increase in knowledge of ASD and ABA concepts, increase in ABA implementation skills, higher satisfaction with training, and more miles saved by traveling to a local telehealth site versus to a farther mental health center to receive face-to-face services.

Such gains are promising in that they can lead to further dissemination and implementation of ABA services in rural or remote areas, as parents will have the opportunity to be trained to serve as the primary therapist for their children. The OASIS program's technology of combining online tutorials with live coaching via video calls allows the parents to practice and review skills on their own first before generalizing them to their child with the live support of a provider. Using this integrated technique can address barriers among people in rural communities by reducing the need for travel while also increasing access to resources in the comfort of their own home.

Another intervention known as the Parent-Implemented Communication Strategies (PiCS) program (Meadan, Angell, Stoner, and Daczewitz, 2014), focuses on improving social-communication skills in children with ASD who have deficits in expressive language. This program uses a family-assisted intervention to help generalize strategies in naturalistic settings. Meadan, Meyer, Snodgrass, and Halle (2013) modified this program in order to implement delivery via an internet-based approach (known as the i-PiCS program). Through the use of direct audio and visual communication between providers and parents, this intervention can be implemented to families via a long-distance "Internet relationship." The phases included in this program include (1) a pre-intervention evaluation, (2) a technology training, (3) a naturalistic teaching strategies training, (4) a naturalistic teaching strategies coaching, and (5) a post-intervention evaluation. Parents and children benefited from this intervention when delivered at home, and as a result, the researchers believe this program will be able to improve access to services in remote or rural areas and have positive outcomes. This treatment provides strong support similar to that of the OASIS program, as it increases access to multiple resources from a remote setting, but also has a well-organized structure for assessing outcomes of the

intervention. A treatment structure that incorporates online training (either through modules or a live lecture), in-vivo coaching, and assessment of outcomes provides a solid foundation for a technology-based intervention that can be easily applicable to educating and treating families living in rural areas.

The Current Study

As previously mentioned, C-HOPE is an effective parent training intervention for behavior management with children with ASD (Ruble et al., 2012). C-HOPE includes the essential components of online training and instruction, outcome assessments, as well as individual and group coaching. Because C-HOPE is easily accessible in remote areas through the group sessions presented via a supportive teleconference setting in addition to tailored one-on-one individual sessions over the phone, it proves to be a sustainable candidate for the current study. The purpose of this study is to examine the outcomes of C-HOPE, delivered via telehealth, in rural versus urban communities in order to evaluate if benefits are seen across both settings. Due to the lack of resources available in rural areas, being able to generalize this treatment to both rural and urban communities will provide a new resource to help communities in need gain access to effective, evidence-based treatments. The aim of this project was to identify the differences in treatment outcomes, if any, of this C-HOPE telehealth-delivery in rural versus urban communities. Due to the small sample, the proposed hypotheses and analytic plan were largely exploratory. It was expected that the telehealth treatment condition would show a pre- to post- decrease in child problem behaviors and increase in parental activation, self-management, perceived competence, and knowledge across both groups. Larger effects were expected in the rural group, possibly due to higher levels of severe behaviors present at pre-treatment in the children from rural areas. Additionally, exploratory analyses were expected to reveal significant

baseline differences between the rural and urban groups in demographics (e.g., parent years of education, income, ethnicity, number of parents in the home services received outside of school), parent measures, and child behaviors. Exploratory analyses also examined inter-relationships among demographics and pre-post change in parent and child variables in order to better understand how rural/urban differences in these other factors might be related to outcomes.

Method

Participants

Parents and their children with ASD were sampled from both rural and urban sites for a larger study conducted through the University of Louisville School of Medicine & the University of Kentucky (Kuravackel et al., 2018) and randomized to telehealth or face-to-face treatments. The study occurred over an 18-month period at four locations (two rural sites and two university sites).

Participants were recruited through various methods, including flyers posted at the two university sites and support group websites. Eligibility criteria included the following: (a) the child's age can only range between 3 to 12 years (b) the child must have a DSM-IV or DSM-5 diagnosis of ASD verified by the Autism Diagnostic Observation Schedule (ADOS-2; McCrimmon and Rostad, 2014) (c) the child must be eligible for special education services for ASD (d) the child must have an identified target problem behavior. Additionally, the participants agreed to the following: random assignment to a condition, audiotaped sessions, commitment to activities related to the condition, and they had no plans to relocate during the timeframe of the study. Parents and their children underwent a screening processing in which the child was administered the Modified Checklist for Autism in Toddlers (M-CHAT; Robins Fein, Barton, & Green, 2001) or Social Communication Questionnaire (SCQ; Rutter, Bailey, & Lord, 2003),

which then was followed up by an intake appointment to confirm a diagnosis of ASD, pending the child's score on either of these screening measures. All participating parents provided written informed consent prior to the start of the study.

Thirty-three parents ($n_{\text{Males}}=7$, $n_{\text{Females}}=26$) with children from 3-12 years of age ($M=8.17$, $SD=2.5$) with a prior diagnosis of ASD were sampled from two rural sites and two urban sites (rural $n=12$, urban $n=21$) in Kentucky. 44% percent of sampled families represented single-parent homes. The participants were randomly assigned to waitlist control (WLC; $n=10$), C-HOPE telehealth (TH; $n=10$), and C-HOPE face-to-face (FF; $n=13$). The participants in the waitlist condition later received the C-HOPE telehealth treatment. The face-to-face condition is not being considered in this study.

The current study examined the 20 children (WLC $n=10$; TH $n=10$) who received the C-HOPE telehealth treatment (rural $n=12$, urban $n=8$) and their caregiver. The children ($n_{\text{Males}}=15$, $n_{\text{Females}}=5$) ranged from 3-12 years of age ($M=7.67$, $SD=2.68$), and were primarily of Caucasian background (Caucasian $n=17$, African American $n=2$, Asian $n=1$). Most households consisted of two-parents (mother and father $n=13$; parent and stepparent $n=2$), but also included single-parent (mother only $n=4$) or homes. One participant did not report on number of caregivers in the home. Caregiver years of education ranged from 12-18 years ($M_{\text{mother}}=15.12$, $SD_{\text{mother}}=2.03$; $M_{\text{father}}=14.00$, $SD_{\text{father}}=2.24$). Family total household income level was reported based on the selection of one of five categories: less than \$10,000 ($n=1$), \$10,000-24,999 ($n=4$), \$25,000-\$49,999 ($n=6$), \$50,000-\$100,000 ($n=7$), or \$100,000 or more ($n=1$).

Treatment was conducted by two licensed psychologists and one trained doctoral student in school psychology. The rural settings were located in eastern and southeastern Appalachia. These locations were considered rural because they were located about 120 miles from a center

that offered specialized ASD services. Group sessions were conducted at a distant education center with the help of research assistants, and individual sessions were conducted over the phone and allowed for one-on-one discussions with the treatment facilitator in order to work on individualized goals for each participant. The setting of the telehealth sessions was comparable to the face-to-face treatment, as both settings included research assistants working at the center with the materials and handouts necessary to complete all the assignments and group activities.

Power Analyses

A power analyses was conducted for the primary analysis in this study (paired sample t-tests), using the G*Power statistical software, to determine minimum sample size needed to detect small (Cohen's $d = 0.20$), medium (Cohen's $d = 0.50$), or large (Cohen's $d = 0.80$) effects, with power = .8 and $p = .05$. A sample size of $n = 156$ would be required to detect a small effect, $n = 27$ to detect a medium effect, and $n = 12$ would be required to detect a large effect. The current sample size of 20 is sufficient to detect a medium to large effect. This study is exploratory because of the importance and novelty of the topic, and therefore effect sizes (ES) will be reported to inform future research, using Cohen's d (Cohen, 1998).

Measures

The parents completed the following measures pre- and post-treatment that were used for the purposes of the current study:

A demographic questionnaire was given to parents to gather background information on the parents and their children. The following data were gathered through this questionnaire: child age, child gender, child ethnicity, services received by child, household income, mother's years of education, father's years of education, and the number of caregivers in the home. The current study used these variables to examine differences between the rural and urban groups.

The *Eyberg Child Behavior Inventory* (ECBI; Eyberg and Pincus, 1999) measured the intensity of child problem behaviors. The ECBI is a 36-item measure of problem behaviors in children ages 2-16 years of age. The items are rated on the Intensity and Problem Scales, and are rated on 7-point Likert scale (ranging from *Never* to *Always*). The total score calculated from the Intensity scale, which measures total frequency of the 36 behaviors, was used for the analyses in the current study. The change score from pre- to post-treatment was also used; this was calculated by subtracting the pre-score from the post-score. Positive change scores indicate higher frequency of problem behaviors from pre to post-treatment, whereas negative change scores reveal a decrease in frequency of problem behaviors from pre- to post-treatment. The ECBI's test-retest reliability (>0.75) and internal consistency are at high levels (>0.90) (Funderburk et al. 2003).

The *Parent Activation Measure for Developmental Disabilities* (PAM-DD; Hibbard et al., 2004) assessed confidence and knowledge, taking action, beliefs in the importance of taking an active role, and confidence in staying focused under stress. The PAM-DD was created as a parent-adapted version of the original PAM (Hibbard et al. 2004). The PAM achieved high internal consistency (0.85; Pennarola et al. 2011). In PAM-DD, the items were slightly modified to reflect services used for children with developmental disabilities such as ASD. Items are scored on 4-point Likert scale (ranging from *Disagree Strongly* to *Agree Strongly*), and summed to create a weighted score, in which higher scores indicate higher activation. The internal consistency on the PAM-DD was 0.83. A change score from pre- to post-treatment on the PAM-DD was also included in the analysis, in which the pre-score was subtracted from the post-score. Positive change scores indicate improved parent activation from pre to post-treatment.

The *Self-Management Assessment* (SMA) rated how well parents can manage their

child's behavior across five areas: sleep, behavior, eating, toileting, and school issues). The SMA was created by the Cincinnati Children's Hospital Medical Center and was reviewed based on input from parents of children with ASD. Each area is scored on an 11-point scale (ranging from *Cannot Manage* to *Can Fully Manage*). The mean score for each of the areas was used for the current analyses, as well as a change score from pre- to post-treatment, which was calculated by subtracting the pre-score from the post-score. Positive change scores indicate improved self-management skills in parents from pre to post-treatment. The internal consistency of the SMA is 0.57 (Ruble et al. 2018).

The *Being a Parent Scale* (BPS; Johnston and Mash, 1989) to measure parent's views of their own competence in the parenting role. The BPS is a 16-item questionnaire that includes questions categorized in two dimensions: satisfaction with the parenting role (9 items) and feelings of self-efficacy as a parent (7 items). These items are scored on a 6-point Likert scale (ranging from *Strongly Disagree* to *Strongly Agree*), and are given a total score. The total score and the pre to post-change score were used in this study. The change score was calculated by subtracting the pre-score from the post score, and positive change scores indicate higher perceived competence in parents from pre to post-treatment. The internal consistency of the BPS is 0.82 (Whittingham et al. 2009).

Additionally, parents completed the *Parent Knowledge Questionnaire* (PKQ) to assess parents' knowledge of parent training and supportive strategies. The PKQ is an 18-item scale that is scored on a 4-point Likert scale (ranging from *Not Much* to *Very Much*). The measure was scored based on how many items were endorsed, indicating how much parents' knowledge increased as a result of the C-HOPE program from pre- to post-treatment. Both the total score and the change score from pre-to post-treatment were used in the current study. The change score

was calculated by subtracting the pre-score from the post score, and positive change scores revealed an increase in parent knowledge from pre to post-treatment.

Data Analysis Plan

Due to the small sample size, an exploratory analysis was conducted to examine treatment outcomes in rural (n=12) versus urban (n=8) participants. The following analyses were conducted: (1) Chi-square tests, Mann-Whitney U tests, and independent t-tests examined differences in the rural and urban groups before treatment on demographic variables (e.g., parent years of education, income, ethnicity, services received outside of school, number of caregivers per household), parental measures, and child behaviors; (2) Paired t-test analyses of parent data examined changes in efficacy from pre- to post- treatment in the outcome variables, separately in the rural and urban groups; and (3) Correlational analysis examined if demographics and overall change in parent data correlated with the change in child problem behaviors. Specifically, correlations between change in parent and child outcomes, parent demographics and change in child outcomes, and parent demographics and change in parent outcomes were examined.

Results

Baseline Differences (Table 1)

Chi-square tests were conducted to examine the discrepancies in ethnicity, services received, and number of caregivers per house between rural versus urban groups before treatment. When examining differences in ethnicity between groups, results did not reveal a statistically significant association between group and ethnicity $\chi(2) = 5.294, p = .071; d = .13$. This ES was below Cohen's convention for a small effect ($d = .20$). A significant discrepancy in enrollment in individual therapy services was found, with more urban families enrolled in individual therapy than rural families $\chi(1) = 3.997, p = .046; d = .20$, indicating a small effect.

However, there were no significant differences in whether children were enrolled in the following services: applied behavior analysis therapy $\chi(1) = 2.249, p = .134; d = .11$, physical therapy $\chi(1) = 3.333, p = .068; d = .17$, medical $\chi(1) = .003, p = .960; d = 0$, occupational $\chi(1) = .029, p = .865; d = 0$, or speech and language therapy $\chi(1) = 1.046, p = .306; d = .05$. The ES were all below Cohen's convention for a small effect ($d = .20$). Additionally, in terms of caregivers per household, only 2 participants in the rural group and 2 participants in the urban group were in single-parent homes, with the other 16 participants living with two caregivers.

Descriptives of the percentages for participant ethnicity and services previously received across the two groups were also noted. In the rural group, 100% of participants identified as Caucasian. In the urban group, 62.5% of participants identified as Caucasian, 25% African American, and 12.5% Asian. For applied behavior analysis therapy, 37.5% of urban participants and 8.3% of rural participants were enrolled. For speech and language therapy, 75% of urban participants and 91.7% of rural participants were enrolled. For occupational therapy, 62.5% of urban participants and 75% of rural participants were enrolled. 25% of urban participants were enrolled in physical therapy. For individual therapy, 50% of urban participants and 8.3% of rural participants were enrolled. Lastly, 37.5% of urban participants and 33.3% of rural participants previously received medical services.

Because the data for total income and parent years of education were not normally distributed, a Mann-Whitney U test examined income and parent education differences between both groups. Results showed no significant differences across rural and urban participants, with very small effects for income and mother's education, and small effects for father's education, according to Cohen's convention of ES (total household income: $U = 43, p = .931; d = .03$,

mother years of education: $U = 31, p = .362; d = .10$, father years of education: $U = 24.5, p = .836; d = .42$).

Independent t-tests examined group differences in parent data and child behaviors before treatment. Surprisingly, no significant differences between groups were noted for the parent measures of competence (BPS) $t(11) = -.369, p = .326; d = .22$, parent activation (PAM) $t(13) = 1.036, p = .453; d = .29$ and parent knowledge (PKQ) $t(13) = 1.787, p = .385; d = .99$, or child behaviors (ECBI) $t(15) = -.564, p = .566; d = .29$. Despite nonsignificance, however, ES for parent competence, activation, and child behaviors exceeded Cohen's convention of a small effect ($d = .20$), whereas the ES for parent knowledge exceeded that of a large effect ($d = .80$). As seen in Table 1, rural participants reported higher baseline scores on the PKQ and the PAM compared to urban participants, but reported lower baseline scores on the BPS. Rural participants also reported fewer child behavior problems than urban participants prior to treatment. For parent self-management skills, significant differences were found in the parent management of their child's toileting issues $t(14.726) = -.919, p < .05; d = .48$, with rural parents reporting fewer management skills than urban parents, noted at approaching a medium ES, according to Cohen ($d = .50$). However, no significant group differences for the management of the other four areas of behavior were noted: sleep $t(16) = .552, p = .363; d = .28$, behavior $t(16) = .177, p = .401; d = .10$, eating $t(16) = -.149, p = .996; d = .08$, and school issues $t(17) = -1.571, p = .962; d = .76$. Group difference in management of sleep exceeded Cohen's convention of a small effect ($d = .20$), whereas the ES for behavior and eating were below that value. School issues, however, was reported to be closer to Cohen's convention of a large effect ($d = .80$). Rural participants reported greater management skills for sleep and behavior issues compared to the urban participants, but

fewer management skills for eating and school issues. Results from the independent t-tests can be found in Table 1.

Outcomes for Rural and Urban Groups (Table 2)

Outcome results from pre- to post- treatment can be found in Table 2. Paired sample t-tests were conducted to examine changes from pre- to post-treatment in the parent outcome variables using the pre- and post- scores of each measure, in order to examine the presence of significant change. Results revealed a significant mean pre- to post- increase in parent knowledge on the PKQ for urban, $t(8) = -3.925, p < .05; d = 1.31$, but not for rural families $t(5) = -2.529, p = .053; d = 1.03$, although the ES was large for both. There was no significant change in parent activation on the PAM for both urban, $t(6) = 2.413, p = .052; d = .91$, and rural families, $t(1) = -3.000, p = .205; d = 2.12$, although the ES was large for both, and means showed opposite patterns. This revealed decreased activation scores in the urban group, but increased activation scores in the rural group, following treatment. Parent competence, as measured by the BPS, also did not show a significant change in either urban, $t(8) = -1.331, p = .220; d = .44$, or rural, $t(5) = -1.609, p = .169; d = .66$, participants, although the ES was small for the urban group and medium for the rural group in the direction of increased competence for both.

The current study also examined a change in the parent's self-management skills of their children from pre- to post-treatment. The SMA collected data on five categories: sleep, behavior, eating, toileting, and school issues. Rural participants showed significant improvement in managing toileting issues, $t(5) = -3.627, p < .05; d = 1.48$, but no significant changes were reported on sleep, $t(5) = -1.968, p = .377; d = .40$, behavior, $t(5) = -1.265, p = .262; d = .52$, eating, $t(5) = -1.627, p = .165; d = .66$, and school, $t(5) = -.359, p = .734; d = .15$, issues. The ES for changes in managing toileting issues were found to exceed Cohen's convention for a large

effect ($d = .80$). For changes in managing behavior and eating issues, the ES were found to exceed a medium effect ($d = .50$), whereas the ES for changes in managing sleep ranged between a small ($d = .20$) to medium effect. The ES for managing school issues were below Cohen's convention for a small effect.

Urban participants did not show significant changes in self-management skills on any of the five areas of sleep, $t(8) = -.447, p = .667; d = .15$, behavior, $t(9) = .408, p = .693; d = .13$, eating, $t(9) = -.287, p = .780; d = .09$, toileting, $t(9) = -1.797, p = .106; d = .57$, and school issues, $t(9) = 0, p = 1.00; d = 0$. The ES for changes in managing sleep, behavior, eating, and school issues were below Cohen's convention for a small effect ($d = .20$). However, the ES for improved management of toileting issues exceeds a medium effect ($d = .50$).

Relationships to Change in Outcome (Table 3)

Lastly, bivariate correlations were conducted for change in overall outcomes. A change score was calculated, subtracting the pre-scores from the post-scores on each measure, such that positive scores indicated increased parent competence (BPS), parent knowledge (PKQ), parent activation (PAM), and child behavior problems (ECBI). When examining change in parent and child outcomes, a significant negative correlation emerged between changes in parent competence and child behavior problems, $r = -.814; p < .05$, such that increased parent competence was associated with decreased child behavior problems (Figure 1). Additionally, when the parent demographics (years of education, income, and ethnicity) and change in parent outcomes were examined, a significant negative correlation was noted between total family household income and change in parent competence ($r = -.781; p < .05$), such that higher incomes were associated with decreases in parent competence (Figure 2). However, mother's years of education $r = .340; p = .280$, father's years of education $r = .092; p = .777$, income $r = .146; p =$

.634, and ethnicity $r = .151$; $p = .606$ did not reveal a significant correlation with change in child outcomes following treatment. No significant relationships between the remaining variables were noted. Correlations can be found in Table 3.

Discussion

This current study used a technology-based implementation of a parenting group therapy program for children with ASD. This format is especially notable, given the treatment outcomes are primarily focused on parenting outcomes in addition to child behavior outcomes. Following the C-HOPE telehealth treatment, it was expected that there would be a significant improvement in child behaviors, parent activation, self-management, perceived competence, and knowledge. The effects following treatment were expected to reveal greater improvement in the rural group compared to the urban group due to the greater need for caregiver training and support (e.g., less perceived competence, greater behavior problems) in the rural community.

At baseline, few significant differences were observed between the two groups. Significantly more urban participants were enrolled in individual therapy than rural participants, and this was demonstrated with a small ES according to Cohen's d . A medium effect (according to Cohen) was noted when examining self-management skills of toileting issues, which were significantly higher in urban compared to rural participants.

Following treatment, a significant large effect was found for increased parent knowledge in urban participants. Results on parent knowledge for rural participants were not significant, but a large effect for increased knowledge was also noted. No significant change was revealed for change in parent activation in both rural and urban participants, but a large effect was noted for both groups. Additionally, results showed a decrease in activation for the urban group, and increased in activation for the rural group. For change in parent competence, no significant

changes were noted for either group; these results revealed a medium effect for rural participants and a small effect for urban participants, with an increase of parent competence in both groups.

In regard to change in parent self-management skills, improvement of managing toileting issues was found to be significant for rural participants, with a large ES. For urban participants, results were shown to be insignificant and met criteria for a medium ES. Changes in the other four areas following treatment (sleep, behavior, eating, and school issues) were not significant for both urban and rural groups. For urban participants, the ES were below Cohen's convention for a small effect. For rural participants, a medium effect was noted for changes in managing behavior and eating issues, a small effect was noted for changes in managing sleep issues, and an ES below Cohen's convention for a small effect was noted for changes in managing school issues.

Lastly, change in overall outcomes was analyzed, revealing a significant correlation that suggests a negative relationship between increased parent competence and decreased child problem behaviors from pre- to post- treatment (Figure 1), which indicated a strong relationship between both outcomes variables. A significant negative relationship was also noted between increase household income and decrease parent competence (Figure 2), which also indicated a strong correlation between both variables.

Baseline Differences

When examining families in rural and urban groups, some differences were noted at baseline. Surprisingly, children in rural areas were reported to have fewer behavioral problems prior to treatment compared to children in urban areas. Demographic data revealed no significant differences in ethnicity, income, and years of education, which was also unexpected. Additionally, rural and urban parents reported some differences in self-management techniques,

with rural parents reporting higher management skills with behavior and sleep issues, and urban parents reporting higher skills with eating, toileting, and school issues. It is possible that the children from rural areas began treatment with fewer behavior problems than those from urban areas because rural parents noted higher behavior management techniques at baseline. In regard to treatment services previously received, many rural and urban participants received similar services such as speech and language therapy, occupational therapy, and medical services, with only a few families receiving individual therapy services. This lack of experience with other psychological therapy services may have contributed to the increase in parent knowledge and competence that both groups reported following treatment. The C-HOPE intervention utilized a supportive model, consisting of both group and individual sessions; group facilitators reported a positive therapeutic alliance in which parents actively participated in discussions with other group members. This openness during parent training sessions could have contributed to the increase in some of the parent treatment outcomes (e.g. knowledge, competence).

Treatment Effects

As previously discussed, rural and underserved areas are limited in access to health care, especially for children with ASD. Because of the multitude of barriers for both families and service providers in these areas, it is essential to utilize efficient ways to deliver services, such as technology-based approaches. Research has shown the success of teaching evidence-based strategies to parents of children with ASD, through positive outcomes in both parents and children (Brookman-Frazee and Koegel, 2004; Rocha, Schreibman, & Stahmer, 2007; Bearss et al. 2015). Therefore, parent training interventions are a sustainable option when developing programs for rural areas. Similar to that of parent training programs such as PRT and COMPASS, C-HOPE is focused on parent education and skill development as the main

treatment target. Increasing parent knowledge, competence, and mood, while decreasing stressors and negative behaviors in both children and parents, are fundamental outcomes in many parent training programs that have proved to be efficient (Koegel, Bimbela, & Schreibman, 1996; Ruble et al. 2013).

Correlational Findings

The current study revealed a significant correlation, indicating a decrease in child behavior problems as parent competence increased from pre- to post- treatment. This outcome matches the results of the original COMPASS (Ruble et al. 2013) study, which also noted a decrease of child problem behaviors and an increase in parent competence. This suggests that both interventions (COMPASS & C-HOPE) are comparable across platforms (face-to-face versus technology) for both urban and rural groups. C-HOPE also examined the integration of web-based calls with easy-to-following training sessions on parent management techniques, similar to the OASIS (Buzhardt & Heitzman-Powell, 2005; Heitzman-Powell et al. 2014) and iPICS program (Meadan et al., 2013). Both the OASIS and C-HOPE treatments revealed an increase of knowledge in parenting strategies and management skills. Particularly, the C-HOPE rural participants noted an increase in self-management techniques following treatment. However, iPICS & OASIS used in-vivo coaching in addition to online training, which provided live feedback to parents, as they practiced strategies with their children with ASD. C-HOPE's format did not follow this approach, but may benefit from this addition in order to improve child behavior outcomes.

Limitations

The present study includes some limitations. First, the sample size for this study ($n= 20$) was small, resulting in an exploratory data analysis of the pre- and post-treatment data. Second,

baseline data only included demographic information of ethnicity, parent years of education, income, number of services received, and number of parents in the home. There was not a specific variable for socioeconomic status (SES) to further compare the rural and urban groups. It would also be important to collect more detailed participant information at pre-treatment and during follow-up to note changes in outcome among rural and urban groups (e.g. behavioral changes in the child, changes in parent-perception). Additionally, many of the measures used in the current study demonstrated a wide standard deviation (see Table 1 and Table 2). Because the standard deviations were relative large compared to the means of the rural and urban groups, the data were spread out over a wider range of values. This is likely due to the small sample size of this study and the variation amongst participant data. Third, although this telehealth treatment appeared to be effective for some outcomes in rural and urban areas (e.g. parent activation, knowledge, self-management skills), it is important to assess whether a remote treatment is still able to foster participation in the group. According to anecdotal reports from the principle investigators and facilitators of the treatment groups, participants reported high group alliance and overall openness to many back and forth discussions. It was suggested that participation was not compromised. Additionally, no concerns were noted in regards to confidentiality, as the telehealth sessions occurred under a secure network at a school education center.

Future Directions

Understanding how services are currently implemented in different areas can help bridge the gap between rural communities and access to services for children with ASD. However, there are potential barriers that need to be considered. Families in rural areas may not have access to the Internet or the technology needed to implement telehealth services. Reaching out to areas with local community centers that have access to technology is central to telehealth services,

especially when clients do not have technology at home. Keeping that in mind, security and privacy is also necessary to avoid any ethical issues. Families in rural populations live in a close-knit social community, and the cultural differences in terms of the mental health stigma and potential discomfort with outside professionals can be difficult when serving rural families. Taking this into consideration, in-home online treatment can be appealing to some of these families if it is accessible to them. They also may not be comfortable with or knowledgeable about certain technology, so including technology training in treatment will assure that both the client and provider are well versed in the approach that will be utilized. Showing respect and understanding of the community's strengths and barriers can lead to a strong therapeutic relationship and an increase in positive treatment outcomes (Antezana, et al. 2017).

Future studies on the C-HOPE intervention, or any other telehealth-based treatments for parents of children with ASD, should promote generalization to larger, diverse populations, especially those living in underserved, rural, and/or low-income communities (West et al. 2016). Multiple factors should be considered to better tailor telehealth treatments to these remote populations. Social support should be assessed as a part of pre-treatment, in order to gain information on how the presence of a support system (or lack thereof) may impact treatment outcomes (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2011; Luther, Canham, & Cureton, 2005). Additionally, the present study collected data on services received prior to enrolling in C-HOPE, but collecting independent follow up data on the participants would further inform the effectiveness of the treatment and also provide information on other services or supports the participants sought after completing the study.

Implementation should also further assess the feasibility of the form of technology used for treatment, including how comparable it is to face-to-face treatment. More sophisticated

technology methods should also be considered, such as in-vivo and instructional teleconferencing, smartphone applications or modules (e.g. similar to the OASIS modules), or ecological momentary assessments (EMA; Shiffman, Stone, & Hufford, 2008). The primary technology platform used in the C-HOPE intervention was video teleconferencing, which is a low-cost technology that allows providers and clients to communicate with each other. This form of communication Buchter and Riggleman (2018) discussed the benefits of using teleconferencing to overcome the challenges of serving remote areas. This form of communication is an effective alternative to traveling, both for the families and the providers, and it increases productivity as it allows more families to gain access to services in a shorter amount of time. Additionally, the ability for the providers to videoconference live with the family and their child with ASD allows for service in a naturalistic setting without the provider possibly influencing outcomes in a way that may occur if they were actually in the home. Families are also able to use teleconferencing to access a variety of professionals with diverse training backgrounds that can cater to particular needs depending on the child with ASD.

EMA (Shiffman, Stone, & Hufford, 2008) is also a viable approach to more intensive measures of behavior and well-being. This methodology involves participants completing ratings at various times throughout the day when prompted. By delivering assessments via phone messaging or websites, EMA can be administered relatively easily and quickly to parents or children who only have access to a cellular phone. The assessments can include current self-report measures of one's current mental state, in their natural environment (e.g., stress, mood). These frequent in-the-moment assessments offer many advantages, as it provides a unique perspective of the parents or child's experiences over time. By capturing momentary states that are often responses to certain events, EMA allows for the assessment of highly dynamic

outcomes, which may vary on a day-to-day or hour-to-hour basis, demonstrating the trajectory and patterns of these outcomes. Incorporating the technology methods mentioned would allow for a streamlined assessment of treatment outcomes and provide easily accessible treatment options to families in remote areas that can be more affordable.

The current findings provide preliminary evidence that the telehealth delivery of C-HOPE can be effective in improving parent and child outcomes across both rural and urban populations. This study revealed some important differences between the two groups, such as knowledge of self-management techniques, with rural and urban groups having different levels of management skills prior to treatment, and changes in improvement of these skills. Similarities were also noted in regard to some of the treatment services previously received and improvement on outcomes in parent competence and knowledge. Regardless of these comparisons, the overall outcomes of this intervention are promising. Future dissemination and implementation of C-HOPE should consider the practical barriers of access to technology in larger rural populations, as some technology platforms can be limited in remote or underserved areas.

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Table 1: Baseline Differences (Independent Samples T-test)

Baseline Variable	Rural Pre <i>M (SD)</i>	Urban Pre <i>M (SD)</i>	<i>t</i>	<i>Cohen's d (ES)</i>
BPS	23.17 (36.00)	48.67(28.56)	-.369	.22
PAM	45.50 (.71)	39.57 (3.74)	1.036	.29
PKQ	39.83 (22.56)	33.00 (21.37)	1.787	.99
SMA Sleep	7.67 (2.73)	6.22 (3.27)	.552	.28
SMA Bx	6.17 (1.72)	4.90 (2.42)	.177	.10
SMA Eat	6.17 (3.43)	6.30 (2.79)	-.149	.08
SMA Toilet	2.50 (1.97)	6.50 (4.06)	-.919*	.48
SMA School	5.83 (2.32)	6.40 (2.91)	-1.571	.76
ECBI	106.3 (55.62)	122.67 (25.40)	-.564	.29

Note: BPS = Being a Parent Scale; PAM = Parent Activation Measure; PKQ = Parent Knowledge Questionnaire; SMA Sleep = Self Management Assessment Sleep; SMA Bx = Self Management Assessment Behavior; SMA Eat= Self Management Assessment Eating; SMA Toilet = Self Management Assessment Toileting; SMA School = Self Management Assessment School Issues; ECBI = Eyberg Child Behavior Inventory; * $p < .05$

Table 2: Outcomes for Rural and Urban Groups (Paired Sample T-test)

Outcome	Rural Pre <i>M (SD)</i>	Rural Post <i>M (SD)</i>	<i>t</i>	<i>Cohen's d</i> <i>(ES)</i>
BPS	23.17 (36.00)	64.00 (32.36)	-1.609	.66
PAM	45.50 (.71)	50.00 (2.83)	-3.000	2.12
PKQ	39.83 (22.56)	61.50 (8.26)	-2.529	1.03
SMA Sleep	7.67 (2.73)	8.67 (2.16)	-.968	.40
SMA Bx	6.17 (1.72)	7.5 (2.59)	-1.265	.52
SMA Eat	6.17 (3.43)	7.67 (4.08)	-1.627	.66
SMA Toilet	2.50 (1.97)	5.83 (2.93)	-3.627*	1.48
SMA School	5.83 (2.32)	6.5 (3.56)	-.359	.15
ECBI	106.3 (55.62)	107.0 (30.48)	-.023	.01

Outcome	Urban Pre <i>M (SD)</i>	Urban Post <i>M (SD)</i>	<i>t</i>	<i>Cohen's d</i> <i>(ES)</i>
BPS	48.67(28.56)	63.89 (14.62)	-1.331	.44
PAM	39.57 (3.74)	37.00 (4.00)	2.413	.91
PKQ	33.00 (21.37)	61.33 (5.43)	-3.925*	1.31
SMA Sleep	6.22 (3.27)	6.89 (2.93)	-.447	.15
SMA Bx	4.90 (2.42)	4.70 (1.34)	.408	.13
SMA Eat	6.30 (2.79)	6.50 (2.72)	-.287	.09
SMA Toilet	6.50 (4.06)	8.60 (1.78)	-1.797	.57
SMA School	6.40 (2.91)	6.40 (2.95)	.000	0
ECBI	122.67 (25.40)	129.33 (23.22)	-1.066	.36

Note: BPS = Being a Parent Scale; PAM = Parent Activation Measure; PKQ = Parent Knowledge Questionnaire; SMA Sleep = Self Management Assessment Sleep; SMA Bx = Self Management Assessment Behavior; SMA Eat= Self Management Assessment Eating; SMA Toilet = Self Management Assessment Toileting; SMA School = Self Management Assessment School Issues; ECBI = Eyberg Child Behavior Inventory; * $p < .05$

Table 3: Relationships to Change in Outcome (Bivariate Correlation)

		1.	2.	3.	4.	5.	6.	7.	8.	9.
Parent Outcome	1. PKQ Change	1								
	2. PAM Change	.785	1							
	3. BPS Change	.898	-.037	1						
	4. Sleep Change	.401	.420	.132	1					
	5. Bx Change	.614	.347	-.572	.432	1				
	6. Eat Change	.026	.470	-.594	.616*	.676**	1			
	7. Toilet Change	.733*	.632	-.060	.185	.479	.264	1		
	8. School Change	.534	.536	-.321	.321	.682**	.469	.442	1	
Child Outcome	9. ECBI Change	-.188	-.177	-.814*	-.574	-.437	-.526	-.370	-.088	1
Demographics	10. Mo. Education	-.434	-.092	-.374	-.300	-.434	-.322	-.041	-.050	.340
	11. Fa. Education	.305	.413	.359	-.182	-.149	-.252	.065	.308	.092
	12. Ethnicity	.143	-.256	.258	-.072	-.228	-.223	-.297	-.092	.151
	13. Income	.403	.331	-.781*	-.065	.291	.086	.231	.443	.146

Note: PKQ Change = Parent Knowledge Questionnaire change score; PAM Change = Parent Activation Measure change score; BPS Change = Being a Parent Scale change score; Sleep Change = Self Management Assessment sleep change score; Bx Change = Self Management Assessment behavior change score; Eat Change = Self Management Assessment eating change score; Toilet Change = Self Management Assessment toileting change score; School Change = Self Management Assessment school issues change score; ECBI Change = Eyberg Child Behavior Inventory change score; Mo. Education = Mother’s years of education; Fa. Education = Father’s years of education; Ethnicity = Race (Caucasian, African American, or Asian); Income = Total household income; * $p < .05$, ** $p < .01$

Figure 1: Relationship between Change in Number of Child Problem Behaviors on the ECBI and Change in Parent Competence on the BPS

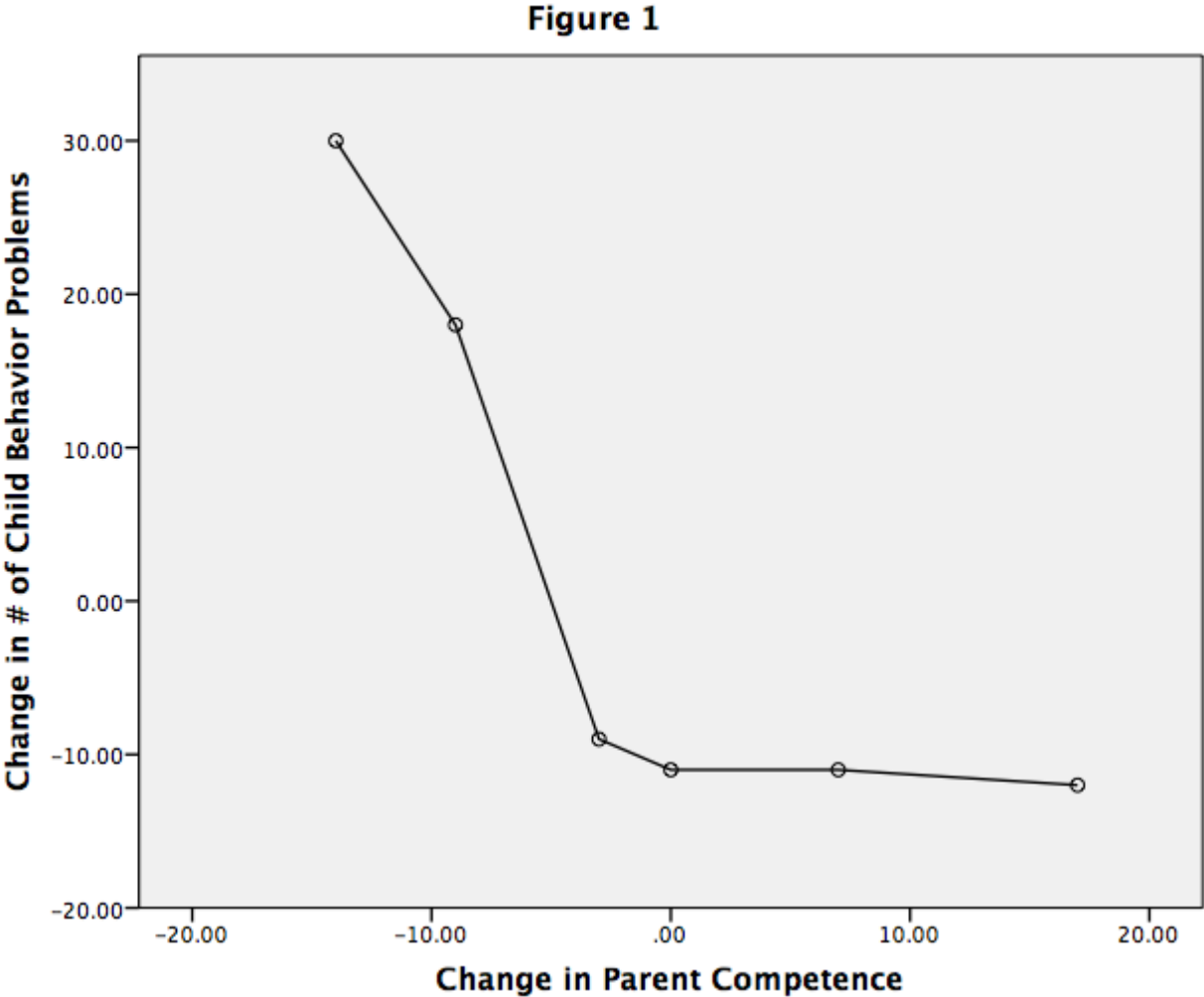
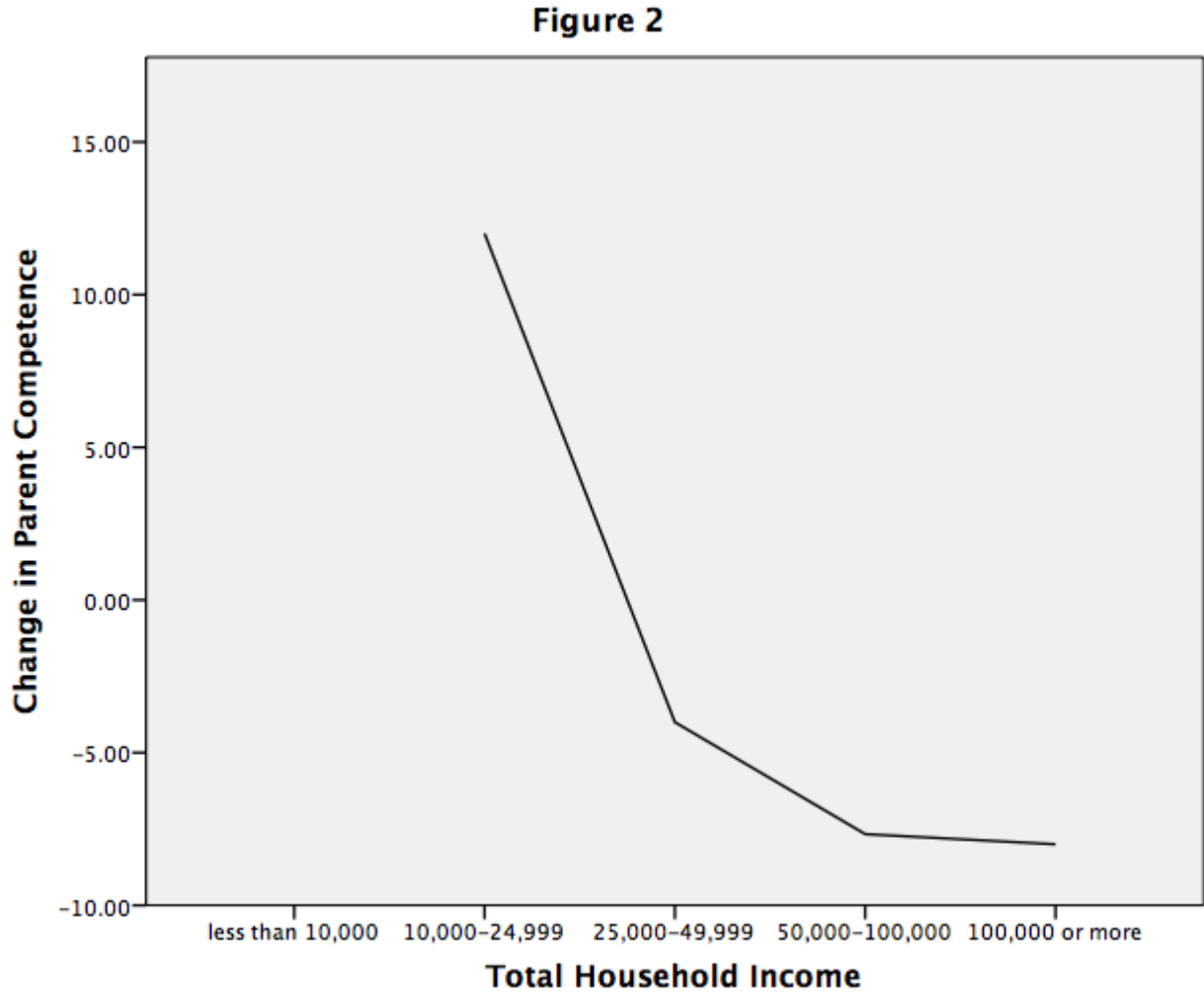


Figure 2: Relationship between Total Household Income and Change in Parent Competence on the BPS



Appendix A

Construct: Conduct Problems

Scale Name: Eyberg Child Behavior Inventory (ECBI)

Developers: Eyberg, S.

Items:

Below are a series of phrases that describe children's behavior. Please (1) circle the number describing how often the behavior currently occurs with your child, and (2) circle either "yes" or "no" to indicate whether the behavior is currently a problem.

How often does this occur with your child?

	Never	Seldom	Sometimes	Often	Always	Is this a problem for you?			
1. Dawdles in getting dressed	1	2	3	4	5	6	7	Yes	No
2. Dawdles or lingers at mealtime	1	2	3	4	5	6	7	Yes	No
3. Has poor table manners	1	2	3	4	5	6	7	Yes	No
4. Refuses to eat food presented	1	2	3	4	5	6	7	Yes	No
5. Refuses to do chores when asked	1	2	3	4	5	6	7	Yes	No
6. Slow in getting ready for bed	1	2	3	4	5	6	7	Yes	No
7. Refuses to go to bed on time	1	2	3	4	5	6	7	Yes	No
8. Does not obey house rules on own	1	2	3	4	5	6	7	Yes	No
9. Refuses to obey until threatened with punishment	1	2	3	4	5	6	7	Yes	No
10. Acts defiant when told to do something	1	2	3	4	5	6	7	Yes	No
11. Argues with parents about rules	1	2	3	4	5	6	7	Yes	No
12. Gets angry when doesn't get own way	1	2	3	4	5	6	7	Yes	No
13. Has temper tantrums	1	2	3	4	5	6	7	Yes	No
14. Sasses adults	1	2	3	4	5	6	7	Yes	No
15. Whines	1	2	3	4	5	6	7	Yes	No
16. Cries easily	1	2	3	4	5	6	7	Yes	No
17. Yells or screams	1	2	3	4	5	6	7	Yes	No
18. Hits parents	1	2	3	4	5	6	7	Yes	No
19. Destroys toys and other projects	1	2	3	4	5	6	7	Yes	No
20. Is careless with toys and other objects	1	2	3	4	5	6	7	Yes	No
21. Steals	1	2	3	4	5	6	7	Yes	No
22. Lies	1	2	3	4	5	6	7	Yes	No
23. Teases or provokes other children	1	2	3	4	5	6	7	Yes	No
24. Verbally fights with friends own age	1	2	3	4	5	6	7	Yes	No

25. Verbally fights with sisters and brothers	1	2	3	4	5	6	7	Yes	No
26. Physically fights with friends own age	1	2	3	4	5	6	7	Yes	No
27. Physically fights with sisters and brothers	1	2	3	4	5	6	7	Yes	No
28. Constantly seeks attention	1	2	3	4	5	6	7	Yes	No
29. Interrupts	1	2	3	4	5	6	7	Yes	No
30. Is easily distracted	1	2	3	4	5	6	7	Yes	No
31. Has short attention span	1	2	3	4	5	6	7	Yes	No
32. Fails to finish tasks or projects	1	2	3	4	5	6	7	Yes	No
33. Has difficulty entertaining self alone	1	2	3	4	5	6	7	Yes	No
34. Has difficulty concentrating on one thing	1	2	3	4	5	6	7	Yes	No
35. Is overactive or restless	1	2	3	4	5	6	7	Yes	No
36. Wets the bed	1	2	3	4	5	6	7	Yes	No

Appendix B

PARENT
ACTIVATION
MEASURE FOR
DEVELOPMENTAL
DISABILITIES

PAM13DD

INSTRUCTIONS

BELOW ARE SOME STATEMENTS THAT PEOPLE SOMETIMES MAKE WHEN THEY TALK ABOUT THEIR CHILD'S HEALTH. PLEASE INDICATE HOW MUCH YOU AGREE OR DISAGREE WITH EACH STATEMENT AS IT APPLIES TO YOU PERSONALLY BY CIRCLING YOUR ANSWER. *YOUR ANSWERS SHOULD BE WHAT IS TRUE FOR YOU AND NOT JUST WHAT YOU THINK THE DOCTOR WANTS YOU TO SAY.*

NOTE: IF THE STATEMENT DOES NOT APPLY TO YOU, CIRCLE N/A.

KEY

DS	DISAGREE STRONGLY
D	DISAGREE
A	AGREE
AS	AGREE STRONGLY
N/A	NOT APPLICABLE



1. I BELIEVE THAT I AM THE PERSON WHO IS RESPONSIBLE FOR TAKING CARE OF MY CHILD'S BEHAVIORAL AND DEVELOPMENTAL NEEDS.	DS	D	A	AS	N/A
2. TAKING AN ACTIVE ROLE IN MY CHILD'S BEHAVIORAL AND DEVELOPMENTAL CARE IS THE MOST IMPORTANT THING THAT AFFECTS HIS/HER DEVELOPMENTAL OUTCOMES.	DS	D	A	AS	N/A
3. I AM CONFIDENT I CAN PREVENT OR REDUCE PROBLEMS ASSOCIATED WITH MY CHILD'S BEHAVIOR AND DEVELOPMENT.	DS	D	A	AS	N/A
4. I KNOW WHAT EACH OF MY CHILD'S MEDICATIONS ARE FOR.	DS	D	A	AS	N/A
5. I AM CONFIDENT THAT I CAN TELL WHEN I NEED TO GET SERVICES FOR MY CHILD AND WHEN I CAN HANDLE MY CHILD'S BEHAVIOR AND DEVELOPMENT CONCERNS MYSELF.	DS	D	A	AS	N/A
6. I AM CONFIDENT I CAN TELL MY SERVICE PROVIDER CONCERNS I HAVE ABOUT MY CHILD, EVEN WHEN HE OR SHE DOES NOT ASK.	DS	D	A	AS	N/A
7. I AM CONFIDENT THAT I CAN FOLLOW THROUGH ON BEHAVIORAL AND DEVELOPMENTAL TREATMENTS I NEED TO DO FOR MY CHILD AT HOME.	DS	D	A	AS	N/A
8. I UNDERSTAND THE NATURE AND POSSIBLE CAUSES OF MY CHILD'S BEHAVIOR OR DEVELOPMENTAL CONCERNS.	DS	D	A	AS	N/A
9. I KNOW WHAT TREATMENTS ARE AVAILABLE FOR MY CHILD'S BEHAVIOR AND DEVELOPMENT.	DS	D	AS	AS	N/A
10. I HAVE BEEN ABLE TO IMPLEMENT RECOMMENDATIONS TO HELP MY CHILD MAINTAIN BEHAVIORAL AND DEVELOPMENTAL SKILLS.	DS	D	A	AS	N/A
11. I KNOW HOW TO PREVENT PROBLEMS WITH MY CHILD'S BEHAVIOR.	DS	D	A	AS	N/A
12. I AM CONFIDENT I CAN FIGURE OUT SOLUTIONS WHEN NEW SITUATIONS ARISE WITH MY CHILD'S BEHAVIOR AND DEVELOPMENT	DS	D	A	AS	N/A
13. I AM CONFIDENT I CAN HELP MY CHILD MAINTAIN CHANGES (PROGRESS), EVEN DURING TIMES OF STRESS.	DS	D	A	AS	N/A



Appendix C

Division of Developmental and Behavioral Pediatrics (DDBP)

SELF-MANAGEMENT ASSESSMENT

1. What concerns you most about your child?

2. In general, how do you feel you/your child is doing?

3. How do concerns about yourself/your child affect your life / family?

4. On a scale of 0-10, how certain are you that you can MANAGE you/your child's: (Please choose only those that apply)
0=Not managing at all 10=Managing well
 - Sleep 0 1 2 3 4 5 6 7 8 9 10
 - Behavior 0 1 2 3 4 5 6 7 8 9 10
 - Eating 0 1 2 3 4 5 6 7 8 9 10
 - Toileting 0 1 2 3 4 5 6 7 8 9 10
 - School Issues 0 1 2 3 4 5 6 7 8 9 10

5. Are there things going on at home that affect your ability to care for yourself or your child?

6. What if any questions or concerns do you have about your child's therapies or treatments?

Appendix D

ID: _____ Date: _____

On this questionnaire are 16 items relating to your feelings about being a parent. Please read each item carefully and rate whether you feel it applies to you, by circling a number from 1 (strongly agree) to 6 (strongly disagree) on the scale.

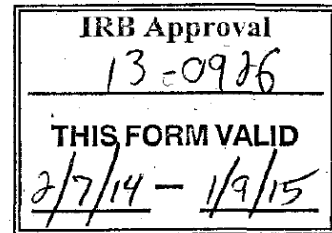
The rating scale is as follows:

- 1 Strongly agree
- 2 Agree
- 3 Mildly agree
- 4 Mildly disagree
- 5 Disagree
- 6 Strongly disagree

- | | |
|---|-------------|
| 1. The problems of taking care of a child are easy to solve once you know how your actions affect your child, an understanding I have acquired. | 1 2 3 4 5 6 |
| 2. Even though being a parent could be rewarding, I am frustrated now while my child is at his/her present age. | 1 2 3 4 5 6 |
| 3. I go to bed the same way I wake up in the morning – feeling I have not accomplished a whole lot. | 1 2 3 4 5 6 |
| 4. I do not know what it is, but sometimes when I'm supposed to be in control, I feel more like the one being manipulated. | 1 2 3 4 5 6 |
| 5. My mother/father was better prepared to be a good mother/father than I am. | 1 2 3 4 5 6 |
| 6. I would make a fine model for a new mother/father to follow in order to learn what she/he would need to know in order to be a good parent. | 1 2 3 4 5 6 |
| 7. Being a parent is manageable, and any problems are easily solved. | 1 2 3 4 5 6 |
| 8. A difficult problem in being a parent is not knowing whether you're doing a good job or a bad one. | 1 2 3 4 5 6 |
| 9. Sometimes I feel like I'm not getting anything done. | 1 2 3 4 5 6 |

- | | |
|--|-------------|
| 10. I meet my own personal expectations for expertise in caring for my child. | 1 2 3 4 5 6 |
| 11. If anyone can find the answer to what is troubling my child, I am the one. | 1 2 3 4 5 6 |
| 12. My talents and interests are in other areas, not in being a parent. | 1 2 3 4 5 6 |
| 13. Considering how long I've been a mother/father, I feel thoroughly familiar with this role. | 1 2 3 4 5 6 |
| 14. If being a mother/father of a child were only more interesting, I would be motivated to do a better job as a parent. | 1 2 3 4 5 6 |
| 15. I honestly believe I have all the skills necessary to be a good mother/father to my child. | 1 2 3 4 5 6 |
| 16. Being a parent makes me tense and anxious. | 1 2 3 4 5 6 |

Appendix F



Consent to Participate in a Research Study

Autism Spectrum Disorder Family Support Project – Wave 2

WHY ARE YOU BEING INVITED TO TAKE PART IN THIS RESEARCH?

You are being invited to take part in a research study about how to best help families support families in the interactions they have with their child with autism spectrum disorder. You are being invited to take part in this research study because you have a child with an autism spectrum disorder. If you volunteer to take part in this study, you will be one of about 180 people to do so in central and eastern Kentucky.

WHO IS DOING THE STUDY?

The person in charge of this study is Dr. Jeff Reese of University of Kentucky Department of Educational, School, and Counseling Psychology. There may be other people on the research team assisting at different times during the study.

WHAT IS THE PURPOSE OF THIS STUDY?

Children with autism spectrum disorders don't often respond like other children when learning how to interact with others, talk, and respond. The purpose of this project is to test a method for helping parents understand their child's behavior and how to best teach them and respond to them when there are behaviors of concern or safety.

By doing this study, we hope to learn ways to help parents feel less stress and better about how to help their child with autism spectrum disorder learn to do things using face-to-face meetings or web-based meetings.

ARE THERE REASONS WHY YOU SHOULD NOT TAKE PART IN THIS STUDY?

Parents who are unable to complete all study tasks, plan to move within six months, or will not agree to the activities based on group assignment will not be asked to participate. Also, each parent must be age 18 or older to participate.

WHERE IS THE STUDY GOING TO TAKE PLACE AND HOW LONG WILL IT LAST?

The research procedures will be conducted at the University of Kentucky's CASPER clinic or the University of Louisville Autism Center. You will need to come to the clinic closest to you for a total of 10 meetings. Each of those visits will take about 1.5 to 2 hours. The total amount of time you will be asked to volunteer for this study is will be between 14 and 20 hours over the next three months.

WHAT WILL YOU BE ASKED TO DO?

The table below outlines all study activities. First, you and your child will complete a baseline assessment. Your child will participate in activities with the researcher. The activities will be similar to those provided in school, but also include assessment of his / her autism severity and social communication skills. The assessment will be video recorded to better understand your child's behavior. You will be asked to complete forms about your child's



adaptive skills, behavioral concerns, stress, and competence in parenting your child. Then you will be either assigned to a group that receives parent training or a group that does not receive the training immediately. For those who receive the training immediately, they will be randomly assigned to receive the training using a videoconferencing format or an in-person format. If you are in the group that does not receive the training immediately, you will be asked to wait for three months and then complete the initial baseline assessment again. After the initial baseline assessment, you will be randomized to attend four group sessions with other parents in either a videoconferencing or in-person format. We expect that five parents will be in each group. Each session will last about 2 hours and will focus on understanding autism, how autism affects your child, the basics of behavior management, how to prevent problem behaviors, how to respond to problem behaviors, and how to develop and implement a plan for behavior and learning. After the group sessions, we will have three more sessions that will focus on your child's plan and his / her success. The last visit will repeat what was done during the baseline assessment occurred at the first session.

#	Format	Activities	Anticipated Time
1	Individual	Conduct baseline assessment; Identify parents' top concerns	90 – 120 min
2	Group	Review of autism; effects of autism on behavior and the family; Basics of behavior management	120 min
3	Group	Understanding your child's behavior	120 min
4	Group	Preventing problem behaviors	120 min
5	Group	Intervening when problem behavior occurs	120 min
6	Individual	Review individual plan; make adjustments	60 min
7	Individual	Review progress; make adjustments to plan	60 min
8	Individual	Conduct final assessment of progress	120 min

To decide if you will start the sessions immediately, or be delayed by three months, randomization will occur. Randomization is like tossing a coin. We will randomly assign you to one of the two groups. You will have a 50:50 chance of getting into one of the two groups.

WHAT ARE THE POSSIBLE RISKS AND DISCOMFORTS?

To the best of our knowledge, the things you will be doing have no more risk of harm than you would experience in everyday life.

The investigators, Ruble & Kuravackel, have worked with children with autism for more than 50 years combined, including children with autism with severe problem behaviors. The assessments provided are standard assessments used during psychological testing. We will set up positive work-reward routines to keep your child interested. If your child begins to show disruptive behaviors (pushing away materials, running away), we will increase our use of positive reinforcers. But if the child continues to protest, we will stop testing. For you, it is possible you will find some questions we ask you to be upsetting or stressful. We will review with you as part of the informed consent procedures, your right to refuse to answer any questions as well as your right to withdraw from study participation. Your child may become fatigued or distressed during the evaluation. If your child becomes distressed, testing will stop. In order to reduce the likelihood of stress for your child, the researcher will use strategies to motivate your child to complete tasks and help children understand that they can take breaks.

WILL YOU BENEFIT FROM TAKING PART IN THIS STUDY?

There is no guarantee that you or your child will get any benefit from taking part in this study. However, participating parents will develop a specific plan for their child and a written summary of the plan. We cannot and do not guarantee that you or your child will receive any personal benefits from taking part in this study. You and your child's willingness to take part, however, may, in the future, help society as a whole better understand this research topic.



DO YOU HAVE TO TAKE PART IN THE STUDY?

If you decide to take part in the study, it should be because you really want to volunteer. Neither you nor your child will lose any benefits or rights you would normally have if you choose not to volunteer. You and your child can stop at any time during the study and still keep the benefits and rights you had before volunteering. If you or your child decide not to take part in this study, this decision will have no effect on the quality of care and services that you and your child will receive.

IF YOU DON'T WANT TO TAKE PART IN THE STUDY, ARE THERE OTHER CHOICES?

If you do not want to be in the study, there are no other choices except not to take part in the study. However, you can still receive services as usual from the clinic.

WHAT WILL IT COST YOU TO PARTICIPATE?

The only foreseeable cost to you may be in travel expenses to the clinic.

WILL YOU RECEIVE ANY REWARDS FOR TAKING PART IN THIS STUDY?

You will receive \$100 for taking part in this study. If you should have to quit before the study is through, the payment you receive will be based on the amount of time you were in the study.

WHO WILL SEE THE INFORMATION THAT YOU GIVE?

Your information will be combined with information from other people taking part in the study. When we write about the study to share it with other researchers, we will write about the combined information we have gathered. You will not be identified in these written materials. We may publish the results of this study; however, we will keep your name and other identifying information private.

We will keep private all research records that identify you to the extent allowed by law. However, there are some circumstances in which we may have to show your information to other people. For example, the law may require us to show your information to a court or to tell authorities if we believe you have abused a child or are a danger to yourself or someone else. Also, we may be required to show information which identifies you to people who need to be sure we have done the research correctly; these would be people from such organizations as the University of Kentucky.

We will make every effort to prevent anyone who is not on the research team from knowing that you gave us information, or what that information is. For example, your name will be kept separate from the information you give, and these two things will be stored in different places under lock and key.

CAN YOUR TAKING PART IN THE STUDY END EARLY?

If you decide to take part in the study you still have the right to decide at any time that you no longer want to continue. You will not be treated differently if you decide to stop taking part in the study and you can continue to receive services at the clinic where you sought services.

The individuals conducting the study may need to withdraw you from the study. This may occur if you are not able to follow the directions they give you, if they find that your being in the study is more risk than benefit to you, or if the agency funding the study decides to stop the study early for a variety of scientific reasons. In such a case, reimbursement will be based on portion of the study completed.

WHAT ELSE DO YOU NEED TO KNOW?

This is a collaborative project between the University of Kentucky and the University of Louisville. Both universities are providing financial support and/or material for this study.



WHAT IF YOU HAVE QUESTIONS, SUGGESTIONS, CONCERNS, OR COMPLAINTS?

Before you decide whether to accept this invitation to take part in the study, please ask any questions that might come to mind now. Later, if you have questions, suggestions, concerns, or complaints about the study, you can contact the investigator, Jeff Reese at (859) 257-4909. If you have any questions about your rights as a volunteer in this research, contact the staff in the Office of Research Integrity at the University of Kentucky at 859-257-9428 or toll free at 1-866-400-9428. If you agree to participate, you will sign this form and a copy will be provided to you for your records.

Signature of person agreeing to take part in the study

Date

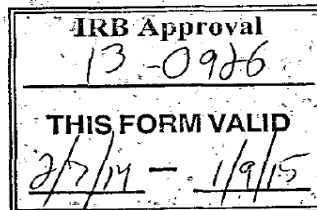
Printed name of person agreeing to take part in the study

Name of (authorized) person obtaining informed consent

Date

Appendix G

F2.0200



ASSENT FORM

Autism Spectrum Disorder Family Support Project

You are invited to be in a research study being done by Drs. Jeff Reese, Grace Kuravackel, and Lisa Ruble from the University of Kentucky and University of Louisville.

If you agree to be in the study, you will be asked to play some games with the researcher and answer questions that might be like school. You will come 1 time to see the researcher.

Your family will know that you are in the study. If anyone else is given information about you, they will not know your name. A number or initials will be used instead of your name.

If something makes you feel bad while you are in the study, please tell Ms. Lisa or Ms. Grace. If you decide at any time you do not want to finish the study, you may stop whenever you want.

You can ask Ms. Lisa or Ms. Grace questions any time about anything in this study. You can also ask your parent any questions you might have about this study.

(If child has the ability to respond) Do you want to take part in the research study?

Name of Person Obtaining Informed Assent

Date

Appendix H



Division of Scholarly Integrity and
Research Compliance
Institutional Review Board
North End Center, Suite 4120 (MC 0497)
300 Turner Street NW
Blacksburg, Virginia 24061
540/231-3732
irb@vt.edu
<http://www.research.vt.edu/sirc/hrpp>

MEMORANDUM

DATE: February 28, 2019
TO: Angela Scarpa-Friedman, Angela Verma Dahiya-Singh
FROM: Virginia Tech Institutional Review Board (FWA00000572, expires January 29, 2021)
PROTOCOL TITLE: Efficacy of a Telehealth-Based Parent Training for Children with Autism Spectrum Disorder: Rural versus Urban Areas
IRB NUMBER: 19-146

Based on the submitted project description and items listed in the Special Instructions section found on Page 2, the Virginia Tech IRB has determined that the proposed activity is not research involving human subjects as defined by HHS and FDA regulations.

Further review and approval by the Virginia Tech HRPP is not required because this is not human research. This determination applies only to the activities described in the submitted project description and does not apply should any changes be made. If changes are made you must immediately submit an Amendment to the HRPP for a new determination. Your amendment must include a description of the changes and you must upload all revised documents. At that time, the HRPP will review the submission activities to confirm the original "Not Human Subjects Research" decision or to advise if a new application must be made.

If there are additional undisclosed components that you feel merit a change in this initial determination, please contact our office for a consultation.

Please be aware that receiving a "Not Human Subjects Research" Determination is not the same as IRB review and approval of the activity. You are NOT to use IRB consent forms or templates for these activities. If you have any questions, please contact the Virginia Tech HRPP office at 540-231-3732 or irb@vt.edu.

PROTOCOL INFORMATION:

Determined As: **Not Human Subjects Research**
Protocol Determination Date: **February 28, 2019**

ASSOCIATED FUNDING:

The table on the following page indicates whether grant proposals are related to this protocol, and which of the listed proposals, if any, have been compared to this protocol, if required.

Invent the Future

VIRGINIA POLYTECHNIC INSTITUTE AND STATE UNIVERSITY
An equal opportunity, affirmative action institution