

**Comprehensive Final Report
Maternal and Child Health Research**

**“Telehealth Delivery of a Family-Focused Intervention to Reduce Anxiety in Youth with
Autism Spectrum Disorders in Rural Colorado”**

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I. INTRODUCTION

A. Nature of the Research Problem

Persons with Autism Spectrum Disorders (ASD) are underserved in several aspects of health care (Krauss et al, 2003; Liptak et al, 2008). Families living in rural areas experience even more significant obstacles to appropriate treatment, particularly for mental health concerns (Boydell et al, 2006). Clinically significant internalizing disorders are common and debilitating for youth with ASD and these conditions tend to get worse if untreated (Myers & Johnson, 2007). Psychiatric comorbidity is associated with poorer youth and family outcomes (Kendall et al, 2001). Fortunately, evidence is building for the efficacy of modified cognitive-behavioral interventions to reduce anxiety in youth with ASD (Lang et al, 2010; Reaven et al, 2011). A natural next step is to develop, refine, and evaluate telehealth delivery of these evidence-based interventions in an effort to improve access to care for people with ASD and their families, particularly for those who live far from specialty medical centers.

B. Purpose, Scope, and Methods of Investigation

The goals of the "TeleCopes Project" are to develop, pilot, refine and evaluate the feasibility and potential efficacy of using a commercially-available videoconferencing program to connect families of psychiatrically complex youth with ASD, living in rural Colorado, with clinical psychologists who specialize in treatment of anxiety and coping problems in youth with ASD. The purpose of this project is to complete the tasks necessary to pursue a randomized controlled trial of the intervention. The project was conducted in two phases: (1) Development and (2) Evaluation.

The *Development Phase* involved the following steps: (1) explore technological options for delivering psychosocial treatment from clinics-to-homes; (2) consider ethical issues and input from expert clinicians; (3) conduct focus groups with rural families with ASD; (4) make decisions about technology and create technical supports; (5) help clinicians to adjust to new mode of communicating; (6) find ways to build therapeutic alliance with complex youth via video-conferencing; (7) adapt our manualized intervention for telehealth delivery; (8) deliver the intervention in various formats to pilot families; (9) reflect, revise, and try again. Qualitative methods were used during the Development Phase, with some piloting of quantitative measures to inform the assessment process.

During the *Evaluation Phase*, we used a multi-method assessment strategy to assess processes and outcomes. Parent/child pairs from rural Colorado participated in a 10-session treatment course of "Facing Your Fears" (Reaven et al, 2011), delivered via videoconferencing in either 1-family, 2-family, or 4-family groups, based upon family preferences and developmental matching of youth participants. Participating youth and parents completed process and outcome measures before, during, and after treatment through the RedCap database, which enables online, confidential data collection. Therapists completed session ratings and semi-structured interviews to inform the feasibility and acceptability of the delivery model. All treatment sessions were filmed and are being coded for active engagement of child participants and demonstration of targeted strategies using the Noldus Behavioral Coding System¹.

C. Nature of the Findings

Findings from this study are clustered into two categories: *Process Variables* (e.g., credibility, acceptability, feasibility) of telehealth delivery of the intervention and *Outcome Variables* (e.g., youth anxiety symptoms (severity, pervasiveness, interference), impact of youth's mental health challenges on family functioning, and parenting sense of competence in the parenting role.) Study findings are relevant for telehealth clinical practice guidelines, enhanced manualization for dissemination efforts, and preparation for conducting a randomized clinical trial of telehealth delivery of psychosocial intervention for families of complex youth with ASD and mental health concerns.

¹ Behavioral coding is ongoing.

II. REVIEW OF THE LITERATURE

Persons with Autism Spectrum Disorders (ASD) are an underserved population in several aspects of health care, including general preventative care (Liptak et al., 2008), specialized medical care (Kraus et al., 2003), and mental health services (Mandell et al., 2005). Cost-effective service delivery models are greatly needed (Jacobson & Mulick, 2000; Myers & Johnson, 2007). There is a particular need to modify the delivery methods of evidence-based mental health interventions in order to improve service utilization by underserved populations (Feil et al., 2008; Hollon et al., 2002), such as youth with ASD.

Families of children with ASD in rural areas experience even more significant obstacles to health care, particularly in access to mental health services (Chen, Liu, Su, Huang, & Lin, 2008). Few specialists practice in remote areas, and those who do report feeling isolated and limited in ongoing professional developmental opportunities (Symon, 2001). Services are more difficult to obtain and coordinate in rural areas (Boydell et al., 2006), and wait periods for mental health treatment are often exceedingly long (Owens et al., 2002).

The high prevalence of psychiatric comorbidities in persons with ASD poses significant challenges to families, health care providers, and systems of care. Untreated co-occurring conditions, such as anxiety and mood disorders, are associated with a number of negative outcomes for the person with ASD and for family members (Borthwick-Duffy & Eyman, 1990; Kendall, Brady, & Verduin, 2001). A limited repertoire of coping strategies and a lack of social support contribute to increased caregiver strain (Magliano et al., 1998). Without opportunities for parent education, coaching, and social connection, parents in rural areas are, therefore, at increased risk for experiencing significant caregiver strain.

Fortunately, evidence-based, family-focused treatments targeting mental health concerns in youth with ASD are available for implementation by skilled clinicians. The success of anxiety treatments for children with ASD has been demonstrated (see Lang, Regester, Lauderdale, Ashbaugh, & Haring, 2010, for a recent review) using both a group format (Chalfant, Rapee & Carroll, 2007; Reaven et al., 2011) and individual therapy modalities (Wood et al., 2009). Clinical researchers can now turn to investigating effective methods of disseminating these evidence-based interventions to underserved populations.

Telehealth delivery has the potential to be a cost-effective approach to disseminating specialized mental health intervention to underserved families, particularly those in rural areas. Specifically, inexpensive, commercially available videoconferencing platforms now allow for both synchronous (i.e., real-time) and asynchronous (i.e., recorded) clinician-patient interactions through the use of web cameras on personal computers. This technology has been used successfully in providing mental health services to youth in rural areas with a range of complex psychiatric issues (Nelson & Palsbo, 2006; Pesamaa et al., 2004 for review).

Only a few recent studies of the efficacy of videoconferencing to support intervention for persons with ASD are present in the literature, and none of these are focused on delivering mental health care specifically (see Boisvert et al., 2010 for review). None of these studies have examined the clinical utility of connecting clinicians to family homes to deliver psychosocial intervention, and none have used inexpensive, off-the-shelf videoconferencing platforms in their studies. With the long-term goal of developing a sustainable and ecologically valid strategy for improving access to mental health care, studies of home-to-clinic telehealth applications that do not require specialized equipment and extensive technical knowledge are needed.

III. STUDY DESIGN AND METHODS

A. *Study Design*

This is a quasi-experimental development and feasibility study that includes a multi-method assessment strategy of both process and outcome variables. Process variables were measured across treatment and included assessments of credibility (e.g., parent and youth perception of potential of intervention), acceptability (e.g., parent, youth and therapist satisfaction), and feasibility (e.g., log of technical difficulties, attendance, treatment completion, behavioral coding of child

engagement in sessions, parent adherence to treatment recommendations, therapist ratings of session quality, youth and parent perception of quality of therapeutic alliance). Youth and family outcome variables were assessed before and after treatment, and included parent report of the youth's anxiety symptoms and fears, youth self-report of anxiety and fears, parent self-report of perceived competence as a parent, and parent report of youth impact on the family. Qualitative data were also collected through in-depth exit interviews with all participants.

B. Population Studied

This study is focused on rural youth with ASD and co-occurring anxiety disorders and their parents.

C. Sample Selection

Participants were recruited through outreach efforts led by the project's Parent Liaison and the PI. We partnered with parent leaders from rural areas of the state and they contacted families, professionals and persons with ASD in their area who were interested in sharing their perspectives with our team. We conducted 7 focus group meetings in Year 1, the results of which are discussed in Kaiser's (2011) article for *Exceptional Parent* magazine. Consistently, parents and providers requested that we broaden our use of technology beyond the delivery of intervention and consider delivering workshops and/or webinars to educators, families, and professionals around the state. With our project's focus on helping families to coach youth with ASD and mental health concerns to cope better, we developed several presentations on promoting effective coping for a variety of audiences. Over the 2-year project period, we delivered 4 webinars, 16 full-day workshops, and 8 2-hour presentations for families, educators and providers in rural Colorado. Content from these trainings is now available on our websites (www.telecopes.org and www.facingfears.org). Approximately 1200 individuals attended one or more of these community education offerings. These outreach efforts built awareness for the project and all participant recruitment was completed by the 9th month of the project.

Participant Characteristics

During the *Development Phase* ($n=42$), 28 adults (21 parents of persons with ASD and 7 self-advocates with ASD) participated in focus groups and provided qualitative feedback regarding needs, barriers, and resources in their rural communities. Twelve school-aged children (with ASD and anxiety) and their mothers participated in pilot versions of the TeleCopes intervention and provided qualitative feedback that informed program revisions. Thus, a total of 30 adults and 12 children participated in the Development Phase. All participants lived 1.5 hours or more from specialty medical centers, 68% resided in rural Colorado and 32% in frontier areas of Colorado. The sample was 88% Caucasian, 8% African-American, 4% Biracial. Sixteen percent of the sample was Hispanic/Latino. Median education level was "some college", with an equal number of adults completing graduate school as those who completed high school only. Overall, the sample could be described as middle class. Notably, 4 of 30 participating adults and 1 of the youth were (or had been) homeless for at least 9 months.

During the *Evaluation Phase* ($n=40$), twenty parent/child pairs were enrolled and completed pre-treatment qualification and baseline measures. All enrolled youth (ages 7-18 years) had a confirmed diagnosis of ASD and exceeded risk cutoffs for one or more anxiety disorders on the Screening for Anxiety and Emotion-Related Disorders (SCARED). In an effort to improve accessibility for families of less verbal youth, we piloted a "minimally verbal" version of the intervention with 4 families, the remaining 16 youth were verbally fluent. Fifteen of the youth were attending school and 5 were being educated on "home-bound" programs, due to the severity of their co-occurring autism and mental health symptoms. All participants lived 2.5 hours or more from specialty medical centers, with 72% residing in rural Colorado and 28% in frontier regions of the state. Approximately 90% of participants were Caucasian, 8% were African-American, and 2% were Asian. Ten percent were Hispanic/Latino. Eighteen parent/child pairs completed 10 sessions

of "Facing Your Fears", delivered via videoconferencing. Two parent/child pairs withdrew from treatment, due to the severity of their mental health conditions, and study staff assisted in obtaining in-patient crisis services for both families in Denver.

D. Instruments Used

Demographic Variables

Family Questionnaire (Wehner, 1999; Revised, 2007)

Confirmation of ASD

Social Responsiveness Scale (SRS; Constantino, 2002)

Copy of clinical evaluation and/or *Autism Diagnostic Observation Schedule* (ADOS, Lord et al, 1999)

Process Variables

Credibility Scale (Borkovec & Nau, 1972)

Therapeutic Alliance Scale for Children & Teens – Revised (TASC-R; Shirk & Saiz, 1992)

FYF Satisfaction Scale (Reaven & Blakeley-Smith, 2009)

FYF Fidelity Checklist (Reaven & Blakeley-Smith, 2010)

Outcome Variables:

The Family Impact Questionnaire (FIQ; Donenberg & Baker, 1993)

Parenting Sense of Competence Scale (PSOC; Johnston & Mash, 1989)

Screen for Anxiety Related Emotional Disorders in Children (SCARED, Birmaher et al. 1999)

Fears Survey Scale for Children (FSSQ; Ollendick et al, 1998).

E. Statistical Techniques Employed

One of the primary aims of this proposal involves examining the feasibility and acceptability of the intervention, gathering process data from a variety of sources in order to inform the development of telehealth delivery of this mental health intervention. For these research questions, there are no planned statistical tests; rather data analysis involves examining rates and percentages of variables. Qualitative information gathered in focus groups and exit interviews with therapy participants and therapists are being analyzed using thematic abstraction techniques. Changes in outcome measures (for the youth and the family) were analyzed using paired t-tests (or an exact permutation Wilcoxon rank test, as is appropriate for the data). Comparisons between intervention delivery methods (i.e., Live vs Telehealth) were examined using a repeated measures ANOVA. For all statistical tests described here, the results need to be considered in light of the very small sample size.

IV. DETAILED FINDINGS

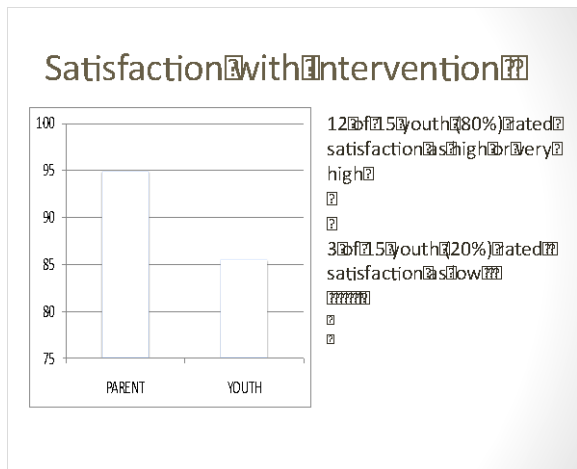
Process Variables

Participation. During the 2-year project period, 4 clinicians delivered 326 intervention sessions to 32 parent-youth pairs from rural Colorado. Twelve families participated in piloting efforts and 20 were enrolled in the efficacy trial. Approximately 40% of families participated in individual sessions (1 family X 1 clinician); the majority participated in multi-family sessions (2-4 families X 1-2 clinicians). Duration of sessions ranged from 29 minutes to 1 hour and 35 minutes, with a mean of 33 minutes per session for youth and 58 minutes for parents. Families participated in 6-14 sessions, depending upon their enrollment status (i.e., Phase I or Phase II). The finalized manualized version of the TeleCopes Intervention (which was provided to all participants in Phase II) is 10 sessions. The waitlist for intervention continues to build for the project.

Attrition. Of the 32 participating families, 2 did not complete the intervention. One dropped out prior to starting treatment, due to the parent's concerns about their son's motivation to participate and the other participated in 2 group sessions prior to requiring hospitalization for an acute psychological crisis. Study clinicians assisted in the referral for inpatient services and provided follow-up with the mother via videoconferencing for approximately three months after the youth was hospitalized. Total attrition is estimated at 6.25%, which is slightly lower than we have observed in our live intervention groups (9.8%).

Credibility. Parent and youth perception of credibility of the TeleCopes Project was high, both before and after treatment. Upon completion of the program, 92% of parents stated they would recommend the program to another family. None of the participating parents reported concerns about the security of the telehealth sessions and all 32 parents identified the potential of telehealth delivery as "better than current available options for local services".

Satisfaction. Parent satisfaction ratings with treatment were very high. See Figure A.



Two-thirds of school-aged children reported high satisfaction with the telehealth intervention, as did half of participating teens. Lower satisfaction ratings reported by teens is consistent with our experiences facilitating live groups, and our team is exploring novel ways to engage adolescents in therapeutic dialogue in ways they may find more satisfying.

Figure A

Therapeutic Alliance. Youth ratings of therapeutic alliance were moderate-strong, similar to results obtained in "live" groups. This was consistent across intervention formats (individual vs. group) and age of the participating youth. See Figure B.



Given that the quality of the therapeutic alliance is thought to be essential for effective psychosocial intervention (Chu & Kendall, 2006), these results provide support for the feasibility and potential efficacy of using videoconferencing to deliver treatment to youth with ASD.

Figure B

Youth Engagement in Sessions. Although the behavioral coding of child engagement in sessions is ongoing, the available data suggest active engagement in session activities is similar to what we have observed in live group sessions. Figures C & D (below) depict the exhibition of appropriate/on-task comments made by school-aged boys with ASD and anxiety during a 4-family TeleCopes group.

"Appropriate comments" was defined as a statement or question that indicates an attempt to engage with the therapist, parent, or other youth on the intervention topic that is being discussed in group. Verbalizations not related to therapeutic content are not counted here. Verbalizations may be initiated by the youth or may be a response to a direct question from a therapist or other group member. The goal of 10 statements per child per session was based upon analysis of videotaped sessions of live groups facilitated previously at our center. All 4 participants met this goal for 85% or more sessions.

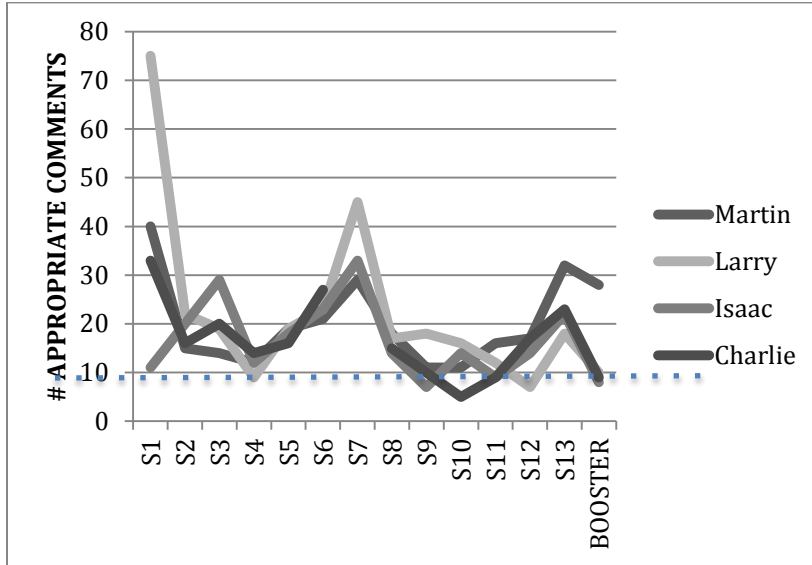


Figure C

Percent of time engaged in therapy sessions was calculated by coding the amount of time each youth was actively engaged in session activities, as evidenced by: verbalizing about session content, sharing information with other participants, and/or focusing attention on completing activities with a parent during session time. Time spent listening to therapists or other participants was not counted as engagement, even though the youth may have been attending - we found this was too difficult to code reliably. The goal of 30% active engagement was derived from tapes coded of live therapy sessions.

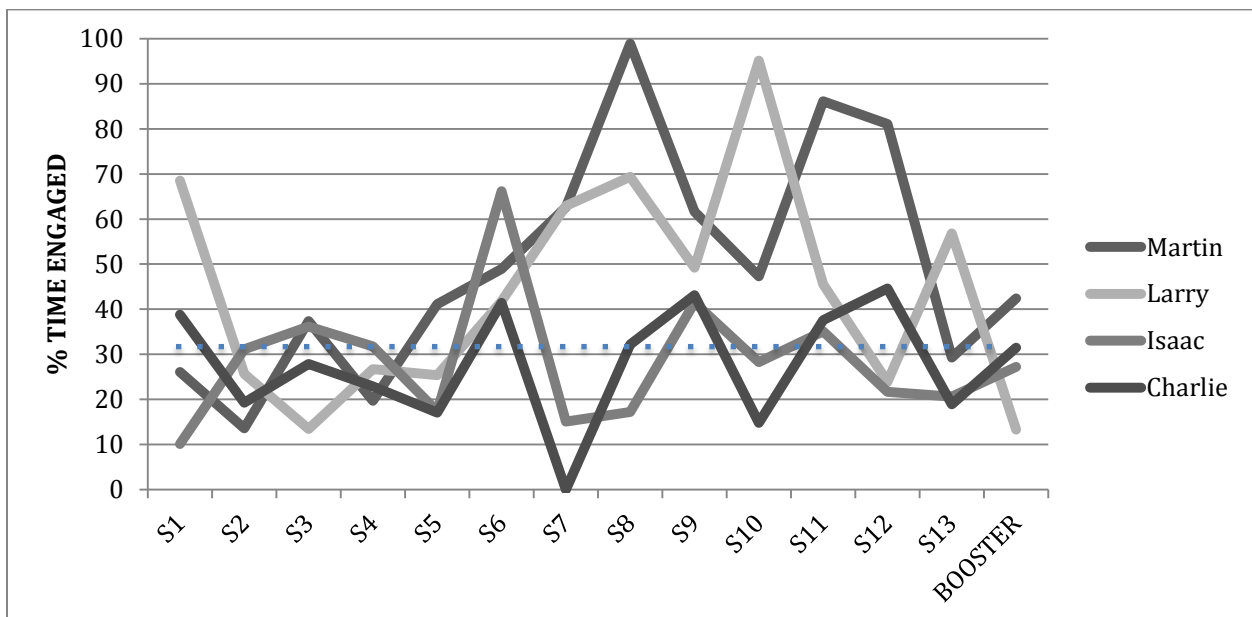


Figure D

The youth varied in participation and preliminary analyses suggest that active engagement as coded here was not associated with magnitude of treatment response in this 4-person group. Notably, sessions with the highest youth engagement scores were: (1) free of technical glitches; and (2) during the second half of treatment, which includes more child-specific activities instead of broad psychoeducational content. All data need to be coded in order to more clearly understand the possible factors that influence active youth engagement in telehealth intervention; however, these preliminary results are encouraging, as they suggest that youth attend to the content at similar rates via telehealth as they do in live sessions.

Technical Difficulties. Therapists provided subjective ratings of the interference of technological factors on session quality for every session they facilitated using a likert scale of 1 (quality of interactions not at all adversely affected by technological issues) to 3 (quality of interactions substantially affected by technological problems). See Figures E-G (below).

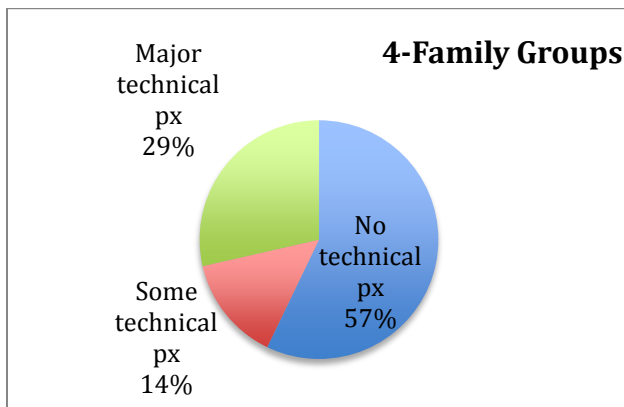


Figure E

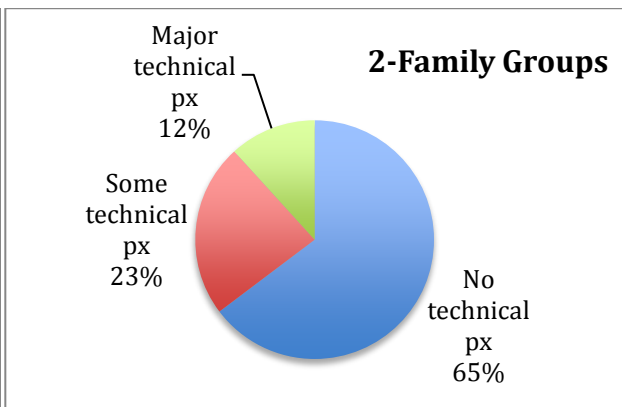


Figure F

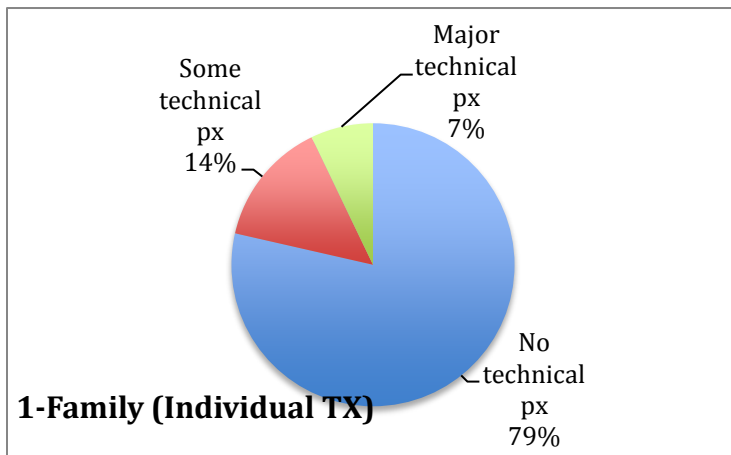


Figure G

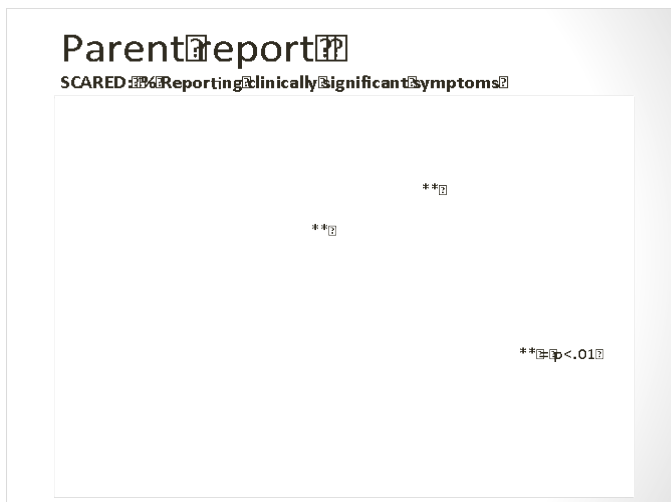
Therapist Ratings were consistently high for most 1:1 and 2:1 delivery formats, with less satisfaction reported for 4-family groups (due, primarily, to connectivity problems associated with bandwidth burden across simultaneous users). Session quality tended to improve over time. There was a 70% chance of technical problems adversely impacting the first 2 sessions and only a 30% of technical glitches impacting the last 2 sessions. Technical support was essential in improving session quality.

Outcome Variables.

Youth Anxiety Symptoms. The SCARED was used as the primary measure of youth anxiety and includes both parent and child self-report. Higher scores indicate more anxiety symptoms. The SCARED provides subscales for generalized anxiety, separation anxiety and social phobia, as well as a total score. A total score exceeding 25 indicates that the youth is at significant risk for an anxiety disorder and further evaluation and/or intervention is recommended.

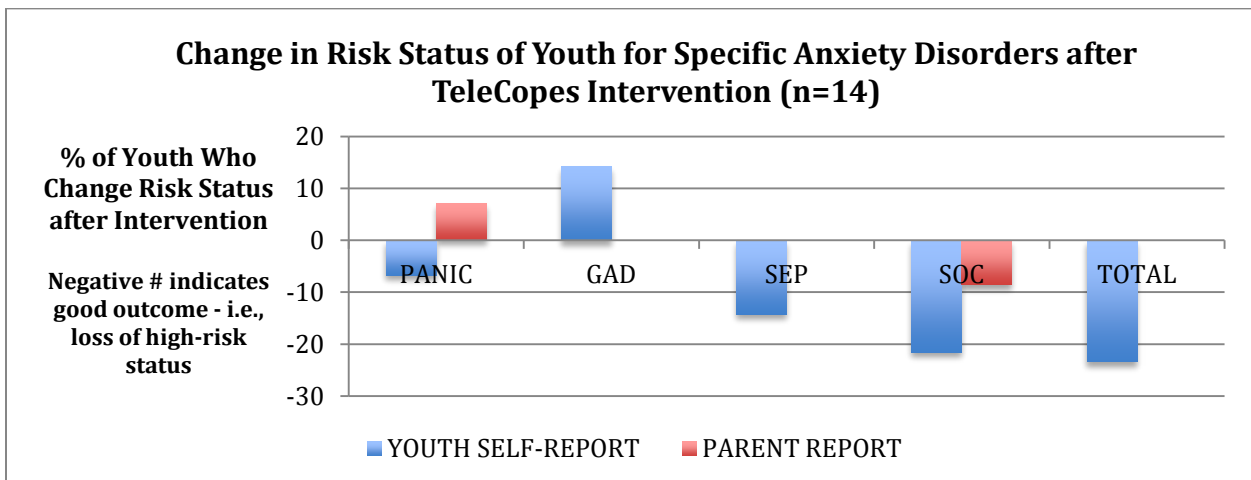


Youth self-report of total anxiety symptoms, social phobia, panic, and school-related anxiety were significantly lower after participating in the TeleCopes intervention; $t = 2.11$; $p < .01$. (Note: these analyses included 15 participants, as 3 were not verbally fluent enough to provide reliable responses to the SCARED items.) Bonferroni correction procedure was used and the p was set at .01 in consideration of multiple comparisons.



Parent report of youth anxiety symptoms indicated a significant decrease in social phobia and total anxiety, but no significant changes in other forms of anxiety. Bonferroni correction procedure was used and the p was set at .01 in consideration of multiple comparisons.

Twenty-one percent of youth participants reported post-treatment anxiety symptoms that were below the risk cutoff for anxiety disorders on the primary outcome measure; however, this change in risk status was not observed through parent report on the SCARED. (See Figure H).



Child Fears. Child and parent report of total fears from the FSSQ were significantly lower at post-treatment, relative to baseline: $t =$

Comparison with Live Delivery of FYF Intervention. In our previous work conducting efficacy research on "live" delivery of FYF, we collected data on the SCARED as one of our outcome measures. For the purposes of comparing the relative impact of telehealth delivery, we randomly selected participants from our previous treatment research cohorts to provide pair-wise matching to our TeleCopes participants on the following variables: age, verbal ability, gender, race, initial severity of anxiety (i.e., total anxiety score of SCARED within 3 points) and specific diagnosis on the autism spectrum. We could only match 12 TeleCopes participants, as we served youth with more impaired verbal skills in the TeleCopes project and we excluded less verbal participants from the live FYF groups. See Figures H & I.

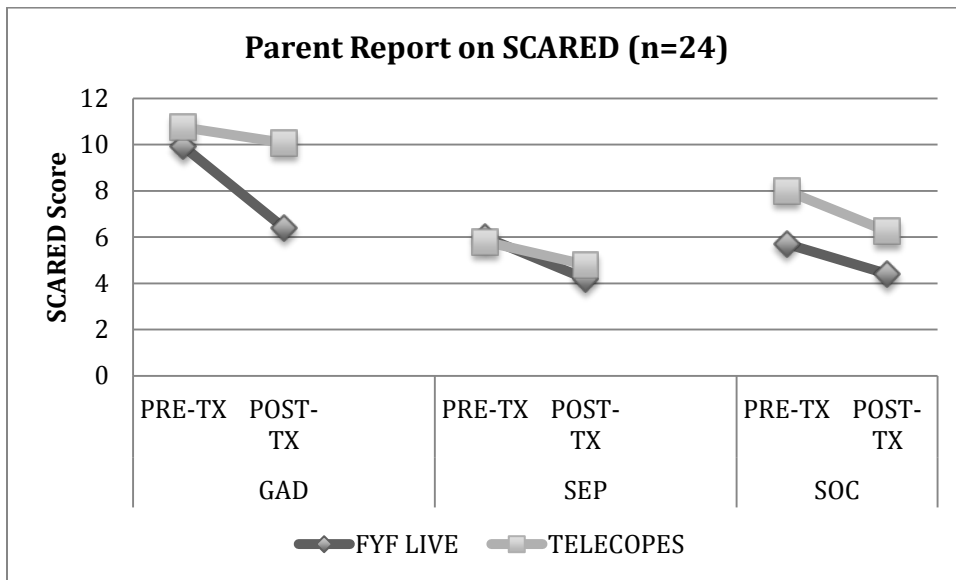


Figure H

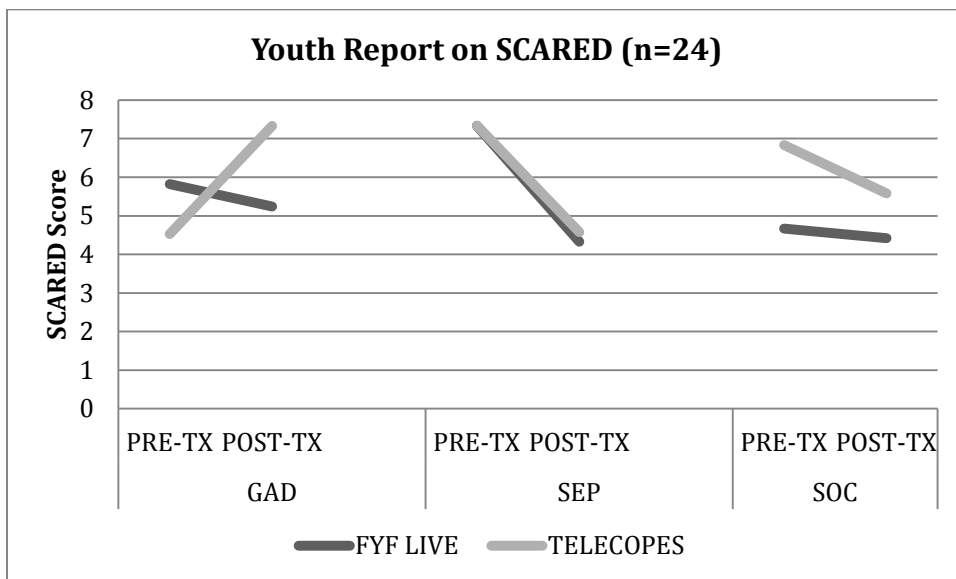


Figure I

Outcomes observed in the telehealth delivery of the intervention are comparable to the results obtained in live delivery of the intervention.

In summary, the results of this quasi-experimental pilot study are very promising, suggesting that further study with larger samples in a randomized comparison trial (e.g., live delivery vs. telehealth delivery of treatment) could be an appropriate next step.

Family Outcomes

Parenting Sense of Competence. There were no significant changes in parent report of sense of competence as a parent; notably, the majority of participating parents reported relatively high levels of parenting competence at baseline.

Family Impact. Social isolation of the family was reported to improve significantly after treatment. Twenty-five percent of parents reported less negative overall impact of the child on the family at the end of intervention, as compared to baseline ratings.

Summary. There is some preliminary support for the intervention's positive impact on the family, although the effects are modest and the samples are very small.

V. DISCUSSION AND INTERPRETATION OF FINDINGS

A. Conclusions to be Drawn from Findings

The results of this study suggest that *videoconferencing from homes to clinics is a feasible, acceptable method for delivering psychosocial interventions to families of complex youth with ASD.* Therapeutic alliance was moderate-to-strong, which is critical for the potential efficacy of interventions of this kind. Technical problems could be prevented and managed with the assistance of a part-time technical support professional. The youth were actively engaged in most session activities at a rate similar to what we have observed in our live group interventions. Therapists needed time to develop new ways of communicating through this new medium, and experience and practice were essential in promoting therapist satisfaction with sessions. Family participation was consistently high and parent and youth ratings of satisfaction with the experience were, for the majority of participants, high. Adolescents rated satisfaction less favorably, which is also consistent with our experiences in live delivery of the intervention. Exit interviews with parents suggested that they appreciated the ongoing support of a trained clinician and viewed the experience as "better than the alternative...no services whatsoever!"

Some aspects of therapeutic content appear to be a better fit for delivery over videoconferencing. Active child engagement was highest in structured activities that included clear products that could be shared visually with other participants. Psychoeducational content that was presented in multimedia formats appeared to be more engaging than worksheets. Problem-focused content was more engaging than insight-driven content. It was challenging for the therapists to coach parents in real-time if a youth participant was upset. Targeting specific fears (as opposed to generalized anxiety symptoms) was more feasible through this media in the opinions of the therapists in the project.

Session format impacts the therapist experience, perhaps more than the family experience. Individual (one family interacting with one clinician) sessions were rated more highly by therapists than dyad or small group sessions, although therapeutic alliance and participant satisfaction did not differ markedly by intervention format. Therapists reported increased fatigue after group sessions. Some therapists managed multiple participants with relative ease, while others reported significant challenges trying to shift attention across participants. All therapists agreed that practicing in a 1:1 format was critical before trying to facilitate a group.

Videoconferencing provided the opportunity to connect families facing similar challenges and several project families continue to communicate with each other through this modality. Without an attentional control arm of this intervention pilot, we cannot assess whether the positive outcomes we observed were related to simply being "connected" with others (i.e., social support) or to the therapeutic intervention. This is an important question for future research.

Rural outreach efforts connecting families to specialists is a good first step; however, to be sustainable, the outreach efforts must also interact with systems of care. The TeleCopes Project expanded into using technology to reach rural professionals in both the educational and medical

systems, which, we realized was essential as we conducted our initial focus groups. Webinars, online courses, case consultation through videoconferencing are three ways we are now trying to extend our intervention efforts in rural Colorado.

B. Exploration of Study Limitations

There are several limitations that must be considered when interpreting the results of this study - particularly in the efficacy pilot study. The sample size was quite small and the primary outcomes were all parent or youth report. There was no control group specifically recruited as an attentional control. Our sample, though representative of rural Colorado, was not diverse with regard to race or ethnicity, and most of our participating families were middle class. Participants were highly motivated and a selection bias likely operated in the recruitment strategy (i.e., obtaining participants through community workshops). Generalization of findings is thus limited by the relatively narrow range of participant characteristics described here.

C. Comparison of Findings with Other Studies

Use of Videoconferencing to Support Persons with ASD. Only a few recent studies of the efficacy of videoconferencing to support intervention for persons with ASD are present in the literature, and none of these are focused on delivering mental health care specifically. Boisvert, Lang, Andrianopoulos & Boscardin (2010) conducted a systematic review of the literature on telehealth applications in ASD and describe eight studies, involving a total of 46 participants, which met their scientific standards for inclusion in the review. Of these studies, two detail behavioral assessments using videoconferencing (Barretto, Wacker, Harding, Lee & Berg, 2006; Machalicek et al, 2009); three report on efforts to integrate assessment, intervention and training within classroom settings (Gibson et al, 2009; Machalicek et al, 2008; Machalicek et al, 2010) one examines the usefulness of videoconferencing in IEP development (Rule et al, 2006), one outlines methods for conducting psychiatric diagnosis via clinic-to-clinic videoconferencing (Savin, Garry, Zuccaro, & Novins, 2005) and one demonstrates an innovative approach for training early intervention staff to deliver an evidence-based, comprehensive treatment in home settings (Visamara et al, 2009). Overall, videoconferencing was shown to be a feasible and promising strategy for providing behavioral assessment, consultation and training to classroom teachers (Gibson et al, 2009; Machalicek et al, 2008, 2009, 2010) and home-based clinicians (Visamara et al, 2009), but was marred by technical challenges in the case study described by Rule and colleagues(2006). As Boisvert et al (2010) summarize, a lack of technical support may have compromised the latter study, which is instructive for clinicians attempting to implement interventions through this novel media. Given the case study nature of most of the empirical work on this topic, the results of this body of research can be considered promising, but certainly more work is needed to firmly establish an evidence base for telehealth practice in developmental disabilities.

Videoconferencing may fit particularly well with the social style, interests, and learning strengths of persons with ASD. Previous research reports increased engagement in persons with ASD, including those with moderate to severe symptoms, when technology-based interventions were implemented (Goodwin, 2008; Kimball & Smith, 2007; Passerino & Santarosa, 2008). Videoconferencing and computer-assisted learning can be appealing to visual learners (Pacifci et al., 2006), a style characterizing many persons with ASD (Cohen & Sloan, 2007). Persons with ASD who have co-occurring mental health conditions may have difficulty attending to, and staying engaged with, a live therapeutic interaction in an office setting, but may be more able to participate from a familiar setting, such as their homes. Further, parents, especially those from rural areas, may appreciate the relative convenience and efficiency of accessing specialized clinical care without the costs and time commitment associated with travel to therapy.

Further supporting the use of this technology among persons with ASD, videoconferencing facilitates a therapist's ability to observe and coach patients and their caregivers through real-world situations in natural environments. Youth with ASD need frequent opportunities in a variety of

settings and situations to learn adaptive coping skills (Bellini, 2004). Parents and caregivers can be guided and coached to facilitate adaptive coping throughout these naturally occurring learning opportunities (Kaminski, Valle, Filene, & Boyle, 2008). As parents observe positive changes in their children's behaviors, they may develop more confidence in their ability to facilitate adaptive skill development (Koegel, Bimbela, & Schreibman, 1996). The opportunity to provide coaching and support within natural settings may promote better generalization than can be obtained in clinic-based settings or didactic staff trainings (Scheuermann, Webber, Boutout, & Goodwin, 2003). For example, Gibson and colleagues (2009) report on the use of videoconferencing to support behavioral consultation in a preschool classroom. Functional behavioral assessment, teacher training, intervention development and implementation were all supervised from a distance via desktop video conferencing, resulting in significant improvement in a young student's participation in group instruction. The technology was described as inobtrusive and thought to have little impact on the antecedent events which impacted the student's problem behaviors. This may not be the case if additional adults were physically present in the classroom environment. Baharav & Reiser (2010) compared two models for delivering communication intervention to families of young children with ASD, with the goal of examining carry-over to parent-child interactions. The "traditional model" involved twice weekly sessions with a speech therapist providing direct intervention to the child while integrating parent coaching into the clinic-based sessions. The "clinic/telepractice model" involved one clinic-based session conducted by the speech therapist each week, followed by a home-based session facilitated by the parent with coaching through videoconferencing by the therapist. The results of this case study support the feasibility, acceptability and potential effectiveness of combining live and telehealth sessions to promote skill gains in children in their home setting, with their parents, which is a challenge in clinic-facilitated sessions.

Only a few recent studies of the efficacy of videoconferencing to support intervention for persons with ASD are present in the literature, and none of these are focused on delivering mental health care specifically (see Boisvert et al, 2010 for review). None of these studies have examined the clinical utility of connecting clinicians to family homes to deliver psychosocial intervention, and none have used inexpensive, off-the-shelf videoconferencing platforms in their studies.

D. Possible Application of Findings to Actual MCH Health Care Delivery Situations

Telehealth approaches to treating psychopathology demonstrate strong promise for improving the mental health and quality of life of youth with ASD. However, to maximize the effectiveness of telehealth approaches, researchers and practitioners will need to generate creative solutions to as-of-yet unresolved limitations.

Most practitioners today likely received training primarily (or exclusively) in traditional, live-format psychotherapy approaches. Well-intentioned and skilled therapists will still require re-training to be competent in conducting therapy using videoconferencing or computer-mediated formats. Even with adequate re-training, many practitioners will need to rebuild or reconceptualize their "toolbox" of clinical techniques. For example, traditional motivational tools, such as proximity during difficult tasks or pulling out reliable games during key therapy moments, may have little utility when engaged in videoconferencing. Consequently, devising innovative methods of connecting with clients through telehealth technology will be crucial in enhancing the success of such treatments.

Clinic-to-clinic videoconferencing for the purposes of identifying youth with ASD has potential and warrants further study. Our team is embarking on a 2-year project to pilot case consultation via videoconferencing with school teams and with a developmental disabilities center in rural Colorado. We will be facing issues of economics that impact the sustainability of these efforts and will need to find ways to maintain these clinical services in the absence of grant funding.

E. Policy Implications

There are ethical issues inherent to practicing psychological or behavioral interventions via technology, which impact policy in this area. Careful attention to confidentiality and security of online interactions is warranted and disclosure of possible risks associated with interacting with a mental health professional through the internet needs to be provided to prospective patients or research participants. Given the costs of some technological interventions, there still remains the challenge of accessibility for families without the resources to access technology and there are still parts of the country that are not served by the internet. Public resources, such as libraries, schools and community mental health centers, could be involved in this effort in order to improve access.

F. Suggestions for Further Research

As in other areas of research on technological interventions, most of the available data is either descriptive, generated within a case study approach, or emphasize feasibility and acceptability without providing rigorous tests of efficacy or effectiveness. Clearly, carefully designed studies, using appropriate controls and randomized assignment to intervention condition, are needed. Most of the research currently being conducted is being done by the developers of the technology themselves; it is important to pursue objective empirical evaluation of these novel approaches, conducted by persons without intellectual investment in the product being studied. Clear delineation of inclusion criteria, careful identification of appropriate outcome measures, and comprehensive descriptions of study procedures methods (i.e., in enough detail to support independent replication) are necessary for this body of research to move forward.

Practitioners continue to delineate the appropriate realms of practice for telehealth – for example, crisis intervention services require person-to-person interactions. More information is needed to understand which kinds of supports, for which mental health conditions, are most appropriate for using technology. More research on hybrid models (i.e., those that combine face-to-face interactions with computer-based encounters) are needed.

Larger trials that include culturally diverse samples are needed to evaluate these intervention delivery systems. Most products and services are delivered in English and have been developed and tested in samples that are not particularly diverse or representative of different ethnicities and cultures. Families with fewer resources, who do not have access to computers in their own homes, have not been actively engaged in this kind of dissemination research. Studies that utilize public computers (such as in libraries and schools) would be important for extending the access to a more diverse sample of families.

Finally, the field would benefit from research examining a broader array of treatments for comorbid psychopathology specifically for youth with ASD and their families. There is a dearth of technology applications targeting siblings and peers, which could be helpful in supporting the mental health of family members as well as promoting inclusion. On a positive note, professional associations focused on educating and treating persons with autism and other developmental disabilities are increasingly incorporating sessions on technology. As our culture adapts to rapid growth in communications, our clinical practice and research efforts are likely to converge in a similar manner; and those of us in the social sciences will be challenged to integrate human factors into technological interventions.

VI. LIST OF PRODUCTS

CLINICAL MANUALS

Reaven, J., Blakeley-Smith, A., Nichols, S., & Hepburn, S. (2011). *Facing your fears: A family-focused intervention to reduce anxiety in youth with Autism Spectrum Disorders (Facilitator's Manual, Parent Manual, Child Workbook)*. Baltimore, MD: Brookes Publishing.

PEER-REVIEWED JOURNAL ARTICLES

Blakeley-Smith, A., Reaven, J., Ridge, K. & Hepburn, S. (2012). Parent-child agreement of anxiety symptoms in youth with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 6, 707-716.

Lickel, A., MacLean, W.W., Blakeley-Smith, A., & Hepburn, S. (2012). Assessment of prerequisite skills for cognitive-behavioral therapy in children with and without autism spectrum disorders. *Journal of Autism and Developmental Disorders*, epub (August 5, 2012). PMID: 21818677.

Reaven, J., Blakeley-Smith, A., Culhane-Shelburne, K., & Hepburn, S. (2012). Group cognitive behavior therapy for children with high-functioning autism spectrum disorders and anxiety: A randomized trial. *Journal of Child Psychology & Psychiatry*, 53(4), 410-419.

BOOK CHAPTERS

Hepburn, S. & Wolff, B. (In press.) Self-regulation in persons with autism spectrum disorders. In K.C.Barrett & G. Morgan (Eds.), *Handbook on self-regulatory processes in development: New directions and international perspectives*. New York: Taylor & Francis Publishers.

POPULAR PRESS

Kaiser, K. (2011). Telehealth: Families finding ways to connect in rural Colorado. *Exceptional Parent*, April, 18-19.

SCIENTIFIC PRESENTATIONS

Work Specific to TeleCopes (in chronological order)

Blakeley-Smith, A., Reaven, J., Leuthe, E., Moody, E., & Hepburn, S. (2010). *Incorporating technology into a pilot behavioral therapy group*. Poster presented at the International Meeting for Autism Research (May, Chicago).

Hepburn, S. (2010). *Delivering psychosocial interventions to families of youth with autism through videoconferencing*. Webinar presented for the Maternal & Child Health Bureau Research Series (April).

Hepburn, S. & Reaven, J. (2011). *TeleCopes: Family-focused telehealth intervention to reduce anxiety in youth with autism spectrum disorders in rural Colorado*. Roundtable session at the AUCD Combating Autism Act Meeting (December, Washington, DC).

- Hepburn, S., Reaven, J., Blakeley-Smith, A., Wolff, B., & Kaiser, K. (2011). *Delivering psychosocial interventions through videoconferencing: Pilot efforts to reach rural families*. Poster presented at the International Meeting for Autism Research (May, Philadelphia).
- Hepburn, S. (2012). *Reaching families through videoconferencing: The TeleCopes Project*. Invited lecture at the Florida State University Summer Autism Institute (June, Tallahassee).
- Hepburn, S. (2012). *The TeleCopes Project: Videoconferencing to extend access to psychosocial intervention for rural families*. Presentation for "Innovative Practices for Youth with Autism Spectrum Disorders" (Webinar) for the Maternal & Child Health Bureau/AUCD (July, Washington, DC.)
- Hepburn, S.L. (2012). *The TeleCopes Project: Delivering psychosocial interventions through videoconferencing to families of youth with autism in rural Colorado*. Invited presentation at the "Expert Workshop on Developing Interventions for Underserved Families with Autism", Maternal & Child Health Bureau (April, Washington, DC.)
- Hepburn, S. & Katz, T. (2012). *Improving educational identification in rural communities: The potential of teleconferencing*. Invited presentation at the Global Autism and Public Health Forum at the International Meeting for Autism Research (May, Toronto).
- Related Work on Anxiety Treatment in ASD*
- Blakeley-Smith, A., Reaven, J., & Hepburn, S. (2011). *Examining the impact of cognitive behavioral group therapy on quality of life in adolescents with high-functioning autism spectrum disorders*. Poster presented at the International Meeting for Autism Research (May, Philadelphia).
- Blakeley-Smith, A., Reaven, J., & Hepburn, S. (2011). *Outcomes of a pilot study of cognitive-behavioral group intervention for adolescents with ASD: Using technology to promote self-monitoring*. Paper presented at the Annual Conference on Theory, Research and Practice in Developmental Disabilities (March, Annapolis).
- Leuthe, E., Blakeley-Smith, A., Wolff, B., Hepburn, S., & Reaven, J. (2011). *Cognitive-behavioral group therapy for children with autism spectrum disorders and anxiety: Moderating influence of negative cognitions*. Poster presented at the International Meeting for Autism Research (May, Philadelphia).
- Reaven, J., Blakeley-Smith, A., Culhane-Shelburne, K., & Hepburn, S. (2012). *A randomized trial: Group cognitive behavioral therapy for children with high-functioning autism and anxiety*. Invited presentation at the Annual Conference of the Anxiety Disorders Association of America (September, New York).
- Reaven, J.A., Blakeley-Smith, A., & Hepburn, S. (2010). *Treatment for adolescents with high-functioning autism spectrum disorders*. Poster presented at the International Meeting for Autism Research (May, Chicago).
- Reaven, J., Blakeley-Smith, A., Leuthe, E., & Hepburn, S. (2011). *A family-focused group cognitive-behavioral therapy for adolescents with high functioning autism spectrum disorders and anxiety*. Paper presented at the International Meeting for Autism Research (May, Philadelphia).

WEBSITES

As part of this project, we created **two websites** (www.telecopes.org and www.facingfears.org), which link to each other and to master website (www.jfkpartners.org). We decided on this structure so that families interested in anxiety and ASD in general can access the "facingfears" pages, and those participating in the TeleCopes project have access to protected pages through www.telecopes.org). Products we have created for families are available through these sites and include archived webinars by our team, videos created by youth participants that they wanted to share, and tip sheets and materials for families.

VII. REFERENCES

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