Crisis Prevention Institute (CPI) Verbal and Physical Management Training for Parents of Children with ASD (P-CPI)

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Detailed Protocol Version: 2/1/21

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Background & Significance

Autism spectrum disorder (ASD) is currently understood as a spectrum of neurodevelopmental symptoms, including deficits in social interaction and communication, as well as the presence of restricted, repetitive, and stereotyped patterns of behavior (American Psychiatric Association [APA], 2013). The overall point prevalence among 8-year-old children in the United States is currently estimated to be 1 in 68 (with approximately 1 in 42 boys affected; CDC, 2014). While social communication deficits are unquestionably considered the hallmark characteristic of ASD, associated challenging behaviors are both frequent and debilitating (Matson and Nebel-Schwalm, 2007).

While the current literature defines and measures behavior problems in various ways, most studies to date conceptualize aggression, self-injury, and property destruction as the most impairing or severe problem behaviors in ASD (Doehring, Reichow, Palka, Phillips and Hagopian, 2014) and those in most need of acute intervention (Akram, Batool, Rafi, and Akram, 2017; Mandell, 2008; Matson and Nebel-Schwalm, 2007). Not only can aggressive and self-injurious behaviors in the home cause serious injury (Allen, Hawkins and Cooper, 2006), but aggression has been identified as the primary cause of residential placement for children and adolescents with ASD (Mandell, 2008) and frequently necessitates police involvement (Tint, Paluka, Bradley, Weiss, Lunsky, 2017). When patients with ASD require emergency department care, many families have a negative experience as emergency department staff receive minimal formal training and have limited experience treating those within this unique population (McGonigle, Venkat, Beresford, Campbell, and Gabriels, 2014).

While many individuals with ASD who reside with a caregiver receive educational, community-based, and/or in-home behavioral services, managing severe problem behaviors in the home often falls on the caregiver(s). Not surprisingly, Hall and Graff (2011) found that the average total parenting stress in their sample of 75 caregivers of children with ASD was above the 95th percentile (as measured by the PSI-SF; Abidin, 1995), and severe behavior is consistently identified as a primary predictor of this parenting stress (Beck, Hastings, Daley, and Stevenson, 2004; Davis & Carter, 2008; Hastings and Brown, 2002; Higgins et al., 2005).

While researchers continue to highlight the need for more parent training and support to manage severe behavior problems (e.g., Bultas, Johnson, Burkett, and Reinhold, 2016; Doehring, 2014), there is a significant paucity of research and/or public policy on how to best equip families to manage these potentially harmful behaviors. In addition, a recent survey-based study in the UK found that despite not having adequate training, parents frequently use physical intervention strategies to manage aggression and self-injury (Allen, 2006). The same study (Allen, 2006) also found that childrens' aggressive behavior results in minor injuries to family members 69.4% of the time and major injuries

12.5% of the time. Existing studies almost exclusively focus on behavioral techniques administered by expert professionals (e.g., Doering, 2014) or psychopharmacological interventions (e.g., Carroll et al., 2014). The few parent intervention studies that have been published either do not specify which aspects of the multi-faceted parent training were beneficial or do not include physical management strategies (Rundberg-Rivera et al., 2015; Tellegen and Sanders, 2014). Only one clinical trial has compared parent training with parent education, finding that parents who received a 24-week parent training program reported greater reductions in disruptive behavior than parents who received education only (Bearss et al., 2015). Despite some preliminary and emerging research, it is important to note that no parent-specific physical intervention training programs exist (i.e., none commercially available). Given the prevalence of severe behaviors in this population, the public health impact of relying on emergency services and more restrictive (i.e., residential) placements, and the effect that these behaviors have on parenting stress and household functioning, the lack of evidence-based and widely available parent physical management training programs is a significant omission.

The Crisis Prevention Institute (CPI) has developed an internationally recognized program designed to teach professionals and educators how to keep these children safe in institutional settings. To address the need for parent physical management training, the current study has adapted the CPI professional training program for parents and caregivers of individuals with ASD. The overall aims of the current project are to develop a one-day CPI-based parent training program to better equip caregivers to manage severe behavior problems in the home, to gather initial treatment feasibility, acceptability, and satisfaction, and to explore preliminary intervention outcomes, including parent self-efficacy, family home functioning, parental stress, and a possible reduction in behavioral symptoms.

I. Specific Aims

Specific Aim 1: We will develop and evaluate a parent-based physical intervention training called "Parent-based Crisis Prevention Institute (CPI) physical management training program" (i.e., P-CPI). We will demonstrate the feasibility and acceptability of P-CPI by administering the training program to 30 parents/caregivers of children with ASD as part of a small, randomized pilot study. We wll report descriptive statistics on parental knowledge and P-CPI competency post-treatment, as well as summarize average Likert ratings for parental satisfaction with treatment.

Specific Aim 2: We will conduct a preliminary assessment of the efficacy of P-CPI intervention. Thirty parents/caregivers of children with ASD will be randomized to each the P-CPI intervention group and a Waitlist Control (WLC) group in our pilot study. Change in outcome measures will be compared between P-CPI and WLC at 2-weeks, 1-month, 2-months, and 3-months post-intervention.

We will test the following hypotheses in support of specific aim 2:

Primary Hypothesis

Hypothesis I: Participants in P-CPI will demonstrate a greater increase in parental self-efficacy in the two weeks following intervention than WLC. Our primary outcome will be 2-week change (2-week score minus baseline score) in the

Childhood Adjustment and Parent Self-Efficacy Scale - Developmental Disabilities (CAPES-DD) parental self-efficacy scale total score. The scale will be modified to ask about child behavior in the previous two weeks instead of the previous four weeks. We will compare mean 2-week change between P-CPI and WLC.

Secondary Hypotheses

Hypothesis II: Participants in P-CPI will demonstrate a greater decrease in self-reported parenting stress at two weeks following intervention than WLC. Our secondary outcome measure for hypothesis II will be 2-week change (2-week score minus baseline score) in the Parent Stress Index – Short Form (PSI-SF) total score. We will compare mean 2-week change between P-CPI and WLC.

Hypothesis III: Participants in P-CPI will demonstrate a greater increase in self-reported family quality of life at two weeks following intervention than WLC. Our secondary outcome measures for hypothesis III will be 2-week change (2-week score minus baseline score) in the Family Quality of Life Scale (FQOL) total score. The scale will be modified to ask about family quality of life in the previous two weeks instead of the previous 12 months. We will compare mean 2-week change between P-CPI and WLC.

Exploratory Hypotheses

Hypothesis IV: Participants in P-CPI will demonstrate a greater decrease in self-reported family home dysfunction at two weeks following intervention than WLC. Our exploratory outcome measures for hypothesis IV will be 2-week change (2-week score minus baseline score) in the Family Impact of Childhood Disability Scale (FICDS) total score. We will compare mean 2-week change between P-CPI and WLC.

Hypothesis V: Children whose parent/caregiver participates in P-CPI will demonstrate a greater decrease in aggressive behavior at two weeks following intervention than WLC. Our exploratory outcome measures for hypothesis V will be 2-week changes (2-week score minus baseline score) in the Abberant Behavior Checklist (ABC) irritability subscale and the Modified Overt Aggression Scale (MOAS) total score. We will compare mean 2-week change between P-CPI and WLC.

Hypothesis VI: Participants in P-CPI and children whose parent/caregiver participates in P-CPI will demonstrate improved outcomes at 1-month, 2-months, and 3-months post-intervention relative to WLC. Our exploratory outcome measures for hypothesis VI will be 1-month, 2-month, and 3-month changes in the same scores used to address hypotheses I-V. We will compare mean 1-month, 2-month, and 3-month changes between P-CPI and WLC.

II. Subject Selection

We propose to recruit 60 adult subjects that complete this study. We plan to enroll 100 subjects with the knowledge that we will have attrition due to withdrawals and drop-outs. The subjects will be parents/caregivers of children who are Lurie Center for Autism patients that are between the ages of 5-12 years, have an ASD diagnosis, and live at home. The subjects will be randomly assigned to the P-CPI group or the WLC group. Both groups will be screened and administered baseline measurements on parental self-efficacy, parenting stress, family home functioning, P-CPI competency, and child behavior.

a. Inclusion/Exclusion

- Inclusion Criteria:
    - Each subject must be an adult caregiver/parent of a Lurie Center for Autism patient with 'patient' defined as having at minimum one visit/contact per year with any Lurie Center for Autism clinician. The patient (child) must:
        - Be from 5-12 years of age (inclusive).
        - Live at home with caregiver.
        - Have an ASD diagnosis per the DSM-5 checklist confirmed by expert clinician (MD or PhD) at the Screening Visit.
        - Have a symptom severity score of 13 or greater on the ABC Irritability subscale as confirmed by an expert clinician at the Screening Visit.
    - The subject may have any primary language but must be comfortable speaking and reading English without translation.
    - The subject must be the self-identified primary caregiver of the Lurie Center for Autism patient.
    - The subject must be recommended by a Lurie Center for Autism clinician.
    - The subject must be able to attend in person the training session on the specified date/time/location.
    - The subject must be willing to complete the assessment measures.
    - Only one subject per family may participate.

- Exclusion Criteria:
    - The subject must not have any self-identified physical limitations or disabilities that prevent the use of physical intervention techniques.
    - The patient (child) must not have had seizures within four weeks prior to the Baseline Visit.
    - The patient (child) should have no new psychotropic drug or non-drug treatments (including ABA and parent-training) within four weeks prior to the Baseline Visit.

b. Source of Subjects/Recruitment Methods

Subjects will be recruited from the large patient base of the MGH Lurie Center for Autism, including our affiliated Aspire and Spaulding Outpatient Center for Children (Lexington) divisions via direct clinician referral. Subjects can learn about the study through flyers posted throughout the clinic and Lurie Center for Autism electronic media postings. Additionally, we

may directly contact adults who are enrolled in the Lurie Center's Research Registry (IRB# 2008P001092), who have consented to be contacted about research studies for which they or their children may qualify, and who have children who are Lurie Center for Autism patients.

Other recruitment materials will include a cover letter, the study information sheet, and an opt-in/opt-out form.
Those who express interest in participation will be called by a member of the research team who will explain the study, will answer any questions and will ensure that participants qualify for participation. The recruitment materials will be mailed or read to the subjects over the phone. Those who did not return the opt out card may be called by the research team within two weeks of the mailing date.

The research team will be available to answer questions from potential participants. All subjects (parents) who fulfill the study criteria will be invited to participate. No one will be excluded based on age, gender, race, or ethnic background.

III. Subject Enrollment

a. Enrollment
Those who qualify and consent to participation will be considered enrolled and will be provided the study's baseline packet. Packets will include:

- Welcome Letter
- Baseline Study Questionnaires

Names, e-mail addresses, and telephone numbers of the parent participants will be collected for follow-up contact during the study. As part of the study data, the birthdate of their child (the Lurie Center patient) will also be collected to calculate the child's age. Finally, their mailing address will be collected in order to mail the participants their gift card compensation.

b. Informed Consent Procedures
Informed consent will be obtained from participants by authorized study staff who have been certified in human research subject protection and who are knowledgeable as to the proper consenting procedures according to the guidelines set forth by Partners Healthcare.

The informed consent process will occur via phone or in-person. Whenever consent occurs by phone, subjects will be required to sign, date and return a copy of the consent form prior to participation in any study procedure. A signed and dated copy of the consent form will be provided to all participants. The original will be filed in a locked cabinet with the subject's other protected health information.

Whenever possible, those who are interested in taking part in the research will be given a minimum of 24 hours to review the consent prior to their visit. However, some subjects may be referred to the study staff following their appointment with a clinic physician and may not choose to review the study information for 24 hours prior to enrollment. Study staff will make clear that even if they sign the consent form, they are free to withdraw their participation at any time.

c. Randomization Procedures

After completion of informed consent and the Screening Visit, participants will be randomly assigned (1:1 ratio) to the Treatment or Waitlist Control groups, and will be notified of their condition in person or via secure e-mail or phone.

IV. Study Procedures

a. Study Visits

All Treatment Group participants will complete a packet of assessments at the Screening Visit, on the day of training (considered baseline assessment), and at 2-week, 1-month, 2-months, and 3-months following the baseline assessment. The Treatment Group will also participate in-person with a Follow-up Group Qualitative Interview.

All Control Group participants will complete a packet of survey assessments at the Screening Visit; the baseline assessments within five days of the Treatment Group's training; and at 2-week, 1-month, 2-months, and 3-months post baseline. On the day of the Control Group's training (to be scheduled approximately 3 months after screening), the Control Group participants will complete the assessments related to the training (P-CPI Knowledge Based Assessment and P-CPI Course Evaluation Assessment). Every effort will be made to have Control Group participants complete their baseline assessments in person but these assessments may be completed remotely for those participants unable to visit the Lurie Center in person within the five-day window.

The measures above will be presented using a counterbalanced design in order to reduce the chances that the order of the measures adversely impacts the results.

To help participants defray costs of travel and compensate them for their time, we will provide participants a total of $150.00 for their participation in the form of a check. Compensation will be prorated with payment of $25 for completion of each of the following: Screening Visit, Training Visit, 2-week assessments, 1-month assessments, 2-month assessments, and 3-month assessments.

b. Treatment and Control Groups

Parents will be permitted to pursue medical care, support and/or therapeutic services as they typically would during study participation, except for other parent behavior training services.

Treatment Group:

The treatment group (n=30) will receive a one-day (6-hour) training in CPI's Nonviolent Crisis Intervention® including the use of nonverbal, paraverbal, verbal, and physical intervention techniques. The Lurie Center has worked with CPI to modify their current parent and caregiver curriculum to include appropriate physical intervention techniques into a revised workbook, CPI Training for Parents®, that will be given to each participant and followed during the training. There will be 3-4 trainings offered to achieve the sample size of 30 with 6-12 subjects per group.

Waitlist Control Group:

The Waitlist Control group (n=30) will receive the same one-day (6-hour) training in CPI's Nonviolent Crisis Intervention® including the use of nonverbal, paraverbal, verbal, and physical intervention techniques 3 months after the completion of the baseline assessments.

c. Parameters to be Measured

The following assessments will be administered in this investigation based on the schedule outlined in Section "D" below. All measures (with the exception of the P-CPI Knowledge Based Assessment and P-CPI Course Evaluation Assessment which are original measures unique to this study) have been selected based on construct validity and have been evaluated for sound psychometric properties by the investigators.

DSM-5 Checklist for Autism Spectrum Disorder: The proposed DSM-V criteria for ASD will be documented in the form of a checklist for an MD/PhD to complete.

Inclusion/Exclusion: A checklist will be completed to ensure all inclusion and exclusion criteria are met.

Demographics Review: Information such age, race, ethnicity, family status, address, phone number, and e-mail address will be collected.

Aberrant Behavior Checklist (ABC; Aman, Singh, Stewart, and Field, 1985). The ABC consists of five subscales and takes about 10-15 minutes to complete. The ABC checks symptoms of irritability and agitation, lethargy and social withdrawal, stereotypic behavior, hyperactivity and non-compliance, and inappropriate speech.

Parenting Stress Index-Short Form (PSI-SF; Abidin, 1995). The PSI-SF is a self-report measure of severity and domain of parenting stress which includes 36 items rated on a 5-point, Likert scale. The PSI-SF has been the single most utilized measure of parenting stress, particularly in the ASD literature (e.g., Davis & Carter, 2008; Hall & Graff, 2011).

Modified Overt Aggression Scale (MOAS; Knoedler, 1989): This four-part behavior rating scale is designed to measure aggressive behavior as witnessed in the past week. Each section consists of five questions, with the first section regarding verbal aggression, the second focusing on aggression against property, the third section measuring autoaggression, and the fourth section concerning physical aggression. Respondants are asked to check whether each statement describes the child's behavior over the previous week.

Child Adjustment and Parent Efficacy Scale-Developmental Disability (CAPES-DD; Emser, Mazzucchelli, Christiansen, and Sanders, 2016): A brief outcome measure in the evaluation of individual parenting interventions. The scale consists of a 30-item itensity scale with two subscales measuring children's behavior problems and emotional maladjustment and a 20-item self-efficacy scale that measures parents' self-efficacy in managing specific child behavior problems.

Family Impact of Childhood Disability Scale (FICDS; Trute, Hiebert-Murphy, and Levine, 2007). The Family Impact of Childhood Disability Scale is a 20-item measure assessing parents' appraisal of the specific family consequences of having a child with a disability.

Family Quality of Life Scale (FQOL; Beach Center on Disability, 2012): The Family Quality of Life Scale is a 25-item measure assessing families' perceptions of their satisfaction with different aspects of family quality of life.

P-CPI Knowledge Based Assessment: The P-CPI Knowledge Based Assessment is a 12-item questionnaire assessing knowledge gained during the P-CPI training. The questionnaire was adapted from existing CPI post training assessments (CPI, 2006).

P-CPI Course Evaluation Assessment: The P-CPI Course Evaluation Assessment is a self-report measure of satisfaction of the P-CPI course. This is an 8-item questionnaire rated on a 5-point Likert scale. The questionnaire was adapted from existing CPI course evaluations (CPI, 2006).

Safety Event Tracking Log: This form will be used to track any patient event of physical aggression towards others, self-injury, or property destruction.

Follow-up Group Qualitative Interview: Group interview led by expert clinician to obtain qualitative data from subjects in Treatment Group.

d. Schedule of Measures

Measures	Screen Visit	Baseline	After Training	2-week, 1-month, 2-month, 3-month Post-Baseline
Informed Consent	X			
DSM-5 Checklist for ASD	X			
Inclusion/Exclusion Criteria	X			
Demographics Review	X			
Randomization to Intervention or Control Group	X			
Aberrant Behavior Checklist (ABC)	X	X		X
Parenting Stress Index (Short Form)	X	X		X
Modified Overt Aggression Scale (MOAS)	X	X		X
Childhood Adjustment and Parent Self-Efficacy Scale - Developmental Disabilities (CAPES-DD)	X	X		X
Family Impact of Childhood Disability Scale (FICDS)	X	X		X
Family Quality of Life Scale (FQOL)	X	X		X
P-CPI Knowledge Based Assessment			X	
P-CPI Course Evaluation Assessment			X	
Safety Event Tracking Log*		X		X

*Logs reviewed at these time points.

V. Sample Size Considerations

In order to allow for unforeseen difficulties in retaining or scheduling study participants, we assumed 10% dropout for each group when performing sample size calculations. Based on sample size calculations for a two-sample t-test, 27 per group provides greater than 80% power to detect a standardized effect size of 0.8. We consider this reasonable based on an effect size of approximately this magnitude observed for reduction of parental stress associated with an intervention targeting parents of children with ASD (Tellegen & Sanders, 2014).

VI. Biostatistical Analysis

Demographic characteristics and frequency of study drop-out will be compared between P-CPI and WLC using two-sample t-tests and Fisher's exact test. Summary statistics, including mean and standard deviation or median and interquartile range as appropriate, will be calculated for the P-CPI Knowledge Based Assessment score and the P-CPI Course Evaluation Assessment Likert ratings.

To address hypotheses I-V, primary, secondary, and exploratory outcome measures will be compared between P-CPI and WLC at 2-weeks (hypotheses I-V) using repeated measures linear regression models (as implemented using SAS PROC MIXED) with score at screening, time (in categories, baseline or two-weeks), group (P-CPI or waitlist) and time x group interaction as covariates. Our hypotheses will be addressed by testing the significance of the time x group interactions from these models. To address hypothesis VI, exploratory analyses will incorporate 1-month, 2-month, and 3-month measurements as outcomes (hypothesis VI). All partially observed outcomes from participants missing data will be incorporated. Statistical tests will be two-sided and conducted at the test-wise alpha=0.05 level.

VII. Risks

It is unlikely that parent-participants will be caused any legal, or social harm by participating in this research. Vulnerable populations are not targeted for this project and no deception will be used. The assessments completed for the study are of low risk (i.e., are not likely to elicit an acute psychological reaction) and the liklihood of a psychological event is low.

Parent participants will be informed that the physical management training involves physical contact and a risk of injury is possible. However, it is important to highlight that parents already use physical intervention strategies to manage aggression and self-injury (Allen, 2006) without training, and that the benefit of how and when to utilize these physical interventions may result in the benefits outweighing the risks.

It is unlikely, but possible that during the training that participants could disclose child abuse in the context of discussing parenting skills and behaviors. If this occurs, the group leader, [redacted] will follow the Commonwealth of Massachusetts guidelines as described by the Department of Children and Families guidelines for mandated reporting of disclosed evidence of suspected child abuse/neglect and the Department of Children and Families will be notified.

In addition, if participants require additional psychiatric or psychological support they will be referred to the appropriate level of care. Further, it is possible that confidentiality of participants

may be breached during the training, therefore, the investigators will give a verbal confidentiality warning to participants at the initial group training.

An additional risk to participants is likely the breach of privacy in that they must provide an e-mail address or a phone number to be contacted for the subsequent assessment periods. They will be fully informed of the study expectations prior to consenting and will be able to terminate from the study at any time. To minimize this risk, all data will remain strictly confidential. Data from parent-participants will be identified by a unique code number. Consent forms will not be linked to data packets. The data from this study as well as the file linking the subjects' names to their unique code number will be stored electronically in a password protected file on password protected computers. The only individuals with access to these computers are the IRB approved investigators. If any of the results of the study are published or presented in a research forum, summary group-level data and individual examples may be reported. Individual examples will be completely de-identified.

Parent-participants may find the time commitment to be overwhelming and/or inconvenient. They may also experience boredom while completing the measures. Parent-participants will be informed of their right to refuse to answer any questions.

VIII. Benefits

It is anticipated that parents randomized to the Treatment group may benefit psychologically from the training. This may include (but is not limited to) decreases in stress as well as higher reports of quality of life. It is possible that study results will be utilized to inform healthcare professionals, behavior specialists, autism communities, future research and parents themselves about the application of trained physical intervention techniques for parents of children with ASD. Results from the present study will be utilized by the research team to further develop a scientifically-sound, physical intervention training for parents.

IX. Monitoring & Quality Assurance

As the procedures described in this protocol are unlikely to affect the safety of subjects, it is extremely unlikely that there would be clinical reasons for stopping the study. However, the Principal Investigator will be responsible for monitoring the occurrence of adverse events. Events determined by the Principal Investigator to be unanticipated problems involving risks to subjects or others will be reported by the PI according to the Partners Human Research Committee's reporting policies.

It will be the responsibility of the Principal Investigator to obtain IRB approval of the protocol, informed consent. All research personnel assigned to the protocol, including the Investigator(s), Clinical Coordinator(s), and study staff, will be required to complete a computer-based training course on the Protection of Human Research Subjects as required by Partners Institutional Review Board. The Study Coordinator will maintain annual documentation of continuing IRB approval. Within three (3) months of study completion or termination, the Principal Investigator will provide a final report to the IRB. The Principal Investigator will ensure compliance with regulations related to protection of human subjects, specifically including Title 21 CFR 50, 56, and 312 and Title 45 CFR 46, the ICH Harmonized Tripartite Guideline for Good Clinical Practice (ICH E6 GCP) and for international trials, the International Ethical Guidelines for Biomedical Research Involving Human Subjects, published by the Council for International Organizations of Medical Sciences (CIOMS), in collaboration with the World Health Organization (WHO).

Protocol adherence will be monitored by the Principal Investigator. If protocol changes are needed, a modification request will be submitted to the IRB. Protocol changes will not be implemented prior to IRB approval unless necessary to eliminate apparent immediate hazards to the research subjects. In such a case, the IRB will be promptly informed of the change as per the Partners Human Research Committee policy.

X. Optional Sponsor-Initiated Focus Group

All participants who complete the P-CPI training will receive a recruitment letter in the mail offering an opportunity to take part in a focus group. This focus group will be run by the sponsor or a third-party delegate, and the goal will be to better understand parent feedback about the training and what an ideal parent training would look like. The focus group will be conducted virtually via Microsoft Teams. It will run for about 90 minutes. Parents may also be asked to complete a brief initial survey. The focus group questions will center on: timing and logistics of an ideal offering, desire for virtual options, the perceived value of the training, and whether parents would want refreshers or ongoing communication.

If parents wish to participate in the focus group, the Lurie Center research staff will provide details on how they may sign up with the sponsor directly. The sponsor will work with parents to schedule/conduct the focus group.

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