Mindfulness and Parent Stress Reduction: Improving Outcomes for Children With Autism Spectrum Disorder

NCT03459625

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PROTOCOL

PROJECT INFORMATION

Project Title: Mindfulness Awareness for Parenting Stress (MAPS) Project for Parents of Children with Developmental Delays
Funding: Funding comes from Dr. Neece's start-up research funds that she received as part of her package at Loma Linda University
Phase of Study: This is the first phase of MAPS study and the first IRB application that has been submitted for this study.

PRINCIPAL INVESTIGATOR'S INFORMATION

Principal Investigator: Cameron L. Neece, Ph.D.

- Address: Loma Linda University, Department of Psychology, 11130 Anderson St., Loma Linda, CA 92350
- Phone Number: (909) 558-8615
- Email: cneece@llu.edu

STUDY PERSONNELL

All other personnel are currently doctoral students in the Ph.D. or Psy.D. Clinical Psychology programs at Loma Linda University. Their names are listed below and their certificates certifying that they have completed the human subjects training are also include in this application.

Name	Doctoral Program at LLU	Year in Program
John Bellone	Ph.D. in Clinical Psychology	2nd
Kristin Crocfer	Psy.D. in Clinical Psychology	2nd
Robyn Finckbone	Psy.D. in Clinical Psychology	2nd
Andrea Lewallen	Ph.D. in Clinical Psychology	3rd
Derek Matthies	Ph.D. in Clinical Psychology	1st
Kathleen Parker	Ph.D. in Clinical Psychology	1st
Merideth Robinson	Psy.D. in Clinical Psychology	2nd

STUDY INFORMATION

The MAPS Project is a low-risk social/behavioral study that examines the efficacy of a stress-based intervention for parents of children with developmental delays (see description below for more detail). Laboratory assessments will take place in Dr. Neece's laboratory in the Psychology Department (11130 Anderson St., Loma Linda, CA 92350, Rooms 5 and 6). The intervention will be delivered at the Behavioral Health Institute (1686 Barton Road, Redlands, 92373).

Timeline for the study is as follows:

	Oct '11	Nov '11	Dec '11	Jan '12	Feb '12	Mar '12	April '12	May '12	June '12	July '12	Aug '12	Sept '12
Recruitment (N=90)	X	X	X	X	X							
Pre-Intervention Group Assessments for Spring and Summer Groups (N=90)		X	X	X	X							
Spring Group Intervention (N=45)						X	X					
Post-Intervention Assessments for Spring Group (N=45)								X				
Second Pre-Intervention Assessment for Summer Group (N=45)								X				
Summer Group Intervention (N=45)									X	X		
Post-Intervention Assessments for Summer Group (N=45)											X	

NOTE: Follow-up assessments will be conducted after 6 months post-intervention. They will occur in November 2012 for the Spring group and in February 2013 for the Summer group.

INCLUSION/EXCLUSION CRITERIA

All individuals invited to participate in the study will be parents of children with developmental delays and clinically significant behavior problems. When there are two parents in the family, both parents will be invited to participate in the study; however, two parents from the same family will only count as one family. In other words, we plan to recruit the parent(s) of 90 children with developmental delays. Criteria for study entry are: (1) Having a child ages 3 to 5, (2) child has been determined by Regional Center (or by an independent assessment) to have a developmental delay, (3) parent(s) report more than 10 child behavior problems (the recommended cutoff score for screening children for treatment of conduct problems) on the Eyberg Child Behavior Inventory (ECBI; Robinson, Eyberg, & Ross, 1980), (4) the parent(s) is not receiving any form of psychological or behavioral treatment at the time of referral (e.g. counseling, parent training, parent support group, etc.), (5) parent(s) agree(s) to participate in the intervention (this requirement will be determined based on whether the parent(s) signs the consent form), and (6) parent(s) must speak and understand English.

Exclusion criteria include parents of children with debilitating physical disabilities or severe intellectual impairments that prevent them from participating in the assessment tasks described in the protocol (e.g. child is not ambulatory). As mentioned above, the child is only involved in the assessment aspects of the study pre-intervention, post-intervention, and at follow-up. During these assessments the child is instructed to play on the floor with the parent for 25 minutes. This task requires the child to understand the researcher's directions, sit-up on his/her own, explore different toys in the room, and interact with the parent. Therefore, if the child has a physical disability or severe intellectual impairment that prevents him or her from participating in the play task the family will be excluded from the study.

Robinson, E. A., Eyberg, S. M., & Ross, A. W. (1980). The standardization of an inventory of child conduct problem behaviors. *Journal of Clinical Child Psychology, 9*, 22-29.

SUBJECT RECRUITMENT & SCREENING

The goal is to recruit 90 families during the first 5 months of the study (October through February). When there are two parents in the family, both parents will be invited to participate in the study; however, two parents from the same family will count as one family. In other words, we plan to recruit the parent(s) of 90 children with developmental delays. We anticipate that about 20% of the sample will not complete the intervention leaving a total sample of about 70 families for the complete study. According to power calculations, sample size of 70 is sufficient to detect a medium size effect with a power of .80, giving us an 80% chance of detecting a significant effect if it is there.

Participants will be limited to parents of children ages 3 to 5 who are English-speaking. The rationale for the age restriction is that parents of children often exhibit heightened stress during the preschool years, while simultaneously experiencing a reduction in services because Early Start services in California terminate when the child is 3 years of age (Neece, Green, & Baker, in press).

This intervention is targeted for this specific risk group. Additionally, all parents must speak and understand English because the Principal Investigator who will be delivering the intervention is monolingual English speaking. Other than these two restrictions, recruitment will be open to parents of all races/ethnicities, socio-economic classes, sexual orientations, and religions.

In terms of vulnerable subjects, this research primarily involves parents of children with developmental delays and elevated behavior problems. The research focuses on the questions of (1) how parental stress contributes to subsequent behavior problems in children with delays and (2) how reducing parental stress and promoting parent's mental health impacts children's behavior over time. Children will only be asked to participate in a 25-minute play assessment pre and post-intervention as well as at the follow-up assessment. This study is minimal risk to children and their families.

Subjects will be primarily recruited through the Inland Empire Regional Center. The Principal Investigator (PI) has established collaborations with Regional Center and the Director of the agency, Carol Fitzgibbons, has committed to helping Dr. Neece recruit participants for the MAPS study (see enclosed letter from Regional Center). Families who meet the study criteria will be identified from the Regional Center's computerized data bases, and screened by agency staff. In order to protect confidentiality, letters to prospective families will be sent by the Regional Center staff, informing parents about our project (We have enclosed a sample letter). Interested parents will either contact the MAPS project by phone, return a postcard requesting us to contact them, or submit their contact information on the MAPS website. If the family indicates interest in participation the PI or her staff will conduct a phone screen (please refer to enclosed phone screen document). If the family meets eligibility for the study, an appointment will be scheduled for the initial laboratory assessment.

Neece, C.L., Green, S., Baker, B.L. (in press). Relationship between parenting stress and child behavior problems: An examination across time. *Journal of Intellectual and Developmental Disabilities.*

INFORMED CONSENT PROCESS

Informed consent will be obtained at the first laboratory assessment. Parents will be given the informed consent form (see included consent form) and asked to read the form. If the parent prefers, the experimenter will read the form to the parent. The experimenter will also provide a summary of study (e.g. timeline for intervention, expectations with regard to pre, post and follow up assessments, compensation, components of assessment, and potential risks of study). Parents will be informed that intervention group assignment is random and that they may be assigned to the Spring group (March through April 2012) or the Summer group (June through July 2012). The experimenter will be available to answer any and all questions the parent(s) has and to address any concerns. Parents will be reminded that their consent is voluntary, that they can withdrawal from the study at any point, and that they do not have to answer any question or participate in any task that they do not want to. Given the young age of the children in the study (ages 3 to 5), parents will consent for their own and their child's participation. The PI for this project has had extensive training in conducting research with similar families and has completed the HIPAA compliance training online (certificate is included). Graduate students working on

the project as research assistants have also completed the HIPAA training online and are completing training with the PI on providing informed consent and administering the standardized protocol.

STUDY DESIGN

Background. Parents of children diagnosed with developmental delays consistently report higher levels of parenting stress compared to parents of typically developing children (Dyson, 1993). These parents are faced with many challenges across their child's lifespan, including overcoming the disappointments related to the original diagnosis, securing school placements, and learning to navigate the health and educational systems (Glidden 1989; Floyd et al. 1996; Chen & Tang 1997). As a result, parents of children diagnosed with developmental disabilities are likely to have ongoing and new stressors that maintain and even increase stress levels across time, suggesting the stress of parents of children with developmental disabilities can be chronically high. Elevated stress levels are a concern because studies indicate that elevations in stress among parents of children with developmental disabilities are associated with anxiety, depression, and other mental health problems (Olsson & Hwang, 2001; Yirmiya & Shaked, 2005) as well as poor physical health, particularly in with respect to cardiovascular, immune, and gastrointestional systems (Miodrag & Hodapp, 2010).

Additionally, research conducted by the PI of the MAPS Project, Dr. Cameron Neece, and others indicates that parental stress and well-being have significant implications for children with developmental delays. Dr. Neece has shown that early elevations in parenting stress are associated with poorer social skills later in development (Neece & Baker, 2008), higher levels of behavior problems (Neece, Green, & Baker, in press), as well as a later ADHD diagnosis (Baker, et al, 2010) among children with developmental disabilities. Furthermore, research indicates that the treatment of children with developmental delays may be compromised when parents are experiencing overwhelming levels of stress (Robbins, Dunlap, & Plienis, 1991).

Given the negative consequences of stress for parents and their children, we must provide support to parents as well as their children. The MAPS Project was developed to reduce parenting stress in order to improve parental well-being, thereby optimizing outcomes for children with delays. MBSR, the intervention delivered in the MAPS Project, is an evidence-based stress-reduction intervention program supported by over two decades of extensive research showing its effectiveness in reducing stress, anxiety, and depression, and promoting overall well-being (Chiesa & Serretti, 2009; Grossman, Niemann, Schmidt, & Walach, 2004). These studies indicate that the majority of people who complete the 8-week program report greater ability to cope more effectively with both short and long-term stressful situations, which are critical skills for parents of children with developmental delays. MBSR may also help to improve one's parenting experience. Mindfulness helps parents to slow down, notice impulses before they act, really listen to their children, and come to a more relaxed and peaceful state of mind, which in turn has a positive effect on children with developmental delays.

MBSR is an empirically-supported secular (non-religious) based intervention that can be beneficial to people of all backgrounds. The MBSR course offers intensive training in relaxation techniques, meditation, gentle Yoga-based stretching, lectures in various aspects of health and

wellness, and supportive group discussions. The program includes eight weekly 2.5 hour sessions, a day-long meditation retreat, daily home practice based on audio CDs with instruction, and daily record keeping of mindfulness exercises. The emphasis on Mindfulness, which simply means paying attention to each moment in a non-judgmental way, fosters a practical way to apply these methods in everyday life.

Although MBSR has not been evaluated as an intervention for parenting stress, studies have supported the efficacy of other mindfulness interventions with parents, suggesting that this type of intervention is feasible and effective with this population. More specifically, "mindful parenting" interventions have been found to be effective in reducing children's externalizing behaviors and attention problems as well as improving children's self-control, compliance, and attunement to others (Singh et al., 2010). This is a manualized parenting intervention that incorporates mindfulness, self-awareness, and intentionality. In contrast to MBSR where the focus is on the parents' personal stress, the focus of this approach is on the parent-child relationship and the intervention teaches parents to identify interactions that result in relational disconnectedness (Placone-Willey, 2002). This intervention has been used with the parents of typically developing children with externalizing behavior problems as well as children with autism (Singh et al., 2006). These studies support the efficacy of using mindfulness interventions for parents; however, they generally have small samples and lack random assignment or control groups, suggesting there is still a clear need for research in this area.

In addition to hopefully helping families cope with children's behavior more effectively, this study is also important because it is a rigorous, experimental test of the PIs theoretical model. This study will experimentally manipulate parenting stress and then look for subsequent changes in child behavior problems. If there are changes, this provides stronger evidence that parenting stress has an effect on the development of children's behavior problems.

Baker, B.L., Neece, C.L., Fenning, R., Crnic, K. A., & Blacher, J. (2010). Mental disorders in five year old children with or without intellectual disability: Focus on ADHD. *Journal of Child Clinical and Adolescent Psychology, 49,* 492-505.

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Chen, T. Y., & Tang, C. S. (1997). Stress appraisal and social support of Chinese mothers of adult children with mental retardation. *American Journal on Mental Retardation, 101*, 473-482.

Chiesa, A., & Serretti, A. (2009). Mindfulness-based stress reduction for stress management in healthy people: A review and meta-analysis. *The Journal of Alternative and Complementary Medicine, 15*(5), 593-600.

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Miodrag, N., & Hodapp, R. M. (2010). Chronic stress and health among parents of children with intellectual and developmental disabilities. *Current Opinion in Psychiatry, 23*(5), 407-411.

Neece, C.L. & Baker, B.L. (2008). Predicting maternal parenting stress in middle childhood: The roles of child intellectual status, behavior problems, and social skills. *Journal of Intellectual Disability Research, 52,* 1114-1128

Neece, C.L., Green, S., Baker, B.L. (in press). Relationship between parenting stress and child behavior problems: An examination across time. *Journal of Intellectual and Developmental Disabilities.*

Olsson, M. B., & Hwang, C. P. (2001). Depression in mothers and fathers of children with intellectual disability. *Journal of Intellectual Disability Research.Special Issue: Mental Health and Intellectual Disability: IX, 45*(6), 535-543.

Placone-Willey, P. M. (2002). *A curriculum for mindful parenting: A model development dissertation.* ProQuest Information & Learning). *Dissertation Abstracts International: Section B: The Sciences and Engineering, 63*(1-B).

Robbins, F. R., Dunlap, G., & Plienis, A. J. (1991). Family characteristics, family training, and the progress of young children with autism. *Journal of Early Intervention, 15*(2), 173-184.

Sanders, J. L., & Morgan, S. B. (1997). Family stress and adjustment as perceived by parents of children with autism or down syndrome: Implications for intervention. *Child & Family Behavior Therapy, 19*(4), 15-32.

Singh, N. N., Lancioni, G. E., Winton, A. S. W., Fisher, B. C., Wahler, R. G., McAleavey, K., ... (2006). Mindful parenting decreases aggression, noncompliance, and self-injury in children with autism. *Journal of Emotional and Behavioral Disorders, 14*(3), 169-177.

Singh, N. N., Lancioni, G. E., Winton, A. S. W., Singh, J., Singh, A. N., Adkins, A. D., & Wahler, R. G. (2010). Training in mindful caregiving transfers to parent–child interactions. *Journal of Child and Family Studies, 19*(2), 167-174.

Yirmiya, N., & Shaked, M. (2005). Psychiatric disorders in parents of children with autism: A meta-analysis. *Journal of Child Psychology and Psychiatry, 46*(1), 69-83.

Objectives

Aim 1: To determine whether MBSR is a feasible intervention with parents of children with developmental delays.

- Hypothesis: The majority of parents (minimum of 60%) who enter the program complete the full 8 weeks of the program. Although we hope for less attrition, this is a conservative estimate given that attrition from child psychotherapy in general is high, ranging from 40% to 60% (Wierzbicki & Pekarik, 1993).

Aim 2: To examine whether MBSR leads to reductions in parenting stress.

- Hypothesis: Parents will self-report significantly lower levels of stress post-intervention and at follow-up.

Aim 3: To investigate whether MBSR is associated with changes in parenting behavior.

- Hypothesis: Parent receiving the intervention will exhibit less negative and intrusive behavior and more positive and sensitive behavior compared to controls as evidenced in observational as well as self-report measures.

Aim 4: To determine whether reductions in parenting stress are associated with decreases in child behavior problems at post-intervention and at follow up.

- Hypothesis: Children of parents receiving MBSR will show greater reductions in behavior problems compared to children of waitlisted parents as evidenced by the participating parent, spouse/significant other, and teacher reports.

Aim 5: To evaluate whether parenting behavior mediates the relationship between parenting stress and child behavior problems.

- Hypothesis: Parenting behavior will mediate the relationship between parenting stress and child behavior problems such that, once parenting behavior is accounted for, the relationship between parenting stress and child behavior problems will be significantly reduced (partially mediated) or no longer significant (fully mediated).

Aim 6: To examine variables that may moderate the effect of the intervention (reducing parental stress) on child behavior problems.

- Hypothesis: The effect of the intervention in reducing parents' levels of stress and children's subsequent behavior problems will be greater for parents with less social support (e.g. marital adjustment, family support) and who have fewer psychological resources (e.g. low dispositional optimism, less feelings of self-mastery), are less satisfied with their parenting, and have a more negative relationship with their child pre-intervention. Additionally, parents of children with more difficult temperaments will also evidence greater intervention gains.

References

Wierzbicki, M., & Pekarik, G. (1993). A meta-analysis of psychotherapy dropout. *Professional Psychology: Research and Practice, 24*(2), 190-195

Procedures

Interested parents will either contact the MAPS project by phone, return a postcard requesting the PI to contact them, or submit their information on the MAPS website. If the family indicates interest in participation, the PI will conduct a phone screen (please refer to enclosed phone screen document). If the family meets eligibility for the study, an appointment will be scheduled for the initial laboratory assessment.

Prior to the initial laboratory assessment, parents will be mailed a packet of questionnaires that they will complete prior to coming into the lab. Only parents participating in the study will complete the packet; however, each parent's significant other (or if it is a single parent family another significant adult in the child's life) will complete two questionnaires (one about the child's behavior problems and about the child's social skills) in order to minimize shared method variance.

At the initial assessment, parents will be given an informed consent form that the PI or her staff will review with the parent (see informed consent procedures described above). After that, the parent and the child will participate in a 25-minute play assessment in the lab, which will be videotaped for later coding. Parent and child will be given a standardized set of toys and there

are 3 parts of the assessment: (1) *Child-led play* (parent is instructed to allow the child to choose any activity and play along with the child); (2) *Parent-led play* (parent is instructed to select an activity and to keep the child playing according to the parent's rules); and (3) *Clean-up* (parent is instructed to give the child a command to clean up). This task is standard procedure for the Dyadic Parent-Child Interaction Coding System (DPICS, Robinson & Eyberg, 1981), which will be used in this study to measure parenting behavior. After the observation task with the child, parents will meet with the experimenter to complete a demographic questionnaire and the Children's Global Assessment of Functioning Questionnaire. Parents will also be given a letter and two questionnaires for the child's teacher to complete. After completing these measures, the parents will draw a piece of paper out of a box which informs them whether they will be in the spring or summer intervention group.

Parents assigned to the spring group will begin intervention in March and parents assigned to the summer intervention will begin intervention in June. The intervention will follow the MBSR manual outlined by Dr. Jon Kabat-Zinn (Kabat-Zinn et al., 1992). The intervention consists of three main components: (1) didactical material covering the concept of mindfulness, the psychology and physiology of stress and anxiety, and ways in which mindfulness can be implemented in everyday life to facilitate more adaptive responses to challenges and distress, (2) mindfulness exercises during the group meetings and as homework between sessions, and (3) discussion and sharing in pairs and in the larger group. The MBSR program includes eight weekly 2.5 hour sessions, a day-long meditation retreat after class 6, and daily home practice based on audio CDs with instruction. Formal mindfulness exercises include the body scan, sitting meditation with awareness of breath, and mindful movement. MBSR is an empirically supported secular (non-religious) based intervention that can be beneficial to all people. The PI has undergone formal training in MBSR through InsightLA (http://www.insightla.org) and has multiple collaborations with formal MBSR teachers. Currently, Dr. Neece is planning to deliver the intervention herself; however, if funding permits she will hire a certified MBSR teacher (who will complete HIPAA certification and obtain IRB approval before teaching).

After the completion of the project (all assessments have been conducted) parents will receive a short summary of their child's current and previous behavioral functioning in order to reinforce parents' efforts to improve their parenting skills as well as raise awareness of remaining concerns.

Kabat-Zinn, J., Massion, A. O., Kristeller, J., & Peterson, L. G. (1992). Effectiveness of a meditation-based stress reduction program in the treatment of anxiety disorders. *The American Journal of Psychiatry, 149*(7), 936-943.

Robinson, E. A., & Eyberg, S. M. (1981). The dyadic parent–child interaction coding system: Standardization and validation. *Journal of Consulting and Clinical Psychology, 49*(2), 245-250.

Measures and Data Collection

See table below for information on measures and data collection time points (pre-intervention, post-intervention, and follow-up)

Measures for MAPS Program (Mindful Awareness & Parenting Stress)

Measure	Pre-Tx	Post-Tx	Follow-Up	Description	Type of Measure
Outcome Measures of Child Functioning					
Dyadic Parent-Child Interaction Coding System (DPICS)	X	X	X	Coding system that measures child behaviors that including whine, cry, yell, physical negative, smart talk, destructive, and noncompliance. These scores combine into a Total Child Deviance composite score.	Lab Observation
Child Behavior Checklist (Ages 1.5-5)	X	X	X	One of the most widely used measures of child behavior problems Each CBCL item indicates a child problem (e.g. fails to finish things he/she starts, temper tantrums or hot temper, sleeps more than most kids). For each item parent will indicate whether it is "not true" (0), "somewhat or sometimes true" (1), or "very true or often true" (2), now or within the past two months. This measure will be completed by participating parent as well as the spouse or other significant person nominated by spouse in order to minimize shared method variance.	Parent Report
Caregiver-Teacher Report Form for Ages 1.5-5	X	X	X	Childcare provider/teacher version of CBCL	Teacher Report
Eyeberg Child Behavior Inventory	X	X	X	The Eyberg Child Behavior Inventory (ECBI), designed to assess parental report of conduct behavioral problems in children and adolescents ages 2-16, measures the number of difficult behavior problems and the frequency with which they occur. Studies have indicated that the ECBI has good reliability and validity.	Parent Report
Social Skills Improvement System (SSIS)-Preschool Version, Parent Report	X	X	X	Child social skills will be measured using the SSIS. We believe that reductions in parenting stress may indirectly lead to improvements in children's social abilities. The SSIS is a widely used measure of social skills that asks parents to rate behaviorally specified social skills on two dimensions. The frequency dimension consists of a 3-point rating scale, including 0 (not true of the child), 1 (sometimes true), and 2 (often true). The second	Parent Report

Measure	Pre-Tx	Post-Tx	Follow-Up	Description	Type of Measure
Social Skills Improvement System (SSIS)-Preschool Version, Parent Report Continud	X	X	X	dimension, the importance of each skill, will not be assessed for this study. The scale yields scores that can be converted to standard scores (M = 100; SD = 15). The SSRS-P measures the domains of Communication, Cooperation, Assertion, Responsibility, Empathy, Engagement, Self-Control and yields a Total Social Skills score	Parent Report
Social Skills Improvement System (SSIS)-Preschool Version, Teacher Report	X	X	X	Teacher version of SSIS; also includes ad Academic Competence Scale score that not in parent version.	Teacher Report
Children's Global Assessment of Functioning (C-GAS)	X	X	X	The Children's Global Assessment Scale (CGAS) is a numeric scale (1 through 100) where parents rate the general functioning of children under the age of 18.	Parent Interview
Independent Variable Measures of Parental Stress and Overall Parental Functioning					
Parenting Stress Index-Short Form	X	X	X	The PSI-SF (Abidin, 1995) is a 36-item questionnaire designed to measure the extent to which parents are experiencing stress. The PSI-SF contains subscales assessing stress in three domains on a 5-point scale: Parent-Child Dysfunctional Interaction (e.g. "My child rarely does things for me that make me feel good."), Difficult Child (e.g. "My child gets upset easily over the smallest thing"), and Parental Distress (e.g. "There are quite a few things that bother me about my life"). The sum of these three subscales creates a Total Parenting Stress score. The measure has high validity and good internal consistency (Reitman, Currier, & Stickle 2002).	Parent Report
Center for Epidemiological Studies- Depressed Mood Scale (CES-D)	X	X	X	In order to look at the impact of the MAPS Project on parental depression, parents will complete the CED-D, a 20-item self-report measure of depressive symptoms including mood, somatic complaints, and cognitions. Total scores can range from 0 to 60, with a cut- off of 16 for the clinical range. The CES-D has four subscales – somatic symptoms (7 items), depressed affect (7 items), positive affect (reverse scored; 4 items), and interpersonal functioning (2 items).	Parent Report

Measure	Pre-Tx	Post-Tx	Follow-Up	Description	Type of Measure
Symptom Checklist-35 (SCL-35)	X	X	X	A 35-item questionnaire completed by parents that measures perceived levels of distress and addresses psychological symptomatology across dimensions of anxiety, depression, hostility, and interpersonal relatedness.	Parent Report
Family Impact Questionnaire	X	X	X	50-item questionnaire designed to measure parents' perceptions of the impact of a child on the family relative to the impact that "most children his/her age have on their family".	Parent Report
Measures of Mediating Variables					
Dyadic Parent-Child Interaction Coding System (DPICS)	X	X	X	Coding system that measures parenting behavior including the following codes: Positive Parenting (DPICS–PP; includes praise, positive affect, and physical positive); Negative Parenting (DPICS–NP; includes negative commands, critical statements, and physical negative); and Total Commands (DPICS–TC; includes indirect and direct commands).	Lab Observation
Alabama Parenting Questionnaire-Parent Global Report	X	X	X	This questionnaire will be used to assess self-reported parenting practices. The APQ consists of 42 items presented with a 5-point endorsement scale (Never, Almost Never, Sometimes, Often, Always), which map onto five subscales (Poor Monitoring and Supervision, Inconsistent Discipline, Corporal Punishment, Positive Parenting Techniques, Parental Involvement), as well as the three broad factors structure (Positive Involvement, Negative/Ineffective Discipline, Deficient Monitoring). The APQ is a widely used self-report measure of parenting behavior.	Parent-Report
Parent Practices Interview	X	X	X	This questionnaire was adapted from the Oregon Social Learning Center's (OSLC) discipline questionnaire and revised for young children. The PPI can be administered as an interview or used as a self-report questionnaire completed by the child's primary caregiver. It has the following composites: Harsh Discipline, Harsh for Age, Inconsistent Discipline, Appropriate Discipline, Positive Parenting, Clear Expectations, and Monitoring.	Parent-Report

Measure	Pre-Tx	Post-Tx	Follow-Up	Description	Type of Measure
CCNES: Coping with Children's Negative Emotions Scale	X	X	X	A 72-item questionnaire measuring the degree to which parents perceive themselves as reactive to young children's negative affect in distressful situations. Six subscales are derived that reflect the specific types of coping responses parents tend to use in these situations (distress reactions, punitive reactions, expressive encouragement, emotion-focused reactions, problem-focused reactions, and minimization reactions).	Parent-Report
Measures of Moderating Variables					
Dyadic Adjustment Scale (DAS)	X	X	X	32-item self-report measure of marital adjustment. It has 4 subscales: Dyadic Consensus, Dyadic Satisfaction, Affectional Expression, and Dyadic Cohesion	Parent-Report
LOT-R: Life Orientation Test-Revised	X	X	X	The Life Orientation Test-Revised (LOT-R) assesses individual differences in generalized optimism versus pessimism. This measure has been used in a good deal of research on the behavioral, affective, and health consequences of this personality variable.	Parent-Report
Life Experiences Survey	X	X	X	49-item questionnaire regarding major events that have occurred within the past 6 months and the perceived degree of impact (or stress) related to these individual events.	Parent-Report
Family Relationship Index of the Family Environment Scale	X	X	X	The Family Relationship Index of the Family Environment Scale has three subscales that measure family Cohesion (the degree of commitment and support family members provide for one another), Expressiveness (the extent to family members are encouraged to express their feelings directly), and the Conflict (amount of openly expressed anger and conflict among family members).	Parent-Report
General Life Satisfaction Index	X	X	X	A 1-item measure asking parents to rate their satisfaction with their current life situation.	Parent-Report

Measure	Pre-Tx	Post-Tx	Follow-Up	Description	Type of Measure
Family Support Scale	X	X	X	The self-report Family Support Scale (FSS) measures parents' satisfaction with the support they receive in raising a young child. The scale consists of 18 items covering such sources of support as the immediate family, relatives, friends and others in the family's social network, social organizations, and specialized and generic professional services. In addition, the scale provides 2 open-ended items for parents to assess other sources of support not included in the 18 items. The parent rates each source of support on a 5-point Likert scale (ranging from not at all helpful (1) to extremely helpful (5)).	Parent-Report
Self-Mastery Scale	X	X	X	A 7-item questionnaire completed by parents measuring perceived level of control over life events.	Parent-Report
Child Behavior Questionnaire	X			The Children's Behavior Questionnaire has been designed to measure temperament in children. The CBQ assesses fifteen dimensions of temperament.	Parent Report
Parenting Relationship Questionnaire	X	X	X	47-item questionnaire designed to capture a parent's perspective of the parent-child relationship. Subscales: Attachment, Discipline Practices, Involvement, Parenting Confidence, and Relational Frustration.	Parent-Report
Child Rearing Inventory (CRI)	X	X	X	The CRI is an 11-item parent report measure of tolerance for child misbehavior.	Parent Report
Parental Satisfaction Scale	X	X	X	Questionnaire designed to assess parents' attitudes toward parenting. It has 3 subscales: Satisfaction with Spouse/Ex-Spouse Parenting Performance, Satisfaction with the Parent-Child Relationship, and Satisfaction with Parenting Performance.	Parent-Report
Acceptance and Action Questionnaire-II	X	X	X	Measures psychological acceptance in parents of children with disabilities	Parent

Measure	When Assessed	Description	Type of Measure
Process Variables			
Attendance	Taken at each group session	Yes/no was the participant at session	Group leader
Treatment evaluation form	Completed by parents at 4th and last session	Measure of treatment satisfaction and program evaluation	Parent-Report
Ratings of primary stressors	Completed by parents at 1st, 4th and last session	Parents list their top 3 stressors and rank how stressful they are on a scale from 1 to 10.	Parent-Report
Five Facets of Mindfulness Questionnaire	Completed at sessions 1, 4, and 8	Self-report inventory for the assessment of general mindfulness skills. Subscales include: Observe, Describe, Act with Awareness, Nonjudge, and Nonreact	Parent-Report
Mindful Parenting Scale	Completed at sessions 1, 4, and 8	Self-report inventory for the assessment of how parenting incorporate mindfulness into their parenting. Subscales include: Observe, Describe, Act with Awareness, Nonjudge, and Nonreact	Parent-Report
Family Information Form (FIF)	X	Family demographic and health history completed as an interview with the parents during the lab visit.	Parent Interview

DATA STORAGE

Usual procedures are used to safeguard participants in this research. All participants are protected by the applicable laws and professional regulations and ethics from disclosures of confidential information. The confidentiality of all information obtained in the study will be protected, and all study personnel will be trained in the strict requirement of not disclosing any information obtained in the study.

To protect confidentiality, data will be coded by subject number rather than name, and all identifying information will be kept separate from the data. All hard copies of instruments will be kept in a locked storage cabinet that is kept in a locked room within a locked research building. In addition, all hard copy and electronic data will be stored by identification number only. Electronic copies of the data will be stored on computers and servers with strong passwords for future analyses. Data will only be saved in a secure location on the LLU server. If a portable device (e.g. laptop) is used at any point in the study, the device will be encrypted, data will onlt be stored on the device temporarily, and the device will be stored in a physically secure location (e.g. locked in laboratory room). Access to the data is restricted to authorized study personnel. Data will be retained in locked files until it is clear that no further analyses will be done.

The informed consent form states that information about the family cannot be released to anyone other than the consenting parent unless the investigators have signed written permission. The informed consent form states that information about the child can be released only if the investigators learn of physical or sexual abuse of the child or the investigators learn that someone is in imminent danger of harm. There is no plan to release data to any agency. Information provided by one study participant (mother, father, teacher, youth) will not be shared with any other participants.

These stringent safeguards are likely to be effective and will remain to fully protect the participants, with very little likelihood of risk.

DATA ANALYSIS

Data analysis will primarily use parametric statistics to examine (1) whether there is a significant reduction in parenting stress as a result of the intervention (e.g. dependant sample t-tests), (2) whether there is a significant reduction in children behavior problems as a result of the intervention (e.g. dependant sample t-tests), (3) whether parenting behavior mediates the relationship between reductions in parenting stress and subsequent reductions in child behavior problems (e.g. hierarchical multiple regression and univariate analysis of variance), and (4) whether the impact of the intervention on parenting stress and/or children behavior problems changes as a function of the specified modifying variables (e.g. hierarchical multiple regression and univariate analysis of variance). Hierarchical Linear Modeling (HLM) may be employed after the project is completed to examine growth trajectories of the variables of interest over time.

POTENTIAL RISKS AND DISCOMFORTS

Risks for participants are minimal. All procedures for this study have been used widely in previous research, with little to no discomfort or risk to either the parents or the child. Nevertheless, some of the questions in the questionnaires and interviews do seek personal information, and might be considered an invasion of privacy (e.g. questions about the marriage). Only the parent is asked to provide information and complete questionnaires. The child is not interviewed or asked to complete any measures. However, the child is asked to participate in a play task with the parent(s) and during this task the child might experience some mild frustration (e.g. during the clean-up task). In the PI's experience using these tasks in similar studies, the risks or likelihood of discomfort is minimal. Additionally, if the parent and/or child decide to not complete the assessment (e.g. not complete a questionnaire, refuse to participate in the play assessment) the family will still be compensated for the assessment. The parent(s) and child have the right to refuse to answer any question or terminate their involvement in the study at any time.

In order to minimize risks, participants will be free to choose not to respond to any item or participate in any activity they find potentially objectionable. The PI (who is a clinical psychologist) will be available at all times to address any concerns subjects may have. The assessment will not be longer than 40 minutes in order to minimize demands on the parent and child. However, parents and children will also be able to take breaks as needed. Additionally, in the event that an assessment needs to be rescheduled, the family will be compensated upon completion of the rescheduled assessment. Finally, as described above, if the parent and/or child decide to not complete the assessment once the assessment as already begun (e.g. not complete a questionnaire, refuse to participate in the play assessment) the family will still be compensated for the assessment. However, if the family withdraws from the study before completion, they will not receive the remaining payments.

BENEFITS

Potential benefits to the family include: (1) possible reduction in parental stress and improvement in parents' mental health following the intervention, (2) possible decline in children's behavior problems and improvement in their social competence following the intervention, and (3) possible increase in positive parenting behavior and decrease in negative/intrusive parenting behavior following the intervention. Additionally, families will have access to specialists in child development, the opportunity to learn more about their children's abilities through the laboratory assessment, and receipt of feedback about their children's behavioral development after the intervention is completed.

Benefits to society include the identification of intervention programs that may help reduce parental stress and child behavior problems, both of which are a significant concern among families of children with developmental delays. Furthermore, this study may help to elucidate the processes that pose risk for children with developmental delays, as well as identify processes that serve as protective factors for these children's emerging abilities. More specifically, we will examine the mechanisms through which parental stress and mental health problems impact the development of children's behavioral difficulties and this information can be used to further develop preventive intervention programs for children and families.

COMPENSATION

To compensate families for their participation and to keep attrition to a minimum, we will offer subject payments to families. Families will receive amounts of $10 (pre-intervention assessment), $15 (post-intervention assessment), and $50 (follow-up assessment), resulting in total payments of $75 for these visits. The amount increases as the study progresses, reflecting the increased value of longitudinal subjects over time. Other benefits to the families include paid parking during lab visits, childcare provided during intervention groups, access to specialists in child development, the opportunity to learn more about their children's abilities across various situations, and receipt of feedback about their children's behavioral development at the end of the intervention.

INSTITUTIONAL REVIEW BOARD
CHANGE REQUEST FORM

Research Protection Programs • 24887 Taylor Street • Suite 202 • Loma Linda, CA 92350
(909) 558-4531 (voice) • (909) 558-0131 (fax)

IRB# 5110264
Printed: 12/12/2017 12:45:01 PM

Principal Investigator: **Neece, Cameron L**
Department: **Psychology**
Protocol Title: ***Mindful awareness for parenting stress (MAPS) project for parents of children with developmental delays***
Current Approval Period: **8/21/2017** to **8/20/2018**
Current Stipulations: <None Specified>

I. CHANGE REQUEST DUE TO:

☒ *Initiated by local (LLU) Investigator.*

II. PROTOCOL CHANGES:

a. Summary: ***We need to change the title of the study to match the NIH grant title***
b. Classification of significant change(s):
ADMINISTRATIVE ONLY.
c. CHECKLIST OF ITEMS TO INCLUDE: Documentation regarding administrative changes.

"I accept responsibility for the factual content of this report and am available for discussion if additional questions are raised."

Signature of Principal Investigator

12/12/17
Date (information provided as of this date)

***Please return form, together with the appropriate attachments, to:* Office of Sponsored Research**

OFFICE USE ONLY

INSTITUTIONAL REVIEW BOARD ACKNOWLEDGEMENT and REPORT TO PRINCIPAL INVESTIGATOR.

☒ Change Report is accepted as submitted. Summary will appear in Research Report at conclusion of approval period.
☒ Further information required, as follows: Provide Change Request amending title on consent and any other subject related document
☐ PI needs consultation with IRB chair.
☐ Amendment requires full board review. Submit 4 packets - original and three copies.

Loma Linda University
Adventist Health Sciences Center
Institutional Review Board
Approved Lynda C Haltiwanger
Date 12/14/17

RECEIVED

JUL 0 3 2018

LLUH Responsible
Research Services

Institutional Review Board
CHANGE REQUEST FORM

RESEARCH PROTECTION PROGRAMS | LOMA LINDA UNIVERSITY | Office of Research Affairs
24887 Taylor Street, Suite 202 Loma Linda, CA 92350 *(909) 558-4531 (voice) / (909) 558-0131 (fax)/e-mail: irb@llu.edu*

Principal Investigator: Cameron Neece
Department: Psychology
Protocol Title: Mindful awareness for parenting stress (MAPS) project for parents of children with developmental delays
IRB #: 5110264 Approval End Date: Aug 20, 2018
Current Stipulations: N/A

I. This Change Request is a result of: (check all that apply)

☐ Initiated by Sponsor.
☒ Initiated by local (LLU) Investigator.
☐ Result of Adverse Event;
re: AE report submitted: ("Unique Identifier")
☐ Protocol change was necessary to eliminate apparent immediate hazards to subject(s).

II. Protocol Change(s):

a. Briefly summarize this Change Report, using the preferred wording to appear in the IRB's approval letter.
(This is also the only description appearing in future protocol profiles.)

We are submitting changes to our phone screen, consent form, and questionnaire measures to be consistent with our recently awarded NIH grant (LLeRA 2170159) which falls under this IRB. More specifically, for the phone screen, we are going to ask parents whether their child has an autism spectrum diagnosis, administer the Parenting Stress Index-Short Form 4th Edition instead of the Perceived Stress Scale during the phone screen, and screen for exclusionary criteria. A very similar phone screen was approved for another study of mine (HS 5170325) and these questions have worked very well.

With regard to the consent form changes, we have updated the our previous consent form from the MAPS project to reflect the revised aims and procedures for the NIH grant. We have included a clean copy of our new consent form (title is Stress-reduction techniques for effective parenting skills (STEPS) project), our previous MAPS consent with the track changes, as well as a clean copy of the approved MAPS consent form in order to make the changes clear.

With regard to questionnaires, for the NIH grant we have added a few parent questionnaires. More specifically, we have included a revised version of the Parenting Stress Index (we are now using the 4th edition instead of the 3rd edition that we used on MAPS), the Social Communication Questionnaire, Attachment Q-Sort questionnaire, Beck Anxiety Inventory, Behavioral Inhibition Questionnaire, Preschool Anxiety Questionnaire, Repetitive Behavior Scale-Revised, Family Resource Scale, Parenting Scale, and Parental Flooding Scale. We have also added one teacher-report questionnaire, the Preschool Anxiety Questionnaire-teacher report version. All of these measures are psychometically sound and have been frequently used with families of young children with developmental delays and Autism Spectrum Disorder.

b. Classification of significant change(s):
☐ SAFETY
1a. List any change(s) in monitoring (number each change):
1b. If any item(s) listed above DECREASE monitoring, explain why subject safety will NOT be adversely affected.

☒ PROCEDURES

2a. List any change(s) in subject-related intervention (number each change): None
2b. What is the scientific justification for item(s) above, and explain how risk to subjects is affected:

There is no additional risk to subjects. The changes are scientifically justified because the revised changes to the phone screen, consent, and questionnaires will more accurately identify the families eligible for this study (phone screen), provide more accurate information to participants about what the study will entail (consent), add additional psychometrically sound measures to assess the constructs of interest, and is in line with the NIH funded proposal.

☒ SUBJECTS
3a. List any change(s) that remove exclusion criteria or broaden inclusion criteria (number each change): The study will now focus on children with Autism Spectrum Disorder specifically, rather than children with developmental delays more broadly.

3b. Justify any item(s) above that remove safety exclusion or modifies fairness in subject selection: This is what was approved by NIH for this project.

☒ ADMINISTRATIVE
4a. Change study title of IRB approval to the following: Stress-reduction techniques for effective parenting skills (STEPS) project
4b. If study personnel will be changed, use the "Request to Change IRB Study Personnel" form.
4c. If sponsor has changed, name of sponsor is:

c. If an updated Investigator's Brochure or Supplement accompanies this Change Request, choose one of the following options:
☐ Attach a Summary of specific changes addressed in the Investigator's brochure.
☐ Principal Investigator will review Investigator's brochure and attest to nonsubstantive content of changes.

III. Change(s) in informed consent:

a. Does the Change Request affect the process of obtaining informed consent?
☐ No
☒ Yes, describe: See notes under section II. Also, see track changes in consent documents.

b. Does the Change Request affect the IRB-approved Informed Consent Document (ICD)?
☐ No
☒ Yes, *submit revised ICD with changes highlighted for IRB review/approval, and clean copy for the IRB authorization stamp.*
NOTE: If sponsor has changed (as stated in section II-b), ICD should reflect the new sponsor.

c. Does the Change Request involve re-consenting subject(s) already enrolled?
☒ No, provide a brief rationale: Previous subjects will not be involved in this new NIH study.

☐ Yes, describe how this will occur: If a new consent document will be used, check here ☐ and attach for IRB review/approval.

IV. CHECKLIST OF ITEMS TO INCLUDE:

☒ Revised consent document is attached, with a copy highlighting requested changes.

V. PI's ATTESTATION:

I accept responsibility for the factual content of this report and am available for discussion if additional questions are raised.

Signature of Principal Investigator

7/3/18
Date

OFFICE USE ONLY

RPP ACKNOWLEDGEMENT and REPORT TO PRINCIPAL INVESTIGATOR.

☑ Change Report is accepted as submitted. Summary will appear in the Research Report for this study at the conclusion of this study's approval period.

☐ Further information required, as follows: _____

☐ PI needs consultation with IRB chair.

☐ Amendment requires full board review. Submit 26 copies of this report to the IRB to be scheduled on the agenda.

Signature of IRB Representative

7-16-18
Date

Version date: 3/07/17

LOMA LINDA UNIVERSITY

INFORMED CONSENT

TITLE: Stress-reduction Techniques for Effective Parenting Skills (STEPS) Project

SPONSOR: National Institute of Health (NIH)

PRINCIPAL INVESTIGATOR Cameron L. Neece, Ph.D.
Address: Loma Linda University, Department of Psychology,
11130 Anderson St., Loma Linda, CA 92350
Phone Number: (909) 558-8615
Email: cneece@llu.edu

1. WHY IS THIS STUDY BEING DONE?

The purpose of this study is to compare two interventions aimed at increasing parental well-being in order to ultimately improve child behavioral outcomes. There will be two intervention groups, a mindfulness group and a parent education group. They will be similar in duration and intensity but will vary in content. We are interested in seeing how either the mindfulness or educational programs affect both immediate and longer-term outcomes for your family.

The rationale for this study is drawn from research, which suggests that parents of children with Autism Spectrum Disorder (ASD) often experience heightened parenting stress, compared to parents of typically developing children. High levels of parenting stress may affect your family over time and decrease the effectiveness of interventions. The goal of this project is to test how effective these programs are in decreasing parenting stress and in turn, how it affects child-behavior problems. You are invited to participate in this research study because you are a parent of a young child who has been identified as having ASD.

Approximately 140 subjects will participate in this study at Loma Linda University. Your participation in this study may last up to 18 months. Your family's participation in the project would consist of four lab visits over the course of 18 months. The first visit is about 2.5 hours long and the other three are about one hour long. Because we are interested in learning about the effect of the intervention on you and your child across time, we are seeking your participation from the pre-intervention assessment until the completion of the follow-up assessments (see details below). Your decision to participate or withdraw from this study will have no effect on other services you may be receiving (e.g. from the regional center or from Loma Linda University).

2. HOW WILL I BE INVOLVED?

Participation in this study involves the following:

Pre-Intervention Assessment: **An initial enrollment interview will be conducted at the first lab visit. This consent form will be mailed to you before the visit.** Additionally, you will be mailed a packet of questionnaires that should be completed by the participating parent(s) prior to the first lab assessment.

The pre-intervention visit will consist of several parts. First, you will be given an opportunity to ask further questions about the study and then we will obtain your consent. Next, you will engage in an observational play activity with your child for about 15 minutes. **This observation will be videotaped with your consent**. After the observation, you will be interviewed to obtain basic demographic and family background information, discuss your feelings about your child, as well as complete a semi-structured interview to get a better sense of your child's skills and behaviors. While you are being interviewed, your child will participate in a developmental evaluation. Once your child has completed the developmental assessments, an experimenter will go over any remaining questionnaires from the packet that was mailed prior to the visit.

After the assessment is complete, you and your child will have a short break while the research assistants will meet together to determine if you are eligible for the study. If you are to be eligible for the study, you will continue with the remainder of the assessment. If you are not eligible, we will compensate you for the baseline assessment and you can go home. There is a chance that the scores may need to be discussed with the Project Directors before determining eligibility. In this case, we may ask that you come in at a later date to complete the remainder of the assessment. In this situation, you will be compensated for your time and the project coordinator will call you within a week to set up a time for you to finish the visit.

The last portion of this assessment involves a brief interview where the research assistant will provide an overview of the interventions and spend about 20 minutes going over possible barriers to successful results and trouble-shoot how to address them. We will then confirm your teacher contact information and then give you your group assignment.

At the completion of the baseline lab assessment, you will be randomly assigned to either the mindfulness group or the parent education group. Both intervention groups will begin mid January of 2019. **We cannot guarantee your assignment to a particular group. This means that your group could meet on either a Tuesday or Wednesday and we cannot assign groups based on preference. Therefore, in consenting to participation, you are agreeing to participate in either group.**

The Intervention: Parents randomly assigned to the mindfulness group will receive eight sessions of Mindfulness-Based Stress Reduction (MBSR). This group consists of 8-weekly 2-hour group sessions, a day-long 6 hour meditation retreat during week 6 which will be held on a Sunday, 30–45 minutes of daily home practice guided by instructional audio CDs, and an MBSR parent workbook. Formal mindfulness exercises aim to increase the capacity for mindfulness (present-moment awareness with a compassionate, nonjudgmental stance) and include a body scan, mindful yoga, and sitting meditation. In the sessions, participants practice formal mindfulness exercises and ask questions relating to the practice of mindfulness in everyday life, and the instructor provides didactic instruction on stress physiology and using mindfulness for coping with stress in daily life.

Parents randomly assigned to the parent education group will receive eight sessions of education about children with developmental disabilities. The education group will also consist of 8-weekly 2-hour education sessions, a day-long (6hr) Family Resource Fair during week 6 which will be on a Sunday, daily homework to monitor progress on goals identified each session, and a workbook that provides families with information regarding their child's development, disability, and associated considerations. Each week has a general topic for discussion. Topics include Preparing for Individualized Education Plan (IEP) meetings, Navigating the Regional Center and Developmental Service Agencies, Communicating with Teachers, Advocacy, Sibling Issues, and Community Resources. At the start of each session, group leaders provide some educational material on the topic. Parents then break up into pairs for small group discussion followed by a larger group discussion and questions.

Subject Initials _____

Date _____

Post-Intervention Assessment: After the completion of the intervention, you will be asked to schedule a second lab assessment. A similar set of questionnaires will be mailed to your home that we ask you to complete prior to the lab visit. During the post-intervention visit, you and your child will complete a similar play activity for 15 minutes. This task will be recorded with the your permission. The post-intervention assessment will be shorter than the pre-intervention assessment and should last about one hour.

Follow-Up Assessments: Six and 12 months after the groups have finished, you will be asked to come back to the lab for a follow-up assessment to see how you and your child are doing. At this assessment, again you will be asked to complete a packet of questionnaires prior to the visit and will participate in a 15-minute play activity. The task will be recorded with your permission.

Teacher Assessment: Additionally, because we feel that input from each child's teacher is a critical element in gaining a complete picture of the child, each school year we will ask you to complete a permission form allowing your child's teacher to provide information to us. You will be asked to provide your child's teacher's/therapist's contact information so that we may mail a questionnaire packet to them before the intervention, at the end of the intervention, at 6 months, and at 12 months after the intervention is completed.

3. VIDEO RECORDING AGREEMENT

By signing this consent form, you give the researchers permission to video record the lab observations. These recordings will only be used for research purposes. All videos will be downloaded onto the lab computers in Dr. Neece's lab at Loma Linda University and stored on a secure server. A copy of the recordings will be uploaded to a secure server so that Dr. Rachel Fenning, Ph.D., a Co-Investigator of the current study and Associate Professor California State University Fullerton, and her staff may access them for coding purposes.

4. WHAT ARE THE REASONABLY FORESEEABLE RISKS OR DISCOMFORTS I MIGHT HAVE?

The committee at Loma Linda University that reviews human studies (Institutional Review Board) has determined that participating in this study exposes you to minimal risk.

We anticipate few discomforts or risks will be involved in your family's participation in this project. In fact, in our experience, families usually very much enjoy their participation. Nevertheless, some of the questions in the questionnaires do address personal information about you and your family. Also, some young children may show mild frustration or distress during the lab situations involving you placing demands on your child (e.g. asking them to clean up). Your child may also face some mild frustration / boredom in the lab visits during the developmental assessment that will take approximately 40-60 minutes. There is a risk of confidentiality breach, as your child's teachers will be asked to complete questionnaires about your child. The letters mailed to the teachers will describe the study and the importance of maintaining confidentiality. They will be informed of minor risks. Teachers will be asked to mail us their address in order to receive their honorarium. For these mild or minor risks, a member of our staff will always be available to address your questions or concerns.

5. WILL THERE BE ANY BENEFIT TO ME OR OTHERS?

Potential benefits to your family following the intervention include: (1) possible reduction in parental stress, (2) possible improvement in parenting behaviors, and (3) possible decline in children's behavior problems. You will also receive a financial honorarium and after completion of the 12-month follow-up visit, you will receive a short summary of your child's current and previous behavioral functioning based on study assessments. In addition, as part of the study you will have access to a research staff with expertise in child development who will be able to answer your questions about your child's development, need for services, and local resources.

Subject Initials _____

Date _____

6. WHAT ARE MY RIGHTS AS A SUBJECT?

You have the right to refuse to answer any question or terminate your involvement at any time. Additionally, you may review all video and/or audio tapes that are made during any visit, and you have the right to request that any such tape be erased in full or in part. Participation is voluntary, and should you wish to terminate your participation in the project at any time, you may do so without penalty. You are not waiving any legal rights, claims, or remedies because of your participation. If you have questions regarding your rights as a research subject, contact the Office for Protection of Research Subjects at 24888 Prospect Avenue, Loma Linda, CA 92354, (909) 558-8544.

7. WILL I BE INFORMED OF SIGNIFICANT NEW FINDINGS?

You will receive the latest information about the results of our research at the end of the study. Dr. Neece and her research assistants will invite you to a colloquium where they will review the results.

8. HOW WILL INFORMATION ABOUT ME BE KEPT CONFIDENTIAL?

All the information collected from the laboratory visits and intervention, as well as from the questionnaires, will remain confidential and will be disclosed only with your permission or as required by law. Under California law, the privilege of confidentiality does not extend to information about sexual or physical abuse of children or the elderly, in the event of suicide risk, and/or court subpoena of records. If any member of the project staff has or is given such information, he or she is required to report it to authorities. The obligation to report includes alleged or probable abuse as well as known abuse. In addition, all original data will be stored at LLU in locked files that can be accessed only by project staff. Copies of the data and video recordings will be sent to Cal State University Fullerton through a secure server. Dr. Rachel Fenning and her staff are part of Cal State University Fullerton are a party of the research team for this study. All information will remain confidential and be kept in a secure location. You will not be identified by name in any publications describing the results of this study

9. WHAT COSTS ARE INVOLVED?

There is no cost to you for participating in this study.

10. WILL I BE PAID TO PARTICIPATE IN THIS STUDY?

We will provide you with monetary compensation for your participation and investment of time and energy. For each lab visit, you will receive a payment. These payments will be $15 at each lab visit (pre-intervention assessment, post-intervention assessment, 6-month follow-up assessment, and 12-month follow-up assessment). In addition to the $15, another $15 will be held in "escrow" each time an assessment is completed. These escrow funds ($60 possible) are held and then paid to you at the completion of the final 12-month follow-up assessment. This results in a total of $120 by the end of the study is all assessments are completed. **If your family withdraws from the study before completion, you will not receive the remaining payments. In the event that a visit needs to be rescheduled, your family will be compensated upon completion of the rescheduled visit.**

Your child's teacher will also receive $25 each time he/she completes the questionnaires about your child (total of 4 times over the course of the study for $100 total).

11. WILL STUDY STAFF RECEIVE PAYMENT?

The study sponsor, National Institute of Mental Health, is paying Dr. Neece and study staff for their work in this study.

Subject Initials _____

Date _____

12. WHO DO I CALL IF I HAVE QUESTIONS?

If you wish to contact an impartial third party not associated with this study regarding any questions about your rights or to report a complaint you may have about the study, you may contact the Office of Patient Relations, Loma Linda University Medical Center, Loma Linda, CA 92354, phone (909) 558-4647, e-mail patientrelations@llu.edu for information and assistance.

If you have any questions for the staff regarding your child, the intervention, study procedures, or scheduling, you may contact us at Loma Linda University, Department of Psychology, 11130 Anderson St., Loma Linda, CA 92350, call (909) 558-8615, or email Dr. Neece directly at cneece@llu.edu.

13. SUBJECT'S STATEMENT OF CONSENT

- I have read the contents of the consent form and have listened to the verbal explanation given by the investigator.
- My questions concerning this study have been answered to my satisfaction. This protocol has been explained to my child at a level that he/she can comprehend and I give permission for my child to participate in the study.
- Signing this consent document does not waive my rights nor does it release the investigators, institution or sponsors from their responsibilities.
- I may call (909) 558-8615 during routine office hours if I have additional questions or concerns.
- I hereby give voluntary consent to participate in this study.

I understand I will be given a copy of this consent form after signing it.

_____ _____

Signature of Participant | Printed Name of Participant

_____

Date

14. INVESTIGATOR'S STATEMENT

I have reviewed the contents of this consent form with the person signing above. I have explained potential risks and benefits of the study.

_____ _____

Signature of Investigator | Printed Name of Investigator

_____

Date

LOMA LINDA UNIVERSITY

Department of Psychology

INFORMED CONSENT

TITLE: **MINDFULNESS INTERVENTION AND PARENTING STRESS (MAPS) INTEVENTION PROJECT**

SPONSOR: Loma Linda University

PRINCIPAL INVESTIGATORS:

Cameron L. Neece, Ph.D.
Address: Loma Linda University, Department of Psychology, 11130 Anderson St., Loma Linda, CA 92350
Phone Number: (909) 558-8615
Email: cneece@llu.edu

Lisa R. Roberts, Dr.PH
Address: Loma Linda University, School of Nursing, 11262 Campus St., Loma Linda, CA 92350
Phone Number: (909) 558- 1000, ext. 83830
Email: lroberts@llu.edu

1. WHY IS THIS STUDY BEING DONE?

The purpose of this study is to examine whether a particular intervention is effective in reducing stress and promoting mental health among parents of children with developmental delays. The intervention called Mindfulness-Based Stress Reduction (MBSR), is an empirically supported stress intervention that has been widely used with a variety of populations and has shown promising effects. We are also interested in learning about how parents and children behave and interact and how these processes influence the children's course of development.
The rationale for this study is drawn from research, which suggests that parents of children with developmental delays often experience heightened parenting stress, compared to parents of typically developing children. High levels of parenting stress have also been associated with negative outcomes for children over time. Therefore, the goal of the project is to help parents cope with the high levels of stress that accompany caring for a child with special needs and subsequently optimize the development of their children. You are invited to participate in this research study because you are a parent of child who has been identified as having developmental concerns.

Approximately 80 subjects will participate in this study at Loma Linda University. Your participation in this study may last up to 18 months. Your family's participation in the project would consist of three or four laboratory visits spaced across 1-1.5 years. Each visit is about 1 hour long. Because we are interested in learning about the effect of the

intervention on you and your child across time, we are seeking your participation from the pre-treatment assessment until the completion of the follow-up assessment (see details below).

2. HOW WILL I BE INVOLVED?

Participation in this study involves the following:

Pre-Treatment Assessment. An initial enrollment interview will be conducted at the MAPS laboratory. We will have mailed this consent form to you before the visit. Additionally, parents will be mailed a packet of questionnaires that should be completed by the participating parent(s) prior to the laboratory assessment. We will also ask that the parent(s)' spouse or another significant adult in the child's life complete two questionnaires about the child prior to the lab visit.

The pre-treatment visit will consist of three parts. First, parents will be given an opportunity to ask further questions about the study and then we will obtain your consent. Next, parents will engage in an observational play activity with their child for about 15 minutes. This observation will be videotaped with the parent(s)' consent. After that parent(s) will be interviewed to obtain basic demographic and family background information. Any remaining questionnaires regarding parental attitudes, family functioning, and perceptions of your child will be also completed. Additionally, parent's blood pressure and pulse will be measured during this time. While you are being interviewed, your child will participate in a brief developmental evaluation as well as a short delay-of-gratification task where we will present him or her with a toy and then ask them to wait until we return to play with the toy. This observation will also be videotaped with the your consent.

At the end of the pre-treatment assessment, you will either be randomly assigned to the immediate treatment group, which will take place during June and July of 2014, or the delayed treatment group, which will take place during September and October of 2014. We can not guarantee your assignment to a particular group. Therefore, in consenting to participation, you are agreeing to participate in either group. Additionally, if you are assigned to the delayed treatment group there will be an additional assessment immediately before starting the intervention. Thus, you will have an initial pre-treatment assessment and a second pre-treatment assessment at the end of the immediate treatment intervention and before the delayed group begins. This assessment will take place in August of 2014 and will include the same questionnaires and parent-child interaction task that was completed during the pre-treatment assessment.

In addition, we will ask you to collect saliva samples. You will be given a collection kit complete with instructions. You will collect the saliva samples at home the day after your pre-treatment assessment. A second, and possibly a third, collection will be asked for later in the study. We will use the saliva samples to measure cortisol, a biological marker related to stress.

The Intervention. The MBSR intervention consists of three main components: (1) didactical material covering the concept of mindfulness, the psychology and physiology of stress and anxiety, and ways in which mindfulness can be implemented in everyday life to facilitate more adaptive responses to challenges and distress, (2) mindfulness exercises during the group meetings and as homework between sessions, and (3) discussion and sharing in pairs and in the larger group. The MBSR program includes eight weekly 2.5 hour sessions, a day-long meditation retreat after class 6, daily home practice based on audio CDs with instruction, and a daily record keeping of mindfulness exercises. Formal mindfulness exercises include the body scan, sitting meditation with awareness of breath, and mindful movement. MBSR is an empirically supported secular (non-religious) based intervention that can be beneficial to people of all religious backgrounds. Parent(s) are expected to attend all sessions in order to maximize the benefit of the intervention.

Post-Treatment Assessment. After the completion of the MBSR intervention, parent(s) and their child are asked to come back for another laboratory assessment. A similar set of questionnaires will be mailed to your home that we ask you to complete prior to the lab visit. Similar to the pre-treatment assessment, we ask that the parent(s)' spouse or another significant adult in the child's life complete the same two questionnaires about the child prior to the post-treatment lab visit. Parent's blood pressure and pulse will again be measured. During the post-treatment lab visit, parent(s) and child will complete a similar play activity for 20 minutes.

Follow-Up Assessment. Six months after the MBSR group has finished you will be asked to come back to the lab for a follow-up assessment to see how you and your child are doing. Parent's blood pressure and pulse will be measured one last time. At this assessment, again you will be asked to complete a packet of questionnaires prior to the visit and will participate in a 20-minute play activity.

Teacher Assessment: Additionally, because we feel that input from each child's teacher is a critical element in gaining a complete picture of the child, each year we will ask you to complete a permission form allowing your child's teacher to provide information to us. Parents will give a short questionnaire packet to the teacher before the intervention, at the end of the intervention, and 6 months after the intervention is completed.

3. WHAT ARE THE REASONABLY FORESEEABLE RISKS OR DISCOMFORTS I MIGHT HAVE?

The committee at Loma Linda University that reviews human studies (Institutional Review Board) has determined that participating in this study exposes you to minimal risk.
We anticipate few discomforts or risks will be involved in your family's participation in this project. In fact, in our experience, families usually very much enjoy their participation. Nevertheless, some of the questions in the questionnaires do address personal information about you and your family. Also, some young children may show mild frustration or distress during the lab situations involving parents placing demands on their child (e.g. asking them to clean up).

For these mild or minor risks, a member of our staff will always be available to address your questions or concerns.

4. WILL THERE BE ANY BENEFIT TO ME OR OTHERS?

As participants in our study, you will hopefully benefit from the MBSR intervention, as many others have. MBSR has over two decades of published research -- and more than 18,000 participants – which indicates that the majority of people who complete the 8-week program report greater ability to cope more effectively with both short and long-term stressful situations. By learning to actively participate in the management of health and well being, many participants report they are better able to manage stress, fear, anger, anxiety, and depression both at home and in the workplace. Participants have stated that they feel less judgmental and critical of themselves and subsequently to others. MBSR may also help to improve your parenting experience. Mindfulness helps us to slow down, notice impulses before we act, really listen to our kids and to come from a more relaxed and peaceful state of mind, which in turn has a positive effect on our children.

In addition, as part of the study you will have access to a research staff with expertise in child development, and will receive feedback at the end of the study summarizing the effect of the intervention you and your family.

5. WHAT ARE MY RIGHTS AS A SUBJECT?

You have the right to refuse to answer any question, or collect saliva, or terminate your involvement at any time. Additionally, you may review all video and/or audio tapes that are made during any visit, and you have the right to request that any such tape be erased in full or in part. Participation is voluntary, and should you wish to terminate your participation in the project at any time, you may do so without penalty. You are not waiving any legal rights, claims, or remedies because of your participation. If you have questions regarding your rights as a research subject, contact the Office for Protection of Research Subjects at 24888 Prospect Avenue, Loma Linda, CA 92354, (909) 558-8544.

6. WILL I BE INFORMED OF SIGNIFICANT NEW FINDINGS?

You will receive the latest information about the results of our research as it becomes available to us.

7. HOW WILL INFORMATION ABOUT ME BE KEPT CONFIDENTIAL?

All the information collected from the laboratory visits, saliva samples, and intervention, as well as from the questionnaires will remain confidential and will be disclosed only with your permission or as required by law. Under California law, the privilege of confidentiality does not

extend to information about sexual or physical abuse of children or the elderly. If any member of the project staff has or is given such information, he or she is required to report it to authorities. The obligation to report includes alleged or probable abuse as well as known abuse. In addition, all original data will be stored at LLU in locked files that can be accessed only by project staff. You will not be identified by name in any publications describing the results of this study.

8. WHAT COSTS ARE INVOLVED?

There is no cost to you for participating in this study.

9. WILL I BE PAID TO PARTICIPATE IN THIS STUDY?

We will provide you with monetary compensation for your participation and investment of time and energy. For each lab visit, you will receive a payment. These payments begin at $10 (at pre-treatment assessment), and increase as you continue to $15 (post-treatment assessment) and $50 (follow-up assessment). Additionally, you will be paid $20.00 for collection of saliva samples resulting in a total of $115 to 145 that you will receive over the course of the study, depending on which group you are assigned to. **If your family withdraws from the study before completion, you will not receive the remaining payments. In the event that a visit needs to be rescheduled, your family will be compensated upon completion of the rescheduled visit.**

10. WILL STUDY STAFF RECEIVE PAYMENT?

The study sponsor, Loma Linda University, is paying Dr. Neece, Dr. Roberts, and study staff for their work in this study.

11. WHO DO I CALL IF I AM INJURED AS A RESULT OF BEING IN THIS STUDY?

If you are injured, you should immediately contact Dr. Cameron Neece during routine office hours at (909) 558-8615. During non-office hours, call (909) 558-4000 and ask for the doctor on call. In the case of injury or illness resulting from this study, emergency medical treatment is available but will be provided at the usual charge. The Emergency Department at Loma Linda University Medical Center is located on the corner of Barton and Campus roads. No funds have been set aside to compensate you in the event of injury.

12. WHO DO I CALL IF I HAVE QUESTIONS?

If you wish to contact an impartial third party not associated with this study regarding any questions about your rights or to report a complaint you may have about the study, you may contact the Office of Patient Relations, Loma Linda University Medical Center, Loma Linda, CA 92354, phone (909) 558-4647, e-mail patientrelations@llu.edu for information and assistance.

13. SUBJECT'S STATEMENT OF CONSENT

- I have read the contents of the consent form and have listened to the verbal explanation given by the investigator.
- My questions concerning this study have been answered to my satisfaction. This protocol has been explained to my child at a level that he/she can comprehend and I give permission for my child to participate in the study.
- I have received a copy of the California Experimental Subject's Bill of Rights and have had these rights explained to me.
- Signing this consent document does not waive my rights nor does it release the investigators, institution or sponsors from their responsibilities.
- I may call (909) 558-8615 during routine office hours if I have additional questions or concerns.
- I understand that if I am enrolled in an in-patient study, my primary care physician may be notified of my participation, for proper coordination of care.
- I hereby give voluntary consent to participate in this study.

I understand I will be given a copy of this consent form after signing it.

Box 1 –If adult subjects are involved:

Signature of Subject

Printed Name of Subject

Date

AM / PM

For inpatient studies, add: Time

15. INVESTIGATOR'S STATEMENT

I attest that the requirements for informed consent for the medical research project described in this form have been satisfied – that the subject has been provided with a copy of the California Experimental Subject's Bill of Rights, that I have discussed the research project with the subject and explained to him or her in non-technical terms all of the information contained in this informed consent form, including any risks and adverse reactions that may reasonably be expected to occur. I further certify that I encouraged the subject to ask questions and that all questions asked were answered. For in-patient studies, I understand that it is my responsibility to notify the subject's primary care physician of study participation, as needed, for proper

coordination of care. I will provide the subject or the legally authorized representative with a signed and dated copy of this consent form.

Signature of Investigator	Printed Name of Investigator
Date	*For inpatient studies, add:* Time AM / PM

S.T.E.P.S.
Phone Screen Instructions

1. "Hi, my name is _____ and I am calling from Loma Linda University. You had expressed interest in the PRO-Parenting Project and asked to be placed on a waitlist for future studies. We are now recruiting for an intervention study for parents of children with autism and would like to see if you were interested in participating?"

If yes: "Great! Before I go over all of the study details, I would like to point out that this particular intervention is for parents of children with ASD. Is your child currently diagnosed with an autism spectrum disorder?"

Complete Section I

If yes:
"If you have a few minutes, I'd like to tell you a little more about this study. Is now a good time?"

If no:
Explain that we're only recruiting children with an ASD diagnosis at this time so they will not be eligible for the study but we plan on having more groups for parents of children with developmental delays. Ask if they would like to be placed on the waitlist to be contacted for the next study. Thank them for reaching out and for taking the time to hear about the study. After hanging up, add family to the waitlist and input all of the necessary info.

2. Brief Summary of the Intervention:

"The STEPS Project is an intervention study taking place at Loma Linda University in collaboration with Cal State Fullerton for parents of children with autism spectrum disorder. It was put in place to provide support for parents and to reduce parenting stress. Our hope is that this experience will help reduce your parenting stress, enable you to feel more confident as a parent, reduce concerns you have about your child, and in turn, improve your child's behavior.

As a part of this study, you would participate in one of two parent interventions. One intervention focuses on mindful awareness and the other is an educational parent support group. Both groups run for 8 weeks and have one 6-hour weekend event during week 6. If you choose to enroll in the program, it will be very important for you to attend all 8 intervention sessions and the weekend event. Childcare will be provided. Groups will be either Monday or Wednesday night and both will begin mid-January 2019 and end in March 2019. You will be randomly assigned to a group, like the flip of a coin. We will let you know which group you will be assigned to after your first lab assessment.

As I said, we are offering these interventions as part of a research study and therefore, in order to determine how effective the treatments are, we are asking that families participate in five lab visits for assessments. There will be two before the group begins, one immediately after the group is completed, one 6 months after the group is done, and one 12 months after the group is done.

In addition to the free intervention services, you will be compensated for your participation and will receive $120 over the course of the study if you complete all the assessments.

Do you have any questions about the study or what it entails?"

3. "Does our study sound like something that you would be interested in?"

If no: **"Could I send you some more information about our study, so you can think about it?"** (Offer to call back if you need to.)

If yes: **"I'd like to ask you some general questions about your child and your family. This will give me a better sense of whether our study seems appropriate for your family or not. It should take about 30 minutes and all of your responses will be confidential, except in rare cases when your safety or a child's safety are a concern. Do you have time now?"**

If not: get phone number and <u>specific</u> time to call.
If so: **Continue to Section II**

4. Guidelines for Section II:

Age Limit:
Please keep in mind that the child must be between 3 and 5 years old by their first lab visit to meet inclusion criteria for the study. Type birthdate into age calculator on scoring sheet and check that they will be in the right age range for their initial lab visit.

If the child is between 2y6m and 3 at the time of the phone screen, their initial lab visit must be scheduled a few months from now when they are at least 3 years old. (Latest acceptable birthdate is 1/07/16 → would be scheduled for last lab visit on 1/07/19)

- E.g. If a child is born on 12/01/2015 and is screened in June 2018, they would only be 2y 6m old. If their lab visit is scheduled after 12/1/18, they would then be 3y old and eligible to participate.

If the child is between 5y6m and 6 at the time of the phone screen, their initial lab visit must be scheduled soon, before they turn 6 years old.
(Earliest acceptable birthdate is 7/17/2012 → would be scheduled for the first lab visit on 7/16/2018)

- E.g. If a child is born on 7/25/2012 and is screened in June 2018, they would already be 5y 11m old. Their lab visit needs to be scheduled before their birthday (7/25/18) so that they would still be 5y 11m old at baseline and eligible to participate.

***If the child is too young to participate in this study, inform the parent that we plan on having additional studies with a similar intervention in the near future and ask if they would like to remain on the waitlist.

- If yes: "**Great! I will add your information to our waitlist and we will reach out as soon as we begin recruitment for the next study.**" ***Confirm name, two contact numbers, and an email address. Also note if child has an ASD diagnosis and is Spanish-speaking or not. Fill in all the columns on the waitlist with info already collected***

- If no: **"Thank you for taking the time to reach out and hear more about the STEPS Project. Have a great day."**

***If the child is too old to participate in this study, inform the parent that we are currently only recruiting children between the ages of 3 and 6. Thank them for their time and for expressing interest in the study.

*****MAKE SURE TO GET PC MIDDLE NAME**

Because suicidality will be screened for later in the call, you need to get the parent's current location. Ask the parent, "Where are you now?" and try to obtain a physical address.

Make sure to get 2 phone numbers whenever possible (even if one is a relative).

5. Guidelines for section III:

When asking about diagnosis and details, be sensitive to the parent's educational level as well as comfort level.
If they don't seem to understand some of the terminology (e.g. *diagnosis*), use the suggested alternatives to phrase the questions.

6. Guidelines for section IV:

Ask the parent the PSI-4 Short Form questions provided on the phone screen. As you go thru the questions, make sure to enter answers on the Excel sheet to get a total score. As you type in responses, make sure to use the right scale by checking the scoring keys on the right. If the parent dos not reach the clinical cut off (score of 110), they will not be eligible for the study.

If eligible: ***Continue on to Section V***

If not eligible: **"Unfortunately, for this study we are only including families with a certain level of parenting stress. Based on your responses, you do not meet criteria at this time. We will have more parenting groups coming up that you may still be eligible for. Would you like to be added to that waitlist?"**

If yes: Add to waitlist, make sure to collect all the information that you have not already gotten in this screen

If no: Thank them for their time and for reaching out.

Parents may be sensitive in discussing their stress levels. If necessary, reassure them that you ask the same questions of every parent and that many of these feelings are common.

7. Guidelines for section V:

Ask for specifics on any services the parent has received or is currently receiving.

If the parent is currently receiving services for himself/herself, inform him/her that because we are looking at the impact of this particular intervention on families we are asking that parents not receive any other psychotherapy services for themselves while the intervention is taking place. This is to ensure that any effects we observe are a result of our intervention and not other psychotherapy services. However, we will take their information and speak with the principle investigator for a case-by-case decision regarding their current services. Children can continue to receive behavioral and psychotherapy services.

8. Guidelines for section VI:

Ask these questions to assess parent / child exclusionary criteria.

Child Exclusionary Criteria Questions:

If the child meets an exclusion criterion, inform him/her that we will be unable to accept them for the study at this time. Explain why the format of the study would make it difficult for their child to participate. Sympathize with their disappointment and ask if they would be interested in other referrals. If the parent expresses interest, let them know that you will inform Dr. Neece and she will call within a week to discuss their situation and to offer useful resources.

If you are unsure if a child meets an exclusion criterion, notify the parent of your concern, and let them know that we will need to call them back later for more information. (Continue with screen)

Parent Exclusionary Criteria Questions:

When asking the parent these questions, be aware that they may be sensitive topics for some individuals. Take notes as necessary and write down details/clarifications that parents provide for these questions on the phone screen document.

If parent endorses drug use / psychosis items and / or you are not sure if they should be excluded for drug use:
Inform the parent that they may not meet some of the study requirements. Ask is they are okay with Dr. Neece calling within the next week to follow up for more details and to discuss their eligibility for the study. She will also be able to provide some potentially useful resources if they are interested. (Continue with phone screen)

If parent endorses suicidality items:

- Endorses first question of letter "I": passive ideation
  - Complete the top section of the Suicide Risk Assessment Form (Assessment of Suicidal Thoughts)
  - Let the parent know that Dr. Neece will follow up within the next 24 hours
- Endorses "I" and "1": Strong Intent
  - Complete an in depth risk assessment. Fill out the entire Suicide Risk Assessment Form (1 page)
  - "I am going to ask Dr. Neece to call you within 24 hours. How confident are you that you can keep yourself safe until then?"
    - Confident that they will not harm themselves: Reassure that they will be getting a call from Dr. Neece within the 24 hour time frame.
    - Not able to keep themselves safe: go thru procedure for 'imminent risk' as seen below
- Endorses "I", "1" and "2": Imminent Risk
  - Complete an in depth risk assessment. Fill out the entire Suicide Risk Assessment Form

    - Suggest to the parent that they seek help quickly.
    - Ask if they are willing to go to the hospital voluntarily.
        - Yes: "Do you have a way to get there?" (i.e. family or friend to drive them)
        - No: call 911 immediately
- Endorses "c" under question "K" –
    - Complete an in depth risk assessment. Fill out the entire Suicide Risk Assessment Form.
        - Will either qualify as strong intent or imminent risk
            - Respond accordingly using guide seen above.
- After any level of endorsement for suiciadlity, call Camie immediately following the phone screen: (510) 453 - 4274

9. Guidelines for section VII:

Ask the family for the name, address and phone number of AT LEAST one person who will always know how to contact them. This is extremely important, as we may not have contact with these families again for a few months.

Use this section to give parents control of the conversation and to talk briefly about their children. Give them the opportunity to voice any concerns they may have and answer their questions as best as you can (see point 10).

Make note of any possible exclusionary concerns (and mention them to the parent, following the above guidelines).

If you don't know the answer to any questions they have, write the question down and tell the parent you will have the project director call them back.

10. <u>ALWAYS</u> complete Section VII immediately after doing the screen.

If they can do a baseline assessment: **Based off of this screen, we would like to schedule you for the first of two lab assessments for the baseline visit. It should take about an hour to complete.**

- Yes: Schedule first baseline assessment.

When scheduling initial visit, refer to the lab's Google calendar and make sure to schedule the family when a lab visit is available. If none of the times listed on the calendar work for the family, let them know that you will keep their contact information and call them to schedule a lab visit as soon as more days/times become available.

Double check that the child is within the age limit. Use the age calculator on the excel sheet to confirm when the child is 3 and 6 years old. Make sure to schedule the visit sometime after their 3rd birthday or before their 6th birthday.

*If child does not turn three for a few months, let them know we will call sometime in September to schedule the visit at that time.

- No: Ask if they would be interested in being sent more information about the study. Thank them for their time and mark requested more information.

Be sure to detail how you left things with the parent and any specific concerns about the child or family.

GUID#: _____
Interviewer: _____
Date: _____

S.T.E.P.S. Project
PHONE SCREENING FORM

I. **Autism Diagnosis: Yes No**

II. **Family Information**
Child's Name:_____
Sex: M F
Date of Birth: _____ Age: ____yr.

****Child must be between 3y 0m and 5y 11m at time of initial visit. SEE INSTRUCTIONS FORM FOR MORE SPECIFICS ON AGE LIMITS. CHECK EXCEL AGE CALCULATOR*****

Child speaks English: Yes No

Who is the primary caregiver? Mom Dad
(OR "Who is the main person that takes care of your child?", "Who spends the most time with the child?")

City of birth(for PC):_____

Mother's Name: _____
Date of Birth: _____
Relation to child:
Biological Step Adoptive/Legal Guardian Foster
If non-natural, length of time living with child:_____

Father's Name: _____
Date of Birth: _____
Relation to child:
Biological Step Adoptive/Legal Guardian Foster
If non-natural, length of time living with child: _____

Marital Status:
Married Living Together Separated/Divorced Never Married

Siblings:
S1 Name: _____
Date of Birth: _____

S2 Name: _____
Date of Birth: _____

S3 Name: _____
Date of Birth: _____

S4 Name: _____
Date of Birth: _____

Home Address: _____
_____

Phone #: _____ Home
_____ Work
_____ Cell (Mom)
Texting?: Yes No
_____ Cell (Other Caregiver)
Texting?: Yes No

Email: Mother: _____
Other Caregiver: _____

Preferred Method of Contact: _____

"Before we proceed can you let me know where you are right now? Our safety protocols mandate that we know your physical location when we do these phone screens."
Current Location: _____
_____

III. Diagnosis Information

When was your child first diagnosed with an ASD?:
_____
Who first gave the diagnosis?:
_____

IV. Parenting Stress

We are now going to ask you a few more questions. There are several so hang in there with me. Please indicate if you strongly disagree, disagree, are not sure, agree, or strongly agree with each statement I read.

Strongly Agree=5 Agree=4 Not Sure=3 Disagree=2
Strongly Disagree=1

1. I often have the feeling that I cannot handle things very well.
2. I find myself giving up more of my life to meet my child's needs than I ever expected.
3. I feel trapped by my responsibilities as a parent.
4. Since having this child, I feel that I have been unable to do new and different things.

5. Since having a child, I feel that I am almost never able to do things I like to do.

6. I am unhappy with the last purchase of clothing I made for myself.

7. There are quite a few things that bother me about my life.

8. Having a child has caused more problems than I expected in my relationship with my spouse / parenting partner.

9. I feel alone and without friends

10. When I go to a party, I usually expect not to enjoy myself.

11. I am not as interested in people as I used to be.

12. I don't enjoy things as I used to.

13. My child rarely does things for me that make me feel good.

14. When I do things for my child, I get the feeling that my efforts are not appreciated very much.

15. My child smiles at me much less than I expected.

16. Sometimes I feel my child doesn't like me and doesn't want to be close to me.

17. My child is very emotional and gets upset quickly.

18. My child doesn't seem to learn as quickly as most children.

19. My child doesn't seem to smile as much as most children.

20. My child is not able to do as much as I expected.

21. It takes a long time and it is very hard for my child to get used to new things.

---

22. I feel that I am:

1 = a very good parent.
2 = a better than average parent.
3 = an average parent.
4 = a person who has some trouble being a parent.
5 = not very good at being a parent.

Strongly Agree=5 Agree=4 Not Sure=3 Disagree=2 Strongly Disagree=1

23. I expected to have closer and warmer feelings for my child than I do, and this bothers me.

24. Sometimes my child does things that bother me just to be mean.

25. My child seems to cry or fuss more often than most children.

26. My child generally wakes up in a bad mood.

27. I feel that my child is very moody and easily upset.

28. Compared to the average child, my child has a great deal of difficulty in getting used to changes in schedules or changes around the house.

29. My child reacts very strongly when something happens that my child doesn't like.

30. When playing, my child doesn't often giggle or laugh.

31. My child's sleeping or eating schedule was much harder to establish than I expected.

---

32. I have found that getting my child to do something or stop doing something is:

5 = much harder than I expected.
4 = somewhat harder than I expected.
3 = about as hard as I expected.
2 = somewhat easier than I expected.
1 = much easier than I expected.

---

33. Think carefully and count the number of things which your child does that bothers you. For example, dawdles, refuses to listen, overactive, cries, interrupts, fights, whines, etc.

1 = 1-3
2 = 4-5
3 = 6-7
4 = 8-9
5 = 10+

Strongly Agree=5 Agree=4 Not Sure=3 Disagree=2 Strongly Disagree=1

34. There are some things my child does that really bother me lot.

35. My child's behavior is more of a problem than I expected.

36. My child makes more demands on me than most children.

*****Score the PSI on excel spreadsheet. If total stress score is at or above 85th percentile (raw score of 110 or higher) then proceed with phone screen. If parent has a score below the 85th percentile let parent know we are looking for parents who have high levels of parenting stress and, at this point in time, the parent does not meet that criteria.**

V. **Service Information-**
Thank you for answering those. Just a few more questions. Are you currently receiving any psychological or behavioral services for yourself such as counseling, parent training class, or participating in a regular parent support group?
Yes No
If yes:
Type of service received:
_____
Where: _____
When: _____
Ongoing? Yes No
By whom: _____

*****If parent is receiving ongoing services inform him/her that *"Due to the nature of this intervention, if you are currently receiving psychological services I will review your specific case with the principal investigator and get back to you regarding your eligibility."***
Continue with phone screen and bring services to Dr. Neece's attention.

VI. **Exclusion Criteria Checklist**

A. Is child able to walk unassisted? Yes No
B. Does child have issues seeing or hearing? Yes No
If yes…
- "Is your child blind? / Is your child deaf?"
- Extent of hearing / seeing issues:_____

_____

*****If child is blind or deaf, inform the parent, "Due to the nature of this intervention, we will not be recruiting children with significant vision or hearing difficulties at this time. The child will be asked to follow verbal directions and respond to certain visual patterns during the developmental evaluation. The presence of sight /**

hearing issues would make this portion of our study difficult for your child."

*****If child is non-ambulatory, note this but complete the phone screen. At the end of phone screen let parent know you need to bring this case to the research team and follow up with them in 1 week or less."**

Interviewer: I just have a few questions about problems you may have had. For this phone screen we have to ask about a whole range of experiences. Some of these experiences are quite rare, but it would be great if you could bear with us and answer the questions I am going to ask you now.

A. Has there been a time in your life when you had five or more drinks (beer, wine, or liquor) on one occasion?
   a. Yes No
   b. **If yes,** "Do you currently drink five or more drinks on any one occasion?
      i. Yes No

B. Have you ever used street drugs?
   a. Yes No
   b. **If yes,** "Do you currently use street drugs?
      i. Yes No

C. Have you ever gotten "hooked" on a prescribed medicine or taken a lot more of it than you were supposed to?
   a. Yes No
   b. **If yes,** "Are you currently hooked on a prescribed medicine?
      i. Yes No

D. Over the past year, have there been times when you felt extremely happy without a break for days on end?
   a. Yes No
   b. **If yes,** "Was there a reason for this?"
      i. Yes No
      ii. If yes, what was the reason? _____

E. Over the past year, have you ever felt that your thoughts were directly interfered with or controlled by some outside force or person?
   a. Yes No
   b. **If yes,** "Did this come about in a way that many people would find hard to believe, for instance, through telepathy?
      i. Yes No

F. Over the past year, have there been times when you felt that people were against you?
   a. Yes No

b. **If yes**, "Have there been times when you felt people were deliberately acting to harm you or your interests?
   i. Yes No
      1. If yes, "Have there been times when you felt that a group of people was plotting to cause you serious harm or injury?"
         a. Yes No

G. Over the past year, have there been times when you felt that something strange was going on?
   a. Yes No
   b. **If yes**, "Did you feel it was so strange that other people would find it very hard to believe?
      i. Yes No

H. Over the past year, have there been times when you heard or saw things that other people couldn't?
   a. Yes No
   b. **If yes**, "Did you at any time hear voices saying quite a few words or sentences when there was no one around that might account for it?
      i. Yes No

I. Have you ever wished you were dead or wished you could go to sleep and not wake up?
   a. Yes No
   b. **If yes**, "Did you have any of these thoughts in the past week, including today?"
      i. Yes No
         1. Have you had a strong urge to kill yourself at any time in the past week? (Tell me about that.) In the past week, did you have any intention to attempt suicide? (Tell me about that.)
            a. Yes No
         2. In the past week, have you thought about how you might actually do it? (Tell me about what you were thinking of doing.) Have you thought about what you would need to do to carry this out" (Tell me about that. Do you have a means to do this?)

J. Have you ever tried to intentionally harm yourself?
   a. Yes No

K. Have you ever tried to kill yourself?
   a. Yes No
   b. **If yes**, "What did you do?" (Tell me what happened.) Were you trying to end your life?"
      i. Yes No
   c. Have you made any suicide attempts in the past week, including today?

i. Yes No

VII. Concerns, Comments, Questions
Can I please have the contact information of at least one person (family, friend, etc.) who will always know how to reach you?

Name: _____Relationship:_____
Address: _____
_____
Phone Number: (____)_____

Name:_____Relationship:_____
Address:_____
_____
Phone Number: (____)_____

Do you have any concerns or questions about the study at this time?
If yes, specify: _____
_____
_____
What do you hope to get out of the study?
_____
_____
_____
Is there anything important you think we should know about your child before we see you?
_____
_____
_____

"Thank you for your interest in our project. Would you like to come in for the initial lab visit?"

If yes: "Great. We will mail you a packet with a consent form to review, questionnaires to fill out, and a contact sheet for your child's teacher. The baseline assessment consists two lab visits that take about an hour each. Please have this packet completed by your first assessment. The first meeting will take about one hour and you will receive $15 for your visit at that time."

"As we mentioned before, our groups are going to be held on either Monday or Wednesday evenings. Both groups will start mid-January of 2019 and will meet from 6-8:00 pm. Once you complete the second lab visit, we will let you know which group you are in."

"At this point you are eligible it's very important that families attend the sessions, so I would like to confirm that you would be available Monday and Wednesday nights since you will be randomly assigned to one of the two days."
Confirm availability for Monday and Wednesday nights

If available Mon. AND Wed.: Schedule family for initial baseline assessment (see phone screen instructions)
If not available one of the days / "strongly prefers" a specific day: Let them know that because this is a research study, participants need to be randomly assigned to groups and we cannot guarantee a particular day. If they are not available both days, we can add them to a waitlist for this study.
Add participant to STEPS Recruitment Waitlist

VIII. **Action Taken**

****Make sure child is between 3 and 5 by the time of the lab visit. If close to cutoffs, confirm using age calculator (see instructions page)*****

Set up initial visit:
- Date_____

Need to call back to schedule visit. Date/time when parent prefers to be called back:
- _____

Hold for further discussion:
- Reason- _____
  _____
  _____

Clearly inappropriate for study:
- Reason- _____
  _____

Requested more information:
- Date sent _____

Notes:

_____
_____
_____
_____
_____
_____
_____
_____
_____

PSI-4 SHORT FORM

Record/Profile Form

Richard R. Abidin, EdD

Instructions:

On the inside of this form, write your name, gender, date of birth, ethnic group, and marital status; today's date; and your child's name, gender, and date of birth. This questionnaire contains 36 statements.

Read each statement carefully. For each statement, please focus on the child you are most concerned about and circle the response that best represents your opinion. **Answer all questions about the same child.**

Circle SA if you strongly agree with the statement.

Circle A if you agree with the statement.

Circle NS if you are not sure.

Circle D if you disagree with the statement.

Circle SD if you strongly disagree with the statement.

For example, if you sometimes enjoy going to the movies, you would circle A in response to the following statement:

I enjoy going to the movies. SA (A) NS D SD

While you may not find a response that exactly states your feelings, please circle the response that comes closest to describing how you feel. **Your first reaction to each question should be your answer.**

Circle only one response for each statement, and respond to all statements. **Do not erase!** If you need to change an answer, mark an "X" through the incorrect answer and circle the correct response. For example:

I enjoy going to the movies. SA A NS (X) (SD)

Loma Linda University Health
Institutional Review Board
Approved 7/16/2018
IRB# 5110264

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Answer Sheet

PSI-4 SHORT FORM

Name _____ Gender _____ Date of birth ___/___/___

Ethnic group _____ Marital status _____ Today's date ___/___/___

Child's name _____ Child's gender _____ Child's date of birth ___/___/___

SA = Strongly Agree **A = Agree** **NS = Not Sure** **D = Disagree** **SD = Strongly Disagree**

1.	I often have the feeling that I cannot handle things very well.	SA	A	NS	D	SD
2.	I find myself giving up more of my life to meet my children's needs than I ever expected.	SA	A	NS	D	SD
3.	I feel trapped by my responsibilities as a parent.	SA	A	NS	D	SD
4.	Since having this child, I have been unable to do new and different things.	SA	A	NS	D	SD
5.	Since having a child, I feel that I am almost never able to do things that I like to do.	SA	A	NS	D	SD
6.	I am unhappy with the last purchase of clothing I made for myself.	SA	A	NS	D	SD
7.	There are quite a few things that bother me about my life.	SA	A	NS	D	SD
8.	Having a child has caused more problems than I expected in my relationship with my spouse/parenting partner.	SA	A	NS	D	SD
9.	I feel alone and without friends.	SA	A	NS	D	SD
10.	When I go to a party, I usually expect not to enjoy myself.	SA	A	NS	D	SD
11.	I am not as interested in people as I used to be.	SA	A	NS	D	SD
12.	I don't enjoy things as I used to.	SA	A	NS	D	SD
13.	My child rarely does things for me that make me feel good.	SA	A	NS	D	SD
14.	When I do things for my child, I get the feeling that my efforts are not appreciated very much.	SA	A	NS	D	SD
15.	My child smiles at me much less than I expected.	SA	A	NS	D	SD
16.	Sometimes I feel my child doesn't like me and doesn't want to be close to me.	SA	A	NS	D	SD
17.	My child is very emotional and gets upset easily.	SA	A	NS	D	SD
18.	My child doesn't seem to learn as quickly as most children.	SA	A	NS	D	SD
19.	My child doesn't seem to smile as much as most children.	SA	A	NS	D	SD
20.	My child is not able to do as much as I expected.	SA	A	NS	D	SD
21.	It takes a long time and it is very hard for my child to get used to new things.	SA	A	NS	D	SD
22.	I feel that I am: (Choose a response from the choices below.)	1	2	3	4	5

1. a very good parent.
2. a better-than-average parent.
3. an average parent.
4. a person who has some trouble being a parent.
5. not very good at being a parent.

23.	I expected to have closer and warmer feelings for my child than I do, and this bothers me.	SA	A	NS	D	SD
24.	Sometimes my child does things that bother me just to be mean.	SA	A	NS	D	SD

SA = Strongly Agree	A = Agree	NS = Not Sure	D = Disagree	SD = Strongly Disagree

25. My child seems to cry or fuss more often than most children. ..... SA A NS D SD
26. My child generally wakes up in a bad mood. ..... SA A NS D SD
27. I feel that my child is very moody and easily upset. ..... SA A NS D SD
28. Compared to the average child, my child has a great deal of difficulty in getting used to changes in schedules or changes around the house. ..... SA A NS D SD
29. My child reacts very strongly when something happens that my child doesn't like. .. SA A NS D SD
30. When playing, my child doesn't often giggle or laugh. ..... SA A NS D SD
31. My child's sleeping or eating schedule was much harder to establish than I expected. SA A NS D SD
32. I have found that getting my child to do something or stop doing something is: (Choose a response from the choices below.)..... 1 2 3 4 5
    1. much harder than I expected.
    2. somewhat harder than I expected.
    3. about as hard as I expected.
    4. somewhat easier than I expected.
    5. much easier than I expected.

33. Think carefully and count the number of things which your child does that bothers you. For example, dawdles, refuses to listen, overactive, cries, interrupts, fights, whines, etc. (Choose a response from the choices below.)..... 1 2 3 4 5
    1. 1-3
    2. 4-5
    3. 6-7
    4. 8-9
    5. 10+

34. There are some things my child does that really bother me a lot. ..... SA A NS D SD
35. My child's behavior is more of a problem than I expected. ..... SA A NS D SD
36. My child makes more demands on me than most children. ..... SA A NS D SD

Please do not write in this area.

Social Communication Questionnaire (SCQ) — Lifetime
PC Answer Sheet

Michael Rutter, M.D., F.R.S., Anthony Bailey, M.D., Sibel Kazak Berument, Ph.D.,
Catherine Lord, Ph.D., and Andrew Pickles, Ph.D.

Name of Subject: _____ D.O.B.___/___/___ Interview Date ___/___/___ Age _____

Gender: ____ F ____ M Name of Respondent: _____ Relation to Subject: _____

Directions: Thank you for taking the time to complete this questionnaire. Please answer each question by circling *yes* or *no*. A few questions ask about several related types of behavior; please circle *yes* if *any* of these behaviors have ever been present. Although you may be uncertain about whether some behaviors were ever present or not, please answer *yes* or *no* to every question on the basis of what you think.

1.	Is she/he now able to talk using short phrases or sentences? If *no*, skip to question 8.	**yes**	**no**
2.	Can you have a to and fro "conversation" with her/him that involves taking turns or building on what you have said?	**yes**	**no**
3.	Has she/he ever used odd phrases or said the same thing over and over in almost exactly the same way (either phrases that she/he has heard other people use or ones that she/he has made up)?	**yes**	**no**
4.	Has she/he ever used socially inappropriate questions or statements? For example, has she/he ever regularly asked personal questions or made personal comments at awkward times?	**yes**	**no**
5.	Has she/he ever gotten her/his pronouns mixed up (e.g., saying *you* or *she/he* for *I*)?	**yes**	**no**
6.	Has she/he ever used words that she/he seemed to have invented or made up her/himself; put things in odd, indirect ways; or used metaphorical ways of saying things (e.g., saying *hot rain* for *steam*)?	**yes**	**no**
7.	Has she/he ever said the same thing over and over in exactly the same way or insisted that you say the same thing over and over again?	**yes**	**no**
8.	Has she/he ever had things that she/he seemed to have to do in a very particular way or order or rituals that she/he insisted that you go through?	**yes**	**no**
9.	Has her/his facial expression usually seemed appropriate to the particular situation, as far as you could tell?	**yes**	**no**
10.	Has she/he ever used your hand like a tool or as if it were part of her/his own body (e.g., pointing with your finger, putting your hand on a doorknob to get you to open the door)?	**yes**	**no**
11.	Has she/he ever had any interests that preoccupy her/him and might seem odd to other people (e.g., traffic lights, drainpipes, or timetables)?	**yes**	**no**
12.	Has she/he ever seemed to be more interested in parts of a toy or an object (e.g., spinning the wheels of a car), rather than using the object as it was intended?	**yes**	**no**
13.	Has she/he ever had any special interests that were *unusual* in their intensity but otherwise appropriate for her/his age and peer group (e.g., trains, dinosaurs)?	**yes**	**no**
14.	Has she/he ever seemed to be *unusually* interested in the sight, feel, sound, taste, or smell of things or people?	**yes**	**no**
15.	Has she/he ever had any mannerisms or odd ways of moving her/his hands or fingers, such as flapping or moving her/his fingers in front of her/his eyes?	**yes**	**no**
16.	Has she/he ever had any complicated movements of her/his whole body, such as spinning or repeatedly bouncing up and down?	**yes**	**no**
17.	Has she/he ever injured her/himself deliberately, such as by biting her/his arm or banging her/his head?	**yes**	**no**
18.	Has she/he ever had any objects (*other* than a soft toy or comfort blanket) that she/he *had* to carry around?	**yes**	**no**
19.	Does she/he have any particular friends or a best friend?	**yes**	**no**

For the following behaviors, please focus on the time period between the child's fourth and fifth birthdays. You may find it easier to remember how things were at that time by focusing on key events, such as starting school, moving house, Christmastime, or other specific events that are particularly memorable for you as a family. If your child is not yet 4 years old, please consider her or his behavior in the past 12 months.

20. When she/he was 4 to 5, did she/he ever talk with you just to be friendly (rather than to get something)?	**yes**	**no**
21. When she/he was 4 to 5, did she/he ever *spontaneously* copy you (or other people) or what you were doing (such as vacuuming, gardening, or mending things)?	**yes**	**no**
22. When she/he was 4 to 5, did she/he ever spontaneously point at things around her/him just to show you things (not because she/he wanted them)?	**yes**	**no**
23. When she/he was 4 to 5, did she/he ever use gestures, other than pointing or pulling your hand, to let you know what she/he wanted?	**yes**	**no**
24. When she/he was 4 to 5, did she/he nod her/his head to mean *yes*?	**yes**	**no**
25. When she/he was 4 to 5, did she/he shake her/his head to mean *no*?	**yes**	**no**
26. When she/he was 4 to 5, did she/he usually look at you directly in the face when doing things with you or talking with you?	**yes**	**no**
27. When she/he was 4 to 5, did she/he smile back if someone smiled at her/him?	**yes**	**no**
28. When she/he was 4 to 5, did she/he ever show you things that interested her/him to engage your attention?	**yes**	**no**
29. When she/he was 4 to 5, did she/he ever offer to share things other than food with you?	**yes**	**no**
30. When she/he was 4 to 5, did she/he ever seem to want you to join in her/his enjoyment of something?	**yes**	**no**
31. When she/he was 4 to 5, did she/he ever try to comfort you if you were sad or hurt?	**yes**	**no**
32. When she/he was 4 to 5, when she/he wanted something or wanted help, did she/he look at you and use gestures with sounds or words to get your attention?	**yes**	**no**
33. When she/he was 4 to 5, did she/he show a normal range of facial expressions?	**yes**	**no**
34. When she/he was 4 to 5, did she/he ever spontaneously join in and try to copy the actions in social games, such as *The Mulberry Bush* or *London Bridge Is Falling Down*?	**yes**	**no**
35. When she/he was 4 to 5, did she/he play any pretend or make-believe games?	**yes**	**no**
36. When she/he was 4 to 5, did she/he seem interested in other children of approximately the same age whom she/he did not know?	**yes**	**no**
37. When she/he was 4 to 5, did she/he respond positively when another child approached her/him?	**yes**	**no**
38. When she/he was 4 to 5, if you came into a room and started talking to her/him without calling her/his name, did she/he usually look up and pay attention to you?	**yes**	**no**
39. When she/he was 4 to 5, did she/he ever play imaginative games with another child in such a way that you could tell that they each understood what the other was pretending?	**yes**	**no**
40. When she/he was 4 to 5, did she/he play cooperatively in games that required joining in with a group of other children, such as hide-and-seek or ball games?	**yes**	**no**

8. My child readily lets new adults hold or share things he/she has, if they ask to.

1	2	3	4	5	6	7	8	9
Very Unlike My Child		Unlike My Child		Neither Like Nor Unlike		Like My Child		Most Like My Child

9. My child keeps track of my location when he/she plays around the house.

Calls to me now and then.
Notices me go from room to room.
Notices if I change activities.
(Low Score: Doesn't keep track)

1	2	3	4	5	6	7	8	9
Very Unlike My Child		Unlike My Child		Neither Like Nor Unlike		Like My Child		Most Like My Child

10. My child tries to get me to imitate him/her, or quickly notices and enjoys it when I imitate him/her on my own.

1	2	3	4	5	6	7	8	9

11. If I laugh at or approve of something my child has done, he/she repeats it again and again.

1	2	3	4	5	6	7	8	9

12. If I move very far, my child follows along and continues his/her play in the area I have moved to. (Doesn't have to be called or carried along; doesn't stop play or get upset.)

1	2	3	4	5	6	7	8	9
Very Unlike My Child		Unlike My Child		Neither Like Nor Unlike		Like My Child		Most Like My Child

Beck Anxiety Inventory

Below is a list of common symptoms of anxiety. Please carefully read each item in the list. Indicate how much you have been bothered by that symptom during the past month, including today, by circling the number in the corresponding space in the column next to each symptom.

	Not At All	Mildly but it didn't bother me much.	Moderately - it wasn't pleasant at times	Severely – it bothered me a lot
Numbness or tingling	0	1	2	3
Feeling hot	0	1	2	3
Wobbliness in legs	0	1	2	3
Unable to relax	0	1	2	3
Fear of worst happening	0	1	2	3
Dizzy or lightheaded	0	1	2	3
Heart pounding/racing	0	1	2	3
Unsteady	0	1	2	3
Terrified or afraid	0	1	2	3
Nervous	0	1	2	3
Feeling of choking	0	1	2	3
Hands trembling	0	1	2	3
Shaky / unsteady	0	1	2	3
Fear of losing control	0	1	2	3
Difficulty in breathing	0	1	2	3
Fear of dying	0	1	2	3
Scared	0	1	2	3
Indigestion	0	1	2	3
Faint / lightheaded	0	1	2	3
Face flushed	0	1	2	3
Hot/cold sweats	0	1	2	3
Column Sum				

Behavioural Inhibition Questionnaire (Parent Form)

The following statements describe children's behaviour in different situations. Each statement asks you to judge whether that behaviour occurs for your child "*hardly ever*", "*infrequently*", "*once in a while*", "*sometimes*", "*often*", "*very often*", or "*almost always*". Please circle the number "1" if the behaviour "*hardly ever*" occurs, the number "2" if it occurs "*infrequently*", etc. Try to make this judgement to the best of your ability, based on how you think your child compares with other children about the same age.

1 Hardly Ever	2 Infrequently	3 Once in a While	4 Sometimes	5 Often	6 Very Often		7 Almost Always
1. Approaches new situations or activities very hesitantly	1	2	3	4	5	6	7
2. Will happily approach a group of unfamiliar children to join in their play	1	2	3	4	5	6	7
3. Is very quiet around new (adult) guests to our home	1	2	3	4	5	6	7
4. Is cautious in activities that involve physical challenge (e.g., climbing, jumping from heights)	1	2	3	4	5	6	7
5. Settles in quickly when we visit the homes of people we don't know well	1	2	3	4	5	6	7
6. Enjoys being the centre of attention	1	2	3	4	5	6	7
7. Is comfortable asking other children to play	1	2	3	4	5	6	7
8. Is shy when first meeting new children	1	2	3	4	5	6	7
9. Happily separates from parent(s) when left in new situations for the first time (e.g., kindergarten, preschool, childcare)	1	2	3	4	5	6	7
10. Is happy to perform in front of others (e.g., singing, dancing)	1	2	3	4	5	6	7
11. Quickly adjusts to new situations (e.g., kindergarten, preschool, childcare	1	2	3	4	5	6	7
12. Is reluctant to approach a group of unfamiliar children to ask to join in	1	2	3	4	5	6	7

Continued next page

1 Hardly Ever	2 Infrequently	3 Once in a While	4 Sometimes	5 Often	6 Very Often	7 Almost Always

13. Is confident in activities that involve physical challenge (e.g., climbing, jumping from heights)	1	2	3	4	5	6	7
14. Is independent	1	2	3	4	5	6	7
15. Seems comfortable in new situations	1	2	3	4	5	6	7
16. Is very talkative to adult strangers	1	2	3	4	5	6	7
17. Is hesitant to explore new play equipment	1	2	3	4	5	6	7
18. Gets upset at being left in new situations for the first time (e.g., kindergarten, preschool, childcare)	1	2	3	4	5	6	7
19. Is very friendly with children he or she has just met	1	2	3	4	5	6	7
20. Tends to watch other children, rather than join in their games	1	2	3	4	5	6	7
21. Dislikes being the centre of attention	1	2	3	4	5	6	7
22. Is clingy when we visit the homes of people we don't know well	1	2	3	4	5	6	7
23. Happily approaches new situations or activities	1	2	3	4	5	6	7
24. Is outgoing	1	2	3	4	5	6	7
25. Seems nervous or uncomfortable in new situations	1	2	3	4	5	6	7
26. Happily chats to new (adult) visitors to our home	1	2	3	4	5	6	7
27. Takes many days to adjust to new situations (e.g., kindergarten, preschool, childcare)	1	2	3	4	5	6	7
28. Is reluctant to perform in front of others (e.g., singing, dancing)	1	2	3	4	5	6	7
29. Happily explores new play equipment	1	2	3	4	5	6	7
30. Is very quiet with adult strangers	1	2	3	4	5	6	7

PRESCHOOL ANXIETY SCALE
(Parent Report)

Your Name: _____ **Date:** _____

Your Child's Name: _____

Below is a list of items that describe children. For each item please circle the response that best describes your child. Please circle the **4** if the item is **very often true, 3** if the item is **quite often true, 2** if the item is **sometimes true, 1** if the item is **seldom true** or if it is **not true at all** circle the **0**. Please answer all the items as well as you can, even if some do not seem to apply to your child.

		Not True at All	Seldom True	Sometimes True	Quite Often True	Very Often True
1	Has difficulty stopping him/herself from worrying.....	0	1	2	3	4
2	Worries that he/she will do something to look stupid in front of other people.....	0	1	2	3	4
3	Keeps checking that he/she has done things right (e.g., that he/she closed a door, turned off a tap).....	0	1	2	3	4
4	Is tense, restless or irritable due to worrying.....	0	1	2	3	4
5	Is scared to ask an adult for help (e.g., a preschool or school teacher).....	0	1	2	3	4
6	Is reluctant to go to sleep without you or to sleep away from home.....	0	1	2	3	4
7	Is scared of heights (high places).....	0	1	2	3	4
8	Has trouble sleeping due to worrying.....	0	1	2	3	4
9	Washes his/her hands over and over many times each day.....	0	1	2	3	4
10	Is afraid of crowded or closed-in places.....	0	1	2	3	4
11	Is afraid of meeting or talking to unfamiliar people.....	0	1	2	3	4
12	Worries that something bad will happen to his/her parents.....	0	1	2	3	4
13	Is scared of thunder storms.....	0	1	2	3	4
14	Spends a large part of each day worrying about various things.....	0	1	2	3	4
15	Is afraid of talking in front of the class (preschool group) e.g., show and tell.....	0	1	2	3	4
16	Worries that something bad might happen to him/her (e.g., getting lost or kidnapped), so he/she won't be able to see you again.....	0	1	2	3	4
17	Is nervous of going swimming.....	0	1	2	3	4

		Not True at All	Seldom True	Sometimes True	Quite Often True	Very Often True
18	Has to have things in exactly the right order or position to stop bad things from happening.....	0	1	2	3	4
19	Worries that he/she will do something embarrassing in front of other people.....	0	1	2	3	4
20	Is afraid of insects and/or spiders.....	0	1	2	3	4
21	Has bad or silly thoughts or images that keep coming back over and over.....	0	1	2	3	4
22	Becomes distressed about your leaving him/her at preschool/school or with a babysitter.....	0	1	2	3	4
23	Is afraid to go up to group of children and join their activities.....	0	1	2	3	4
24	Is frightened of dogs.....	0	1	2	3	4
25	Has nightmares about being apart from you.....	0	1	2	3	4
26	Is afraid of the dark.....	0	1	2	3	4
27	Has to keep thinking special thoughts (e.g., numbers or words) to stop bad things from happening.....	0	1	2	3	4
28	Asks for reassurance when it doesn't seem necessary.....	0	1	2	3	4

REPETITIVE BEHAVIOR SCALE – Revised (RBS-R)

Instructions:

Please rate this person's behavior by reading each of the items listed and then choosing the score that best describes how much of a problem the item is for the person. Be sure to read and score all items listed. Make your ratings based on your observations and interactions with the person over the last month. Use the definitions in the box given below to score each item.

0 = behavior does not occur
1 = behavior occurs and is a mild problem
2 = behavior occurs and is a moderate problem
3 = behavior occurs and is a severe problem

At the end of each section, there will be three questions asking you to rate that section's behaviors in terms of (a) how frequently they occur, (b) how upset the person becomes when repetitive behaviors are interrupted, and (c) how much the behaviors interfere with ongoing events. You will indicate the score by marking along each line, which represents a range of frequencies and severities. For example, if this person does those behaviors many times a day you may put the mark quite close to the right side:

I. Stereotyped Behavior Subscale

(DEFINITION: apparently purposeless movements or actions that are repeated in a similar manner)

1	WHOLE BODY (Body rocking, Body swaying)	0	1	2	3
2	HEAD (Rolls head, Nods head, Turns head)	0	1	2	3
3	HAND/FINGER (Flaps hands, Wiggles or flicks fingers, Claps hands, Waves or shakes hand or arm)	0	1	2	3
4	LOCOMOTION (Turns in circles, Whirls, Jumps, Bounces)	0	1	2	3
5	OBJECT USAGE (Spins or twirls objects, Twiddles or slaps or throws objects, Lets objects fall out of hands)	0	1	2	3
6	SENSORY (Covers eyes, Looks closely or gazes at hands or objects, Covers ears, Smells or sniffs items, Rubs surfaces)	0	1	2	3

Please answer the following questions about the behaviors described above (put a vertical mark (|) on the line to show your answer):

How **often** do they happen?
(If *Never, skip to Section II)*

How **upset** does this person get when interrupted?

How much do these behaviors **get in the way of ongoing events?**

0 = behavior does not occur 1 = behavior occurs and is a mild problem 2 = behavior occurs and is a moderate problem 3 = behavior occurs and is a severe problem

II. Self-Injurious Behavior Subscale

(DEFINITION: movement or actions that have the potential to cause redness, bruising, or other injury to the body, and that are repeated in a similar manner)

7	HITS SELF WITH BODY PART (Hits or slaps head, face, or other body area)	0	1	2	3
8	HITS SELF AGAINST SURFACE OR OBJECT (Hits or bangs head or other body part on table, floor or other surface)	0	1	2	3
9	HITS SELF WITH OBJECT (Hits or bangs head or other body area with objects)	0	1	2	3
10	BITES SELF (Bites hand, wrist, arm, lips or tongue)	0	1	2	3
11	PULLS (Pulls hair or skin)	0	1	2	3
12	RUBS OR SCRATCHES SELF (Rubs or scratches marks on arms, leg, face or torso)	0	1	2	3
13	INSERTS FINGER OR OBJECT (Eye-poking, Ear-poking)	0	1	2	3
14	SKIN PICKING (Picks at skin on face, hands, arms, legs or torso)	0	1	2	3

Please answer the following questions about the behaviors described above (put a vertical mark (/) on the line to show your answer):

How **often** do they happen?
(If *Never, skip to Section II*)

Never ——————————— **Constantly**

How **upset** does this person get when interrupted?

Not at all ——————————— **Extremely**

How much do these behaviors get **in the way of ongoing events?**

Not at all ——————————— **Severe interference**

0 = behavior does not occur
1 = behavior occurs and is a mild problem
2 = behavior occurs and is a moderate problem
3 = behavior occurs and is a severe problem

III. Compulsive Behavior Subscale

(DEFINITION: behavior that is repeated and is performed according to a rule, or involves things being done "just so")

15	ARRANGING / ORDERING (Arranges certain objects in a particular pattern or place; Need for things to be even or symmetrical)	0	1	2	3
16	COMPLETENESS (Must have doors opened or closed; Takes all items out of a container or area)	0	1	2	3
17	WASHING / CLEANING (Excessively cleans certain body parts; Picks at lint or loose threads)	0	1	2	3
18	CHECKING (Repeatedly checks doors, windows, drawers, appliances, clocks, locks, etc.)	0	1	2	3
19	COUNTING (Counts items or objects; Counts to a certain number or in a certain way)	0	1	2	3
20	HOARDING/SAVING (Collects, hoards or hides specific items)	0	1	2	3
21	REPEATING (Need to repeat routine events; In / out door, up / down from chair, clothing on/off)	0	1	2	3
22	TOUCH / TAP (Need to touch, tap, or rub items, surfaces, or people)	0	1	2	3

Please answer the following questions about the behaviors described above (put a vertical mark (/) on the line to show your answer):

How **often** do they happen?
(If *Never, skip to Section II*)

Never ——————————— **Constantly**

How **upset** does this person get when interrupted?

Not at all ——————————— **Extremely**

How much do these behaviors **get in the way of ongoing events?**

Not at all ——————————— **Severe interference**

0 = behavior does not occur
1 = behavior occurs and is a mild problem
2 = behavior occurs and is a moderate problem
3 = behavior occurs and is a severe problem

IV. Ritualistic Behavior Subscale

(DEFINITION: performing activities of daily living in a similar manner)

23	EATING / MEALTIME (Strongly prefers/insists on eating/drinking only certain things; Eats or drinks items in a set order; Insists that meal related items are arranged in a certain way)	0	1	2	3
24	SLEEPING / BEDTIME (Insists on certain pre-bedtime routines; Arranges items in room "just so" prior to bedtime; Insists that certain items be present with him/her during sleep; Insists that another person be present prior to or during sleep)	0	1	2	3
25	SELF-CARE – BATHROOM AND DRESSING (Insists on specific order of activities or tasks related to using the bathroom, to washing, showering, bathing or dressing; Arranges items in a certain way in the bathroom or insists that bathroom items not be moved; Insists on wearing certain clothing items)	0	1	2	3
26	TRAVEL / TRANSPORTATION (Insists on taking certain routes/paths; Must sit in specific location in vehicles; Insists that certain items be present during travel, e.g., toy or material; Insists on seeing or touching certain things or places during travel such as a sign or store)	0	1	2	3
27	PLAY / LEISURE (Insists on certain play activities; Follows a rigid routine during play / leisure; Insists that certain items be present/available during play/leisure; Insists that other persons do certain things during play)	0	1	2	3
28	COMMUNICATION / SOCIAL INTERACTIONS (Repeats same topic(s) during social interactions; Repetitive questioning; Insists on certain topics of conversation; Insists that others say certain things or respond in certain ways during interactions)	0	1	2	3

Please answer the following questions about the behaviors described above (put a vertical mark (/) on the line to show your answer):

How **often** do they happen?
(If *Never, skip to Section II)*

Never ——————————— **Constantly**

How **upset** does this person get when interrupted?

Not at all ——————————— **Extremely**

How much do these behaviors **get in the way of ongoing events?**

Not at all ——————————— **Severe interference**

0 = behavior does not occur 1 = behavior occurs and is a mild problem 2 = behavior occurs and is a moderate problem 3 = behavior occurs and is a severe problem

V. Sameness Behavior Subscale

(DEFINITION: (resistance to change, insisting that things stay the same)

29	Insists that things remain in the same place(s) (e.g. toys, supplies, furniture, pictures, etc.)	0	1	2	3
30	Objects to visiting new places	0	1	2	3
31	Becomes upset if interrupted in what he/she is doing	0	1	2	3
32	Insists on walking in a particular pattern (e.g., straight line)	0	1	2	3
33	Insists on sitting at the same place	0	1	2	3
34	Dislikes changes in appearance or behavior of the people around him/her	0	1	2	3
35	Insists on using a particular door	0	1	2	3
36	Likes the same CD, tape, record or piece of music played continually; Likes same movie / video or part of movie / video	0	1	2	3
37	Resists changing activities; Difficulty with transitions	0	1	2	3
38	Insists on same routine, household, school or work schedule everyday	0	1	2	3
39	Insists that specific things take place at specific times	0	1	2	3

Please answer the following questions about the behaviors described above (put a vertical mark (/) on the line to show your answer):

How often do they happen?
(If Never, skip to Section II)

Never ——————————— **Constantly**

How **upset** does this person get when interrupted?

Not at all ——————————— **Extremely**

How much do these behaviors **get in the way of ongoing events?**

Not at all ——————————— **Severe interference**

0 = behavior does not occur 1 = behavior occurs and is a mild problem 2 = behavior occurs and is a moderate problem 3 = behavior occurs and is a severe problem

VI. Restricted Behavior Subscale

(DEFINITION: Limited range of focus, interest or activity)

40	Fascination, preoccupation with one subject or activity (e.g., trains, computers, weather, dinosaurs)	0	1	2	3
41	Strongly attached to one specific object	0	1	2	3
42	Preoccupation with part(s) of object rather than the whole object (e.g., buttons on clothes, wheels on toy cars)	0	1	2	3
43	Fascination, preoccupation with movement / things that move (e.g., fans, clocks)	0	1	2	3

Please answer the following questions about the behaviors described above (put a vertical mark (/) on the line to show your answer):

How often do they happen?
(If *Never, skip to Section II)*

Never ——————————— **Constantly**

How **upset** does this person get when interrupted?

Not at all ——————————— **Extremely**

How much do these behaviors get **in the way** of ongoing events?

Not at all ——————————— **Severe interference**

FINAL QUESTION: Overall, if you "lump together" all of the behaviors described in this questionnaire, how much of a problem are these repetitive behaviors (both for the person with autism, as well as how they affect the people around them)? Please rate on a scale from 1 to 100, where 1 = not a problem at all, and 100 = as bad as you can imagine:

Score from 1-100: _____

Family Resource Scale

Dunst & Leet, 1987

Form not done ☐ Reason: _____

This scale is designed to assess whether or not you and your family have adequate resources (time, money, energy, and so on) to meet the needs of the family as a whole as well as the needs of individual family members. For each item, please circle the response that best describes how well the needs are met on a consistent basis in your family (that is, month-in and month-out).

To what extent are the following resources adequate for your family:

To what extent are the following resources adequate for your family:	Does not apply	Not at all adequate	Seldom adequate	Sometimes adequate	Usually adequate	Almost always adequate
1. Food for 2 meals a day	NA	1	2	3	4	5
2. House or apartment	NA	1	2	3	4	5
3. Money to buy necessities	NA	1	2	3	4	5
4. Enough clothes for your family	NA	1	2	3	4	5
5. Heat for your house or apartment	NA	1	2	3	4	5
6. Indoor plumbing/water	NA	1	2	3	4	5
7. Money to pay monthly bills	NA	1	2	3	4	5
8. Good job for yourself or spouse	NA	1	2	3	4	5
9. Medical care for your family	NA	1	2	3	4	5
10. Public assistance (SSI, AFDC, Medicaid, etc.)	NA	1	2	3	4	5
11. Dependable transportation (own car or provided by others)	NA	1	2	3	4	5
12. Time to get enough sleep/rest	NA	1	2	3	4	5
13. Furniture for your home or apartment	NA	1	2	3	4	5

Family Resources Scale

To what extent are the following resources adequate for your family:	Does not apply	Not at all adequate	Seldom adequate	Sometimes adequate	Usually adequate	Almost always adequate
14. Time to be by self	NA	1	2	3	4	5
15. Time for family to be together	NA	1	2	3	4	5
16. Time to be with children	NA	1	2	3	4	5
17. Time to be with spouse or close friend	NA	1	2	3	4	5
18. Telephone or access to a phone	NA	1	2	3	4	5
19. Babysitting for your child(ren)	NA	1	2	3	4	5
20. Child care/day care for your child(ren)	NA	1	2	3	4	5
21. Money to buy special equipment/supplies for child(ren)	NA	1	2	3	4	5
22. Dental care for your family	NA	1	2	3	4	5
23. Someone to talk to	NA	1	2	3	4	5
24. Time to socialize	NA	1	2	3	4	5
25. Time to keep in shape and looking nice	NA	1	2	3	4	5
26. Toys for your child(ren)	NA	1	2	3	4	5
27. Money to buy things for self	NA	1	2	3	4	5
28. Money for family entertainment	NA	1	2	3	4	5
29. Money to save	NA	1	2	3	4	5
30. Travel/vacation	NA	1	2	3	4	5

Parent Emotional Flooding Scale

Instructions: Please use the following scale to rate how often you fell this way when you have conflicts with the *target* child.

	Almost Always	Often	Sometimes	Rarely	Never
1. I find my child's distress to be overwhelming	1	2	3	4	5
2. My child tends to explode without any warning signs	1	2	3	4	5
3. I get all jumbled when my child is upset	1	2	3	4	5
4. I get so stressed when my child blows up at me that I shut down	1	2	3	4	5
5. My brain short-circuits when my child gets upset	1	2	3	4	5
6. My child's distress seems to come out of nowhere	1	2	3	4	5
7. My child's distress overpowers me	1	2	3	4	5
8. Distress from my child makes me unable to focus	1	2	3	4	5
9. The intensity of my child's distress	1	2	3	4	5
10. I feel flooded by my child's distress	1	2	3	4	5
11. I cannot predict when my child will blow up at me	1	2	3	4	5
12. I feel paralyzed during my child's outbursts	1	2	3	4	5
13. I am taken aback by how upset my child gets during an argument	1	2	3	4	5
14. My child's distress leaves me feeling disorganized and stressed	1	2	3	4	5
15. I cannot think straight when my child is upset with me	1	2	3	4	5

Scale Developed by Susan G. O'Leary, David S. Arnold, Lisa S. Wolff, & Maureen M. Acker.
Psychology Department, Stony Brook University, Stony Brook, NY 11794-2500

Time ☐ GUID ☐☐☐☐

Mom ○ Dad/Other ○

Parenting Scale

At one time or another, all children misbehave or do things that could be harmful, are "wrong," or that parents don't like. Examples include: hitting someone, forgetting homework, having a tantrum, whining, throwing food, lying, arguing back, not picking up things, refusing to go to bed, coming home late. Parents have many different ways or styles of dealing with these types of problems. Below are items that describe some styles of parenting.

For each item, fill in the bubble that best describes your style of parenting during the ***PAST TWO MONTHS*** with the child with you here today.

Ex.	At meal time... *I let my child decide how I decide how much to eat*	○	○	●	○	○	○	○	*I decide how much my child eats*

IN THE PAST TWO MONTHS

1. When my child misbehaves... *I do something right away*	○	○	○	○	○	○	○	*I do something later*
2. Before I do something about a problem... *I give my child several reminders and warnings*	○	○	○	○	○	○	○	*I use only one reminder or warning*
3. When I'm upset or under stress... *I am picky and on my child's back*	○	○	○	○	○	○	○	*I am not more picky than usual*
4. When I tell my child NOT to do something... *I say very little*	○	○	○	○	○	○	○	*I say a lot*
5. When my child pesters me... *I can ignore the pestering*	○	○	○	○	○	○	○	*I can't ignore the pestering*
6. When my child misbehaves... *I usually get into a long argument with my child*	○	○	○	○	○	○	○	*I don't get into an argument*
7. I threaten to do things that... *I'm sure I can carry out*	○	○	○	○	○	○	○	*I know I won't actually do*
8. I am the kind of parent that... *Sets limits on what my child is allowed to do*	○	○	○	○	○	○	○	*Lets my child do whatever he/she wants*
9. When my child misbehaves... *I give my child a long lecture*	○	○	○	○	○	○	○	*I keep my talks short and to the point*
10. When my child misbehaves... *I raise my voice or yell*	○	○	○	○	○	○	○	*I speak to my child calmly*
11. If saying no doesn't work right away... *I take some other kind of action*	○	○	○	○	○	○	○	*I keep talking and try to get through to my child*
12. When I want my child to stop doing something... *I firmly tell my child to stop*	○	○	○	○	○	○	○	*I coax or beg my child to stop*
13. When my child is out of sight... *I often don't know what my child is doing*	○	○	○	○	○	○	○	*I always have a good idea of what my child is doing*

14. After there's been a problem with my child... *I often hold a grudge*	○	○	○	○	○	○	○	*Things get back to normal quickly*
15. When we're not at home... *I handle my child the way I do at home*	○	○	○	○	○	○	○	*I let my child get away with a lot more*
16. When my child does something I don't like... *I do something about it every time it happens*	○	○	○	○	○	○	○	*I often let it go*
17. When there is a problem with my child... *Things build up and I do things I don't mean to do*	○	○	○	○	○	○	○	*Things don't get out of hand*
18. When my child misbehaves I spank, slap, grab, or hit my child... *Never or rarely*	○	○	○	○	○	○	○	*Most of the time*
19. When my child doesn't do what I ask... *I often let it go or end up doing it myself*	○	○	○	○	○	○	○	*I take some other action*
20. When I give a fair threat or warning... *I often don't carry it out*	○	○	○	○	○	○	○	*I always do what I said*
21. If saying "no" doesn't work... *I take some other kind of action*	○	○	○	○	○	○	○	*I offer my child something nice so he/she will behave*
22. When my child misbehaves... *I handle it without getting upset*	○	○	○	○	○	○	○	*I get so frustrated or angry that my child can see I'm upset*
23. When my child misbehaves... *I make my child tell me why he/she did it*	○	○	○	○	○	○	○	*I say "no" or take some other action*
24. If my child misbehaves and then acts sorry... *I handle the problem like I usually would*	○	○	○	○	○	○	○	*I let it go that time*
25. When my child misbehaves... *I rarely use bad language or curse*	○	○	○	○	○	○	○	*I almost always use bad language*
26. When I say my child can't do something... *I let my child do it anyway*	○	○	○	○	○	○	○	*I stick to what I said*
27. When I have to handle a problem... *I tell my child I'm sorry about it*	○	○	○	○	○	○	○	*I don't say I'm sorry*
28. When my child does something I don't like, I insult my child, say mean things, or call my child names *Never or rarely*	○	○	○	○	○	○	○	*Most of the time*
29. If my child talks back or complains when I handle a problem... *I ignore the complaining and stick to what I said*	○	○	○	○	○	○	○	*I give my child a talk about not complaining*
30. If my child gets upset when I say "no"... *I back down and give in to my child*	○	○	○	○	○	○	○	*I stick to what I said*

PRESCHOOL ANXIETY SCALE (Teacher Report)

Teacher's Name: _____ **Date:** _____

Child's Name: _____

Below is a list of items that describe children. For each item please circle the response that best describes the child. Please circle the 4 if the item is very often true, 3 if the item is quite often true, 2 if the item is sometimes true, 1 if the item is seldom true or if it is not true at all circle the 0. Please answer all the items as well as you can. There are no right or wrong answers.

	Not True at All	Seldom True	Sometimes True	Quite Often True	Very Often True
1. Repeatedly asks about parent(s) during the day	0	1	2	3	4
2. Has difficulty stopping him/herself from worrying.....	0	1	2	3	4
3. Keeps checking that he/she has done things right..... (e.g., that he/she closed a door, turned off a tap)	0	1	2	3	4
4. Complains of headaches or stomachaches when it is time to be dropped off at preschool/school.....	0	1	2	3	4
5. Is tense, restless or irritable due to worrying.....	0	1	2	3	4
6. Is scared to ask an adult for help (e.g., a preschool or school teacher).....	0	1	2	3	4
7. Is scared of heights (high places).....	0	1	2	3	4
8. Washes his/her hands over and over many times each day....	0	1	2	3	4
9. Is afraid of meeting or talking to unfamiliar people.....	0	1	2	3	4
10. Worries that something bad will happen to his/her parents.....	0	1	2	3	4
11. Spends a large part of each day worrying about various things	0	1	2	3	4
12. Is afraid of talking in front of the class (preschool group) e.g., show and tell.....	0	1	2	3	4
13. Worries that something bad might happen to him/her (e.g. getting lost or kidnapped), so he/she won't be able to see his/her parents again	0	1	2	3	4
14. Has to have things in exactly the right order or position to stop bad things from happening.....	0	1	2	3	4
15. Worries that he/she will do something embarrassing in front of other people.....	0	1	2	3	4

	Not True at All	Seldom True	Sometimes True	Quite Often True	Very Often True
16. Is afraid of insects and/or spiders.....	0	1	2	3	4
17. Has bad or silly thoughts or images that keep coming back over and over.....	0	1	2	3	4
18. Becomes distressed when he/she is dropped off at preschool/school	0	1	2	3	4
19. Is afraid to go up to group of children and join their activities	0	1	2	3	4
20. Has to keep thinking special thoughts (e.g., numbers or words) to stop bad things from happening.....	0	1	2	3	4
21. Asks for reassurance when it doesn't seem necessary.....	0	1	2	3	4
22. Cries for parent whilst at preschool/school	0	1	2	3	4