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# A PILOT WELLNESS INTERVENTION FOR PARENTS OF SCHOOL-AGED CHILDREN WITH EMOTIONAL AND BEHAVIORAL DISORDERS: FEASIBILITY, ACCEPTABILITY, AND PRELIMINARY IMPACT

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#### ABSTRACT

The present study used an exploratory sequential mixed method design to evaluate characteristics and needs of parents of children with emotional and behavioral disabilities (EBDs) and what services may feasibly and acceptably promote wellness and mindful parenting and alleviate parenting stress in this population. Phase One of the study qualitatively explored the needs of parents of children with EBDs and identified factors of feasibility and acceptability of services to address these needs. Parents reported several themes surrounding their experience of parenting a child with an EBD and the types of services that would meet those needs: including 1) the hectic but valued experience of parenting a child with an EBD, 2) sources of parenting stress, 3) contributors and barriers to parent wellness, 4) familiarity with and views of mindfulness, and 5) issues of feasibility and acceptability in developing programming that may meet their parenting needs.

This then informed Phase Two, a concurrent quantitative and qualitative evaluation of the feasibility, acceptability, and preliminary impact of an eight-session pilot parent support intervention. The intervention utilized mindfulness strategies, provided support informed by focus group data from Phase One, and aimed to increase parent wellness and mindful parenting and to decrease parenting stress. Among the seven parents who provided pre- and post-intervention data, parents did not report clinically significant change in parenting stress, parent wellness, or mindful parenting. In addition, levels of mindful parenting did not change over the course of the intervention. Regarding

feasibility and acceptability, attendance declined over the course of the intervention, but parents gave sessions ratings of 31.96 and above on a scale of 0 to 40. Participants reported that they most highly valued sessions using *mindfulness* components such as the three-minute breathing space and loving-kindness practice (wishing themselves, loved ones, and all human beings well with the goal of forming the intention to be kind, compassionate, and loving) and *support* components including the resource book as well as avenues for local advocacy and support. Overall, parents perceived notable value of the intervention in their experience of parenting and further research may explore how to increase feasibility for acceptable interventions such as parent support groups.

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#### CHAPTER 1

## Introduction

The current study aimed to develop and evaluate the feasibility, acceptability, and preliminary impact of a support intervention for parents of children with emotional and behavioral disabilities (EBDs), including Autism Spectrum Disorder and Attention Deficit/Hyperactivity Disorder. Previous literature has described 1) the symptomatology of EBDs and its contribution to parenting stress; 2) components of this parenting stress and, conversely, parent wellness; and 3) strategies, such as mindfulness, to decrease parenting stress and increase wellness. Much work has also examined interventions targeting parent-focused outcomes, though gaps remain in the research literature regarding parent support beyond parent training for parents of children with EBDs.

# **Emotional and Behavioral Disabilities in School-Aged Children**

In the education literature, emotional and behavioral disabilities and difficulties involve behavioral and emotional responses that are markedly different from appropriate developmental and cultural norms and hinder the child's academic, social, vocational, and personal skills (Council for Children with Behavioral Disorders, 1989). EBDs are typically composed of at least one of two behavior patterns: an externalizing pattern characterized by disruptive behavior and/or an internalizing pattern characterized by anxious, depressed, and somatic symptoms (Gresham, 1998; Lane et al., 2008).

While child adaptive functioning levels have been found to inconsistently predict levels of caregiver stress, such child behavior problems are a unique contributor to parenting stress in parents of children with disabilities (Lecavalier, Leone, & Wiltz, 2006; Tomanik, Harris, & Hawkins, 2004). Thus parents of children with disorders such as Autism Spectrum Disorder (ASD) and Attention Deficit/Hyperactivity Disorder (ADHD) that include behavioral difficulties as a prominent challenge should be especially considered for services targeting their probability for high levels of parenting stress. ASD and ADHD are each characterized by a set of specific symptoms that may impact children and their families behaviorally as well as socially, emotionally, and functionally. The symptoms are outlined by *The Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; DSM-5; American Psychiatric Association, 2013) and qualitative research with parents of children meeting these diagnostic criteria has examined the role of these disorders in families' lives.

## Autism

The DSM-5 identifies ASD, or autism, as consisting of deficits in two areas: 1) social communication and 2) restricted, repetitive patterns of behavior, interests, and activities. These deficits must be present in early development and cause impairment at a clinically significant level (American Psychiatric Association, 2013). Landa (2007) notes that as early as six months old, children with autism display deficits in social responsiveness, social initiation, social-emotional interaction, communication, and play, as well as sensory, motor, and attention behaviors.

In addition to those with an autism diagnosis according to the DSM-5, some individuals may have been grandfathered into a current diagnosis of autism after

receiving a diagnosis under the criteria of the previous edition of the Diagnostic and Statistical Manual of Mental Disorders (4<sup>th</sup> ed., text rev.; DSM-IV-TR; American Psychiatric Association, 2000). As a result, youth participating in studies about autism spectrum disorder may have initially received a diagnosis through either set of criteria. The DSM-IV-TR included Autistic Disorder as a Pervasive Developmental Disorder along with Asperger's disorder, Pervasive Developmental Disorder- Not Otherwise Specified (PDD-NOS), Rett's Disorder, and Childhood Disintegrative Disorder. In DSM-IV-TR criteria, symptoms of pervasive developmental disorders, including autism, involved deficits in social interaction, communication, and restricted and repetitive behaviors (American Psychiatric Association, 2000).

A national profile of children with autism (Montes & Halterman, 2006) indicated that school-aged children with autism are likely to be male, from a low-income family, and/or from a family that receives Medicaid and welfare. Students with autism attend public school at the same rate as their typically developing peers, but are less likely to receive grades of A and B and are more likely to have teachers contact their parents about behavior problems. Many children with autism also have comorbid diagnoses including Attention Deficit/Hyperactivity Disorder (54%), learning disability (67%), speech impairment (58%), emotional disturbance (32%), and intellectual disability (24%). About 75% of these children receive services through a school district (Montes & Halterman, 2006), but parents of children with autism have noted a need for accessible community-based services as well (Dymond, Gilson, & Myran, 2007).

Several qualitative studies investigated the experience of parents of a child with autism. Werner (2000) conducted in-depth interviews with parents of children with

autism and identified five themes of their parenting experience in their responses: 1) a notable portion of family life revolves around the child's needs; 2) the family dedicates an overwhelming amount of energy to the symptoms of autism; 3) the family misses opportunities for participating "normal" family activities and tangible support for each member of the family, including siblings; 4) families frequently use strategies to distract or relax their child to reduce difficult-to-manage behavior; and 5) families expressed a lack of inner satisfaction and meaningful family experiences.

Woodgate, Ateah, and Secco (2008) interviewed 21 parents of children with autism and identified what the authors termed an "essence" of this parenting experience: "living in a world of our own." The authors identified components of parenting a child with autism for these parents, including anticipating their child's healthcare needs, exhausting all opportunities to help their child reach his or her full potential, and pursuing what they think is best for their child. Additional components included parents balancing different aspects of their own life (beyond parenting a child with autism), celebrating milestones in their child's development, letting go of what they cannot control, and being direct in requests for support and treatment for their child. Parents also described educational components of their experience such as learning as much as possible about raising a child with autism and sharing those lessons with others (Woodgate et al., 2008).

# **Attention Deficit/Hyperactivity Disorder**

The DSM-5 notes that ADHD is a "persistent pattern of inattention and/or hyperactivity/impulsivity" (p. 60) that interferes with development or social functioning (American Psychiatric Association, 2013). According to a meta-analysis of prevalence

studies, the average prevalence of ADHD is 7.2% (Thomas, Sanders, Doust, Beller, & Glasziou, 2014).

Deficits in developmental functioning compared to same-aged typically developing peers may occur across five domains for children with ADHD: adaptive functioning (which includes problems with social functioning); motor coordination; language ability; learning difficulties; and self-perception (Weyandt & Gudmundsdottir, 2014). In the context of a developmental-transactional model, these characteristics contribute to the parent-child relationship. When this relationship is paired with positive processes (e.g. effective parenting, use of strategies to address EBD symptoms in both parents and children), it contributes to more adaptive outcomes; when paired with negative processes, such as the unresolved stress of behavioral concerns, it can lead to more adverse outcomes (Johnston & Chronis-Tuscano, 2014). School-aged children with ADHD may also face difficulties in extrafamilial peer relationships as a result of their externalizing behaviors and experience more peer rejection than their same-aged peers (Hoza et al., 2005; McQuade & Hoza, 2008).

As was the case with parents of children with autism, several qualitative studies have been conducted globally to learn about the experiences of parents of children with ADHD. In interviews with parents of British children with recently-diagnosed ADHD, parents expressed feeling blamed for their child's misbehavior by others, including teachers, family members, and strangers, who did not acknowledge the behaviors as symptoms of a disorder. They also noted perceiving a lack of support from partners; described battling with teachers, family members, and "unsympathetic and patronizing" professionals; and reported struggles with their psychological well-being including issues

with anxiety, sleeplessness, weight gain, guilt, and self-blame, among other concerns (Harborne, Wolpert, & Clare, 2004). In a qualitative study with Australian mothers, four dominant issues in parenting a child with ADHD arose: 1) the overwhelming responsibility of caring for a child with an EBD: 2) guilt and self-blame, as was the case with British mothers as well; 3) feeling stigmatized, scrutinized, and criticized; and 4) the mother serving as an advocate for the child (Peters & Jackson, 2008). The literature lacks a qualitative evaluation of American parents' experiences parenting a child with ADHD, but in a quantitative study evaluating the perspectives of parents of school-aged children with ADHD, parents reported that their greatest concerns about their child centered on their child's general emotional or behavioral disturbances, academic performance, and social role functioning (Bussing, Gary, Mills, & Garvan, 2003).

As noted in the studies above, parents of children with autism and ADHD often carry the responsibility of coping with their child's unique needs. While parents of children with EBDs report positive aspects of their parenting experiences, such as positive changes in their belief systems, their worldview, and the ways that they note their child positively contributing to his or her surroundings (King et al., 2006), they may also face stigma and other negative interactions from other parents, school personnel, and other adults as a result of their child's disability (Gray, 2002), in addition to the stresses of symptomatology innate to EBDs. These factors and others are potential contributors to parenting stress, which has unique applications to parents of children with EBDs.

# **Parenting Stress**

While stress alone refers to "an individual's emotional and behavioral response to some unpleasant event [and] involves some level of distress that adversely affects

subsequent behavior and functioning" (Crnic & Greenberg, 1990, p. 243), parenting stress is specific to parenting and considers parents' sense of their role as a parent being a stressful one (Levendosky & Graham-Bermann, 1998). Deater-Deckard (2008) specifically defines parenting stress as "a set of processes that lead to aversive psychological and physiological reactions arising from attempts to adapt to the demands of parenthood... [that] involves a broad set of complex, dynamic processes linking the child and [his or] her behaviors, perceived demands of parenting, parenting resources, physiological reaction to the demands of parenting, qualities of the parent's relationships with the child and other family members, and links with other people and institutions outside of the home" (p. 6).

This stress specific to the parenting role arises from an imbalance of perceived demands on the parenting role and access to resources to address these demands (Goldstein, 1995). Abidin's (1992) theory of parenting stress notes three sources of these demands: the parent-child relationship, the parent, and the child. Each of these three domains involves specific stressors. The parent-child/adolescent relationship domain considers parents' levels of satisfaction and positive emotions in response to interactions between the parent and their child. The parent domain involves parental attachment, parental sense of competence, restriction of parental role, depression, social support, and health concerns. The child domain includes the child's adaptability, acceptability, demandingness, mood, hyperactivity/distractability, and parent reinforcement. As children age into adolescence, youth-based stressors may include moodiness/emotional lability, social isolation/withdrawal, delinquency/antisocial behavior, and failure to achieve or persevere (Sheras, 1998). Additional demands may stem from daily hassles,

child's basic survival needs, the child's psychological needs, and components of child behavior (Crnic & Low, 2002; Deater-Deckard, 2008).

The relationship between child behavior and parenting stress is a particularly interesting one as it may be bidirectional (Deater-Deckard, 2008; Karraker & Coleman, 2005; Patterson & Fisher, 2002), allowing for points of intervention with both the child and parent. Deater-Deckard's (1998) model of parenting stress additionally noted that parenting stress may impact parenting behaviors, which in turn influence child behaviors. As also noted in previously discussed literature, child behaviors then impact parenting stress, creating a cycle of influence and three areas where intervention may take place: at the level of parenting stress, of parenting behaviors, and/or of child behaviors. In situations when child behaviors are at a clinically significant level of deviation from the norm, as is the case in children with EBDs, parents may be susceptible to additional stressors and benefit from supports in these areas.

Deater-Deckard's model of parenting stress has been specifically applied to parenting a child with EBDs in Hastings' (2002) model, which expands the original Deater-Deckard (1998) model to include parents' psychological resources and negative emotional reactions. In the expanded model, child behavior problems contribute to parental psychological resources and negative emotions as well as parenting stress. Parental psychological resources contribute to parental negative reactions and parenting stress and moderate the relationship between child behavior problems and parenting stress. Parents' psychological resources also moderate the relationship between child behavior problems and parental negative emotional reactions, which contribute to parenting stress. Hastings (2002) makes six predictions based on the model: 1) child

behavior problems will predict more parenting stress than other aspects of the child domain of parenting stress; 2) parents of children with EBDs will participate in parenting behaviors that contribute to child behavior concerns when levels of parenting stress are high; 3) parenting behaviors will be connected to more behavior problems because of reinforcement processes; 4) psychological resource variables will mediate and/or moderate the relationship of child behavior problems and parental stress or well-being; 5) parents' negative emotional reactions to children's behavior may be a "key mechanism" in the development of daily parenting stress responses to children's behavior; and 6) the overall model may interact with other processes, such as socioeconomic, cultural, and neurobiological variables.

Indeed, parenting a child with an EBD in particular is linked to parenting stress significantly above that experienced by parents of typically developing children and children with chronic medical conditions, particularly across the parent and child domains of development in areas such as distractibility, adaptability, and demandingness (Gupta, 2007). Behavior problems in children with EBDs have also been noted to contribute to parenting stress (Hastings, 2002), which has a unique relationship with both autism and ADHD.

## **Parenting Stress and Autism**

Much of the literature considering parenting stress in parents of children with autism has focused on parents of *young* children with autism. In this case, specific child behaviors contributing to maternal stress in mothers of two- to seven-year-olds with autism included irritability, social withdrawal, hyperactivity/non-compliance, reliance on parents for care, and communication difficulties (Tomanik et al, 2004). In a study of

families with children under five years old, reports of stress among parents of children with autism were also related to integral components of an autism diagnosis including social communication deficits (Kasari & Sigman, 1997).

Trends of higher levels of parenting stress continue in parents of school-aged children with autism. One study of 265 parents of children (Mage = 13.51 years old) with autism reported significantly higher levels of parenting stress than parents of children with Down's syndrome (Hamlyn-Wright, Draghi-Lorenz, & Ellis, 2007), who have been noted to experience more stress than parents of typically developing children (Roach, Orsmond, & Barratt, 1999). Another study similarly also found that nineteen mothers of 4- to 17-year-old children with autism reported significantly higher levels of parenting stress than did mothers of children with Down syndrome (Griffith, Hastings, Nash, & Hill, 2010). As was the case among parents of younger children with autism, mothers of children in this broader age range noted that their children had low social competence and exhibited self-injurious and stereotypical behaviors.

In another comparison of parents of typically developing children and parents of children with autism, parents in the latter group were again found to experience significantly more elevated levels of stress (Rao & Beidel, 2009). The study included parents of fifteen 8- to 14-year-old males with high-functioning autism and fourteen parents of age-, race-, and IQ-matched controls. Parents specifically reported that stressors were mediated through child behaviors including hyperactivity, demandingness, and mood concerns (Rao & Beidel, 2009). However, further literature identifying specific behavioral contributors to parenting stress in parents of school-aged children with autism is limited. Even with a need for continued research regarding contributors to parenting

stress in this population, prior research indicates that levels of parenting stress related to autism consistently surpasses those in parents of typically developing children *and* children with other developmental disorders, indicating a need for support in this area.

# **Parenting Stress and ADHD**

Parents of school-aged children with ADHD have been noted to experience higher levels of parenting stress than other parents, in part because of the characteristics of the child, such as severity of ADHD, aggressive and oppositional-defiant behavior, and health status, (Anastopoulos, Guevremont, Shelton, & DuPaul, 1992; Harrison & Sofronoff, 2002; Podolski & Nigg, 2001; Theule, Wiener, Tannock, & Jenkins, 2012). Parent characteristics are a critical contributor to parenting stress as well; one study that noted the impact of child symptom severity reported that a lack of perceived parental control of these behaviors was predictive of higher levels of parenting stress (Harrison & Sofronoff, 2002). Parents' physical health, mental health, and receipt of social support have also been noted as significant predictors of variance in parenting stress (Anastopoulos et al., 1992; Theule et al., 2012). Parents' mental health concerns may include ADHD, which is associated with difficulty with positive parenting; depression, experienced by nearly half of mothers of children with ADHD; and anxiety (Chronis et al., 2003). Additional parental factors, including interparental conflict and alcohol/substance use problems, may also contribute to the interaction of parent behaviors and child behaviors (Johnston & Chronis-Tuscano, 2014).

Thus despite some observed and valuable benefits of parenting a child with a disability, parenting a child with an EBD is linked to unique stressors that may begin to exceed parents' coping abilities and generate a need for both informal and formal training

and support (Luther, Canham, & Cureton, 2005). Hastings' (2002) model of parenting stress has a two-fold implication for such intervention with parents. First, it is of import to improve parents' behavioral management skills because of impacts on child behavior and, in turn, parenting stress. Second, interventions should target the reduction of parenting stress because of its consequences on parent behavior and as a result, child behavior (Hastings, 2002). While substantial literature has focused on parent training to address parenting and ultimately child behavior, less has focused on interventions specifically addressing parenting stress in these populations.

## **Interventions for Parenting Stress**

Interventions aiming to alleviate parenting stress may target child outcomes (e.g. behavior, etc.) or parent outcomes (e.g. wellness, self-efficacy, etc.). While a focus on child outcomes is beneficial, particularly in the context of Deater-Deckard's (1998) model of parenting stress that notes the relationship between child and parent characteristics, fewer programs have focused on parent needs and outcomes. In one study focusing on outcomes for both parents and children, therapists offered parent problemsolving sessions to some parents of children with behavior problems (Kazdin & Whitley, 2003). In the first session, parents participated in an interview about life stressors including work problems, marriage and relationships, financial difficulties, and involvement with support services. Parents then shared what would make life more enjoyable for them. Parents most commonly identified having more time with their partner and for themselves and overcoming job- and finance-related stress. Therapists used this information in discussions of problem-solving skills to address these stressors. Parents were encouraged to identify and implement adaptive solutions for stressor-laden

situations. The subsequent four 50-minute sessions occurred every two to four weeks and involved three phases: 1) gathering specific details about the sources of stress, 2) considering cognitions and affect about the problem, and 3) developing a plan for altering or coping with the situation. For "homework" after each session, parents applied one to three solutions to stressful situations (Kazdin & Whitley, 2003). Compared to parents who did not participate in the problem-solving intervention, participating parents reported a significantly greater reduction in parenting stress, positive therapeutic change in children, and reduced barriers to participation in treatment (Kazdin & Whitley, 2003).

Another quasi-experimental study implemented a successful parent program that targeted the outcomes of increased parent self-efficacy and reduced parenting stress (Keen, Couzens, Muspratt, & Rodger, 2010). Seventeen parents of two- to four-year-olds with autism participated in a workshop-based intervention with 10 home visits and another 22 parents of same-aged children participated in a self-directed video intervention. The workshop provided visually-aided lectures information regarding "autism; social communication; play; sensory; behavior; strategies to improve social interaction and communication; embedding strategies within daily routines; using a balanced approach; and selecting a child-focused early intervention program [combined with] structured interactive group activities... to promote parent-to-parent interaction and opportunities to individualize the information and strategies to particular children and families" (Keen et al., 2010, p. 233). Parents that used the video intervention received information about the same strategies taught in the workshop through an instructional DVD and related activity sheets. Parents in the workshop/home visit group reported decreased child-related parenting stress and increased parent self-efficacy compared to

the video-based group (Keen et al., 2010), suggesting a benefit of the interpersonal group structure.

Another intervention of parenting stress management (PSM) groups for parents of 6- to 15-year-old children with ADHD met for nine weeks at a research clinic and reported decreased parent domain-based parenting stress and improved parenting behaviors (Treacy, Tripp, & Baird, 2005). The first session focused on orienting parents to the program and the recognition and nature of stress involved in parenting a child with ADHD. The second session featured education about causes, symptoms, outcomes, and treatment for ADHD; the third addressed educational and financial rights and how to identify and utilize community resources; and the fourth taught problem-solving skills aimed at developing adaptive responses to situations that generate stress in parenting a child with an EBD. Session five took a cognitive-behavioral approach and focused on developing parents' adaptive and realistic thoughts about their children and themselves in lieu of faulty cognitions, which similarly aimed to reduce negative emotional responses to stressors. In session six, group leaders described and modeled effective styles of communication with children, partners, school personnel, and health professionals. In session seven, group leaders emphasized the role of self-care in stress reduction through the use of time-management skills and relaxation techniques. Session eight involved a review of behavior management techniques to meet an ethical concern about addressing the use of discipline practices among parents under high levels of stress. The final session reviewed previously taught material and addressed parents' remaining questions. The authors noted that the program significantly decreased parent-domain parenting stress and improved parenting style in mothers, but yielded only changes in aspects of parenting

style for fathers. Additionally, the use of a group format alone was ineffective in improving parents' social support networks, indicating the need for outside supports as well (Treacy et al., 2005).

While these findings indicate an encouraging trend in the usefulness of stress reduction programs for parents of children with EBDs, these parents also express a largely unaddressed need for support for themselves (Falk, Norris, & Quinn, 2014). Programs that encourage parent wellness, including parent support, for parents of schoolaged children with EBDs are under-discussed in the literature. However, some research has evaluated the construct of parent wellness and interventions aimed at increasing it by targeting one of its primary components: parent support.

#### **Parent Wellness**

Parent wellness, or subjective well-being, can be measured through life satisfaction, which addresses several domains. The domains include global life satisfaction, marital satisfaction, and satisfaction with parenthood. Parents assess these domains differently and specifically use unique criteria to assess their satisfaction with parenting (Ishii-Kuntz & Ihinger-Tallman, 1991).

An examination of a dynamic model of parent well-being (Resch, Benz, & Elliott, 2012) with parents of children with disabilities including autism, intellectual disabilities, and other health impairment (e.g. ADHD) identified four contributors to parent well-being. Higher levels of resources/supports, growth appraisals (i.e. perception of benefiting or growing from raising a child with a disability), and parental problem solving skills contributed to higher levels of parent well-being while threat appraisals (i.e. perception of raising a child with a disability as a potential threat to certain areas of the

parent's life such as life goals, relationships, and well-being) decreased parent well-being (Resch et al., 2012). The study also indicated that the level of impact of the child's disability on their activities of daily living was not a significant direct predictor of parent well-being, but did significantly contribute to growth appraisals and threat appraisals, which were also impacted by resources/supports and problem solving skills. While parents' efforts in their child's activities of daily living have been reported as nonsignificant predictors of parent well-being (Resch et al., 2012), no similar investigation has evaluated parents' efforts in response to behavior problems in their child with a disability.

Parenting stress has also been noted to be negatively correlated with parent wellness (Gillingham, 2009). However, use of coping strategies is associated with higher parent well-being in parents of children with disabilities (Glidden, Billings, & Jobe, 2006) and some have asserted that wellness in parents is dependent in part on support given to them by their community (Rickel & Becker, 1997). While parents may employ some informal strategies for stress reduction, there are several evidence-based strategies that may be particularly beneficial for increasing perceived support in parents of children with disabilities. Strategies that parents use to meet the needs that contribute to wellness and detract from stress are often conceptualized as aspects of *social support*, which contributes to parent well-being through the use of social integration, emotional support, problem solving, esteem support, and concrete aid (Armstrong, Birnie-Lefcovitch, & Ungar, 2005; McLanahan, Wedemeyer, & Adelberg, 1981).

# **Parent Support**

Social support for parents, or parent support, may take a variety of forms. It provides indirect support to children with disabilities by serving parents' needs and alleviating negative parent behaviors (Bearss, Burrell, Stewart, & Scahill, 2015; Deater-Deckard, 2008), but retains its focus on *parents'* experiences and needs. These needs may be practical (e.g. finding services for their child, having help at home, etc.) or emotional (e.g. feeling alone, knowing someone understands, etc.; Kerr & McIntosh, 2000). In the emotional realm, some have noted that a critical mechanism of stress reduction is parents' ability to share experiences with others in their situation (Kerr & McIntosh, 2000; Santelli, Turnbull, Marquis, & Lerner, 1997). More practically, such support activities as access to information and resources, inclusion and acceptance into one's social environment, and fewer financial barriers were noted to be significant predictors of parent well-being in a mixed methods study with parents of children with disabilities (Resch et al., 2012). The fulfillment of these supports becomes particularly salient for parents of children with disabilities as these parents, in addition to experiencing higher levels of stress as a result of their child's behavior, often feel estranged from a society that focuses on "typical children" and normalcy (Ainbinder et al., 1998). Yet while much research has focused on child outcomes, minimal literature presents the needs of parents of children with disabilities and how support for these needs might be provided in a community intervention setting. Among the limited extant literature are parent-led interventions aimed at increasing wellness in parents of children with disabilities.

#### **Extant Parent Wellness Interventions**

Wellness interventions for families can occur at various levels, the most effective of which is socially focused, involving collaboration with others and peer or community support in addition to support provided by professionals (Prilleltensky & Nelson, 2000). Such social support interventions are broadly defined as "small-scale efforts to augment the personal resources and/or the social resources available to an individual or family" (Cameron, 1990, p. 146).

One such intervention involving a self-identifying support group, *Parent to* Parent, aimed to meet parent needs by providing support based in four components: perceived sameness with the person(s) providing support, common experiences with others and sharing of information, easily accessible support, and bi-directional or mutual support (Ainbinder et al., 1998). The Parent to Parent program achieves these goals by involving parents of children with disabilities who previously participated in the program as the primary support. These "supporting parents" were available round-the-clock to share experiences and information and to receive the same from participating parents. Parents participating in the program reported feeling empowered, experiencing less isolation, and having improved well-being, but also noted some barriers including limited availability, a lack of perceived sameness between parents, technical issues with phones, and negligent supporting parents (Ainbinder et al., 1998). Thus an intervention that feasibly gathers parents with similar child-rearing experiences may overcome these barriers to increase the likelihood of positive outcomes surrounding wellness and parenting stress.

Another intervention similarly incorporated the use of an experienced parent as a source of support, here termed a *Family Facilitator*, who was hired using private funding to lead a *Peer Support Group* for parents of children with a variety of disabilities linked to communication difficulties (Kingsnorth, Gall, Beayni, & Rigby, 2011). The youth, whose ages ranged from 12 to 18, were participants in a communication support intervention. The parents attended two-hour peer support group sessions each month. Parents reported feeling inspired by the facilitator as a role model and appreciated the opportunity to share experiences and information with other parents with similar families (Kingsnorth et al., 2011).

However, such parent support interventions may additionally benefit from a combination of strategies that have been noted in the literature to affect wellness outcomes for parents. Various strategies, and particularly those that emphasize positive emotional qualities, may generate change in stress and wellness through skills-based training that then impacts neurobehavioral functioning linked to stress and wellness domains (Davidson & McEwen, 2012). In creating these changes in functioning, parents may be more able to apply support strategies and embrace support they receive both in and outside of structured groups. The principles of mindfulness, for example, have been successfully applied to decrease parenting stress and expand capacity for practicing aspects of support (Dumas, 2005; Duncan, Coatsworth, & Greenberg, 2009). The skills and benefits acquired with mindfulness practice, then, may be a strong contributor to parent-focused interventions.

#### Mindfulness

Mindfulness is "the awareness that emerges through paying attention, on purpose, in the present moment, and nonjudgmentally to the unfolding of experience moment by moment" (Kabat-Zinn, 2003, p. 145). The converse is automaticity, which involves habitual reactions in both cognitive and behavioral form to experiences (Dumas, 2005).

# **Mindfulness for Parenting Stress**

Mindful parenting applies the concepts of mindfulness to the context of parenting (Duncan et al., 2009) to combat the automaticity of negative patterns that parents of children with EBDs may face in managing their child's symptomatology. Dumas (2005) noted family members facing notable stressors, such as those associated with a child with disruptive behavior, may be especially likely to rely on overlearned and automatic coping strategies that are ineffective, associated with negative emotion, and lack much conscious effort. Conversely, a more conscious and mindful model of coping engages more effective strategies. Duncan and colleagues' (2009) model, for example, identifies five dimensions of mindful parenting: 1) listening with full attention, 2) nonjudgmental acceptance of self and child, 3) emotional awareness of self and child, 4) self-regulation in the parenting relationship, and 5) compassion for self and child.

The first dimension, listening with full attention, promotes the parent's accurate discernment of their child's behavioral and verbal cues and reduces their use of previously developed cognitive constructions and expectations. The second dimension, nonjudgmental acceptance of self and child, aims to limit parents' unrealistic expectations of their child and improve parenting self-efficacy, low levels of which are associated with diminished satisfaction in their role as parents (Johnston & Mash, 1989)

and higher levels of behavior problems in children (Hastings & Brown, 2002; Mouton & Tuma, 1988). Parent self-efficacy is "parents' self-referent estimations of competence in the parental role or... perception of their ability to positively influence the behavior and development of their children" (Coleman & Hildebrandt Karraker, 2000, p. 13). The construct can also be evaluated from a task-specific approach that focuses on specific tasks within the parenting domain, which in the case of the current study, may involve exhibiting parenting behaviors facilitating physical health in children with autism (Coleman & Hildebrandt Karraker, 2000). Nonjudgmental acceptance of self and child can also promote a more healthy balance of goals for the child, parent, and parent-child relationship. The third dimension, emotional awareness of the self and child, limits child discipline as a result of negative parent emotion and support responsiveness to the needs and emotions of the child. The fourth dimension, self-regulation in the parenting relationship, also limits this form of discipline as it facilitates parents' emotion regulation and encourages parenting that is congruent with the parent's goals and values. Finally, the last dimension, compassion for self and child, promotes positive affection between parent and child and decreases parents' self-blame when they do not achieve their goals.

One intervention used an eight-week mindful parenting training program for parents of 8- to 12-year-old children with ADHD, who concurrently received mindfulness training. Parents reported a significant increase of mindful awareness and a reduction of parenting stress, parenting over-reactivity, and parental ADHD symptoms (van der Oord, Bögels, & Peijenburg, 2012). The parent component of the intervention involved eight 90-minute sessions for groups of four to six parents. Children participated in a simultaneous but primarily separate mindfulness intervention, though some sessions

involved activities alongside the child. The parent intervention was based on Mindfulness-Based Cognitive Therapy (MBCT; Teasdale et al., 2000). The first session taught psychoeducation on ADHD and mindfulness, breathing meditation, and completing intervention homework. The second session taught breathing meditation and an MBCT "body scan," which was similarly reviewed in session three along with breathing space and body-awareness meditation. Sessions four and five targeted automatic responding and practiced awareness of more positive interactions with the child. The sixth session worked to improve communication with the child through the use of already-taught mindfulness exercises, the seventh session was about accepting your child, and the eighth session focused on being on their own and developing a meditation schedule, and learning to let go. A similar eight 90-minute session intervention adjusted for parents of adolescents with ADHD focused on: being attentive through bringing mindfulness to routine activities; being at "home in your body;" practicing breath and developing an unpleasant event calendar; answering; acceptance of what can and cannot be changed; identity of the self and the child; mindful communication with the child, and goals for the parent and their child; and plans for future use of mindfulness and coping (Bögels, Hoogstad, van Dun, Schutter, & Restifo, 2008).

Mindfulness has also been an effective component of parenting interventions when integrated into parent-focused interventions with other components (Duncan et al., 2009). In the study by Duncan and colleagues, an average of two mindful parenting activities was added into each session of a pre-existing parent-focused program. Parents met for seven two-hour sessions and noted that shortening didactic and mindfulness activities improved the curriculum. The program with mindfulness demonstrated

significantly stronger intervention effects on mindful parenting, parent-youth relationship quality, and parent mental health and well-being (Duncan et al., 2009). An additional example of this approach is a program for parents of preschool children with behavior problems. This intervention consisted of six 1.5-hour sessions based on Mindfulness-Based Stress Reduction and covered formal (e.g., sitting meditation, body scan, and mindful yoga) and informal (e.g., stress reactivity and responsivity, effects of perception/appraisal, and changing attitudes) techniques and encouraged parents to practice these techniques as "homework" (Walling, 2008).

Many of the principles behind the mindfulness activities in these interventions involve self-regulation, which disrupts automaticity and promotes a shift to mindfulness, particularly through self-monitoring (Langer, 1989). Self-regulation also adds more specific components of goal-setting that contribute to intervention effectiveness (Maes & Karoly, 2005; Sanders & Glynn, 1981).

#### **Self-Regulation**

Karoly (1993) notes that self-regulation "refers to those processes, internal and/or transactional, that enable an individual to guide his/her goal-directed activities over time and across changing circumstances (contexts). Regulation implies modulation of thought, affect, behavior, or attention via deliberate or automated use of specific mechanisms and supportive meta-skills. The processes of self-regulation are initiated when routinized activity is impeded or when goal-directedness is otherwise made salient" (p. 25). Karoly (1993) additionally identifies up to five phases of self-regulation: goal selection, goal cognition, directional maintenance, directional change or reprioritization, and goal termination.

Interventions that aim to institute a positive emotional quality (e.g. mindfulness) require that participants respond to training through skill implementation (Davidson & McEwen, 2012), which involves the goal direction typical of self-regulation. Self-regulation becomes an especially important component of interventions focused on creating change in interpersonal contexts, such as the parent-child relationship present in parenting (Davidson & McEwen, 2012).

In the context of parent-focused programs, interventions with self-regulation components may make parents collaborative, and perhaps guiding, members in their efforts to change their parenting behaviors, rather than following a strict intervention leader-participant hierarchy (Sanders, 2008; Webster-Stratton, 2001). For instance, the Incredible Years parenting training program was described as "highly interactive, collaborative, and self-directed" (Webster-Stratton, 2001, p. 36) and utilized selfmonitoring strategies such as checklists and goal setting alongside support from groups and leaders. Similarly, self-regulation strategies integrated into the Triple P parenting program (Sanders, 2008) include promoting self-sufficiency, increasing parental selfefficacy, using self-management tools, promoting personal agency, and promoting problem solving in part through the direct skills of monitoring their own and their child's behavior, setting goals appropriate to their child's development, using practice tasks, evaluating their own strengths and weaknesses, and setting personal goals for change (Sanders, 2008). Facilitating self-regulation skills in parents as they practice skills both in and outside of intervention settings is among several aspects of successful interventions for parent needs.

#### **Additional Dimensions of Interventions for Parent Outcomes**

Additional literature has broadly reviewed components of parent programs (e.g. structure, format, focus) through which outcomes such as stress, wellness, and mindfulness may be addressed. Effective programs for parents involve individual sessions combined with workshop/group sessions, building parents' knowledge *and* skills, and including overall family support (Karst and Van Hecke, 2012). However, few intervention studies have focused on parent outcomes (e.g. reduction of parenting stress) rather than child outcomes (Karst and Van Hecke, 2012). The limited literature in this area has focused on group interventions for parents of children with EBDs, which have been particularly noted for their beneficial nature as these groups increase parents' feelings of support, decrease feelings of isolation, and empower parents (Pillay, Anderson-Day, Wright, Williams, & Urwin, 2011).

## **Forms of Parent Intervention**

While intervention at the child level can positively impact parent outcomes (Dubbs, 2008), intervention at the parent level can be effective for parent outcomes as well as child outcomes. Bearss and colleagues (2015) identified several forms of parent intervention. Parent training programs can first be divided into the categories of Parent Support and Parent Implementation. Parent Support focuses on providing indirect support to the child by increasing parents' support and knowledge about their child's disability through care coordination and psychoeducation, respectively. Parent Implementation directly impacts the child by working to improve parents' skills through parent-mediated intervention for the core symptoms of EBDs (e.g. promoting social skills) or for managing clinically significant problem behaviors (e.g. aggression, tantrums, food

refusal, etc.; Bearss et al., 2015). Given Deater-Deckard's 2008 model, changes through these essentially child-focused methods may also have positive consequences for parents as well, given the interconnected impact of parent behavior, affected by parent skills and parenting stress; parenting stress, affected by parent support and child behaviors; and child behavior, affected by parent behavior, or parent skills.

Interventions for parents of children with autism typically aim to decrease problem behaviors in children; increase the use of specific skills; improve parenting skills, confidence, and competence; and/or reduce parenting stress (Brookman-Frazee, Vismara, Drahota, Stahmer, & Openden, 2009; McConachie & Diggle, 2007). Many interventions for parents of children with EBDs primarily focus on parents of young children with autism as the recommended early intervention for children with ASD (Rogers, 1996) typically requires parent involvement.

One meta-analytic review (Kaminski, Valle, Filene, & Boyle, 2008) of parent training programs for families with children with behavior problems ages 7 years and below, identified several program elements that were most effective in changing parent and child behaviors. These elements included increasing positive interactions between the parent and child, improving emotional communication skills, teaching specific parent skills, and requiring parents to practice skills during sessions. Conversely, programs involving ancillary services such as stress management or job skills training had smaller effects on parent and child behaviors, though they may be beneficial for other outcomes (e.g. parenting stress, child adaptive functioning). Programs in which parents taught social skills to their children were also less effective, perhaps because of the lack of experience with peers in a more generalizable setting (Kaminski et al., 2008).

However, minimal literature has thoroughly examined parent-focused support in community-based settings with intentionally feasible and acceptable intervention methods. This is especially important in settings where there are few services available for children with disorders such as autism and ADHD and relatedly, few services available for parents. Additionally, while these groups have provided positive outcomes for parents through the use of support from other parents, they may place undue emotional and time burden on parent leaders (Shilling, Bailey, Logan, & Morris, 2014), and lack a clinical component that specifically teaches about stress and evidence-based methods for alleviating it and improving parent wellness. Still, there remains the critical concern of parents' ability and willingness to attend any services to be provided to them, and thus feasibility and acceptability must be considered as well. Some literature has considered this in terms of consumer preferences regarding parenting interventions, which indicate an increased need to focus on parent (consumer) preferences to improve intervention engagement and outcomes (Levant, 1987; Metzler, Sanders, Rusby, & Crowley, 2012; Sanders & Kirby, 2012; Spoth & Molgaard, 1993).

## **Need for Feasible Parent-Focused Programs**

Caregivers of individuals with disabilities may be less likely to participate in services for their own health (Navaie-Waliser et al., 2002) which may attributed to a lack of time and financial resources and support (Resch et al., 2012). Parents in particular may experience negative emotions and higher levels of stress in the face of continued difficulties in accessing services (Wyngaarden Krauss, Wells, Gulley, & Anderson, 2001). As a result, services for families with children with disabilities must consider the

barriers of limited resources and environmental and social restrictions (Lollar, 2008) in the development of programming to meet other needs.

Previous literature has identified several preferred modes of parenting intervention for parents of children with clinically significant behavior concerns, including TV programs, written material, resource centers, therapists, and home visits (Metzler et al., 2012). However, preferences, as well as potential enablers and barriers to engagement, may vary based on characteristics of the consumer, such as child diagnosis, child age, and perceived need (Levant, 1987; Sanders & Kirby, 2012) For instance, in families with children already receiving services, and therefore having overcome certain barriers, parents have a unique opportunity to receive specialized services simultaneously, which may produce positive change in both the parent and child (Bögels et al., 2008; van der Oord et al., 2012).

The literature regarding such simultaneous provision of targeted services for both the child with an EBD and his or her parent(s) is presently limited. Additionally, this literature focuses in part on indirect child-focused intervention via effective *parenting strategies* rather than exclusively considering *parent-focused support*. Thus it becomes valuable to assess aspects of feasibility and acceptability contributing to engagement in parent-focused support interventions for parents of child with EBDs and to integrate these preferences into interventions. Sanders and Kirby (2012) argue that the resulting increased engagement may increase participation in and quality of parent-focused programs for better outcomes for these consumers (Sanders & Kirby, 2012; Spoth & Molgaard, 1993).

## **Current Study**

In summary, school-aged children with EBDs such as autism and ADHD face a number of behavioral struggles that may impact parenting stress and wellness. While support and strategies for parents abound for parents of young children with such disorders, the literature is lacking in interventions aimed at providing support unique to parents' needs when they may particularly benefit from interventions targeting parenting stress, parent wellness, and mindful parenting, which have been linked to positive outcomes for families. It is encouraging to note that group interventions for parents of children with emotional and behavioral disorders have successfully addressed concerns related to parenting stress by increasing parents' skills in areas linked to child behaviors and levels of mindful parenting. However, many of these studies have targeted parent skills training alone or have involved extensive procedures that may not be feasible or acceptable to many parents of school-aged children with EBDs given the demanding characteristics of these disorders. This generates a need for feasible and acceptable interventions focused on parent support beyond parent training.

The current study developed, implemented, and evaluated a pilot intervention using a exploratory sequential mixed-methods approach focused on the critical variables of parenting stress, parent wellness through parent support, and mindfulness strategies implemented through self-regulation practices. These variables were first explored through a qualitative study (Phase One) that gathered parent perspectives on these constructs to inform a quantitative study with embedded qualitative components (Phase Two) that evaluated the feasibility, acceptability, and preliminary impact of an

intervention incorporating data from the first phase, relevant theory, and previous literature.

# CHAPTER 2

## PHASE ONE

## Phase One Method

Phase One was the first in this exploratory sequential mixed methods study. Phase One involved collecting and analyzing qualitative data to build to Phase Two, which incorporated quantitative approaches with concurrently embedded qualitative approaches (see Creswell, 2013). Phase One of the study used three focus groups to assess the needs of parents of children with emotional and behavioral disorders including autism and ADHD and identify factors of feasibility and acceptability of services to address these needs. Focus groups have been noted for their usefulness in gathering participants' perspectives on specific topics (Nastasi & Schensul, 2005) and in the current study noted the perspectives of fifteen parents of children with EBDs (i.e. autism and ADHD). In the process of creating an intervention to support parent needs, the provision of clarity on parents' perception of their needs is integral to the development of an acceptable and effective intervention

# **Procedure**

This portion of the study received IRB approval through the University of South Carolina Institutional Review Board. Parents were recruited from community-based groups for school-aged children with social skills deficits. The social skills groups, which divided children into three sessions primarily by age (see Tables 2.1 - 2.3), were offered at one-hour intervals for ten-week semesters and taught children to socialize, manage

impulsivity, and employ strategies for success in social situations. Parents received tips on how to bolster the use of these skills at home but were historically otherwise uninvolved in groups. Social skills groups were organized and led by a licensed psychologist who also supervised doctoral-level graduate students in their leadership of the groups. The licensed psychologist reported prior to the study that many, though not all, of the parents of children attending these groups typically spent the hour in the waiting room unoccupied aside from talking to one another. She also noted that the parents had expressed interest in receiving parent-focused services during that time.

**Participants.** Parents received written information about this portion of the study along with consent forms for participating in the study and permission to audio record the focus group. Fifteen parents completed consent and the measures, including demographic and clinical measures and the focus group interview. Parents participated in one of three groups based on the time at which their child attended social skills groups. Five parents attended the first group ( $M_{ChildAge} = 7.20$ ), seven attended the second ( $M_{ChildAge} = 12.71$ ), and three attended the third ( $M_{ChildAge} = 13.33$ ). Some parents with multiple children across age ranges typically attended social skills sessions at more than one time, but each of the fifteen parents participated in only one interview.

**Demographic and clinical measures.** Fifteen parents completed a demographic questionnaire, including information about child age, gender, and diagnosis, and rated child symptom severity using the Pediatric Symptom Checklist (PSC-17; Appendix A), which screens for emotional and behavioral issues in children. The measure provides an overall score with a clinical cutoff of scores of 15 or above. There are additional specific clinical scales including internalizing problems (clinical cutoff of scores of 5 or above),

externalizing (clinical cutoff of scores of 7 or above), and attention problems (clinical cutoff of scores of 7 or above). The PSC-17 has demonstrated strong reliability and validity (Stoppelbein, Greening, Moll, Jordan, & Suozzi, 2012).

Focus groups. Across the three social skill group meeting times, fifteen parents (see Tables 2.1 - 2.3) participated in a 30- to 40-minute long focus group during their child's hour-long social skills group session. Focus groups were led by the primary investigator, who also led the subsequent intervention. The discussion was then recorded into digital files to be transcribed. Questions served three main purposes: first, to develop rapport between the moderator and potential parent participants and to establish the trustworthiness of the moderator; second, to identify components of parenting stress and wellness in participating parents; and third, to gauge parents' opinions of potential strategies for managing stress and wellness. The focus group interview guide (included in Appendix B) was flexibly designed to allow for the addition of questions beyond the guide for clarity or elaboration.

# **Data Analysis**

As computer-assisted qualitative analysis is considered most appropriate for qualitative analyses (Joffe, 2012), the researcher used NVivo (NVivo version 10.0°, QSR International, 2014) to assist with the identification and grouping of patterns in the data. Digitally audio-recorded data were transcribed and qualitative data were analyzed in the NVivo (QSR International, 2014) program using the six principles of thematic analysis: familiarizing oneself with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report (Braun & Clarke, 2006). The Interdisciplinary Qualitative Research Subcommittee (IQRS) of the

Task for Evidence-based Interventions in School Psychology notes the importance of coding according to a theoretical-empirical basis (Nastasi & Schensul, 2005), therefore qualitative categories were identified and related back to concepts of parent support, including contributors to parenting stress in parents of children with autism and ADHD and the feasibility and acceptability of different forms of intervention, including mindfulness, in alleviating these concerns.

Qualitative coding. The coder read the full transcripts and used inductive strategies to code the responses for themes, as is recommended for qualitative focus group analysis (Ryan & Bernard, 2003) and has been used as the mode of analysis in similar literature (Ainbinder et al., 1998; Myers, Mackintosh, & Goin-Kochel, 2009; Watson, Hayes, Coons, & Radford-Paz, 2013). Ryan and Bernard (2003) identified several strategies for identifying themes in qualitative data, including looking for repetitions, indigenous typologies or categories, metaphors and analogies, transitions, similarities and differences, linguistic connectors, and theory related material. The authors also suggest being attentive to themes that participants do not mention (e.g. in this case, support strategies that parents do not reference). In the current study, the coder noted repetition, similarities and differences in parents' report of their experiences and preferences, and theory-related material concerning parenting stress, parent support, parent wellness, and the feasibility and acceptability of strategies to address these constructs.

First-level coding utilized pre-set codes (or "tree nodes") based on themes generated from such theory-related material, including "feasibility"; "acceptability"; "child behavior;" "mindfulness," with the subheadings of "familiarity with mindfulness"

and "views on mindfulness"; "stress", with the subheading of "stress management strategies"; and "wellness", including "self-care" and "social support." Other codes ("free nodes") emerged as the coder identified patterns or repetitions, as well as similarities and differences in parent report, in the process of analysis. These emerging codes, or "free nodes," included a "recurring terms" node to track terms and ideas that frequently arose in the discussion of these issues and included "hard/challenge", "understand/accept", and "emotional terms" including "crazy", "frustrating", "stressful", and positive terms such as "help/helps/helped." Inductively derived themes were also identified and coded to allow for consideration of emergent data, which is a particularly valuable form of qualitative data; this included including refining of theory-based codes based on data from participants (Braun & Clarke, 2006; Massey, 2011). The "wellness" tree node was expanded to include "barriers to support", "positive aspects of parenting", and "stress management strategies for child behavior," which was conceptualized to be more of a contributor to wellness than stress as initially thought due to the contexts in which relevant responses arose (e.g. as something that "helped" or connected to resources). The "social support" subheading was changed to "sources of support" including "emotional support" and "instrumental support," with additional subheadings including areas of need within these categories. Parents' expression of acceptability issues were additionally evaluated according to whether they aligned with content in the mindfulness component of the intervention (e.g. creating boundaries, managing emotions), the support component of the intervention (e.g. requests for additional resources), or a component of feasibility or acceptability that would need to be addressed (e.g. wanting accountability from other parents, valuing a private and safe space for group to be held).

Analysis of patterns and trends across these themes contributed to the development of the intervention to be delivered in Phase Two, which is described in the following chapter.

#### **Phase One Results**

## **Descriptive Analysis**

Across the groups, seven parents reported on the demographic questionnaire that their child had autism, but not ADHD; one parent reported that their child had ADHD, but not autism; five parents reported that their child had both autism and ADHD; and two parents noted that their child had a disorder but did not report what the disorder was.

Parents reported overall levels of child behavior nearly within the clinically significant range on the PSC-17 (M = 14.62, SD = 4.93), though overall mean internalizing (M = 3.38, SD = 1.50), externalizing (M = 5.00, SD = 2.20), and attention (M = 6.15, SD = 3.31) concerns did not meet the respective clinical cutoffs. Because the PSC-17 indicates clinically significant concerns, these reports were lower than would be expected given the parents' report of their child's diagnoses. However, when parents qualitatively described their children's behavior, they described notable externalizing and behavioral issues necessitating special education services, community supports, and therapies.

Characteristics of each group, which varied in child age and whether clinical cutoffs were met, are included in Tables 2.1 - 2.3.

#### **Themes and Clusters**

Qualitative theme-based analysis using inductive strategies (Ryan & Bernard, 2003) across the three focus group interviews yielded several themes, including 1) the hectic but valued experience of parenting a child with an EBD, 2) sources of parenting

stress, 3) contributors and barriers to parent wellness, 4) familiarity with and views of mindfulness, and 5) issues of feasibility and acceptability in developing programming that may meet their parenting needs. Selected quotations reflect ideas that were stated similarly by other parents regarding the same theme, as well as statements with which several parents agreed when the statement was made during the focus group.

Theme One: Experience of parenting a child with an EBD. Parents identified a variety of both positive and negative experiences when relating their day-to-day experiences of parenting a child with an emotional and behavioral disorder. Parents described their daily lives using terms such as "hell," "crazy," and "a roller coaster" as they went to work, assisted child(ren) with an EBD and their siblings with their schedules, and helped their children with homework. Other daily activities dealt more specifically with their child's disability, such as needing to bring their child to a variety of therapies and coping with their child's emotional and behavior concerns in the context of a busy day:

I don't know about y'all, but my week is... broken up by how many appointments do we have to get our kid to? With the social group now, there's a least four a week. She's got her OT, her speech, we took off feeding therapy because she's finally at the point where she's doing that. She's got a behavioral therapy... we replaced the feeding therapy with socialization because she got accepted into the elementary school [after-school activity]. A typical day for us is: take them to school. If we're lucky... she gets to stay to the end of school, but two times a week I have to pick her up before the end of school to make it to these different appointments, therapies, stuff like that. Then get home, try to keep her focused on

her homework while helping the other [child], our oldest, with her homework.

[Then] keeping our youngest from going crazy because there's no one to occupy his toddler tantrums while everyone's sitting around the table working.

We're on a time constraint and he's on his own schedule and that doesn't really matter that time is passing because he doesn't have any sense of that. And [for] school, you have to be there by a certain time and I have to be to work, and everybody has to get ready at the same time and when everyone works or goes to school about the same time, it's a very frustrating thing. So, that's what it is for us.

Parents identified several positive aspects of their experience of parenting, particularly when their child experienced something they found positive (e.g. less homework), they encountered strategies that helped to meet their child's needs (e.g. routine, supports at school, medication, successful therapies), and

Yeah, when I have one of those days where the schedule actually looks like that and everybody's happy and cause in there I try and do devotion with the kids, too. And um, when we're able to get through that and everybody's happy, everyone had a good day, I didn't get any emails from the teacher- it's like, I love being a parent.

Parents also referred to enjoying their child, including when their child offered physical affection or was observed learning academic and "life" lessons that may have taken longer than expected for their child to grasp.

Parent 1: [One of the best things about parenting is] when, you know, something that we've been working forever, like the click moment where it all of a sudden Other parents: Mmhmm

Parent 1: Like yeah! That was it! It took us three years! You know, so just little things.

Parent 2: And I think, like, for these kids, it makes the click moments so much better, like, you know, like a typical kid, you know when they get that, you're like, "yay!" and then you kind of move on. With kids that it takes like a year, two years...

Parent 1: To get it, mmhmm, when it actually...

Parent 2: ...three years, to get something, you know, that's like when you tweet it, Facebook it, Instagram it, you know.

Parent 1: It happened!

Well I was just gonna say and this is gonna sound corny, but just sometimes when they- especially now that [older son]'s 15- when they actually look at you and they still love you, like "I love you mom." Or sometimes, you know, this [child participating in social skills groups], he'll have a sweet moment and he'll just give me a hug and a kiss. So it's like you said, the little things when they just love you just because you're mom.

Other positive components of parenting required intention and effort on the part of the parent, for example:

I think that you try and find small pleasures in everything that you do. Like my wife's a student and you know, I work full time and I'm also going to school, so it's you know, it's doing really well in a class or getting a really good grade on a paper that's satisfying enough. So, I guess it's trying to find satisfaction in all the things that you have to do instead of you know, trying to focus on "Oh, I don't have any me time."

Theme Two: Sources of parenting stress. Sources of parenting stress were categorized into 1) daily demands, which are described above, 2) child behavior, 3) communicating with others, 4) communicating with schools, and 5) finding and managing resources. Parents described ways that their child's behavior and diagnosis set their child apart from their peers, which in turn made parents feel isolated or emotional distress for not being able to help their child more.

"No" or anything that is not exactly what you want can turn into a huge [issue]. And it's not just, you know, even "no"s, but the kind of embarrassment that you talked about. You know, why is my kid the only one at the birthday party who's running screaming away from his friends for no apparent reason or things like that that you know, you try karate and my kid won't put the robe on and runs to the window screaming and the other parents look at you like, "control your kid." And it's a constant battle to not- with yourself- to just say "I don't care that I'm getting the looks like 'What are you doing wrong?'" And that is challenging.

I know [child]'s biggest thing is like at church. He [doesn't] have friends at church, he [doesn't] have friends at school. He [doesn't] have frien- he's got one little boy friend that he gets along with well. But, and then he'll say "Nobody likes me!" and he'll cry 'cause they don't want to play with him... I don't know what his problem is; he was like pushing kids. He tries- he'll lay his arm on them and all, and they about got him out of that at school. But it's just that they try to fit in, and they don't fit in.

Because their child's behavior impacted various areas of both the parents' and children's lives, parents reported difficulties communicating with other parents and family members, who parents sometimes perceived as judgmental or misunderstanding.

Well, other parents- you know, it's not like we fit in with the soccer moms. You can't get it together with the social group, with kids with regular ed[ucation] kids because they just can't relate and they don't have any patience. If you're trying to go with group and he's having a meltdown, it's like, that's pretty much the end of that field trip! ...It's very isolating.

I think it's hard to find friends of parents who understand because, oh my gosh, when we were having bathroom trouble, I had friends who are like, "Well, have you tried a potty chart?" and I'm like, "Do you really think if that was the simple solution, I wouldn't have tried it already?" So just like those kind of things.

"Have you tried... grounding them when they misbehave?" (laughter)

Parent 1: But even family, like the other family members are, "He just needs a spanking. You just need to spank him. That'll clear him right up."

Parent 2: (laughs) I've had other parents come up to me and tell me that.

Parent 3: You get a lot of free advice.

(laughter)

Parent 2: From people who have <u>no</u> frame of reference for what we're dealing with.

Parents also spent considerable time discussing issues particular to school, including receiving eligibility for special education services in public schools, difficulty receiving supports from teachers, and supporting their child in completion of homework and other assignments and expectations. For instance:

And from everyone saying this is exact same thing: that's not a single school district issue, that's school districts across the nation. If you bring up any type of behavioral abnormality and you're just asking for acceptance so they don't- they can't or they don't get kicked out of the class when they're not disruptive, they're just fidgety, um, they look at you like you're- like you've got a horn growing out of your head or something.

Well, teachers don't get it either, like, well, she can't eat certain things at school and one day she forgot her lunch, and so the teacher's like "well, I was just gonna make her eat X, Y, and Z, because that- it's gluten free." And I'm like, she doesn't like yogurt, she's not going to eat it, just not understanding that, I mean, we try to get her to try new things and she does a little bit, but just like a lack of

understanding, I guess, in the community, just people just not understanding that it's just not that easy.

Parents additionally referenced difficulty identifying and receiving community services similar to the obstacles encountered in attempts to acquire services in school. In both instances, parents faced a legal process, jargon (e.g. "waivers," "Other Health Impairment (OHI)" etc.), and a complicated path towards the resources that frequently required additional help. Parents expressed a desire for consolidated and clear guidance for resources:

Parent 1: Well we did the [Pervasive Developmental Disorder (PDD) Medicaid] waiver, we, first we did BabyNet [an early intervention system funded through the Individuals with Disabilities Education Act for young children with developmental delays], we got [Applied Behavior Analysis therapy] in BabyNet, then we did private pay until we go the PDD waiver, which was two and a half years, maybe, and then we did the PDD waiver and then we were kind of-you know, just at a place where, where we are [sic] we go now? And I know that there's got to be ABA programs for older kids.

Parent 2: I tell you, if there's somebody that could just map out how to get the resources, what they are, and what you have to go through, because right now, to get like the community supports waiver, we were on a waiting list for years for that. We finally got it.

The kind of stuff that we need for educational, for- it's wonderful that I stumbled on [the social skills groups], but um, there's so many other things that if I hadn't

had the support of other parents here to give me advice when I got a new problem, I wouldn't have help for. And if we, you know, if we could make a resource book, that would help.

Theme Three: Contributors and barriers to parent wellness. Reports of parent wellness included sources of support, self-care, and strategies for managing stressful child behavior. Parents' report of instrumental support was frequently linked to resources that helped them with the stressful process of navigating supports for their child. Parents referenced benefiting from such resources as therapies, respite care, case managers, and advocacy groups. However, considerable areas of instrumental support needs remained: parents expressed a need for more frequent and trustworthy childcare, clarity on how to access resources for their child, and accountability and support from others familiar with the process of obtaining services. Regarding emotional support, parents referenced faith communities, regular meetings with friends, and connecting with other parents of children with special needs.

Now one thing I've started doing- [two friends and I will] go out to dinner like on a Friday once a marking period. That, I mean that's the most we can, and they really had to make me. They were like, she was like, "Okay," and she gave us the same spiel. "Okay, girls, self-care- this is what you need to do." And she's super busy, too, they have a one-year-old and so we have committed...it ends up being four a year, but, um I enjoy it, I enjoy it because it's with other moms.

I mean, there are a lot of churches out there that we've been to, and friends, 'cause we grew up in the church community around here and they're great,

they're like "Oh, well just let us know how we can help you; we'd be glad to help." And like there's so much willingness to help but it's just not understanding, well, it's just gonna be stressful for me. Like sitting in a church service with my, well, I have three, with my children, it's just stressful. Like, so almost like having a someone that they can be with would enable me to enjoy church, hopefully enable them to enjoy church. It's not-I don't think it's like a lack of willingness to help as much as it is just like just not knowing how to help. Or not having the resources to help.

Theme Four: Perspectives of mindfulness. Parents expressed mixed but minimal familiarity with mindfulness. Some parents had never heard of mindfulness strategies, while most were familiar with the word, but not with specific strategies. After the focus group moderator provided a brief explanation of mindfulness, parents reported that they would be interested in learning or trying something new, despite not being sure of what mindfulness strategies may look like in the context of parenting. Some parents indicated that they used components or aspects of mindfulness, including clear communication, journaling, and prayer, but would be interested in learning more, particularly in a context with accountability.

Parent 1: I'd be willing to learn more about it. I mean, I'm not really sure I quite fully understand- I mean, I'm pretty, we're pretty open about uh, things.

Parent 2: Don't leave any stone unturned.

I think we've all kind of started [using mindfulness strategies], like whether it's journaling or- and then you just kind of falls [sic] by the wayside. I guess maybe

if there was some accountability piece to it, like if we came back, and like, you just, like with the phone calls [that children in social skills groups do], if nothing else, we had to let you know, "hey yeah, we did it this week, [or] no we didn't."

Theme Five: Issues of feasibility and acceptability in designing a support group utilizing mindfulness. In describing areas of need, parents contributed to an understanding of beneficial components of a support group, such as instrumental support for resource identification and management as well as emotional support from people who "get it"- namely parents in similar situations and community organizations with adequate resources and understanding. Parents also indicated a need for strategies for managing stressors such as their child's behavior, difficulty communicating with others about their child's situation, and many daily demands.

Because the data were informing an intervention to address parenting stress, parent wellness, and mindful parenting, data were additionally evaluated for characteristics of an intervention targeting these constructs that parents would find most acceptable. In thinking forward to what they would find beneficial and acceptable in a parent-focused intervention, parents indicated that in the area of mindfulness, they would value balancing expectations, identifying what aspects of their child's behavior they could "accept," and coping with the extra emotional energy they exerted in advocating for their child. Parents also valued accountability for self-care and completing steps in pursuing resources, as well as the construction of a collection of resources (e.g. a "resource book") in the area of support. Parents reported that issues of acceptability of a parent-focused intervention would include ensuring that a parent support group would target both emotional and instrumental support needs and occurred in a non-judgmental

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setting that was comfortable, confidential, and convenient. Another consideration in components of an acceptable parent support group, particularly one involving the historically Buddhist practice of mindfulness, was parents' religious beliefs. Several parents reported that they belonged or wanted to belong to a church, which in turn promoted an intervention design that oriented the mindfulness activities in a way that would allow participants to apply strategies in a way that might not be perceived as contradicting their religious beliefs. The mindfulness component of a parent support group intervention for parents reporting these beliefs may then be most acceptable if occurring from a secular standpoint, as Duncan and colleagues (2009) modeled, rather than from a strictly Buddhist or "traditional" perspective.

Finally, parents specifically described what an ideal support group taking place during their child's social skills groups may look like for them:

I think it'd be good if it was like in an environment where, like you're allowed to be frustrated... I've been to one support group once and I was not allowed [to express frustration] - basically was told I just needed to accept things the way they were.

[I'm] just feeling stretched too thin. I don't know. I guess a lot of it's just needing people to- who understand and won't judge you to talk to and then also, people who've been there. Like I said, just someone to just be like, "Hey, are you- how's that paperwork coming?"

Parent 1: Well I mean, I think this is good, having, and I mean, maybe not necessarily all the time, or just you know, whenever, but I think even having opportunities where you have like parent sessions and we can just sit and talk about whatever issues, um, you know are pressing, um because there may be something working for you that um I could try in my home that might work for me. So I think offering um, you know, group sessions for parents, you know, parent sessions, round table sessions.

Parent 2: I think it's also very good because I'm – I mean she's been doing this for a while now, um, but I've learned a lot just from other parents, like "Oh yeah, her case coordinator" and I was like "What is that? Like, where do you, how do you find-" So just, you know, it's just a good way to find out about different resources.

Parent 1: It's just nice to be able to sit down and talk to other people that...

Parent 2: Get it

Parent 1: ...get it. And you don't to like explain it and feel all weird about you know, what you're doing or what you're talking about or have to explain everything. Just be able to get to the point to talk about something, you know. Even if they're not going through exactly the same thing, I mean, 'cause each kid is, you know, different, just like any other kid, but you've come from the same everything springs from the same well. You all kind of get the same-have the same idea of what's going on.

Parents' report of their experiences (the hectic but valued experience of parenting a child with an EBD; sources of parenting stress; and contributions and barriers to parent wellness) and direct commentary on potential intervention components (familiarity with and views of mindfulness; issues of feasibility and acceptability for a parent support group) indicated several areas for consideration in the development of a feasible and acceptable support group intervention, described in Chapter 3, to meet their unique needs.

Table 2.1 Phase One Focus Group 1 Descriptive Statistics.

	n	%	Mean	SD
Group 1	5			
Parent Gender				
Male	2	40%		
Female	3	60%		
Child Gender				
Male	4	80%		
Female	1	20%		
Child Age $(5 - 8 \text{ years old})$			7.20	1.64
Child Behavior			13.6	4.51
Internalizing			3.4	1.95
Externalizing			4.3	1.79
Attention Problems			5.8	2.77
Child Diagnosis				
Autism, no ADHD	2	40%		
Met Internalizing Cutoff	0			
Met Externalizing Cutoff	1			
Met Attention Problems Cutoff	0			
ADHD, no Autism	1	20%		
Met Internalizing Cutoff	0			
Met Externalizing Cutoff	1			
Met Attention Problems Cutoff	0			
Autism & ADHD	2	40%		
Met Internalizing Cutoff	1			
Met Externalizing Cutoff	0			
Met Attention Problems Cutoff	2			

Table 2.2 Phase One Focus Group 2 Descriptive Statistics.

	n	%	Mean	SD
Group 2	7			
Parent Gender				
Male	0	0%		
Female	6	86%		
Not reported	1	14%		
Child Gender				
Male	5	71%		
Female	2	29%		
Child Age $(10 - 21 \text{ years old})$			12.71	3.90
Child Behavior			13.8	6.57
Internalizing			2.33	1.37
Externalizing			5.5	2.43
Attention			4.5	4.59
Child Diagnosis				
Autism, no ADHD	4	57%		
Met Internalizing Cutoff	0			
Met Externalizing Cutoff	1			
Met Attention Problems Cutoff	2			
ADHD, no Autism	0	0%		
Met Internalizing Cutoff	NA			
Met Externalizing Cutoff	NA			
Met Attention Problems Cutoff	NA			
Autism & ADHD	1	14%		
Met Internalizing Cutoff	0			
Met Externalizing Cutoff	1			
Met Attention Problems Cutoff	0			
Not reported	2	29%		

Table 2.3 Phase One Focus Group 3 Descriptive Statistics.

	n	%	Mean	SD
Group 3	3			
Parent Gender				
Male	0	0%		
Female	3	100%		
Child Gender				
Male	2	66%		
Female	1	33%		
Child Age $(12 - 15 \text{ years old})$			13.33	1.53
Child Behavior			17.67	0.58
Internalizing			4.33	1.53
Externalizing			5.33	2.31
Attention Problems			8	1.73
Child Diagnosis				
Autism, no ADHD	1	33%		
Met Internalizing Cutoff	0			
Met Externalizing Cutoff	0			
Met Attention Problems Cutoff	1			
ADHD, no Autism	0	0%		
Met Internalizing Cutoff	NA			
Met Externalizing Cutoff	NA			
Met Attention Problems Cutoff	NA			
Autism & ADHD	2	66%		
Met Internalizing Cutoff	1			
Met Externalizing Cutoff	0			
Met Attention Problems Cutoff	2			

# **CHAPTER 3**

#### PHASE TWO

# **Phase Two Method**

## Procedure

Phase Two was the second phase of the current exploratory sequential mixed methods study. It occurred after the conclusion of all Phase One data collection and analysis and built on the results of Phase One data analysis. Phase Two concurrently used quantitative and embedded qualitative approaches (see Creswell, 2013) to incorporate participants' qualitative perspectives with quantitative results regarding feasibility, acceptability, and preliminary impact of an eight-session pilot parent support intervention. The University of South Carolina Institutional Review Board approved a second IRB proposal for this phase.

Intervention development and content. The current intervention was built on theory of parenting stress and wellness, empirical literature examining the effects of similar interventions, and the qualitative study of parents' perception of their experiences and needs as described in Phase One. Children with emotional and behavioral disorders have characteristics in these domains that necessitate services and notably impact their family's lives (Johnston & Chronis-Tuscano, 2014; Werner, 2000; Woodgate et al., 2008) and contribute to parenting stress (Griffith et al., 2010; Hamlyn-Wright et al., 2007; Harrison & Sofronoff, 2002). While aspects of the cycle of parenting stress (Deater-Deckard, 1998; Hastings, 2002) may be addressed through interventions that target child

behavior, parent behavior and parenting stress have been often-overlooked components of intervention in this cycle. The current intervention was founded on two goals: 1) providing parent support and 2) utilizing mindfulness strategies.

Previous interventions identified successful strategies for alleviating parenting stress including developing problem-solving skills (Kazdin & Whitley, 2003), education about the child's disorder and treatments for it (Treacy et al., 2005). In order to improve parent wellness, other interventions created opportunities for support from other parents and community members (Ainbinder et al., 1998; Kingsnorth et al., 2011). The current intervention utilized these intervention qualities in the "parent support" component: parents were grouped according to shared characteristics (e.g. children with the same type of disorder, of similar age, with social skills difficulties, etc.) and given opportunities to speak freely about their experiences with others who were likely to empathize with those experiences. This included a clinically trained non-parent leader who was able to provide psychoeducation and emotional support.

Parents were also regularly provided with support resources (i.e. handouts and discussion regarding local advocacy and support, strategies for communicating with schools, and strategies for managing child behavior; culminating in a resource book containing information about how to access support services and connect to additional local supports) to assist in educating parents about aspects of their child's disorder and developing problem-solving skills for effects of these behavioral issues. It was hypothesized that these components would decrease feelings of isolation that parents of children with EBDs may perceive (Woodgate et al., 2008) and increase the number of resources that parents have to address their child's behavior, thus decreasing its

contribution to parenting stress, meeting parents' own frequently disregarded needs (Resch et al., 2012) to increase wellness.

Regarding mindfulness, previous interventions used mindfulness practices including a "body scan," "breathing space," tracking pleasant and unpleasant events, and setting goals for mindfulness practice in order to develop the five dimensions of mindful parenting: 1) listening with full attention, 2) nonjudgmental acceptance of self and child, 3) emotional awareness of self and child, 4) self-regulation in the parenting relationship, and 5) compassion for self and child (Bōgels et al., 2008; Duncan et al., 2009). Such interventions noted decreased parenting stress and increased aspects of parent wellness in parents of children with EBDs (Bōgels et al., 2008; Duncan et al., 2009; van der Oord et al., 2012) and these strategies were implemented throughout the sessions in the current intervention. Full-length mindfulness-based stress reduction as described in previous literature is organized into at least eight sessions (Carmody & Baer, 2008; Kabat-Zinn, 1990) and it was relatedly anticipated that at least eight sessions would be necessary to cover relevant mindfulness-based information.

Several other interventions focused on parent needs were also designed to take place over seven to nine sessions (Bögels, Hellemans, van Deursen, Römer, & van der Meulen, 2014; Duncan et al., 2009; van der Oord et al., 2012), and the ten-week social skills program during which the current intervention was implemented allowed for eight content-based sessions with data collection sessions in the weeks before and after.

Additionally, the mindfulness component of the present intervention was modeled directly on relevant interventions and strategies discussed in the Duncan and colleagues' (2009) model of secularized mindful parenting, which includes the dimensions of

listening with full attention, nonjudgmental acceptance of self and child, emotional awareness of self and child, self-regulation in the parenting relationship, and compassion for self and child, and specific activities and handouts and Bögels and Restifo's Mindful Parenting program (Bögels & Restifo, 2014). The program provided a mindful parenting intervention to parents of children primarily with ADHD and autism spectrum disorder, and reported an increase in mindful parenting and decrease in parenting stress (Bögels et al., 2014; Bögels & Restifo, 2014; Meppelink, de Bruin, Wanders-Mulder, Vennik, and Bögels, 2016). Given that these mindfulness practices are evidence-based strategies, it was hypothesized that by teaching and practicing them in sessions, and encouraging and modeling their use outside of sessions, mindfulness practice would significantly increase parents' use of mindful parenting and their parent wellness, as well as decrease their parenting stress.

Finally, the intervention was designed to reflect parents' feedback from Phase

One. Parents reported in the focus groups that they would value balancing expectations,
identifying what aspects of their child's behavior they could "accept," and coping with
the extra emotional energy they exerted in advocating for their child in the area of
mindfulness. These parents also expressed valuing accountability for self-care and
completing steps in pursuing resources, as well as the construction of a collection of
resources (e.g. a "resource book") in the area of support. The parents who participated in
the focus groups additionally indicated that they would find an intervention more
acceptable if it was in a non-judgmental setting; it occurred in a comfortable,
confidential, and convenient place; and it supported parents emotionally and
instrumentally. Several parents also indicated belonging to or wanting to belong to a

church, which promoted an intervention design that oriented the mindfulness activities from an objective, secular standpoint, rather than a traditionally Buddhist perspective, to allow participants to apply strategies in a way that best aligned with their religious beliefs. In considering and addressing components of feasibility and acceptability identified by a group of parents in the same setting as the intervention (i.e. waiting for their child with an EBD attending a social skills group in the southeastern United States), it was hypothesized that the intervention would be able meet these expressed needs and result in positive change for parents and their report of feasible and acceptable intervention. An outline of the content of the eight sessions comprising the intervention and the two data collection sessions that occurred the weeks before and after the intervention are included in Appendix C.

**Participants.** Parents were recruited from social skills groups at a private practice in Columbia, SC to be held from January 2016 to April 2016. Groups were held on Mondays and Wednesdays with sessions at 4:15 p.m. and 5:15 p.m.

Twenty-nine parents were recruited from the parents of children attending 4:15 p.m. and 5:15 p.m. sessions to participate in parent support group sessions. While the children's social skills groups were additionally divided by other characteristics such as gender, parents of all children who attended group at a particular time (e.g. 4:15 p.m.), regardless of these other child characteristics, would attend the parent support groups together at that time. The clinician from the private practice added another social skills group session at 6:15 p.m. part of the way through the intervention, moving teenaged boys (and their parents) to a separate time. Parents who were moved to this time were offered another parent support group that would take place at 6:15 p.m. Only one parent

expressed interest in meeting at this time and was instead invited to continue with the parents at the 5:15 p.m. session. The consort diagram in Appendix D outlines the varying participation of all 29 parents in the research component of parent groups. Of note, only 20 parents completed pre-intervention data collection, including a demographic measure, a report of their child's level of behavior concerns, and measures of parenting stress, parent wellness, and mindful parenting, which are described below in the measures section. Demographic characteristics of participating parents and their children are provided in Table 3.1.

Child characteristics. According to parent report, three children had diagnoses of ADHD, nine children had diagnoses of autism spectrum disorder, and eight children had comorbid diagnoses including at least both ADHD and autism. Six children had one or more additional comorbid diagnoses including anxiety disorders (n = 2), Obsessive Compulsive Disorder (n = 2), Social Communication Disorder (n = 1), Oppositional Defiant Disorder (n = 1), trichotillomania (n = 1), depressive disorders (n = 1), and intellectual disability (n = 1).

Overall, 75% of parents reported symptoms indicating that their child's emotional and behavioral concerns met the clinical cutoff. In addition, 80% of parents reported clinically significant attention problems, 60% reported internalizing issues at clinical levels, and 65% reported externalizing problems above the clinical cutoff. Of the 15 children who met the overall clinical cutoff, two had ADHD, seven had autism, and six had both autism and ADHD. Two of the three children with autism met each of the internalizing problems, attention problems, and externalizing problems cutoffs. Of the nine children with ADHD, a majority met the attention problems (n = 8) and

externalizing problems (n = 6) cutoffs, with just under half meeting the internalizing problems cutoff (n = 4). Amongst the children whose parents reported that their child had both autism and ADHD, two met all clinical cutoffs (i.e. externalizing, internalizing, and attention), four met the internalizing and attention problems cutoffs, and one met only the attention problems cutoff. All of the children with additional comorbid diagnosis met the overall clinical cutoff and the cutoffs for internalizing problems, and attention, problems. All but one of these children met the clinical cutoff for externalizing problems.

There were 17 male children and 3 female children of participating parents with an average child age of 6.57 (range = 5 - 8) years old for the earlier meeting time and an average child age of 13.57 (range = 11-19) years old for the later meeting times.

Among the seven parents who completed all data collection, one reported that their child had autism, but not ADHD, and met the clinical cutoffs for internalizing problems, externalizing problems, and attention problems. Three parents reported that their child had ADHD, but not autism; two of these children met the internalizing problems cutoff, two met the attention problems cutoff, and all three met the externalizing problem cutoff. The remaining three parents reported that their children had both autism and ADHD; one of these children met the attention problems cutoff, but two met the internalizing problems cutoff and all three met the externalizing problems cutoff.

Children ranged in age from 6 to 19 years old (M = 12.43), with six of the seven children participating in the 5:15 p.m. teen group. According to parent report, one child had a diagnosis of ADHD, but not autism; three children had a diagnosis on the autism spectrum, but no diagnosis of ADHD; and three children had diagnoses of both autism and ADHD. Approximately half of the children had additional comorbid diagnoses

including anxiety disorders (n = 1), Obsessive Compulsive Disorder (n = 1), Oppositional Defiant Disorder (n = 1), trichotillomania (n = 1), and Intellectual Disability (n = 1).

*Parent characteristics.* There were 6 participating fathers and 14 participating mothers corresponding to 18 children participating in social skills groups. Ten parents were the only attending parent for their child; six parents were one of two parents who attended one or more sessions, but were the only parent to provide any information; and two sets of parent pairs (i.e. four parents) attended at least one session and participated in data collection. In both cases where both parents attended groups, one parent attended only the session at which they completed the questionnaires, while the other parent attended at least one session initial data collection. Parents ranged in age from 27 to 57 years old (M = 43.10, SD = 8.93). Most parents were married (85%) and parents also reported being partnered (10%), separated (5%), and single (5%).

The seven parents who completed both pre- and post-intervention measures and attended groups were fairly evenly divided by gender (Male n = 3, Female n = 4) and ranged in age from 36 to 57 (M = 49.43, SD = 7.12). Three of the parents were the only group-attending parent of their child. The other four parents were one of two parents who attended groups at any point, but were the only parent of these pairs to complete data. Of the other four parents in these pairs, three did not attend more than one group session.

Parents additionally completed measures of stress, wellness, and mindfulness, as described below, before and after the intervention to evaluate preliminary impact of the intervention, and evaluated satisfaction with the intervention at the conclusion of the intervention. Feasibility and acceptability were measured using session attendance in

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terms of content (e.g. Session 1) and time (e.g. 60 minutes), reasons for non-attendance, and parent and leader fidelity to intervention implementation.

#### Measures

As described previously, parents completed a *Brief Demographic Questionnaire* (Appendix E) that addressed parent and child characteristics, including parent age, education, occupation, relationship status, and relationship to the child participating social skills, and child gender, age, grade, diagnosis, strengths, and areas of concern. Parents also indicated who else lived in the home with the child and described up to five people, organizations, or other sources that provided the most support for their parenting. Child symptom severity was measured using the *Pediatric Symptom Checklist* (PSC-17; Appendix A), which is described in Chapter Two.

**Feasibility and acceptability.** Parents' attendance was recorded at each session to measure attrition and feasibility. Reasons for absence and attrition also informed feasibility and measures of parent fidelity to intervention practices and leader fidelity to intervention implementation informed feasibility and acceptability as well.

To measure acceptability, parents completed the *Group Session Rating Scale* (GSRS; Quirk, Miller, Duncan, & Owen, 2013; Appendix F), a version of the Session Rating Scale designed specifically for use with therapeutic groups, at the conclusion of each session. At the conclusion of all parent sessions, parents completed a Parents' Group Evaluation (Appendix G) adapted from the group evaluation in Bögels and Restifo's (2014) parent group. The Parent Group Evaluation in the current study added questions about parents' awareness and use of support, as well as a Likert-scale rating of how important or valuable various components of the groups were to the parents. Participants

also responded to qualitative questions evaluating their experience in group through focus groups or, if unable to attend, through written response. A question guide is included in Appendix L. These satisfaction measures conveyed parents' overall perception of the acceptability of the intervention, while the brief GSRS ratings focused on the acceptability of individual session content.

Preliminary implementation with parents. Parenting stress was measured using the *Parenting Stress Index, Fourth Edition Short Form* (PSI-4-SF; Appendix H; Berry & Jones, 1995). It consists of 36 questions divided into three domains: Parent Distress, Parent-Child Dysfunctional Interaction, and Difficult Child. Parents respond to each question using a five-point Likert scale from "strongly disagree" to "strongly agree." The PSI-4-SF has been shown to be reliable and valid, with high internal consistency ( $\alpha$  between .88 and .90 for all domains) and correlation between the third and fourth editions of the form (r = .99) (Abidin, 2012). It has been used to evaluate parenting stress in parents of children with EBDs (Anderson & Guthery, 2015; Davis, 2015; Elfert, 2014; Elfert & Mirenda, 2015; Kline, 2014). In the present study, parents completed this measure prior to the intervention during the orientation meeting and at the conclusion of groups.

Parent wellness was evaluated through two brief scales: The *Satisfaction with Life Scale* (SWLS; Diener, Emmons, Larsen, & Griffin, 1985; Appendix I) and selected scales of the Brief COPE Inventory (Carver, 1997; Appendix J). The SWLS has repeatedly demonstrated strong psychometric properties over time (Diener et al., 1985; Pavot & Diener, 1993; Pavot & Diener, 2008; Pavot, Diener, Colvin, & Sandvik, 1991). The five-item scale uses ratings on Likert scale ranging from strongly disagree (1) to strongly

agree (7) of questions regarding the responder's life satisfaction and provides benchmark total scores ranging from "extremely dissatisfied" to "extremely satisfied." The Brief COPE is an abbreviated version of the psychometrically sound COPE inventory, which has been useful in research linked to health outcomes (Carver, Scheier, & Weintraub, 1989), has demonstrated reliability and validity similar that of the original COPE inventory (Carver, 1997). Selected scales included the use of emotional support and use of instrumental support, which load onto one factor, and positive reframing, active coping, and planning scales, which load onto a separate factor (Carver, 1997).

Finally, mindful parenting was measured using the *Interpersonal Mindfulness Scale for Parents* (IEM-P; Duncan, 2007; Appendix K). The IEM-P addresses four domains: 1) emotional awareness, 2) present-centered attention, 3) openness and non-judgmental receptiveness of their child's thoughts and emotions, and 4) low reactivity to their child's behavior. The scale has adequate reliability and validity and has been used in previous evaluations of mindful parenting in parents vulnerable to high levels of parenting stress (Bögels et al., 2014; Geurtzen, Scholte, Engels, Tak, & van Zundert, 2015; MacDonald & Hastings, 2010; Walling, 2008).

## **Data Analysis**

The study employed both quantitative and qualitative methods. Again, qualitative data was analyzed using the six principles of thematic analysis through NVivo (NVivo version 10.0°, QSR International, 2014). Data were grouped according to categories pertaining to the feasibility (e.g. barriers to attendance, convenience of time, etc.) and acceptability (e.g. opinion of content, service delivery, etc.) of the newly developed

intervention. Feasibility and acceptability were measured quantitatively through attendance records and session ratings, respectively.

Preliminary impact of the intervention was evaluated quantitatively using repeated measures ANOVA to evaluate change in parenting stress, wellness, and mindful parenting from prior to the intervention to its conclusion. Because of limitations of sample size, categorical covariates were not included. Thus only the continuous variables of child symptom severity and child age were included as covariates in order to account for the effects of symptoms that are known to contribute to higher levels of parenting stress, as well as for the differing components of stress that occur as children age and supports for children at these ages vary. With the initially proposed sample size, significant change was expected for all three constructs: parenting stress was hypothesized to significantly decrease while parent wellness and mindful parenting were expected to significantly increase. However, given the decreased power due to attrition throughout the study, it was hypothesized that parenting stress would follow a negative trend from pre- to post-intervention while parent wellness and mindful parenting followed a positive trend between the time points.

### **Phase Two Results**

### **Evaluation of Feasibility and Acceptability**

Measures of feasibility and acceptability were collected throughout the intervention using quantitative measures such as the GSRS and rating scale questions on the group evaluation questionnaire. Six of the seven parents who completed post-intervention measures completed the qualitative questions regarding feasibility and

acceptability through interview (n = 1), focus group interview (n = 3), or questionnaire (n = 2).

Feasibility. Parents' attendance was recorded at each session to evaluate attrition and feasibility. Attendance increased from the first to second session, then decreased over the remainder of the intervention (see Table 3.2). Of the 29 parents who completed consent, 7 did not attend any sessions. Seven parents attended only one session, while three parents attended two or three sessions. Twelve parents attended at least half of the sessions. The longest gap between session attendance was three sessions (i.e. parents who missed more than three consecutive sessions did not return to groups). Other than parents who attended only one session or all sessions, parents primarily did not have entirely consecutive attendance (e.g. attending sessions one through six) and instead attended variably (e.g. attending sessions one through five and session seven). Parent attendance over the course of the intervention is also reflected in the consort diagram in Appendix D.

Qualitatively, parents reported in the open-ended questionnaires at the conclusion of groups there were several characteristics of group that made it more feasible. For instance, having the parent support group at the same time as their child's social skills group made the program easier to attend.

The kids' social skills groups focused on this brand of special needs kids and ...

this is the first time it's been group therapy for the parents while the kids were in

their sessions. The first one that we were aware of. Having something that we can

get the kids together and also have adult time with- knowing that they're

physically taken care of and working towards something, that- that's the stress

relief that most parents in this situation don't have. Because trying to go

somewhere where you know your kid's safe and you're not watching them all the time, versus, um, you know they're safe, you can actually focus on something else that's going on. I mean if- I don't know about other people's situations, but I don't know a whole lot of people that can handle one of my kids for an extended period of time versus all three of them for an extended period of time when I have a catalyst like this to set off little emotional time bombs throughout the experience for them.

No, it was perfect that it was the same time his group was. Otherwise I'd be sitting around playing on my phone or something. And I don't need to do that any more than I already do.

However, the link of parents' attendance to child attendance also led to parents missing the support group at times when their child would miss group due to other activities, illness, or homework. Additionally, as many of the participating parents were married or partnered, some parents alternated bringing their child to groups with a spouse, which prevented either parent from attending all groups, those these parents were able to share information and reinforce practice at home together. Finally, if group times changed for logistical reasons, parents had to either separate from their support group or deal with a lack of feasibility. As one parent explained:

The first meeting, it was a scheduling thing and my husband brought him, but it made it easier for me that we did it at the same time he was here... So when his meeting- his time- changed to 6:15, that made it more difficult for me because it

didn't make sense for me to come at 5:15 and then stay until [the 6:15 group ended] ... Bring him early and make him hang around for an hour.

Finally, parents shared mixed reports of whether they would continue to have access to similar supports after the conclusion of groups, with a major issue being one of feasibility, or the ability to make time for this support:

Honestly, I don't know [how to continue interacting with similar parents] because most of the parents that are- that were here, we all fall under the really, really busy, and if it wasn't for- I mean, just from our group, the majority of us are extremely busy and it's not like we're going to have parent conferences and telechats and "so how are you doing" because while we had our initial bond inside the group, once we get home we're so focused on what it is we have to do and what our children are- uh, the additional responsibilities we have just because of our children and keeping the rest of the family whole and sane and safe that I don't have an answer for how we would be able to continue it without groups. I mean, that's kind of why we have support groups. Because if you don't go to a meeting, you don't make time for it.

Parent 1: You know, I don't know that I'll have time to [meet with other parents], but I do talk to his therapist a lot, so that's a good thing.

Parent 2: Yeah, [child]'s counselor has been really helpful. And then, you know, while we were homeschooling, we connected with a couple of other families that were homeschooling for some of the similar reasons we did with the learning

disabilities or whatever, so I do have people I can connect with, I just need to make the effort to do it now.

Parent 3: Yeah, it takes making the effort to do it. But there really is no reason you can't pick up the phone... email...

Parent 1: Yeah

Parent 3: Just sometimes you just don't wanna.

(laughter)

Parent 1: You just want to go to sleep.

Acceptability. Participants quantitatively rated the acceptability of group sessions after the conclusion of each session using the GSRS (Table 3.2). Ratings were on a scale of 0 to 40 and ranged from 31.96 to 38.13. The most highly rated sessions were Session 8 (M = 38.13, SD = 1.79), which involved a gratitude practice, breathing space, loving-kindness exercise, and plan for the coming weeks; Session 4 (M = 37.24, SD = 2.18), including psychoeducation about stress and a three-minute breathing space under stress; Session 7 (M = 37.22, SD = 1.93), in which parents practiced loving-kindness and reviewed the contents of the resource book; and Session 3 (M = 37.20, SD = 1.53), which explored local advocacy and support as well as bringing kindness to oneself. It is of note that the Session 8 rating was based on only two participants.

At the conclusion of the intervention, parents rated the value or importance of components of the intervention on a scale of 1 to 10. The average rating for the group overall was 8.86 (SD = 1.07). Parents rated the group leader's contributions to group discussion (M = 9.14, SD = 0.90) as the most important part of the intervention to them, followed by group discussions with other parents (M = 8.57, SD = 2.15), summary emails

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sent between sessions (M = 8.57, SD = 0.98), mindful parenting handouts (M = 8.43, SD = 0.53), the breathing exercise in the group (M = 8.43, SD = 1.90), support handouts (e.g. Local Advocacy and Support, Communicating with Schools, and Strategies for Child Behavior; M = 8.29, SD = 1.11), practice exercises and handouts (M = 8.14, SD = 0.69), and the resource book (M = 8.00, SD = 0.90). All seven parents also reported that they felt they had gotten something of "lasting value" from participating in parent groups.

Intervention acceptability was also qualitatively assessed using an open-ended questionnaire about how well parents' expectations for the group had been met, what parents would want to keep the same about the group, and what parents would want to change about groups. Parents reported during the concluding interview that they did not have initial expectations for the group, as they had never participated in something similar, and relatedly were largely unsure what they would change to improve groups:

Well, some of these things, you know, you just, you sit through 'em. [Child] is 12, he's been diagnosed since he was 6- I've learned a lot in that time, so you don't expect to learn a whole lot after six years of already being in that. But, I did learn, so I take a lot more time with [child] than I used to.

I wasn't really sure what to expect. And I think my favorite part about it was focusing on yourself and being aware of your feelings or just being self-aware because I've needed that really badly at this time. So that was the best part for me.

My expectations were basically more tools in the toolbag. More ways of coping with stress, more ways of understanding the behaviors, what caused the behaviors and my reactions to it, and the interaction with parents with similar, um, similar issues. So, to have more uh, more support in, basically support numbers. Strength in numbers. For knowing you're not alone. For what I was expecting to get out of it, I believe all of my ideals of what it was supposed to be were met. The um, it would have been nicer for larger groups, but then again, if it was too much larger, it wouldn't have been time for all the discussions with people throwing stuff in- throwing stuff around, but... I came in with a clean slate for- 'cause I had no idea what to expect, so I wasn't- I wasn't exactly sure what, like I said, um, I wasn't sure what to expect, so I can't say there was anything I was expecting that you didn't provide.

However, two recurring themes related to acceptability arose. First, parents occasionally found it difficult to move from the busy pace of life that was described in both Phase One and Phase Two to remaining alert during the calm pace of the mindfulness exercises:

There wasn't anything that I really didn't like about group, um. Being won over by some of the concepts was a- was sometimes a little hard. And having to slow down when I'm normally going 90 miles an hour occasionally almost put me to sleep, so trying to focus and stay awake were a little of a- more of a challenge. Not necessarily a dislike, but a little more of a challenge.

Parent 1: You know, it's hard after a long day to come in and do a body scan or that kind of thing. Because you're tired. And you know, that's tough.

Parent 2: Especially when you can hear [your child] hollering about something.

Second, parents both reported on the open-ended questionnaire and on the open-ended sections of the GSRS throughout the intervention that they viewed time spent freely discussing issues with other parents positively. Parents also mentioned that they would have enjoyed more of that time in groups. As parents shared through the post-intervention open-ended questionnaire:

[I liked] the overall interaction, the resources that you brought, the things that we went over, and the overall discussions... for anything that I'm talking about liking, the majority of it's going to be the interaction of some kind, from leader or peers.

I think you did a really good job of letting us go off on our tangents when we went off on our tangents.

Parent 1: [The best part of group was] conversations with adults.

Parent 2: Yeah, with other parents.

Parent 3: Yeah.

Parent 2: I wish we could add a little bit more time.

Overall, parents summarized their experience in parent group as a positive one: I enjoyed my experience- I don't know anything that I would have necessarily changed. Even the things that I wasn't able to participate in as much as I would have liked to beyond outside of like, trying to fill out the paperwork, like do the

HW, actually take the time out, I know I didn't spend as much time on it as I could have, but that was all on my own- it was of my own doing and it's mostly just 'cause I'm in a transitional period right now.

I think more nights than not I had arguments with [child] about "No we ARE going to social skills group because I'M going to parenting group!"

Because participants may be more likely to find a group acceptable if they perceive evidence of change, questions on the group evaluation questionnaire administered at the conclusion of the intervention additionally assessed areas where parents perceived change as a result of their participation in the group. All parents responded affirmatively to a question on the group evaluation assessing whether they made changes in their lifestyle, dealing with their child or family, or in their child-rearing practice as a result of participating in groups. As part of the group evaluation questionnaire, parents additionally evaluated on a five-point scale how much change they perceived occurring as a result of participating in the parent group, where scores of 1 and 2 indicated negative change, a score of 3 indicated no change, and scores of 4 and 5 indicated positive change. Parents reported that on average, they perceived the most positive change in their ability to deal with emotions in parenting (M = 4.43, SD = 0.53), feeling hopeful as a parent (M = 4.29, SD - 0.49), awareness of stressful parenting situations at the time they are happening (M = 4.29, SD = 0.49), and their ability to handle stressful parenting situations appropriately (M = 4.29, SD = 0.49). Parents reported perceiving the least amount of change in actually taking better care of themselves (M = 3.71, SD = 0.76) and periods of parental stress or frustration (M = 3.86,

SD = 0.38), but they did not identify any areas where *negative* change occurred (i.e. ratings of two or below).

# **Evaluation of Preliminary Impact**

As described in the method section, only seven parents who attended groups completed questionnaires both before and after the intervention to allow for pre- and post-intervention statistical analysis and comparison. Given the notable attrition over the course of the study, data were reviewed for the overall sample, including the 20 parents who completed pre-intervention questionnaires, and reviewed separately for the seven parents who provided data at both pre-intervention and post-intervention time points and who attended at least one group session (i.e. the full analysis sample). Demographic parent and child characteristics for the overall sample are presented in Table 3.1 and these parents' pre-intervention reports of their levels of parenting stress, parent wellness, and mindful parenting are presented in Table 3.3 For parents in the full analysis sample, parent and child characteristics are presented in Table 3.4 with pre-intervention reports of parenting stress, parent wellness, and mindful parenting in Table 3.5. Changes in parenting stress, parent wellness, and mindful parenting were assessed quantitatively, using the PSI-4-SF, Brief COPE and SWLS, and IEM-P, respectively, as well as qualitatively based on parents' mixed-method responses on a survey conducted at the conclusion of groups.

**Parenting stress.** In the overall sample (n = 20), participants reported preintervention levels of parenting stress using the PSI-4-SF. Parents reported overall stress in the  $82^{nd}$  percentile (SD<sub>%</sub> = 13.59), which is at the upper end of the normal range (T<sub>mean</sub> = 60.94, SD = 7.15). The construct of parenting stress is additionally divided into three domains that were assessed by the PSI-4-SF: the difficult child domain, which evaluates the effects of child characteristics such as hyperactivity and adaptability on parenting stress; the parent-child dysfunctional interaction domain, which considers parents' satisfaction with interactions with their child; and the parent distress domain, which evaluates parent characteristics, such as sense of competence and parental role, and their contribution to parenting stress. Parent report of the difficult child component of parenting stress was in the 89<sup>th</sup> percentile (SD<sub>%</sub> = 12.03) in the clinically significant range ( $T_{mean} = 65.17$ , SD = 7.65). Stress related to the domain of parent-child dysfunctional interaction was in the 77<sup>th</sup> percentile (SD<sub>%</sub> = 16.71) and in the normal range ( $T_{mean} = 58.47$ , SD = 7.84). Stress linked to the domain of parent distress was also in the normal range ( $T_{mean} = 57.26$ , SD = 8.76) in the 73<sup>rd</sup> percentile (SD<sub>%</sub> = 21.26) at the pre-intervention time point.

Initial levels of overall parenting stress for the full analysis sample (n = 7) were in the  $84^{th}$  percentile (SD<sub>%</sub> = 11.75), just below the cutoff for "high" scores ( $T_{Mean}$  = 61.86, SD = 6.74). Parents reported clinically significant concerns in the  $94^{th}$  percentile (SD<sub>%</sub> = 7.58) related to the difficult child domain of stress ( $T_{Mean}$  = 69.57, SD = 7.68). Parents' concerns related to parent distress ( $T_{Mean}$  = 57.14, SD = 8.71) and parent-child dysfunctional interaction ( $T_{Mean}$  = 56.14, SD = 5.87) were both rated in the  $73^{rd}$  percentile (SD<sub>PD%</sub> = 21.62, SD<sub>PCDI%</sub> = 11.86).

A repeated measures ANOVA, including covariates of child age and child symptom severity, was conducted for the full analysis sample (n = 7) to determine whether there was a statistically significant difference in parenting stress as measured by the PSI-4-SF over the course of a 10-session parent support group intervention (Table

3.6). Boxplots indicated that there were no outliers (Figure 3.1), and the data were normally distributed at each time point, as assessed by the Shapiro-Wilk test (p > .05), respectively. The parent support group did not elicit statistically significant changes in parenting stress over time and had a small effect size (F = (1, 4) = .218, p = .665, partial  $\eta^2$ = .052), with parenting stress decreasing slightly from pre-intervention (M = 61.86, SD = 6.74) at the beginning of the intervention to (M = 60.00, SD = 6.90) at the conclusion of the intervention.

The group evaluation questionnaire also contained quantitative items regarding the role of the support group in parents' perceived parenting stress. Parents reported perceiving positive change in their awareness of stressful parenting situations at the time the situations were happening (M = 4.29 out of 5, SD = 0.38) and in their ability to handle those situations appropriately. However, parents did not perceive change in how frequently they experienced parenting stress or frustration (M = 3.86 out of 5, SD = 0.76).

**Parent wellness.** Regarding wellness, initial life satisfaction in the overall sample (n = 20) ranged from "extremely dissatisfied" to "highly satisfied" with "average" mean life satisfaction (M = 20.95, SD = 6.58, Range = 5 - 35). Parents reported mean overall perceived support of 29.06 (SD = 5.93) on a scale of 10 to 50. When rating components of perceived support on a scale of 2 to 10, parents reported using active coping (M = 6.23, SD = 1.59), planning (M = 6.20, SD = 1.51), positive reframing (M = 6.22, SD = 1.26), and instrumental support (M = 5.40, SD = 1.64) "a medium amount," as well as emotional support (M = 4.48, SD = 1.89) "a little bit."

For the full analysis sample (n = 7), initial life satisfaction ranged from dissatisfied to very high satisfaction with mean life satisfaction in the average range.

Average report of coping skills across the domains was 29.5 (SD = 7.50), or "a medium amount." Parents reported pursuing positive reframing (M = 6.50, SD = 1.52), planning strategies (M = 6.29, S = 1.50), and instrumental support (M = 5.71, SD = 1.98) "a medium amount" on a scale of 2 to 10. They also noted using emotional support and getting comfort and understanding from others "a little bit" (M = 4.36, SD = 2.01) and overall used active coping strategies "a medium amount." Parents reported using one aspect of active coping (concentrating effort on doing something about their situation) "a little bit" (M = 2.21 out of 5, SD = 1.15) but took action to make the situation better "a medium amount" (M = 3.29 out of 5, SD = 0.76).

To assess whether there was a statistically significant difference in parent wellness in the full analysis sample (n = 7) over the course of the parent support group, repeated measures ANOVAs, including covariates of child age and child symptom severity, were conducted to evaluate change in life satisfaction, as measured by the SWLS, and perceived support, as measured by the Brief COPE (Table 3.7). One parent did not complete the measures in full, further limiting the sample size for the analysis of parent wellness (n = 6). There were no outliers for life satisfaction or perceived support, as assessed by boxplot (Figure 3.2 and Figure 3.3, respectively), and the data were normally distributed at each time point for both components of wellness, as assessed by the Shapiro-Wilk test (p > .05), respectively. Analysis of parents' responses to the both measures indicates that the parent support group did not elicit statistically significant changes in parent wellness over time (F = (2, 2) = .641, p = .610, partial  $\eta^2$  = .390). Parent report of perceived support, as measured by the Brief COPE, had a large effect size (partial  $\eta^2$  = .346) and increased slightly from pre-intervention (M = 29.50, SD = 7.50) to

post-intervention (M = 31.00, SD = 4.69). Parent life satisfaction also had a large effect size (partial  $\eta^2$ = .187) and increased slightly from pre-intervention (M = 22.00, SD = 7.321) to post-intervention (M = 26.17, SD = 6.85).

On the group evaluation questionnaire, all parents reported that they were "more" (n = 4) to "much more" (n = 3) aware of local avenues of support for their parenting following the support group intervention. Every participating parent also noted that they felt they knew both when and how to seek support when needed as a result of parent groups.

Questions on the demographic questionnaire completed at both pre- and post-intervention time points also reflected parents' perception of support: parents were asked to describe up to five people, organizations, or other sources that provided the most support for their parenting. On average, parents reported three sources of support at both the beginning and end of the intervention, including resources such as family members, community programs, respite care, church, and doctors, therapists, and therapeutic organizations, community programs.

**Mindful parenting.** In the overall sample (n = 20), parents' initial report of mindful parenting had a mean of 28.17 (SD = 3.28) on a scale of 5 to 50. Parents reported sub-components of mindful parenting on a scale of 2 to 10 and indicated that they used emotional awareness the most (M = 7.84, SD = 0.90), followed by non-judgment (M = 7.68, S = 1.25), non-reactivity (M = 6.60, SD = 1.27), and attention to their child (M = 6.25, SD = 1.02).

Initial reports of mindful parenting in the full analysis sample (n = 7) paralleled those in the larger group, with a mean of 27.4 on a scale of 5 to 50. Parents reported their

use of specific aspects of mindful parenting on a scale of 2 to 10. Parents indicated that they used emotional awareness the most (M = 7.83, SD = 1.17), followed by non-judgment (M = 7.33, SD = 1.51), non-reactivity (M = 6.71, SD = 0.95), and attention to their child as the least frequently used component of mindful parenting (M = 6.29, SD = 0.76).

A final repeated measures ANOVA, including covariates of child age and child symptom severity, was conducted with the full analysis sample (n = 7) to determine whether there was a statistically significant difference in mindful parenting, as measured by the IEM-P, over the course of a 10-session parent support group intervention (Table 3.8). Two parents did not fully complete the measure, reducing the sample size (n = 5). There were no outliers, as assessed by boxplot (Figure 3.4), and the data were normally distributed at each time point, as assessed by the Shapiro-Wilk test (p > .05), respectively. The parent support group did not elicit statistically significant changes in mindful parenting over time and had a medium effect size (F = (1, 2) = .258, p = .662, partial  $\eta^2$ = .114), with mindful parenting remaining relatively similar from pre-intervention (M = 27.40, SD = 2.97) to post-intervention (M = 27.80, SD = 3.70).

Parents reported on the group evaluation questionnaire that they used mindfulness practices throughout the week: five parents reported that during the eight weeks of groups, they practiced mindful parenting exercises 1 to 2 times a week, while another two parents reported practicing the exercises 3 to 4 times a week. All parents reported on the group evaluation questionnaire that after participating in the intervention, they perceived themselves as paying "much more" attention to their child in the moments they were together. All parents also indicated that they felt they had become more "conscious" in

their parenting and that they intended to continue practicing mindful parenting exercises. Finally, parents rated the components of the intervention, including various mindfulness practices, according to what was important to them on a scale of 1 to 10. Specifically, parents rated the breathing exercise in the group setting (M = 8.43, SD = 1.90) and at home (M = 7.71, SD = 1.89) as the two most important mindfulness strategies, followed by the self-compassion exercise in the group (M = 7.00, SD = 1.53) and at home (M = 7.14, SD = 1.57), the loving-kindness exercise in group (M = 7.00, SD = 1.90), the body scan at home (M = 6.43, SD = 2.76), and the loving-kindness exercise at home (M = 6.14, SD = 1.94).

Table 3.1 Phase Two Overall Sample Descriptive Statistics

	n	%	Mean	SD
Parent Gender	20	100%		
Male	6	30%		
Female	14	70%		
Parent Age			43.10	8.93
Child Gender				
Male	17	85%		
Female	3	15%		
Child Age			10.8	4.05
Child Behavior	18		18.78	4.55
Overall Clinically Significant		75%		
Internalizing	19		5	2.26
Int. Clinically Significant		60%		
Externalizing	19		6.11	2.85
Ext. Clinically Significant		65%		
Attention Problems	19		7.63	1.61
Att. Clinically Significant		80%		
Child Diagnosis				
Autism, no ADHD	3	15%		
Met Internalizing Cutoff	2			
Met Externalizing Cutoff	2			
Met Attention Problems Cutoff	2			
ADHD, no Autism	9	45%		
Met Internalizing Cutoff	4			
Met Externalizing Cutoff	6			
Met Attention Problems Cutoff	8			
Autism & ADHD	8	40%		
Met Internalizing Cutoff	6			
Met Externalizing Cutoff	2			
Met Attention Problems Cutoff	6			

Table 3.2 Session Feasibility and Acceptability

	~ :	GGD G II	0000	0000
	Session	GSRS#	GSRS	GSRS
	Attendance	Completed	Mean	SD
Session 1	13	13	34.51	3.86
Session 2	15	12	31.96	3.89
Session 3	10	10	37.20	1.53
Session 4	10	10	37.24	2.18
Session 5	10	10	35.43	2.60
Session 6	9	8	35.94	2.49
Session 7	9	9	37.22	1.93
Session 8	3	2	38.13	1.79

Table 3.3 Phase Two Overall Sample Pre-Intervention Parent Characteristics

	n	Mean	SD
Initial Parenting Stress T-Score	18	60.94	7.15
Difficult Child Domain T-Score	18	65.17	7.65
Parent-Child Dysfunctional Interaction Domain	19	58.47	7.84
T-Score			
Parent Distress Domain T-Score	19	57.26	8.76
Initial Life Satisfaction	20	20.95	6.58
Initial Perceived Support	18	29.06	5.93
Active Coping	20	6.23	1.59
Emotional Support	20	4.48	1.89
Instrumental Support	20	5.40	1.64
Positive Reframing	18	6.22	1.26
Planning	20	6.20	1.51
Initial Mindful Parenting	18	28.17	3.28
Attention	20	6.25	1.02
Non-judgment	19	7.68	1.25
Non-reactivity	20	6.60	1.27
Emotional awareness	19	7.84	0.90

Table 3.4 Phase Two Full Analysis Sample Descriptive Statistics

	n	%	Mean	SD
Parent Gender				
Male	3	43%		
Female	4	57%		
Parent Age			49.43	7.12
Child Gender				
Male	6	86%		
Female	1	14%		
Child Age	7		12.43	3.99
Child Behavior	7		19.79	3.24
Overall Clinically Significant		100%		
Internalizing	7		5.43	1.90
Int. Clinically Significant		71%		
Externalizing	7		6.21	1.63
Ext. Clinically Significant		43%		
Attention Problems	7		8.14	1.07
Att. Clinically Significant		100%		
Child Diagnosis				
Autism, no ADHD	1	14%		
Met Internalizing Cutoff	1			
Met Externalizing Cutoff	1			
Met Attention Problems Cutoff	1			
ADHD, no Autism	3	43%		
Met Internalizing Cutoff				
Met Externalizing Cutoff	2 3			
Met Attention Problems Cutoff	2			
Autism & ADHD	2 3 2	43%		
Met Internalizing Cutoff	2			
Met Externalizing Cutoff	3			
Met Attention Problems Cutoff	0			

Table 3.5 Phase Two Full Analysis Sample Pre-Intervention Parent Characteristics

	n	Mean	SD
Initial Parenting Stress T-Score	7	61.86	6.74
Difficult Child Domain T-Score		69.57	7.68
Parent-Child Dysfunctional Interaction Domain		56.14	5.87
T-Score			
Parent Distress Domain T-Score		57.14	8.71
Initial Life Satisfaction	7	20.43	<b>7.87</b>
Initial Perceived Support	6	29.50	7.50
Active Coping	7	5.50	1.60
Emotional Support	7	4.36	2.01
Instrumental Support	7	5.71	1.98
Positive Reframing	6	6.50	1.52
Planning	7	6.29	1.50
Initial Mindful Parenting	5	27.40	2.97
Attention	7	6.29	0.76
Non-judgment	6	7.33	1.51
Non-reactivity	7	6.71	0.95
Emotional awareness	6	7.83	1.17

Table 3.6 Parenting Stress Repeated Measures ANOVA

	SS	MS	F	p	$\eta^2$
Time	2.982	2.982	.218	.665	.052
Time * Child Age	7.534	7.534	.552	.499	.121
Time * Child Symptom Severity	.021	.021	.002	.970	.000
Error	54.635	13.659			

Table 3.7 Parent Wellness Repeated Measures ANOVA

	SS	MS	F	р	$\eta^2$
Overall parent wellness				•	•
Time			.641	.610	.390
Time * Child Age			.439	.695	.305
Time * Child Symptoms			.210	.826	.174
Parent Perception of Support					
Time	22.838	22.838	1.590	.296	.346
Time * Child Age	17.005	17.005	1.184	.356	.283
Time * Child Symptoms	7.969	7.969	.555	.510	.156
Error	43.082	14.361			
Parent Life Satisfaction					
Time	17.889	17.889	.689	.467	.187
Time * Child Age	8.982	8.982	.346	.598	.103
Time * Child Symptoms	4.713	4.713	.182	.699	.057
Error	77.883	25.961			

Table 3.8 Mindful Parenting Repeated Measures ANOVA

	SS	MS	F	p	$\eta^2$	
Time	.485	.485	.258	.662	.114	
Time * Child Age	.525	.525	.279	.650	.123	
Time * Child Symptoms	.041	.041	.022	.896	.011	
Error	3.759	1.879				

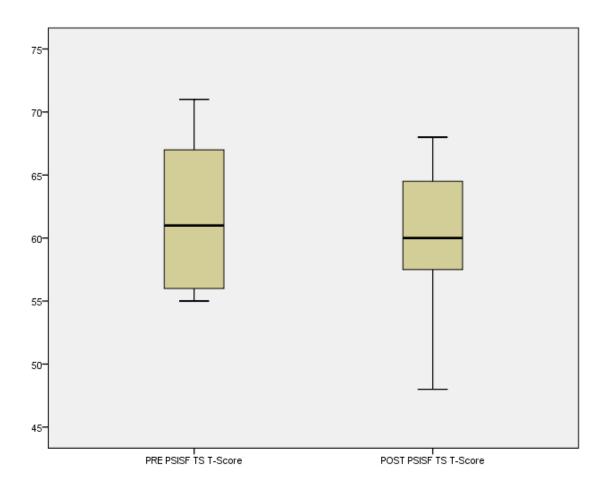


Figure 3.1 Distribution of Overall Parenting Stress Scores

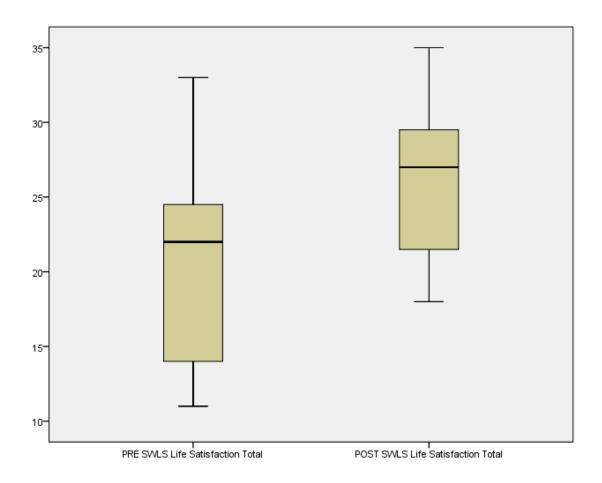


Figure 3.2 Distribution of Life Satisfaction Scores

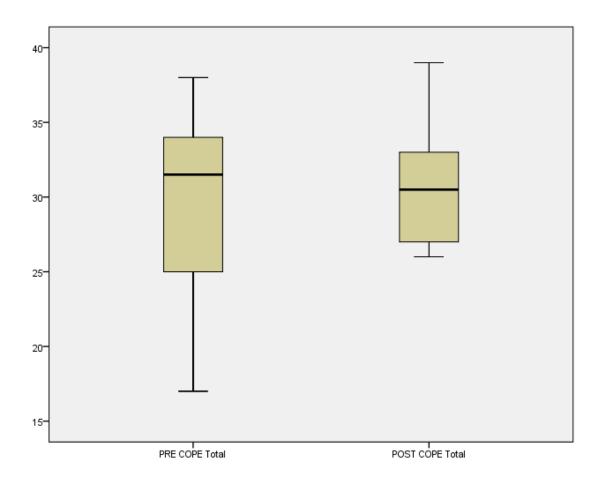


Figure 3.3 Distribution of Perceived Support Scores

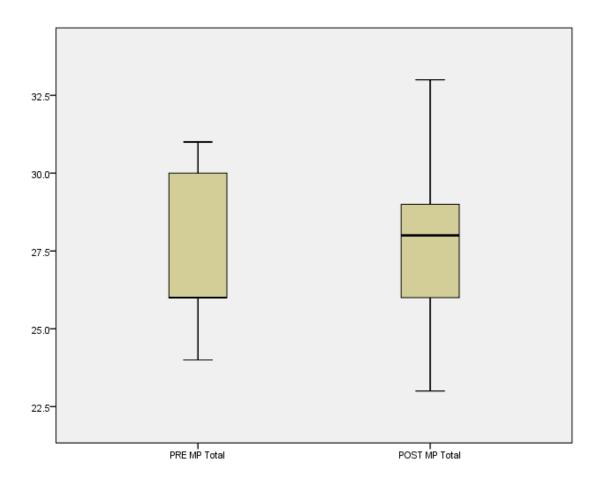


Figure 3.4 Distribution of Overall Mindful Parenting Scores

# **CHAPTER 4**

### **DISCUSSION**

Parenting stress is a significant concern among parents of children with EBDs such as autism and ADHD. These parents often face increased academic, behavioral, and emotional needs in their children (Bussing et al., 2003; Johnston & Chronis-Tuscano, 2014; Montes & Halterman, 2006) and feel isolated from other parents and supports (Harborne et al., 2004; Werner, 2000; Woodgate et al., 2008). The literature identifies several modes for supporting parents such intervention targeting parent behaviors (Bearss et al., 2015), sharing experiences with understanding others (Ainbinder et al., 1998; Kingsnorth et al., 2011) and meeting practical and emotional needs (Kerr & Macintosh, 2000). Some interventions have considered strategies for decreasing parenting stress (Kazdin & Whitley, 2003; Keen et al., 2010; Treacy et al., 2005) and increasing wellness in parents of children with disabilities (Ainbinder et al., 1998; Kingsnorth et al., 2011). However, receiving these supports requires overcoming barriers (e.g. time, finances, etc.) and the literature on *parent*-focused support interventions for families with children with EBDs remains limited.

The present sequential exploratory mixed methods study evaluated characteristics and needs of parents of children with EBDs and what services may feasibly and acceptably promote wellness and mindful parenting and alleviate parenting stress in this population.

#### Phase One

In Phase One, which qualitatively explored the needs of parents of children with EBDs and identified factors of feasibility and acceptability of services to address these needs, parents reported several themes surrounding their experience of parenting a child with an EBD and the types of services that would meet those needs. The first was the hectic but valued experience of parenting a child with an EBD. Second, parents described a variety of sources of parenting stress. Third, parents identified contributors as well as barriers to parent wellness. Fourth, parents shared their familiarity with and views of mindfulness. Fifth, parents identified aspects of feasibility and acceptability in programs and interventions that could meet some of the needs they had previously outlined.

Parents' descriptions of their experiences bore several similarities to the extant literature: parents faced disruptive and demanding child behaviors, schedules dominated by services for their child, and a perceived lack of understanding from others, including family members, other parents, and school personnel. In the current study, parents noted similar concerns and also described specific barriers to their own wellness, their familiarity with mindfulness as a potential strategy for their discussed needs, and ideal components of an intervention to address their aforementioned needs.

Parents' report indicated that they valued being understood and respected by others in a support group. They also mentioned specific ways in which they would like to receive support (e.g. a collection of resources, strategies for overcoming barriers, accountability). These values were incorporated with practices previously utilized in the literature to generate the intervention implemented and evaluated in Phase Two.

### **Phase Two**

In Phase Two, a mixed-methods evaluation analyzed the feasibility, acceptability, and preliminary impact of an eight-session pilot parent support intervention informed by focus group data from the Phase One. There was notable attrition over the course of the intervention: 29 parents completed consent, seven parents did not attend any of the eight sessions, and five parents attended their first and only session during one of the eight content sessions (e.g. not at the introductory session). Fourteen parents attended groups and provided parenting stress, parent wellness, and mindful parenting information prior to the intervention; only seven of these parents provided comparison information at the conclusion of the intervention as well. An additional eight parents attended groups, but did not rate their parenting stress, parent wellness, and mindful parenting practices.

## Feasibility and Acceptability

Regarding feasibility and acceptability, parents overall gave sessions ratings of 31.96 and above. Participants rated sessions using mindfulness components of the three-minute breathing space and loving-kindness practice and support components of the resource book and local advocacy and support most highly. Parents particularly valued times of discussion with people who "got it" and/or responded nonjudgmentally, including the group leader and other parents, and the provision of materials outside of groups (e.g. emails with summaries and reminders, mindful parenting handouts, and practice exercises and handouts), though parents rated conducting mindfulness exercises within the group setting as more important than practicing those exercises at home.

Previous literature has suggested that attention to consumer preferences may improve intervention engagement and outcomes (Levant, 1987; Metzler et al., 2012;

Sanders & Kirby, 2012; Spoth & Molgaard, 1993). Parents with similar characteristics to those participating in the support group intervention (e.g. child with an EBD, participating in social skills groups, living in the same geographical area, etc.) indicated their preferences in the Phase One focus groups, which may have impacted the high acceptability of the intervention. However, despite this direct reference of consumer preferences and generating a convenient intervention group to occur simultaneously with child-focused services, issues of feasibility remained. While those components made the current intervention more acceptable to parents, more work is needed to explore components of feasibility. Some literature has explored providing media such as videos for parents to access at home (Metzler et al., 2012), but a need remains for parents to feasibly and consistently access *group* support. Future research should consider the potential effectiveness of abbreviated interventions, which may lessen attrition over time, and increasingly accessible interventions.

# **Preliminary Impact**

Among the seven parents who provided pre- and post-intervention data regarding preliminary impact, parents did not report clinically significant change in parenting stress, parent wellness, or mindful parenting. However, parenting stress slightly decreased from the beginning to the end of the intervention, though this change was not significant (Table 3.6, Figure 3.1). Parent wellness had a slight, non-significant increase from the beginning to the end of the intervention (Table 3.7, Figure 3.2, Figure 3.3) and levels of mindful parenting did not change over the course of the intervention (Table 3.8, Figure 3.4).

These results indicate that a parent support group can be an important component of parenting a child with an EBD, as it addresses parents' expressed need for accountability; strategies for accessing resources to help their child in the community, school, and at home; and a safe space to discuss a significant part of their lives with others who will be understanding and helpful. Though quantitative analyses were not significant, parenting stress followed a slight decreasing trend, and parent wellness, particularly regarding perceived support, followed a slight positive trend. Parents also qualitatively reported improvements in these areas and noted mindfulness strategies, such as breathing space and loving-kindness exercises, and instrumental and emotional supports, including the provision of resources and time to discuss parenting experiences with other parents of children with EBDs, as important to them.

Overall, the structure of the intervention also addressed aspects of intervention acceptability, though additional factors may have inhibited the effect of the increased feasibility of holding parent-focused sessions at the same time as child-focused sessions. Additionally, parents did not note significant quantitative changes in parenting stress, parent wellness, and mindful parenting as a result of the intervention, but they qualitatively reported perceiving some improvements in these areas.

#### Limitations

This study is most notably limited by the small sample size, which limits power quantitatively and qualitatively lacks the views of many parents impacted by issues of feasibility and acceptability. The qualitative issue is twofold: first, parents may have been unable to attend sessions because of feasibility issues, such as their child's willingness to continue attending groups, an increasing workload and other school demands as students

neared the end of the school year, or competing after-school activities. Conversely, parents may have begun to use some of the strategies discussed in the intervention, which promoted supports the parents had requested, such as strategies for getting reliable babysitters able to work with their child and his or her needs or options for other supports and programming that may have conflicted with the meeting time. In either event, the current study and future studies would benefit from a more thorough investigation of the contributors and barriers to parent attendance and whether these factors were primarily child-based, thus impacting what participating parents identified as the feasibility of attending this support intervention at a time that they were already doing something for their child, or parent-based.

Further studies should evaluate needs of parents of children with EBDs in a more economically, racially, and geographically diverse sample. Parents in the present sample represented a relatively homogenous group from one city in the southeastern United States. As the sample grows more diverse, so should the considerations of consumer preferences to encompass the values and keys to engagement for various parents of children with EBDs. Additionally, some studies only noted significant change at follow-up (Meppelink et al., 2016), which was not included as a time point in the present study. Even had this been the case, it likely would have been difficult to evaluate changes between time points due to attrition. Relatedly, additional research should examine reasons for parent attrition and ways that these causes may be addressed to make parent support more feasible. In the current study, parents were offered the opportunity to comment on the acceptability of each session as they attended. Because acceptability ratings were overall high and parents' qualitative report did not indicate significant issues

with acceptability as the intervention progressed, it is possible that issues of feasibility primarily interfered with parents' ability to attend and gain benefits from the intervention. However, parents also lauded this intervention's feasibility in that it took place at a time when their children were cared for by qualified individuals and receiving their own services. While this is an important step in addressing issues of feasibility in serving the needs of parents of children with EBDs, additional barriers to feasible interventions may remain.

Throughout Phases One and Two of the study, parents repeatedly expressed that they knew "the right thing to do." They knew that self-care and other aspects of wellness were important, but struggled to create time for themselves to receive the varying types of support that they were aware that they needed. While the present parent support group was rated as highly acceptable and exhibited ideal trends in parenting stress and parent wellness, as hypothesized, significant issues of feasibility remain. Additionally, while parents perceived the mindfulness practices as assisting in limiting their parenting stress and coping better with difficult parenting situations, ratings of mindful parenting did not change significantly over the course of the intervention. It may be beneficial to further evaluate the role of mindfulness in changing parents' perceptions, thoughts, and feelings, as well as behaviors.

#### Conclusion

The results of the present study expand the knowledge base regarding feasible, acceptable, and effective interventions supporting parents of children with EBDs including autism and ADHD. In Phase One, parents of children with EBDs shared their experiences as parents of children with EBDs. Parents also indicated their needs and

barriers to receiving services that can inform future parent-focused support interventions. In Phase Two, parents indicated quantitatively and qualitatively that the intervention was highly acceptable in its content and structure, but the intervention was not feasible to a degree that sustained parent attendance throughout the intervention. Parents also did not quantitatively indicate significant change in mindful parenting, parenting stress, or parent wellness, but reported making changes to their behaviors, perceiving improvements in parenting stress, identifying supports to improve wellness, and practicing mindfulness exercises in their parenting at home. Future studies should consider the unique needs of parents of children with EBDs that were expressed in the current study and strategies for developing further feasible, acceptable, and effective interventions to meet these needs.

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### APPENDIX A

# PEDIATRIC SYMPTOM CHECKLIST (PSC -17)

### Please mark under the heading that best describes your child:

	(0) NEVER	(1) SOMETIMES	(2) OFTEN
1. Feels sad, unhappy			
2. Feels hopeless			
3. Is down on self			
4. Worries a lot			
5. Seems to be having less fun			
6. Fidgety, unable to sit still			
7. Daydreams too much			
8. Distracted easily			
9. Has trouble concentrating			
10. Acts as if driven by a motor			
11. Fights with other children			
12. Does not listen to rules			
13. Does not understand other people's feelings			
14. Teases others			
15. Blames others for his/her troubles			
16. Refuses to share			
17. Takes things that do not belong to him/her			

### APPENDIX B

### FOCUS GROUP INTERVIEW GUIDE

What are your day-to-day activities as a parent?

What are the best things about parenting for you?

What are the most stressful things about parenting for you?

What have you found to be useful in managing these stressors?

What are the limitations of strategies that you have used?

What makes it difficult to use some strategies that might be helpful but you haven't been able to try?

What makes it difficult for you to do things for yourself?

[Are you familiar with mindfulness? It is a strategy that aims to relieve stress by increasing awareness of daily experiences through reflection, breathing, and focused communication between you and your child.]

Have you used any of these strategies to cope with your child's behavior?

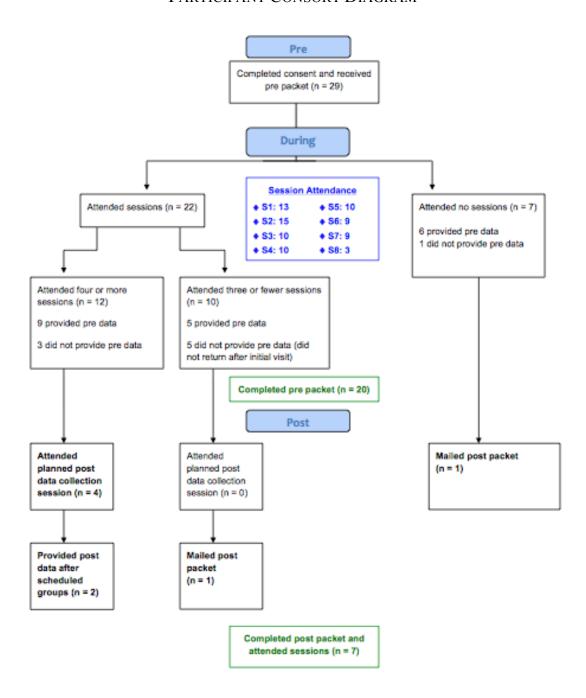
Would you be receptive to trying any of these strategies?

 $\label{eq:appendix} \textbf{APPENDIX} \ \textbf{C}$  Planned Parent Intervention Session Content

Session	Content
Orientation	Practical issues, group rules (10 min)
	Introductions (10 min)
	Assessment and snacks (40 min)
	- PSI-4 SF (10 min)
	- IEM-P (5 min)
	- PSC-17 (5 min)
	- SWLS (3 min)
	- Brief COPE (10 min)
1	Raisin exercise (10 min)
	Rationale for Mindful Parenting (20 min)
	- Being vs. Doing
	<ul> <li>Bringing mindfulness to daily activity</li> </ul>
	Support: Parent Forum, Resource Book Requests (20 min)
	Review and practice assignment (5 min)
2	HW review (10 min)
	Body scan (40 min) *with attention to breathing
	Review and practice assignment (5 min)
3	Home practice review (10 min)
	Stress and bringing kindness to ourselves (15 min)
	Three-minute breathing space (10 min)
	Support: Local Advocacy and Support (10 min)
	Review and practice assignment (5 min)
4	Stressful moments calendar review (10 min)
	Stress psychoeducation (10 min)
	Grasping and pushing away (10-min)
	Three-minute breathing space under stress (5 min)
	Halfway evaluation (10 min)
	Review and practice assignment (5 min)
5	Sitting practice or body scan (15 min)
	Parent-child relationship (20 min)
	Support: Communicating with Schools (15 min)
	Review and practice assignment (5 min)

	<del>_</del>
6	Perspective-taking, repair (40 min)
	Support: Strategies for Child Behavior (10 min)
	Review and practice assignment (5 min)
7	Loving-kindness (40 min)
	Support: Parent Forum and Sharing Resource Book (10
	min)
	Review and practice assignment (5 min)
8	Three-minute breathing space (10 min)
	Review of home practice (10 min)
	Gratitude practice (15 min)
	Plan for coming weeks (15 min)
	Metta/chesed (5 min)
Follow-Up	Focus group review (30 min)
	Assessment and snacks (30 min)
	- PSI-4 SF
	- IEM-P
	- PSC-17
	- SLWS
	- Brief COPE

# APPENDIX D PARTICIPANT CONSORT DIAGRAM



# APPENDIX E

# FOCUS: PARENTS BRIEF DEMOGRAPHIC QUESTIONNAIRE

PARENT INFORMATION	ON				
Parent Name:	Relationsl	nip to Child: _			
Parent Age: Paren	nt Education:	Parent Occ	upation:		
Parent Relationship St	atus (circle one): Married	Partnered	Divorced	Separated	Single
	Othe	er:			
Phone Number:	Email Address:				
CHILD INFORMATION	V				
Child's name:	Gende	r:			
Date of birth:/ Does your child have a If yes:	_/ Age: diagnosis? Yes No	Grade:			
What diagnoses do	oes your child have?				
Approximately wh	en was your child diagnose	d (Month/Dat	te/Year)?	_//	
What are your child's p	orimary strengths?				
What are your primary	oconcerns about your child	?			
OTHER INFORMATIO	N				
Please provide the foll	owing information for other	r individuals c	urrently livi	ng in the hom	e:
Name	Relationship	A	Age	Осс	cupation

# **FOCUS: Parents Brief Demographic Questionnaire**

Please describe up to five people, organizations, or other sources that **provide you the most support for your parenting**:

Name and Relationship of Source (e.g. Sam Jones, spouse or Alex Taylor, therapist)	For how long have you received support from this source? (e.g. two years)	What support do they provide?	How satisfied are you with this support?  1 = very dissatisfied 2 = dissatisfied 3 = neutral 4 = satisfied 5 = very satisfied	Other Notes

### APPENDIX F

# GROUP SESSION RATING SCALE (GSRS)

Please rate today's group by placing a mark on the line nearest to the description that best fits your experience.

	Relationship	
I did not feel understood, respected, and/or accepted by the leader and/or the group.	II	I felt understood, respected, and accepted by the leader and the group.
We did <i>not</i> work on or talk about what I wanted to work on and talk about.	Goals and Topics	We worked on and talked about what I wanted to work on and talk about.
	Approach or Method	
The leader and/or the group's approach are/is not a good fit for me.	II	The leader and the group's approach are a good fit for me.
There was something	Overall	
missing in group today—I did not feel like a part of the group.	II	Overall, today's group was right for me—I felt like a part of the group.

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### APPENDIX G

# FOCUS: PARENT GROUP EVALUATION

1.	Do you feel you got something of last value of important a participating in the FOCUS: Parent groups?	Yes	No				
2.	Have you made any changes in your lifestyle, in dealing w family, or in your child-rearing practice as a result of FOCI			Yes	No		
3.	Did you become more "conscious" in parenting as a result groups? Did this change something in relation to your tho feelings, and your reaction on your thoughts and feelings	rent	Yes	No			
4.	Is it your intention to keep on practicing the mindful pare (e.g. the body scan, breathing exercise, three-minute breat compassion exercise, etc.)?			Yes	No		
5.	Is it your intention to keep on practicing being conscious i life?	ting	Yes	No			
6.	Do you feel you know <u>when</u> to seek support as a result of l groups?	FOCUS: Parent	i	Yes	No		
7.	Do you feel you know <u>how</u> to seek support when needed a FOCUS: Parent groups?	s a result of		Yes	No		
8.	How many times a week, on average, did you practice the mindful parenting exercises during the 8-week groups?	Never	1 - 2 Times	3 - 4 Times	5 - 7 Times		
9.	How many times do you pay attention to your child in moments you are together, compared to before the training?	Less than before	As much as before	More than before	n Much more than before		
10.	How much more aware of local avenues for support for your parenting are you as a result of FOCUS: Parent groups?	Less than before	As much as before	More than before	Much more than before		

Did something change on the following issues as a result of FOCUS: Parent groups?

		Negative Change	Some Negative Change	No Change	Some Positive Change	Positive Change
1.	Knowing to take better care of myself					
2.	Actually taking better care of myself					
3.	Periods of parental stress or frustration					
4.	Intensity of parental stress or frustration					
5.	Believing that I can improve my relationship with my child and family					
6.	Feeling self-confident as a parent					
7.	Feeling hopefully as a parent					
8.	Dealing with emotions (anger, sadness, fear) in parenting					
9.	Awareness of what is stressful in my life					
10.	Awareness of stressful parenting situations at the time they are happening					
11.	Ability to handle stressful parenting situations appropriately					

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# How important was each of the following parts of the FOCUS: Parent groups? (1 = not important at all, 10 = extremely important)

		1	2	3	4	5	6	7	8	9	10
1.	FOCUS: Parent group overall										
2.	Breathing exercise in the group										
3.	Breathing exercise at home										
4.	Body scan in the group										
5.	Body scan at home										
6.	Raisin exercise/beginner's mind in the group										
7.	Raisin exercise/beginner's mind at home										
8.	Self-compassion exercise in the group										
9.	Self-compassion exercise at home										
10.	Loving-kindness exercise in the group										
11.	Loving-kindness exercise at home										
12.	Awareness in daily parenting										
13.	Group discussions with other parents										
14.	Group leader's contributions to group discussions										
15.	Support handouts*										
16.	Practice exercises/handouts										
17.	Mindful parenting handouts										
18.	Session content on Dropbox										
19.	Emails between sessions										
20.	Resource book flash drive										

(Adapted from © Bögels and Restifo, 2014)

Please share any additional comments or thoughts on what aspects of the FOCUS: Parents groups were important to you:

<sup>\*</sup>Local Advocacy and Support, Communicating with Schools, Behavior Management

#### APPENDIX H

### PARENTING STRESS INDEX FOURTH EDITION SHORT FORM (PSI-4-SF)

### (SELECTED SAMPLE ITEMS)

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 <u>strongly agree</u> with the statement.
Circle A if you <u>agree</u> with the statement.
Circle NS if you are <u>not sure</u>.
Circle D if you <u>disagree</u> with the statement.
Circle SD if you <u>strongly disagree</u> 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 sta closest to describing how you feel. Your first reac						nes

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		W	)	(	SD	
				•	2	,	•	ĺ	

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

<ol> <li>Since having a child, I feel that I am almost never able to do things that I like to do.</li> </ol>	SA	A	NS	D	SD
<ol> <li>Sometimes I feel my child doesn't like me and doesn't want to be close to me.</li> </ol>	SA	A	NS	D	SD
<ol> <li>My child's behavior is more of a problem than I expected.</li> </ol>	SA	A	NS	D	SD

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### APPENDIX I

# SATISFACTION WITH LIFE SCALE (SWLS)

Below are five statements that you may agree or disagree with. Using the 1 - 7 scale below, indicate your agreement with each item by placing the appropriate number on the line preceding that item. Please be open and honest in your responding.

1	2	3	4	5	6	7
Strongly Disagree	Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Agree	Strongly Agree

In most ways my life is close to my ideal.
The conditions of my life are excellent.
I am satisfied with my life.
So far I have gotten the important things I want in life.
If I could live my life over, I would change almost nothing.

### APPENDIX J

### **BRIEF COPE INVENTORY**

These items deal with ways you've been coping with the stress in your life as the parent of a child with a disorder. There are many ways to try to deal with problems. These items ask what you've been doing to cope. Obviously, different people deal with things in different ways, but I'm interested in how you've tried to deal with it.

Each item says something about a particular way of coping. I want to know to what extent you've been doing what the item says- how much or how frequently. Don't answer on the basis of whether it seems to be working or not—just whether or not you're doing it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

- 1 = I usually don't do this at all
- 2 = I usually do this a little bit
- 3 = I usually do this a medium amount
- 4 = I usually do this a lot

	1	2	3	4
1. I've been concentrating my effort on doing something about the situation I'm in.				
2. I've been getting emotional support from others.				
3. I've been taking action to try to make the situation better.				
4. I've been getting help and advice from other people.				
5. I've been trying to see it in a different light, to make it seem more positive.				
6. I've been trying to come up with a strategy about what to do.				
7. I've been getting comfort and understanding from someone.				
8. I've been looking for something good in what is happening.				
9. I've been trying to get advice or help from other people about what to do.				
10. I've been thinking hard about what steps to take.				

### APPENDIX K

### INTERPERSONAL MINDFULNESS SCALE FOR PARENTS (IEM-P)

The following statements describe different ways that parents interact with their children on a daily basis. Please tell me whether you think the statement is "Never True," "Rarely True," "Sometimes True," "Often True," or "Always True" for you. Remember, there are no right or wrong answers and please answer according to what really reflects your experience rather than what you think your experience should be. Please treat each statement separately from every other statement.

	Never True	Rarely True	Sometimes True	Often True	Always True
1. I find myself listening to my child with one ear					
because I am busy doing or thinking about					
something else at the same time.					
2. When I'm upset with my child, I notice how I am					
feeling before I take action.					
<ol><li>I notice how changes in my child's mood affect</li></ol>					
my mood.					
<ol> <li>I listen carefully to my child's ideas, even when I</li> </ol>					
disagree with them.					
5. I often react too quickly to what my child says or					
does.					
6. I am aware of how my moods affect the way I					
treat my child.					
7. Even when it makes me uncomfortable, I allow					
my child to express his/her feelings.					
8. When I am upset with my child, I calmly tell					
him/her how I am feeling.					
9. I rush through activities with my child without					
being really attentive to him/her.					
<ol><li>I have difficulty accepting my child's growing</li></ol>					
independence.					

### APPENDIX L

### END-OF-GROUPS EVALUATION QUESTION GUIDE

- Tell me about your experience of parenting. (What is good about it? What is difficult?)
- 2. What have you found to be helpful in improving your wellness or decreasing stress? How well you are taken care of and supported?
- 3. What were your expectations for parent groups? How well have they been met?
- 4. What made the FOCUS: Parents program more easy or difficult to participate in?
- 5. What aspects of the course, if any, would you change? What should we keep the same?
- 6. What are areas of your life that you would like support now that groups have ended?
- 7. Do you have any remaining advice about groups or anything you would like to add?