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Running Head: COMPARATIVE EFFECTS OF MINDFULNESS AND SUPPORT AND INFORMATION PROGRAMS FOR PARENTS OF ADULTS WITH AUTISM SPECTRUM DISORDERS AND OTHER DEVELOPMENTAL DISABILITIES

Comparative effects of mindfulness and support and information group interventions for parents of adults with autism spectrum disorders and other developmental disabilities

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**Abstract**

This study evaluated two community based interventions for parents of adults with autism spectrum disorders and other developmental disabilities (ASD/DD). Parents in the mindfulness group reported significant reductions in psychological distress, while parents in the support and information group did not. Reduced levels of distress in the mindfulness group were maintained at 20 weeks follow-up. Mindfulness scores and mindful parenting scores and related constructs (e.g., self-compassion) did not differ between the two groups. Results suggest the psychological components of the mindfulness based group intervention were effective over and above the non-specific effects of group processes and informal support.

Key Words: Autism Spectrum Disorder, Developmental Disabilities, Mindfulness, Intervention, Parents

Comparative effects of mindfulness and support and information group interventions for parents of adults with autism spectrum disorders and other developmental disabilities

Mindfulness-based interventions have been shown to be an effective method of reducing stress and improving well-being among a variety of populations (Chiesa & Serretti, 2011; Kallapiran et al., 2015; Khoury, et al., 2013; Piet, et al., 2012) including caregivers (Altmaier & Maloney, 2007; Birnie et al., 2010; Bögels et al., 2008; Bögels et al., 2014; Epstein-Lubow et al., 2011; Minor et al., 2006; Van der Oord, et al., 2012; Whitebird et al., 2012). Mindfulness is defined as “purposefully paying attention and being present in the moment” (Kabat-Zinn 2003, p. 145). A central goal of mindfulness-based interventions is to change the way individuals experience negative emotions by teaching non-judgmental acceptance of negative sensations as they are perceived (Marlatt & Kristeller, 1999). These types of interventions are particularly applicable to individuals when they are faced with problems that do not offer immediate solutions.

Mindfulness interventions are especially relevant to parents of adults with autism spectrum disorders and other developmental disabilities (ASD/DD) because of the chronic stress they have experienced (Seltzer et al., 2011; Dillenburger & McKeer, 2011), and because of the unique stressors they face as their children transition into adulthood. One of the biggest issues for this population of adults and families is service availability, with the risk of losing the structure and support of the school system (Neece, Kraemer & Blacher, 2009) and the need to obtain adult services from a new sector. Parents require a different set of services for their adult children, including long term residential placement, respite, in-home care, and specialized psychiatric and behavioural services (Haveman, van Berkum, Reijnders, & Heller, 1997). Such services are limited and have long waiting lists (Lakin, 1998). As a result, parents often remain responsible

for supporting their child with ASD/DD well into adulthood (Braddock, 2001). At the same time, these older parents themselves are increasingly facing their own health issues due to aging, which makes it even more difficult to provide care (Hatzidimitrisdou & Milne, 2005).

Most of what we know about mindfulness as it relates to multi-stressed families of children with disabilities comes from research based on families with younger children. Increased general mindfulness and mindfulness in the parenting role, as well as increased psychological acceptance in general and in the parenting role, have been associated with reduced psychological distress for mothers and fathers of children with ASD/DD (Jones et al., 2014; Lloyd & Hastings, 2008; MacDonald, Hastings & Fitzsimons, 2010; Weiss, Cappadocia, MacMullin, Viecili & Lunskey, 2012).

More than a dozen studies evaluating mindfulness-based interventions for parents of individuals with ASD/DD have been published since 2005. Singh et al., (2006, 2007), using a single case experimental design methodology, showed that mindfulness meditation increased parents' feelings of competence and satisfaction, and decreased aggressive behaviours in their children. Subsequent research has confirmed these early findings (Cachia, Anderson & Moore, 2015) with several studies demonstrating that decreases in parental stress and depression could be maintained several months later (e.g., Bazzano et al., 2013, Ferraioli & Harris, 2013). In addition to studying clinical outcomes of parents and sometimes children, several studies have also measured the effects of mindfulness training on mindfulness based measures such as mindfulness, self-compassion, and mindful parenting, with mixed results (e.g, Bazzano et al., 2013; Ferraioli & Harris, 2013; Jones et al., in press; Lunskey et al., 2015).

We could find only two studies of mindfulness-based interventions for parents that included an active control comparison design. Such designs can test whether the putative benefits

observed for an intervention are specific to the intervention or simply to any support offered to families. Ferraioli and Harris (2013) compared a mindfulness-based parent training group provided to 10 parents of children with an Autism Spectrum Disorder (ASD) to a skills-based parent training group provided to 11 parents. Parents were randomly assigned to one of the two 8-session interventions, with the skills-based parent group serving as an active treatment control. The mindfulness group demonstrated significant reductions in stress and improvements in overall self-reported health relative to the control condition, which showed no significant improvements. Like the majority of descriptive studies and those incorporating a waitlist control group (Benn et al., 2012; Neece, 2014), Ferraioli and Harris (2013) focused on parents of young children. The second active treatment controlled study by Dykens, et al. (2014) had the largest sample to date (243 mothers of children with ASD/DD), and compared parent outcomes of a modified Mindfulness Based Stress Reduction (MBSR) program to a “positive adult development” intervention, each 6 sessions in length and facilitated by mothers who were themselves trained in each intervention. Mothers who attended the mindfulness group showed greater reductions in depression and greater improvements in life satisfaction and sleep compared to the positive adult development group, which also showed significant improvements over the course of treatment. The Dykens et al. study included some older parents, but focused primarily on parents of children and youth, with a mean parent age of approximately 41 years.

The majority of parent mindfulness studies have focused on parents of children and youth with ASD/DD, with only a few studies including any parents of adults in their interventions. Given the importance of psychological supports for parents of adults with ASD/DD, and the reality that most of these families experience significant service gaps, members of our team sought to develop an intervention to meet the unique needs of these parents. In consultation with

one of its authors (Segal), we adapted mindfulness-based cognitive therapy (MBCT: Segal et al., 2002) for parents and adolescents and adults with ASD/DD. Our consultation led to the development of a 4 week pilot, which we then refined into a six week group, with three intervention foci (for further detail on the development and evaluation of our intervention, read Lunsky et al., 2015):

1. These parents have been exposed to chronic stress, some of which cannot be easily resolved. Mindfulness can teach parents to experience difficult situations in a different way, which is less solution focused.
2. Self-care is essential for parents who because of ongoing caregiving requirements can become emotionally and sometimes physically depleted. Mindfulness can teach these parents to become more aware of their physical and emotional needs, to prevent parental exhaustion.
3. There is also stress associated with daily interactions with adult children with IDD, particularly when services are not in place. Parent and child stress combined can lead to reactive interactions which can increase stress. Mindfulness can lead to more mindful parent child interactions, which can reduce this stress.

Our intervention diverged from more standard MBCT and MBSR in a few ways: Given the limited time of parents to practice exercises, we adopted the briefer audio homework recordings from *Finding Peace in a Frantic World* (Williams & Penman, 2011) knowing that families, particularly those with children who were not in any day time programs, might have difficulty finding protected time to complete these practices (see also Jones et al., in press). We provided paper based homework and CD recordings in addition to web based links because not all parents were comfortable with the internet. We emphasized the 3 minute breathing space from MBCT over other practices, and practiced it regularly during group sessions because we

considered it to be the most portable exercise for these parents. We also explored how to weave practices into current life circumstances, as opposed to promoting changing schedules to accommodate more intensive practice which, parents had taught us, was not realistic. In contrast to standard MBSR or MBCT, we did not hold a full day retreat, because we recognized the challenge of scheduling this for families and did not want to limit the number of parents willing to participate in the intervention. In terms of specific in-session practice modifications, we completed the body scan in chairs because it was difficult for several parents to get up and down from the floor. Therapist voices were loud enough to accommodate hearing loss associated with older age.

We included the loving-kindness meditation from MBSR because we thought this concept was particularly relevant to parents of children with disabilities, and we also introduced parents to the idea of performing a mindful activity with their child as part of homework, which they could reflect upon in session. We allowed for extended time within each session, during a 15 to 20 minute tea break, for parents to reflect more generally about their situation, and connect with one another and we promoted the importance of self care activities throughout. In our evaluation of this new intervention (Lunsky et al., 2015), we found that parents of older adolescents and adults reported reductions in stress and general group satisfaction but we did not observe significant improvements in mindfulness ratings. Our initial study, although promising, failed to include any sort of control group, or follow-up component. We could therefore not determine how many of the benefits from this effort were due to the fact that parents, many of them quite isolated, were meeting regularly with other parents for the first time, in a nurturing warm environment, to explore ways to better care for themselves and their children.



The purpose of the present study was to compare clinical outcomes for parents of adults with ASD/DD assigned to one of two parent focused interventions offered while waiting for social services for their children. Our primary research question was whether the mindfulness-based intervention led to lower levels of parent distress compared to the active control intervention (parent support and education). Secondary outcomes included mindfulness, mindful parenting, self-compassion, empowerment, perceptions of positive gain, and caregiver burden.

## **Methods**

### *Design*

This study included two arms: mindfulness, and support and information. Assignment was done sequentially using a pseudo-randomization approach, A - mindfulness, B – support and information, in the order that parents arrived to orientation, after they had completed baseline measures. This was done to ensure that intervention groups of similar size would be filled as soon as possible – due to the tight timelines for the research. Six couples asked to be involved in the study. When parents came as a couple, the couple was assigned as a pair as though they were a single person. At the point of analysis, if both members of the couple had completed questionnaires, one member of the couple was selected randomly for analysis. Parents completed baseline measures after consenting to the study, prior to group assignment. As indicated in the CONSORT diagram (Figure 1), not all parents who completed consent forms and questionnaires came to the first group intervention session.

Baseline measures were completed online or on paper prior to group assignment. Parents in both intervention groups completed the same measures at week 8, and for a third time at week 20, approximately 3 months after interventions were completed. Figure 1 shows that 138 parents of adolescents or adults with ASD/DD expressed an initial interest in participating in the study.

Of these parents, 69 were excluded for a variety of reasons, resulting in 57 who consented and enrolled in the study. Data were excluded from analysis for 4 parents who were part of couples in the mindfulness group and 2 parents who were part of couples in the parent support and information group. An additional person was excluded from analysis because of limited English not recognized during initial telephone screening, leaving 50 cases.

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Insert Figure 1 here

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### *Participants*

Demographics of the 50 parents in the two groups and their children are presented in Table 1. Groups did not differ at baseline with respect to parent age, or in terms of the percentage of mothers (versus fathers), English as a second language, or marital status (all  $p > .15$ ). There were also no baseline differences in child demographics, or percentage of children with a diagnosis of ASD, a genetic syndrome or a psychiatric diagnosis, or in the kinds of activities they primarily engaged in during a typical week (all  $p > .15$ ).

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Insert Table 1 here

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### *Recruitment*

Parents were recruited through Developmental Services Ontario (DSO), Toronto office. The DSO office is the “front door” for services for all adults with ASD/DD in the region and

provides a standardized approach to applying for and obtaining services, across the province.

Eligibility requirements for this study were that parents had to have a child with ASD/DD age 16 and above, had to be waiting for adult services in the Toronto region through the Toronto DSO, and had to have sufficient English to complete written surveys and participate in groups. The age of 16 was selected because that is the age at which parents can apply for adult services through the DSO for their son or daughter in Ontario. This study received ethics approval from relevant university and hospital ethics boards, and was registered with Clinical Trials

([www.clinicaltrials.gov](http://www.clinicaltrials.gov)).

All parents registered with the Toronto DSO office who were waiting for services were sent a letter in the mail, followed by an email when email addresses were available, describing the parent intervention project. This letter explained that the groups for parents would be free, that parents would be compensated for participating in the research, and that free childcare would be provided for their son/daughter during the times of the group session. Interested parents could either complete a form expressing their interest in learning more about the study and mail, email or fax it to the research team, or they could call the research team directly. The research staff screened each parent at this stage, explained the study in greater detail and sent the parent an information letter and consent form. Parents who consented to participate in the study and who met study criteria were then invited to attend the initial orientation, where they completed the consent process, questionnaires and assignment to condition, and orientation.

### *Interventions*

The two interventions were developed to be as similar as possible in terms of group structure. They were offered four times between October 2013 and April 2015. Each group included an orientation session followed by six 2-hour weekly sessions. The interventions were

held simultaneously in the same building with a shared care service available, and parents not using the care service could request a stipend to support off site care costs (\$50.00 CAN). Both groups were co-facilitated by clinicians experienced in either facilitating mindfulness-based interventions, or facilitating support groups and providing parents with information on adult services. Parents in both groups received an orientation package outlining what would be covered within the sessions, and relevant handouts weekly. When the study was completed, parents received a package with information and resources that were distributed to the other group.

The mindfulness-based intervention was co-facilitated by two clinicians with group mindfulness facilitation experience. The first clinician was a psychologist with over 15 years of experience in a specialized mental health service within a university affiliated hospital for adolescents and adults with ASD/DD, and was one of the developers of the treatment manual used in the study. She was trained to facilitate mindfulness based group practices in 2009 at a teaching hospital in Toronto and continues to attend related workshops and retreats. The second clinician, a social worker in the ASD/DD field, had been trained and supervised by expert teachers at the Centre for Mindfulness in Massachusetts, where courses have been delivered for 30 years, and had over 10 years of experience facilitating group based mindfulness based stress reduction for different populations.

Session content focused on experiential learning of meditation techniques (e.g., sitting meditation, walking meditation, gentle yoga), drawing from MBCT (Segal, et al., 2002) and MBSR (Kabat-Zinn, 1990) programs. Practice within sessions ranged from 3 (3-Minute Breathing Space) to 20 minutes, which are briefer than formal mindfulness practices completed in traditional MBSR and MBCT. Each session began with a check-in and review of homework,

followed by some experiential exercises and reflections, with a 15 to 20 minute tea break mid-session.

The parent support and education intervention was co-facilitated by two clinicians who worked for DSO Toronto, assisting parents to find services, and helping them to understand how adult services in Toronto are organized. Together with other members of the research team, these clinicians developed the support and education intervention. Each week, there was an initial check-in, similar to the mindfulness based group, followed by a guest presentation on a topic selected by group members, followed by some facilitated discussion about the weekly topic, in addition to some more general discussion. Like the mindfulness based intervention, each week also included a 15 to 20 minute tea break for parents to interact more informally with one another. Topics included: getting to know adult developmental services and how to access resources; person directed planning; caregiver issues and respite (“taking care of us”); specialized clinical services; crisis supports; and residential alternatives.

### *Measures*

*Primary outcome measure.* A 14-item version of the Depression Anxiety Stress Scale (DASS-21; Henry & Crawford, 2005) was used to assess perceived psychological distress (the seven stress and seven depression items) at each time point, focused on the previous week. This measure was adopted in our prior pilot study of the mindfulness based intervention (Lunsky et al., 2015) and has been used in other mindfulness and acceptance based parent intervention studies (e.g., Jones et al., 2016; Rayan & Ahmad, 2016; Whittingham et al., 2016). Participants responded using a 4-point Likert scale ranging from 0 “did not apply to me at all” to 3 “applied to me very much, or most of the time”, yielding a total score between 0 and 42. An overall psychological distress score was calculated by taking the sum of the 14 items. The combined 14

item psychological distress scale had a Cronbach's alpha of .94 for the 14 items at baseline across the total parent sample.

*Secondary outcome measures.* We selected 4 secondary outcome measures focused on aspects of mindfulness and relationship with child, which we hypothesized could also reflect psychological dimensions that may be affected by the mindfulness intervention and subsequently relate to reduced psychological distress. We also included one secondary outcome measure focused on parent empowerment, which we hypothesized may be increased in the support and information group. We also included a caregiver burden questionnaire to evaluate whether either intervention might influence burden perceptions.

The Five Facet Mindfulness Questionnaire (FFMQ; Baer, Smith, Hopkins, Krietemeyer & Toney, 2006) and the Bangor Mindful Parenting Scale (BMPS; Jones et al., 2014) were adopted to assess mindfulness and mindful parenting respectively. The FFMQ is a 39-item self-report questionnaire that consists of 5 subscales that measure 5 component skills of mindfulness (observing, describing, act awareness, non-judging of inner experiences, and non-reactivity to inner experiences). The measure utilizes a 6 point Likert scale ranging from 0 "almost never" to 5 "almost always", with a higher overall score reflecting greater levels of overall mindfulness. The FFMQ total score had Cronbach's alpha of .89 in this study. The BMPS is a 15-item self-report questionnaire that measures how mindful parents are in their parenting role and in interactions with their children. Each item is rated on a 4-point Likert scale ranging from 0 "never true" to 3 "always true", yielding a total score ranging from zero to a maximum of 45. Cronbach's alpha for the scale was .83, similar to previous reports (Jones et al., 2014). Related to the broader construct of mindful parenting, the Positive Gain Scale (PGS; Pit-ten Cate, 2003) is 7-item measure that assesses caregivers' perceptions of positive contributions their child with

disability has made to their lives. The measure utilizes a 5-point Likert scale, ranging from 1 being "strongly agree" to 5 being "strongly disagree." The positive gain scale has demonstrated good internal consistency with a reported Cronbach's alpha of .84 in the current study.

The Self-Compassion Scale Short-form (SCS-SF; Neff, 2003) is a 12-item self-report scale with higher scores indicating greater levels of self-compassion, a construct highly correlated with general mindfulness, and one which mindfulness based interventions may impact. Responses are scores on a 5-point scale ranging from 1 (almost never) to 5 (almost always). The scale demonstrated good internal consistency with a Cronbach's alpha of .83.

To assess feelings of empowerment, a construct we hypothesized might be targeted in any parent education or skills intervention, two 12-item subscales (Family and Service System) from the 34-item Family Empowerment Scale (FES; Koren et al., 1992) were administered. Responses are given on a 5-point Likert scale ranging from 1 "never" to 5 "very often", with a reported Cronbach's alpha of .83 and .86 respectively in the present study.

Caregiver burden, which we hypothesized could be influenced by either the provision of further information and support, or by developing mindfulness skills was assessed using the Caregiving Burden 9-item subscale of the Revised Caregiving Appraisal Scales (Lawton, Moss, Hoffman & Perkinson, 2000). Items measure caregiver's perception of the negative impact caregiving has had on his or her health, well-being, social life and personal relationships. Responses are scored using a 5-point Likert scale, ranging from 5 "agree a lot" to 1 "disagree a lot. Higher scores reflect greater perceived burden. The scale had a good internal consistency of .85 in the current study.

In addition, parents completed a 10-item measure on intervention group satisfaction (e.g., content relevancy, usefulness, interest level, and feeling valued in the group) on a 5-point Likert

scale from 1 (Strongly Disagree) to 5 (Strongly Agree). The measure demonstrated good internal consistency (Cronbach's alpha = .87).

## **Results**

### *Primary Outcome*

To address our research questions, our analyses focused on group differences at post-intervention (potential effectiveness) and then on the putative maintenance of any intervention group differences over time to 20 week follow-up. Analysis of covariance was used to determine whether groups differed in their psychological distress (composite depression/stress - DASS 14) scores post intervention (Time 2) after controlling for pre-intervention levels (Time 1). As shown in Table 2, results indicated a significant main effect of group assignment on parent psychological distress  $F(1, 43)=11.73, p=.001$ , Cohen's  $d= .81$  at Time 2, in favor of the mindfulness condition. In an exploratory analysis, we considered whether having a different number of children with ASD in the two arms of the trial had any impact on the results. We repeated the main analysis and added an additional covariate (whether the child had an ASD diagnosis). The pattern of results was the same.

To examine the maintenance of the intervention effect on the primary outcome to the 20 week follow-up, we carried out an ANCOVA with time (Time 2, Time 3) as the repeated measures factor, Time 1 DASS-14 score as covariate, and intervention group as the between subject variable. This analysis revealed a significant group effect ( $F(1, 38)= 10.24, p=.003$ ), but no effect of time ( $F(1, 38)= 2.58, p=.12$ ), nor a group x time interaction ( $F(1, 38)= 0.39, p=.84$ ). These results suggest that the intervention group difference at post-intervention was maintained until the 20 week follow-up point.

### *Secondary Outcomes*



With regard to mindfulness outcomes, ANCOVA revealed no significant main effect of group assignment on the FFMQ total score or BPMS scores at Time 2 after controlling for Time 1 scores (as shown in Table 2). Similarly, there was no main effect of group assignment on the other parent measures (Empowerment, Burden, Self-compassion and Positive Gain) scales after controlling for Time 1 scores. Effect sizes for each of the secondary outcomes at Time 2 are displayed in Table 2. As for the primary outcome, we also repeated all analyses of the secondary outcomes including ASD as an additional covariate. Again, the same pattern of findings was obtained.

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Insert Table 2 here

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*Attendance and satisfaction with intervention sessions.* Session participation varied amongst the sample of 50 parents included in the study. Forty-two parents attended the majority of the sessions (at least 4 out of the 6 sessions). Participants attended a mean of 4.88 sessions (SD = 1.31) in the mindfulness group, and 4.29 (SD = 1.49) sessions in the parent support and information group. The most commonly cited barriers to regular attendance included: 1) child issues (e.g. childcare, child health problems), 2) parent issues (e.g. health problems), and 3) transportation. A total of 3 participants dropped out of the support and information group. None dropped out of the mindfulness group. Parents in the mindfulness group completed a feedback questionnaire after the end of each group that included questions about how often they practiced mindfulness skills at home. Of the parents who completed this portion of the survey (n=26),

80.8% indicated that they practiced at least one of the exercises at least 3 to 4 times a week, and 42.3% indicated that they practiced at least one of the exercises 5 or more times a week.

Total satisfaction scores were similar across the mindfulness ( $M=40.21$ ,  $SD=9.02$ ) and support and information groups ( $M=41.44$ ,  $SD=4.62$ ). In the mindfulness group, 66.7% of participants responded that they agreed or strongly agreed to all 10 items of satisfaction, compared to 72.2% of participants in the support and information group. The majority of parents in both groups believed the content to be interesting, that what they learned in the group was useful in their everyday lives, and that they felt supported and valued within the group.

### **Discussion**

To our knowledge, this is the first study evaluating the outcome of a mindfulness based group intervention with an active treatment control for parents of adults with ASD/DD. Despite parents reporting similar levels of satisfaction with both interventions, only parents in the mindfulness group reported significant reductions in psychological distress, which were maintained to follow up at 20 weeks. Our study adds to the growing literature on benefits of this type of intervention for caregivers. In terms of the psychological distress primary outcome, the results suggest that the psychological components of the mindfulness based group intervention were effective over and above the non-specific effects of group processes and informal support. Although not statistically significant in this study, there was also a small to moderate effect size advantage for family empowerment (services) for the support and information intervention – which was the main focus of this group intervention.

To interpret findings from this study, it is important to understand the context for participating parents. Parents of adults who registered for this study came to the attention of service providers because they were seeking and waiting for services for their adult children.

Participating in the information and support group resulted in receiving information about available services and learning that while their efforts were commendable, there would be a long wait for many of the services they were seeking, unless they could pay out of pocket. Although they may have benefited from knowing this information, and from the connections they formed with other parents, it did not help them learn how to cope with their chronic stress. In contrast, mindfulness may be helpful in the context of ongoing sources of frustration that are out of one's control, as it moves away from a focus on problem-solving to instead offering skills to cope with situations that are difficult and may not improve very quickly. Past research with parents of people with ASD has identified that coping strategies focused on psychological acceptance may be better at explaining the link between child-related stressors and parent distress than are problem-focused coping (Weiss, et al., 2012), and the current study extends this line of reasoning to intervention for parents.

Our study results suggest that parents may benefit from the mindfulness approach even if they do not practice mindfulness in as intensive a way as suggested in traditional MBSR and MBCT programs. Traditional mindfulness-based programs are often 2.5-hours long and 6 to 8 sessions in length (Kabat-Zinn et al., 1990; Segal et al., 2002), and invite participants to practice mindfulness activities up to 45 minutes per day with a full day mindfulness retreat. More recently, some mindful parenting approaches have lessened the dose of meditation, yet have maintained a significant effect (Dykens et al., 2014). The current intervention did not employ the full day silent retreat (as used in MBSR and MBCT), and used only shorter formal practices than what are used in traditional programs (as described in Lunsky et al., 2015). Further, our post intervention feedback debriefing revealed that many parents practiced mindfulness sporadically or for a small amount of time or in an informal way. For example, one respondent described

taking a few moments every day after work between parking his car upon returning home and coming inside the house, while another described taking a few moments at her desk at work to practice the 3 minute breathing space. It may be that the current study's treatment effect has to do with the experience of the formal meditation practice within the group itself, rather than the intensity of practice outside of session. When asking parents what they liked the most about the mindfulness group, the majority listed the guided formal 'in session' practices, and anecdotally, they looked forward to this aspect each session, believing that they could not do similar practices on their own or in their current home circumstances. This question of the necessary dose is important for future research, given the multiple stressors and challenges that often come with supporting adult age children with ASD/DD. In addition, more work may be needed to facilitate parents being able to use meditation practices in their daily lives.

It is also interesting that although psychological distress scores were lower following the group, mindfulness scores and mindful parenting scores and related constructs (e.g., self-compassion, parental gain) did not differ between the groups. In other studies, parents have shown improvement in measures of mindfulness (Bazzano et al., 2013; Benn, Akiva, Arel & Roeser, 2012; Ferraioli et al., 2013), although the two studies which measured mindful parenting did not report improvement (Jones et al., in press; Lunsky et al., 2015). We suggest three reasons why we did not see group differences in reports of mindfulness and related constructs. First, it may be that the mechanisms of change across participants are a mix of treatment-specific ingredients, such as the mindfulness activities in session that would work on mindfulness, and of the healing properties of the common factors inherent within therapeutic groups, such as group cohesion, which can be facilitated by shared activities and support, but would not in and of itself impact mindfulness. As noted, parents in the mindfulness group used it as a therapeutic space,

but many did not carry out intensive mindfulness practice outside of sessions. Second, it may be that the mindfulness construct is less amenable to change in older parents than younger parents, especially if baseline mindfulness scores in older adults are higher to begin with (Geiger, et al., 2016). It is also possible that parents of adults, because their children are more likely to be home without the structure of school and children's programming, have less free time to practice. The association between age and mindfulness practice in parents of children with ASD/DD should be further studied. Although findings were not significant for several of the secondary measures, there were still small effects in the predicted direction. For example, there was a medium effect in favour of the mindfulness group on parental gain, small effects in favour of mindfulness for ratings of self compassion and mindfulness, and a small effect in favour of the support and information group on family service efficacy. It is possible that with a larger sample, like that in the Dykens et al. (2014) study, further differences on secondary measures would be apparent.

Although the mindfulness intervention showed promise for parents relative to the active treatment control, it is important to acknowledge that only some parents may be interested or able to participate in these sorts of groups. Recruitment rate for the study was slow, with only about 15% of parents initially contacted able to participate. These parents were approached at a time when they may have been desperate to obtain services for their adult children, and were not focusing on their own needs. It is important to explore other forms of intervention that target parent stress, but that are structured differently, or other ways of delivering mindfulness interventions other than in a traditional group format for such parents. For example, mindfulness-based interventions are increasingly being delivered online through the internet (Spijkerman, Pots, & Bohlemiejer, 2016). In promoting these groups to parents, it is important that we explore multiple ways to engage potential participants. This may include groups which are shorter in

duration, or are embedded within standard services offered as part of intake for all those applying for services for their children. It may be that once parents are successfully introduced to a service targeting parents, they might be more open to committing to further parent focused activities.

This study has several limitations which should be taken into account when interpreting findings. First, this was a small trial, and the study was not powered to detect moderate to small group differences that may still have had clinical meaning. However, the effect size for psychological distress even compared to an active control comparison was large in favor of the mindfulness intervention. Effect sizes were small for secondary outcomes except for positive gain (moderate – see Table 2). Other measures may have been more sensitive to detecting change than the ones adopted in the current study. Although the study was advertised to a large group of parents (all parents in a jurisdiction seeking adult services), those that responded to the advertisement represent only a small proportion of those parents (approx. 24% contacted the research team and only 15% participated). It is possible that these parents differed from other parents in terms of baseline distress.

The allocation procedure used was carried out on a pseudo-randomised basis. This is a limitation of the present pilot RCT since any potential biases relating to the order in which parents came to the research team are unknown. However, the nature of the randomization process was not known to referrers nor to families. Thus, this is unlikely to have introduced a significant bias, and the present study suggests that parents were willing to take part in a study in which they were allocated to an intervention group on a random basis. This suggests that parents may be willing to participate in a larger scale RCT on this basis. A large scale RCT could also include formal measures of treatment fidelity. In the current study, group leaders were the same

for each group, and one of the mindfulness leaders was also a developer of the intervention, but we did not assess treatment fidelity in a formal manner.

A final limitation is with the data analysis. Although retention into the research study was generally high, there were some missing data at post-intervention, and more missing data by the 20 week follow-up. Our statistical analysis focused on full datasets available for each analysis and this again may have introduced some bias. Larger scale studies with higher initial recruitment targets (to account for sample loss), and data analysis strategies explicitly dealing with missing data, are needed in future.

There is an emerging literature to support the continued study of mindfulness-based interventions for parents of people with ASD/DD. Moving forward, we need to continue to design interventions that reach parents directly, and support their needs, as opposed to just the needs of their children. Although parents may not realize they can benefit from such groups, our study would suggest that learning skills related to mindfulness and acceptance might be helpful. We have also shown that it was feasible to recruit parents to a RCT, deliver a brief mindfulness based intervention and active control, and ensure a reasonable level of retention and satisfaction. These results are crucial in planning a definitive large scale RCT, which is needed to further test the efficacious nature of the program, to determine whether smaller effects may occur for secondary outcomes, and to identify potential mechanisms of change.

## References

- Altmaier, E., & Maloney, R. (2007). An initial evaluation of a mindful parenting program. *Journal of Clinical Psychology, 63*(12), 1231-1238.
- Baer, R. A., Smith, G. T., Hopkins, J., Krietemeyer, J., & Toney, L. (2006). Using self-report assessment methods to explore facets of mindfulness. *Assessment, 13*(1), 27–45.
- Bazzano, A., Wolfe, C., Zylowska, L., Wang, S., Schuster, E., Barrett, C., & Lehrer, D. (2015). Mindfulness based stress reduction (MBSR) for parents and caregivers of individuals with developmental disabilities: a community-based approach. *Journal of Child and Family Studies 24*(2), 298-308.
- Benn, R., Akiva, T., Arel, S., & Roeser, R. W. (2012). Mindfulness training effects for parents and educators of children with special needs. *Developmental Psychology, 48*(5), 1476.
- Birnie, K., Garland, S. N., & Carlson, L. E. (2010). Psychological benefits for cancer patients and their partners participating in mindfulness-based stress reduction (MBSR). *Psycho-Oncology, 19*(9), 1004-1009.
- Bögels, S., Hoogstad, B., van Dun, L., de Schutter, S., & Restifo, K. (2008). Mindfulness training for adolescents with externalizing disorders and their parents. *Behavioural and Cognitive Psychotherapy, 36*(02), 193-209.
- Bögels, S. M., Helleman, J., van Deursen, S., Römer, M., & van der Meulen, R. (2014). Mindful parenting in mental health care: effects on parental and child psychopathology, parental stress, parenting, co-parenting, and marital functioning. *Mindfulness, 5*(5), 536-551.
- Braddock, D., Emerson, E., Felce, D., & Stancliffe, R. J. (2001). Living circumstances of children and adults with mental retardation or developmental disabilities in the United



- States, Canada, England and Wales, and Australia. *Mental Retardation and Developmental Disabilities Research Reviews*, 7(2), 115-121.
- Cachia, R. L., Anderson, A., & Moore, D. W. (2016). Mindfulness, stress and well-being in parents of children with autism spectrum disorder: A systematic review. *Journal of Child and Family Studies*, 25(1), 1-14.
- Chiesa, A., & Serretti, A. (2011). Mindfulness based cognitive therapy for psychiatric disorders: a systematic review and meta-analysis. *Psychiatry Research*, 187(3), 441-453.
- Dillenburger, K., & McKerr, L. (2011). 'How long are we able to go on?' Issues faced by older family caregivers of adults with disabilities. *British Journal of Learning Disabilities*, 39(1), 29–38.
- Dykens, E. M., Fisher, M. H., Taylor, J. L., Lambert, W., & Miodrag, N. (2014). Reducing distress in mothers of children with autism and other disabilities: a randomized trial. *Pediatrics*, 134(2), 454-463.
- Epstein-Lubow, G., McBee, L., Darling, E., Armev, M., & Miller, I. W. (2011). A pilot investigation of mindfulness-based stress reduction for caregivers of frail elderly. *Mindfulness*, 2(2), 95–102.
- Ferraioli, S. J., & Harris, S. L. (2013). Comparative effects of mindfulness and skills-based parent training programs for parents of children with autism: feasibility and preliminary outcome data. *Mindfulness*, 4(2), 89–101.
- Geiger, P., Boggero, I., Brake, C., Caldera, C., Combs, H., Peters, J., & Baer, R. (2016). Mindfulness-based interventions for older adults: A review of the effects on physical and emotional well-being. *Mindfulness*, 7(2), 296-307.

- Hatzidimitriadou, E., & Milne, A. (2005). Planning ahead: Meeting the needs of older people with intellectual disabilities in the United Kingdom. *Dementia*, 4(3), 341-359.
- Haveman, M., van Berkum, G., Reijnders, R., & Heller, T. (1997). Differences in service needs, time demands, and caregiving burden among parents of persons with mental retardation across the life cycle. *Family Relations*, 46(4), 417-425.
- Henry, J. D., & Crawford, J. R. (2005). The short-form version of the depression anxiety stress scales (DASS-21): construct validity and normative data in a large non-clinical sample. *British Journal of Clinical Psychology*, 44(2), 227-239.
- Jones, L., Gold, E., Totsika, V., Hastings, R. P., Griffiths, A., Jones, M., & Silverton, S. (in press). A mindfulness parent well-being course: Evaluation of outcomes for parents of children with autism and related disabilities recruited through special schools. *European Journal of Special Needs Education*.
- Jones, L., Hastings, R. P., Totsika, V., Keane, L., & Rhule, N. (2014). Child behavior problems and parental well-being in families of children with autism: the mediating role of mindfulness and acceptance. *American Journal on Intellectual and Developmental Disabilities*, 119(2), 171-185.
- Kabat-Zinn, J. (1990). Full catastrophe living: The program of the stress reduction clinic at the University of Massachusetts Medical Center.
- Kabat-Zinn, J. (2003). Mindfulness-based interventions in context: past, present, and future. *Clinical Psychology: Science and Practice*, 10(2), 144-156.
- Kallapiran, K., Koo, S., Kirubakaran, R., & Hancock, K. (2015). Review: Effectiveness of mindfulness in improving mental health symptoms of children and adolescents: a meta-analysis. *Child and Adolescent Mental Health*, 20(4), 182-194.

- Khoury, B., Lecomte, T., Fortin, G., Masse, M., Therien, P., Bouchard, V., ... & Hofmann, S. G. (2013). Mindfulness-based therapy: A comprehensive meta-analysis. *Clinical Psychology Review, 33*(6), 763-771.
- Koren, P. E., DeChillo, N., & Friesen, B. J. (1992). Measuring empowerment in families whose children have emotional disabilities: a brief questionnaire. *Rehabilitation Psychology, 37*(4), 305.
- Lakin, K. C. (1998). On the outside looking in: Attending to waiting lists in systems of services for people with developmental disabilities. *Mental Retardation, 36*(2), 157-162.
- Lawton, M. P., Moss, M., Hoffman, C., & Perkinson, M. (2000). Two transitions in daughter's caregiving careers. *The Gerontologist, 40*, 437-448.
- Lloyd, T., & Hastings, R. P. (2008). Psychological variables as correlates of adjustment in mothers of children with intellectual disabilities: Cross-sectional and longitudinal relationships. *Journal of Intellectual Disability Research, 52*, 37-48.
- Lunsky, Y., Robinson, S., Reid, M., & Palucka, A. (2015). Development of a Mindfulness-Based Coping with Stress Group for Parents of Adolescents and Adults with Developmental Disabilities. *Mindfulness, 6*(6), 1335-1344.
- MacDonald, E. E., Hastings, R. P., & Fitzsimons, E. (2010). Psychological acceptance mediates the impact of the behaviour problems of children with intellectual disability on fathers' psychological adjustment. *Journal of Applied Research in Intellectual Disabilities, 23*, 27-37.
- Marlatt, G. A., & Kristeller, J. L. (1999). Mindfulness and meditation. In Miller, W.E. (Ed). *Integrating spirituality into treatment: Resources for practitioners* (pp. 67-84). Washington, DC, US: American Psychological Association.

- Minor, H. G., Carlson, L. E., Mackenzie, M. J., Zernicke, K., & Jones, L. (2006). Evaluation of a mindfulness-based stress reduction (MBSR) program for caregivers of children with chronic conditions. *Social Work in Healthcare, 43*(1), 91-109.
- Neece, C. L., Kraemer, B. R., & Blacher, J. (2009). Transition satisfaction and family well being among parents of young adults with severe intellectual disability. *Intellectual and Developmental Disabilities, 47*(1), 31-43.
- Neece, C. L. (2014). Mindfulness-based stress reduction for parents of young children with developmental delays: implications for parental mental health and child behavior problems. *Journal of Applied Research in Intellectual Disabilities, 27*(2), 174–186.
- Neff, K. D. (2003). The development and validation of a scale to measure self-compassion. *Self and Identity, 2*(3), 223-250.
- Piet, J., Würtzen, H., & Zachariae, R. (2012). The effect of mindfulness-based therapy on symptoms of anxiety and depression in adult cancer patients and survivors: A systematic review and meta-analysis. *Journal of Consulting and Clinical Psychology, 80*(6), 1007.
- Pit-ten Cate, I. (2003). Positive gain in mothers of children with physical disabilities (Unpublished Doctoral Dissertation). University of Southampton, United Kingdom.
- Rayan, A., & Ahmad, M. (2016). Effectiveness of Mindfulness-Based Intervention on Perceived Stress, Anxiety, and Depression Among Parents of Children with Autism Spectrum Disorder. *Mindfulness, 1-14*.
- Segal, Z. V., Williams, J. M. G., & Teasdale, J. D. (2002). *Mindfulness-based cognitive therapy for depression*. New York: The Guilford Press.

- Seltzer, M. M., Floyd, F., Song, J., Greenberg, J., & Hong, J. (2011). Midlife and aging parents of adults with intellectual and developmental disabilities: impacts of lifelong parenting. *American Journal on Intellectual and Developmental Disabilities, 116*(6), 479–499.
- Singh, N. N., Singh, J., Lancioni, G. E., Winton, A. S. W., Curtis, W. J., Wahler, R. G., McAleavey, K., Singh, J., & Sabaawi, M. (2006). Mindful staff increase learning and reduce aggression in adults with developmental disabilities. *Research in Developmental Disabilities, 27*(5), 545–558.
- Singh, N. N., Lancioni, G. E., Winton, A. S., Singh, J., Curtis, W. J., Wahler, R. G., & McAleavey, K. M. (2007). Mindful parenting decreases aggression and increases social behavior in children with developmental disabilities. *Behavior Modification, 31*(6), 749–771.
- Spijkerman, M. P. J., Pots, W. T. M., & Bohlmeijer, E. T. (2016). Effectiveness of online mindfulness-based interventions in improving mental health: A review and meta-analysis of randomised controlled trials. *Clinical Psychology Review, 45*, 102-114.
- Van der Oord, S., Bögels, S. M., & Peijnenburg, D. (2012). The effectiveness of mindfulness training for children with ADHD and mindful parenting for their parents. *Journal of Child and Family Studies, 21*(1), 139-147.
- Weiss, J. A., Cappadocia, M. C., MacMullin, J. A., Vecili, M., & Lunsy, Y. (2012). The impact of child problem behaviors of children with ASD on parent mental health: The mediating role of acceptance and empowerment. *Autism, 16*(3), 261-274.
- Whitebird, R. R., Kreitzer, M., Crain, A. L., Lewis, B. A., Hanson, L. R., & Enstad, C. J. (2012). Mindfulness-based stress reduction for family caregivers: a randomized controlled trial. *The Gerontologist, 53*(4), 676-686.

Whittingham, K., Sanders, M. R., McKinlay, L., & Boyd, R. N. (2016). Parenting intervention combined with acceptance and commitment therapy: A trial with families of children with cerebral palsy. *Journal of Pediatric Psychology*, 41(5), 531-542.

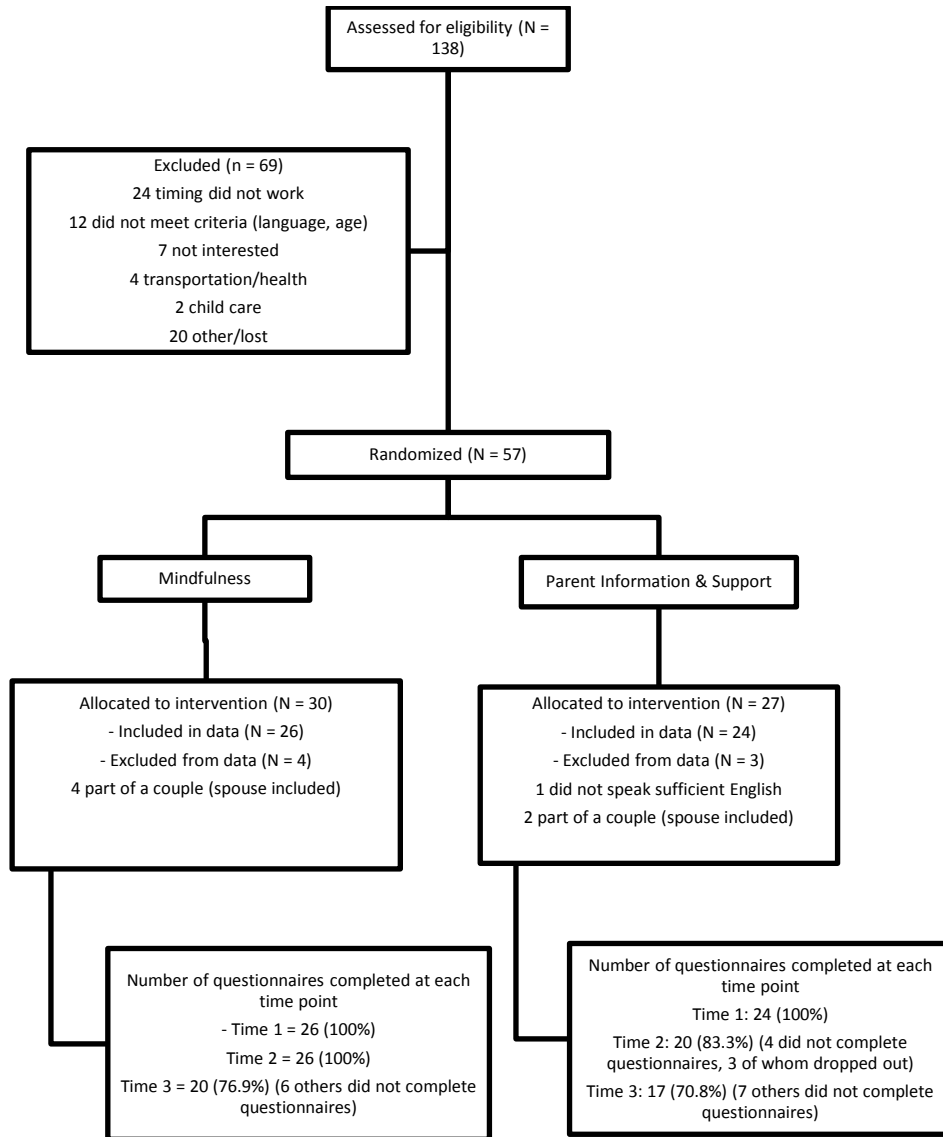
doi:10.1093/jpepsy/jsv118 [doi]

Williams, M., & Penman, D. (2012). *Mindfulness: An eight-week plan for finding peace in a frantic world*. Emmaus, Pennsylvania: Rodale.

**Figure Captions**

*Figure 1.* CONSORT-style diagram for the trial

Figure 1. CONSORT-style diagram for the trial





*Table 1.* Participant demographics

	Mindfulness (N= 26)	Support and information (N=24)	Total (N=50)
<b>Parent Demographics</b>			
Age, mean (SD)	56.3 (8.2)	56.9 (8.7)	56.6 (8.3)
Age min-max	37-77	44-81	37-81
Gender (% female)	19 (73.1)	16 (66.7)	35 (70.0)
Second language (%)	8 (30.8)	12 (50.0)	20 (40.0)
Married (%)	15 (57.7)	11 (73.3)	26 (63.4)
<b>Child Demographics</b>			
Age, mean (SD)	22.7 (5.4)	22.7 (6.0)	22.7 (5.7)
Age min-max	16-40	17-38	16-40
Gender (% female)	13 (52.0)	11 (45.8)	23 (46.0)
<b>Child disability (based on open ended question about child's diagnosis)</b>			
ASD (%)	9 (34.0)	13 (54.2)	22 (44.0)
Genetic syndrome (%)	4 (15.4)	3 (12.5)	7 (14.0)
Psychiatric disorder (%)	4 (15.4)	1 (4.2)	5 (10.0)
<b>Child day activity (based on open ended question about what does your child do each day?)</b>			
School (%)	11 (47.8)	12 (66.7)	23 (56.1)
Home (%)	6 (26.1)	4 (22.2)	10 (24.4)
Work/day program (%)	6 (26.1)	2 (11.1)	8 (19.5)

Table 2. Scores for outcome measures at baseline and post-intervention for both study groups

	Mindfulness		Parent Support		<i>F</i>	ANCOVA	
	Time 1	Time 2	Time 1	Time 2		Cohen's <i>d</i>	<i>P</i> value
DASS 14	16.65 (11.76) (N= 26)	11.21 (7.07) (N=26)	14.15 (8.73) (N= 20)	15.15 (6.59) (N= 20)	11.73	0.81	.001
FES: services	46.77 (6.50) (N= 26)	47.73 (7.58) (N= 26)	42.45 (7.68) (N= 20)	45.69 (7.81) (N= 20)	.52	0.35	.48
FES: family	42.87 (6.99) (N= 26)	45.26 (7.15) (N= 26)	39.25 (4.89) (N= 20)	41.61 (7.72) (N= 20)	.47	0.09	.50
FFMQ	127.95 (17.54) (N= 25)	132.93 (13.22) (N= 25)	126.69 (17.80) (N= 17)	127.79 (18.23) (N= 17)	1.47	-0.26	.23
BMPS	30.52 (6.76) (N=26)	31.35 (5.94) (N= 26)	28.70 (6.86) (N= 20)	29.20 (6.25) (N= 20)	.59	-0.09	.44
Burden	26.58 (9.17) (N= 26)	25.69 (8.35) (N= 26)	24.93 (7.99) (N= 18)	26.11 (8.34) (N= 18)	.45	0.24	.50
Self-compassion scale	37.96 (9.62) (N= 25)	39.20 (8.71) (N= 25)	38.10 (7.28) (N=20)	38.40 (6.47) (N= 20)	.36	-0.13	.55
Positive Gain Scale	12.64 (4.74) (N= 26)	13.88 (6.18) (N= 26)	14.56 (3.64) (N= 20)	13.40 (4.27) (N= 20)	1.64	-0.54	.21

*Note.* FES – Family Empowerment Scale; FFMQ – Five Factor Mindfulness Questionnaire; BMPS – Bangor Mindful Parenting Scale