Parent Perspectives of Applying Mindfulness-Based Stress Reduction Strategies to Special Education

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Abstract

Parents of children with (versus without) intellectual and developmental disabilities report greater stress; such stress may be exacerbated by dissatisfaction with school services, poor parent-school partnerships, and the need for parent advocacy. Increasingly, mindfulness interventions have been used to reduce parent stress. However, it is unclear whether parents apply mindfulness strategies during the special education process to reduce school-related stress. To investigate whether mindfulness may reduce school-related stress, interviews were conducted with 26 parents of children with intellectual and developmental disabilities who completed a mindfulness-based stress reduction intervention. Participants were asked about their stress during meetings with the school, use of mindfulness strategies in communicating with the school, and the impact of such strategies. The majority of parent participants reported: special education meetings were stressful; they used mindfulness strategies during IEP meetings; and such strategies affected parents' perceptions of improvements in personal well-being, advocacy, family-school relationships, and access to services for their children. Implications for future research, policy, and practice are discussed.

Key Words: mindfulness-based stress reduction; intellectual and developmental disabilities; parents; individualized education programs; family-school relationships

Compared to parents of children without disabilities, parents of children with intellectual and developmental disabilities (IDD) experience significantly greater stress (Hayes & Watson, 2013; Oclofsen & Richardson, 2006; Webster, Majnemer, Platt, & Shevell, 2008). Such stress may be exacerbated by the relationship with the school, satisfaction with special education services, and the need for parent advocacy. In a national sample of parents of children with IDD, Burke and Hodapp (2014) found a nonlinear relation between the need for advocacy and stress. Specifically, lower stress levels were primarily shown among mothers with good-to-excellent family-school partnerships (versus poor-to-fair) and who engaged in no (versus any) advocacy activities. When parents engaged in any advocacy activities, had marginal relationships with the school, and were somewhat dissatisfied with services, there was a significant increase in maternal stress.

In special education, parents may feel especially stressed in trying to obtain services for their children with IDD. Many parents report feeling overwhelmed and being frustrated by the school system, as well as unable to access their rights (i.e., understand and enact their procedural safeguards, Burke & Hodapp, 2016). Specifically, parents may feel intimidated by the school (Fish, 2006), disempowered to advocate (Hetherington et al., 2010), and excluded from the decision-making process (Williams, 2007). Parents may feel especially stressed at individualized education program (IEP) meetings (i.e., annual special education meetings between parents and the school). IEP meetings are the primary forums in which parents and school personnel determine a child's services, accommodations, and placement for the upcoming year. At IEP meetings, a common challenge stems from the potential power differential between parents and schools (Leiter & Krauss, 2004) with parents often feeling that they were relegated to passive roles (Kalyanjpur, Harry, & Skrtic, 2000). To ensure their children receive appropriate services, parents may advocate for their children during IEP meetings. Advocacy may include conflict with school personnel which, in turn, can
lead to parent stress (Wang, Mannan, Poston, Turnbull, & Summers, 2004). As a result of increased stress, parents may experience greater depression (Hastings et al., 2008), worse physical health (Eisenhower, Baker, & Blacher, 2009), and less effective parenting (Coldwell, Pike, & Dunn, 2006; Critic, Gaze, & Hoffman, 2005).

Increasingly, interventions are being developed to address the increased stress among parents of children with IDD; several recent studies have focused on mindfulness-based interventions (e.g., Bazzano, 2013; Dykens, Fisher, Taylor, Lambert, & Miodrag, 2014; Neece, 2013). Mindfulness is the awareness that emerges through paying attention on purpose, being in the present moment, and nonjudgmentally responding to the unfolding of experience moment by moment (Kabat-Zinn, 2003). Although mindfulness interventions vary with regard to duration, intensity, format, setting, and content, mindfulness-based stress reduction (MBSR) is the most widely studied mindfulness intervention (Chiesa & Serretti, 2009). Further, most mindfulness interventions use some adaptation of MBSR.

Recent studies support the feasibility (Roberts & Neece, 2015) and effectiveness (Bazzano, 2013; Dykens et al., 2014; Neece, 2013) of MBSR interventions in reducing stress among diverse samples of parents of children with IDD from early childhood to emerging adulthood. For example, in a randomized controlled study with parents of young children with disabilities and challenging behaviors, participants who received MBSR (versus the control group) demonstrated less parent stress and depression, increased life satisfaction, and reduced child behavior problems (Neece, 2013). Given the sometimes stressful nature of the special education process, interventions are needed to help alleviate parent stress related to the school system. The purpose of this study was to determine whether parents report school-related stress, discern whether and, if so, how parents apply mindfulness strategies during the special education process, and the perceived degree of impact of mindfulness strategies. For this study, there were three research questions: (a) How do parents report feeling during meetings with the school? Do parents report feeling stressed? (b) How do parents report the use of mindfulness strategies learned in the MBSR intervention during meetings with the school? And (c) What is the perceived impact of the use of mindfulness strategies during meetings with the school? This study contributes to the extant literature by exploring the use of mindfulness strategies in a special education context.

Method

Participants

Participants consisted of 26 parents of children with IDD who completed the Mindful Awareness for Parenting Stress (MAPS) program between the summer of 2014 and the fall of 2014. MAPS was offered to help parents of children with IDD reduce their stress; for more information about MAPS, see Neece, 2013. These parents represent a subset of the total convenience sample (N = 56) that were willing to participate in a follow-up qualitative interview designed for the current study. There were no demographic differences between participants who agreed to complete the follow-up interview and those who did not. For the MAPS program, inclusion criteria required: (a) having a child aged 2.5–5 years, (b) parent(s) reported the child to have a developmental delay as determined by a Regional Center or by an independent assessment, (c) parent(s) reported more than 10 child behavior problems (the recommended cut-off score for determining risk of conduct problems) on the Eyberg Child Behavior Inventory (ECBI; Robinson, Eyberg, & Ross, 1980), (d) parent was not receiving any form of psychological or behavioral treatment at the time of referral (e.g., counseling, parent training, parent support group), and (e) parent agreed to participate in the intervention and the follow-up qualitative interview. The mean age of participants was 37.14 (SD = 6.13). Of the participants, 53.85% (n = 14) reflected minority backgrounds and 7.69% (n = 2) were male. See Table 1 for more information about the participants; notably, participant names are pseudonyms.

Recruitment

Participants were primarily recruited through the Inland Empire Regional Center, although some participants were recruited through the local newspaper, elementary schools, and community disability groups. In California, nearly all families of individuals with IDD receive services from one of nine Regional Centers. Families who met the inclusion criteria were selected by the Regional Center’s computer databases and received a letter
and brochure informing them of the study. Information about the study was also posted on a website which allowed interested parents to submit their information.

**MBSR Intervention**

The MBSR intervention followed the manual outlined by Dr. Jon Kabat-Zinn at the University of Massachusetts Medical Center (Kabat-Zinn, Massion, Kristeller, & Peterson, 1992). The MBSR program included eight weekly 2-hr sessions, a daylong 6-hr meditation retreat after class six, and daily home practice using audio CDs with instruction. Each session, the retreat, and the home practice reflected three main components: (a) didactical material covering the concept of mindfulness, the psychology and physiology of stress and anxiety, and ways in which mindfulness can be implemented in everyday life to facilitate more adaptive responses to challenges and distress; (b) mindfulness exercises during the group meetings and as homework (e.g., formal meditation practice) between sessions; and (c) discussion and sharing in pairs and in the larger group. Formal mindfulness exercises included the body scan (i.e., a meditative practice to direct awareness to each part of the body sequentially) and sitting meditation with awareness of breath and mindful movement (e.g., yoga and walking meditation). The instructor for the group had over 20 years of experience practicing mindfulness and teaching MBSR, completed the Advanced MBSR Teacher Training at the University of Massachusetts Medical Center, and had received supervision with Senior MBSR Teachers through the Center for Mindfulness at the University of Massachusetts Medical Center.

**Procedures**

A qualitative phenomenological approach, namely individual interviews, was used (Patton, 2002). To develop the semi-structured interview protocol, an extensive literature search was conducted about parent stress and advocacy (e.g., Burke & Hodapp, 2014; Wang et al., 2004). Based on the literature review, an initial interview protocol was developed and reviewed by faculty experts in families of individuals with disabilities, MBSR, parent stress, and advocacy. All expert feedback was addressed in a revised version of the protocol, which was then piloted with a parent of a child with IDD. The final protocol and the overall study were approved by the University Institutional Review Board. See the Appendix for the protocol.

Participants were interviewed at a time and location of their choice. The interviewer was involved in data collection but not the MBSR intervention. In this way, the interviewer had established rapport with the participants from the data collection but had no vested interest in the outcomes of MBSR. All interviews were conducted in-person and in English. Before beginning the interviews, participants were reminded that their participation was voluntary and their responses were confidential and anonymous. All questions on the interview protocol were asked of each participant. Interviews were audiorecorded and transcribed verbatim; there were 48 single-spaced pages of transcription. Transcripts were reviewed for accuracy, and errors were corrected based on the audio recordings.

**Analysis**

The first and third author independently read the responses to familiarize themselves with the data (Tesch, 1990). Each author highlighted the text that pertained to the research questions. The authors then compared their highlighted text to ensure that all relevant text was included in the analysis. After agreeing on the relevant text, constant comparative analysis (Glaser & Strauss, 1967) and emergent coding (Patton, 2002) were used to code the data. Using a line-by-line approach, each piece of data (i.e., each line) was compared with all other data ( Creswell, 2003) to discern whether it represented a novel idea (i.e., new code) or aligned with a previously mentioned idea and should be part of an existing code. After all of the data had been coded, the authors met to discuss the codes and come to consensus. Within this discussion, the authors reviewed each phrase and their suggested codes. If the authors agreed on the code, then they would establish that as a code. If there was not agreement, the authors discussed their rationales for their given codes until they came to a consensus. After reviewing and agreeing upon all of the codes, the authors returned to the data again for analysis. Using the established codes, a codebook was created and the authors coded the data. The authors grouped the codes into categories and organized the categories into themes grounded in the data. After establishing the themes, the
authors then conducted frequency counts of the individual themes to determine prevalence.

For example, to determine the theme "being nonreactive," the authors first independently reviewed the transcripts to become acquainted with the data. Individually, they highlighted text related to the perceived use of mindfulness strategies in IEP meetings. They compared their highlighted text to ensure they were identifying the same text related to the application of MBSR in IEP meetings. After agreeing on the relevant text, they returned to the data. They re-examined the data pertaining to the application of MBSR in IEP meetings. They identified codes that included "trying to remain calm," "keeping composure," "walk in with a level head," and "patience." They discussed these codes with one another and decided that they represented a category of parents trying to listen to what the school is saying in a nonreactive manner. They grouped the codes into categories (listening to the school, being nonreactive) and then organized the categories into a theme, "being nonreactive."

Trustworthiness of the Data
To ensure the trustworthiness of the data, several approaches were undertaken, including peer-debriefing, negative case analysis, member-checking, and an independent coder (Brantlinger, Jimenez, Klingner, Pugach, & Richardson, 2005). Two coders (i.e., the first and third authors) independently coded the data and debriefed with one another. Also, negative case analysis was used to further refine the themes. Specifically, after identifying the themes, the authors carefully reviewed the transcripts to determine whether any phrases contrasted with the identified themes. Relatedly, the full range of themes was included in this study to demonstrate the wide range of findings (Erlandson, Harris, Skipper, & Allen, 1993). All of the themes were member-checked with the participants to ensure their accuracy. Further, an independent coder (i.e., a doctoral student trained in qualitative analyses) coded the entire sample using the codebook. The independent coder confirmed the codes identified by the authors.

Findings

Methods of Advocacy
In the interviews, participants first began discussing how they advocated for services for their children. Only one participant reported that she did not advocate because she was happy with the services her child was receiving. Other participants reported advocating for services in a variety of ways. Participants reported advocating by being informed about their special education rights. Kelly, the mother of a child with autism spectrum disorder (ASD), reported "You have to find out your own rights...knowing that I have rights and just calmly enforcing those and [saying] 'Look, we are going to do what I want to do because really I have the last say.'" Additionally, participants reported that they advocated by requesting services. Such services included an "individual aide" and "related services." Finally, participants reported advocating by being involved in the school. Such involvement included participating in IEP meetings, volunteering at the school, and expressing their concerns to the teachers. Thus, participants advocated in a variety of ways, including relying on their rights, requesting services, and being involved in the school.

After establishing that participants advocated for services, the authors examined their perceptions of stress in IEP meetings, application of mindfulness strategies, and reported impact of the strategies. Regarding stress, most participants reported feeling stressed during IEP meetings; themes included the deficit-based nature of IEP meetings, the onus of being an advocate, and intimidation by the school. Notably, a few participants reported not feeling stressed at IEP meetings. Regarding the application of mindfulness strategies, there were six themes: being nonreactive, being "in the moment," using breathing techniques, focusing on the overall picture, taking a break, and not applying mindfulness strategies. Finally, with respect to the perceived impact of mindfulness strategies, themes included: improved parent well-being, improved advocacy, improved parent-teacher relationship, and improved child services. See Table 2 for more information about each theme.

Stress During IEP Meetings
Stressful IEP meetings: Deficit-based nature. The majority (69.23% or n = 18) of participants reported feeling stressed during IEP meetings. Participants reported that IEP meetings were emotionally loaded because the meetings focused on the deficits of their children and refusal of school services; consequently, participants report-
Participants reported that it was stressful to see the school "shuffle" their children through the grade levels without acknowledging the strengths of each child.

**Stressful IEP meetings: Onus of being an advocate.** Participants also reported that IEP meetings were stressful due to the responsibility of being the child's sole advocate. Robin, the parent of a child with ASD, reported,

> It [the IEP meeting] creates a lot of stress and tension. When there are IEP meetings—to know it is my decision to make for him and I need to make the best decision for him—it just puts a lot of stress on me. It's a stressful time for me.

Participants expressed that meetings were stressful because participants were worried about making the wrong choices for their children. Feeling that they were the child's "voice" at the IEP meeting, the responsibility of advocacy created stress for parents.

**Stressful IEP meetings: Intimidation by the school.** Participants reported feeling intimidated by the school during IEP meetings. Specifically, participants perceived that the school personnel were not interested in the insights of the parents—as such, the school relegated the role of parents to listeners instead of equal partners. Kelly, the parent of a child with ASD, reported,

> They do try and intimidate you. Like you have no control and they have all the control. For many participants, IEP meetings were stressful due to actions taken by the school.

**Nonstressful IEP meetings: Strong family-school partnerships.** Few participants (30.77%, or n = 8) reported that IEP meetings were not stressful. These participants reported that IEP meetings were not stressful because the participants were confident, prepared, and well-tended by the school. Upon reflecting on the IEP meetings for her daughter with Down syndrome, Ashley reported, "I don't find them [IEP meetings] stressful because I've met the principals. I talk to the teachers on a more ongoing basis. So, anything to me is not really a surprise when we show up to the IEP meetings." Participants reported a lack of stress and, relatedly, need for advocacy, because they had positive, strong partnerships with school personnel. As such, advocacy was not necessary.

### The Application of Mindfulness Strategies in IEP Meetings

**Being nonreactive.** Most participants (75.08%, or n = 19) reported using mindfulness strategies in IEP meetings. Specifically, 53.85% (n = 14) participants reported being nonreactive in IEP meetings. Participants reported "staying calm," "being patient," and "keeping composure" during IEP meetings. Elizabeth reported that, by being calm and not interrupt, she didn't interrupt. By being reactive during IEP meetings, participants were able to listen to the school and take time to develop their own responses.

**Being "in the moment."** Also during IEP meetings, many participants (42.31%, or n = 11) reported being "present," another mindfulness strategy and focus of the MBSR intervention. To be "present," participants reported showing up early to IEP meetings to "be in the moment," "thinking" before going to IEP meetings, and "taking it one day" at a time. To ensure they were "in the moment," participants also reported writing questions and communicating with teachers before the meeting. Participants also reported being "present in the moment" during the IEP meeting; by being "present" at IEP meetings, participants were able to concentrate on communicating with the school.

**Breathing techniques.** Further, 42.31% (n = 11) of participants reported that they used mindfulness breathing techniques during IEP meetings. By using the breathing techniques, participants reported that they could bring their heart rates down during IEP meetings and anchor themselves in the present moment. Elizabeth, the parent of a child with ASD, reported,

> I do it (breathing) in the IEP meetings. I did it in her last IEP meeting when they were starting to upset me by talking about a special...
education class for kindergarten when I want her to be in an inclusive classroom. I would just breathe while they were talking.

Participants also reported using breathing techniques to prepare for IEP meetings. Ada reported, “I think about before I go in what I am going to say and I try to breathe deeply so that way I don’t say things that I don’t want to say... I try to think and breathe.”

Focusing on the overall picture. Some participants reported (23.71% or n = 6) that they would focus on seeing the overall picture and not focus on negativity during the IEP meeting. Participants reported that they would try to see the surrounding context and what is causing the problem at hand to happen. Ellen stated,

Sometimes the problems of life ... it’s like suffocating you. But then you pull back and you push that problem far back and you see world around it. And I think that’s what it looks like ... And I have to remember to do that. That IEP is just a small, you know, it’s a little bit of a hurdle. But it’s a small hurdle. And, then when I push it, I see my family and I see my kids and I see my husband and all the blessings we have, and all the things we have to be grateful for, and I’m dealing with that one little speck so that I can have the rest of what’s around it.

By reminding themselves to focus on the overall picture, participants were applying another mindfulness strategy during IEP meetings.

Taking a break. Finally, some (11.54% or n = 3) participants reported taking a break during IEP meetings as a mindfulness strategy. Participants reported that, upon realizing they were feeling anxious, they would ask for a break during an IEP meeting. Bill, the father of a child with ASD, reported,

At least a couple of times during the IEPs, I would I say, “I need a break.” I feel it in my body... I need a break. This is very emotional for me. I feel like I need a moment to step outside, catch my breath, and just really think through what’s being said.

Staying attuned to their body and listening to it prompted the participants to take a break during IEP meetings.

No need for mindfulness. Notably, 26.92% (n = 7) of participants reported not using mindfulness strategies during IEP meetings. These seven participants were also participants who reported that they did not experience stress in IEP meetings. Notably, only one participant reported that she did not experience stress in IEP meetings; yet, she reported using breathing techniques during IEP meetings as part of her daily mindfulness practice. These seven participants reported not using these strategies because there were “no problems with the school” or they had good relationships with the school.

Effects of Mindfulness Strategies in IEP Meetings
Of the participants who used mindfulness strategies in IEP meetings, participants reported that their use of mindfulness strategies positively affected themselves (as parents), their children with disabilities, and their relationships with the school.

Parent effect: Improved well-being. Of the total participants, 69.23% (n = 18) reported that using mindfulness strategies improved their well-being. Such impacts included having more patience, experiencing less stress, feeling more clear-headed, and being less emotional. Amy, the mother of a child with an intellectual disability, reported,

It [mindfulness] just gives me more of a calmness, you know, to be able to deal with it [IEP meetings] without being stressed about it. Try to, you know, take everything as it comes more calmly.

By practicing mindfulness strategies in IEP meetings and reporting less negative emotions (e.g., stress) and more positive emotions (e.g., calmness), it seemed that there was improved well-being among the participants.

Parent effect: Improved advocacy. Many participants (57.69% or n = 15) reported that their use of mindfulness strategies in IEP meetings increased their advocacy skills. Specifically, participants reported that, due to the MBSR intervention, they were able to clearly communicate their child’s needs to the school. Molly, the parent of a child dually diagnosed with ASD and Down syndrome, reported,

It’s [MBSR] helped in the fact that I am able to get a clearer head when I need to. That is always good because when you are advocating...
parents of children with disabilities who already spend additional time on caregiving (Smith et al., 2010), finding the time to attend the MBSR training in its entirety may be difficult. Thus, thinking about providing MBSR via videoconferencing (thereby reducing driving time) or shortening the intervention itself (without sacrificing its effectiveness) may be important considerations.

Regarding policy, this study has implications for the upcoming reauthorization of the Individuals with Disabilities Education Act (IDEA, the federal special education law). Although parent participation is a key component of IDEA, parents often struggle to advocate and, as demonstrated by this study, parents report feeling stressed during the special education process. In the next reauthorization of IDEA, policymakers may consider revising IDEA to address some of the school-related stressors. For example, facilitated IEPs are becoming increasingly common across the United States (Mueller, 2009). Facilitated IEPs include having a neutral person attend an IEP meeting to ensure equal decision-making as well as having a structure to IEPs to ensure their efficiency (Feinberg, Beyer, & Moses, 2002). By having a facilitated IEP, parents may feel less intimidated and stressed in IEP meetings.

Although this study has some promising findings, there are some limitations. First, this sample is based on a convenience sample of a small number of parents representing one state. However, our findings confirm previous research that families experience stress related to the special education process; such stress seems especially prevalent during IEP meetings. As the primary decision-making forums wherein parents and school personnel determine the services for children with IDD, IEP meetings also illustrate the power differential between the parent and the school (Leiter & Krauss, 2004). In response to this power differential, parents may feel compelled to advocate. Wang et al. (2004) found that the need for advocacy inherently includes conflict and stress. Yet, in this study, the findings indicate that mindfulness strategies, when applied in IEP meetings, relate to perceptions of less stress and better parent advocacy. Future research should more closely examine the triadic relationship between advocacy, stress, and mindfulness to understand the directional influences upon each other.

In addition, future research should also include multiple measures of stress before, during, and after IEP meetings (i.e., longitudinal measures of stress in relation to special education). This study was limited to parent perceptions. By having additional measures and sources of data, we could better determine the relation between advocacy, stress, and MBSR. Given that parents reported increased stress and (correspondingly) use of mindfulness strategies in IEP meetings, future research should include a time-sensitive measure to understand how stress increases during IEP meetings. One way to collect such data is by collecting biological markers of stress. Cortisol, for example, is a hormonal marker of stress; upon encountering a stressful situation, cortisol is released triggering a “fight or flight” response to the immediate challenge (Flinn, 2006). Although parents of children with (versus without) IDD report chronic stress, which is represented as consistently low cortisol, stress may be moderated by specific events or child characteristics (e.g., child maladaptive behavior, Seitzer et al., 2010). Future research should collect cortisol samples before, during, and after IEP meetings as well as quantify parent advocacy and mindfulness strategies used to better understand the relations between stress, advocacy, and mindfulness in the actual context of IEP meetings. Additionally, this study only considers the perspectives of parents—school professionals may have different perceptions about the nature of IEP meetings and ways to address parent well-being. Future research may include diverse data sources (e.g., school professionals) to examine their perceptions.

Even in light of these limitations, this study provides a jumping off point to understanding that mindfulness may be an effective way to reduce school-related stress. Given that parents of children with (versus without) IDD report increased stress, it is crucial to continue to identify evidence-based interventions to address parent well-being. MBSR may be one such intervention that could assist in not only improving parent well-being but also increasing parent advocacy, family-school partnerships, and reception of services.

References


M = mindfulness
P = partnerships/collaboration/teams
S = stress
I = IEP meetings
A = Advocacy


Applying Mindfulness-Based Strategies


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Appendix

Interview Protocol

We are about to begin our interview. Before we begin, please remember that all responses here are confidential. To that end, we will not be using names in any of the products that result from this research. Feel free not to answer any questions. You can withdraw from the interview at any time. The purpose of this interview is to discuss the relation between the mindfulness training and how you advocate for your child in the school setting.

A. Advocacy/School Experiences
   a. Tell me about your experience with the school. Can you walk me through how you advocate for services for your child?
   b. How do you feel during IEP meetings with the school?
      1. Have any meetings been stressful? Why?
   c. Since you have attended the mindfulness training, have you used any of the mindfulness strategies when working with the school?
      1. Can you give examples of when you used mindfulness strategies with the school?
      2. What kind of mindfulness strategies have you used?
      3. What was the result of using the mindfulness strategies?
   d. How has mindfulness affected your advocacy on behalf of your child?
   e. How has mindfulness affected your relationship with the school?

B. Possible follow-up questions:
   a. Can you tell me more about that experience?

C. Possible probes
   a. That's interesting... can you tell me more about that?
   b. Can you give me an example of that?

D. Concluding the interview:
   Thank you so much for taking the time to answer these questions—we really appreciate it!

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