



# Online Mindfulness Stress Intervention for Family Carers of Children and Adults with Intellectual Disabilities: Feasibility Randomized Controlled Trial

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## Abstract

**Objectives** Family carers of people with intellectual disabilities (ID) are twice as likely as other carers to experience stress and mental ill-health, but research exploring interventions is sparse. Online mindfulness may provide an accessible, cost-effective resource. The addition of guided telephone support could help to tailor an existing intervention for this population. A feasibility randomized controlled trial (RCT) was conducted to inform the development of a definitive RCT.

**Methods** Sixty participants were randomized to complete Be Mindful (a brief online mindfulness intervention) either with or without additional Peer Mentor support. Feasibility of recruitment, retention, intervention adherence, and acceptability of study design was examined. Preliminary analyses were undertaken on participant-reported outcomes pre- and post-intervention. Eighteen semi-structured interviews were conducted as a process evaluation.

**Results** Feasibility outcomes indicate that it would be possible to recruit and retain (88%) participants to a definitive RCT, and that the study design and intervention are acceptable. The addition of guided telephone support was not burdensome; indeed, it was additionally motivating. Telephone support can be delivered with high fidelity, but this is inconsistent and requires further piloting. Preliminary comparison data indicate small, but non-significant, improvements for participants receiving guided telephone support relative to those who did not over time.

**Conclusions** It is feasible to deliver online mindfulness with additional telephone-guided support to family carers of people with ID, and this may lead to small benefits over receiving online mindfulness alone. A definitive RCT can be planned to examine the effectiveness and cost-effectiveness of this intervention.

**Keywords** Mindfulness · Stress · Family carers · Intellectual disability · Randomized controlled trial · Intervention

While parents who have children with intellectual disability (ID) experience positive outcomes and have positive life and

child-related experiences (Hastings 2016; Hastings and Taunt 2002), they are often also at increased risk for stress and mental health problems. This risk has been understood for several decades, and increasingly sophisticated research designs and representative population-based data confirm, for example, that UK mothers of children with ID are approximately twice as likely to have clinically concerning levels of psychological distress on a mental health screening questionnaire than other mothers (Totsika et al. 2011). In addition, compared with other carers from a representative survey of English households, carers (mostly parents) of children and adults with ID reported a higher caring load, more financial struggles, a more negative impact of caring on their personal life (e.g., social or leisure activities, reduced time spent with other family members/friends), and overall poorer health (e.g., disturbed sleep, feeling depressed) (Totsika et al. 2017).

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Stress and mental health problems in parents of children and adults with ID are not only concerning directly for the quality of life and well-being of the parents themselves but also for the children. Longitudinal data, allowing causal inferences, confirm that children with ID whose parents (especially mothers) experience significant stress or mental health problems are more likely (than those with less severe difficulties) to experience increased behavioral and emotional problems over time (e.g., Bailey et al. 2019; Hastings et al. 2006; Lecavalier et al. 2006; Neece et al. 2012; Totsika et al. 2013). Such findings can be understood from a family systems perspective, such that the well-being of one family member will affect other individual family members and family subsystems (such as couple relationships, parent-child relationship quality, and sibling relationship quality) (Cridland et al. 2014; Seligman and Darling 2009; Trivette et al. 2010).

Although carers' needs for support are recognized by professionals and services, and in policy internationally, there is surprisingly little high-quality research evidence relating to effective interventions for reducing parental stress. A number of parenting programs adapted from mainstream versions have been shown to be potentially effective in terms of their impact on parents' well-being, with some randomized controlled trials with positive results for the Stepping Stones Triple P program (Tellegen and Sanders 2013) and the Incredible Years parenting program (McIntyre 2013). However, parenting programs are focused mainly on child outcomes and parenting rather than directly targeting parent well-being. Psychological supports directly targeting the well-being of parents of individuals with ID have rarely been tested robustly in randomized trials (Glidden et al. *in press*).

Mindfulness-based interventions are a worthwhile focus for improving parents' well-being for a number of reasons. First, there is gathering evidence that mindfulness-based interventions are effective for improving well-being and reducing stress in a variety of settings and with a variety of populations (e.g., Chiesa and Serretti 2011; Kallapiran et al. 2015; Khoury et al. 2013; Piet et al. 2012). Second, the challenges faced by parent carers of children and adults with ID are often chronic and potentially less amenable to adjustment through approaches such as cognitive behavior therapy (Lunsky et al. 2017). Third, increased avoidant coping (Hastings et al. 2005) and decreased state or trait mindfulness and psychological acceptance (Jones et al. 2014; MacDonald et al. 2010; Weiss et al. 2012) have been shown to be associated with increased stress and mental health problems in parents of children with ID. Therefore, targeting these processes (reducing avoidance, and increasing mindfulness and psychological acceptance) could be appropriate targets for change. Fourth, there have been a number of recent positive evaluations of mindfulness-based interventions for parents of children with ID in which these processes were targeted, including some

randomized trials (e.g., Dykens et al. 2014; Jones et al. 2018; Lunsky et al. 2017; Neece 2014).

Despite some encouraging outcome data, a significant issue with existing evaluations of mindfulness-based interventions for family carers of children and adults with ID is that the interventions are delivered either by experienced mindfulness teachers or those delivering the interventions need to be trained and supervised by experienced mindfulness teachers. In addition, family carers find it difficult to commit to attending a regular group session in person due to difficulties finding childcare and transport to the sessions, and child and parent health problems (Lunsky et al. 2017). Thus, there are considerable barriers to the wide-scale implementation of these interventions likely leading to only a small reach when it comes to addressing family carers' needs. Online delivery of mindfulness-based interventions might offer a solution since the expertise is invested in the development of the intervention, but access is not limited by the lack of availability of mindfulness-trained individuals or the unpredictability of parental care commitments. We could find no data on the feasibility of online mindfulness interventions with parents of children or adults with ID and no studies of parents of children or adults with ID were identified in a recent systematic review of online mindfulness evaluations (Spijkerman et al. 2016).

Published evaluations of an online version of Mindfulness-Based Cognitive Therapy (MBCT), Be Mindful, support its acceptability for participants and also effectiveness in terms of reductions in stress, anxiety, and depression pre-post intervention (Krusche et al. 2013), and improvements in work-related well-being in a randomized controlled trial (Querstret et al. 2016). A recent meta-analysis of 15 randomized trials of online mindfulness interventions also supported their effectiveness especially for reductions in stress (summary effect size .51) (Spijkerman et al. 2016). A sub-group analysis suggested that online mindfulness interventions were more effective when the interventions were guided (i.e., where some support and contact were offered alongside the online course) (Spijkerman et al. 2016). Previous research using modified versions of MBCT (Jones et al. 2018; Lunsky et al. 2017) also suggested that parents value the chance to relate mindfulness intervention with their experiences caring for their offspring with ID. Existing research (Dykens et al. 2014; Lunsky et al. 2018) suggests that involving parents in intervention delivery with other parents adds value to the experience and outcome for participants.

The present study contributes to practice knowledge by using an established program with a new population, caregivers of people with ID. The overall aim of the current feasibility study was to examine whether Be Mindful can be delivered successfully to family carers of children or adults with ID, and whether it would be feasible to conduct a later definitive randomized controlled trial of the effectiveness and cost-effectiveness of Be Mindful. Based on the literature

supporting the addition of guided peer support, we developed a peer mentoring “add-on”—guided support element for Be Mindful through a co-production process with family carers. Peer mentors were not intended to deliver a mindfulness-based intervention, but instead to provide peer support to participants who were engaging with the online intervention. The feasibility questions were addressed in the context of a two-arm trial comparing Be Mindful to Be Mindful with mentoring support. The feasibility questions were as follows: (1) What are the most effective pathways to recruit family carers of children or adults with ID, and what recruitment rate for family carers (including the proportion of mothers and fathers) can be achieved? (2) Can peer mentors be recruited and trained to deliver telephone guided support sessions for the study? (3) Are family carers willing to be randomized within the context of a randomized trial? What design would be acceptable to family carers for a future randomized trial? (4) Can peer mentors deliver telephone guided support sessions with a high degree of fidelity? (5) What proportion of family carers complete the Be Mindful online intervention in each arm of the trial, and what is the typical time taken to complete the intervention? What proportion of the telephone guided support sessions do family carers receive? (6) What proportion of family carers are retained in the research study to the 6-month post-randomization follow-up? (7) What stress/well-being interventions do family carers receive typically, and how is this “usual practice” different from the program content of Be Mindful? (8) Do family carers complete the outcome measures for the study? And, (9) What is the feasibility of collecting resource use and health-related quality of life data for family carers?

## Methods

### Participants

Participants were a self-selected sample who responded to recruitment advertisements, all of whom underwent a short screening telephone call to determine their eligibility for the project. Family carers were eligible for the study if they were 18 years old or over, a family carer of a person (child or adult) with ID who lived with them, not currently receiving individual or group therapy (including mindfulness-based interventions) for their mental health, able to access the online mindfulness intervention, and had not already completed Be Mindful. Previous engagement in mindfulness-based interventions was not a reason for exclusion. ID was defined administratively by family carers reporting that the child or adult had received a diagnosis and/or was in receipt of ID services. Foster carers were eligible for the study, provided the placement was not due to end during the study period. All participants completed the Vineland Adaptive Behavior Scales

(VABS) (3rd edition) Domain Level Interview Form (Sparrow et al. 2016) during this telephone call to assess the level of adaptive functioning of the person with ID to enable description of the participating sample.

Participants were recruited during a 2 and a half month period (October–December 2018) and were randomized throughout the study period by an independent statistician at the University of Warwick on a 1:1 basis using minimization, balancing the age of the person with ID (under 18 years old; 18 years old and over) between the two arms of the trial (*Be Mindful* vs *Be Mindful* plus guided telephone support [*Be Mindful+*]). A power calculation was not undertaken for this study as it was a feasibility study to inform a later trial (Arain et al. 2010). The researcher responsible for data collection remained blind to the allocations until after the final data collection point. Participants could not be blinded to their allocation, but were recruited prior to randomization.

Participants ( $n = 60$ ) were predominantly female ( $n = 55$ ), White British ( $n = 48$ ) family carers of people with ID with a mean age of 46.09 (SD = 7.71; range = 33–62). Participants were mostly educated to university degree level ( $n = 32$ ), and most were either employed ( $n = 21$ ) or looked after their home and family ( $n = 22$ ). The majority of participants had never previously engaged in any mindfulness-based interventions ( $n = 46$ ).

The people for whom the participants cared were mostly under 18 years of age ( $n = 47$ ), with a mean age of 13.73 (SD = 8.97; range = 1–55 years), and there was a fairly even split of males ( $n = 33$ ) and females ( $n = 27$ ). The mean Vineland Adaptive Behavior Scale (VABS) Domain Level ABC score was 42 (SD = 13.47; range = 20–69), and they had a range of diagnoses, including dual diagnoses, with the majority having diagnoses of ID ( $n = 54$ ) and/or autism ( $n = 41$ ). Separate demographic data for both arms of the trial are presented in Table 1.

### Procedures

This feasibility randomized controlled trial (RCT) was retrospectively registered on 21st September 2018 (ISRCTN20615805) before recruitment and randomization commenced. A two-arm RCT design was used to examine the feasibility of delivering an online mindfulness intervention (*Be Mindful*), with or without additional guided telephone support, to family carers of children or adults with ID, and the feasibility of a definitive RCT examining effectiveness and cost-effectiveness. Ethical approval was granted by the University of Warwick’s Humanities & Social Sciences Research Ethics Committee (58/17-18).

Family carers who expressed interest in participating in the study after reading an information sheet underwent a short screening telephone call to determine their eligibility. Eligible participants were offered a choice of questionnaire

**Table 1** Participant demographics split by trial arm

Demographics	Be Mindful		Be Mindful+	
	<i>N</i>	%	<i>N</i>	%
Gender				
Male	3	10	2	6.7
Female	27	90	28	93.3
Mean age (SD)	46.65 (7.3)		45.57 (8.17)	
Relationship to child				
Biological mother	25	83.3	27	90
Biological father	3	10	2	6.7
Adoptive mother	2	6.7	0	0
Other	0	0	1	3.3
Ethnicity				
White British	13	76.7	25	83.3
Asian/Asian British	3	10	3	10
White Other	2	6.7	2	6.7
Black British	1	3.3	0	0
Mixed race	1	3.3	0	0
Educational level				
Some GCSE passes	2	6.7	4	13.3
5+ GCSEs at A* - C	4	13.3	2	6.7
5 A/AS levels	1	3.3	1	3.3
Other higher education below degree level	6	20	8	26.7
Degree (bachelors) or higher	17	56.7	15	50
Employment				
Currently working	10	33.3	11	36.7
On maternity/paternity/parental leave	0	0	1	3.3
Self-employed	3	10	4	13.3
Full-time student	0		1	3.3
Voluntary work	1	3.3	1	3.3
Look after home and family	11	36.7	11	36.7
Other	5	16.7	1	3.3
Child gender				
Male	26	43.3	40	66.7
Female	34	56.7	20	33.3
Child mean age (SD)	13.63 (8.39)		13.83 (9.67)	

completion method (postal, online, or telephone). Informed consent was taken by a researcher (for postal or telephone completions) or online, before participants completed the baseline questionnaire. Participants were then allocated randomly to either *Be Mindful* or *Be Mindful+* and were informed of their allocation by an email invitation to start *Be Mindful* (*Be Mindful* arm) or a text message/telephone call from a Peer Mentor (*Be Mindful+* arm). Participants in the *Be Mindful+* arm received an email invitation to start *Be Mindful* after their first telephone mentoring session. Once enrolled on *Be Mindful*, participants used it at their own pace, with *Be Mindful+* participants being offered a further two telephone mentoring sessions (as described below).

All participants received follow-up questionnaires at 12 weeks and 6 months post-randomization. Participants received a £10 high-street voucher for each time point they returned the questionnaires.

**Be Mindful Online Intervention** *Be Mindful* is a publicly available online mindfulness program developed by the Mental Health Foundation, which has ten easy-to-follow online sessions based on the elements of MBCT. The recorded audio and video instructions and exercises are presented by two qualified mindfulness trainers. It can be completed in as few as 4 weeks, and is accessible on any device with a web browser and an internet connection. Twelve assignments to practice

**Table 2** Be Mindful online intervention content

Week/session	Content	Homework
Getting started	Registration; introduction to course; completion of Stress, Anxiety, and Depression assessment	N/A
Week 1 – Stepping out of automatic pilot		
Session 1	Body scan; being mindful doing routine activities; mindful eating	Practice body scan
Session 2	Dealing with barriers	N/A
Week 2 – Reconnecting with body and breath		
Session 1	Mindful breathing	Practice mindful breathing; keeping an Event Awareness Journal; practice moving mindfully
Session 2	Physical barometer	N/A
Week 3 – Working with difficulties		
Session 1	Breathing space; sitting meditation	Practice breathing space and sitting meditation
Session 2	Thoughts are just thoughts	N/A
Week 4 – Mindfulness in daily life		
Session 1	Preparing for stress; reflection on stress strategies	Practice activity awareness, breathing space, and action step; stress strategies
Session 2	Mindful walking	N/A
Going forward	Additional resources; completion of Stress, Anxiety, and Depression assessment; completion certificate	N/A

in daily life are also included, along with six downloadable course handouts, and auto-generated supporting motivational emails throughout. An overview of Be Mindful is presented in Table 2.

**Additional Peer Mentor Support** Additional Peer Mentor support is not a standard element of Be Mindful, and was included solely for the purposes of this study. Peer Mentors for this study were parent carers of people with ID who co-produced the Mentoring Manual, and were subsequently trained in how to use it during a 1-day workshop. The manual (and training) contained detailed information about the purpose and focus of each telephone call (developed using the GROW [Goals, Reality, Options, Way Forward] Model [Whitmore 1996]), information about the study and Be Mindful, and a Frequently Asked Questions section to provide answers to potential queries or problems (e.g., who to contact if a participant was having difficulty accessing the online intervention). Peer Mentors were required to complete Be Mindful before they could mentor participants, as although Peer Mentors were not experts in mindfulness, they needed to have an understanding of (familiarity with) the intervention itself as well as potential barriers family carers might face.

Participants allocated to the *Be Mindful+* arm of the trial were offered three 30-min telephone calls from a Peer Mentor in addition to Be Mindful. This additional element of support was designed to encourage participants to start Be Mindful and stay motivated to complete it. Peer Mentors supported participants to identify ways to protect their time and provided

space for participants to troubleshoot their previous strategies should things not have gone to plan in the preceding weeks. An overview of the Peer Mentor telephone calls is presented in Table 3. Telephone calls were timed to coincide with usual completion of key milestones (“Weeks”) in the intervention: (1) before starting Be Mindful, to prepare participants, (2) at the start of “Week 2” of Be Mindful, and (3) at the start of “Week 4” of Be Mindful. The average length of telephone calls with Peer Mentor 1 was 20 min, and 11 min with Peer Mentor 2.

## Measures

**Demographics** At baseline, participants provided demographic data about themselves, their family, and the person with ID for whom they cared. These data included the following: the person with ID’s age, sex, and diagnosis, the participant’s relationship to the person with ID, their sex, ethnicity, educational qualifications, employment status, and whether they had previously participated in any mindfulness-based interventions. Demographic questions about their family were measures of financial hardship and the number of people in the household.

**Feasibility Outcomes** Feasibility was the primary outcome in this trial, and was measured using a combination of descriptive, quantitative, and qualitative data to answer the questions detailed earlier: (1) recruitment rates; (2) recruitment and training of Peer Mentors; (3) acceptability of the research

**Table 3** Peer Mentor telephone call content

Telephone call	Intended point of delivery	Content
1	Before participants start Be Mindful	Introductions; explanation of Peer Mentor role; preparing participant for Be Mindful; supporting participant to plan for starting Be Mindful (including making time to start, planning to protect this time, setting a target for the next session)
2	During “Week 2” of Be Mindful, approximately 10 days after the first telephone call	Reviewing plan to get started; planning how to move forward with Be Mindful (including planning time to do it, trouble-shooting how to protect time based on what worked/didn’t work previously, setting a target for the next session)
3	During “Week 4” of Be Mindful, approximately 2 weeks after the second telephone call	Reviewing plan from previous telephone call; planning how to move forward with Be Mindful (including planning time to do it, trouble-shooting how to protect time based on what worked/didn’t work previously, setting a target for the next session); how to use mindfulness in their daily lives (if finished Be Mindful already); closing down mentoring relationship

design; (4) fidelity of the telephone calls to the manual (using telephone call recordings); (5) adherence to the intervention; (6) participant retention; (7) usual practice; (8) feasibility of outcome measures; and (9) design and methods for future health economic analysis.

**Participant-Reported Outcomes** The primary outcome for a later definitive RCT is proposed as psychological well-being, as measured by the Warwick-Edinburgh Mental Well-being Scale (WEMWBS; Tennant et al. 2006). This 14-item measure is scored on a 5-point Likert scale (1: *None of the time* to 5: *All of the time*) and asks participants to rate their feelings and thoughts over the preceding 2 weeks. Questions include “I’ve been feeling good about myself.” Higher scores on this scale indicate higher levels of psychological well-being. The internal consistency of this measure at baseline was  $\alpha = .93$  in this study.

Other outcomes included (all internal consistencies reported for baseline data) psychological distress (Hospital Anxiety and Depression Scale [HADS; Zigmond and Snaith 1983];  $\alpha = .86$ ); health-related quality of life (EQ-5D-5L; van Hout et al. 2012); participant perceptions of family functioning (Family APGAR scale; Smilkstein 1978;  $\alpha = .88$ ); parenting efficacy (Parenting Sense of Competence Scale; Johnston and Mash 1989;  $\alpha = .84$ ); participant-partner relationship (Millennium Cohort Study Wave 2 [2003–2005]); participant-partner agreement (Millennium Cohort Study Wave 2 [2003–2005];  $\alpha = .81$ ); positive impact of the person with ID on the carer and family (Positive Gains Scale; Jess et al. 2020);  $\alpha = .81$ ); participant-child relationship (Child-Parent Relationship scale; Pianta 1995;  $\alpha = .83$ ); and financial indicators to inform the feasibility of future economic analyses.

**Intervention Fidelity** Peer Mentors recorded one of the three telephone calls (selected at random prior to the commencement of the trial) with each participant, with their consent, to

measure the fidelity to the mentoring manual. Peer Mentors were also asked to complete a self-assessment checklist for every telephone call to measure their self-reported adherence to the manual. The fidelity checklist and Peer Mentor self-assessment checklist were developed using information from the manual.

The fidelity checklist was completed by the first author for all recordings, and three recordings (one for each telephone mentoring session) were rated by a second, independent researcher. The fidelity checklist had two sections. The first measured fidelity to the Mentoring Manual, and was tailored to each of the three telephone calls. Each sub-component was rated on a scale of 0–1 (0 = missing/hardly delivered, 2 = fully/mostly delivered), with a maximum score of 14 for session 1, six for session 2, and eight for session 3; scores were converted into percentages. The second section of the fidelity checklist consisted of five global ratings of the telephone mentoring call: positive interactions between mentor and mentee, the active participation of mentees in developing their goals, mentor having good time management, mentor remaining in control of the call, and mentor actively promoting dignity and respect. The maximum score for the global ratings of the telephone calls was ten, using a 0–2 rating scale (0 = missing/hardly present, 1 = partially present, 2 = fully/mostly present).

**Qualitative Data** Semi-structured telephone interviews, informed by the feasibility questions, were conducted with a sample of participants from both arms of the trial. In addition to trial arm, interviews were stratified by whether participants completed Be Mindful and the age of the person with ID to ensure participants with different experiences were included. Participants who disengaged from the study (i.e., did not complete at least the final questionnaire) were also invited to be interviewed. Eighteen participants consented to be interviewed (nine in each trial arm). Within each sub-sample of nine participants, five had completed Be Mindful (and additional telephone calls, where applicable) and four had not.

No participants who disengaged from the study agreed to participate. Recordings of participant interviews were, on average, 31 min long ( $SD = 10.97$ ).

## Data Analyses

**Participant-Reported Outcomes** Primary analysis compared scores on the WEMWBS (psychological well-being) 6 months post-randomization by trial arm using a linear regression model, adjusted for baseline WEMWBS scores, and the prognostic factor of age. Similar methods were applied to the other nine outcomes.

Exploratory analyses used repeated mixed-effects linear models to estimate the time-related changes in all outcomes for both groups combined (to examine overall improvement in outcomes, regardless of trial arm), and also trial arm differences over time, with random intercepts specified for individuals. Four models were run for each outcome, two comparing linear time and then the interaction between time and trial arm. Two further models examined firstly the relationship between logarithmic time-related change and all outcomes (to examine whether the impact of the intervention persisted for both groups combined), followed by the interaction between logarithmic time and trial arm. Comparative fit between the linear change in time and the logarithmic change in time was examined by comparing the  $-2$  log-likelihood of these models.

**Qualitative Analysis** Interviews were transcribed verbatim and analyzed using a deductive framework analysis approach (Ritchie and Spencer 1994), structured with reference to an analytical framework developed to reflect the feasibility questions (including an “other” code to capture data that were interesting, but would not fit into any pre-defined categories). Before analysis could begin, this process involved repeated reading of the transcripts (familiarization), noting initial impressions, and piloting the analytical framework on the first three transcripts. Analysis began with an indexing stage, using the pre-defined analytical framework, and a sample was reliability checked by an independent researcher. Once indexing was complete, a framework matrix was downloaded from NVivo 12 to interpret the data, including the identification of similarities, differences, and patterns.

## Results

### Feasibility Outcomes

**Participant Recruitment and Retention** One hundred and four family carers expressed interest in participating, of these, 64 were screened, and 61 consented to participate. Sixty participants completed baseline measures, representing a 58% recruitment rate. Interviewed participants’ ( $n = 18$ ) main

motivations to participate (some participants provided more than one response) were to reduce stress levels or improve well-being ( $n = 12$ ), and to contribute to research ( $n = 8$ ). Three participants withdrew from the research between baseline data collection and 6 months post-randomization. Reasons for non-participation and participant withdrawal are presented in the CONSORT diagram (Fig. 1).

Of the 57 participants recruited to this feasibility study who did not withdraw, 50 completed measures at the 6-month post-randomization follow-up, an 88% follow-up rate. No participants who disengaged from the research study were interviewed, despite all participants in this category being invited. It is, therefore, not possible to ascertain why they disengaged.

**Peer Mentor Recruitment and Retention** Four parent carers of people with ID (three mothers and one father) were recruited through personal contacts of a member of the research team to be Peer Mentors. Of the four recruited parent carers, three were fully trained within the training timeframe. Two of the three trained Peer Mentors undertook the role, as one Peer Mentor was unable to commit to the role at that time. One Peer Mentor provided support to 17 participants, and the other to 13; this was more than the planned eight participants per Peer Mentor had all four mentors undertaken the role.

**Acceptability of Research Design** Interviewed participants were happy with the randomization procedure and their allocation, although one participant expressed some initial disappointment “because, maybe I thought speaking to someone would be helpful [...] but as the study went on I didn’t mind not having ‘phone calls” (Participant A47, *Be Mindful*, completed). No family carers indicated that the randomization procedure was a reason for them not to participate or withdraw from the study.

Participants allocated to *Be Mindful+* found that the telephone calls reminded and motivated them to do *Be Mindful*. The calls also provided reassurance and time to reflect on their strategies for completion. Some participants thought that they “could probably have managed without [the calls] but it was nice to have them.” (Participant B14, *Be Mindful+*, completed). Participants allocated to *Be Mindful* generally felt that they were able to complete the course at their own pace, and that they did not have time to speak to a mentor as well. No participants allocated to *Be Mindful+* who did not complete all three telephone calls agreed to be interviewed; we are therefore unable to establish whether this might have been a reason for their disengagement. One participant in the *Be Mindful* arm indicated that they did not think that “speaking to anyone would have made any difference” to their propensity to complete *Be Mindful* (Participant C24, *Be Mindful*, did not complete).

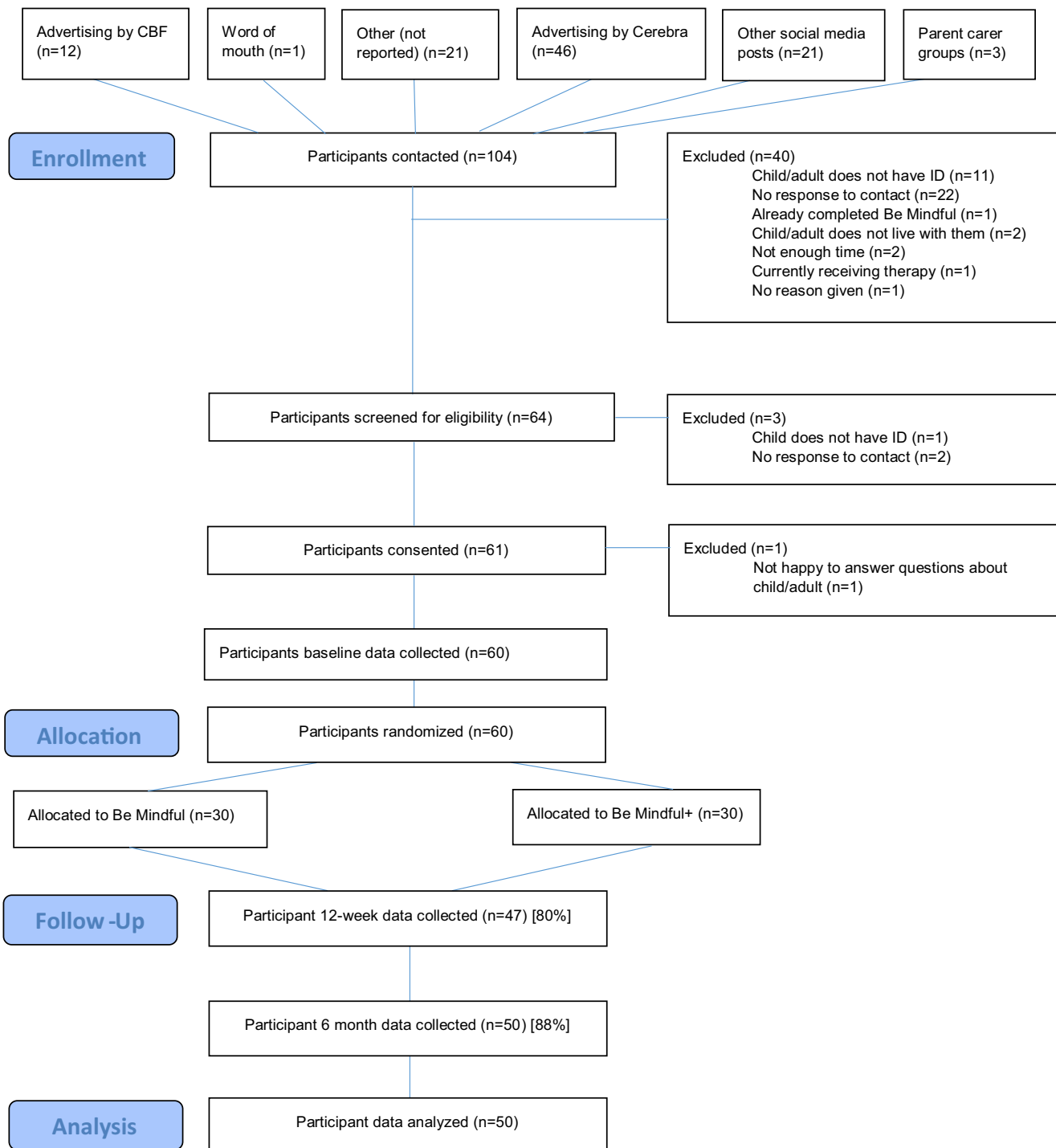


Fig. 1 MOST-ID CONSORT flowchart

**Fidelity of Intervention Implementation** The fidelity checklist assessed the fidelity of the Peer Mentor telephone calls and global ratings of the sessions; summary data are presented in Table 2. Consistently missing elements were outlining the purpose of the session, asking the participant to summarize their plan to start/continue/complete Be Mindful, and asking the participant to set a goal to achieve before the next

telephone call. Only one of the Peer Mentors completed the self-assessment checklists (summary data in Table 4).

**Intervention Adherence** Thirteen *Be Mindful* participants (from 30) fully completed Be Mindful before the end of the trial (43%). Fourteen of the 27 (three participants in this arm withdrew before the end of the trial) *Be Mindful+* participants



**Table 4** Summary statistics of fidelity to the manual by mentoring session

	Fidelity to the manual checklist							Self-assessment checklist			
	Fidelity to the manual (%)				Global rating (%)			Fidelity to the manual (%)			
Mentoring session	<i>n</i>	Median	IQR	Min to max	Median	IQR	Min to max	<i>n</i>	Median	IQR	Min to max
1	5	71	57 to 71	50 to 79	90	90	90 to 100	17	90	90 to 100	50 to 100
2	7	67	50 to 75	50 to 100	100	90 to 100	80 to 100	13	86	86 to 100	71 to 100
3	10	63	53 to 75	25 to 75	100	85 to 100	60 to 100	12	100	100	86 to 100
All	22	65	50 to 75	25 to 100	100	90 to 100	60 to 100	42	100	90 to 100	50 to 100

*IQR* interquartile range

fully completed *Be Mindful* (52%). Further adherence data is presented in Table 5.

Of the 27 participants to complete *Be Mindful*, three completed within the intended timeframe (four weeks). The mean time taken to complete *Be Mindful* for all 27 completers was 65 days (median = 58.5 days, range = 31–133 days). For *Be Mindful* participants, the mean time to complete the intervention was 61 days (median = 54 days, range = 31–133 days), and for *Be Mindful+* participants, it was 70 days (median = 68 days, range = 31–130 days). A between-subjects *t* test showed that the time taken to complete *Be Mindful* did not significantly differ between participants in the *Be Mindful* and the *Be Mindful+* groups ( $t = .21(12)$ ,  $p = .84$ ).

Of the 30 *Be Mindful+* participants, 23 received all three Peer Mentor telephone calls; 14 of these participants completed the intervention. One participant received no Peer Mentor telephone calls, five received one call, and one received two calls; none of these seven participants completed the intervention. Interviewed participants reported that their Peer Mentors were supportive and encouraging, and that the telephone calls helped to “sort your own problem out, [...] just having the conversation allowed me to answer my own questions” (Participant B14, *Be Mindful+*, completed). Some *Be Mindful* participants said that a Peer Mentor could have helped

to “remind you of the day to day challenges” and “of the direction I needed to be going on.” (Participant C7, *Be Mindful*, did not complete).

**Usual Practice** Twenty-two participants reported, at baseline, that they were currently receiving support for their mental health/well-being, with some participants receiving more than one intervention. Medication was most common ( $n = 19$ ), followed by seeing a psychologist ( $n = 4$ ), psychiatrist ( $n = 3$ ), and attending parent carer forums/support groups ( $n = 3$ ). Although two-thirds of participants were not receiving any support for their well-being, interviewed participants recognized that it was important “to look after your own mental health and actually it doesn’t need to take a long time to do that.” (Participant B12, *Be Mindful+*, completed). While it was acknowledged that mindfulness was not intended to change what was happening in family carers’ lives, interviewed participants were aware of the differences that *Be Mindful* had made to their perceptions about their lives and interactions with their family members. This was particularly evident with the people with ID for whom they cared, whereby participants reported being calmer which led to less stressful interactions.

Interviewed participants highlighted that *Be Mindful* was easy to use on a range of electronic devices (i.e., laptop/desktop, tablet computer, mobile telephone) and meant that they could “do it at home, I don’t have to go anywhere, I can do it when I want to” (Participant A47, *Be Mindful*, completed) making it easier to access for busy family carers than face-to-face interventions as there was no need to travel and it can be completed in their own time, around other commitments. However, the online nature of *Be Mindful* sometimes made it difficult to keep going when other aspects of life became busy; this was attributed to not having anyone to “hold them accountable.”

**Feasibility of Outcome Measures** Participants were offered a choice of three methods of questionnaire completion: online, post, or telephone. Forty-seven participants elected to

**Table 5** Adherence data by trial arm

	<i>Be Mindful</i> ( <i>n</i> = 30)	<i>Be Mindful+</i> ( <i>n</i> = 27)
Did not start <i>Be Mindful</i>	4	1
Stopped after introduction	3	5
Stopped after “Week 1”	4	5
Stopped after “Week 2”	1	1
Stopped after “Week 3, Day 1”	1	0
Stopped after “Week 3”	4	3
Stopped after “Week 4”	0	1
Fully completed <i>Be Mindful</i>	13	14

complete questionnaires online, 10 in the post, and three via telephone (one changed from telephone to online after the baseline questionnaire). Interviewed participants were happy with their completion method, with online completers stating that it was convenient, did not take very long, and it seemed easier than the other methods. Postal completers were generally reluctant to use technology to complete questionnaires, and were grateful for a postal option. No telephone completers were interviewed. Personal questions were difficult to think about for four interviewed participants, but this was not prohibitive of them completing questionnaires, nor was it detrimental to their overall sense of well-being.

At baseline, participants ( $n = 60$ ) generally completed all outcome measures. However, there was a small amount of missing data for questions about finances (weekly income,  $n = 6$ ; raising £2000 in an emergency,  $n = 2$ ), participant-partner agreement ( $n = 1$ ), partner relationship satisfaction ( $n = 1$ ), and the number of people living in the household ( $n = 1$ ). Some participants did not complete every question on the Parenting Efficacy Scale, so this could not be summed and used in the analyses for them ( $n = 3$ ). One interviewed participant found the questions about finances to be intrusive, and so elected not to answer them; this may be reflective of other participants' feelings about these questions.

Forty-seven participants completed outcome measures 12 weeks post-randomization, with a small amount of missing data for questions about participant-partner agreement ( $n = 1$ ) and partner relationship satisfaction ( $n = 2$ ). There were some missing data on the HADS ( $n = 2$ ), Family APGAR ( $n = 4$ ), Child relationship scale ( $n = 3$ ), and the Parenting Efficacy Scale ( $n = 5$ ), meaning that these could not be summed and analyzed for these participants.

Fifty participants completed outcome measures 6 months post-randomization, and three of these were minimum datasets (including only Positive Gains Scale, WEMWBS, and Family APGAR). Missing data on the HADS ( $n = 4$ ), Family APGAR ( $n = 1$ ), Child relationship scale ( $n = 4$ ), and the Parenting Efficacy Scale ( $n = 5$ ) meant that these could not be summed and analyzed for those participants.

**Design and Methods for Future Health Economic Analysis** At baseline, participants ( $n = 60$ ) generally completed all resource use questions and the health-related quality of life measure, except for two participants who did not complete the resource use section in its entirety. At 12 weeks post-randomization, participants ( $n = 47$ ) completed all resource use and health-related quality of life questions, with a small number of exceptions, these were health-related quality of life ( $n = 1$ ) and how is your health today ( $n = 1$ ), and three participants did not complete the resource use section in its entirety. Participants ( $n = 50$ ) completed the all health-related quality of life outcome measures at 6 months post-randomization, except for the three participants who only completed the minimum dataset

(as described above). Two other participants did not complete the resource use section in its entirety.

## Exploratory Analysis of Participant Outcomes

**Between Group Differences at 6 months** At 6 months post-randomization, there was a greater increase for psychological well-being for *Be Mindful+* compared with *Be Mindful*, but this was not statistically significant ( $\beta = 2.88, p = .32$ ).

Comparative decreases at 6 months for *Be Mindful+* versus *Be Mindful* were observed for psychological distress ( $\beta = -.08$ ), health-related quality of life ( $\beta = -.04$ ), perception of family functioning ( $\beta = -1.16$ ), parenting efficacy ( $\beta = -.04$ ), and the Positive Gains Scale ( $\beta = -.41$ ). However, these differences were not statistically significant. Other outcomes showed an increase at 6 months for *Be Mindful+* relative to *Be Mindful*. These group differences for participant-partner relationship ( $\beta = .47$ ), participant-partner agreement ( $\beta = .31$ ), participant-child conflict ( $\beta = .57$ ), and participant-child closeness ( $\beta = .33$ ) were not statistically significant. Results for all outcomes at 6 months are outlined in Table 6.

Between trial arm effect sizes are displayed in Fig. 2. The largest effect sizes were observed for psychological well-being (SMD = .27), participant-partner relationship (SMD = .30), family functioning (SMD =  $-.38$ ), and participant-partner agreement (SMD = .26). These effect sizes were small to moderate (Cohen 1988), albeit with rather large confidence intervals. Somewhat smaller effect sizes were observed for psychological distress (SMD =  $-.10$ ), parenting efficacy (SMD =  $-.07$ ), Positive Gains Scale (SMD =  $-.09$ ), participant-child conflict (SMD = .09), and participant-child closeness (SMD = .06). Again, wide confidence intervals for all outcomes suggested imprecision of the effect sizes estimated.

**Combined Group Analyses** When participants from both trial arms were combined, there was a significant time-related increase for psychological well-being ( $\beta = 1.15, p < .001$ ). Furthermore, the logarithmic change in psychological well-being was also statistically significant ( $\beta = 3.96, p < .001$ ), suggesting that the initial increases in psychological well-being reduced over time. Indeed, the logarithmic model showed better overall fit than the linear model ( $-2LL = 1129.90$  vs  $1134.18$ ). However, these time-related changes did not differ between the two trial arms for either linear ( $\beta = .40, p = .40$ ) or logarithmic ( $\beta = 1.37, p = .39$ ) change.

Furthermore, both psychological distress ( $\beta = -1.16, p < .001$ ) and participant-child conflict ( $\beta = -.49, p < .001$ ) showed significant decreases over time. Logarithmic trajectories suggested that these time-related improvements were greatest between baseline and 12 weeks, but slowed over time for both psychological distress ( $\beta = -3.94, p < .001$ ) and

**Table 6** Between-arm comparisons for outcomes at 6 months post-randomization

	Be Mindful	Be Mindful+	Adjusted mean difference*	<i>p</i> value
Psychological well-being				
Baseline	37.93 (8.58)	38.70 (9.77)	-	
6 months post-randomization	43.52 (10.23)	47.43 (10.69)	2.88 (- 2.88 to 8.63)	.319
Psychological distress				
Baseline	22.60 (6.00)	20.97 (8.30)	-	
6 months post-randomization	15.32 (7.08)	13.71 (9.59)	- .08 (- 4.64 to 4.48)	.971
Health-related quality of life				
Baseline	.73 (.25)	.75 (.20)	-	
6 months post-randomization	.80 (.15)	.75 (.19)	- .04 (- .10 to .03)	.273
Participant-partner Relationship				
Baseline	4.64 (1.62)	4.57 (1.50)	-	
6 months post-randomization	5.00 (1.56)	5.21 (1.58)	.47 (- .22 to 1.15)	.173
Perceived family functioning				
Baseline	5.23 (3.29)	5.00 (2.64)	-	
6 months post-randomization	5.19 (3.06)	10.00 (3.87)	- 1.16 (- 2.60 to .28)	.687
Parenting efficacy				
Baseline	27.32 (6.43)	30.24 (7.61)	-	
6 months post-randomization	27.96 (6.64)	30.60 (5.17)	- .04 (- 3.43 to 3.35)	.980
Positive Gains Scale				
Baseline	26.97 (5.03)	28.16 (4.16)	-	
6 months post-randomization	27.34 (5.12)	28.30 (3.69)	- .41 (- 2.44 to 1.63)	.691
Participant-partner agreement				
Baseline	4.24 (1.40)	3.55 (1.48)	-	
6 months post-randomization	4.36 (1.09)	4.41 (1.33)	.31 (- .39 to 1.00)	.375
Participant-child conflict				
Baseline	25.73 (6.25)	23.30 (6.90)	-	
6 months post-randomization	22.00 (6.21)	21.05 (6.24)	.57 (- 2.49 to 3.63)	.707
Participant-child closeness				
Baseline	25.87 (5.56)	24.27 (5.85)	-	
6 months post-randomization	25.80 (5.07)	25.67 (5.53)	.33 (- 1.73 to 2.40)	.748

Data are mean (SD) or mean (95% CI)

\*Models adjusted for baseline scores and age. All analyses are based on a linear regression model. Grouping variable coded *Be Mindful* = 0, *Be Mindful+* = 1

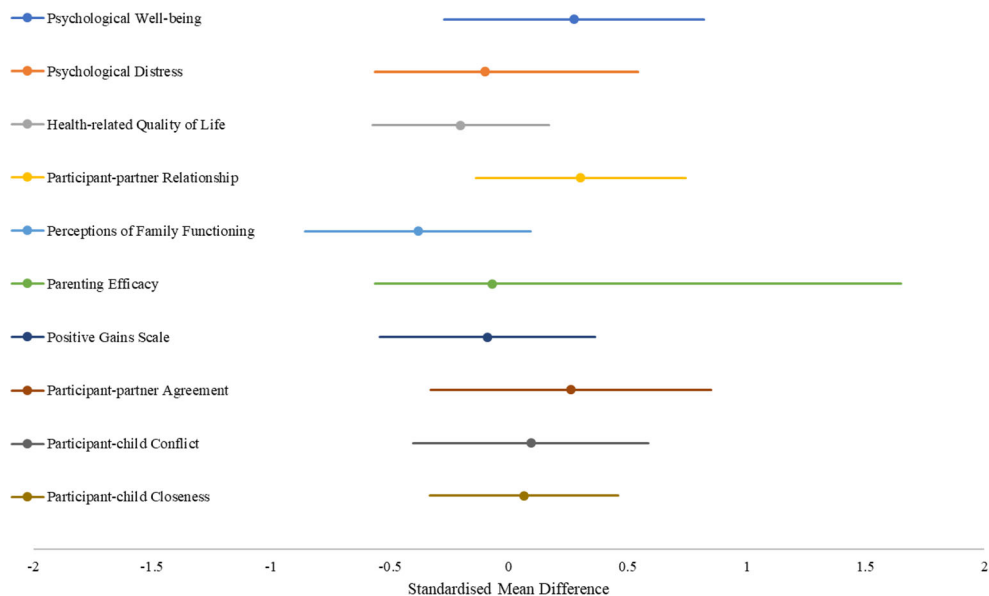
participant-child conflict ( $\beta = -1.65, p < .001$ ). For psychological distress, the logarithmic model again showed better overall fit than the linear model (-2LL = 1001.19 vs 1006.32); this was also the case for participant-child conflict (-2LL = 917.97 vs 921.22). However, the aforementioned time-related changes did not differ between the two trial arms for either linear or logarithmic change.

Participant-partner relationship ( $\beta = .08, p = .01$ ) and participant-partner agreement ( $\beta = .06, p = .03$ ) also showed significant increases over time. As with previous statistically significant linear outcomes, logarithmic trajectories suggested that these time-related increases showed a statistically significant slowing over time for both participant-partner relationship ( $\beta = .28, p = .01$ ) and participant-partner agreement ( $\beta =$

$.20, p = .03$ ). The logarithmic model for participant-partner relationship showed better overall fit than the linear model (-2LL = 322.13 vs 324.46); this result was mirrored for participant-partner agreement (-2LL = 331.32 vs 334.24). However, neither linear nor logarithmic change time-related changes showed statistically significant differences between the two trial arms.

When the remaining outcomes were analyzed for the combined sample, neither health-related quality of life, perceptions of family functioning, parenting efficacy, Positive Gains Scale, or participant-child closeness showed significant linear or logarithmic change over time. These linear and logarithmic patterns of time-related change did not differ between the two groups. All longitudinal models are further detailed in Table 7.

**Fig. 2** Standardized mean differences (and accompanying 95% confidence intervals) of outcomes at 6 months post-randomization between trial arms



### Discussion

The feasibility outcomes indicate that it would be possible to recruit and retain family carers to a definitive RCT of this intervention, and that the study design and methods (e.g., randomization, outcome measures) are acceptable to participants. Be Mindful and the additional Peer Mentor telephone calls were well received (in terms of intervention and telephone call adherence, and qualitative process evaluation data) by family carers of people with ID. This finding highlights that the additional element was not burdensome for participants; indeed, it was an additional motivation for participants to complete Be Mindful. The Peer Mentor telephone support sessions can be delivered with high fidelity to the manual, but this is

inconsistent and requires further development and piloting work (e.g., increased training for Peer Mentors). Two-thirds of family carers in this study were not receiving any therapeutic intervention for their well-being at baseline and, as such, there would be little overlap with existing services and this intervention. From the preliminary comparison data, there are small, but non-significant, improvements for *Be Mindful+* relative to *Be Mindful* over time.

The study design appears to be acceptable to participants, who were happy to be randomized and to complete questionnaires at all three time points with minimal missing data. It was feasible to collect data about resource use and health-related quality of life, although it was never the intention to analyze these data within this feasibility study. As it has been

**Table 7** Longitudinal models examining time-related change in outcomes

Variable	Psychological well-being		Psychological distress		Health-related quality of life		Participant-partner relationship		Perceived family functioning	
	Coefficient	SE	Coefficient	SE	Coefficient	SE	Coefficient	SE	Coefficient	SE
Linear time slope (random)	1.15*	.24	- 1.16*	.17	.01	.00	.08*	.03	- .09	.10
Logarithmic (Ln) change in time	3.96*	.79	- 3.94*	.57	- .02	.01	.28*	.10	- .26	.32
Condition * Linear slope	.40	.48	.06	.35	- .01	.01	.07	.22	- .17	.19
Condition * Ln change	1.37	1.58	.10	1.15	- .01	.022	.22	.20	- .48	.64
Variable	Parenting efficacy		Positive Gains Scale		Participant-partner agreement		Participant-child conflict		Participant-child closeness	
	Coefficient	SE	Coefficient	SE	Coefficient	SE	Coefficient	SE	Coefficient	SE
Linear time slope (random)	.11	.23	.05	.08	.06*	.03	- .49*	.12	.13	.09
Logarithmic (Ln) change in time	.66	.77	.23	.26	.20*	.09	- 1.65*	.41	.44	.31
Condition * Linear slope	- .13	.47	- .11	.15	- .08	.06	.29	.25	.11	.19
Condition * Ln change	- .61	1.55	- .38	.51	.31	.19	.95	.82	.31	.62

\**p* < .05. Coefficient is unstandardized beta

established that it is possible to collect these data, full health economic analyses can be undertaken in a future definitive trial.

Data pertaining to usual practice for well-being interventions indicates that two-thirds of participants are not receiving any support. Interviewed participants recognized that it is important for family carers of people with ID to look after their own mental health and well-being, but this can be difficult for many family carers to achieve due to competing commitments and being unable to attend regular in-person interventions (Lunsky et al. 2017). The provision of a straightforward, online intervention offers a potential solution to this, as it can be completed alongside other commitments in a flexible way. Interviewed participants indicated that *Be Mindful* was successful in improving their perceptions of their experiences, and in reducing stressful encounters with the person with ID for whom they cared. These findings provide merit to continuing research to establish an evidence-base for the use of online mindfulness interventions for family carers of people with ID.

When both groups were combined, there were significant improvements in participant-reported well-being, psychological distress, participant-child conflict, participant-partner relationship, and participant-partner agreement; however, these changed less over time. Preliminary analysis of the intervention effectiveness between groups should be interpreted with caution due to the small sample. The current study was not powered to detect differences in outcomes between the two arms of the trial and this was not the purpose of this feasibility study. Preliminary results indicate that there is a small, but non-significant, benefit to being in the *Be Mindful+* arm across the outcomes. Mindfulness measures were not included in this feasibility study, and in a larger definitive trial, it will be important to include appropriate measures as it will then be possible to undertake exploratory analyses of intervention effects mediated by changes in key process measures.

Furthermore, there was no difference in the adherence to *Be Mindful* between the two groups, indicating that the additional element of telephone support was not burdensome. Telephone support, despite the inconsistencies in fidelity, was reported to be beneficial to participants' motivation to continue with *Be Mindful*, and provided a space for reflection about their completion of the course. This finding is reflected in the wider literature about guided support for online interventions (Spijkerman et al. 2016). This additional element, therefore, provides the opportunity to tailor support to family carers in a way that appears to offer a small benefit over not receiving additional support and remains easy to access for family carers of people with ID. The addition of telephone support is a time- and cost-effective strategy of tailoring an existing intervention for family carers of people with ID, and should be extended and examined further in future research.

## Limitations and Future Research

While recruitment was completed with minimal effort (online through a small number of sources) in a short space of time, most participants were mothers which does not provide data on pathways to recruit other family carers of people with ID. Recruitment efforts in a future trial should, therefore, be such to engage a wider cross-section of family carers (e.g., fathers, grandparents, adult siblings). Furthermore, study retention at 6 months post-randomization was high, suggesting that a larger trial is feasible in this respect. The fidelity to the *Mentoring Manual* was inconsistent, and perhaps an artifact of limited time available to train Peer Mentors in this study. Future research should seek to rectify this by providing ample training time for Peer Mentors and ensuring that all Peer Mentors understand the importance of fidelity.

It was possible to recruit Peer Mentors, but only 50% of the recruited mentors were trained and able to commit to the project before it began. We would likely need to over-recruit Peer Mentors to this role in a future study to ensure that there was an appropriate number of mentors to deliver telephone support. Sufficient time to complete training activities is also required for a future trial, and the time taken to do this should not be underestimated. The fidelity to the *Mentoring Manual* was inconsistent, and this would need reviewing before a future trial in conjunction with a revision of the Peer Mentor training activities. While there is increasing recognition of the importance of structured peer support from people share circumstances (e.g., they are a family carer of a person with ID) (Dykens et al. 2014; Lunsky et al. 2018), it is important to understand their training and support needs (Lunsky et al. 2018); this will be important to maintaining intervention fidelity. The consistently missing elements of the mentoring calls were directly related to the GROW model (Whitmore 1996) and, upon reflection, the importance of including these elements was perhaps not clear to the Peer Mentors; this would be rectified in future training activities. It is also clear, from these data in conjunction with the self-assessment data, that recordings are needed in a future definitive RCT to establish the fidelity to the manual, as there are inconsistencies between the scores using the two methods for fidelity (Mentor and Researcher ratings).

These results indicate that it is feasible to deliver *Be Mindful* with additional Peer Mentor telephone support to family carers of people with ID, and to research the effectiveness of this intervention using the design and methods in this feasibility trial. Further research should now be undertaken to answer some of the outstanding questions (e.g., recruitment of a wider cross-section of family caregivers) and to evaluate the effectiveness and cost-effectiveness of offering *Be Mindful* plus additional telephone support to family carers of people with ID in improving their well-being.

**Author Contributions** SF contributed to study design, designed and prepared materials, undertook data collection and analysis, and wrote the paper. RH designed and developed the study, oversaw data collection, and collaborated on analysis and writing of the paper. CB and SH contributed to study design, data collection, and writing of the paper. YL and JW contributed to study design and writing of the paper. TB undertook participant randomization, some data analysis, and wrote part of the method and results.

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## Compliance with Ethical Standards

**Ethical Approval** This study was approved by the University of Warwick's Humanities & Social Sciences Research Ethics Committee (58/17-18) and has been performed in accordance with the ethical standards laid down in the 1964 Declaration of Helsinki and its later amendments.

**Consent to Participate** All participants gave their fully informed consent prior to their inclusion in this study. All details that might disclose the identity of participants have been omitted.

**Consent to Publish** All participants gave their consent for their pseudonymized data to be published in a research article.

**Conflict of Interest** CB and SH both work for the Mental Health Foundation, who developed and launched Be Mindful with their technical partner Wellmind Media in 2012. Neither CB or SH was involved in the analysis or interpretation of the data.

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