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Mindfully Valuing People Now

An evaluation of *Introduction to Mindfulness Workshops* for people with learning disabilities

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SUMMARY

Background

This report describes the findings of an evaluation of the *Mindfully Valuing People Now* project. This project involved the development of easy read information on mindfulness and a mindfulness CD, and a series of *Introduction to Mindfulness* workshops for people with learning disabilities, their families and staff that were held in the North West of England in 2011. Pathways Associates and the North West Training and Development Team carried out the project which was funded by Improving Access to Psychological Therapies (iapt). Researchers from Manchester Metropolitan University and Manchester Learning Disability Partnership were commissioned to carry out an evaluation of the project. The evaluation consisted of a systematic literature review and feedback from people who took part in the project via workshop evaluation forms and in depth qualitative interviews.

Mindfulness

Mindfulness is the practice of focussing attention in a non-judgemental, non-reactive way on the present moment and what is happening in an individual's mind, body and the world around them. Mindfulness forms the basis of mindfulness-based stress reduction and mindfulness-based cognitive therapy programmes and there is growing evidence of the benefits of mindfulness for managing a range of difficulties including stress, anxiety, depression, pain and disordered eating.

Mindfulness has not been widely used with people with learning disabilities, although they may experience significantly more mental health problems than the general population. The literature review identified some research studies, the majority of which have been carried out by Nirbhay Singh and colleagues in the USA. These studies suggest that mindfulness training and practice can lead to improvements in behaviour, psychological well-being and lifestyle for people with learning disabilities, and improve the quality of the support that they receive. Mindfulness training has been provided directly to people with learning disabilities, their family or staff. However, these studies are small-scale and methodological weaknesses make it difficult to draw firm conclusions about the effectiveness of mindfulness and the generalisability of the study findings.

The Mindfully Valuing People Now project evaluation: methods and key findings

People who took part in the *Introduction to Mindfulness* workshops were asked to complete a workshop evaluation form. 110 evaluation forms were filled in at 8 workshops held during self-advocacy group meetings and healthy lifestyles events. In addition, people were randomly selected to be invited to take part in interviews about their experiences of the workshop and whether they had used mindfulness since the workshop; six interviews were carried out.

The feedback on the workshops was generally positive:

- 88% of people scored the workshops as 'good' or 'very good' on the evaluation forms

- Evaluation forms and interviews showed that people found the workshops very relaxing, in particular the body scan, and that they valued the opportunity to talk about their experiences with other people
- People were overwhelmingly positive about the workshop facilitator who was described as very relaxing and calming
- It is important that mindfulness sessions are held in a quiet venue that is large enough for the number of people who attend
- People appreciated being given a copy of the mindfulness CD to take home to listen to in future
- Three of the people who were interviewed had listened to the CD since the workshops. Two of these people had found the CD useful in terms of helping them to relax and cope with phobias and stress resulting from harassment from the local community
- People wanted more mindfulness sessions and felt that other people with learning disabilities would benefit from mindfulness.

Conclusions

The interviews revealed that people with learning disabilities may have very stressful lives which can impact on their mental health and quality of life. Mindfulness could be a useful way of helping people to cope with such stress. The mindfulness sessions were clearly acceptable to people with learning disabilities who found them very relaxing and wanted further sessions. Further work is needed to develop and evaluate a series of mindfulness sessions and an accompanying manual. Due to the paucity of published research on the use of mindfulness with people with learning disabilities it is important that any developments are evaluated and the findings published and shared.

INTRODUCTION

This report provides the findings from an evaluation of *Mindfully Valuing People Now,* a project that aimed to introduce mindfulness to people with learning disabilities, their families and staff in the North West of England. The report gives some background to mindfulness and the project, systematically reviews the literature on mindfulness relating to people with learning disabilities, and explores the experiences of mindfulness reported by people with learning disabilities who took part in mindfulness workshops held as part of the project.

Mindfulness

Mindfulness is the practice of focussing attention purposefully in a non-judgmental, non-reactive way on the present moment and what is happening in an individual's mind, body and the world around them:

> *Being mindful* can be described as having a clear, calm mind that is focused on the present moment in a nonjudgmental way. Mindfulness allows an individual to consider alternative ways to perceive and respond to a situation, beyond what he or she previously realised. (Singh, Lancioni, Winton, Fisher, Wahler, McAleavey, Singh, & Sabaawi, 2006, p170)

Mindfulness approaches differ from existing therapy programmes as they seem to improve the acceptance of symptoms which are difficult to change, help people to focus on the present moment, and install a 'cognitive metareflective capacity that enhances the degree of freedom of patients' (Fjorback, Arendt, Ørnbøl, Fink, & Walach, 2011, p. 103). There is growing evidence of the benefits of mindfulness for managing a range of difficulties including stress, anxiety, depression, pain and disordered eating (Baer, 2003).

Mindfulness is a core strategy within comprehensive treatment packages such as mindfulness-based stress reduction (Kabat-Zinn, 1990) and mindfulness-based cognitive therapy (Segal, Williams, & Teasdale, 2002). Mindfulness-based stress reduction is a structured group programme that uses mindfulness meditation to improve physical and psychological well-being:

> Participants are invited to focus with an interested, accepting and non-judgemental attitude on their pain, difficult sensations, emotions, cognitions and behaviour. This practice may lead to change in thoughts and behavioural patterns or in the attitudes towards thoughts, sensations and emotions. The improved self-observation may promote use of better coping skills (Fjorback, et al., 2011, p. 103)

Mindfulness-based stress reduction consists of eight weekly 2-2½-hour sessions with daily home assignments and a day retreat between week 6 and 7 (Kabat-Zinn, 1990). The programme cultivates mindfulness through formal practices such as body scan and sitting meditation and encourages the integration of these practices into everyday life as a coping resource (Fjorback, et al., 2011). Mindfulness-based cognitive therapy is an adaptation of mindfulness-based stress reduction which incorporates elements of cognitive therapy to facilitate a 'detached or decentred view of one's thoughts'

(Fjorback, et al., 2011, p. 103). Mindfulness-based cognitive therapy consists of eight weekly 2-hour sessions and focuses more on thoughts than mindfulness-based stress reduction. National Institute for Health and Clinical Excellence guidelines recommend mindfulness-based cognitive therapy for people who have experienced depression (National Institute for Health and Clinical Excellence, 2009).

Mindfully Valuing People Now

To date, mindfulness has not been widely used with people with learning disabilities, even though this population experiences significantly more mental health problems than the general population (Emerson & Baines, 2010). In 2010 Pathways Associates and the North West Training and Development Team gained funding from Improving Access to Psychological Therapies (iapt) to introduce mindfulness to people with learning disabilities, their families and staff across the North West region through the *Mindfully Valuing People Now* project. This project consisted of introduction to mindfulness workshops for people with learning disabilities, their families and staff, the development of mindfulness easy read training material and a mindfulness CD, and an evaluation of the project.

Twelve workshops were provided as part of the project. 171 people took part in the workshops: approximately 114 people with learning disabilities and 57 family carers and staff[1]. Six workshops were held with self advocacy groups, one workshop was held at the 2011 North West Conference for Self Advocates, three workshops were held with carers groups and two workshops were held as part of health events organised by local learning disability services. The majority of workshops were facilitated by an experienced mindfulness practitioner (Dene Donalds), although one workshop was facilitated by two community learning disability nurses who had attended an introductory workshop. Each workshop included a brief background to mindfulness and the body scan where participants are led through a guided relaxation exercise focusing on different parts of their body.

As part of the project an evaluation of the workshops was carried out by researchers from the Manchester Learning Disabilities Research Group[2]. The evaluation consisted of three components:

- Literature review
- A questionnaire evaluation of the workshops
- Interviews with workshop participants

The methods used and key findings from each component of the evaluation are summarised below.

[1] It is not possible to give exact numbers of people with learning disabilities, paid staff and family carers as this information was not asked for on the signing in sheets for the workshops.
[2] The Manchester Learning Disabilities Research Group consists of researchers and practitioners from Manchester Metropolitan University (MMU) and Manchester Learning Disability Partnership (MLDP)

SYSTEMATIC LITERATURE REVIEW AND NARRATIVE ANALYSIS

There have been a number of systematic reviews and meta-analysis reviews of the use of mindfulness-based interventions (for example, Baer, 2003 and Fjorback, et al., 2011). However, these have not focused on people with learning disabilities. Some useful literature reviews have been written looking at the use of mindfulness with people with learning disabilities (Office of the Senior Practitioner., 2007; Robertson, 2011); however, these have not been carried out very systematically and do not include recent studies. Therefore, a systematic literature review of existing research evaluating the use of mindfulness with people with learning disabilities was carried out to provide a context to the evaluation. The review objective was to assess the effectiveness of mindfulness training and practice in relation to people with learning disabilities.

Methods

Identification and selection of studies

The following databases were searched in December 2011: EMBASE, MEDLINE, AMED, CINAHL, PSYCHINFO using the following search strategy:
(learning AND disab*) OR (mental* AND retard*) OR (intellectual* AND disab*) OR (developmental* AND disab*) AND mindfulness.

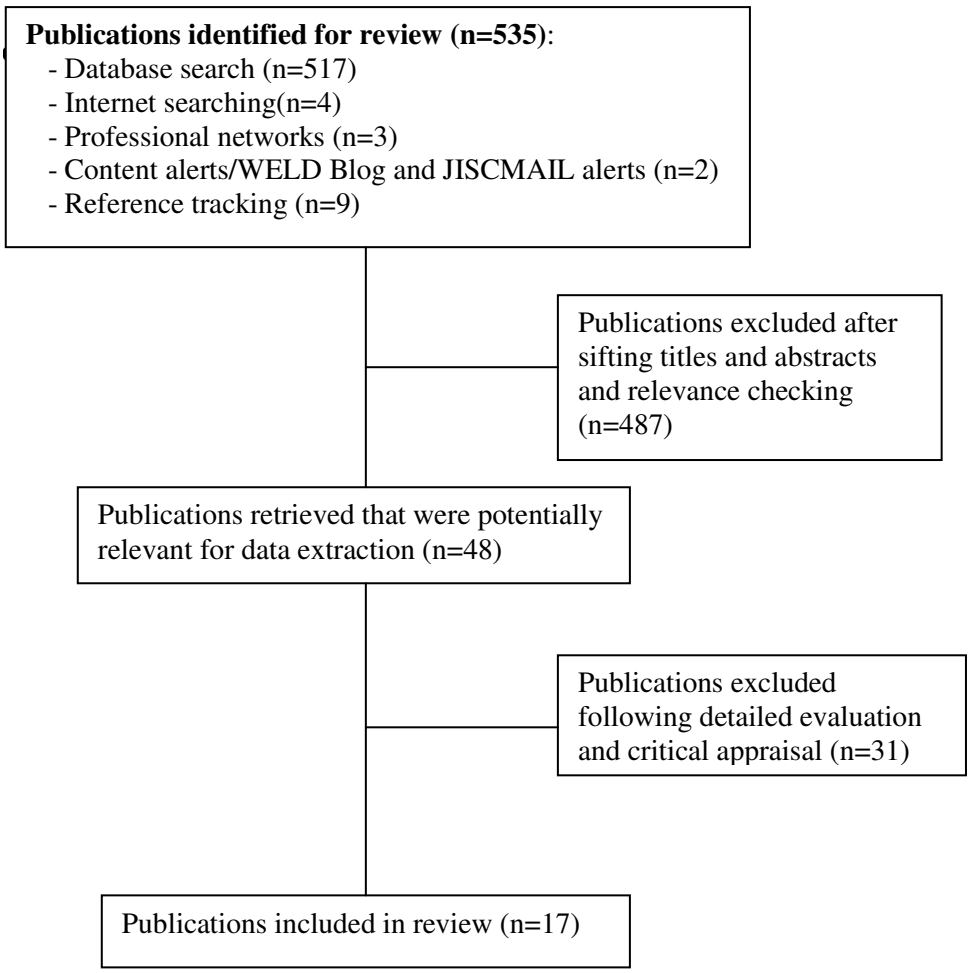
A message was also posted on the Jiscmail list *Mindfulness and IDD* to find out if any professionals or academics interested in the field were aware of any additional publications. Citation tracking and checking of reference lists from journal articles identified by the search were also carried out.

Papers were included if they described a study evaluating mindfulness with people with learning disabilities, their family members or staff and were published in an English language journal from 1980-Dec 2011. Papers were excluded if they involved (i) people with Autistic Spectrum Conditions, ADHD, conduct disorder or educational disabilities (e.g. dyslexia) but not learning disabilities, or (ii) people who had brain injuries acquired during adulthood. Studies which described an intervention of which mindfulness formed a component (e.g. Dialectical Behaviour Therapy, Acceptance and Commitment Therapy) were also excluded as mindfulness is not the main component and it would not be possible to distinguish whether it was mindfulness or another aspect of the intervention which was having an impact. A study which examined the impact of mindfulness training for staff working with people with learning disabilities on their interactions with their non-disabled children was also excluded as it did not look at the impact on people with learning disabilities (Singh et al., 2010).

The reviewer (MC) read the titles and abstracts of the papers identified by the search in order to screen for eligibility. Full texts of potentially relevant papers were then obtained and read in full to determine whether they were eligible for inclusion in the review. If there were any doubts about a paper's relevance this was determined by contacting lead authors or through discussion with the reviewer's supervisor (DM) and a clinical psychologist.

Figure 1 gives details of the selection process.

Figure 1: Quality of reporting of meta-analyses (QUORUM) flow diagram



Data extraction

Information was extracted from relevant papers on study aims, design, intervention, sample, setting, length of follow-up, outcomes, and key findings.

Analysis

As the studies identified were not randomised controlled trials a meta-analysis was not possible. Instead a narrative analysis was carried out describing the main findings from the evidence and discussing the methodological strengths and weaknesses of the included studies

Review findings

Seventeen relevant studies were identified. Of these:

- Ten studies evaluated mindfulness training and practice for people with learning disabilities (Table 1)
- Five studies evaluated mindfulness training and practice for staff members or teams working with people with learning disabilities (Table 2)
- Two studies evaluated mindfulness training and practice for parents of people with learning disabilities (Table 3).

The majority of studies (12) were carried out by Nirbhay Singh and colleagues in the United States.

1. Mindfulness training and practice for people with learning disabilities

Singh and colleagues carried out nine of the ten studies focusing on the provision of mindfulness training directly to people with learning disabilities. Mindfulness procedures have been taught to help people with learning disabilities deal with behavioural issues such as anger, aggression and inappropriate sexual arousal, psychological wellbeing, and lifestyle issues such as smoking and weight.

Provision of mindfulness training

Mindfulness training in the studies has incorporated a number of meditation procedures provided over different timeframes in both institutional and community settings by people from a range of backgrounds as described below.

As demonstrated in Table 1 the most commonly taught meditation procedure was *Soles of the Feet* (Adkins, Singh, Winton, McKeegan, & Singh, 2010; Singh, Lancioni, Winton, Adkins, & Singh, 2011; Singh, Lancioni, Winton, Adkins, et al., 2007; Singh, Lancioni, et al., 2011a; Singh, Lancioni, et al., 2011b; Singh, Lancioni, Winton, Singh, Adkins, et al., 2008; Singh et al., 2003). The *Soles of the Feet* meditation procedure:

> Enables the individual to divert attention from an emotionally arousing thought, event or situation to an emotionally neutral part of one's body [the soles of the feet]. The individual is able to stop, focus the mind back on the body, calm down and then make a choice about how to react to the thought, event or situation that triggered the arousal response. Once the procedure is mastered to the point of automaticity, the individual can use it in multiple contexts, whether sitting, standing or walking slowly. It provides the individual with an internalized response that is easy to master and can be accessed in almost any situation. (Singh, et al., 2003, p. 162)

In training individuals are first taught to recognise triggers of, or precursors to, a behaviour and then guided through the specific steps of the Soles of the Feet procedure.

In addition to Soles of the Feet, other mindfulness techniques have been taught to people with learning disabilities in the studies. Mindful eating, visualising and labelling hunger were used in addition to Soles of the Feet in a mindfulness based health wellness programme (Singh, Lancioni, Singh, et al., 2011; Singh, Lancioni, Winton, Singh, McAleavey, et al., 2008). Mindful observation of thoughts, a series of

mindfulness procedures (e.g. focusing on the breath, visualising and observing thoughts as clouds passing through awareness), was taught to sexual offenders to help them to disengage themselves from their thoughts (Singh, Lancioni, Winton, Adkins, et al., 2011). The mindfulness-based smoking cessation programme reported in Singh, Lancioni, Winton, et al. (2011a) consisted of three components: intention, mindful observation of thoughts and Soles of the Feet. Chilvers, Thomas and Stanbury (2011) taught a range of mindfulness practices (e.g. observing breathing, observing noises and objects).

In the majority of studies mindfulness training was provided to participants with learning disabilities individually; however, Chilvers et al. (2011) held group sessions. Mindfulness training programmes have been provided in institutional settings such as psychiatric hospitals and forensic mental health facilities (Chilvers, et al., 2011; Singh, Lancioni, Winton, Adkins, et al., 2011; Singh, Lancioni, Winton, Singh, Adkins, et al., 2008; Singh, et al., 2003), and community settings with people living in group homes or with their family (Adkins, et al., 2010; Singh, Lancioni, Singh, et al., 2011; Singh, Lancioni, Winton, Singh, McAleavey, et al., 2008; Singh, Lancioni, Winton, Adkins, et al., 2007; Singh, Lancioni, Winton, et al., 2011a; Singh, Lancioni, Winton, et al., 2011b).

The length and manner of training in mindfulness techniques has varied. Training in the *Soles of the Feet* technique to deal with behavioural issues has tended to involve five consecutive days of intensive training with daily supervised role-play and practice sessions, followed by home practice assignments (Singh, Lancioni, Winton, Adkins, et al., 2007; Singh, Lancioni, Winton, Singh, Adkins, et al., 2008; Singh, et al., 2003). In the study by Adkins and colleagues (2010) participants received 1 hour training per day, 5 days a week for 2, 4 or 5 weeks, followed by practice twice daily and whenever a trigger was present. Chilvers et al. (2011) held twice weekly 30-minute mindfulness sessions over a 6-month period. Each session consisted of three exercises (one 'observation', one 'description' and one 'participation') focusing on different mindfulness practices (e.g. observing breathing, observing noises and objects). In the recent study where a person with learning disabilities taught the *Soles of the Feet* technique to his peers at their request, there was 1-hour initial training in the first week, followed by meeting twice in the second week, then weekly for several weeks. They also saw each other regularly as friends (Singh, Lancioni, Winton, et al., 2011b). In another recent study by Singh and colleagues (Singh, Lancioni, Winton, Adkins, et al., 2011) the participants had already received mindfulness training in the 2008 study; in the later study they received four formal sessions per week on Mindful Observation of Thoughts for 35-40 weeks.

Mindfulness training to improve lifestyle has tended to take longer. The health wellness programme reported in Singh, Lancioni, Winton, Singh, McAleavey et al. (2008) consisted of a 12 month exercise programme, followed by a 12 month exercise and food awareness programme, followed by a 24 month exercise, food awareness plus mindfulness training phase. For the health wellness programme reported in Singh, Lancioni, Singh et al. (2011) the intervention phase continued until each adolescent achieved their ideal weight (this took between 2-6 years). The smoking cessation programme consisted of an introduction to mindfulness for the participant with learning disabilities and his staff, and a basic breathing meditation to practice daily for 3 months (Singh, Lancioni, Winton, et al., 2011a). After this, during

baseline, the participant was trained on Part I of the mindful observation of thoughts procedure, then 4 days later on Part II, and 6 days after that on Part III. On the fourteenth day of baseline he was taught the right intention procedure through discussion and practice. On the first day of baseline he was taught Part IV of the mindful observation of thoughts procedure and began training on Soles of the Feet during 30-minute supervised role-play and practice sessions, twice a day for 5 days. He was then given practice assignments to control his desire to smoke and criterion changes were then made whereby the participant reduced his cigarette intake by one each time he was able to maintain 3 days on his previous level of cigarettes.

A range of people with different levels of mindfulness skills and experience have provided mindfulness training. In the majority of studies mindfulness training has been provided by Nirbhay Singh who has extensive experience of mindfulness teaching and practice (Singh, Lancioni, Winton, Adkins, et al., 2007; Singh, Lancioni, Winton, et al., 2011a; Singh, Lancioni, Winton, Singh, Adkins, et al., 2008; Singh, et al., 2003). Training has also been provided by ward or community-based therapists trained to teach mindfulness techniques (Adkins, et al., 2010; Chilvers, et al., 2011), by mothers who received a day's training or remote personalised support from Nirbhay Singh (Singh, Lancioni, Winton, Singh, McAleavey, et al., 2008), or by the person with learning disabilities who was trained in the meditation technique in the original Soles of Feet study in 2003 (Singh, Lancioni, Winton, et al., 2011b). The person with learning disabilities enjoyed teaching Soles of the Feet and this seemed to increase his sense of self worth.

The impact of mindfulness training

All of the studies found improvements after the mindfulness training and practice. The study findings in relation to aggression, sexual arousal, lifestyle and participant's feedback on mindfulness are summarised below.

(i) Aggression

In relation to behaviour Singh et al. (2003) found major decreases in the number of incidents of aggression, increases in self-control, and reduction and discontinuation of medication for the man who was trained in Soles of the Feet.

Singh, Lancioni, Winton, Adkins et al. (2007) found reductions in aggressive behaviour during mindfulness training, with further reductions during follow-up. After two years the three participants were still managing their aggressive behaviour and had been able to remain in their community placements.

Singh, Lancioni, Winton, Singh, Adkins et al. (2008) found that physical and verbal aggression decreased substantially, with the number of physically aggressive behaviours declining to zero and none of the six participants making a physically aggressive response for at least 6 months before the 27 months of training ceased. The measure of participants' self control increased and no PRN (as needed) medication or physical restraint was required. In addition there was a reduction in the number of staff days absent and the wage and medical costs associated with absenteeism.

Adkins et al. (2010) found that target behaviours decreased as mindfulness training proceeded and during mindfulness practice were maintained at near-zero levels. Low levels continued to be maintained during follow-up, although with some variability. Most psychological well-being scores improved.

Chilvers et al. (2011) found a decrease in the number of incidents of aggression (including directed at oneself) leading to the use of interventions (use of the observation lounge, physical intervention or seclusion). There was a relatively sharp reduction when the sessions were introduced, followed by a more gradual increase and then further reduction.

Singh, Lancioni, Winton et al. (2011b) found that after mindfulness training from a peer, the frequency of anger and aggressive events decreased to zero over the mindfulness practice phase. Whilst the three participants reported occasional incidents of anger during the 2-year follow-up, there were no reported instances of aggression.

(ii) Sexual arousal

Singh, Lancioni, Winton, Adkins et al. (2011) found that mean weekly ratings of sexual arousal for the three participants reduced from 12 at baseline to 8.75, 10 and 10.75 during the self control phase, to 7.77, 7.38 and 6.92 at the Soles of the Feet phase. During the mindful observation of thoughts phase ratings reduced to 2.95, 3.03 and 1.51 respectively.

(iii) Lifestyle change

In terms of the potential of mindfulness training and practice supporting lifestyle change, Singh, Lancioni, Winton, Singh, McAleavey et al. (2008) found that, although weight reduced with regular exercise and a healthy living programme, the most consistent and sustained changes occurred when mindfulness training was added. The participant's mean weight reduced from 256 lb at baseline to 198 lb during the 3-year follow-up. The man who took part in the Singh, Lancioni, Winton et al. (2011a) study reduced his cigarette smoking from 12 a day at baseline to 0 within 3 months and had abstained from smoking for 3 years at follow-up. Singh, Lancioni, Singh et al. (2011) found that the three participants all reached their desired body weights, enhanced their lifestyles and maintained their desired body weights during the 3-year maintenance period.

(iv) Feedback from participants

Feedback from participants suggests that they may initially find procedures such as Soles of the Feet difficult to understand as they cannot easily remember and visualise past events (Singh, Lancioni, Winton, Adkins, et al., 2007). Participants found the mindful observation of thoughts technique difficult to understand at first because they could not understand the instruction 'observe your thought' (Singh, Lancioni, Winton, Adkins, et al., 2011). Repeated practice, the use of role-plays to recreate situations and discriminative stimulus being added to the soles of their feet helped to overcome such difficulties (Singh, Lancioni, Winton, Adkins, et al., 2011; Singh, Lancioni, Winton, Adkins, et al., 2007). Adkins et al. (2010) found that participants varied in

their ability to initiate the meditation without prompting. The participants who were taught by their peer found the Soles of the Feet procedure easy to master but initially difficult to implement, although this became easier as the intervention progressed (Singh, Lancioni, Winton, et al., 2011b). Participants found it more difficult to use Soles of the Feet for deviant sexual arousal compared to using the technique for the precursors of aggression due to their emotional attachment to the strong pleasurable sexual thoughts (Singh, Lancioni, Winton, Adkins, et al., 2011).

People with learning disabilities who have received mindfulness training have reported that they valued learning to control their own feelings rather than being told to calm down by others, and found this reinforcing. Similarly participants in Singh, Lancioni, Winton, Adkins et al. (2011) reported that although the mindfulness techniques required a lot of effort and practice they preferred them to other techniques they had been taught as it was their responsibility to change their behaviour rather than following directions from other people. They valued being able to calm down and the feeling of being 'in control' rather than simply reacting to others.

2. Mindfulness training and practice for staff working with people with learning disabilities

Table 2 summarises the five studies carried out evaluating the impact of mindfulness training and practice for people working with people with learning disabilities; again, the majority of studies have been carried out by Singh and colleagues in the USA.

Singh et al. (2002) provided mindfulness-based mentoring to three multidisciplinary treatment teams working in a facility for non-verbal people with profound learning disabilities who had psychiatric disorders and persistent behaviour problems. Over a week, the teams were provided with 8 instructional mindfulness based mentoring sessions of 2 hours in a classroom setting. Mentoring on actual cases was then provided during treatment-planning meetings. Nirbhay Singh provided the training and mentoring. After an initial discussion session, three training sessions covered mindfulness and mindlessness in the context of clinical services, Kabat-Zinn's seven characteristics of mindfulness (non-judging, patience, a beginner's mind, trust, non-striving, acceptance and letting go), meditation practices based on the breath and maintaining attention in the present moment, and the application of mindfulness to treatment planning. The final four sessions involved instructional mentoring on the technicalities of integrating psychopharmacological and behavioural treatments. The study found that the level of integration of psychopharmacological and behavioural treatments increased for the three treatment teams over the course of the study: from baseline to follow-up Team 1 increased from 43.3% to 84.2%, Team 2 increased from 59.2% to 90.5% and Team 3 increased from 51.7% to 87.8%.

Singh et al. (2004) measured changes in happiness levels for 3 adults with profound learning disabilities living in group homes when supported by staff who had been trained in mindfulness techniques compared with staff who had received the same amount of training in behavioural methods training. The mindfulness training involved choosing a book to read (all participants chose Hanh (1991)) followed by 8 sessions covering knowing your mind, appreciating oneness of everything, being in the present moment, beginner's mind, being the activity and meditation exercises. Training was provided by Nirbhay Singh. The study found that observed happiness

for each person with learning disabilities increased to a much greater extent for each adult when supported by the staff member trained in mindfulness (an increase of 146% when supported by the person trained in mindfulness compared to 11% for the untrained caregiver for the first person, 322% to 1% for the second person, and 437% compared to 10% for the third person).

Singh, Lancioni, Winton, Curtis et al. (2006) provided mindfulness and behavioural training to fifteen staff working in three group homes for people with severe or profound learning disabilities. Staff received a 5-day intensive training programme in behaviour management. After a number of weeks where staffing ratios were varied, staff took part in a 5-day intensive mindfulness training programme. The mindfulness training included concepts of mindfulness and mindlessness, philosophical differences between behavioural training and mindfulness training, mindfulness in everyday life, mindfulness in wisdom traditions, methods for enhancing mindfulness (e.g. non-judging, patience and perseverance, beginner's mind, trust, non-striving, letting go, doing without a focus on personal reward, active observation of oneself, engaging in loving kindness, being in the present moment), and applications of mindfulness in everyday life. Each session also included meditation postures, mindful breathing, returning attention to the breath and objective viewing of the mind. After the behavioural training there were minor reductions in the number of staff interventions for aggression and very little change in the number of daily living skills learned by people with learning disabilities. The mindfulness training was followed by clinically significant effects under different staffing ratio conditions, with decreases in the number of staff interventions for aggression, increases in the number of learning objectives achieved and an increase in socially and physically integrated community activities for people with learning disabilities. Staff satisfaction was highest following mindfulness training, as were ratings of staff by parents and friends of the people with learning disabilities.

In another study Singh and colleagues provided mindfulness training to 23 members of staff working in four group homes for people with mild to profound learning disabilities (12 of the 20 people with learning disabilities had severe learning disabilities) (Singh, Lancioni, Winton, Adkins, & Singh, 2009). The 12 2-hour training sessions were held weekly and covered meditation methods, knowing your mind, focused attention, being in the present moment, beginner's mind, non-judgmental acceptance, letting go, loving kindness, problem solving and using mindfulness in daily interactions. The use of physical restraints for aggressive behaviour decreased, with almost no use being recorded by the end of the study. The use of verbal redirections by staff and PRN (as needed) medication also decreased. Staff and peer injuries were close to zero levels during the latter stages of mindfulness practice.

Although the training provided to 34 support staff working in a variety of community residential settings for adults with learning disabilities reported in the study by Noone and Hastings (2011) was based on ACT principles, the study has been included as it was carried out in the UK and a large component of the training used mindfulness techniques. A one-day workshop used mindfulness exercises to undermine the literal control language can have, to discriminate self from thoughts, and distinguish core values. The follow-up half-day session held several weeks later allowed practice of other mindfulness and acceptance techniques. The study found a statistically

significant improvement in staff psychological well-being over time and a small reduction in work stressor scores. There was greater positive change for staff who were not professionally trained and for those who reported most stress and psychological distress before the workshops.

3. Studies evaluating mindfulness training and practice for parents of people with learning disabilities

Two studies have evaluated the impact of providing mindfulness training to parents of people with learning disabilities.

In the study by Singh, Lancioni, Winton, Singh et al. (2007) four mothers of children with learning disabilities received one-to-one mindfulness sessions following the same programme as Singh, Lancioni, Winton, Fisher et al. (2006). All of the four children showed a decrease in the mean number of aggressive behaviours during the training stage, followed by more systematic and substantial reductions during the mindfulness practice stage until aggressive behaviour was minimal. There were improvements in interactions between the child with learning disabilities and their siblings, and mothers' self-ratings of parental satisfaction, parental stress and mother-child interaction improved.

Bazzano et al. (2010) provided a community based mindfulness-based stress reduction programme for parents/caregivers of children with learning disabilities. The programme consisted of two concurrent classes twice weekly in English with Spanish translation over 8 weeks. Classes consisted of meditation practice, supported discussion of the stressors parents faced and yoga. Parents were also given a 30 minute CD for daily practice. Attendance was good with 78% attending 6 or more classes. Parents reported statistically significant less stress and statistically significant increases in mindfulness, self-compassion and well-being after the programme.

Parental feedback suggests that people need to be disciplined in their meditation practices and exercises in order to achieve consistent, enduring practice on a daily basis. Mothers found mindfulness training to be different to previous training programmes they had attended, leading to transformational change rather than providing them with specific rules or techniques to use with their child (Singh, Lancioni, Winton, Fisher, et al., 2006). They felt that the training had enabled them to have a more holistic view of their child within the context of family, social and physical environments and helped them to respond in a calm, positive manner to their child which pre-empted maladaptive behaviour and encouraged positive social behaviour.

Study quality

There are a number of methodological weaknesses to the studies included in the review relating to the research design, participants, sample size, and outcome measurement.

The majority of studies by Singh and colleagues use a multiple baseline design. Multiple baseline design tends to be used to study programmes or interventions where a participant is taught a skill. Some of the advantages of a multiple baseline design

are that it does not necessitate the withdrawal of a potentially effective intervention, it parallels the practice of many clinicians and it is relatively easy to conceptualise and implement. If done well it can show a causal effect between an intervention and the outcome. Researchers can get a better understanding of individual differences rather than needing to carry out statistical testing to identify differences between groups which means that it has often been considered the best research design when measuring behavioural change (Cooper, Heron, & Heward, 2007). However, due to the small number of participants, this design will have poor external validity, limiting the ability to generalise the findings to a wider audience (Silver Pacuilla, Brown, Overton, & Stewart, 2011).

A major weakness with the design in all of the studies included in the review is that there is no comparison with other treatments to tell whether the improvements observed in the study are due to receiving some form of treatment or due to the impact of the therapist. Nirbhay Singh provided the mindfulness training reported in many of the studies and it may be that his interpersonal skills and style are leading to change rather than mindfulness *per se*. Singh and colleagues do not state which mindfulness approach they are following (mindfulness-based stress reduction or mindfulness-based cognitive therapy) and their training does not follow the typical timeframes and content of mindfulness-based stress reduction and mindfulness-based cognitive therapy programmes. There is also no independent assessment of the quality of the intervention or how closely it follows mindfulness principles.

In some studies it is difficult to determine whether it was the mindfulness training and practice or another component of the intervention that led to improved outcomes. For example, in the two studies using criterion changes it may have been the structured reduction in smoking and weight which led to the changes rather than the mindfulness programme (Singh, Lancioni, Singh, et al., 2011; Singh, Lancioni, Winton, et al., 2011a). Sequence effects could be the reason for greater improvements in all measures following mindfulness training in some studies; for example in the study by Singh, Lancioni, Winton, Curtis et al. (2006) when mindfulness training was provided after behavioural training, would the same pattern of improvement have been seen had been if the mindfulness had been provided before the behavioural training? Similarly, the Singh et al. (2002) study cannot separate out the differential contributions of the enhanced mindfulness skills and the improved skills at integrating behavioural and pharmacological treatments.

In addition, the sample sizes within the studies are small. It is not always clear how participants were recruited and how representative they are of other people with learning disabilities, parents or staff. Some people contacted Nirbhay Singh and may be more motivated to change than other people. All of the participants in the studies where mindfulness training was provided directly to people with learning disabilities had mild or moderate learning disabilities. Therefore, it is difficult to generalise the findings to other people with learning disabilities, particularly people with moderate or severe learning disabilities.

In relation to outcome measurement most of the studies by Singh and colleagues have more than one observer of the targeted behaviours to ensure reliability of data and reported inter-observer reliability ratings are generally high. However, there is no reliability or validity data for many of the monitoring instruments and scales reported

in the studies to determine how appropriate or accurate they are (for example, Bazzano et al. (2010)) and the Integration of behavioural and psychopharmacological treatments monitoring instrument developed for the Singh et al. (2002) study).

Finally, there is a lack of detail about how the qualitative data from informal interviews and anecdotal evidence was gathered; for example, there is no information about whether an interview guide was used, whether interviews were recorded, and the method of analysis used. If Nirbhay Singh carried out the interviews about the mindfulness training he provided it is possible that participants would have responded more positively than if an independent person had carried out the interviews.

Therefore, whilst the majority of published studies suggest that mindfulness based training can have a positive impact on people with learning disabilities, their family members and paid carers, these findings need to be treated with caution due to the methodological limitations of the studies.

Table 1: Studies evaluating mindfulness training and practice for people with learning disabilities

Study	Country	Aims	Study type	Sample	Outcomes measured
Singh et al. (2003)	United States	To explore the possibility of teaching a mindfulness-based technique, Soles of the Feet, to self-regulate aggression	Single subject case study with an AB design 12 month follow-up	27 year-old male with mild learning disabilities who was an inpatient in a psychiatric hospital.	Incidents of physical and verbal aggression
Singh, Lancioni, Winton, Adkins, et al. (2007)	United States	To evaluate the impact of teaching a mindfulness technique (Soles of the Feet) to adults with moderate learning disabilities	Multiple baseline design across participants 2 year follow-up	Three Caucasian adults with moderate learning disabilities at risk of losing their community placements in group homes because of aggressive behaviour. Aged 27-43. One female, two males.	Physical aggression
Singh, Lancioni, Winton, Singh, McAleavey, et al. (2008)	United States	To evaluate the effectiveness of a mindfulness-based health wellness program (Soles of the Feet, mindful eating, visualizing and labelling hunger)	Partially controlled case study with an ABCD design 3 year follow-up	17 year old male with Prader-Willi syndrome and mild learning disability living with his parents	Weight
Singh, Lancioni, Winton, Singh, Adkins, et al. (2008)	United States	To evaluate the effectiveness of a mindfulness-based procedure (Soles of the Feet) for physical aggression	Multiple baseline design across participants Final measure at 27 months of mindfulness training.	6 male offenders with mild learning disabilities from a forensic mental health facility for people with learning disabilities. All had a history of physical aggression against staff. Aged 23-36. 3 Caucasian, 1 African American, 1 White Hispanic, 1 Non-white Hispanic.	Physical aggression Medication Physical restraint Staff and peer injuries Lost days of work Cost of medical and rehabilitation due to injury caused by participants
Adkins et al. (2010)	United States	To explore the impact of community-based therapists providing mindfulness training (Soles of the Feet) to people with learning disabilities	Multiple baseline across individuals 4-8 weeks follow-up	3 Caucasian people with mild learning disabilities, living in a group home or with their parents, who were at risk of losing their job, living placement, preferred staff or funding Aged 22-42. 2 male, 1 female..	Behaviour Psychological well-being (stress, obsessive-compulsive symptoms, depression, state and trait anxiety)
Chilvers et al. (2011)	UK	To investigate impact of mindfulness group sessions on the aggressive behaviour of women with learning disabilities in a forensic medium secure psychiatric unit.	Repeated measures design No follow-up	15 women with mild to moderate learning disabilities in a forensic medium secure psychiatric unit. Aged 18-47.	Incidents of aggression towards self and others resulting which resulted in interventions

Singh, Lancioni, Singh, et al. (2011)	United States	To evaluate the impact of a mindfulness-based health wellness program for people with Prader-Willi syndrome	Changing criterion design 3 year follow-up	3 adolescent males with Prader-Willi syndrome and mild learning disabilities who were obese and lived with their families. Aged 16-19.	Weight
Singh, Lancioni, Winton, et al. (2011a)	United States	To evaluate the effects of a mindfulness-based smoking cessation programme (Soles of the Feet and mindful observation of thoughts)	Changing criterion design 3 year follow-up	31 year old man with mild learning disabilities who lived in a group home and had been a smoker for 17 years	Cigarettes smoked
Singh, Lancioni, Winton, et al. (2011b)	United States	To evaluate the impact of mindfulness practice (Soles of the Feet) when taught by a peer with learning disabilities	Multiple baseline design across participants Interviews 2 year follow-up	3 adult males with mild learning disabilities who lived in the community in supported living and had anger and aggression issues at work. Aged 26-32.	Aggression
Singh, Lancioni, Winton, Adkins, et al. (2011)	United States	To examine whether meditation procedures (Soles of the Feet and mindful observation of thoughts) could change sexual offenders' inappropriate sexual arousal	Multiple baseline design across participants Interviews Final measure at 35-40 week mindful observation of thoughts phase.	3 men with mild learning disabilities from a forensic mental health facility for people with learning disabilities who had been sentenced for aggravated sexual assault on a minor or incest and rape of children. Aged 23-34. 1 African American, 1 Caucasian, 1 White Hispanic.	Level of sexual arousal

Table 2: Studies evaluating mindfulness training and practice for staff members or teams working with people with learning disabilities

Study	Country	Aims	Study type	Sample	Outcomes measured
Singh et al. (2002)	United States	To examine whether mindfulness-based mentoring enhanced the ability of multidisciplinary treatment teams to integrate behavioural and pharmacological interventions	Multiple baseline design across treatments team 6 month follow-up	3 multidisciplinary treatment teams in a facility for people with profound learning disabilities who had psychiatric disorders and persistent behaviour problems	Behavioural and psychiatric treatment integration
Singh et al. (2004)	United States	To investigate whether mindfulness training for paid caregivers would increase levels of happiness for adults with profound multiple disabilities	Alternating treatments embedded within a multiple baseline across subjects design Final measure taken at end of 16 week mindfulness practice phase	6 female African American caregivers who worked in 4 group homes. 3 males with profound learning disabilities and complex medical and physical problems.	Happiness
Singh, Lancioni, Winton, Curtis, et al. (2006)	United States	To assess whether behavioural and mindfulness-based training to staff working in group homes leads to better provision in care	Multiple baseline design across group homes	15 direct care staff working in group homes who were responsible for 18 adults with severe or profound learning disabilities	Staff interventions for aggression Daily living skills Use of restraints Socially and physically integrated community activity Staff satisfaction with their work
Singh, Lancioni, & Winton (2009)	United States	To assess how training staff members in mindfulness affected their use of physical restraints	Multiple baseline design across two staff shifts Final measure taken at end of 22 week mindfulness practice phase	23 staff members working in four group homes for 20 people with learning disabilities	Number of potential and actual incidents of physical or verbal aggression Physical restraints Staff verbal redirections Medication Staff and peer injuries
Noone & Hastings (2010)	UK	To investigate the impact on staff of Promotion of Acceptance in Carers and Teachers training	Single group pre-post design	34 support staff working in a variety of community residential service settings for adults with learning disabilities	General psychological well-being Staff perceptions of work stressors

Table 3: Studies evaluating mindfulness training and practice for parents of people with learning disabilities

Study	Country	Aims	Study type	Sample	Outcomes measured
Singh, Lancioni, Winton, Singh, et al. (2007)	United States	To assess the effects of mindfulness training for parents of children with learning disabilities on the children's behaviour and interactions with siblings, parental stress, and parental satisfaction with parenting skills and interactions with their children	Multiple baseline design across participants (parent-child dyads) Interviews with parents Final measures taken after a 52 week mindfulness practice stage	Four African American mother-child dyads. All children attended a day centre for children with learning disabilities	Child's aggression towards mother or siblings Child's social interactions with siblings Mother's satisfaction with their own parenting skills and their interactions with their child Mother's use of mindfulness in parenting Parents' experiences and perceived outcomes of mindfulness
Bazzano et al. (2010)	United States	To evaluate the feasibility of a mindfulness-based stress reduction community-based program for parents/caregivers of children with learning disabilities	Participatory research using a single group pre-post design	37 parents of children with learning disabilities	Mindfulness Self-compassion Psychological well-being General and parenting stress

A QUESTIONNAIRE EVALUATION OF THE WORKSHOPS

Methods

At the end of each workshop participants were asked to complete a brief easy read questionnaire asking about:

- The reason they came to the workshop
- What they thought was good about the workshop
- If they thought that anything could be improved about the workshop.

The questionnaire also asked if participants would be willing to take part in an interview about the workshop. A copy of the questionnaire is included in Appendix 1.

The data from the questionnaires was entered onto an SPSS database to organise analysis. Responses to open questions were categorised into broad themes and entered onto the database.

Key findings

110 evaluation forms were filled in at 8 workshops; 6 workshops were organised through self advocacy groups, 2 workshops were provided at 2 healthy lifestyles days organised by local learning disability services.

76 forms were completed by people with learning disabilities
2 forms were completed by a family carer
28 forms were completed by paid carers and People First supporters
51 men and 31 women completed forms[3]

The most common reasons people went to the workshops were:

- To learn to relax or deal with stress, anxiety, panic attacks or mood swings (N=38)
- As the workshops were being held as part of a meeting or event they were attending (N=35)
- To support people with learning disabilities attending the workshop (N=17)
- To find out about mindfulness (N=16)

"I came to the workshop to relax my neck and to keep calm" (ID32)
"I came because I needed to relax and to release me and my body about stress" (ID48)
"Because I like coming to the People First meetings" (ID 81)

Feedback about the workshops was generally positive:

- 61% of people felt that the workshops were 'Very Good'
- 27% of people felt that the workshops were 'Good'
- 11% of people felt that the workshops were 'OK'
- 1% of people felt that the workshops were 'Very bad'

[3] Totals are less than 110 due to missing information.

The most common responses to the question about what was good about the workshop were:

- That it helped people to relax (N=53)
- The body scan exercise (N=20)
- Sharing experiences and talking about feelings (N=16)
- Learning new skills and techniques (N=11)
- The facilitator (N=10)

"I enjoyed it. It helped me to relax my mind and breath easy." (ID74)

"Taught you how to not think about anything. Just think about the present. I did feel my mind wandering but I could bring it back. I will use it in the future." (ID79)

However, not all of the feedback was positive. One person felt that it "didn't help me relax" (ID59) and another person felt it was "a bit difficult" (ID83).

41 people made suggestions about how the workshops could be improved. The most common suggestions for improvement were:

- A longer workshop (N=19)
- A quieter venue (N=6)
- Relating to music on the CD (N=6)
- More comfortable flooring (e.g. mats, pillow) for people lying down during the body scan (N=6)
- More guidance and support needed through the body scan exercise (N=3)
- More sessions (N=3)

Whilst some people commented that the workshop was easy to understand two people felt that the language needed to be more accessible and one person felt that the body scan instructions could be clearer:

"I have ASD and the instructions were a bit confusing as they said breathe in, but didn't say breathe out so I was holding my breath a lot" (ID 94).

Additional comments included:

- General positive comment about the workshop (N=45)
- Interested in further sessions and learning more (N=9)
- Positive that people were given a CD and brochure (N=7)
- The workshops may be useful for others (N=5)
- That people hope to use the CD and techniques they have learnt (N=4)

INTERVIEWS

Methods

In depth qualitative interviews were carried out with people who took part in the workshops. Using the computer package SPSS, people were randomly selected from those who had indicated on the evaluation form that they were willing to take part in an interview.

An initial interview was conducted to find out whether people remembered the *Introduction to Mindfulness* workshops and whether they would be willing to take part in a further face-to-face interview. Thirteen initial interviews were carried out over the telephone by MC (N=7) or completed with a People First supporter (N=6). If people wanted to talk about the mindfulness sessions further a face-to-face interview was arranged.

Six face-to-face qualitative interviews were carried out with people with learning disabilities. An interview schedule was used to explore:

- Why people went to the mindfulness session
- What they remembered about the session
- What they thought was good about the session
- Whether they thought anything could be improved
- Whether they are still using the mindfulness techniques they were taught at the session
- Whether they felt that anything had changed as a result of what they learnt at the session
- What the impact of using the mindfulness techniques had been.

After one of the face-to-face interviews a follow-up telephone interview was conducted with one person to find out if they had used the mindfulness CD they were given at the initial interview (they had misplaced the original CD). A mother, a community learning disability nurse and a service manager were present during three of the interviews; whilst they were primarily present to support the person with learning disabilities, they also gave their own views about mindfulness and the sessions.

Analysis

The face-to-face interviews were audio-recorded with participants' permission and transcribed *verbatim.* If participants did not wish the interview to be recorded then detailed notes were taken. Thematic analysis of the interviews was carried out to explore the impact of the mindfulness sessions and any other issues raised by participants relating to the sessions (Braun & Clarke, 2006). Thematic analysis identifies, analyses and reports patterns within data. This method of qualitative analysis involves moving back and forth throughout the following different phases: familiarisation with the data, generating initial codes, searching for, reviewing, defining and naming themes, and writing the report. The analysis was led by MC; however, DM read through three interview transcripts independently to identify

patterns in order to ensure that important themes were not omitted and to improve the validity of the analysis.

Findings

- *Reasons for going to the workshops*

Two of the people who were interviewed went to the workshops because it was part of a People First meeting. Three people had been encouraged to go to a session which was being held during a health event by their community learning disability nurse. There was a general sense of not knowing what the mindfulness session would involve; however, some people went specifically to find out more about mindfulness or to help them to cope:

> Interviewer: Can you remember why you went to the workshop?
> ID8: Managing with how I feel. Sometimes I get really down, sometimes I don't.

> ID79: I just heard that Dene was coming to talk about to do a session on mindfulness and relaxation and that's really what. But when I went I didn't really know what that involved until I actually turned up.

- *Experiences of the workshops*

Some people felt nervous about going to the workshop because they did not know the other people there or were not sure about what would happen during the workshop. However, the overwhelming impression was that people found the workshops enjoyable and relaxing. The body scan exercise was particularly relaxing and could help people to take their mind off their problems:

> ID88: I laid on the floor and listened to some music. Relaxing music.
> Interviewer: How did you feel after listening to the music?
> ID88: Quite settled.
> Interviewer: Would you like to do it again?
> ID88: Yes
> Interviewer: Why?
> ID88: Because it was nice and relaxing

> ID79: I liked that [the body scan]. I found that very relaxing that part of it. And you know when you sort of get up afterwards, because it was so relaxing your brain feels a little bit sort of foggy, well not foggy, but it's like until you sort of start pulling yourself together you think where am I? You know a bit like if you've been asleep or something it was that sort of feeling. And I think some people, I'm sure some people did nearly fall asleep [laughs]

It was also helpful for people to share their experiences and feelings during the session and to realise that other people might have similar experiences or difficulties:

> Interviewer: What do you remember about the session?

> ID8: So easy to talk to somebody who had similar problems to myself, certain things frightened them. Nice to talk about things with other people.

People were unanimously positive about the personal qualities of the facilitator. They felt that he had a relaxing manner and a very calming voice:

> ID8: Can't forget [the facilitator]. Very good. Very laid back.

> ID79: I thought [the facilitator] was really good actually at that. Because he's got a nice calming voice hasn't he?

The comments showed that it is important that mindfulness sessions are held in a quiet venue that is large enough for the number of people who are taking part:

> The nurse said that because it was such a busy day and so well attended the session was a bit noisy. There were about 20 people in the session. It was a bit rushed as they had a half hour time slot. [ID90]

Some people felt that the session could have been longer and that some parts of the session were difficult to understand (although this may have been due to feeling so relaxed):

> ID116: At some parts where we felt it was hard to understand, you know, to follow it, but it might just have been zoning out you know going into a relaxed state. I don't know.

People wanted further mindfulness workshops; these would be useful for 'refreshing your memory' [ID79] about mindfulness and the technique. Generally, participants felt that other people would also benefit from attending:

> Interviewer: So if there were more sessions like this, do you think you'd go to them?
> ID90: Definitely. I'd enjoy those sorts of things. It's the sort of thing I do need….
> Interviewer: Do you think other people would benefit from going to mindfulness sessions?
> ID90: Yeah.
> Interviewer: What sort of things do you think it would help with?
> ID90: It'll help with helping them to calm down and unwind and relax

> ID116: Possibly could promote mindfulness in day centres and the like.
> Interviewer: What would be a good way to do that?
> ID116: Another round of Dene going out I would have thought
> Interviewer: And do you think that one session like Dene did was enough or do you think he should do more than one session with people?
> ID116: If he could manage it, 2 or 3 sessions, multiple sessions might be better. But it might be impossible
> Interviewer: Is there a reason that you think it would be better to have more than one session?
> ID116: Just to give a better picture. A better feeling about mindfulness.

However, some people did not feel that everybody would benefit from mindfulness or felt that some people would benefit more than others:

> Service manager: I think that it would be good to have mindfulness but I don't think that a group would work well with all of the people here. [ID88] would go to a group because he'd done it before and I think his housemate would be keen to try it out. Another young man would do it because he was asked to but would have no understanding of why or the purpose behind it. The people we support are at the severe end of learning disabilities and can have challenging behaviour and autism. [ID88] is the most able.

This participant felt that it would be useful to develop a manual or a toolkit which could be used to guide mindfulness training with people with learning disabilities:

> Service manager: It would be good to have an instructional thing on how to run a session and have the tools to do it so that care workers could catch the right time to do it. A toolkit people could use with the individuals they work with would be great. Something for careworkers. It would need to be individualistic, not generic, something that is adaptable and changeable.

- *The mindfulness CD*

People who attended the workshops and health events were given a mindfulness CD to take home with them. The CD included an introduction to mindfulness, breathing space and body scan exercises and a reflection. People were asked whether they had used the CD since the session. Three people had listened to the CD at the time of the initial interview; one person had been encouraged to do so by their mother and another by their community learning disability nurse. Two people had not used the CD; one had misplaced the CD and one person did not remember getting a CD (it was difficult to determine whether the sixth person was using the CD or not as their regular support worker was not present).

Two people found that the CD had helped them to relax and cope with their phobias and harassment from the local community. Another person had listened to the recording to try to cope with the pain of toothache; however, this had not been helpful. Two people felt that they did not need to listen to the recording at the moment but that they would do so in future if they were stressed:

> Interviewer: Have you used anything you learnt at the workshop to help?
> ID79: I have actually. I do try and relax when I can and I have got one of those CDs, that mindful, and I keep meaning to do it. I keep saying I'm going to do it one day and you know what it's like you just don't get round to doing it but I do plan on doing it that CD…. I think if I did find that I was stressed then I would probably do it then. You know if I was feeling quite stressed to calm my nerves down…. At the moment things have settled down for me as well. Yes it would be good to have there but I don't feel like I really need to at the moment.

It was important that people had a private, quiet space that they could listen to the recording on their own; this was often the person's bedroom. One person felt it would be difficult to find a quiet time to listen to the CD due to the noise made by the other people he shared the house with and the lack of time he spent on his own:

> Interviewer: Do you have something you can listen to the CD on?
> ID8: Yes, but everyone would have to be downstairs or out because it would be hard if there was noise or banging. I sometimes get half an hour on my own. It's not that long, only 20 minutes

Another person felt that their neighbours were complaining about the noise when she listened to the CD, even when using headphones.

It was also important that people had appropriate technology to listen to the CD on. One person used the CD player in their bedroom. However, a range of technologies exist nowadays; one person had bought a portable CD player, one person had put a copy of the CD onto their mobile telephone, and another person would have needed help to put a copy of the recording onto their MP3 player. Such portable devices or a portable CD player allow people to listen to the recording wherever they may be; for example, away from home and on holiday.

- *Stress and resilience*

It was clear from the interviews that all of the people with learning disabilities had significant sources of stress in their lives which had the potential to impact on their mental health and quality of life. One person talked about how a major source of stress was lack of employment opportunities:

> Interviewer: What sort of things stress you out?
> ID116: Employment mostly.
> Interviewer: Right. You're not working at the moment?
> ID116: No. But I hope to be very soon.
> Interviewer: Are you looking?
> ID116: Yeah…
> Interviewer: So you find that stressful not having a job?
> ID116: Yeah. There's loads of people that don't want a job
> Interviewer: But you do
> ID116: Yeah.

The same person then talked about how stressful having inappropriate day services was and how they:

> ID116: feel trapped in some respects. Particularly at the day centre. Because I ended up going to a day centre which isn't really suitable. In the meantime before you know, while I wait to get a job and I don't really want to and it's not really relevant for me really because on group of people's there [puts hand down] and, I hate the use of the word normal, but people with more abilities there [puts hand on top] and I'm somewhere in between, in the middle and it's not a good place to be.

People also talked about how work or living situations, managing money, separation from family, life events such as bereavement, not being listened to or being told what to do, and a lack of control over one's life could be stressful. Some people found it difficult if they felt let down by other people, or if they thought that they were letting others down. Some sources of stress were directly related to the impact of disability, or from other people's reactions to disabled people. For example:

> ID79: I think it all started really because of my disability. I've always had to overcome obstacles and then when my sight deteriorated quite rapidly about 15 years ago I think I just got to that stage, I can't do this, I just can't do this anymore.

People talked about the stigma and harassment they experienced:

> Mother: Very often some of them are very affected by what other people do and say. Like [my daughter] doesn't like to be stared at do you?
> Daughter: No I don't
> Mother: And very often. Tell [the interviewer] what you did that one day that you came back from the shops. Do you want to tell her?
> Daughter: You will
> Mother: You want me to. She actually said she wanted to die It's children staring at her you see and it annoys me that mothers don't teach the children that not everything's perfect in this world and to stare at people isn't nice. … Cos she will say I hate being a Downs. I say to her well most Downs are wonderful people. It's the other people that have got the problem not you. So it's very difficult for her I think.

> ID90: I'm having quite a lot of problems with neighbours at home. Name-calling….
> Learning disability nurse: It's difficult with the children when they're outside
> ID90: And then you get the parents and the people in the flats turned against me. The neighbours. Everybody…..
> Interviewer: How long's this been going on?
> ID90: Years.
> Learning disability nurse: You've moved haven't you?
> ID90: Several times because of it. Where I used to live I got it every day. Every night. Soon as they wake up they start. Soon as they come out of the door they start.
> Interviewer: How does it make you feel that name calling?
> ID90: I hate it. I just hate it. Sometimes I hate even living.
> Learning disability nurse: It makes you poorly sometimes doesn't it?

The people who took part in the interviews had experienced low self confidence, anxiety, depression, mood swings, phobias, obsessions, anger and frustration and feelings of being trapped. This could impact on their own quality of life and that of family members or housemates. They had found a range of ways to cope. Sometimes people might ignore a problem for a while or remove themselves from a situation, for example, by going on holiday. However, this rarely worked in the long term. Support from family and friends and having somebody to talk to was important:

> ID 88 said "Sometimes I get angry." The service manager explained that [ID88] is not very good at waiting because of his understanding of time. When he is waiting for something to happen he can get frustrated. They usually have a little talk and that helps. A change of face also helps.
>
> ID79: I think talking to people helps, you know, sort of, when things do get tough, I do talk to people. I mean after saying that I don't to start with and then once I acknowledge that there is something there then I do
> Interviewer: And you've got certain people that it sounds like you'd go to talk to
> ID79: Yes, I've got [my friend] and I've got my support worker and I do talk to me mum sometimes but I think who does talk to their parents? But me mum is there to listen when I need her to.

Services had provided useful support; for example learning disability nurses, counsellors, general practitioners and social workers. However, such support was often time-limited, mainstream services may not be made available or considered appropriate for people with learning disabilities, and there could be long waiting times or complicated processes to access services:

> ID8: I've rung up about CBT, cognitive behavioural therapy, but I have to go through my learning disability nurse so they won't accept me. I thought this was a bit strange. I thought I was on the waiting list. I'm still under it but I'm going to have to go through a learning disability nurse to get seen. Sometimes you have to wait 9, 12 months to be seen.

Sometimes support, although appreciated, could be disempowering:

> ID8: My disability nurse who I don't see now which is a shame because I formed a good friendship with my nurse although sometimes she was a little bit too caring or trying to speak to much for me rather than let me say what I want to say. My social worker let me think and say.

Some people had found medication useful. Other strategies included putting in place structure, rules and clear boundaries and distraction.

Some people talked about how they tried to alter their ways of thinking:

> ID116: To try and concentrate, well it's difficult, but to try and concentrate on the good things rather than the not so good I would guess

Another person had drawn on self-help literature. Behavioural techniques such as monitoring behaviours and desensitisation had been tried with regards to phobias. Lifestyle factors could play an important part; such as improving work-life balance or doing exercise:

> ID8: I had really, really poor depression. Exercise helps that. A friend of mine was telling me she went with her support to do Zumba. I'm thinking of going to Zumba.

Two people talked about they turned to food when they were stressed, 'comfort-eating':

> ID88 said, "I worry. Thinking in head." The service manager explained that ID88 likes to know who is going to be on duty and when. When the interviewer asked ID88 what helped when he worries he said, "Take my mind off things. Go for cake. Chocolate cake. Milky coffee." The service manager explained that distraction and changing focus helps.

People also mentioned other ways of relaxing included listening to music, watching television and reading.

CONCLUSIONS

The studies identified by the literature review indicate that mindfulness training and practice can lead to improvements in problem behaviours, psychological well-being and lifestyle for people with learning disabilities. Mindfulness has been used to address aggressive behaviour, inappropriate sexual arousal, smoking and weight. The studies also show that benefits can be achieved by providing mindfulness training and practice directly to people with mild and moderate learning disabilities, the staff that support people with learning disabilities, and family members. Mindfulness training can be provided in a range of community and institutional settings, and by experienced mindfulness practitioners, staff trained in mindfulness techniques, family members, and people with learning disabilities themselves. Mindfulness is also acceptable to people from a range of cultural backgrounds.

However, the methodological limitations of the published studies mean that these conclusions should be treated with caution. The positive findings could be a consequence of bias in relation to simply receiving a form of intervention, the skills and personality of the person providing mindfulness training, or the ways in which the samples were selected. Further research with larger sample sizes and random allocation to comparison groups are needed before the improvements seen can be more confidently attributed to mindfulness. Future research needs to identify which components of mindfulness lead to change and whether mindfulness approaches are more effective than other approaches or interventions. Research into whether mindfulness is best taught on a one-to-one basis or in a group setting would also be useful. Methodologically robust qualitative research is also needed to gain insight into the perspectives of those receiving mindfulness training and to identify what they feel the impact of mindfulness has been.

This evaluation adds to the existing literature on the use of mindfulness with people with learning disabilities. It is clear from the interviews that people with learning disabilities may have very stressful lives and that this can impact on their psychological well-being and quality of life. Mindfulness could play an important role in helping people to cope with such stress and is being increasingly used with the general population. However, mindfulness programmes are rarely made available to people with learning disabilities and existing programmes may not be accessible (for example, due to the length of sessions and the language and abstract concepts used). This is the only published report from the UK that we are aware of on the provision of mindfulness training directly to people with learning disabilities in a community setting, and as one participant commented this is ‘trying to break new ground’ [ID116].

The evaluation shows that mindfulness is clearly an acceptable approach to people with learning disabilities. There were very positive reactions to mindfulness sessions from participants who found them very relaxing. People wanted more than one session, indicating the need to develop a programme of mindfulness sessions. Developing a manual to guide a programme would form an important part of this and is a common component of existing mindfulness programmes. Such a manual could support the provision of mindfulness in a range of settings (for example, day services, supported housing) and would help to equip other people with the tools to provide

mindfulness training and to support people with learning disabilities with mindful practice.

Whilst half of the people interviewed had listened to the CD and two of these had found this very useful, other people may need encouragement to listen to the CD and an appropriate place or equipment to listen to the recording at a time that they will not be disturbed. It is important that mindfulness programmes explore whether people are able to listen to the CD and identify and overcome any barriers to listening to the recording.

This evaluation indicates a clear need to develop a series of mindfulness sessions and to evaluate how effective these are. Future evaluations would need to be more methodologically robust, with larger sample sizes. Future research needs to identify which components of mindfulness participants find most useful (for example, the body scan, information provision about mindfulness, the opportunity to talk to other people who had similar experiences, listening to the CD), and to explore which factors impact on the success of mindfulness (e.g. facilitator characteristics, support, communication needs and cognitive abilities).

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Appendix 1: Workshop evaluation questionnaire

Workshop date:
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Mindfulness workshops
Feedback form

We would like to find out what you think about today's workshop.

Why did you come to the workshop?

Did you think the workshop was:

Very good ☐ Good ☐ Ok ☐ Bad ☐ Very bad ☐

What was good about the workshop?

Could anything have been better at the workshop?

Is there anything else you would like to say about the workshop?

Some researchers at Manchester Metropolitan University would like to talk to people about these workshops.

If you would like to talk to the researchers please give your contact details below:

Name

Address

Telephone

Email

THANK YOU FOR FILLING IN THIS FORM