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Power, N., Rawlings, G.H. [orcid.org/0000-0003-4962-3551](https://orcid.org/0000-0003-4962-3551) and Bennett, C. (2022) Evaluating a mindfulness-based group intervention for adults with intellectual disabilities. *Advances in Mental Health and Intellectual Disabilities*, 16 (3). pp. 135-146. ISSN 2044-1282

<https://doi.org/10.1108/amhid-01-2022-0001>

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### Abstract

**Purpose:** There is growing evidence examining mindfulness-based interventions (MI) for people with intellectual disabilities (ID). As discussed in the article, MI may be particularly suited for people with ID given high rates of difficulties in identifying and regulating emotions, and as this approach may rely less on cognitive ability compared to other therapies. This evaluation assessed the acceptability and preliminary effectiveness of a six-session MI group (the Coping Well Group; CWG) delivered within routine clinical practice.

**Methodology:** Six separate cohorts (n=25) of adults with ID attended CWG. Quantitative data were collected from service users, including a pre- and post-quality of life (QoL) measure, and qualitative data from group facilitators.

**Findings:** Roughly one-half (53%) of service users invited to the group attended at least one session, with low levels of drop out observed among group-attendees. A significant improvement in QoL was reported demonstrating a small effect ( $d=0.46$ ,  $p=0.022$ ) after attending the group. Most service users (72%) were referred to the CWG for help managing difficult emotions. One-half (44%) of attendees required individual therapy after attending the group. Limitations of the evaluation and potential future research are discussed.

**Originality:** The current evaluation contributes a practice-based service evaluation of an MI group for people with ID and mental health difficulties to the currently limited evidence base. This is one of the first studies to investigate the impact of group psychological interventions collecting data across cohorts and assessing QoL, a more general measure of wellbeing than has been used previously.

### Key Words:

Learning disability; Stepped care; Quality of life; Qualitative; Third-wave

### Introduction

People with an intellectual disability (ID) are at a greater risk of experiencing mental health conditions than the general population. For example, a review of the 2011 Scotland Census found in individuals aged 16-64 years old, 23.4% of people with ID reported a mental health condition compared to 5.3% in those without ID (Hughes-McCormack *et al.*, 2017). While it was once believed that psychological therapies were not appropriate, nor effective for this population, the ever-growing number of studies in this area have helped to largely dispel such long-held assumptions (Hassiotis *et al.*, 2011). Indeed, current clinical guidelines in the United Kingdom (UK) recommend the use of psychological treatments for this population; however, interventions must be tailored to the client's preferences, level of understanding, strengths and needs, among other considerations (NICE, 2016).

In the UK, primary care mental health services for the general population aim to deliver interventions using a 'stepped care' model (Layard & Clark, 2014). This means, those presenting with acute or mild-moderate symptoms receive less intensive support than those experiencing more severe or persistent difficulties. People can be 'stepped up' (or down) depending on their difficulty and how they respond to initial treatments. Stepped care means people receive the level of care appropriate to their needs while optimising resources. This is particularly important given the current climate in health and social care services of limited resource and long-waiting lists, which unfortunately means there is a risk of some clients deteriorating while waiting for care (Reichert & Jacobs, 2018).

Within the stepped care model, psychological therapies can be routinely delivered within a group format, usually provided to those with mild to moderate symptoms. Group interventions are typically time-limited, evidence and theory informed, and focus on a particular difficulty that group members all have in common, such as depression (Huntley *et al.*, 2012), anxiety (Barkowski *et al.*, 2020) or substance use (Lo Coco *et al.*, 2019). Group interventions have been successfully delivered to people across the lifespan, presenting with a range of difficulties and within health

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services around the world. Similarly, a recent systematic review synthesised the growing evidence from 21 studies demonstrating the effectiveness of group interventions for people with ID utilising different approaches, including cognitive behavioural therapy (CBT), psychodynamic therapy, narrative therapy and compassion focused therapy (Bourne *et al.*, 2021).

‘Mindfulness’ has been defined as “the awareness that emerges through paying attention on purpose, in the present moment, and non-judgementally” (Kabat-Zinn, 2003). Mindfulness-based interventions (MI) are a collection of therapeutic approaches which aim to cultivate mindfulness to help clients build self-regulative practical techniques to develop tolerance and regulation of emotional arousal (Robertson, 2011). Meta-analyses have shown that MI can lead to moderate improvements in anxiety ( $g=0.63$ ) and mood symptoms ( $g=0.59$ ; Hofmann *et al.*, 2010) and small improvements in depression ( $d=0.26$ ) and anxiety ( $d=0.24$ ) in the context of chronic somatic diseases (Bohlmeijer *et al.*, 2010) in clinical non-ID populations.

Although the evidence-base for MI in people with ID is less than that of other populations, it has grown considerably over the past decade. MI appear to be particularly relevant to people with ID due to [1] the increased risk of emotional and psychological difficulties in this population, with some individuals experiencing difficulties in regulating their emotions (Felce *et al.*, 2009) and [2] behaviours that challenge, which are prevalent in people with ID (Bowring *et al.*, 2017) and often associated with heightened emotional arousal (McDonnell *et al.*, 1998). There is also some evidence that the presence of difficulties, such as physical aggression, is associated with deficits in awareness of bodily signals (known as ‘Interoceptive Awareness’, IA; Bellemans *et al.*, 2017) in children with ID (Emck *et al.*, 2012). There have been very few studies on the topic of IA in adults with ID, although there are preliminary studies indicating that body-oriented interventions (including MI) may reduce anger in people with ID (Bellemans *et al.*, 2017). However, it remains unclear whether MI leads to therapeutic effects in people with ID through the mechanism of increasing IA, as has been shown in non-ID individuals with chronic pain, for instance (Roberts *et al.*, 2022).

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To gain a greater understanding of how MI in a group format may be helpful in ID, studies have explored experiences of people with ID who have engaged in MI. Individuals have described how MI can lead to improvements in learning useful skills to feel more relaxed and less distressed, in addition to some benefits of belonging to a group (Dillon *et al.*, 2018; Currie *et al.*, 2019; Yildiran & Holt, 2015). Moreover, evidence attesting to the acceptability and positive impact of MI in ID is growing. For example, a systematic review of twelve studies investigating MI with individuals with intellectual and developmental disabilities found all studies reported positive outcomes (Hwang & Kearney, 2013). Since then, a number of studies have been conducted further demonstrating the helpful effects of MI for emotional difficulties, such as reducing symptoms of depression and anxiety (Idusohan-Moizer *et al.*, 2015), and reducing addictive behaviours such as smoking (Singh *et al.*, 2013; 2014).

The impact of MI on more general aspects of wellbeing in people with ID, however, has not been investigated. As in the general population, mental health conditions have been associated with lower Quality of Life (QoL) in people with ID (Noorthoorn *et al.*, 2021). Moreover, there is evidence to suggest that MI may improve QoL in the general population. For example, a Mindfulness Based Stress Reduction (MBSR) group was shown to significantly improve health-related QoL (Roth & Robbins, 2004) with mindfulness seeming to mediate this relationship (Nyklíček & Kuijpers, 2008). Exploration of the relationship between mindfulness interventions and QoL is needed with people with ID in order to offer meaningful and valuable interventions for this population.

While there is some preliminary evidence to suggest group-based MI are generally effective for people with ID in terms of improving health outcomes (Singh & Hwang, 2020); this is still an area that needs much more attention if the size and quality of the evidence base is to come close to parity with that in non-ID clinical populations. The aim of this paper was to evaluate the use of an MI group, named the ‘Coping Well Group’ (CWG), for adults with an ID delivered as part of routine practice at a community ID health service. More specifically, quantitative data were

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collected from clients with the aim of assessing the acceptability and preliminary effectiveness of the intervention. This was supplemented with qualitative data gathered from group facilitators to help further examine the use of MI groups for adults with ID. Although 'acceptability' is frequently ill-defined in studies (Sekhon *et al.*, 2017), for the purposes of this evaluation, acceptability was measured by service user attrition and facilitator perspectives. This is consistent with Sekhon *et al.*'s (2017) definition of acceptability which refers to 'the degree to which people delivering or receiving an intervention consider it to be appropriate'.

## Method

### Service

The current evaluation was conducted in an NHS (National Health Service) community ID health service in the North of England. The population of the city it serves is over 700,000 people. According to the 2011 Census, the city's ethnic composition included, 84% White, 8% Asian, 3.6% Black, 1.5% Arab, 2.4% mixed race and 0.7% other ethnic group (UK Census Data, 2011).

The article is a retrospective analysis of data collected as part of routine practice. Given the current article is a service evaluation, ethical approval was not required however the authors confirm that the study meets the journal's view on ethical standards. The evaluation was authorised by the local NHS Trust audit department. It was agreed that consent from service users were required to take part in treatment, but not for their data to be used for the purpose of the evaluation as all data were anonymised following guidance from the Trust. Group facilitators provided informed consent for their data to be used for the purpose of the evaluation.

### Service users

All service users had been referred to the Psychology department and were subsequently waiting to receive either a group intervention or individual psychological intervention. All clients were assessed for suitability to take part in the group by a Clinical Psychologist who considered

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their needs, cognitive and social functioning and preference for treatment. Given the cognitive functioning level needed to engage in psychological therapy, especially within a group setting, the treatment was aimed at clients with borderline, mild and some cases, moderate ID. No formal eligibility criteria were used, instead the acceptability of the referral was based on clinical judgement in line with routine practice. We have expanded on this in the discussion as a limitation.

Client's progress was monitored throughout their involvement with the group, which was used to inform their next steps in care, for example, stepping them up (e.g., to individual psychological therapy) or down (e.g., discharged from the Psychology team after group completion). In summary, the intervention was used as a stand-alone-treatment, as well as to help people develop coping strategies while they were waiting for therapy with the aim of fostering positive therapeutic alliances, helping them to develop skills in preparation for individual therapy, and try to prevent client's mental health deteriorating while on the waitlist.

### **Group facilitators**

Facilitators of groups included Clinical Assistants, Assistant Psychologists, Trainee Clinical Psychologists and Clinical Psychologists. All aspects of the group were supervised by a Clinical Psychologist. A maximum ratio of one facilitator to three group participants was recommended, which was based on the clinical judgement of members of the facilitator team. The aim of this was to help client better understand course materials; for example, at times, the cohort had to separate into two allowing facilitators to recap what had been discussed by adapting information to individual clients, which was easier in smaller groups. A minimum of two facilitators were present for each session. Service users had the option to bring their own support/carer into group sessions, but they were asked to specifically support the service user to engage rather than engaging with the material/content themselves. Group facilitators surveyed for the purpose of the evaluation were selected by CB.

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### Intervention

The CWG was a six-session, weekly group that aimed to provide services users with psychoeducation on emotions and an introduction to mindfulness skills. Each session lasted between 60-90 minutes, and services users were encouraged to practice skills between sessions as homework. The topics (see Table I) of each session were developed by a Clinical Psychologist in the service and described in a sessional easy-read service-user booklet and facilitator-manual (which may be available upon request). Although the developer of the programme (CB) was not a certified mindfulness-based therapist, the programme contained aspects of Robertson's (2011) three components of MI: self-reflection, self-regulation and mind-body relaxation. These three elements have been matched to each session's content in Table 1 in order to demonstrate some categorical adherence to the philosophy of MI.

After the completion of each group cohort, the group facilitation team reflected on the programme, including whether any amendments to the formatting or content of sessions would improve the acceptability or content of the intervention. The group was therefore iteratively refined through a 'reflective cycle' of group development. Service user workbooks and the facilitator manual were also amended accordingly after each cohort.

### Table I.

#### Measures

##### *EUROHIS-QoL-8*

The EUROHIS-QoL-8 (Power, 2003) was routinely used to measure QoL of services users within the service. Services users completed the EUROHIS-QoL-8 measure pre- and post-intervention. The EUROHIS-QoL-8 is an 8-item self-report measure derived from the WHOQOL-BREF and WHOQOL-100. Overall, QoL score is a summation of scores across the eight items with higher scores suggesting better QoL. All answer scales have a 5-point response format on a Likert scale, ranging from 'Not at all' to 'Completely', for instance.



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The EUROHIS-QoL-8 has shown good internal consistency with UK samples (Cronbach's  $\alpha = 0.8$ ; Power, 2003), and satisfactory convergent and discriminant validity (Schmidt *et al.*, 2006). EUROHIS-QoL-8 is also acceptable cross-culturally (Power, 2003; de Rocha *et al.*, 2012) and accessible to adults with ID (Jeffrey & Hurtado, 2015).

### ***Facilitator Experiences' Questionnaire***

A structured qualitative questionnaire (see Supplementary Information) was developed by authors to examine facilitators' experience of the CWG. The questionnaire had two background questions (professional role and number of years working with people with ID) and four open questions investigating what they thought service users gained from the group; barriers and facilitators to taking part; and from their experience, how MI may be helpful for people with ID. Five facilitators were invited to take part (two of whom were current authors - NP and CB).

### **Data Analysis**

Acceptability has been assessed by examining uptake of the CWG and the demographics of service users who engaged. Responses from group facilitators have also been summarised using a descriptive approach grouping data by the question asked i.e., barriers, facilitators.

To examine feasibility, dropout rates were reported. Moreover, the lead author, NP, reviewed service users electronic care records to identify reasons for referral. Content Analysis (CA) was used to structure the analysis of records. CA has been described as a procedure whereby "objective, systematic counting and recording procedures produce a numerical description of the content in a text" (Neuman, 2011, p. 361). A coding scheme and electronic recording sheet was developed which included definitions of each code to be used.

For preliminary effectiveness, change between pre-and post-group scores on the EUROHIS-QoL-8 measure were assessed using a paired samples t-test. Data were available for  $n=22$ . Cohen's  $d$  was calculated as a measure of effect size, which was interpreted using the cut-offs 0.2, 0.5 and 0.8 for small, medium, and large effects respectively (Cohen, 1992). A procedure suggested by Morris and DeShon's (2002) to estimate single-group pre-post effect sizes was used. Any missing

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data were handled by the Last Observation Carried Forward (LOCF) procedure. Group-attendees who did not complete a full baseline measure (n=3) were not included in the EUROHIS-QoL-8 analysis. Attendees with missing items from their post-intervention timepoint (n=7) were treated as missing post-intervention data (LOCF applied) – this procedure was taken to reduce to chance of selection bias. The remainder of the sample (n=15) provided full baseline and post-intervention measures. Finally, the lead author reviewed electronic care records to examine post-group service outcome. Similar procedures described above to ascertain reasons for referral were used to gather information on post-group service outcome.

## Results

### **Acceptability**

#### ***Service Users***

Data were collected from six different group cohorts. Overall, 47 service users had been invited to take part in the CWG, 25 of whom attended at least one session. Unfortunately, we do not have the number of service users who were screened for the group or reason for attrition. The mean age of services users (n=25) was 33.3 years (standard deviation=14.9). The youngest service user was 20 years old and the oldest 72 years, suggesting the group was acceptable to individuals across the age range. Overall, 60% were female (40% male) and 80% were White British (20% unknown).

#### ***Group facilitators***

Of the five facilitators interviewed, two were Clinical Psychologists (one qualified, one trainee) and three were Assistant Psychologists. Facilitators had worked with people with ID for a mean of 9.4 years (max. 12 years, min. 2 years).

Facilitators felt services users gained a range of strategies from the intervention, such as practical skills to manage difficult emotions, **improving understand** of their feelings and how they linked with thoughts and behaviours, and gained confidence in sharing their feelings with others. Facilitators discussed the perceived benefits associated with group therapy; for example, service users having their experiences and difficulties validated and normalised by others, receiving and

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offering peer support, and an opportunity to socialise with other people with ID providing a sense of not being alone. The benefits of practicing MI activities within groups were also discussed, such as individuals learning to consciously shift their attention to different things without judgement, as well as developing a practice they can use in their every-day life. Moreover, groups were seen as helping to provide a prompt service to service users.

The most common perceived barrier was service users finding it difficult to understand some of the information, either due to their level of ability or English not being their first language. Moreover, some service users could be disruptive to other members, for example saying inappropriate comments. Another common barrier was service user's anxiety about being in a group and meeting new people.

When facilitators were asked what helped overcome such barriers, all five described the importance of adequately supporting service users by having their carers involved in groups or enough facilitators to provide personalised support. This seemed to help service users engage with group materials, as well as support them in practicing their skills outside of sessions. Other strategies included, keeping to the same session format helping to orientate members, providing workbooks, including practical exercises and metaphors to help reinforce messages and acquire skills, adapting the content of information to the client's level of understanding such as having easy-to-read materials, and going through information in more depth. It was helpful if facilitators were aware beforehand of the ability of service users allowing them to plan in advance to best accommodate users' needs. Helping groups develop ground rules, supporting everyone to get involved and empowering service users were also seen as important.

In terms of why MI may be particularly helpful to people with ID, facilitators believed the practical nature of mindfulness techniques means it may be easier for some to engage with than solely talking therapies. For example, MI may rely less on cognitive capacity and communication skills, and also carers can learn the skills themselves to support the individual. Moreover, people with ID can practice skills in the 'here and now', which they can use themselves without necessarily

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needing support from others – this may help to promote empowerment and autonomy to make positive changes in their own lives. One facilitator reflected how sometimes people with ID can experience strong emotions resulting in them acting in ways that might be harmful to themselves or others. Indeed, mindfulness can help people to be curious about their emotions and thoughts, teaching individuals an alternative way to respond to their feelings in order to reduce their arousal and distress.

### ***Reason for referral***

Review of service users' care records for reason for referral to the CWG suggested n=18 (72%) were referred to the group to help with regulating their emotions, such as developing skills in identifying, communicating, and coping with their feelings. Five (20%) were referred to the group while they were waiting for individual psychological therapy - although this was often in service users in the initial cohorts. Finally, two (8%) users received the CWG for multiple reasons such as difficulties coping with their feelings in addition to a lack of social connection with others.

### ***Attrition***

As reported, an overall uptake rate of 53% was observed (n=25). Of those who did attend, the majority (n=18, 72%) of service users attended five or all six of the sessions (Table III).

### **Table II.**

### **Table III.**

## **Preliminary effectiveness**

### ***Quality of Life***

The average overall EUROHIS-QoL-8 score was significantly higher ( $t=2.14$ ,  $df=21$ ,  $p=0.022$ ) at post-intervention (mean=22.18, SD=5.18) compared to pre-intervention (mean=20.73, SD=4.68). This demonstrated that those in the intervention did not deteriorate over time and in fact, reported an improvement in QoL. Cohen's  $d$  suggested a small effect ( $d=0.46$ ) of the CWG on QoL.

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### *Post-Group Service Outcome*

Analysis of service users' involvement with the service following their engagement in the CWG demonstrated that, eleven (44%) went on to receive individual psychological therapy; ten (40%) received an individual MI session at a later date for instance as a follow-up before a planned discharge, and four (16%) were discharged from Psychology without requiring any further input - for example, either being referred to a different discipline (n=2, 8%) or discharged from the service (n=2, 8%). In other words, under half of service users who engaged in the CWG required more than one session from psychology.

### **Discussion**

The current evaluation aimed to investigate the acceptability and preliminary effectiveness of a mindfulness-based intervention delivered in a group format as part of routine practice. Findings add to the limited, but growing evidence, demonstrating the acceptability and positive outcomes associated with group psychological interventions (Borune *et al.*, 2021) and more specifically, mindfulness-informed programmes (Burns & Waite, 2019) designed for adults with ID. Quantitative data was gathered from 25 service users across six different CWG cohorts, and qualitative data was collected from five group facilitators.

There are very few studies investigating group therapy utilising MI or examining QoL as an outcome measure. Notwithstanding this, a systematic review and meta-analysis of psychological-based group therapy delivered to 477 individuals with ID revealed a medium effect size ( $g=0.558$ , 95% CI .212, .903) suggesting the effectiveness of the current intervention ( $d=0.46$ ) was at least comparable. In the review, attrition appeared more difficult to examine as it was not always reported or due to the variation in how it was calculated i.e. number of people approached or attrition of consenting participants (Vereenoghe & Langdon, 2013). One of the largest studies to date involving 179 participants reported an uptake of 79.9% (Willner *et al.*, 2013) suggesting rates are higher than observed here (53%). Taken together, the findings suggest more research is needed to help identify factors that would help predict those who would be suitable for and likely to benefit

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from group therapy. Indeed, the current findings suggest groups are acceptable to people across the age range, and male and females. Furthermore, the current findings have implications for improving service user adherence; for example, psychological groups are likely to benefit from an iterative development process, as well as reviewing outcomes over time. For example, groups in other services may have stopped after the first cohort due to poor uptake - as reported here with a value of 28.6%, when in fact, through refinement this increased to 85.7% in cohort four. Some of the adjustments included greater collaboration with staff from other teams making them aware of the benefits of the group and changing the content of the group (e.g., making content more concrete through practical exercises). However, the possibility that the types of service user need that were deemed suitable for the group and therefore who was invited to the group changed as programmes progressed cannot be ignored. This is a further benefit of examining interventions across cohorts as programmes are iteratively refined.

Group facilitators discussed the benefits of practical strategies considering the ability of groups. For example, previous research has suggested the amount of time practicing mindfulness techniques mediated the relationship between mindfulness interventions and improved patient outcomes (Anderson *et al.*, 2021). Moreover, having carers involved in group was also perceived to be beneficial to service users (e.g., sitting together and supporting with practical activities and communicating with others). This has notable implications given the current pandemic (COVID-19), as some services may have restrictions on the number of people allowed in one room. It may be more helpful to reduce the number of service users in groups to allow space for carers.

It was promising to find only the minority of service users required individual therapy following engagement in the group. This is in line with a stepped care approach to health services suggesting most individuals in the current evaluation received an appropriate level of care in the first instance, as opposed to all being referred to more intensive treatment if the group was not available. This will have also eased demand on the service and prevented clients from being added to a waiting list delaying care and possibly deteriorating. However, this could also be interpreted as

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44% of participants required further psychological treatment and therefore, group therapy was not sufficient given their level of needs. Notwithstanding this argument, groups interventions may still have been associated with benefits within this subgroup; for example, it may have helped to reduce the number of individual sessions they went on to receive as their care was stepped up. In addition, as described by group facilitators, service users also developed additional insight and a range of coping strategies, which may have facilitated engagement and outcome of individual psychological therapy. Further research is required to examine the range of benefits of group therapy in the long term, including impact on service utilisation. Such evidence will help provide further insight into how group therapies could be used in stepped care in ID.

Findings offer preliminary evidence suggesting group interventions can be effective in improving QoL in adults with ID as statistical difference was observed between pre- and post-scores demonstrating a small effect. Most studies to date have, albeit importantly, investigated effects of group interventions on specific outcomes, such as mood and compassion (Idusohan-Moizer *et al.*, 2015), opposed to general wellbeing in adults with ID. That said, it is a limitation of the current study that no mindfulness-specific measure, such as the Mindful Attention Awareness Scale (Brown & Ryan, 2003) was used in addition to QoL. Therefore, we cannot make any strong arguments regarding whether factors targeted by MI were an active mechanism of change. An alternative interpretation of the improved QoL after the group may have been due to being part of a group and feeling less isolated, for instance. Similarly, there were no active checks of facilitator implementation factors (e.g., adherence or competence) during group sessions and thus it may be that the intervention was not delivered as intended (or delivered differently between facilitators). We also cannot report on the longevity of positive outcomes as no follow-up was provided (Bourne *et al.*, 2021). This has implications for the design of groups, for example, clients may benefit from a top-up session at a later date or being offered a greater number of initial sessions.

It is also a limitation that service users who engaged and those who did not were not interviewed about their experiences of groups. As shown elsewhere, service user voices can provide

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invaluable insights into the helpful and clinically meaningful aspects of group interventions (Dillon *et al.*, 2018; Currie *et al.*, 2019). The perspectives that were gathered were those of previous facilitators of the group. Although this provides novel perspectives to the literature in the context of group MI for people with ID, it is a limitation that two of the facilitators surveyed were co-authors of the current paper which may have led to a biased view on how helpful/effective the group was.

Finally, given our aim was to investigate acceptability, it was a limitation that we do not know how many people had been screened nor have a more systematic report of clinical reasons for exclusion. This is associated with the limitations of retrospective services evaluation; however, we can report that factors such as, severity of ID, risk to self/others and presenting problems were amongst some of the reasons why people were not included.

In conclusion, the current evaluation suggests a six-week MI group intervention was acceptable and associated with positive patient-reported and service outcomes for adults with ID referred to a secondary-care health service. More prospective studies are required which incorporate specific mindfulness measures, use mental health clinical outcome measures (at numerous timepoints including follow-up) assessing clinical and cost-effectiveness, and larger sample sizes. Qualitative studies gathering experiences of individuals with ID who attended and chose not to attend MI group sessions will also be valuable. These efforts would undoubtedly further develop our understanding of when, how and why MI groups can be helpful for people with ID and emotional difficulties.



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