

Northumbria Research Link

Citation: Currie, Tammy-Lee, McKenzie, Karen and Noone, Steve (2019) The experiences of people with an intellectual disability of a mindfulness-based program. *Mindfulness*, 10 (7). pp. 1304-1314. ISSN 1868-8527

Published by: Springer

URL: <https://doi.org/10.1007/s12671-019-1095-4> <<https://doi.org/10.1007/s12671-019-1095-4>>

This version was downloaded from Northumbria Research Link:
<http://nrl.northumbria.ac.uk/id/eprint/37517/>

Northumbria University has developed Northumbria Research Link (NRL) to enable users to access the University's research output. Copyright © and moral rights for items on NRL are retained by the individual author(s) and/or other copyright owners. Single copies of full items can be reproduced, displayed or performed, and given to third parties in any format or medium for personal research or study, educational, or not-for-profit purposes without prior permission or charge, provided the authors, title and full bibliographic details are given, as well as a hyperlink and/or URL to the original metadata page. The content must not be changed in any way. Full items must not be sold commercially in any format or medium without formal permission of the copyright holder. The full policy is available online: <http://nrl.northumbria.ac.uk/policies.html>

This document may differ from the final, published version of the research and has been made available online in accordance with publisher policies. To read and/or cite from the published version of the research, please visit the publisher's website (a subscription may be required.)



The Experiences of People with an Intellectual Disability of a Mindfulness-Based Program

Tammy-Lee Currie¹ · Karen McKenzie¹  · Steve Noone²

© The Author(s) 2019

Abstract

Objectives There has been an increasing interest in the use of mindfulness-based practices by people with an intellectual disability (ID); however, research about the perspectives of people with ID is limited. The aim of the study was to explore the experiences of people with ID of mindfulness practice.

Methods This qualitative study involved semi-structured interviews with 6 participants with ID (4 males and 2 females, aged 18–53, $M = 36.17$) who had taken part in a mindfulness programme. Interpretative phenomenological analysis was used to analyse the data.

Results Two themes were revealed: “The impact of mindfulness” and “The mechanisms of the group”. The results indicated that the participants perceived a number of psychological benefits of attending the programme including improved self-esteem, confidence, self-control, and compassion for oneself and others. A full understanding of what mindfulness is or its purpose was not required in order to lead to therapeutic gains.

Conclusions The results suggest that mindfulness may represent an effective psychoeducational approach for some people with ID.

Keywords Intellectual disability · Mindfulness · Mental health · Qualitative

People with an intellectual disability (ID) experience health inequalities that significantly impact on their life span, quality of life, health, and wellbeing (Brown et al. 2011; Owen and Sayce 2006). While there is some inconsistency in prevalence rates, due to methodological differences between studies, the evidence suggests that approximately 40% of people with ID may develop mental health difficulties such as anxiety, depression, eating disorders, and psychosis, compared to 25% of the general population (e.g. Buckles et al. 2013). There are a number of suggested reasons for this greater prevalence. People with ID are at increased risk of exposure to environmental stressors and traumatic life events, including physical and sexual abuse (Reiter et al. 2007); living in poverty and deprivation (Emerson 2004); injury or illness, unemployment, abuse, and neglect (Hastings et al. 2004); poorer social

support and relationships (Walsh et al. 2003), and stigmatisation (Paterson et al. 2012).

Despite their increased vulnerability to mental health problems, there is a limited range of evidence-based psychotherapeutic interventions that have been developed for people with ID. A review by Gustafsson et al. (2009) concluded that the effectiveness of cognitive behaviour therapies (CBT) and behavioural therapies for people with ID with mental health problems was weak. Beail (2003) and Willner (2005) suggest that many people with ID can engage and benefit from psychotherapeutic interventions, especially when adaptations are made. Brown et al. (2011) noted, however, that current psychotherapeutic interventions may not be effective for people with ID, possibly due to the reliance they place on the ability to report thoughts and feelings, to consider and evaluate evidence, and to engage in a variety of abstract verbal skills.

More recently, Griffith et al. (2016) suggested that interventions integrating mindfulness may be useful for people with ID, as unlike multicomponent procedures, the core of mindfulness is centred on one aspect: the ability to shift the focus of one’s attention, allowing an individual time to calm themselves and choose how to react to a triggering thought or event (Adkins et al. 2010). There are many definitions of mindfulness; however, it is generally understood as

✉ Karen McKenzie
k.mckenzie@northumbria.ac.uk

¹ Northumbria University, Northumberland Building, Northumberland Road, Newcastle NE18ST, UK

² Northumberland Tyne and Wear NHS Foundation Trust, Newcastle, UK

intentionally focusing one's attention on the present moment experience, in a non-judgemental and accepting way (Kabat-Zinn 1990). Mindful practice encourages individuals not to shut out thoughts or memories which are discomforting to them but, instead, to face them and recognise their transient nature, understanding that they are simply thoughts that will pass, rather than identifying with them, and thus altering their perspective regarding negative cognitions or emotions (Needleman and Cushman 2010).

These principles have been incorporated into a number of mindfulness-based approaches. Research with typically developing individuals indicates that mindfulness-based practices can reduce anxiety (Miller et al. 1995); pain (Kabat-Zinn et al. 1987); and depression (Williams et al. 2000); as well as increase subjective wellbeing and reduce emotional reactivity (Keng et al. 2011). Similarly, randomised control trials have demonstrated that mindfulness-based stress reduction (MBSR: Kabat-Zinn and Hanh 2009) can reduce the psychological morbidity associated with medical illness (Reibel et al. 2001) as well as reduce stress and increase emotional wellbeing in non-clinical samples (Williams et al. 2001).

The research into mindfulness-based practices used with people with ID is more limited; however, researchers have reported reductions in physical and verbal aggression (Singh et al. 2008); depression (Idusohan-Moizer et al. 2015), anxiety and aggression (Adkins et al. 2010); and deviant sexual arousal (Singh et al. 2011). A systematic review (Hwang and Kearney 2013) and a systematic review and narrative analysis (Chapman et al. 2013) of mindfulness-based approaches for people with ID found a number of methodological limitations in the reviewed papers (some of which were included in both reviews). It was, however, concluded that mindfulness-based approaches had benefits, particularly in relation to reduction in aggression, which were sustained over the longer term. While this body of research indicates that mindfulness-based approaches show promise as psychotherapeutic approaches for people with ID, the studies are largely based on very small sample sizes and the effective components are not always clear when a range of techniques have been used (e.g. Idusohan-Moizer et al. 2015).

There is an increasing acknowledgement of the right to, and value of, people with ID expressing their opinions about the therapy they undergo (e.g. Brown et al. 2011). It is argued that this helps improve the quality and effectiveness of therapy (e.g. Walmsley 2004). There is, however, limited research exploring the views of people with ID about their experiences of mindfulness-based approaches.

Some researchers have obtained feedback from participants. For example, Singh et al. (2011) included some information about the perspective of participants who were sex offenders who participated in a mindfulness-based intervention to reduce levels of inappropriate sexual arousal. While it was seen as having the benefits of improving relationships

with staff, aspects of the intervention, such as the language used in relation to focusing on thoughts, were found to be challenging for some participants. Similarly, Thornton et al. (2017) obtained feedback from questionnaire responses from five adolescents with ID who attended a mindfulness-based group. The young people identified a number of different exercises that they had found helpful and nothing was identified that they disliked.

Some authors have obtained more detailed information about participants' views. Clapton et al. (2018) used a mixed-methods approach, including focus groups with six participants with a mild ID who had attended a compassion-focused therapy group. The authors reported three themes which covered the benefits and challenges of the group and the resultant changes in the group members. Chapman and Mitchell (2013) conducted interviews with six individuals with ID who had attended short introductory mindfulness workshops. The participants valued the opportunity to share experiences and two of the three who subsequently listened to the recorded mindfulness exercises found them beneficial in dealing with anxiety and stress. Both Yildiran and Holt (2015) and Dillon et al. (2018) conducted interviews with individuals with ID who also had mental health difficulties. Both studies highlighted some benefits of the group, for example improved ability to relax, and some aspects of the exercises that participants found difficult or ineffective.

The present study aims to add to this research by using semi-structured interviews to obtain the views of a group of people with ID about their experiences of undergoing MBSR. Our study explores participants' views following an 11-week programme which took place in a community setting in partnership with a third sector organisation.

Method

Participants

Seven participants took part in the study, although only the data from six were analysed. This was due to the difficulties one participant encountered in expressing his views of the mindfulness programme. As an inclusion criterion of the study was that participants were required to have the expressive language abilities to allow them to participate in the interviews, it was not considered that the participant met all the inclusion criteria, and therefore, his data should be omitted. The six remaining participants were aged 18–53 ($M = 36.17$). All but one received support to travel to the venue where the programme was held. All of the included participants had the verbal abilities to give their views and respond to questions; however, no formal measure of their level of intellectual ability was available. This sample size was chosen as IPA is committed to a detailed interpretative account of the cases

included, with researchers suggesting that this can only realistically be done on a small sample (Smith 2015). Table 1 summarises the participants' characteristics.

Procedure

Design

Ethical approval for the study was obtained from the first author's university ethics committee. The study was qualitative, and data were analysed using interpretative phenomenological analysis (IPA: Smith 2015). IPA was chosen because it has previously been used successfully in research with people with ID (e.g. Corby et al. 2015; Kaspar and Kroese 2017; Sullivan et al. 2013), it and tries to explore in detail an individual's personal perception of an event or experience.

Participants were recruited, using a purposive sampling method, from a user-led voluntary organisation for people with ID in the North East of England. Staff were provided with information about the project and individuals were invited to participate if they met the inclusion criteria. These were aged 18 or over, having completed a mindfulness programme based on Kabat-Zinn's (1990) MBSR curriculum at the organisation, self-identified as having an ID, and with a level of expressive language abilities which would enable them to take part in the interviews.

All interviews took place at the organisation's premises in a private, quiet room. All participants were interviewed within 6 weeks of the programme being completed. In order to ensure consent was informed, a three-step process was used. First, potential participants were initially identified via the voluntary organisation. The staff working there knew the individuals well and only suggested the study to those considered able to give informed consent. Following this, potential individuals met individually with the first author, who subsequently conducted the interviews. At this point, potential participants were provided with further written and verbal information about the study, asked to clarify their understanding of what the research would entail, and invited to ask questions or for clarification. Participants were reminded of their right to withdraw at any time, and if they still wished to take part, they were asked to provide written consent. Individual interviews were then arranged with those who consented. The process

was repeated at the point of interview, in order to ensure that the participant understood and retained the information about the research and the implications if they took part. They were again reminded of their right to withdraw and asked to confirm their consent to ensure that they could communicate their decision.

The interviews were semi-structured and were guided by a prompt sheet. This allowed the researcher and participant to engage in a dialogue in which initial questions were altered in light of their responses. This flexible approach facilitated the exploration of topics as they emerged. The interviews used open-ended questions and optional prompts, as many people with ID can find open-ended questions difficult to answer (Sullivan et al. 2013). For instance, "What helps you to remember the different things you learn?" may be followed by "do you practice at home or attend the refresher sessions?"

All interviews were digitally recorded. The interviewer was mindful of threats to the quality of transcription, such as missed context and attempting to tidy up the text (McLellan et al. 2003); therefore, the interviews were transcribed verbatim, retaining non-fluency features such as grammatical errors, pauses, and word repetition, in an attempt to make the transcripts as close to a true account of the recordings as possible. During the transcription process, any names mentioned by participants were anonymised. After each interview, an early memo was written to reflect on the interview.

The Mindfulness Programme

The programme, "Mindfulness for life," was adapted to maintain the essential teaching goals and meditation practices of mindfulness-based stress reduction (Kabat-Zinn 1990). To maintain integrity, the programme leader had undertaken training to fulfil standards set by the UK Network for Mindfulness-Based Teachers (2015). The first adaptation was to offer a second practice meeting 2 days after each weekly session. This comprised of informal peer-led sessions which took place in the same building as the mindfulness group, but which were run by the group participants with support from a member of the third sector organisation staff. This helped clarify ideas discussed in the workshop and to offer additional practice time.

A second adaptation was to extend the traditional 8-week programme by 3 weeks to allow more time to familiarise people with core ideas. Each session lasted 2 h. The programme offered a series of mindfulness practices that are exactly like any MBSR programme. These include the following: eating meditation; developing an awareness of the breath; mountain pose and bringing an intention to practice. Other traditional MBSR exercises had some variations (see Table 2). These included the body scan, yoga stretching, and mindful walking. The body scan was repeated throughout the programme but was introduced initially in shorter practice sessions. Following

Table 1 Summary of the participants' characteristics

Participant pseudonym	Gender	Age
Sharon	F	53
Andrew	M	32
Callum	M	36
Peter	M	18
Dean	M	33
Rachel	F	45

Table 2 Outline of the programme, compared with a traditional MBSR programme, with associated comments

MBSR	Mindfulness for life
<p>Session 1: Introducing mindfulness</p> <ul style="list-style-type: none"> • Body scan • Raison exercise 	<p>Sessions 1–3</p> <ul style="list-style-type: none"> • Encourage group cohesion by: <ul style="list-style-type: none"> - Encouraging everyone to contribute - Using examples and language of group members - Offer a new perspective: we are all the same. - Normalising distress - Enabling meditation practice • Introducing short meditations • Standing/ body scans/ meditation of breath. • Raison exercise.
<p>Session 2: Handling stress</p> <ul style="list-style-type: none"> • Body scan • Mindfulness of breath • Positive events diary 	<p>Session 4</p> <ul style="list-style-type: none"> • Using the body board to understand how stress/ distress turns up in people's lives. • Introducing the sweet spot jar to record positive life events • Time spent identifying the good things that happen in life. • Mixing up sitting, lying and walking meditations to increase tolerance and capacity for practice • Metaphor of thought train to explain choice of engaging with thinking
<p>Session 3: The power of being present</p> <ul style="list-style-type: none"> • Mindfulness walking • Mindfulness movement • 3 three step breathing space • Unpleasant events diary 	<p>Session 5</p> <ul style="list-style-type: none"> • Mindfulness walking • Mindfulness movement • Introducing 3-step breathing space • Time for consolidation. • Review the “sweet spot” jar
<p>Session 4: Learning about our patterns of reactivity to stress</p> <ul style="list-style-type: none"> • Understanding how stress operates 	<p>Session 6</p> <ul style="list-style-type: none"> • Extending practice – body scan now for 30 min • Introduce sour events jar for recording difficult experiences • Time to review practice and ideas for implementing into daily life
<p>Session 5: Coping with stress</p> <ul style="list-style-type: none"> • Using mindfulness to respond instead of react • Sitting meditation • 3-step breathing space 	<p>Session 7</p> <ul style="list-style-type: none"> • We are not our thoughts: <ul style="list-style-type: none"> - Use of role play to show how our thoughts impinge on our life and how stressful thoughts can lead to avoidance. - Introduce “monsters on the bus” metaphor • Appreciating being in a group • Sitting meditation • 3-step breathing space
<p>Full day silent retreat</p>	<p>No full day retreat</p>
<p>Session 6</p> <ul style="list-style-type: none"> • Stressful communications and interpersonal mindfulness. 	<p>Sessions 8–9</p> <ul style="list-style-type: none"> • Review of progress and how we can bring mindfulness into our lives. • Introduce new exercise – mindfulness handwashing • 3-step breathing space
<p>Session 7</p> <ul style="list-style-type: none"> • Life-style choices – how can I best look after myself? • What depletes and what nurtures • 3-step action 	<p>Session 10</p> <ul style="list-style-type: none"> • Preparing for ending • Review all practices: <ul style="list-style-type: none"> - Participants choose the mindfulness exercises they want to practice. - The teaching goals that have been recorded throughout the programme are reviewed.
<p>Session 8</p> <p>Keeping your mindfulness alive:</p> <ul style="list-style-type: none"> • Body scan, stretching • Walking • Planning for the future 	<p>Session 11: Keeping your mindfulness alive</p> <ul style="list-style-type: none"> • Celebration of what has been achieved • Everyone has a chance to say what they have gained from being in the group • Body scan • Invitation to join an ongoing, weekly practice group in the local area.

earlier pilot work, extra care was taken with stretching exercises because participants found standing for long periods difficult; therefore, short, focused movements were encouraged as part of the movement exercises.

New exercises were added to the traditional practices, for example, washing hands mindfully with scented soap enabled the participants to keep their focus on their physical experience. A variety of metaphors and similes were used to help explain the processes to participants, for example choosing not to get on the “thought train”. A second example was conceptualising frightening thoughts as being like monsters on a bus we are driving. The challenge was to continue to drive towards our chosen values rather than stop the bus just so the monsters will sit down.

A further innovation that arose from the additional practice group was to encourage members of the group to lead individual mindfulness exercises. The aim of this was to help participants to generalise their practice when facilitated by different practice leaders and to enable the person leading the meditation to better internalise the practice. Other modifications included the use of drawings to capture the teaching goals at the end of each session.

Participation in the group and attendance at the additional informal practice sessions were voluntary. Attendance at the group was between 70% and 100% for all participants, except one, who attended half of the sessions. People who already used the services of the voluntary organisation were made aware of the group through posters on the premises and word of mouth. Those who were interested in attending met with a staff member from the organisation and one of the group facilitators to discuss what participation would entail. Numbers of people attending each session could vary, but was approximately ten per group. Support staff were also welcome to attend when invited to do so by participants and four participants were joined in the group by their support workers.

Data Analysis

A critical realist approach using IPA was adopted to underpin the methodology and analysis of this research as it was concerned with the detailed understanding of how people with ID view and experience mindfulness. IPA was chosen as it provides the researchers with an opportunity to engage in a dynamic and close way with the reflections of participants about their experiences (Smith 2015). At the heart of IPA is the double hermeneutic: an explicit recognition of the interpretative nature of the process and that any findings are a result of this interpretative process. This occurs initially as the participant uses the interview process to interpret their experiences and make sense of them in the context of the interviewer’s questions. The researcher then interprets the participants’ interpretations at the analysis stage, both in the context of his/her own experience and beliefs and that of the collective sense-making of all participants.

In order to do this, the interviewer read and reread the transcripts, and initial notes and comments were made separately on

each transcript, highlighting the content of the account, the use of specific language, and potential conceptual and contextual elements. This idiographic focus enabled the researcher to become immersed in each individual interview, identifying any emergent themes by exploring patterns across the initial notes.

The emerging themes were then grouped together, and connections between them were explored to produce higher level superordinate themes. This iterative process led to the movement from individual to overarching themes and to the production of superordinate themes that represent the whole cohort. Participants were given pseudonyms and any identifying information was changed. Where extracts have been edited, (...) indicates omitted material and [] indicates additional information added by the researcher. Text was written to reflect the local dialect as it was spoken with words that may be more difficult for the reader who is unfamiliar with the dialect to understand, being clarified in text in square brackets.

Researcher Reflexivity

It is recognised that the researcher cannot be a completely neutral bystander and will have preconceptions that could introduce bias. A reflexive diary was kept throughout the analysis process to increase the trustworthiness of the analysis (Kaspar and Kroese 2017) and the issues were discussed with the research team. This highlighted a number of issues for consideration for the interviewer, for example an initial sense that she may be sticking too rigidly to the semi-structured interview schedule, rather than facilitating a wider exploration of the issues raised by participants. The interviewer was also aware of having a particular interest in which exercises were experienced as most useful by participants and reflected on whether this was an overshadowing aspect that participants felt was more important. Reflection on these issues and discussion of the process and themes with all research team members allowed issues to be addressed if required, for example using the interview schedule in a more flexible and responsive way. The interviewer, while a psychologist, did not have a clinical background. It was considered that this factor may have influenced the analysis by making her less likely to interpret participants’ responses from the perspective of a mental health professional, particularly as the programme was set up in a community setting and presented as “mindfulness for life”. The other members of the research team were clinical psychologists, which allowed for some discussion of the potential implications and benefits of offering, what is often presented as a psychotherapeutic intervention for people with particular psychological and behavioural difficulties, in this context.

Results

Two superordinate themes were identified. The first, “The impact of mindfulness” had the associated subthemes of “Just breathe”,

“Everyday life”, and “It works, but we’re not sure how.” The second “The mechanisms of the group” had the associated sub-themes of “We’re all the same” and “Thinking of others”.

The Impact of Mindfulness

Attending the mindfulness group had an effect on all of the participants physically and/or psychologically, either directly after taking part in the group exercises or in their everyday lives as a result of attending the programme. The subthemes are outlined below.

Just Breathe

The subordinate theme of “Just breathe” highlights the way in which breathing was a crucial component for each participant from the mindfulness skills that they had learned, and how they were able to incorporate this technique into their everyday lives, resulting in them being less reactive to their emotions. The participants provided several examples of the intentional use of breathing techniques to enable them to overcome situations they were finding stressful or difficult. This suggested that the skill had generalised beyond the confines of the room in which the mindfulness sessions took place. Furthermore, many of participants appeared confident in the effectiveness of the technique, even in situations where arousal levels were high:

Coz [because] when am on the bus if a er coz a suffer from anxiety panic attacks (...) N what a dee [do] is if a feel a attack coming on a just shut me eyes n just concentrate on me breathing (...) N it helps. (Dean)

A had to go for a test at the doctors (...) erm am usually dead [really] tense n actually the nurse done it the second time the test because a was just controlling me [my] breathing. (Rachel)

For some, the techniques were used apparently without much conscious thought and appeared to have been incorporated as a coping strategy in everyday life: “Just when a sit down on the settee (...) A can feel meself [myself] doing it”. (Rachel). For others, the breathing exercises were not always helpful, but were still drawn upon as a potential coping strategy in difficult situations:

Sometimes but a think sometimes probably doesn’t really help (...) because if yi get that worked up n stuff n then yi try to do yi breathing n then maybe then yi think about it in yi head n sometimes it doesn’t really help. (Peter).

Mindfulness-based interventions all follow a similar format of multiple exemplar learning. The essential premise focuses on increasing a capacity to pay attention on purpose without judgement. Learning how to direct attention to various parts of the body, either in movement or in stillness, is underpinned by the capacity to locate attention to the breath. This is because the breath remains a continuous stimulus that is always available and participants are taught to use it as a default position when attention is lost during any meditation. Through practice, it is hoped that the breath can also become an anchor to direct attention in times of stress and ameliorate its impact. The participants appear to have adopted these principles into their methods of coping, suggesting that the programme was successful in providing a functional understanding of stress and how mindfulness can be used to reduce it. Key mindfulness exercises have also been incorporated into the conceptual framework and habits of the participants. Indeed, the participants identified the ability to pay attention to, and control their breathing as the most important, useful, accessible, and memorable skill they learnt on the programme, enabling them to remain calm in stressful situations.

Everyday Life

This subtheme reflects the way in which participants believe mindfulness has helped them in several diverse areas of their lives. The impact of mindfulness on issues that ranged from attitude towards housework to issues of self-confidence, anger management, and pain control were perceived as significant and life-changing to participants. There was a sense that mindfulness had permeated all aspects of the participants’ lives and had changed their world view in many areas.

It’s a it’s a it’s helped with a big part of me life erm its changed me life a bit because a used to be very stressed and a don’t care if me house is a mess not bothered anymore (...) Al tidy up al tidy up when a can get up n do it. (Sharon)

Consistent with the concept of re-perceiving, Sharon indicates that mindfulness has helped her to shift her perspective, even when her external world has not changed. She moves away from her previous perception of a messy house as something that needs to be dealt with immediately and of herself as a person who is somehow lacking if she does not tidy it straight away. She demonstrates an ability to accept a situation that previously caused her stress and to be more forgiving towards herself for not dealing with her messy house immediately.

The increasing recognition of the subjective nature of reality and self-identity gained through mindfulness practice is also demonstrated by Andrew and Dean. Andrew describes the process of re-perceiving his subjective responses and makes an interesting distinction between his initial emotional

responses and his perception of “reality” after accepting these emotional responses:

Er it helps is by er by accepting the that that my eh thoughts and feelings are there nd erm n then it helps is er to ease that feeling help me to cool calm and and help is to bring back to reality. (Andrew)

Similarly, Dean describes a shift in his sense of self from a somewhat negative identity, to a person who has more confidence in his own value and who has the ability to control his pain to some extent.

Made is [me] feel a bit better in meself (...) Like like a used to be a bit of a twat but er now am more confident in meself. (Dean)

When yi shut yi eyes n concentrate on like if yiv [you have] got pain in yi arm or sumik [something] just like focus on the pain then the pain went away n then it come back. (Dean)

Each participant benefitted in his or her own way from the programme; Sharon is more compassionate towards herself, being less worried about chores such as housework, Andrew is more accepting of his emotions and is able to live in the present, rather than becoming caught up in the thoughts inside his head, and Dean views himself more positively and uses the techniques to help relieve physical pain. While this suggests that such approaches could be used effectively as a therapeutic intervention with those with specific mental health difficulties, such as anxiety, a strength of the group appeared to be that participants did not view it in this light. Instead, perhaps because of the community setting in which it took place, voluntary participation and the presentation of the programme as “Mindfulness for Life”, as opposed to an intervention for people with mental health problems, mindfulness appeared to have become a perspective and source of resilience that many participants had integrated, often without conscious thought, into their everyday lives.

It Works, but We Are Not Sure How

Each of the participants described benefit from the mindfulness exercises; however, the extent to which they articulated how or why certain exercises were able to have such an effect differed. Dean was unaware of how the breathing exercises made him feel calmer, even though they were effective in reducing his anxiety: “That’s what a done last neet [night] focused on me breathing n then er a just felt a bit calmer (...) a just divn’t kna [don’t know] how it happened though”.

(Dean), while Andrew highlights the purpose of the mindfulness exercises, as well as the underlying mechanisms which result in him being less reactive to his emotions:

It’s erm basically it’s about understand aware and accept of ev- everything around yi when like when yi when yi about to feel stress or anxious (...) n yi n yi bring yiself back into er to yi breathing jus- jus- just noticing you’re the heat of your body or or the or the fast yi breathing... And just fi- find the best that yi can to to slow it down. (Andrew)

Callum, as well as recognising that certain exercises are able to keep him calm, also describes the effect that practicing certain exercises can have neurologically: “Yeah if you do more and more of it your brain gets rewired, Yeah so you can stay calm more” (Callum). Here, Callum appears to be using the metaphor of brain rewiring to describe the process whereby repeated practice of the mindfulness exercises results in re-perceiving, which in turn allows him to view life with more equanimity. Irrespective of the participants’ level of understanding or expectations about the underlying mechanisms or purpose of mindfulness, each described benefit from the exercises. Participants also appeared unconcerned that they did not completely grasp all of the mindfulness concepts, suggesting that a complete understanding is not necessary for mindfulness to be beneficial.

The Mechanisms of the Group

This theme explored the way that participants felt that being part of the group changed the way they viewed themselves and others. This included increased acceptance of themselves and others, and a recognition of the factors that united them.

We Are All the Same

Participants highlighted the pleasure they felt in simply being part of a group and having a sense of belonging. This is reflected in Peter’s growing social confidence due to being part of the group:

Mostly about talking about like point of view nd like saying what like a wana [want to] say n like because when a first went a wasn’t really that chatty n then now a was. (Peter).

Other participants stressed the importance of being with others who they saw as being like themselves. For many, this similarity related to having ID: “Interacting with other people (...) Meeting people with different disabilities (...) N learning difficulties (...) N it makes yi think well am not the only one who’s got disabilities.” (Dean) and “N a think with wu all

being in a big group it's made yi understand that we are the same." (Sharon).

This feeling of being the same as others seemed comforting and empowering to participants. This appeared to go beyond simply spending time with others who have disabilities, as some participants found comfort in their own realisation that everyone experiences difficulties, irrespective of whether they have ID:

A think it helps yi be calm because yi realise there's a whole world out there n they're all the same as you (...) N they're all probably stressed somewhere along the line (...) Am not the only one. (Sharon).

Erm (.) a think it's because erm of the fact that we all get stressed at times nd eh some- sometimes we don't even know how to calm down or (...) Erm (.) what av learnt is that it it happens to everyone. (Andrew)

While the sense of group belonging was seen as an important factor in the increased welling of participants, it was not viewed in isolation from the mindfulness exercises and was contrasted with other groups where they would not have been as confident: "A would of just sat there quietly." (Rachel). Participants felt strongly that being part of a group helped increase their confidence; they became more able to give their views and engage with others both in the group setting and outside of this. Rachel described being less concerned about being judged by others if she expressed herself: "a don't care where I am when am saying it anymore," while Dean reported being more accepting of himself and an associated increase in mood and activities out of his home: "N more happy within meself instead of being like staying in the hoos [house] being depressed all the time, a gan oot n dee things [go out and do things]" Peter was more confident, after attending the group, about confiding in other people about his thoughts and feelings as an effective coping mechanism:

Mostly just talk to someone instead of getting meself worked up."

Did yi do that before the course or not? (Interviewer)

Hm not really.

Thinking of Others

As well as providing a sense of belonging and a recognition that everyone experiences difficulties in their lives at some point, participants also described an increased empathy and compassion for others and ability to look at life from another's perspective: "To think about other people how, how they're

feeling inside it's not just about me it's about everyone" (Sharon). Mindfulness practice helped Sharon to shift her perspective from herself to others, particularly her daughter. She takes the time to think and consider before acting. As a result, she acts in a more compassionate, empathetic way; understanding that her daughter may be having a difficult time: "A think it's different because a sit n think about it first a look at a n a think oh she must be tired or the could be other things that's bothering a." Taking this perspective helped her change her behaviour by reducing the number of times she phoned her daughter.

A think about how irritating it would be if someone rings me twenty-four seven (...) N it's made me realise like yi know yi know it's made me think more on her part. (Sharon).

Peter also considers the perspective of others and recognises the frustrations that people with different forms of disabilities may experience and how mindfulness might help them:

...it [mindfulness] would help like the people in wheelchairs n stuff coz like the must find it hard to like sit in a wheelchair all day n yi know get stressed out (...) N like other special needs they'll probably get stressed out about like the staff annoying them n stuff. (Peter)

Discussion

The aim of the study was to explore how people with ID attending a mindfulness group viewed the experience. The study adds to the previous literature, by exploring a group which was based in a community setting, provided in partnership with a third sector organisation and with participants who are not restricted to those with mental health difficulties or referred to the group by someone else. The results indicate that the participants felt that attending the mindfulness group led to a number of psychological benefits, including increased self-esteem, confidence, self-control, equanimity, and compassion for themselves and others.

Research with typically developing individuals has also found that mindfulness-based practices can impact on several areas of functioning and can result in a sense of calmness or relaxation (Kerrigan et al. 2011; Mason and Hargreaves 2001) and being less reactive to emotions (Chadwick et al. 2011). The integration of mindfulness approaches into so many aspects of the everyday lives of the participants may reflect that the group was run in a community setting. Mindfulness did not appear to be perceived by participants as a specific therapeutic intervention to be used to address particular mental

health difficulties. Instead, it seemed to be viewed as a way of thinking and a set of coping strategies that could be applied to a range of difficult situations that arise in daily life.

Breathing techniques were identified by many participants as being central to these improvements, as highlighted in the subtheme “just breathe”. The benefits of mindfulness practices such as bringing attention to the breath to create a sense of agency in specific situations have also been identified in studies with people without ID (Kerrigan et al. 2011; Mason and Hargreaves 2001). It is suggested that the repeated practice of giving full attention to the feeling of the breath trains the mind to be less reactive (Kabat-Zinn 1990). Behavioural relaxation techniques, of which a focus on breathing is an important component, have been shown to be effective for people with ID in reducing aggressive and disruptive behaviours (To and Chan 2000) and anxiety (Lindsay et al. 1989) by reducing physiological arousal and creating a physiological state incompatible with anxiety or aggressive behaviour (Lopata 2003).

The participants varied in their understanding of the purpose and underlying mechanisms of the mindfulness exercises, with some participants reporting benefits despite being unaware of how the exercises contributed. For example, a number of participants gave examples of re-perceiving through mindfulness practice (Shapiro et al. 2006), even though they did not label the process in this way. This suggests that a full understanding of, or clear expectations about, mindfulness is not necessary to be able to feel the positive effects (Mason and Hargreaves 2001). It is perhaps unsurprising, given the large literature that attempts to explain the underlying mechanisms of mindfulness, that the participants differed in the extent to which they understood the mechanisms and purpose of mindfulness. What may be more important is simply repeatedly and regularly practicing the techniques (Siegel 2007), as suggested by the participant Callum, in terms of his brain becoming “rewired” through practice. Mindfulness, therefore, appears to offer a beneficial intervention for those who may not possess the cognitive and socio-emotional abilities that many mainstream psychotherapeutic interventions require.

The study also highlighted the importance of the social aspects of the mindfulness group. Research suggests that social networks act to increase and sustain the quality of life, self-esteem, and confidence of people with ID (Srivastava 2001), with social support being believed to act as a protective barrier to mental health problems such as depression (Brackenridge and McKenzie 2005). Consistent with other research findings (Mishna and Muskat 2004), not only being part of a group, but belonging to a group of people similar to themselves, acted as a source of comfort to the participants in the present study.

Research indicates that some people with ID are aware that a stigma can be attached to having ID (Craig et al. 2002),

which can have a negative impact on their self-esteem (Abraham et al. 2002) and lead to attempts to distance themselves from this identity (Harris 1995). By contrast, the participants in the present study felt the group provided the opportunity for them to experience mutual support from others similar to themselves, in an accepting environment that was adapted to meet their needs. Such an environment can improve social skills, increase self-esteem, and decrease the sense of isolation, through the acceptance participants receive from peers and the ability to help others (Mishna and Muskat 2004). One reason for this may be because mindfulness is centred on cultivating attitudes of non-judgement, a beginner’s mind, non-striving, and acceptance (Kabat-Zinn 2009).

Previous qualitative research with those with (Yildiran and Holt 2015) and without ID has indicated that mindfulness can also foster the qualities necessary for developing compassion for the self and others (Kristeller and Johnson 2005). This can be expressed as a shift in perspective (Kerrigan et al. 2011) or a greater sense of acceptance (Chadwick et al. 2011; Mason and Hargreaves 2001). These processes were also apparent in the current study, with many of the participants expressing a greater understanding of, and empathy towards, the perspective of others, as well as being more accepting and forgiving towards themselves. There was also a recognition of the universal vulnerabilities that were part of being human (Crane 2008) and that all people, irrespective of whether they have ID or not, will experience some difficulties in their lives at some point.

Limitations and Future Research

The study did have limitations. Some participants found it difficult at times to verbalise their opinions, and one account was excluded from the analysis due to the participant’s expressive difficulties. Many people with ID experience difficulties in recognising and communicating emotions (Scotland et al. 2015) and the use of images, prompts (Corby et al. 2015), and alternative methods of communication may have enabled the views of participants to be expressed more fully and the inclusion of those with greater difficulties with verbal communication.

The programme provided the participants with tools for self-control, in particular breathing techniques, and offered new ways of viewing the world that they may have previously not considered. The results suggest that mindfulness may represent a viable and effective intervention for some people with ID. Further research is needed to explore whether offering mindfulness-based interventions in community-based settings may help reduce the stigma that is often associated with mental health interventions, while still producing desirable psychological outcomes, such as reduced anxiety and aggression and increased confidence. There is also a need for research to differentiate the specific effects of mindfulness practices from

the social benefits of group therapy. This might be done by comparing the outcomes from individual and group approaches to mindfulness and by comparing outcomes from mindfulness groups and other group therapies while controlling for factors such as number of sessions, participant numbers, and individual characteristics.

Acknowledgements We would like to thank all participants and the organisation who supported the project.

Author Contribution TC and KM designed the study; TC collected the data and conducted the initial analysis of the data; KM and SN assisted with the subsequent data analyses. All authors contributed to writing the paper and approved the final version of the manuscript for submission.

Compliance with Ethical Standards

Ethical Approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Ethical approval for the study was obtained from the Faculty of Health and Life Sciences Ethical committee, Northumbria University.

Informed Consent Informed consent was obtained from all individual participants included in the study.

Conflict of Interest The authors declare that they have no conflict of interest.

Open Access This article is distributed under the terms of the Creative Commons Attribution 4.0 International License (<http://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons license, and indicate if changes were made.

Publisher's Note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

References

- Abraham, C., Gregory, N., Wolf, L., & Pemberton, R. (2002). Self-esteem, stigma and community participation amongst people with learning difficulties living in the community. *Journal of Community & Applied Social Psychology, 12*(6), 430–443.
- Adkins, A. D., Singh, A. N., Winton, A. S., McKeegan, G. F., & Singh, J. (2010). Using a mindfulness-based procedure in the community: Translating research to practice. *Journal of Child and Family Studies, 19*(2), 175–183.
- Beail, N. (2003). What works for people with mental retardation? Critical commentary on cognitive-behavioral and psychodynamic psychotherapy research. *Mental Retardation, 41*(6), 468–472.
- Brackenridge, R., & McKenzie, K. (2005). The friendships of people with a learning disability: What do friendships mean to people with learning disabilities? *Learning Disability Practice, 8*(5), 12–17.
- Brown, M., Duff, H., Karatzias, T., & Horsburgh, D. (2011). A review of the literature relating to psychological interventions and people with intellectual disabilities: Issues for research, policy, education and clinical practice. *Journal of Intellectual Disabilities, 15*(1), 31–45.
- Buckles, J., Luckasson, R., & Keefe, E. (2013). A systematic review of the prevalence of psychiatric disorders in adults with intellectual disability, 2003–2010. *Journal of Mental Health Research in Intellectual Disabilities, 6*(3), 181–207.
- Chadwick, P., Kaur, H., Swelam, M., Ross, S., & Ellett, L. (2011). Experience of mindfulness in people with bipolar disorder: a qualitative study. *Psychotherapy Research, 21*(3), 277–285.
- Chapman, M. J., & Mitchell, D. (2013). Mindfully valuing people now: an evaluation of Introduction to Mindfulness workshops for people with intellectual disabilities. *Mindfulness, 4*(2), 168–178.
- Chapman, M. J., Hare, D. J., Caton, S., Donalds, D., McInnis, E., & Mitchell, D. (2013). The use of mindfulness with people with intellectual disabilities: a systematic review and narrative analysis. *Mindfulness, 4*(2), 179–189.
- Clapton, N. E., Williams, J., Griffith, G. M., & Jones, R. S. (2018). “Finding the person you really are... on the inside”: Compassion focused therapy for adults with intellectual disabilities. *Journal of Intellectual Disabilities, 22*(2), 135–153.
- Corby, D., Taggart, L., & Cousins, W. (2015). People with intellectual disability and human science research: a systematic review of phenomenological studies using interviews for data collection. *Research in Developmental Disabilities, 47*, 451–465.
- Craig, J., Craig, F., Withers, P., Hatton, C., & Limb, K. (2002). Identity conflict in people with intellectual disabilities: what role do service-providers play in mediating stigma? *Journal of Applied Research in Intellectual Disabilities, 15*(1), 61–72.
- Crane, R. (2008). *Mindfulness-based cognitive therapy: distinctive features*. London: Routledge.
- Dillon, A., Wilson, C., & Jackman, C. (2018). “Be here now” – service users’ experiences of a mindfulness group intervention. *Advances in Mental Health and Intellectual Disabilities, 12*(2), 77–87.
- Emerson, E. (2004). Poverty and children with intellectual disabilities in the world’s richer countries. *Journal of Intellectual and Developmental Disability, 29*(4), 319–338.
- Griffith, G. M., Jones, R., Hastings, R. P., Crane, R. S., Roberts, J., Williams, J., et al. (2016). Can a mindfulness-informed intervention reduce aggressive behaviour in people with intellectual disabilities? Protocol for a feasibility study. *Pilot and Feasibility Studies, 2*(1), 58.
- Gustafsson, C., Öjehagen, A., Hansson, L., Sandlund, M., Nyström, M., Glad, J., et al. (2009). Effects of psychosocial interventions for people with intellectual disabilities and mental health problems: a survey of systematic reviews. *Research on Social Work Practice, 19*(3), 281–290.
- Harris, P. (1995). Who am I? Concepts of disability and their implications for people with learning difficulties. *Disability & Society, 10*(3), 341–352.
- Hastings, R. P., Hatton, C., Taylor, J., & Maddison, C. (2004). Life events and psychiatric symptoms in adults with intellectual disabilities. *Journal of Intellectual Disability Research, 48*(1), 42–46.
- Hwang, Y.-S., & Kearney, P. (2013). A systematic review of mindfulness intervention for individuals with developmental disabilities: long-term practice and long lasting effects. *Research in Developmental Disabilities, 34*(1), 314–326.
- Idusohan-Moizer, H., Sawicka, A., Dendle, J., & Albany, M. (2015). Mindfulness-based cognitive therapy for adults with intellectual disabilities: an evaluation of the effectiveness of mindfulness in reducing symptoms of depression and anxiety. *Journal of Intellectual Disability Research, 59*(2), 93–104.
- Kabat-Zinn, J. (1990). *Full catastrophe living: using the wisdom of your body and mind to face stress, pain, and illness*. London: Delta.
- Kabat-Zinn, J. (2009). *Wherever you go, there you are: mindfulness meditation in everyday life*. London: Hachette.

- Kabat-Zinn, J., & Hanh, T. N. (2009). *Full catastrophe living: using the wisdom of your body and mind to face stress, pain, and illness*. London: Delta.
- Kabat-Zinn, J., Lipworth, L., Burney, R., & Sellers, W. (1987). Four-year follow-up of a meditation-based program for the self-regulation of chronic pain: treatment outcomes and compliance. *The Clinical Journal of Pain*, 3(1), 60.
- Kaspar, P., & Kroese, B. S. (2017). What makes a good mother? An interpretative phenomenological analysis of the views of women with learning disabilities. *Women's Studies International Forum*, 62, 107–115.
- Keng, S.-L., Smoski, M. J., & Robins, C. J. (2011). Effects of mindfulness on psychological health: a review of empirical studies. *Clinical Psychology Review*, 31(6), 1041–1056.
- Kerrigan, D., Johnson, K., Stewart, M., Magyari, T., Hutton, N., Ellen, J. M., et al. (2011). Perceptions, experiences, and shifts in perspective occurring among urban youth participating in a mindfulness-based stress reduction program. *Complementary Therapies in Clinical Practice*, 17(2), 96–101.
- Kristeller, J. L., & Johnson, T. (2005). Cultivating loving kindness: a two-stage model of the effects of meditation on empathy, compassion, and altruism. *Journal of Religion and Science*, 40(2), 391–408.
- Lindsay, W. R., Baty, F. J., Michie, A. M., & Richardson, I. (1989). A comparison of anxiety treatments with adults who have moderate and severe mental retardation. *Research in Developmental Disabilities*, 10(2), 129–140.
- Lopata, C. (2003). Progressive muscle relaxation and aggression among elementary students with emotional or behavioral disorders. *Behavioral Disorders*, 28(2), 162–172.
- Mason, O., & Hargreaves, I. (2001). A qualitative study of mindfulness-based cognitive therapy for depression. *Psychology and Psychotherapy: Theory, Research and Practice*, 74(2), 197–212.
- McLellan, E., MacQueen, K. M., & Neidig, J. L. (2003). Beyond the qualitative interview: data preparation and transcription. *Field Methods*, 15(1), 63–84.
- Miller, J. J., Fletcher, K., & Kabat-Zinn, J. (1995). Three-year follow-up and clinical implications of a mindfulness meditation-based stress reduction intervention in the treatment of anxiety disorders. *General Hospital Psychiatry*, 17(3), 192–200.
- Mishna, F., & Muskat, B. (2004). “I’m not the only one!” Group therapy with older children and adolescents who have learning disabilities. *International Journal of Group Psychotherapy*, 54(4), 455–476.
- Needleman, L. D., & Cushman, C. (2010). Mindfulness in cognitive-behavioral therapy. In S. G. Hofmann & S. C. Hayes (Eds.), *Cognitive-behavioral therapy with adults: a guide to empirically-informed assessment and intervention* (pp. 163–179). Cambridge: Cambridge University Press.
- Owen, J., & Sayce, L. (2006). Equal treatment: closing the gap. *Learning Disability Practice*, 9(8), 8–10.
- Paterson, L., McKenzie, K., & Lindsay, B. (2012). Stigma, social comparison and self-esteem in adults with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 25(2), 166–176.
- Reibel, D. K., Greeson, J. M., Brainard, G. C., & Rosenzweig, S. (2001). Mindfulness-based stress reduction and health-related quality of life in a heterogeneous patient population. *General Hospital Psychiatry*, 23(4), 183–192.
- Reiter, S., Bryen, D. N., & Shachar, I. (2007). Adolescents with intellectual disabilities as victims of abuse. *Journal of Intellectual Disabilities*, 11(4), 371–387.
- Scotland, J., Cossar, J., & McKenzie, K. (2015). The ability of adults with an intellectual disability to recognise facial expressions of emotion in comparison with typically developing individuals: a systematic review. *Research in Developmental Disabilities*, 41, 22–39.
- Shapiro, S., Carlson, L., Astin, J., & Freedman, B. (2006). Mechanisms of mindfulness. *Journal of Clinical Psychology*, 63(3), 373–386.
- Siegel, D. J. (2007). Mindfulness training and neural integration: differentiation of distinct streams of awareness and the cultivation of well-being. *Social Cognitive and Affective Neuroscience*, 2(4), 259–263.
- Singh, N. N., Lancioni, G. E., Winton, A. S., Singh, A. N., Adkins, A. D., & Singh, J. (2008). Clinical and benefit—cost outcomes of teaching a mindfulness-based procedure to adult offenders with intellectual disabilities. *Behavior Modification*, 32(5), 622–637.
- Singh, N. N., Lancioni, G. E., Winton, A. S., Singh, A. N., Adkins, A. D., & Singh, J. (2011). Can adult offenders with intellectual disabilities use mindfulness-based procedures to control their deviant sexual arousal? *Psychology, Crime & Law*, 17(2), 165–179.
- Smith, J. A. (2015). *Qualitative psychology: a practical guide to research methods* (pp. 53–80). London: Sage.
- Srivastava, A. (2001). Developing friendships and social integration through leisure for people with moderate, severe and profound learning disabilities transferred from hospital to community care. *Tizard Learning Disability Review*, 6(4), 19–27.
- Sullivan, F., Bowden, K., McKenzie, K., & Quayle, E. (2013). “Touching people in relationships”: a qualitative study of close relationships for people with an intellectual disability. *Journal of Clinical Nursing*, 22(23–24), 3456–3466.
- Thomton, V., Williamson, R., & Cooke, B. (2017). A mindfulness-based group for young people with learning disabilities: a pilot study. *British Journal of Learning Disabilities*, 45, 259–265.
- To, M. Y. F., & Chan, S. (2000). Evaluating the effectiveness of progressive muscle relaxation in reducing the aggressive behaviors of mentally handicapped patients. *Archives of Psychiatric Nursing*, 14(1), 39–46.
- UK Network of Mindfulness Teacher Training Organisations (2015). Good practice guidance for teachers. Available at: http://www.breathworks-mindfulness.org.uk/images/UK_MB_teacher_GPG_2015_final.pdf. Accessed 12 Nov 2018.
- Walmsley, J. (2004). Involving users with learning difficulties in health improvement: lessons from inclusive learning disability research. *Nursing Inquiry*, 11(1), 54–64.
- Walsh, P. N., Kerr, M., & van Schroyenstein Lantman-De Valk, H. (2003). Health indicators for people with intellectual disabilities: a European perspective. *The European Journal of Public Health*, 13, 47–50.
- Williams, J., Teasdale, J. D., Segal, Z. V., & Soulsby, J. (2000). Mindfulness-based cognitive therapy reduces overgeneral autobiographical memory in formerly depressed patients. *Journal of Abnormal Psychology*, 109(1), 150–155.
- Williams, K. A., Kolar, M. M., Reger, B. E., & Pearson, J. C. (2001). Evaluation of a wellness-based mindfulness stress reduction intervention: a controlled trial. *American Journal of Health Promotion*, 15(6), 422–432.
- Willner, P. (2005). The effectiveness of psychotherapeutic interventions for people with learning disabilities: a critical overview. *Journal of Intellectual Disability Research*, 49(1), 73–85.
- Yildiran, H., & Holt, R. R. (2015). Thematic analysis of the effectiveness of an inpatient mindfulness group for adults with intellectual disabilities. *British Journal of Learning Disabilities*, 43(1), 49–54.