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How Services Address the Needs of Individuals with an Intellectual Disability: A Thesis Portfolio

The Effectiveness of Group Mindfulness Interventions for individuals with an Intellectual Disability: A systematic review.

&

‘How does this fit?’ A Qualitative Analysis of a Multidisciplinary Team’s experience of Trauma-Informed Care in An Intellectual Disability Service.

Sarah Gardner

Doctorate in Clinical Psychology
School of Health in Social Science, The University of Edinburgh
01.03.2024

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Acknowledgements

Firstly, a huge thankyou to all the intellectual disability team who agreed to take part in this study. I really appreciated how honest and willing you all were to share your experiences with me. Thank you to Dr Rachel Happer, my academic supervisor who provided valuable guidance throughout this process. Your reassurance kept my anxiety at bay when I felt overwhelmed. You were enthusiastic about this project from the start and that really encouraged me to power through. Dr Rowan Reffold, thank you for sharing your knowledge in this area and for keeping my recruitment on track. Thank you to Dr Juliane Kloess for all your help on my analysis and not judging any of my silly questions.

Thank you to my family who have provided endless support to allow me to get to this point. Without you this would not have been possible. I will forever be grateful for this. To all of my psychology friends, Jamie, Tara, Sarah, Freddie, Jess and the rest of my cohort, thankyou for listening to my thesis rants and being up for pub nights when we all just needed a distraction. To my non-psychology friends, Mairead, Lucy, Jess and Jenny thank you for your continued support and friendship. Most of you have been confused about this whole process, yet have listened to my limited topics of conversation and provided distraction in the form of walks, runs, wine or food.

Finally, thankyou to my partner, Cameron, who has provided support, encouragement and love throughout this full process, even though sometimes I’m sure you wanted to kill me in these last few months as my favourite phrase was “I can’t…I’m doing my thesis”.


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Portfolio Abstract

**Background:** Individuals with an intellectual disability are more vulnerable to abuse and mental health difficulties than the general population. Research into psychological therapies and services for this population is therefore of utmost importance. Previous research has lacked clarity for this distinct population and little research has been conducted on the experiences of those individuals’ delivering services.

**Method:** This research portfolio uses two research methods. Firstly, a systematic review of quantitative papers to determine the effectiveness of group-based mindfulness interventions for individuals with an intellectual disability. Secondly, an empirical project that produced a qualitative paper utilising interpretative phenomenological analysis to examine a multidisciplinary teams experience of trauma informed care.

**Results:** The systematic review procedure identified 11 articles that fitted with the inclusion and exclusion criteria. The methodological quality of the included studies was found to be largely weak due to small sample sizes and a lack of reliable and valid outcome measures. However, group mindfulness interventions were found to be effective in reducing mental health and behavioural problems. Studies also suggested that individuals with an intellectual disability can adequately learn the skills of mindfulness. The empirical project examined the experience of 11 professionals from multiple different disciplines. Analysis of the interviews using IPA produced 3 themes: Change over Time: A Sense of Awareness and Understanding, Thinking Outside the Box and Carrying the Burden. The final theme contained three subthemes: relationship with families, informal supports and burnout. All 11 participants connected with each theme in individual ways.

**Conclusion:** The review contributes to findings that individuals with an intellectual disability can benefit from mindfulness interventions. It specifically shows that group-based mindfulness interventions are effective for numerous mental health and behavioural difficulties. However, these results need to be interpreted with caution due to the weak methodological quality of the included studies. Future studies should expand on the current research and include larger
studies with clearly defined intellectual disability and reliable outcome measures. Qualitative findings suggest that professionals acknowledge the positive aspects and more challenging aspects of delivering trauma-informed care. This resulted in clinical implications including the importance of screening for trauma using routine outcome measures, balancing giving staff appropriate guidance whilst respecting autonomy to help them feel empowered but supported. Lastly, services should place focus on supporting staff wellbeing by continuing to encourage peer relationships and putting more structures support procedures in place.
Portfolio Lay Summary

Systematic Review:
- 11 studies were evaluated to assess whether group-based mindfulness interventions were effective for individuals with an intellectual disability.
- The review found that group-based mindfulness interventions were effective for several mental health difficulties such as anxiety, depression and low self-esteem. It also found that the intervention was effective for reducing challenging behaviour such as aggression and violence. It also evidenced that individuals with an intellectual disability can apply the skill of mindfulness regardless of their intellectual functioning. The studies included in this review were assessed on their methodological quality and they were found to be largely weak with only two having moderate quality. Therefore, these findings need to be considered in the context of low-quality papers.
- Group-based mindfulness interventions should be considered by services as an acceptable psychological intervention. Services should consider the adaptations needed for individuals with an intellectual disability to effectively engage with the therapy.
- Future studies should clearly define an intellectual disability and use outcome measures that are reliable.

Empirical Project:
- This research study explored healthcare professionals’ experiences of trauma informed care within an NHS intellectual disability team. 11 participants were interviewed all from different professions.
- The interviews were analysed using Interpretative Phenomenological Analysis (IPA). The findings show that participants knowledge and awareness of trauma in this population has increased over the years. It also shows how unique individuals with an intellectual disability are and therefore, standardised policies and procedures are harder to implement in this population. Lastly, participants acknowledged difficulties with creating positive relationships with families and the importance of relying on each other
for support to minimise burnout. It was also acknowledged that relying on each other for support may also increase burnout.

- Services should routinely screen for trauma and focus should be placed on offering staff structured support to help mitigate the impact of hearing about trauma. This will allow services to become more trauma-informed.
- Future studies could investigate the impact of implementing trauma-informed care by collecting both qualitative and quantitative data at different timepoints to determine the effectiveness of techniques/principles put in place by a service.
Chapter 1- Systematic Review

The Effectiveness of Group Mindfulness Interventions for individuals with an Intellectual Disability: A Systematic Review

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Review abstract

**Background:** The evidence base for mindfulness interventions for individuals with intellectual disabilities is growing. Mindfulness interventions are increasingly being suggested to individuals with an intellectual disability due to the effectiveness of these techniques found in the mainstream adult population. Yet, no systematic review of the literature on group-based mindfulness for this distinct population has been conducted. Therefore, this review aims to provide an up-to-date synthesis of the literature in this field.

**Method:** A systematic search was carried out by searching the following bibliographic databases: PsycINFO, PTSDPubs, MEDLINE, Web of Science, Scopus, CINAHL, Cochrane Database, EMBASE, ERIC via ProQuest. The methodological quality of the included studies was assessed using the EHPP tool (National Institute for Health and Clinical Excellence, 2006).

**Findings:** 11 articles were identified. Group-based mindfulness interventions were found to be effective in reducing mental health and behavioural problems. Studies also suggested that individuals with an intellectual disability can adequately learn the skills of mindfulness. The methodological quality of the included studies was found to be largely weak due to small sample sizes and a lack of reliable and valid outcome measures.

**Conclusions:** This review provides favourable evidence for the use of group-based mindfulness interventions for a variety of different mental health and behavioural difficulties for individuals with an intellectual disability. Services should consider delivering mindfulness in a group format, incorporating family members to increase repetition and practice of skills. Other adaptations such as simpler language and easy read summaries of skills are also advantageous. Future studies should expand on the current research and include larger studies with clearly defined intellectual disability and reliable outcome measures.
Introduction

Intellectual disabilities

An intellectual disability is characterised by significant limitations in intellectual functioning and adaptive behaviour that have been present before the age of 22. This is also known as a ‘disorder of intellectual development’ or ‘intellectual developmental disorder’ in the International Classification of Diseases 11th revision and Diagnostic Statistical Manual 5th edition, respectively (WHO, 2019; American Psychiatric Association, 2013). Standardised tests such as WAIS IV (Weschler, 2008) along with clinical judgement are used to diagnose someone with an intellectual disability (Gomez et al., 2021).

Research shows that individuals with an intellectual disability are at higher risk of mental health difficulties than the general population (Dagnan et al., 2018). Reasons include social isolation, increased bullying throughout childhood, stigma and increase likelihood to be exposed to sexual, physical, and verbal abuse (Moran et al., 2019; Gilmore and Cuskelly, 2014; Stacey & Edwards, 2013). Furthermore, an estimated 10 to 15% of individuals with an intellectual disability are labelled as having behaviour that presents a challenge (Bowring et al., 2019, Kinney et al., 2020). Behaviour that presents a challenge could be interpersonal violence, destruction of property, verbal aggression, and challenges with personal care (Dreyfus & Dowsen 2020). Psychological and behavioural problems alongside cognitive and social deficits makes for a complex presentation.

Psychological Therapies and Intellectual Disabilities

It has been recognised that there is inequality in health service provision between the general population and people with an intellectual disability (NICE, 2021). The UK government concluded that individuals with an intellectual disability should have the same access to evidence-based interventions as those without an intellectual disability. Subsequently, frameworks such as The Keys to Life have been produced (Scottish Government, 2019). This focusses on reducing inequalities for this population in 4 key areas: living, learning, working and wellbeing. The wellbeing component of this places focus on the delivery of psychological therapies.
Past assumptions have been made about the cognitive abilities of individuals with an intellectual disability, including that they are unlikely to benefit or be able to participate in psychological therapy (Huntington & Bender, 1993). In the last 20 years this assumption has been strongly disputed and evidence is mounting regarding the effectiveness of psychological interventions for an array of mental health problems for this population (Gomez et al., 2021).

For example, cognitive behavioural therapy (CBT) for depression and anxiety has shown to have positive effects on both adults and children with an intellectual disability (Unwin et al., 2016; Dagnan et al., 2018). More evidence exists for purely behavioural approaches such as Positive Behavioural Support (PBS). This behavioural approach focuses on systemic methods to be proactive and uses pre-emptive strategies to reduce the likelihood of individuals with an intellectual disability displaying behaviours that present as a challenge (Beqiraj et al., 2022). It is also recognised that these interventions need to be suitably adapted for the population to increase effectiveness (Taylor et al., 2013). Involving parents/carers, delivering in a smaller group size, using simpler language and repetition of techniques are all modifications shown to increase effectiveness of the intervention (Fynn et al., 2023).

As with many studies in this population the quality of evidence for the effectiveness of psychological intervention is varied due to the usual small sample sizes and lack of comparison groups. A review showed that CBT and dialectical behavioural therapy (DBT) can improve psychological wellbeing, reduce distress, help individuals feel empowered and improve quality of life in this population (McNair et al., 2017). The efficacy of compassion focused therapy (CFT) for individuals with an intellectual disability is slim and as far as the author is aware is based on two studies (Clapton et al., 2018; Goad and Parker, 2020). One which found a significant reduction in self-criticism and social comparisons (Clapton et al., 2018). Another study reported no statistically significant differences pre and post CFT group, suggesting limited impact (Goad and Parker, 2020). Clapton and colleagues (2018) reported that this population benefited from presenting material in a concrete and visual manner, avoiding abstract language and providing a support manual which visually summarised the material from sessions. Again, reinforcing the importance of modifying the intervention techniques and delivery format to improve effectiveness of the psychological technique/therapy being delivered. CBT, DBT and CFT all include components of mindfulness within the intervention. However, as mindfulness is one of a collection of therapeutic techniques, little emphasis is
placed on this within these therapies (Gu et al., 2015). Mindfulness techniques are also offered as a sole intervention, named mindfulness-based interventions (MBI) and these interventions incorporate multiple aspects of mindfulness (Bishop et al., 2004).

**Mindfulness and intellectual disabilities**

Mindfulness is paying attention to the present moment in an open minded, non-judgemental manner (Kabat-Zinn, 2003). It involves being fully present by maintaining a moment-by-moment awareness and being observant of thoughts, emotions and the surrounding environment (Fjorback et al., 2011). Mindfulness may take the form of mindful movement, body scan and meditation and other formal practices. These exercises should be deliberate, sustained and non-judgemental. Mindful activities teach individuals to reduce automatic responding and gain emotional regulation and attentional control through nonreactive focusing on internal or external cues (Bishop et al, 2004). Mindful interventions encourage individuals to cultivate mindful activities into everyday life so that they become psychological and physical coping tools (Fjorback et al., 2011).

The popularity and concept of mindfulness has been increasing due to the increase in standardised, widespread mindfulness-based interventions (MBI) (Kabat- Zinn, 1990; Segal et al., 2002). The term ‘MBI’ is an umbrella term that incorporates different mindfulness practices such as mindfulness-based stress reduction (MBSR) (Kabat- Zinn, 1990), mindfulness-based cognitive therapy (MBCT) (Segal et al., 2002) and mindfulness-based cognitive behavioural therapy (MBCBT) (Segal et al., 2002). Randomised controlled trials have shown the effectiveness of MBI’s in the adult population for depression (Hargus et al., 2010), mood disorders (Raes et al., 2009), anxiety (Brown and Hooper, 2009), aggressive behaviour (Adkins et al., 2010) and deviant sexual arousal (Singh et al., 2011).

MBI’s have also been effective for people with developmental disabilities (Singh and Hwang, 2020). The terms ‘developmental disabilities’ is a broad term that captures those with many different types of disorders including autism, ADHD, brain injury and intellectual disability (Hwang and Kearney, 2013). This systematic review is focused specifically on individuals with an intellectual disability. A small number of studies have investigated the effectiveness of different MBI’s in the intellectual disability population and the evidence so far is mixed (Manoj
& Rush, 2014, Williams et al., 2001; Anderson et al., 2019). However, Fjorback and colleagues (2011) found that mindfulness can be useful for individuals with an intellectual disability to accept their feelings and helps these individuals to learn strategies for managing emotions and difficult situations and encourages resilience and wellbeing.

Mindfulness Based Stress Reduction (MBSR) is an 8-week group intervention which includes meditation, relaxation, and gentle yoga (Kabat-Zinn, 1982). This intervention showed improvements in wellbeing and reduction of stress in typically developing individuals (Manoj & Rush, 2014, Williams et al., 2001). Anderson and colleagues (2019) explored the impact of a 12-week MBSR intervention on a non-clinical sample of people with an intellectual disability. There results were mixed with the intervention having a significant positive impact on wellbeing, but no differences found pre to post intervention for understanding of mindfulness.

Mindfulness-Based Cognitive Therapy (MBCT) (Segal et al., 2002) and Mindfulness-Based Cognitive Behavioural Therapy (MBCBT) (Segal et al., 2002) are both 8-week group interventions which are goal-orientated, and skills based. These approaches focus on increasing awareness of emotions, behaviours, and cognitions. MBCT places more importance on cognitions and MBCBT places more emphasis on behavioural changes. Singh and colleagues (2003) designed ‘soles of the feet’, a mindfulness meditation practice originating from the principles of MBCBT. It was specifically developed for those with an intellectual disability. This intervention teaches individuals to focus external attention to the neutral internal feelings in their feet. An RCT using this intervention showed a significant reduction in physical and verbal aggression (Singh et al., 2013). Gore and Hastings (2016) showed that reducing some of the cognitive load of more traditional CBT mindfulness methods has a positive impact on individuals with intellectual disabilities ability to engage with mindful practices. Thus, adaptations to traditional therapeutic delivery methods will understandably be needed to help engage a population with below average IQ.

Along with specific interventions branded as mindfulness-based, various therapeutic interventions have incorporated mindfulness into their therapeutic approach such as Acceptance and Commitment Therapy (ACT: Hayes et al., 1999) and Dialectical Behavioural Therapy (DBT) (Linehan, 1993). ACT is an individualised, flexible treatment that can be delivered in group and individual format. This therapy encourages the use of experiential
exercises such as imagery and ‘river of thought’ metaphor. ACT has been found to be effective for an individual with a mild intellectual disability who should improvement in auditory hallucinations, suicidal ideation, and delusions about health problems (Pankey and Hayes, 2003). DBT is based on cognitive and behavioural principles and is most commonly used for those that experience intense emotions (Linehan, 1993). It helps individuals learn new skills and strategies to manage their emotions better. It also incorporates core mindfulness skills (Linehan, 1993). This therapeutic approach has been successfully adapted for individuals with intellectual disabilities (Charlton, 2006). Charlton (2006) identified that simplifying language, concrete activities, modelling, structure, shorter sessions, and consideration about how to present information are all important considerations.

Previous reviews

To the authors knowledge there has only been 3 reviews that have relevance to this current review. Hwang and Kearney’s (2013) review included both individual and group delivery format of mindfulness interventions for individuals with developmental disorders. They included studies with individuals with an intellectual disability, Prader-Willi Syndrome, learning difficulties (dyslexia, dyspraxia) and autism spectrum disorder. This review concluded that individuals with developmental disorders can effectively engage with mindfulness activities, and this reduces behavioural and psychological difficulties.

Chapman and Colleagues (2013) conducted a review focussing specifically on individuals with an intellectual disability and their families/carer. This review included mindfulness interventions delivered to staff, carers and those with an intellectual disability. It also included two delivery formats with most being delivered in a 1-1 format and one group delivery. The majority of the studies in this review used ‘soles of the feet meditation’ delivered on a 1-1 basis (Singh et al., 2003). All studies found improvement after mindfulness intervention. Specifically, the frequency of challenging behaviour reduced and improvement in psychological wellbeing observed.

Patterson and Golightly (2022) conducted a systematic review and meta-ethnography on studies using third-wave therapies (which utilised some mindfulness techniques) with
individuals with intellectual disabilities. They found that these interventions can be a ‘transformational process’ for adults with intellectual disabilities and identify three main stages: concealment, opening up and flourishing. Meaning that individuals move from being unwilling to express emotions to developing a sense of safety and trust to changing the way they viewed themselves. The researchers also emphasised the importance of the therapeutic process in creating group safety and trust.

Necessity of current review

The evidence base for mindfulness interventions for individuals with intellectual disabilities is growing. Mindfulness interventions are increasingly being suggested to individuals with an intellectual disability due to the effectiveness of these techniques found in the mainstream adult population. The majority of interventions are normed for the general populations and clinicians are left to determine how best to adapt a therapeutic technique for individuals with an intellectual disability. Unfortunately, this pattern is not uncommon in the field of intellectual disabilities. This leads to several disadvantages for the population. Therapists are left to adapt techniques and information, that has been shown to be effective for one population, without evidence of effectiveness for individuals with an intellectual disability. Fortunately, research into the effectiveness of mindfulness interventions is continuing and more studies have been added to the evidence base. Previous reviews have included all individuals who fall within the remit of ‘developmental disabilities’ and not specifically on intellectual disabilities. Reviews have also included a combination of studies providing group and 1-1 mindfulness interventions. Family members or carers were also included in the inclusion criteria for one systematic review. To the authors knowledge, no previous reviews have focused solely on group delivery of mindfulness for the intellectual disability population. Those with an intellectual disability are usually seen within a specialist service and understanding the effectiveness of mindfulness for this distinct population will help provide the most effective evidence-based care. Furthermore, focusing specifically on group delivery will be helpful in identifying the effectiveness of this delivery format. Thus, it is important that a thorough review of the current literature is completed to determine the effectiveness of this delivery format for the intellectual disability population.
Aims

This paper aims to systematically review papers that have self-report quantitative outcome measures for group mindfulness interventions. It will examine the quality of included papers which should help promote future, high quality studies of effectiveness. Furthermore, an amalgamation of findings from different papers will help identify helpful adaptations to group mindfulness for this population. It aims to answer the question:

How effective are group mindfulness interventions for individuals with an intellectual disability?

Method

Protocol and registration

A review protocol for this systematic review is available on the International prospective register of systematic reviews (PROSPERO). The full protocol is available from https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42022373211 and can be found in Appendix B. The registration number for this protocol is CRD42022373211.

Search strategy

Several scoping searches were conducted in September and October 2022, prior to the main search. The main search was carried out by searching the following bibliographic databases: PsycINFO, PTSDPubs, MEDLINE, Web of Science, Scopus, CINAHL, Cochrane Database, EMBASE, ERIC via ProQuest. Studies were searched for from their initial launch date to October 2023. Previous systematic reviews in this subject area were also hand searched and reference lists from these papers were scrutinised. The specific search terms used for each database were within 3 main subject areas:

1. ‘Intellectual disability’ relating to cognitive functioning level.
2. ‘Group therapy’ - treatment delivery format.
3. ‘Mindfulness’ - type of intervention delivered.
A summary of search terms can be found in table 1. Truncation (*) was used to maximise the search sensitivity for each database.

### Table 1

**Search Terms**

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<th>Subject</th>
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<td>Intellectual disability</td>
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<tr>
<td></td>
<td><strong>AND</strong></td>
</tr>
<tr>
<td>Group therapy</td>
<td>Group therap* OR group psychotherapy OR remote group therap* OR group OR group intervention*</td>
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<td></td>
<td><strong>AND</strong></td>
</tr>
<tr>
<td>Mindfulness</td>
<td>Mindfulness OR mindful OR meditat* OR relax* OR mindfulness based cognitive therapy OR MBCT OR MBI OR Mindfulness based intervention OR MBSR OR mindfulness-based stress reduction</td>
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**Eligibility Criteria**

To meet inclusion criteria each study had to meet the following inclusion and exclusion criteria:

**Inclusion criteria:**

1. Participants diagnosed with borderline, mild, moderate, or severe intellectual disability.
2. Involve a mindfulness intervention.
3. Treatment delivered in a group format.
4. Intervention delivered by a professional member of staff (not family/carer).
5. Participants completed pre and post outcome measures.

Exclusion criteria:
1. Participants did not have a diagnosis of an intellectual disability.
2. Individuals that had other developmental disabilities but did not fit the criteria of intellectual disability.
3. Studies that consisted of group mindfulness intervention for carers/family members of individuals with an intellectual disability.
4. Intervention was not delivered in a group format.
5. Relied solely on qualitative outcomes.
6. Studies which had quantitative outcome measures completed by carer/family (no self-report measures).

PICOSS (population, intervention, comparators, outcomes, study design) is a useful framework to formulate eligibility criteria. Thus, the following PICOSS criteria (table 2) was used to help identify eligible studies to answer the research question.

Table 2

<table>
<thead>
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<tr>
<td><strong>Population</strong></td>
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<td><strong>Intervention</strong></td>
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<td><strong>Comparators</strong></td>
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<td><strong>Outcomes</strong></td>
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<tr>
<td><strong>Study design</strong></td>
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<tr>
<td><strong>Setting</strong></td>
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Screening and Selection

The screening and selecting process was completed using COVIDENCE review management software (covidence systematic review software, 2023). After removal of duplicates from the initial search, all titles and abstracts produced by the search were screened. If it was unclear from reading the title or abstract as to whether the study fitted the inclusion criteria, the study was included at this point. The remaining articles were read in full, and a screening and selection tool used to guide decision making on eligibility (figure 1). To reduce bias in decision making a fellow Trainee Clinical Psychologist specialising in intellectual disabilities acted as a second reviewer and dual screened 10% of titles and abstracts for suitability, based on the screening and selection tool. Reasons for exclusion were noted. Any inconsistencies were discussed, and a consensus reached.

Figure 1

Screening and selection tool

<table>
<thead>
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<th>Mindfulness interventions for Intellectual Disabilities Screening and Selection Tool</th>
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<tr>
<td>Reviewer Name:</td>
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<td>Study design</td>
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Data Extraction

Data extraction was conducted solely by the researcher. Items included in extraction were as followed; study name, author, publication year and study characteristics including i) study design, ii) study setting, iii) study inclusion and exclusion criteria, iv) participant number (including dropout), v) intervention and comparator, vi) outcome measures and timepoint of outcome measure, vii) intervention facilitator, viii) methods of data analysis, ix) main study findings and x) feasibility statistics. Relevant participants demographic information was also extracted including i) participants age range, ii) sex, iv) intellectual disability diagnosis, v) other diagnoses. Authors were contacted when missing data was identified to provide clarification.

Quality assessment tool

Quality assessment was conducted after data extraction so that the researcher was blind to study quality at the time of data extraction to reduce bias.

The Effective Public Healthcare Practice Project (EPHPP) Quality Assessment Tool (National Institute for Health and Clinical Excellence, 2006; Appendix C) was chosen to conduct quality assessment for the included studies. This tool has shown to be effective across several quantitative research designs. It has also been used in previous reviews conducted in the intellectual disability population (Bourne et al., 2022; Maber-Aleksandrowicz et al., 2016; Mikton et al., 2014; Sturgeon, 2021). It has demonstrated reliability, content, and construct validity and good inter-rater agreement for overall ratings (Armijo-Olivo et al., 2012; Thomas et al, 2004). An accompanying dictionary to address any queries when using the EPHPP tool helps reduce uncertainty in rating papers. Papers are rated either strong, moderate, or weak quality based on the following methodological standards: selection bias, study design, confounders, blinding, data collection method and withdrawals and dropouts. An overall global rating for the paper is then decided. A strong rating cannot be given if any of the above 6 components have a weak rating. Two or more weak ratings conclude that the paper has a global rating of weak. The tool also allows raters to rate methodological quality of intervention integrity and analysis but these are not included for the global rating. Finally, to reduce bias
and ensure inter-rater reliability a second reviewer quality assessed all included articles using the EPHPP tool.

Results

Study selection

Both electronic and hand searches found 1000 articles with the search terms included in the abstract. A further 3 studies were found via google scholar and reference lists of identified studies). 583 studies were left once duplicates were removed and the titles and abstracts of these articles were assessed. Once this process was complete 54 articles remained, and the full text was read for each of these articles. The author managed to gain access to all but one of the articles in full. The study author was contacted, and the full text article was emailed to the researcher. Inclusion and exclusion criteria were applied to these articles and 43 were excluded for differing reasons outlined in Figure 2. Eleven studies were included in the final review.
Figure 2

PRISMA flow diagram (2020): Flow diagram of the review process


For more information, visit www.prisma-statement.org.
Quality Assessment

THE EPHPP assessment tool (Thomson et al., 2004) is in an ordinal structure with categorical ratings and thus Cohen’s Kappa (κ) was used as a measurement of inter-rater reliability. An almost perfect rate of agreement for inter-rater reliability was found for the current review (κ= 0.89).

Table 3 provides a breakdown of the individual quality assessment scores for each study. Methodological quality of the included studies was mixed. Out of the eleven studies included in the systematic review process none received a strong global rating, two received a moderate global rating and nine received a weak rating. With regards to design, nine out of eleven studies were cohort or cohort analytical designs and the EPHPP tool guidance (Thomson et al., 2004) stipulated that a strong rating could only be given for a randomised control trial (RCT) or a controlled clinical trial (CCT). No studies included in this review were RCT’s and only two were CCT’s. The two that were CCT’s received a moderate rating for design and the other nine received a weak rating. Given the lack of randomised control studies including in this review no studies used random assignment for participants. Therefore, all eleven studies scored moderate on selection bias as they were referred/picked from a source which was usually a day centre/school or intellectual disability clinics.

Two studies sufficiently described confounding variables in participants, one gaining a strong rating and the other a moderate rating. However, nine out of the eleven studies did not describe confounding variables and thus scored weak on this subscale. This was largely because the studies were a cohort design therefore not lending itself for confounders. It was unclear in two of the eleven studies as to whether the participants were blinded to the research question or not. Thus, as per EPHPP tool guidance (Thomson et al., 2004), these studies were rated moderate as the guidance stated that if you ‘can’t tell’ if double blinding had occurred in both the assessors and participants then it was to be rated as moderate. In the other nine studies blinding did not occur as it was not appropriate to the design of the study and thus had to be given a weak rating.

Data collection methods were found to be strong in one study, moderate in two and weak in eight studies. Those that were rated as weak in this section was largely due to authors stating validity and reliability of the outcome measures in the general population but then adapting
these measures to be accessible for the intellectual disability population. This was the case for six of the eight weak rated studies. The other two studies that gained a weak rating failed entirely to report reliability or validity of the outcome measures they used. Overall studies performed well on the withdrawals/dropout section with five strong ratings, four moderate ratings and two weak ratings. Most studies at minimum reported attrition rate, however only five of eleven study reported a follow up rate of above 80%, gaining a strong rating. Four of eleven studies received moderate rating and two of eleven studies received a weak rating as they did not describe withdrawals/dropouts. Although not included in the global rating, the quality assessment measure tool had two other subheadings to rate papers on: intervention integrity and analysis. Nine of eleven studies conducted appropriate statistical analysis however, two studies did not conduct any statistical analysis reporting mean scores at pre and post intervention only.

**Table 3**

**Quality Assessment of included studies**

<table>
<thead>
<tr>
<th>Authors</th>
<th>Selection bias</th>
<th>Design</th>
<th>Confounders</th>
<th>Blinding</th>
<th>Data Collection</th>
<th>Withdrawal/Dropouts</th>
<th>Global Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>Craven and Shelton, 2020</td>
<td>Moderate</td>
<td>moderate</td>
<td>weak</td>
<td>weak</td>
<td>Weak</td>
<td>Moderate</td>
<td>weak</td>
</tr>
<tr>
<td>Haydicky, 2012</td>
<td>Moderate</td>
<td>Strong</td>
<td>strong</td>
<td>moderate</td>
<td>Weak</td>
<td>moderate</td>
<td>moderate</td>
</tr>
<tr>
<td>Idaoh/cmizer et al., 2015</td>
<td>moderate</td>
<td>Moderate</td>
<td>weak</td>
<td>weak</td>
<td>Weak</td>
<td>Weak</td>
<td>weak</td>
</tr>
<tr>
<td>Jonas and Finch, 2020</td>
<td>Moderate</td>
<td>Moderate</td>
<td>weak</td>
<td>weak</td>
<td>Weak</td>
<td>strong</td>
<td>weak</td>
</tr>
<tr>
<td>Lobo and McHale, 2021</td>
<td>moderate</td>
<td>moderate</td>
<td>weak</td>
<td>weak</td>
<td>moderate</td>
<td>strong</td>
<td>weak</td>
</tr>
<tr>
<td>Maloney Devita et al., 2017</td>
<td>moderate</td>
<td>moderate</td>
<td>weak</td>
<td>weak</td>
<td>Weak</td>
<td>Strong</td>
<td>weak</td>
</tr>
<tr>
<td>Malboeuf-Hurtubise et al., 2017</td>
<td>moderate</td>
<td>Moderate</td>
<td>weak</td>
<td>weak</td>
<td>Weak</td>
<td>strong</td>
<td>weak</td>
</tr>
<tr>
<td>Malboeuf-Hurtubise et al., 2019</td>
<td>moderate</td>
<td>Moderate</td>
<td>weak</td>
<td>weak</td>
<td>Strong</td>
<td>weak</td>
<td>weak</td>
</tr>
<tr>
<td>Thornton et al., 2017</td>
<td>Moderate</td>
<td>moderate</td>
<td>weak</td>
<td>weak</td>
<td>Strong</td>
<td>Weak</td>
<td>weak</td>
</tr>
<tr>
<td>Power et al., 2022</td>
<td>Moderate</td>
<td>Weak</td>
<td>weak</td>
<td>weak</td>
<td>Moderate</td>
<td>weak</td>
<td>weak</td>
</tr>
<tr>
<td>Sánchez, 2019</td>
<td>moderate</td>
<td>Strong</td>
<td>moderate</td>
<td>moderate</td>
<td>Weak</td>
<td>moderate</td>
<td>moderate</td>
</tr>
</tbody>
</table>
Data Synthesis

A meta-analysis was considered due to eligible studies having quantitative outcome data. However, this method was excluded for several reasons. The quality of the included controlled trials was poor and the protocols varied in terms of intervention delivered, time frame of collected outcomes and outcome measures used. This lack of homogeneity meant that a narrative synthesis was concluded as the most applicable review method for this paper. A narrative synthesis offered a comprehensive description of the similarities and differences between the studies (Lisy & Porritt, 2016).

Study characteristics

The included studies were conducted between 2012 and 2022 in a variety of locations. 6 studies were delivered in England, 3 in Canada, 1 in America and 1 in Ireland. A variety of different study designs were evident but most common was a cohort study design. Several interventions were described each differing in the overall length of treatment (ranging from 6 to 20 weeks) and duration of each group session (45 minutes to 2.5 hours). All mindfulness interventions were delivered by a facilitator who had an awareness of mindfulness, yet the level of training for each facilitator was not always specified in the studies.

Intervention content

All interventions comprised of an element of mindfulness delivered in a group format. All studies included guided meditation such as body scan or mindful breathing. 3 studies delivered ‘soles of the feet’ meditation (Idusohan-Moizer et al., 2015; Thornton et al., 2017; Sanchez, 2019). The soles of the Feet meditation (Singh et al, 2003) focusses on enabling clients to turn attention from an emotionally provoking thought or situation to a neutral part of the body, the soles of the feet. 2 studies followed the ‘I Can Feel Good Programme’ (ICFG-Ingamells and Morrissey, 2014) (Craven & Shelton, 2020; Jones & Finch, 2020). ICFG is an adapted DBT skills program which contains a mindfulness module focusing on increasing self-awareness,
acceptance, self-monitoring and detaching from thoughts and feelings. The other 6 studies incorporated different elements from MBSR and MBCT such as body-scan, progressive muscle relaxation, mindful movement, mindful stopping, and mindful breathing adapting these to suit their participants needs (Haydicky, 2012; Lake and McHale, 2021; Mahoney Davies et al., 2016; Malboeuf-Hurtubise et al., 2017; Malboeuf-Hurtubise et al., 2019; Power et al., 2022).

**Characteristics of instruction**

Consistent with inclusion criteria all studies were delivered in a group format. All studies indicated a degree of adaptation to delivery techniques based on the participants needs. Along with verbal instructions, 4 studies introduced visual representations to aid learning of mindfulness techniques for example visual metaphors or visual prompts for deep breathing.

Seven studies encouraged the involvement of carers/teachers/family members either by attending the sessions with the individual with an intellectual disability or by meeting with them separately to introduce techniques learned and encourage practice outside of the intervention. This encouraged generalisability of techniques. Four studies provided easy read material of the techniques learned in the group which again allowed for a reminder of techniques learned. The shortest group which was 45 minutes in length, suggested that they reduced the time of the group to help participants retain information. Another study utilised role-play as a means of learning techniques. Table 4 outlines the main characteristics for each study including location, design, sample size, study location and intervention content and adaptations.
<p>| <strong>Table 4</strong>  |
|---|---|---|---|---|---|---|---|
| <strong>Study characteristics</strong> |
| <strong>Author + Location of study</strong> | Design | Control (if applicable) | Sample size | Study setting/recruitment | Intervention content | Intervention adaptations | Intervention duration | Facilitator |
| Craven and Shalton, 2020 (England) | Cohort study design | NA | 7 | Male rehabilitation hospital | ICFG (Ingram and Morrissey, 2014) Components—mindfulness, managing feelings, coping in crisis and people skills. | Staff member engagement Repetition Increased use of senses | 20 sessions | Psychological staff trained in DBT skills |
| Haydicky, 2012 (Canada) | Controlled trial | Waiting list control | 49 in treatment group, 28 on waiting list | Patients attending a child mental health centre. | Mindfulness, CBT, and mixed martial arts. Components—body scan, sitting meditation, walking meditation, mindful activity. | Modelling Parent involvement | 20 weekly 1.5 hour sessions | Instructor of MMA |
| Idsosho-Moizer et al., 2015 (England) | Cohort analytical design | NA | 15 (split in to two groups) | Community learning disability teams | MBCT programme Components—Mindfulness of the breath, SOE, present day awareness training. | CD Caregiver involvement Reduced number of skills Increased repetition | 9 weekly 1.5 hour sessions | 2 Clinical Psychologists, 2 trainee Clinical psychologists and 2 assistants |
| Jones &amp; Finch, 2020 (England) | Cohort study design | NA | 9 | Referrals on psychology waiting list and nursing caseload | ICFG (Ingram and Morrissey, 2014) Components—mindfulness, managing feelings, coping in crisis and people skills. | Visual supports Easy read summary Caregiver involvement | 8 weekly 1 hour sessions | 2 Trained facilitators |
| Lake and McHale, 2021 (Ireland) | Cohort study design | NA | 7 | Recruited from training centre supporting individuals with ID | MBiSR Components—deep breathing, Progressive muscle relaxation, mindful activity, guided imagery. | Easy read summary Teacher involvement | 8 weekly 2.5 hour sessions | Clinical psychologist and a behavioural support therapist |
| Maisonne Devine et al., 2016 (England) | Cohort study design | NA | 12 | Day service for individuals with an intellectual disability | 5 ways of wellbeing Components—mindful awareness, mindful activity | Group discussion Activity based learning Role play | 10 weekly 2 hour sessions | Clinical Psychologists supported by 2 members of staff from council-funded service |</p>
<table>
<thead>
<tr>
<th>Study</th>
<th>Design Type</th>
<th>Control Group</th>
<th>Sample Size</th>
<th>Setting</th>
<th>Comparator</th>
<th>Intervention</th>
<th>Session Details</th>
<th>Healthcare Provider</th>
</tr>
</thead>
<tbody>
<tr>
<td>Malboeuf-Hurtubise et al., 2017 (Canada)</td>
<td>Cohort study design</td>
<td>NA</td>
<td>14</td>
<td>Special education class</td>
<td>Inspired by MBCT Components: body scan, breathing, meditation, sitting, mindful movement, mindful activity.</td>
<td>Shorter sessions Recorded guided meditation. Teacher engagement</td>
<td>8 weekly 1 hour sessions</td>
<td>Graduate psychologist with MBSR-teens training and school social worker</td>
</tr>
<tr>
<td>Malboeuf-Hurtubise et al., 2019 (Canada)</td>
<td>Experimental longitudinal randomised cluster trial</td>
<td>Active control (social skills curriculum)</td>
<td>23</td>
<td>Special education class</td>
<td>Mindfulness based intervention- mission meditation (Malboeuf-Hurtubise &amp; Lacourse, 2010) Components: sitting meditation, mindful stopping, mindful listening, walking meditation and body scan.</td>
<td>Teacher engagement</td>
<td>8 weekly 45 min to 1-hour sessions</td>
<td>Trained community involvement school counsellor with training in mindfulness practice</td>
</tr>
<tr>
<td>Thornton et al., 2017 (England)</td>
<td>Cohort study design</td>
<td>NA</td>
<td>5 (one group)</td>
<td>Active in CAMHS intellectual disability team</td>
<td>SOF, Components- Mindful breathing, movement, and senses.</td>
<td>Easy read summary-Carer engagement-Visual aids</td>
<td>6 weekly 1 hour sessions</td>
<td>Clinical Psychologist</td>
</tr>
<tr>
<td>Power et al., 2022 (England)</td>
<td>Cohort analytical design</td>
<td>NA</td>
<td>25 (split in to 6 groups)</td>
<td>NHS Community intellectual disability health service in England</td>
<td>Psychoeducation on emotions and an introduction to mindfulness skills Components- self reflection, self regulation, and mind-body relaxation.</td>
<td>Easy read summary-Visual aids-Standardised facilitator manual</td>
<td>6 weekly 60-90 sessions</td>
<td>Clinical psychologists, assistant psychologists, trainee clinical psychologists</td>
</tr>
<tr>
<td>Sanchez, 2019 (America)- THESIS</td>
<td>Controlled trial</td>
<td>Waiting list control</td>
<td>36</td>
<td>Referred to NHS psychology service</td>
<td>MBCT Components- body scan, mindful movement (yoga), SOF.</td>
<td>Visual aids-More detailed scripts</td>
<td>8 weekly 1 hour sessions</td>
<td>Clinical Psychologist</td>
</tr>
</tbody>
</table>

*Note: ICFG- I can feel good programme; MBCT- mindfulness based cognitive therapy, MBSR- mindfulness based stress reduction, SOF- soles of feet meditation, DBT- Dialectic behavioural therapy, MMA- mixed martial arts.*
Participant characteristics

Participants throughout the 11 studies ranged in age from 11-61 years old and were a combination of female and male participants both within and between groups. The mean age across the 6 studies that reported a mean was 32. Studies also focused on different mental or behavioural difficulties including anxiety, low mood, sexual offences, anger, and substance use. Some studies broadly defined ‘behavioural problems’ or ‘psychological distress’ as the mental health condition. Studies varied on the classification of individuals with an intellectual disability and the way this diagnosis was confirmed by the study. Some studies conducted neuropsychological testing to confirm IQ via WASI (Weschler, 1999), WISC V (Wechsler, 2014) or WAIS V (Weschler, 2008). However, others simply accepted a diagnosis based on the school or day centre setting they were associated with. Those who did assess for IQ or had evidence of prior neuropsychological assessment stated that all included participants had an IQ within the range of an intellectual disability. There was clear evidence of this in 10 of the 11 studies which found participants to have an IQ of less than 85 meaning a borderline, mild or moderate. However, one study stated participants fitted criteria for an intellectual disability yet reported WASI scores within the average range (mean IQ score= 101.38). No studies included individuals with a severe intellectual disability. Table 5 provides an overview of the participant characteristics in each study.
<table>
<thead>
<tr>
<th>Author(s)</th>
<th>Participants</th>
<th>Age range</th>
<th>ID Diagnosis/definition</th>
<th>Mental health presentation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Craven and Shelton, 2020</td>
<td>7 males</td>
<td>20-61 age range Mean age=33.8</td>
<td>Mild to borderline IQ (55-83) assessed using WAIS IV</td>
<td>Intellectually disabled offenders with offences of sexual and violence.</td>
</tr>
<tr>
<td>Haydick, 2012</td>
<td>49 boys 21 in treatment group, 28 on WL</td>
<td>12-19 age range</td>
<td>Scored above 80 on WASI</td>
<td>ADHD and anxiety or mood disorder.</td>
</tr>
<tr>
<td>Ihsahan-Moizer et al., 2015</td>
<td>8 females 7 males</td>
<td>21-44 age range Mean age=31</td>
<td>Borderline, mild, or moderate ID (severe ID excluded)</td>
<td>One or more episode of depression or generalised anxiety.</td>
</tr>
<tr>
<td>Jones and Finch, 2020</td>
<td>9 participants</td>
<td>not stated</td>
<td>Mild ID</td>
<td>Anxiety/anger</td>
</tr>
<tr>
<td>Laks and McHale, 2021</td>
<td>3 females 4 males</td>
<td>18-22 age range</td>
<td>Mild to moderate ID</td>
<td>Psychological distress (non-clinical) 1 participant had ADHD.</td>
</tr>
<tr>
<td>Mahoney Davies et al., 2016</td>
<td>11 males 1 female</td>
<td>22-55 age range Mean age=36.6</td>
<td>Mild to moderate ID</td>
<td>Non-clinical population</td>
</tr>
<tr>
<td>Malhousif-Hurtubise et al., 2017</td>
<td>8 females 6 males</td>
<td>9-12 age range Mean age=10.7 years</td>
<td>Borderline ID (shown by extensive evaluation of cognitive skills)</td>
<td>Behavioural problems</td>
</tr>
<tr>
<td>Malhousif-Hurtubise et al., 2019</td>
<td>23 participants</td>
<td>9-12 age range</td>
<td>Borderline ID (IQ between 70 and 79)</td>
<td>Behavioural problems</td>
</tr>
<tr>
<td>Thornton et al., 2017</td>
<td>2 females 3 males</td>
<td>13-15 age range</td>
<td>Mild to moderate ID</td>
<td>Anxiety, low mood, low self-esteem, social skills difficulties, and aggression.</td>
</tr>
<tr>
<td>Study</td>
<td>Sample Size</td>
<td>Age Range</td>
<td>Intellectual Disability</td>
<td>Behavioral Problem</td>
</tr>
<tr>
<td>-------------------------</td>
<td>-------------</td>
<td>-----------</td>
<td>------------------------</td>
<td>--------------------</td>
</tr>
<tr>
<td>Power et al., 2022</td>
<td>25 individuals</td>
<td>20-72 years</td>
<td>Borderline, mild, or moderate ID</td>
<td>Emotional dysregulation, social connection problems</td>
</tr>
<tr>
<td></td>
<td>60% female, 40% male</td>
<td>Mean age = 33.3 years</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sanchez, 2019</td>
<td>16 males, 20 females</td>
<td>23-77 years</td>
<td>Mild or moderate ID</td>
<td>aggression</td>
</tr>
<tr>
<td></td>
<td>Mean age = 47 years</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Note:* ID - intellectual disability, ADHD - attention deficit hyperactivity disorder, WAIS - Wechsler Adult Intelligence Scale, WASI - Wechsler Abbreviated Scale of Intelligence, WL - waiting list, IQ - intelligence quotient
Study outcomes

**Outcome measures**

Outcome measures varied largely between studies due to the different intervention objectives of each study. Studies tended to use either behavioural or subjective measures, but a few studies used a combination of both. Behavioural measures were administered when the intervention focussed on behavioural change such as aggressive or destructive behaviour and subjective measures were used when the intervention focused on a specific mental health difficulty such as anxiety, depression, or low self-esteem. In total 20 different measures were used throughout the included studies.

The most frequently used measures were:

- 2 studies used the Cognitive and Affective Mindfulness Scale- Revised (CAMS-R) (Feldman et al., 2007).
- 2 studies used The Children and Adolescent Mindfulness Measure (CAMM) (Greco et al., 2011)
- 2 studies used the Rosenberg Self-esteem scale (Rosenberg, 1965). Both studies adapted the self-esteem scale to be more user friendly for the population.

A summary of outcomes from each study is provided in Table 6.
### Table 6: Study outcomes

<table>
<thead>
<tr>
<th>Authors(s)</th>
<th>Outcome measure(s)</th>
<th>Primary outcomes</th>
<th>Measure of effect</th>
<th>Time points</th>
</tr>
</thead>
<tbody>
<tr>
<td>Craven and Shelton, 2020</td>
<td>EPS (4 subscales) (Prout and Strolmer, 1991)</td>
<td>EPS-BRS (behaviour rating subscale) Subscale EBP: Reduction in scores (signifying reduction in problem behaviour) between pre and post but not statistically significant, (z = -1.83, p &gt; 0.05, r = -0.58).</td>
<td>Not stated</td>
<td>Pre and post</td>
</tr>
<tr>
<td></td>
<td>(CAMS-R) (Feldman et al., 2007)</td>
<td>EPS-IBP (low self-esteem, and depression subscales): Decrease in scores (signifying increase in self-esteem and in mood) between pre and post scores but not statistically significant, (z = -0.14, p &gt; 0.05, z = -0.37, p = 0.03).</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>EPS-IBP (anxiety subscale): increase in scores (signifying an increase in anxiety symptoms) between pre and post scores but not statistically significant (z = -0.67, p = 0.06)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>CAMS-R Staff rated improvements in observed mindfulness abilities but not statistically significant, (z = 0.813, p &gt; 0.05). Participants rated no improvements in ability to regulate attention, awareness of experiences or non-judgemental attitudes but not statistically significant, (z = 0.405, p &gt; 0.05).</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Haydicky, 2012</td>
<td>BRIEF (Gioia et al., 2000)</td>
<td>BRIEF</td>
<td>(N^2 = 0.39)</td>
<td>Pre and post</td>
</tr>
<tr>
<td></td>
<td>CBRS (Conners, 1997)</td>
<td>CBRS</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>CBCL (Achenbach, 2001)</td>
<td>CBCL (parent rated scale) Social problems subscale showed a reduction in symptoms (F(1,10) = 12.86, p = 0.002, n^2 = 0.39) suggesting the intervention improved social problems. There was a reduction in oppositional defiant problems (F = 1.96, p = 0.18, n^2 = 0.08), conduct problems (F = 1.68, p = 0.23, n^2 = 0.07) and ADHD problems (F = 2.63, p = 0.12, n^2 = 0.10) but none of these were at a significant level. There was a significant main effect for Conduct problems (F = 5.389, p = 0.027, n^2 = 0.26).</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>YSR (Achenbach, 2001)</td>
<td>YSR (self-report version of CBCL) Anxiety subgroup showed significant improvement in symptoms (F = 6.75, p = 0.016, n^2 = 0.27) social problems (F = 0.30, p = 0.59, n^2 = 0.01), ADHD problems (F = 0.02, p = 0.89, n^2 = 0.01), oppositional defiant (F = 1.40, p = 0.25, n^2 = 0.06), conduct problems (F = 0.13, p = 0.70, n^2 = 0.01)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Idaaamah-Moizer et al., 2015</td>
<td>HADS (Zigmond &amp; Snaith, 1983)</td>
<td>HADS</td>
<td>Not stated</td>
<td>Pre, post and 6 week follow up</td>
</tr>
<tr>
<td></td>
<td>Compassion Scale (Neff, 2003)</td>
<td>Participants experienced lower levels of anxiety post group compared to pre-group (t(11) = 3.29, P &lt; 0.01, r = -0.70). This difference was maintained at follow up (t(9) = 2.73, p = 0.05, r = -0.67).</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Participants depression scores were significantly lower post-group compared to pre-group (z = -2.36, P &lt; 0.05, r = -0.68).</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
HADS depression scores were not significantly lower at the 6-week follow-up compared to pre group ($z = -2.05, P = 0.06, r = -0.64$) suggesting lower levels of depression was not maintained.

**Compassion Scale**

Participants compassion towards themselves shows significant improvement between pre and post scores ($z = -2.20, P < 0.02, r = -0.64$). There was no significant difference between post group scores and 6 week follow up scores ($z = -0.426, P = 0.73, r = -0.13$) suggesting improvements were maintained at follow up.

<table>
<thead>
<tr>
<th>Jones and Finch, 2020</th>
<th>1. GAS-ID (Mindham &amp; Espes, 2003)</th>
<th>No statistical analysis conducted.</th>
<th>Not stated</th>
<th>Pre and post</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2. CAMS-R (Feldman et al., 2007)</td>
<td>GAS-ID Reduction in mean score post group 6 participants had a decrease in anxiety symptoms post intervention (lower post intervention score). 2 participants had an increase in anxiety symptoms post intervention (higher post intervention score). CAMS-R 5 participants reported increased mindful qualities post intervention (higher post intervention score) 2 participants reported decreased mindful qualities post intervention (lower post intervention score) 1 participants pre and post scores stayed the same.</td>
<td>Not stated</td>
<td>Pre and post</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Lake and McHale, 2021</th>
<th>1. CORE LD (Brooks et al., 2013)</th>
<th>No statistical analysis conducted.</th>
<th>Not stated</th>
<th>Pre and post</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2. Rosenberg Self-esteem scale (Rosenberg, 1965)-adapted by authors</td>
<td>Core-LD mean score was 7.7 reduced to 2.3 at post group (lower score indicate improved overall wellbeing). This was significant, $p=0.001$. Rosenberg adapted mean score was 15.9 increased to 17.9 at post group (higher score indicates improved self esteem). Not significant, $p=0.04$.</td>
<td>Not stated</td>
<td>Pre and post</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Mahoney Davies et al., 2016</th>
<th>1. Rosenberg self esteem scale (Rosenberg, 1965)-adapted by authors</th>
<th>Self esteem Scale</th>
<th>Not stated</th>
<th>Pre and post</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2. SWEMWBS (Stewart-Brown et al., 2009)-adapted by authors</td>
<td>A repeated measures ANOVA found a significant effect between time points on the Rosenberg Self-Esteem Scale $[F (2,14) = 4.4, P = 0.03]$.</td>
<td>Not stated</td>
<td>Pre and post</td>
</tr>
<tr>
<td></td>
<td>3 The Wellbeing outcome scale (Mahoney Davies et al., 2016)</td>
<td>SWEMWBS</td>
<td>Not stated</td>
<td>Pre and post</td>
</tr>
</tbody>
</table>
No significant differences found between pre, mid and post scores \( (P=0.05) \) suggesting no change to mental wellbeing.

**Wellbeing outcome scale**

No statistical analysis on this scale. Average increased on mindfulness questions between pre and post scores. No change noticed on other questions of scale.

---

1. **BASC-II (Reynolds & Kamphaus, 2004).**

   Teacher report—significant reduction in aggression \( [F(1, 13)=8.35, P=0.01, \text{partial } \eta^2=0.39] \). Teacher report significant reduction in conduct problems \( [F(1, 13)=21.12, P=0.001, \text{partial } \eta^2=0.61] \). Teacher report significant differences were found for inattention \( [F(1, 13)=6.63, P=0.02, \text{partial } \eta^2=0.31] \). No significant differences were found between pre and post teacher rated scores for anxiety \( [F=1.13, P=0.31, \text{partial } \eta^2=0.08] \), depression \( [F=4.24, P=0.06, \text{partial } \eta^2=0.25] \) or hyperactivity \( [F=3.34, P=0.09, \text{partial } \eta^2=0.21] \).

   Significant reduction in levels of anxiety between pre and post scores \( [F(1, 13)=6.80, P=0.02, \text{partial } \eta^2=0.34] \). Significant decrease in depression scores between pre and post scores \( [F(1, 13)=6.73, P=0.03, \text{partial } \eta^2=0.34] \). No significant differences found for hyperactivity \( [F=0.15, P=0.71, \text{partial } \eta^2=0.01] \) and attention problems \( [F=1.39, P=0.26, \text{partial } \eta^2=0.10] \) from pre to post scores.

2. **CAMM (Greco et al., 2011).**

---

1. **BASC-II (Reynolds & Kamphaus, 2004).**

   A significant main effect was found for anxiety levels between pre and post outcome measures \( [\text{Wilks Lambda}=0.61, F(2,42)=6.19, P=0.008, \text{partial } \eta^2=0.33] \) suggesting the intervention significantly reduced anxiety symptoms. No significant main effect was found for depression between pre and post outcome measures \( [F(2, 20)=1.35, P=0.28, \text{partial } \eta^2=0.23] \). Suggesting the intervention did not significantly improve depression.
<table>
<thead>
<tr>
<th>Study</th>
<th>Measure/Method</th>
<th>Findings</th>
<th>Effect Size</th>
<th>Time Points</th>
</tr>
</thead>
<tbody>
<tr>
<td>Thornton et al., 2017</td>
<td>1. SCARED (Birmaher et al., 1997)</td>
<td>No statistical analysis conducted and no data given</td>
<td>Not stated</td>
<td>Pre and post</td>
</tr>
<tr>
<td></td>
<td>2. Parent questionnaire (Thornton et al., 2017)</td>
<td><em>One young person showed a slight reduction in the score for social anxiety disorder and school avoidance</em></td>
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<td></td>
<td>Parent questionnaire</td>
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<tr>
<td></td>
<td><em>Following completion of the group, all parents reported that their child continued to have similar difficulties relating to anxiety. Impact scores had reduced slightly, by one point for two of the families and by three points for another family.</em></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Power et al., 2022</td>
<td>1. EUROHIS-QoL-8 (Schmutz et al., 2006)</td>
<td>EUROHIS-QoL-8 score was significantly higher (t=2.14, df=21, p=0.022) at post-intervention (mean=22.18, SD=3.18) compared to pre-intervention (mean=20.73, SD=4.68). Suggesting an improvement in quality of life.</td>
<td>Cohen's d = 0.46</td>
<td>Pre and post</td>
</tr>
<tr>
<td></td>
<td>2. Qualitative questionnaire</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sanchez, 2019</td>
<td>1. MOAS (Silver &amp; Yudofsky, 1991)</td>
<td>MOAS</td>
<td>Not stated</td>
<td>Pre and post</td>
</tr>
<tr>
<td></td>
<td>2. CAMM (Greco et al., 2011)</td>
<td>Scores not significantly different between pre-test and post-test [F(1, 34) = 0.88, p = .221] suggesting the intervention did not have an effect on aggression.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>CAMM</td>
<td>CAMM scores were significantly different between pre and post-test (within subjects) [F (1, 34) = 4.99, p=0.032] and between subjects effect for group was significant [F (1,34) =16.04, p=0.001]. This suggests that the intervention improved participants mindfulness skills.</td>
<td></td>
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</tbody>
</table>

**Note:** MOAS- Modified Overt Aggression Scale; CAMM- Child and Adolescent Mindfulness Measure; GAS-ID- Glasgow Anxiety Scale for Intellectual Disabilities; CAMS-R- Cognitive and Affective Mindfulness Scale-Revised; CORE-LD- Clinical Outcomes in Routine Evaluation - Learning Disability; Rosenberg Self Esteem Scale- Adopted; BASCS- Behaviour Assessment System for Children Second Edition; SCARED- Screen for Child Anxiety Related Disorders; MAAS- Mindfulness Attention Awareness Scale; EUROHIS-QoL-8- Quality of life measure; EPS- emotional problems scale; SWEMWBS- Short Warwick-Edinburgh Mental Well Being Scale; BRIEF- Behaviour Rating Inventory of Executive Function; CPRS- Conners’ Scale; CBCL- Child Behaviour Checklist.
**Intervention effects**

**Behaviour that challenges**

Four out of the eleven studies measured group mindfulness interventions for behaviour that presents as a challenge. One study found a significant reduction of aggression and conduct issues post intervention (Malbouef-Hurtubise et al., 2017) and one study found inattention improved at post intervention (Haydicky, 2012). Another study did find clinical improvement in behaviour presentation, but this was not statistically significant (Craven and Shelton, 2020). One study found no significant reduction in aggressive behaviour; however, they did find that individual’s concept of mindfulness had improved post group and subsequently they were more mindful of aggressive behaviour (Sanchez, 2019).

**Self-esteem**

Four of the eleven studies had a measure for self-esteem. All four studies found an increase in self-esteem post mindfulness intervention. One of these studies reached significance (Mahoney Davies et al., 2016) however, the other three found no significant difference pre and post intervention (Craven and Shelton, 2020; Idusohan-Moizer et al., 2015; Lake & McHale, 2021).

**Wellbeing and Quality of Life**

Three of the eleven studies had a measure for wellbeing or quality of life. Two studies found a significant improvement in wellbeing/quality of life post mindfulness intervention (Lake & McHale, 2021; Power et al., 2022). One study found no significant different between pre and post measures for mental wellbeing (Mahoney Davies et al., 2016).

**Anxiety and Depression**

Six of the eleven studies had a measure for anxiety, four of which showed an improvement in levels of anxiety following mindfulness intervention (Haydicky, 2012; Jones & Finch, 2020; Idusohan-Moizer et al., 2015; Malboeuf-Hurtubise et al., 2017; Thornton et al., 2017). Three of these showed a significant difference (Haydicky, 2012; Idusohan-Moizer et al., 2015; Malboeuf-Hurtubise et al., 2017) and two studies showed a reduction in mean anxiety scores pre to post intervention however no statistical analysis was conducted therefore the significance of this cannot be determined (Thornton et al., 2017 Jones & Finch, 2020). Malboeuf-Hurtubise et al (2019) found that the intervention did reduce anxiety symptoms, however, it was not significantly more useful than the active control group. Finally,
one study found an increase in anxiety post intervention, but this was not at a significant level (Craven and Shelton, 2020).

Four of the eleven studies had a measure for depression. Two of these studies found a significant decrease in depression post intervention (Idusohan-Moizer et al., 2015; Malboeuf-Hurtubise et al., 2017). One study found a reduction in symptoms but at a non-significant level (Craven and Shelton, 2020) and one study found that group mindfulness did not have a significant impact on depressive symptoms (Malboeuf-Hurtubise et al., 2019).

Mindfulness skills

Four of the eleven studies measured participants use of mindfulness skills. Three of the eleven studies showed an increase in mindfulness skills post intervention (Jones & Finch, 2020; Mahoney Davies et al., 2016; Sanchez, 2019). One study found no improvement in mindfulness skills post intervention, but this was not at a significant level (Craven and Shelton, 2020).

Discussion

This systematic review aimed to investigate the effectiveness of group mindfulness interventions for individuals with an intellectual disability. The quality of the eleven included quantitative studies was assessed using The EPHPP Quality Assessment Tool (Thomson et al., 2004) and a summary of the results is reported.

Principle findings

This review demonstrates that group-based mindfulness interventions lead to positive outcomes for a variety of mental health and behavioural difficulties in the intellectual disability population. Most of the studies that utilised measures for anxiety, behaviour, quality of life, depression and self-esteem showed positive outcomes. Other research has reported similarly positive results (Patterson et al., 2019; Byrne & O’Mahony, 2020; Chapman et al., 2013; McNair et al., 2017; Patterson and Golightly, 2023). These findings suggest that a group format is an acceptable delivery format for mindfulness interventions. A sense of belonging to a group has been found to be important in increasing wellbeing and connection of participants (Currie et al., 2019). Therefore, the group format may be a component in increased self-esteem and quality of life. This appears to be regardless of the level of intellectual functioning, although it is important to note that no studies included
in the review were conducted with individuals with a severe intellectual disability. This is likely because they may not have the cognitive abilities to complete self-report outcome measures.

All eleven studies had a degree of adaptation to the delivery of the intervention. The review identified key adaptations that are important for helping individuals with an intellectual disability engage positively with a group mindfulness approach. This did not vary depending on whether individuals had borderline, mild or moderate intellectual functioning. Adaptations included visual aids, including an easy read summary of what skills were taught during the session, shorter sessions, simplifying skills, and more repetition of skills. This echoes a previous review that identified the importance of concrete and simple examples when introducing an individual with an intellectual disability to new mindfulness concepts (Patterson and Golightly, 2023).

Studies that involved parents/carers/family members had more positive outcomes than those studies that only worked directly with the individual with an intellectual disability. This is likely due to the encouragement by family/carers for the individual to use the skills learnt outside of the group. This compliments findings on the importance of modelling and repetition of techniques in helping individuals with an intellectual disability learn new skills (Fynn et al., 2023, Siegel, 2007). This review therefore adds to the evidence that individuals with an intellectual disability can learn the skills of mindfulness if the correct adaptations and supports are put in place. Previous research has found that clear expectations and understanding about mindfulness is not needed for individuals with an intellectual disability to feel the positive effects of the intervention (Mason & Hargreaves, 2001). Yet, a review that explored individuals with intellectual disabilities experiences of engaging with group based third wave therapies showed that following the intervention they described deeper level changes including an ability to mentalise, use of defences and internal working models (Patterson & Golightly, 2023). Thus, it appears overall that those with an intellectual disability respond well to a group-based mindfulness intervention which challenges previous assumptions made that the concept of mindfulness could be cognitively challenging for this population to engage with (Huntington & Bender, 1993).

Third wave therapies incorporate elements of mindfulness and they have been studies more intensely in this population than mindfulness-based interventions. The results of this review adds to previous reviews on the positive effects of third wave therapies on individuals with an intellectual disability or developmental difficulties (Patterson et al., 2019; Byrne & O’Mahony, 2020; Chapman et al., 2013; McNair et al., 2017). The studies included in these reviews had elements of mindfulness included in the intervention such as acceptance and commitment therapy or dialectic behavioural therapy with components of mindfulness. This review suggests that mindfulness alone can have a positive impact on individuals with an intellectual disability without incorporating the other aspects of third waves therapies. It also suggests that mindfulness, regardless of the form it takes, has a positive effect on individuals mental health and behaviour. The studies included in
this review had different mindfulness content including I can feel good (Ingamells and Morrissey, 2014), MBCT, MBSR, soles of the feet meditation (Singh et al., 2003) all of which showed positive results.

Implications

This review raises important service implications. In an environment where demand is increasing for psychological therapies, yet resources are limited, this review provides evidence of a cost effective solution; offering mindfulness therapy in a group format. This will reduce waiting list times resulting in earlier interventions which should result in less severe presentations resulting in shorter episodes of care. To encourage individuals to use the mindfulness skills they have learnt in the group sessions, family members should be consulted and encouraged to model techniques out with sessions. Furthermore, appropriate adaptations should be made to mindfulness interventions including using simpler language, providing visual material, shorter sessions and repetition of skills.

Evaluation of studies and research recommendations

The overall methodological quality of the studies included in the review is weak. Thus, it is important to consider this when evaluating the strength of the above findings. Yet there was a relative strength of the included studies in their reporting of dropouts and withdrawals. This transparency increased the validity of the results and allowed for exploration of reasons for withdrawals resulting in less bias.

With regards to selection of appropriate participants, each study identified those with an intellectual disability in varying ways. For example, some re-administered a cognitive assessment such as a WASI (Weschler, 2008) to confirm an IQ within intellectual disability range, where others took for granted that someone had an intellectual disability depending on the environment they recruited from, for example a ‘special school’. Furthermore, some studies stated that individuals with an IQ below 80 were classified as having an intellectual disability but guidance in the United Kingdom differs and an IQ below 70 along with adaptive behavioural difficulties since childhood is classified as an intellectual disability. Studies were conducted in different worldwide locations so cultural challenges regarding the diagnosis and labelling of an intellectual disability are apparent. These differences in identifying an intellectual disability means it is difficult to pool conclusions for this population. The differences between papers on what defines an ‘intellectual disability’ meant that those studies that recruited participants with ‘borderline intelligence’ were also included in this review. The researcher is aware that these individuals do not have a diagnosis of an intellectual disability and therefore it may be difficult to generalise results due to inconsistencies in measuring intellectual functioning. The
intellectual disability field need to become more harmonious in their criteria for inclusion. Those with an intellectual disability usually have a unique service provision, separate from mainstream adults. Thus, it is important the studies containing individuals solely with an intellectual disability diagnosis are conducted and not always mixed with those with other developmental disabilities. This would allow more understanding on the impact of the degree of an intellectual disability on the effectiveness of psychological interventions.

Outcome measures were inconsistent between papers. Different measures were used depending on the behavioural or psychological target. Some researchers also adapted measures that were shown effective in the mainstream population but did not specify what adaptations were put in place. This makes it difficult to make conclusions or determine how valid they are for use in the intellectual disability population. Furthermore, the difficulties with using self-report measures with the intellectual disability population is well reported. Due to cognitive demands and difficulty understanding contextual aspects of assessment measures (Finlay and Lyons, 2001). Future research could include a mixed method study that includes valid and reliable self-report outcome measures along with qualitative reports. For example, the Child and Adolescent Mindfulness Measure (Greco et al., 2011) for a measurement of mindfulness skills and Glasgow Anxiety Scale for Intellectual Disabilities for anxiety (Mindham & Espie, 2003). The qualitative aspect of this would give rich data on the experience of individuals with an intellectual disability and this qualitative account would improve the understanding of mindfulness for the population.

Furthermore, there are limited RCT’s available in this field meaning that the studies included are all non-randomised, and as such have a higher likelihood of selection bias. 3 studies include less than 8 participants (Craven and Shelton, 2020; Lake & McHale, 2021; Thornton et al, 2017), these smaller sample sizes cause weak external validity thus limiting the generalisability of the results. If studies were adequately powered, then they may have produced more significant results. Furthermore, only one studied provided follow up data so maintenance of any progress is difficult to determine. Future studies would benefit from focus on improving the quality of the study by including larger sample sizes and in which the intellectual disability is clearly defined. Furthermore, the field would benefit from more randomised control trials (RCT’s) that use consistent outcome measures for specific problems. RCT’s would allow for allocation concealment and blinding, reducing bias and improving generalisability of findings. It would also allow for future meta-analysis to be conducted in this area as at present there is too much heterogeneity in intellectual disability studies for this to be explored.

Additionally, studies varied on their reporting of what intervention adaptations were put in place to engage participants. Studies could be elevated by focussing on detailing the degree and nature of intervention...
adaptations they utilised when delivering mindfulness interventions. This would improve treatment fidelity and allow future studies to replicate the intervention and adapted outcome measures, creating treatment fidelity. Lastly, a quantitative study comparing individual and group mindfulness interventions for this population would provide evidence on what format is more effective in this population.

Review strengths and weaknesses

This review provides a synthesis of the most up to date evidence for the effectiveness of mindfulness interventions for the intellectual disability population. Numerous strengths can be identified within the current review. Firstly, to ensure inter-rater reliability of the review, a second reviewer quality assessed all included studies strengthening the quality assessment results. Another strength is that the study includes a doctoral thesis. This reduces the risk of publication bias but still ensures included study is peer review so of a good methodological standard. Another strength of the review is that it investigated a population that is usually overlooked in research. It therefore adds to a small evidence base and encouraging equality of care for this vulnerable group.

A few limitations of the current review exist. Firstly, the use of a generic quality assessment tool (EHPPQ) may mask the strengths associated with some of the study designs. However, this was one of the few quality assessment measures that has shown validity across different study designs (Thomas et al, 2004). Secondly, due to the limited number of studies in this population, any mental health or behavioural problem was included in the review thus this may reduce the generalisability of the results and contributes to heterogeneity. If more quantitative studies existed on group mindfulness interventions for a specific disorder in the intellectual disability population, this may have produced more concise results on the effectiveness of group mindfulness for a specific mental health difficulty. A further limitation of the review is the exclusion of qualitative material. This may have provided rich information in terms of the experiential aspects including how the group format may have felt for the individual. Due to the smaller sample sizes usually present in intellectual disability studies, qualitative information can be a valuable addition. Lastly, the review pulls on literature that spans back further than 10 years ago. Unfortunately, due to the limited research done in this field there were limited contemporary studies available. Thus, these sources were used to make the review as inclusive as possible to provide an overview of this topic area.
Conclusion

Evidence from this review suggest that individuals with an intellectual disability can learn the skills to implement and practice mindfulness. It also suggests that group mindfulness interventions can improve mental health symptoms and behaviour that challenges. The review has also identified the importance of systemic working (including family/carers) to encourage practice of mindfulness skills out with the group sessions. It also identified specific adaptations that helped individuals with an intellectual disability engage in the group including role play, simplistic language, repetition of skills. However, these findings must be interpreted with caution due to the poor methodological quality of the included studies. Future research could focus on better quality studies that have larger sample sizes, better outcome measures and detail the degree and nature of adaptations to increase treatment fidelity. Finally, more research on intervention effectiveness for the intellectual disability population rather than in developmental disabilities more generally to help understand the degree of intellectual disability on intervention effectiveness.


Covidence systematic review software (2023), Veritas Health Innovation, Melbourne, Australia. Available at [www.covidence.org](http://www.covidence.org).


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Chapter 2: Empirical project

‘How does this fit?’ A Qualitative Analysis of a Multidisciplinary Teams experience of Trauma-Informed Care in An Intellectual Disability Service.

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Empirical Project Abstract

**Background:** Individuals with an intellectual disability are more vulnerable to traumatic experiences and abuse than the general population. There is therefore a need to make sure that services for these individuals are set up to appropriately respond to trauma both on a 1-1 level and at a systemic level. Trauma informed care is a systems level approach that has 5 key principles: Trustworthiness, choice and voice, collaboration, empowerment and safety. Investigating how these principles have been incorporated into intellectual disability services is important in developing an understanding of the current context of trauma informed care within services for this vulnerable population.

**Methods:** Members of a multidisciplinary team within an NHS intellectual disability service were interviewed on their experience of trauma-informed care. Results of the interviews were analysed using Interpretative Phenomenological Analysis (IPA).

**Results:** 11 professionals from multiple different disciplines participated in the study. Analysis of the interviews using IPA produced 3 themes: Change over Time: A Sense of Awareness and Understanding, Thinking Outside the Box and Carrying the Burden. The final theme contained three subthemes: relationship with families, informal supports and burnout. All 11 participants connected with each theme in individual ways.

**Conclusion:** This study gives an insight into trauma-informed care within an NHS service from the perspectives of a multidisciplinary team. The positive aspects along with the more challenging aspects are reflected in the identified themes. This has clinical implications including the importance of screening for trauma using routine outcome measures, balancing giving staff appropriate guidance whilst respecting autonomy to help them feel empowered but supported. Lastly placing focus on staff wellbeing and services should put more structured measures of support in place. Lastly future research that may be useful for the field is collecting both qualitative and quantitative data at different timepoints to determine the effectiveness of techniques/principles put in place by a service.
Intellectual Disabilities and Trauma

Individuals with an intellectual disability are more vulnerable to experiencing psychological trauma and abuse than the general population (Byrne, 2022). Multiple factors make them more vulnerable including their limited cognitive abilities which may impact on their ability to problem solve and appraise risk (Tomasulo & Razza, 2007). Furthermore, they may struggle to recall specific information making them uncredible reporters and abuse can therefore be overlooked (McNally et al., 2023). Their limited social and communicative difficulties can increase the likelihood of bullying and domestic abuse as they may have limited opportunities to develop friendships and relationships resulting in acceptance of mistreatment (Horner-Johnson & Drum, 2006; Jones et al., 2012; Leeb et al., 2012; Tomasulo & Razza, 2007). They may also not recognise what constitutes abuse and thus tolerate abusive behaviour (Beadle-Brown et al., 2010; Nixon et al., 2017, McGlivery, 2018). It is also understood that an individual with an intellectual disability may experience trauma relating to having the disability itself and a feeling of being distinct from others (McNally et al., 2021).

Trauma is commonly referred to in two distinct categories. Type 1 trauma is the result of a single incident such as a car crash or criminal violence such as a robbery or rape (Reed et al., 2016). Type 2 trauma refers to complex trauma usually relating to continuous abusive or threatening situations over a long period of time (Reed et al., 2016). This may start in childhood or adulthood and is likely (but not exclusively) perpetrated by those close to the individual (Reed et al., 2016). Evidence suggests that those with an intellectual disability may be more likely to experience prolonged interpersonal trauma (type 2) (Scotti et al., 2012). This is due to their dependency on others for multiple aspects of their care (Tomasulo & Razza, 2007; Wigham & Emerson, 2015).

A study in 2012 by Scotti and colleagues found that 79% of individuals with an intellectual disability had experienced at least one traumatic event but most have been exposed to multiple. The average traumatic experiences was 2.8 (Scotti et al., 2012). These experiences can lead to symptoms of post-traumatic stress disorder (PTSD) (Wigham et al., 2011). The Diagnostic Statistical Manual of Mental Disorders (5th edition) criteria for PTSD includes intrusive distressing memories of the event, recurrent nightmares of the event, dissociative reactions (flashbacks) or prolonged psychological distress which can lead to avoidance of external reminders (American Psychiatric Association, 2022). Lower cognitive abilities have been associated with a higher risk of PTSD and more severe PTSD symptoms (Mevissen & de Jongh, 2010). This is due to individuals with an intellectual disability being less cognitively able to make sense of trauma experiences and their limited
expressive language skills may restrict their ability to describe symptoms or speak about the abuse (Skelly, 2020). This makes it harder to identify trauma in this population and can result in misdiagnosis (Cleary et al., 2018). Furthermore, research shows that individuals with an intellectual disability may display different PTSD symptoms than in the general population (Rittmannsberger et al., 2019). They are more likely than the general population to show behavioural difficulties such as challenging or aggressive behaviour (Rittmannsberger et al., 2019). Thus, it can be difficult to gauge the impact of trauma experiences on individuals with an intellectual disability, especially those with more severe and profound difficulties due to their communication deficits. Clinicians have raised concerns about asking individuals who struggle with their mental health about trauma or delivering trauma focused psychological treatment and its potential to exacerbate symptoms (Frueh et al., 2006). However, evidence shows the detrimental effects of not asking individuals about trauma (Skelly, 2020).

Mounting evidence links experiences of trauma to poorer mental health, physical health and social outcomes (Byrne, 2018; Emerson & Hatton, 2007; Totsika et al., 2011; Santoro et al., 2018). For the general population there is clear guidelines by the National Institute for Care Excellence (NICE) for the treatment of PTSD symptoms (NICE, 2018). Both Eye Movement Desensitisation and Reprocessing Therapy (EMDR) (Shapiro, 2001) and Trauma Focused Cognitive Behavioural Therapy (Tf-CBT) (Beck, 2011) have a strong evidence base in the general population (NICE, 2018). Although the research into psychological treatments for PTSD in the intellectual disability population significantly falls behind the general population, there is a growing body of encouraging evidence for its effectiveness. Studies have shown tf-CBT (Carrigan & Allez, 2017; Kroese et al., 2016) and EMDR (Barrowcliff & Evans, 2015; Karatzias et al., 2019; Mevissen et al., 2011) effective in intellectual disability populations. Furthermore, a recent systematic review for both children and adults with an intellectual disability, that displayed symptoms of PTSD, found both tf-CBT and EMDR acceptable treatment methods (Bryne, 2022). With increasing evidence that trauma interventions are effective for the intellectual disability population there is a call for integrating the individual therapeutic approaches into a wider, systemic, trauma-informed approach.

Trauma-informed Care

Trauma-informed care is based on the idea of integrating trauma-informed principles with national and service level guidelines and policies (Bassuck et al, 2017). It is a framework that is multidimensional and goes beyond guidance on person focussed trauma therapies, promoting understanding and awareness at a broader level (Harris & Fallot, 2001; Bassuck et al., 2017). This shifts the focus of trauma recovery from being exclusively on the individual to develop coping methods and puts responsibility on services to increase the ability for individuals to access services and minimise any potential distress or re-traumatisation (Harris & Fallot, 2001). The key principles behind trauma-informed care are trustworthiness, collaboration, empowerment, physical
and emotional safety and choice (Harris & Fallot, 2006). For these principles to be implemented SAMHSA (2014) outline 4 key assumptions that need to be fulfilled within an organisation. These are:

- Realisation: the importance of all individuals within an organisation to have an awareness and understanding of the impact of trauma.
- Recognition: the importance of all individuals within an organisation to be able to recognise the symptoms of trauma.
- Response: All individuals within an organisation should respond to others in a way that is in keeping with an awareness of trauma.
- Resist re-traumatisation: The organisation should ensure that individuals using the service are not re-traumatised by their experience with the service. This assumption also includes staff being supported in such a way that they are not retraumatised.

Considering these factors reduces the chances of a negative, unhelpful traumatic interaction with services which has been demonstrated to increase the likelihood of individuals utilising the service in the future (Paksarian et al., 2014; Priebe et al., 2005). Trauma-informed care increases patient satisfaction with services and improve the relationship between individuals and mental health professionals (Sturgeon, 2023). It also reduces individuals use of crisis services (Sturgeon, 2023). Aside from thinking about the individual using the service, organisations that implement trauma-informed care have shown improvements in mental health professionals job satisfaction, an increase in confidence in their work and reduction in staff sickness (Hales et al., 2019; Sturgeon, 2023). Therefore, a comprehensive trauma-informed approach benefits both parties (Cleary et al., 2020). How an organisation implements the above principles and assumptions to produce a trauma informed organisation, is not linear and depends on multiple components including the target population, environment and resource availability. The above principles and assumptions were developed for organisations working with the general population and not specific to intellectual disability services.

The National Trauma Training Network (NHS Scotland, 2017) stipulate that trauma should be ‘everyone’s business’. They have established guidance on what trauma-informed care should look like at each stage of interaction with services. The four levels of knowledge base are: Trauma informed practice in all interactions-providing all individuals with a baseline trauma knowledge; Dealing with trauma- for staff that may directly interact with individuals who have experienced trauma; Enhanced support- for staff that directly support or advocate for individuals who have experienced trauma; Specialist trauma- Treatment providers for those who have experienced trauma- both at an individual and organisation level. Those with an intellectual disability are more likely to rely on multiple services for support. Therefore, it is imperative that they have access to trauma-informed practice at all interactions with services. All trauma training should go beyond increasing
individuals’ knowledge and begin to explore options for how this knowledge can be implemented in to practice (Taggart et al., 2021).

Trauma-informed Care in intellectual disability Services

Evaluations of trauma-informed care in intellectual disability services are limited and far behind the research for trauma-informed care in other services (Cleary et al., 2018). Yet in recent years a few studies have been conducted. This has produced useful insights for the intellectual disability field (Goad, 2021; Keesler et al, 2023; McNally et al., 2023).

Goad (2021) wrote a reflective account of the first steps an intellectual disability NHS service took to embrace trauma-informed care. Firstly, developing awareness of the teams understanding of trauma-informed care, identifying the main barriers to change, and assessing the staff’s readiness to make changes, helped integrate trauma-informed care into the teams’ culture and ethos. Secondly, they focused on empowering staff through language, this encouraged staff to share ideas and resulted in a staff led training session which further empowered staff to share experiences of trauma-informed care. A staff led approach to training has shown to be more effected than top-down training styles (West et al., 2014). The next stage was about developing a vision using a model that contained the staff’s objectives. This helped develop collaboration and team direction. Goad’s study goes beyond suggesting ideas for consideration when implementing trauma-informed care and begins to suggest ways that the change can happen.

Keesler and colleagues (2023) conducted a mixed methods pilot study on digital trauma-informed care training delivered to direct service providers. This digital training showed increase staff knowledge in specific areas and a greater alignment with trauma-informed care. Staff also identified organisational assets and barrier to implementation of trauma-informed care. Lastly, McNally and colleagues (2023) were the first to produce a specific framework, the ‘logic framework’, for supported living accommodation for adults with an intellectual disability. Individuals with an intellectual disability and staff supporting them were involved in the co-production of the framework. The framework included the resources and activities needed to become trauma-informed, along with the change mechanisms required. It also gives short, medium, and long term expected outcomes in terms of how these changes will affect residents, staff and the organisation. As this is a relatively new framework no studies have been published that test the operationalisation of this framework. Therefore, currently no evidence exists regarding its effectiveness within residential intellectual disability services.
Current Study

It is promising that there is mounting interest for services to enhance their understanding of trauma and become more trauma-informed organisations. Trauma-informed care can only effectively be implemented when there is readiness to make changes, resources for change and ample knowledge to transform the concept of trauma-informed care into practice (Cleary et al., 2018). After reviewing the evidence on trauma-informed care within this population, it is clear that studies are limited. Previous studies have been focussed on third sector agencies (care providers, residential accommodation services) and only one study has been done within the NHS (Goad et al., 2021). This study was a reflective account and therefore limited in its methodological rigour. Thus, while trauma-informed care has gained recognition both within the NHS and third sector agencies, how fully intellectual disability services have adopted the practice rather than the concept of trauma-informed care, is unknown.

This study aims to explore a multidisciplinary teams experience of trauma-informed care within an NHS intellectual disability service. This will help provide insight into the stage of implementation and the specific components that are useful to consider when supporting this population. This will provide important insights for the future direction of trauma-informed care in intellectual disability services. This research is imperative to support the move towards equality of care in this population.

Methodology

Ethics

The University of Edinburgh School of Health in Social Science Ethics Committee granted ethical approval and sponsorship for this project on 9th February 2023 reference number 317195. The study was also granted local NHS managerial approval via the Integrated Research Application System (IRAS), reference number 2023MH01. Please see Appendices D to G for associated documentation.

Design

This study utilised a qualitative, explorative design using semi-structured interviews with the purpose of gaining a richer understanding of an intellectual disability team’s experience of trauma-informed care.
Participants

Purposive sampling was used to recruit participants. This method of recruitment is favourable for a qualitative approach as it provides the ability to select rich cases for in depth exploration (Patton, 2002). Participants were NHS staff who worked within the intellectual disability department in a single NHS Scotland Health Board. Within the intellectual disability department there were 3 locality teams and all locality teams were contacted regarding the study. Staff were from different specialities including psychology, psychiatry, dietetics, occupational therapy and speech and language. Due to the multidisciplinary nature of this project a sample size of 10-12 participants was identified as appropriate as this allowed for identification of variations between professions whilst still ensuring homogeneity.

Procedure

The researcher contacted potential participants via NHS staff email. An email distribution list for individuals within the 3 learning disability teams already existed and this was used to contact all potential participants. The initial email included a participant information sheet (Appendix H), outlining the main details of the study and what would be involved should they decide to take part. Participants who were interested in the study were asked to respond to the email expressing an interest in participating. The researcher then contacted the individual confirming that they met the inclusion criteria:

- A professional working within any one of the three NHS Intellectual Disabilities Teams
- A professional with regular direct contact with people with an intellectual disability
- A professional who has worked with individuals with an intellectual disability and trauma history.

Once this was confirmed and any questions from the potential participant explored and answered, the participant was then sent the consent form (Appendix I) and a convenient date and time for the interview was agreed. Interviews either took place on NHS premises or via Microsoft teams. At the start of each interview, the researcher recapped the information in the consent form and reiterated that all interviews were audio recorded and following the interview the results would be anonymised and transcribed. At the end of the interview, time was given for any reflections and questions by the participant. The researcher then gave the participant two debrief sheets which included background reading about the study and information on helpful resources should they feel they require any additional support following the interview (Appendix J).
Qualitative Interview

Semi-structured interviews were conducted by the researcher, accompanied with an interview guide. The interview guide was built around the key research question and the guidelines for IPA interviews (Smith et al., 2022). 6-10 open, exploratory questions were developed informed by SAMHSA (2014) key assumptions for trauma-informed care: realisation, recognition, response and resist re-traumatisation. The full interview guide can be found in Appendix K. Those participants who were relaxed and able to express opinions without the use of an interview were engaged in an active researcher-participant dialogue. In these instances, questions were based on the responses given by the participant to fully explore individual experiences (Smith et al., 2022). The interviews were audio recorded and a digital field journal was kept by the researcher. This journal reflected on thoughts and feelings the researcher had during the interview and any other details that the researcher deemed important.

Data Analysis

Interpretative Phenomenological Analysis (IPA) was used to analysis the data. This study seeks to understand professionals experience of trauma-informed care within an NHS intellectual disability context, on which limited research exists. Accordingly, a qualitative approach was considered the most appropriate to address the research question. The essence of IPA allows for a rich detailed account of individual experiences (Flick, 2010). The three major underpinnings of IPA are phenomenology, hermeneutics and ideography (Smith et al., 2022). “Phenomenology” is centred around how individuals make sense of a specific phenomenon, “hermeneutics” is how meaning is made and “ideography” is placing emphasis on each individual’s unique perspective (Smith et al., 2022). As IPA incorporates a participants experience with the researcher’s interpretation of this experience, a “double hermeneutic cycle” occurs across data analysis. This method allowed exploration of individual experiences and helped distinguish common themes. Grounded theory was considered for this study but IPA was considered more appropriate as it seeks to make sense of experiences rather than developing a theory that can be generalised. As there is minimal literature on trauma-informed care in intellectual disabilities a phenomenological underpinning of this topic will be helpful initially and will allow for future research to build upon and generate a more theory driven approach.

Smith and colleagues (2022) seven steps of IPA were followed to ensure commitment in line with IPA guidelines. After the audio recordings were transcribed verbatim, the data was read and re-read. Comments were made on any ideas/interesting data that stood out and the comments facility on Microsoft word was
utilised to keep track of this. This gave rise to a comprehensive list of comments about the data for each individual transcript. After this the researcher re-read the transcript and created another layer of notes named ‘experiential statements’. This created a more structured understanding of the full transcript. The next step in analysis was to search for connections across experiential statements. This was conducted via printing off transcripts with experiential statements and gathering together specific statements on similar themes and creating spider diagrams. This moved the data from being in the order that it was discussed during the interview, to fitting together in an innovative way. The above process was completed for each participant’s data. After this was completed, the researcher began to identify repeated themes across the different transcripts. This was termed ‘group experiential themes’. Appendix L shows an example of transcript analysis. The researcher reports this data analysis in a transparent way that can be easily followed to enhance confidence in the validity of the research (Levitt et al, 2018; Yin, 1989).

Reflexivity

Due to the nature of IPA and the in-depth reflective inquiry required for analysis, it is important to consider any potential bias from the researcher at all steps in the IPA process (Smith et al., 2022). As a result of this, the researcher actively engaged in reflexivity to ensure that there was movement between psychological interpretation of the data and the grounded data (Smith and Osborn, 2008). The researcher revisited the original data, along with the data from the field diary, that included the researchers own perceptions, and this helped ensure reflexivity (Appendix M contains a reflective account; Larkin & Thompson, 2011). Furthermore, academic supervision was used regularly to discuss the analytic process and themes arising from the data. Lastly the researcher engaged in many peer supervisory experiences to discuss the analytic process. The above processes along with presentation of quotations throughout the findings, helps illustrate and support the researcher’s interpretations and construction of themes.

Findings

11 interviews were conducted. 3 psychologists, 3 nursing staff, 2 occupational therapists, 1 dietician, 1 speech and language therapist and 1 psychiatrist were interviewed. Participant characteristics and the length of interview is outlined in table 7. All participants were white females and this lack of diversity is representative of the service being examined. However, this may not be representative of intellectual disability services in other regions. The themes produced may have been different if males and different ethnicities participated in the interviews. The interview times ranged from 41 minutes to 68 minutes.
Table 7

participant information

<table>
<thead>
<tr>
<th>Participant</th>
<th>Profession</th>
<th>Gender</th>
<th>Ethnicity</th>
<th>Length of interview</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Dietician</td>
<td>Female</td>
<td>White</td>
<td>52 minutes</td>
</tr>
<tr>
<td>2</td>
<td>Nurse</td>
<td>Female</td>
<td>White</td>
<td>41 minutes</td>
</tr>
<tr>
<td>3</td>
<td>Nurse</td>
<td>Female</td>
<td>White</td>
<td>44 minutes</td>
</tr>
<tr>
<td>4</td>
<td>Nurse</td>
<td>Female</td>
<td>White</td>
<td>68 minutes</td>
</tr>
<tr>
<td>5</td>
<td>Occupational therapy</td>
<td>Female</td>
<td>White</td>
<td>48 minutes</td>
</tr>
<tr>
<td>6</td>
<td>Occupational therapy</td>
<td>Female</td>
<td>White</td>
<td>42 minutes</td>
</tr>
<tr>
<td>7</td>
<td>Psychiatry</td>
<td>Female</td>
<td>White</td>
<td>41 minutes</td>
</tr>
<tr>
<td>8</td>
<td>Psychology</td>
<td>Female</td>
<td>White</td>
<td>61 minutes</td>
</tr>
<tr>
<td>9</td>
<td>Psychology</td>
<td>Female</td>
<td>White</td>
<td>43 minutes</td>
</tr>
<tr>
<td>10</td>
<td>Psychology</td>
<td>Female</td>
<td>White</td>
<td>47 minutes</td>
</tr>
<tr>
<td>11</td>
<td>Speech and language</td>
<td>Female</td>
<td>White</td>
<td>50 minutes</td>
</tr>
</tbody>
</table>

Analysis of the data produced 3 group experiential themes: Change over Time: A Sense of Awareness and Understanding, Thinking Outside the Box and Carrying the Burden. Group experiential themes were further categorised into subthemes seen in table 8. Group experiential themes were evident in all transcripts with subthemes occurring in the majority of them. This is represented as a percentage in table 8. Each theme and participant quotes in support of each theme are detailed below.

Table 8

Group experiential themes and subthemes

<table>
<thead>
<tr>
<th>Group Experiential Theme (GETS)</th>
<th>Sub-themes</th>
<th>Occurrences</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Change Over Time: A Sense of Awareness and Understanding</td>
<td>11/11</td>
<td>100%</td>
<td></td>
</tr>
<tr>
<td>2. Thinking Outside the Box</td>
<td>11/11</td>
<td>100%</td>
<td></td>
</tr>
<tr>
<td>3. Carrying the Burden</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Families relationship with services</td>
<td>6/11</td>
<td>54%</td>
<td></td>
</tr>
<tr>
<td>• Informal support</td>
<td>11/11</td>
<td>100%</td>
<td></td>
</tr>
<tr>
<td>• Burnout</td>
<td>10/11</td>
<td>91%</td>
<td></td>
</tr>
</tbody>
</table>
The researcher had numerous assumptions at the beginning of this project. Firstly, the researcher expected that trauma training was unlikely to be adapted sufficiently to suit the intellectual disability population. They also assumed that staff turnover and burnout would be an important factor in hindering the implementation of trauma informed care. However, some of the findings surprised the researcher including the lack of formal supports in place and the reliance individuals then had on their colleagues to fill this gap.

**Theme 1: Change over Time: A Sense of Awareness and Understanding**

Members of the multidisciplinary team portrayed the importance of time when describing their experiences of trauma-informed care. Most participants suggested that attitudes and views about trauma and the intellectual disability population/service have changed over their time working within the NHS. Therefore, resonating with the overarching theme ‘Change over Time’.

There was a strong sense that services or those that worked within them, previously did not consider trauma, when working with individuals with an intellectual disability. Mel states:

> It wasn’t something that we thought about previously very often. I think especially within learning disabilities we just assumed that if someone struggled with something it was because of their learning disability and didn’t understand but now we have more awareness. (Mel)

Mel’s use of the word “assumed” portrays an acceptance of truth. Something that was never questioned nor “thought about very often” and accepted that it was the way it was. Her reflection of having “more awareness” suggests there has been a change in her knowledge and perhaps feels more informed about trauma in this population now. Sue related to Mel’s previous experience of a limited understanding and awareness of trauma and suggests there is a generational component to this:

> A lot of our older nurses were learning disability trained so they maybe didn’t come across the trauma stuff. They didn’t really have an awareness and maybe a lot of stigma and damning attitudes. But their skill levels definitely going up because their jobs have changed quite a lot over the years, but certainly the younger nursing staff coming through, you can see that there’s an understanding there already. So I think it’s just upskilling older staff members in that sort of approach. (Sue)
Sue suggests that there has been a generational shift in the nursing profession to become more trauma informed. She associates the lack of awareness with “stigma and damning attitudes” which may be suggestive of the historical stigmatisation of individuals with an intellectual disability. Past attitudes towards individuals with an intellectual disability discriminated them from the rest of society and therefore perhaps these individuals did not access services for trauma symptoms and so staff “didn’t come across trauma stuff”. Sue speaks of the helpfulness of “upskilling” the older generation in trauma-informed approaches yet alludes to an overall feeling that these previous attitudes are already changing. Due to increased skills and knowledge “their skill level is definitely going up”. This is echoed by Tara: “I think there’s a slight shift in peoples understanding of trauma and intellectual disabilities and I think that the ID teams are trying hard to change that by providing training, usually delivered by psychology.”

Tara reflected that training has been important in creating a shift in people’s attitudes but her use of the word “slight” may suggest that she feels there is a long way to go for attitudes to really change. She continued by saying: “I have found that in the NHS...that sometimes a lot of things are built around ethos and culture rather than actual training.” This statement adds to her previous statement that training in itself may only produce a “slight shift” in attitudes and indicates that an organisations culture may have more influence over changing attitudes than individual training.

This increased awareness expressed by the participants appeared to be linked to a better understanding of how individuals with an in intellectual disability may display symptoms of trauma.

*Over time there’s been an additional awareness of how the presentation might look for an individual with an LD who has trauma in their background. It might be expressed more behaviourally because they don’t know how to communicate in any other way. (Linzi)*

Linzi’s reflection of ‘additional awareness’ suggests an evolving understanding of trauma in this population. She suggests that those with an intellectual disability may externalise symptoms of trauma (“expressed more behaviourally”) and links this to communication deficits as a result of their intellectual disability. Most participants agreed with Linzi that one possible reason for the behavioural expression of trauma is likely due to difficulties with communication.

*I suppose, I wonder if a lot of that is linked with behaviour, especially if somebody’s not really able to communicate how they’re feeling or what they’re thinking. We might see that more in the behaviour rather than those classic symptoms in the mainstream population. (Hannah)*
Hannah reiterates the importance of considering the persons deficits to attempt to understand the function of a behaviour. Hannah also considers how this presentation may differ to the general adult population ("mainstream population"). Understanding behaviour and trying to look beyond this can create tolerance and acceptance which may then encourage professionals to work in a more trauma-informed way. Maddie states: “Because if you understand the reasons, it can make people more tolerant and accepting of why people are behaving in that way.” This reflection by Maddie conveys the importance she places on trying to understand someone’s behaviour which will increase compassion and understanding resulting in a more helpful response to the behaviour. It shows understanding that there is often a reason for a behaviour. Viewing someone’s behaviour in this way has become more common place in the intellectual disability service and thus staff have experienced attitudes towards behaviour changing.

Although most staff interviewed shared the experience of individuals having more of an understanding of a person’s behaviour, this was not true for all. Hannah said: “I was a bit taken aback about, you know, the lack of understanding and just making a judgment that this person's behaviour is attention seeking.” Hannah expresses shock at the lack of awareness that she felt some professionals have had when discussing an individual’s behaviour that was challenging. This is also echoed by Linzi:

I don't think this is a kind of a conscious thing, but a lot of times there seems to be blame around certain things and it might be towards the person for behaving in particular ways and I guess not really understanding, you know, that behaviour tends to always serve a function and I guess how open people are to maybe seeing things from a different point of view. (Linzi)

Linzi’s use of the phrase “how open people are” suggests she believes that some people are less open minded and tend to avoid change. It is also suggestive that it is a choice for individuals to not increase their understanding. It may be suggestive that some staff still hold stigma towards this population resulting in negative views and “not really understanding.”

Overall, this theme demonstrates that there has been change over time regarding individual’s awareness and knowledge of trauma in the intellectual disability population. Yet there is some divergence within this theme as to just how much this change has taken place. Some participants expressed limited change in attitudes with stigma still being apparent. Others described a generational shift in this understanding and knowledge and how this awareness has helped them look beyond the behaviour and this fosters compassion.

Theme 2: Thinking Outside the Box
The majority of participants described a sense of having to think outside the box when working with individuals with an intellectual disability who have experienced trauma. They convey a sense of embarking on a process of discovery when working with individuals with an intellectual disability. Especially when it came to exploring their trauma symptoms. Sue states:

> So trying to sort of tease out what is just their voice saying something, you know, as opposed to hearing voices or having those kind of hallucinatory experiences, that's quite difficult to tease apart if someone struggles to understand the difference. That's a bit more straightforward when dealing with trauma in the general adult population, if that makes sense. (Sue)

Sue’s use of the words “tease out” and “tease apart” suggests an intricate process of aiming to understand someone’s symptoms by unravelling various components. Sue suggests this can be because “someone struggles to understand” conveying a deficit caused by their intellectual disability. Hannah further illustrates the idea of both trying to understand someone’s experience but also the impact of their intellectual disability diagnosis on their abilities:

> But what are they actually experiencing? Again, as you come sort of further down the ID ladder, if you like, and there are some people that struggle to speak about their emotions or don’t have the language to use for their emotions. So they might describe different feelings or symptoms resulting in misdiagnosis. (Hannah)

Hannah’s reflection considers the barrier that limited communication may have “don’t have the language to use” and it develops an idea that this deficit could have catastrophic implications such as ‘misdiagnosis’. This could have negative repercussions for their mental health and overall wellbeing. Hannah’s use of a rhetorical question at the start of their reflection evokes reflection on the importance of understanding someone’s “actual experiences”. It connotates again a sense of trying to make sense of this for the people that “don’t have the language”.

As well as a sense that the team feel they have to make sense, by piecing together, experiences for individuals with an intellectual disability, team members also noted the vulnerability of the population in terms of their desire to conform to social norms: “So they’ll tell us everything we would like to hear rather than what's actually going on for them.”. This statement by Sam suggests individuals are potentially trying to conform to whatever they think is accepted in the wider population. Connie corroborates this:
I had a full conversation with someone about what sandwich they had brought for their lunch and it turned out they hadn’t brought a packed lunch at all. There was no benefit behind it that I could see. Could have easily said I’ve not brought it but it was…well we are talking about sandwiches so I will say I’ve got X. (Connie)

Although the content of Connie’s statement is regarding an unmeaningful subject, it illustrates the point of individuals with an intellectual disabilities vulnerability when it comes to trying to conform to social norms. It conveys the idea that it is the responsibility of the clinician to think outside the box to try and understand the reasons why individuals are saying what they are.

Staff shared experiences of continually having to adapt to the needs of their clients. Dot reflected “it’s hard because there is nothing standard about trauma reactions and there’s definitely nothing standard about the deficits each person with an ID has”. Dot’s description of “nothing standard” connotates a difficulty familiarising oneself with “trauma reactions” due to the individual nature of them. Dot’s repetition of the phrase “nothing standard” emphasises her experience of struggling (“it’s hard”) to make sense of each individual’s trauma symptoms. Linzi supported this idea of it being “hard” by saying “it’s really challenging to constantly be adapting material and working on an ad hoc basis. In adult you could just provide a standard handout.” Linzi also introduces the idea of creating material relating to trauma on an “ad hoc” basis suggesting that it cannot be planned or predicted and is something that is formed for individual situations or unique experiences. This is corroborated by Mel who reflected: “there’s never a specific pathway in intellectual disabilities, its individualised to that person and what that person needs….that’s how it should be”. This suggests the importance of being flexible, person-centred and not following ‘specific pathways’. Mel’s statement suggests she feels an obligation to be providing this individualised care ‘that’s the way it should be’. The overall sense here is the inability to be prescriptive with this population due to the individual nature of their presentation. Although adaptation feels like what is needed for the population, some staff have reflected on the challenges this presents. Sue stated ‘it’s a good job that we are so creative because we aren’t provided with anything anyway. We are always forgotten’. This is a powerful sentence by Sue who suggests that this population are rarely considered and continuously overlooked (“always forgotten”) and staff are therefore having to think on their feet a lot of the time.

This sense that staff had of the population being overlooked expands further than the individual work with clients and encompassed a feeling that the training they are provided with as a service is insufficient. Members of the team shared experiences of trauma training not being routinely offered to them. “I don’t think I’ve had any other formal training. I haven’t went out and looked for it and its not routinely offered. Or maybe there is now and I’m not aware.” This reflection by Dot suggests that she felt it would be her responsibility to find
appropriate training. Her use of the words “looked for it” suggests she may feel that there’s an inaccessible aspect to accessing trauma training. This is echoed by Maddie who suggested “There will be stuff out there, but I wouldn’t have a scoobie where to look”. This reflection portrays a sense of personal responsibility to find appropriate training (“where to look”) and her use of the phrase “there will be stuff” could suggest a lack of commitment in doing so.

Those individuals that had been on trauma training shared experiences of attending training developed for the general adult population and therefore lacked adaptation to individuals with an intellectual disability: “you’ve just got to read into the mainstream ones. Like how does that fit for our guys”. Chrissy’s use of the word “fit” suggests trying to make something suitable. This is echoed by Sue: “It’s like trying to put a square peg in a round hole.” This analogy is a powerful illustration of how unsuitable she has found the training provided.

Some staff members had managed to attended training specifically for those with intellectual disabilities. Connie had attended adapted Safety and Stabilisation training ran by National Education for Scotland. She said: “It was lucky that I go that one and not the general one”. Her use of the word lucky could imply that this was by chance and is not routinely offered. Connie continued describing the training:

I really enjoyed it but the handouts they provided as ‘tools’ to use with our patients weren’t even adapted. We all began to discuss as a team how we could adapt this to make it more accessible and easy read. It’s meant to be a specialist course. You’d think I’d have come away with something more specific. (Connie)

Connie conveys disappointment and shock that this “specialist course” did not “even adapt” material for the population they were training on. Sam described some online modules that she had done on trauma and intellectual disabilities stating: “we’ve not had much more than that..which feels a bit insufficient now I think of it”. Corroborating Connie’s sense of disappointment in what has been provided so far. The word “insufficient” conveys an inadequate provision of training they have received so far. It appears that staff feel that a lack of training is offered and when training does arise it is not adapted appropriately to the intellectual population, lending again to being the responsibility of the clinician to adapt this for the client group.

Overall, this theme acknowledges the unique skills needed for professionals working with an individual with intellectual disabilities and trauma. Staff convey the idea of continually having to think on their feet to understand an individual’s presentation/symptomology and playing a detective role to understand reasons behind behaviours. There was a sense of the challenging nature of this paired with a lack of suitably adapted training and resources. Staff feel the guidance they are given is minimal yet there seems to be a mutual
understanding that due to the uniqueness of this population that standardised protocols would not be sufficient. Therefore, there is a reliance on staff thinking outside the box. Thus, creating a vicious cycle of which a visual representation can be found in Figure 3.

**Figure 3**

*A vicious cycle of the complexity of a unique population*

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**Theme 3: Carrying the Burden**

This theme captures the weight that staff feel when trying to juggle the elements of theme 2: Thinking Outside the Box.

*Families relationship with services*

Members of the team mentioned the importance of the relationship with the family members of an individual with an intellectual disability. Especially if they have had previously bad experiences with services or other professionals. Sam reported:

> But you often find in your consultations, they'll say where things have gone wrong in the past, you know, and these are really horrible experiences that they've all had to go through. And I mean, one mum described before to us, you know, she was handed her baby and they said good luck, you know, that's what happened way back in the 70s or even 60s. (Sam)
Sam described a family’s experience as “really horrible”. This conveys empathy for the family and the distressing experience they have been through. Her acknowledgment of “things have gone wrong in the past” emphasises how families have been let down and therefore may lack trust in services. Other members of the team reflected on trying to work closely with families and carers who have previously experienced abuse within the system to rebuild the relationship. Jess said:

> How traumatic it would be for a family to not be able to look after their child and put them somewhere they think is safe and then find out all the carers have been abusing those with LD. The trust is then completely gone. They then become obsessed with picking up on wee things that aren’t quite as they should be. (Jess)

Jess’s reflection speaks of “trust being completely gone” and how families respond to that by perhaps becoming hypervigilant to “wee things”. She again conveys a sense of empathy for the family “how traumatic it would be for a family”. Other members of the team appear to lack this understanding. Maddie said: “I’ve got a few families who just never give any of the professionals a break. Nothing is good enough, nothing is quick enough and I’m assuming that’s because, you know, something that’s happened previously with services”. This reflection gives a sense of frustration with families “never give us a break” suggesting there is a constant pressure on them to deal with the families demands as quickly as possible. The word “break” carries a feeling of exhaustion. There’s also a sense that what they do provide is not “good enough” for the family conveying a sense of trying to please but struggling to meet the mark. Maddie further adds to this by stating: “Lots of stuff on TV recently too showing scandals of care for this population which perpetuates this lack of trust which isn’t making it any easier for us”. Maddie suggests that this “lack of trust” does not just come from families’ personal experiences but from wider influences such as the media. The use of the word “perpetuates” suggests there is a cumulative component that has reinforced families “lack of trust” and this then makes working with them challenging (“isn’t making it any easier for us”).

**Informal support**

All members of the team reflected on the importance of reaching out to each other for support when they are struggling to cope with challenging aspects of their job. Connie said:

> So I think we are quite good in [profession] and in ID as a whole at debriefing. Sitting in a room with coffee and talking to each other. We use supervision etc too and personally I use my garden and my shed...and probably too much prosecco. (Connie)
Connie talked of both formal and informal supports such as “supervision” and “sitting with a coffee” and having a “chat”. All members of the multidisciplinary team spoke about the importance of the informal measures of support provided by their team. Sue said: “There's not a sort of standard setup where you might go along and then happen to just share something that's been bothering you, if that makes sense...it's kind of on you to make that happen.” Sue’s use of “it’s on you” suggests personal responsibility to gain support if you feel it is required. Dot confirms this with: “Within our team we seek help when we need it and use each other as a sounding board.” Overall, there is a sense that having good relationships with team members and taking personal responsibility to reach out and actively “seek” support if needed is important for a clinician’s wellbeing and therefore ability to provide trauma-informed care. There is a sense of gratefulness for their relationships with colleagues. Maddie said:

> You know, you're doing your work, you're feeding back, you're checking in on each other when you've come back from a visit, but it doesn't feel onerous, it doesn't feel like an onerous task because you are all looking out for each other. (Maddie)

This suggests that Maddie experiences this as part of her working day and it does not feel like a burden to her. Her use of the words “checking in” suggest a briefness that may explain why it does not feel “onerous”. It could suggest that if someone needed more support that this may become more difficult to do alongside doing normal work (“you’re doing your job”).

Chrissy suggests that relationships with colleagues are vital:

> And that's the thing... it's because we know each other so well it's easy to say ahh I'm struggling with this and you know they won’t judge or take offence. You don’t need to gear yourself up or rehearse. You can just be yourself. (Chrissy)

Chrissy’s reflection suggests that good supportive relationships with colleagues allows a freedom to “just be yourself”. Her experience places importance to feeling comfortable with colleagues (“they won’t judge”). It may suggest that if she does not have as good relationships with her colleagues then it would be harder to be honest about how she was feeling. Additionally, Linzi said:

> We are working with the most complex cases. There's lots and lots of trauma, really sad stories. People’s narratives are very, very tragic and sad and difficult to hear and read, and that's not for everybody. And you know, to be able to undertake the work with these individuals, who are very
chaotic, you need a supportive team. You need that wee boost from your colleague bringing you in your fav chocolate because they know you’ve had a hard day. (Linzi)

Linzi’s reflection captures the difficult nature of working with individuals who have experienced trauma. There’s a real feeling that the little gestures made by colleagues such as “bringing you in your fav chocolate” can go a long way in helping carry the weight of hearing and reading about “lots and lots of trauma”.

**Burnout**

When discussing the high rate of staff turnover in the NHS and in third sector services participants described elements of burnout. Maddie stated:

(...)

unfortunately, we've had sickness absence and recently we've got a couple of members of staff who are off on sick leave at the moment and they're saying it's due to work stress. (Maddie)

Connie corroborated this: “it’s so important carers understand trauma but carers change so often, it’s really hard to keep on top of it. It’s like starting from scratch every time and that is sooo draining.” Connie identified the problems with high turnover of care staff when trying to create trauma-informed links between NHS and third sector services. Her use of the word “draining” suggests a feeling of mental and physical exhaustion that makes her feel depleted. The phrase “it’s really hard” further suggests that it is emotionally exhausting for her and conveys how challenging she finds this part of her job. Tara echo’s some of Connie’s experience stating:

“I don’t think we do enough self-care. I think this job can lead to burnout and you know, there’s a tendency just to sometimes firefight and keep on going but then there becomes a point where you have to put your hands up and say I’m struggling.”(Connie)

The phrase “firefight” is suggestive of a continual feeling that quick unplanned reactive action is required, and this becomes overwhelming. It also suggests some determination is needed to get through these challenges each day and may be her method of survival. This sense of continuing to keep on going is something Mel has also experienced: “there are times you go home and think I just want to burry myself in the duvet and not get up but you just get up and do it all again the next day”. This provides a sense of wanting and perhaps needing to have a break but showing up regardless. This idea of survival is also endorsed by Linzi who stated: “Trauma-informed care is not always the priority when you’re just trying to survive the day with an insufficient amount of staff”. Linzi’s choice of the word “survive” suggests that she is feeling the strain of her job and it is perhaps at a point where she is feeling a lack of fulfilment in her role. Linzi’s reflection also puts forward
the idea of trauma-informed care being a choice “it’s not always the priority”. It conveys an absence of consistency with this sort of approach. This is corroborated by Sue when she alluded: “Well they have bigger fish to fry at the moment as they’re struggling to recruit.” Signifying that services do not prioritise trauma-informed care when there are other factors that take precedence; specifically staffing concerns.

Overall, this theme demonstrates the burden that staff feel whilst working with this population. They express pressures they face due to the systemic nature of the work, specifically when trying to create positive relationships with family members. They mitigate many of these pressures by using informal support in the form of their colleagues. They experience their peer relationships as invaluable in helping them carry the emotional and psychological toll of the job. Yet, the reliance on informal supports may contribute to burnout as everyone is struggling to get by and informal supports may add to the pressure they already feel. The connections between the themes can be seen in Figure 4.

**Figure 4**

*Mapping of qualitative themes*
Discussion

This study set out to explore trauma-informed care in an intellectual disability service by inviting 11 members of a multidisciplinary team to share their experience. All the stories they shared were personal to them and various similarities were identified across participants experiences. These commonalities were pulled together to produce group experiential themes. 3 group experiential themes were identified: Change Over Time: A Sense of Awareness and Understanding; Thinking Outside the Box and Carrying the Burden. An interpretation of these themes along with the practical implications is outlined followed by the strengths of this research project. Lastly, limitations of this research along with how future research could address these limitations has been identified.

Findings and implications

Various patterns emerged from the data, some consistent with existing literature and some new insights. Participants described a growing awareness and knowledge of trauma within the intellectual disability population. There was a common feeling that older workers may be less likely to acknowledge trauma in the population as opposed to younger workers. A reason for this may be their previous historical segregation from society and so not many individuals with an intellectual disability would be seeking services (Houck & Dracobly, 2022). Thus, professionals were historically less likely to think about trauma in this population. These findings are in line with research that found a barrier to implementation of trauma-informed care in intellectual disability populations was individuals being ‘stuck in their ways’ (Kessler et al, 2023). Yet other research suggests that professionals with more experience were more able to identify behaviour as a possible indicator of trauma, than those professionals with less experience (McNally et al., 2022).

Nevertheless, this raises important implications for practice. It suggests the importance of promoting awareness and understanding of trauma at all levels of experience or length of service. Identifying that someone has a trauma history at the earliest opportunity will encourage staff to engage with individuals in a more trauma-informed way. The ability to identify and assess trauma in individuals is an important initial step in offering trauma-informed care (Reeves, 2015). One method of achieving this is by screening for trauma. Formal assessment tools that could be utilised routinely in clinical practice are: Impact of Events Scale-Intellectual Disabilities (Hall et al., 2014); Bangor Life Events Scale for Intellectual Disabilities (Wigham et al., 2014) and Lancaster and Northgate Trauma Scale (Wigham et al., 2011). There are some opponents to upfront trauma screening who suggest that it removes the choice of individuals sharing this sensitive information with you (Reeves, 2015). However, the routine use of trauma measures would help bolster the
knowledge and awareness that staff have, reducing the risk of misdiagnosis and potential re-traumatisation. It is important to consider that if organisations begin to screen for trauma, a pathway of appropriate response needs to also be identified (McNally et al, 2023). This may include having a pathway for referral to trauma-focused therapy and supporting staff to respond appropriately to trauma disclosures.

Participants also described a constant need to ‘think outside the box’ when working with such a unique population. They described that prescriptive, standardised training and resources do not feel sufficient, so they regularly adapt resources and training to better suit their clients. Participants expressed a lack of guidance in achieving this suitability. This is in line with other research that showed there was a lack of training in trauma-informed care for this population (Schoech, 2017). It is commonly seen that intellectual disability services adapt training to suit their specific population with little to no evidential backup on its effectiveness in this adapted form. A difficulty with this, when considering trauma-informed care, is that for services to deliver effective trauma-informed care, staff members need a level of guidance and appropriate training to allow them to foster a safe environment (McNally et al, 2023). Training in trauma-informed care is the only undisputed recommendation for its implementation in organisations (Branson et al., 2017).

This has important implications for practice. Trauma can be mitigated against by creating good staff training and support (Colins & Murphy, 2022). Therefore, services could consider how training and guidance could be used to reduce the risk of re-traumatisation as this is a key principle in organisations delivering trauma-informed care. Furthermore, a digital staff training platform that was specific to intellectual disability services was created by Keesler and colleagues. (Keesler et al., 2023). It may be useful for services to incorporate this into its mandatory training plan to encourage the continued development of individuals skills and knowledge. Keesler found that implementing the digital training increased staff confidence and knowledge (Keesler, 2023). Thus, this would allow services to achieve a balance of staff empowerment and appropriate guidance to provide the most effective trauma-informed care. and NHS organisations should aim to implement something similar to this.

Participants described the importance of the relationships they have with families of individuals with an intellectual disability. They expressed a hardship in maintaining these positive relationships when families have had previous negative interactions with services. These finding suggests that participants are trying to be collaborative and build trust with families, which are key principles underlying effective trauma-informed care (Harris & Fallot, 2001). They expressed the strain that these relationships put on them day-to-day in an already busy working environment. Participants spoke of using informal measures of support to mitigate some of the emotional and psychological toll of the job. Participants described a personal responsibility to reach out to their colleagues when they are struggling and the invaluable peer support they receive. This is in line with previous research that found a ‘bottom up’ approach has been shown to be more effective for implementing
trauma-informed care than a ‘top down’ approach (West et al., 2014). However, other research suggests that clear boundaries and policies are vital for increasing staff understanding and ensuring safe and effective practice (McNally et al., 2022). Furthermore, burnout has been associated with a lack of structure and guidance and there are higher rates of burnout in mental healthcare than in other healthcare settings (Johnson et al., 2015). This is congruent with the findings that burnout is an element that poses a difficulty in the service. It is perhaps somewhat predictable that if individuals are sacrificing time and energy to be there for their colleagues, without formal support structures in place, that they will ultimately feel the emotional and psychological toll. Previous research found that staff are unlikely to recognise or apply principles of trauma-informed care to themselves and instead they dedicate their thoughts of the effects of the individuals or their colleagues (Keesler et al., 2023). Furthermore, professionals who work in human services have an increased likelihood of Adverse Childhood Experiences (ACE’s) (Esaki & Larkin-Holloway, 2013).

This has important implications for clinical practice. It suggests that organisations should take responsibility to encourage the continued use of informal supports and peer relationships but also to embed more formal structures of support such as structured debriefs, regular team meetings and reflective practice opportunities. Governing the support staff receive will help reduce the personal responsibility that staff feel to support each other and thus may reduce the rate of burnout. McNally and colleagues (2023) reported the benefits of promoting staff wellbeing and resilience by recognising and building on staff’s strengths and support systems (McNally et al, 2023). Thus, supporting staff wellbeing is key to build a trauma-informed culture, where all staff feel valued and supported.

**Strengths**

The current study has multiple strengths. Firstly, a sample size of 11 participants is small enough for the researcher to become familiar with the intricate details of each participants experiences, yet large enough to gain insightful information and provide a deep understanding of the current context of trauma-informed care in the service. The core philosophy of IPA is subjectivity and capturing individuals lived experiences and the current study gives unique insights into how the participants have experienced trauma-informed care in the intellectual disability service. Additionally, the current study utilised a semi-structured interview approach whereby the researcher had an interview schedule but was also led by participants’ responses. This enabled rich data collection. Semi structured interviews are deemed ‘gold standard’ in qualitative data collection (Haines-Saah & Oliffe, 2012). Furthermore, the author spent time practicing their interviewing skills to ensure high quality data was collected. Poor interviewing skills can limit what can be achieved analytically (Smith et al., 2022).
Another strength of the current study is its demonstration of rigour. An example transcript analysis is shown in Appendix L to show transparency in the analytical process. This transparency is seen as a marker of high quality in IPA studies (Smith et al., 2022). Lastly, while there was a degree of homogeneity, participants are from different professions and have different training and clinical experience, this allowed for a broad perspective of trauma-informed care within the service. Furthermore, the interviews allowed space for members of the team to reflect on their experiences of trauma-informed care. The insights gained from exploring their experiences may help them consider gaps in communication, knowledge and understanding, ultimately fostering a space for personal reflection which is beneficial for professional and service development.

Limitations and future research

A central limitation is the lack of descriptive participant characteristics. It would have been helpful to gain more information including age and number of years working in intellectual disability services. This would give the researcher more awareness of a participant’s journey allowing a deeper interpretation of the findings. This would have allowed the results to be placed more in context of the participants specific, unique experience. Future research could include a pre-interview questionnaire that would gather beneficial information about the participants, allowing the researcher to determine that there is a representative sample. This would allow more confidence that any divergence or convergence in subjective experiences are not due solely to demographic factors.

Additionally, it may also be difficult to establish objectivity in IPA research due to the focus on subjective experiences. Although methods of reflexivity were in place including a reflective journal, to reduce research bias, there is still the risk that the researchers own biases may unintentionally influence the interpretation of the participants experiences. This subjectivity could impact the validity and reliability of the studies findings. Future research could include a mixed methods study collecting quantitative and qualitative data at two time points. Outcome measures measuring individuals’ knowledge and awareness of trauma pre and post implementation would help gain an understanding of the impact of implementing trauma-informed care principles within an organisation. This would enhance the validity of the research as different research tools are being utilised and furthermore could help reduce research bias which in turn may increase objectivity.

Furthermore, the current study focused on the experience of staff members from one NHS Healthboard. It is worth considering whether similar themes would arise from a broader recruitment of participants. Future research could recruit from intellectual disability services throughout Scotland. This would allow for a wider interpretation of the current state of trauma-informed care in disability services. This is relevant as one of the governments national drivers is encouraging trauma-informed care in all healthcare settings in Scotland (NES,
Furthermore, future research could include the voice of individuals with an intellectual disability. A key trauma informed principle is to give individuals choice and to work collaboratively. Thus, this research would allow for those with an intellectual disability’s experience of services to be accounted for and this may reduce the likelihood of unintended re-traumatisation by services.

Conclusion

The current study explored a multidisciplinary team’s experience of trauma-informed care within an NHS intellectual disability service. The findings produced multiple themes. Firstly, an increased awareness of trauma in this population over time (Theme 1: Change over Time). Secondly, the uniqueness of the population and therefore the need to adapt communication, resources and training (Theme 2: Thinking Outside the Box). Finally, the challenges associated with the engagement with family members of those with an ID, the importance of informal support measures to help individuals cope and paired with this the lack of formal support structures resulting in high rates of burnout (Theme 3: Carrying the Burden). These findings, along with existing research, produced important clinical implications including the importance of screening for trauma using routine outcome measures, balancing giving staff appropriate guidance whilst respecting autonomy to help them feel empowered but supported. Lastly placing focus on staff wellbeing and services should put more structured measures of support in place. Limitations of the study include the lack of participant descriptive characteristics and its limitation to one Healthboard in Scotland. Future research into the implementation of trauma-informed care in intellectual disability services could focus on collecting both qualitative and quantitative data at different timepoints to determine the effectiveness of techniques/principles put in place by a service.
Empirical Project References


JARID Author Guidelines

1. SUBMISSION
Authors should kindly note that submission implies that the content has not been published or submitted for publication elsewhere except as a brief abstract in the proceedings of a scientific meeting or symposium. Once the submission materials have been prepared in accordance with the Author Guidelines, new submissions should be made via the Research Exchange submission portal: https://wiley.atyponrex.com/journal/JAR. Should your manuscript proceed to the revision stage, you will be directed to make your revisions via the same submission portal. You may check the status of your submission at any time by logging in to submission.wiley.com and clicking the "My Submissions" button. For technical help with the submission system, please review our FAQs or contact submissionhelp@wiley.com.

Wiley Publishing Networks
This journal participates in the Wiley Special Education publishing network and the Wiley Developmental Science Publishing Network. This exciting collaboration amongst our Special Education and Developmental journals simplifies and speeds up the publication process, helping authors find the right home for their research. At the Editors' judgement, suitable papers not accepted by one journal may be recommended for referral to another journal(s) in the network. Authors decide whether to accept the referral, with the option to transfer their paper with or without revisions. Once the referral is accepted, submission happens automatically, along with any previous reviewer reports, thereby relieving pressure on the peer review process. While a transfer does not guarantee acceptance, it is more likely to lead to a successful outcome for authors by helping them to find a route to publication quickly and easily.

2. AIMS AND SCOPE
JARID is an international, peer-reviewed journal which draws together findings derived from original applied research in intellectual disabilities. The journal is an important forum for the dissemination of ideas to promote valued lifestyles for people with intellectual disabilities. It reports on research from the UK and overseas by authors from all relevant professional disciplines. It is aimed at an international, multi-disciplinary readership. In order for a paper to be considered for publication, it must be about people with intellectual disabilities. Manuscripts which focus upon autism will be considered only when the focus is also upon intellectual disabilities. Papers which focus upon autism and exclude people with intellectual disabilities will not be considered. The topics it covers include community living, quality of life, challenging behaviour, communication, sexuality, medication, ageing, supported employment, family issues, mental health, physical health, autism, economic issues, social networks, staff stress, staff training, epidemiology and service provision. Theoretical papers are also considered provided the implications for therapeutic action or enhancing quality of life are clear. Both quantitative and qualitative methodologies are welcomed. All original and review articles continue to undergo a rigorous, peer-refereeing process.

3. MANUSCRIPT CATEGORIES AND REQUIREMENTS
Original Articles, including Clinical Trials (see guidance within section 5), Review Articles and Brief Reports are accepted by the Journal. Theoretical Papers are also considered, provided the implications for therapeutic action or enhancing quality of life are clear. Both quantitative and qualitative methodologies are welcomed. Articles are accepted for publication only at the discretion of the Editor. Authors who are submitting original articles where qualitative methods have been used must ensure that their choice of method is well justified and issues relating to methodological rigor are effectively addressed.

Articles and Theoretical Papers should not exceed 6000 words;
Review Articles should not exceed 7000 words;
Brief Reports should not exceed 2000 words.
All word limits are inclusive of the abstract. References, Words in Tables, Captions/Legends, Figure and Figure captions/legends are excluded from the word limits.

Please note that papers submitted for Special Issues should also not exceed 6000 words.
4. PREPARING THE SUBMISSION

Use of Language

The language used to describe disability differs across countries, cultures and disciplinary fields, and continues to evolve. All manuscripts submitted to JARID must use language that promotes the value of all people as full members of our shared society. Pejorative language inclusive of euphemisms must not be used. For JARID this includes the use of older language that has been used to describe people with intellectual disabilities such as “retarded”, ”special needs”, ”disease”, “handicapped”, or “mentally handicapped”. Using any terms which are offensive, or patronising may lead to rejection of your submitted manuscript.

JARID recommends using person-first and/or identity-first language thoughtfully and appropriately. For example, the language used to describe both people with intellectual disabilities and autistic people has evolved based on recent advocacy efforts. When referring to people with autism, it is acceptable to use either identity-first language (e.g., “autistic people”) or person-first language (e.g., people with autism”), while identity-first language is not used to describe people with intellectual disabilities, where person-first language is preferred. Thus, people with intellectual disabilities should be referred to as people with intellectual disabilities.

We have consulted with over 40 self-advocates through Learning Disability England which included the North West Self-Advocacy Group, as well as Self-Advocacy Together and asked them what language we should use when writing about people with intellectual disabilities. People with intellectual disabilities said that they do not like to be referred to by acronyms or abbreviations. Authors must therefore not use an abbreviation to describe intellectual disabilities such as “ID” or “LD”. Instead, use person-first language such as children, teenagers, adults, or people with intellectual disabilities, avoiding acronyms or abbreviations. The terms “learning disabilities” and “learning difficulties”, though used in some countries to refer to people with intellectual disabilities, can cause confusion among readers. These terms are not used by the journal to refer to people with intellectual disabilities. Authors must only use the term “learning disabilities or difficulties” where this refers to a specific learning disability/disorder – such as a specific learning difficulty in reading, written expression or mathematics. If “learning disabilities” or “learning difficulties” are used, authors must not use an abbreviation.

Free Format Submission

JARID now offers Free Format submission for a simplified and streamlined submission process. Before you submit, you will need:

A Cover Letter
Your manuscript: this should be an editable file including text, figures, and tables, or separate files – whichever you prefer. All required sections should be contained in your manuscript, including titles, keywords, abstract, lay summary, introduction, methods, results, discussion/conclusions and acknowledgements. Figures and tables should have legends. Figures should be uploaded in the highest resolution possible. References may be submitted in any style or format, as long as it is consistent throughout the manuscript. Supporting information should be submitted in separate files. Click here for Wiley's FAQs on supporting/supplemental information.

Note: if data, scripts, or other artefacts used to generate the analyses presented in the paper are available via a publicly available data repository, authors should include a reference to the location of the material within their paper. An ORCID ID, freely available at https://orcid.org (Why is this important? Your article, if accepted and published, will be attached to your ORCID profile. Institutions and funders are increasingly requiring authors to have ORCID IDs.)

The title page of the manuscript, including:
Your co-author details, including affiliation and email address. (Why is this important? We need to keep all co-authors informed of the outcome of the peer review process.)

Statements relating to our ethics and integrity policies, which may include any of the following (Why are these important? We need to uphold rigorous ethical standards for the research we consider for publication):

data availability statement
funding statement
conflict of interest disclosure
ethics approval statement
patient consent statement
permission to reproduce material from other sources
clinical trial registration
JARID has a double-anonymized peer review process so please ensure that all identifying information such as author names and affiliations, acknowledgements or explicit mentions of author institution in the text are on a separate page.

Abstract
All papers should have a structured abstract (maximum 150 words) as follows: Background, Method, Results, and Conclusions. The abstract should provide an outline of the research questions, the design, essential findings and main conclusions of the study. We kindly request that authors place the abstract and title at the beginning of the main manuscript document.

Lay Summary
Please provide 3 or 4 bullet points summarizing the main finding of your work, the impact of it for people with intellectual disabilities and for the research community.

Authorship
On initial submission, the submitting author will be prompted to provide the email address and country for all contributing authors.

The Research Exchange submission system will extract listed affiliations from the manuscript and then ask the submitting author to verify each author’s affiliation institution(s). Authors are encouraged to include the complete affiliation addresses in the manuscript (Institution Name, Country, Department Name, Institution City, and Post Code). When verifying their institution, authors will also be asked to locate their base institution only (not necessarily the department or school).

Please refer to the journal’s authorship policy in the Editorial Policies and Ethical Considerations section for details on eligibility for author listing.

Acknowledgments
Contributions from anyone who does not meet the criteria for authorship should be listed, with permission from the contributor, in an Acknowledgments section. Financial and material support should also be mentioned. Thanks to anonymous reviewers are not appropriate.

Conflict of Interest Statement
Authors will be asked to provide a conflict of interest statement during the submission process. For details on what to include in this section, see the section ‘Conflict of Interest’ in the Editorial Policies and Ethical Considerations section below. Submitting authors should ensure they liaise with all co-authors to confirm agreement with the final statement.

 Appendix B: Prospero Protocol

PROSPERO International prospective register of systematic reviews
The effectiveness of group mindfulness interventions for individuals with an intellectual disability: a systematic review

Citation

Review question
How effective is group mindfulness interventions for individuals with an intellectual disability?

Searches
A systematic search of the following databases: PsycINFO, MEDLINE, Web of Science, Scopus, CINAHL, the Cochrane Library, EMBASE, ERIC via ProQuest. Previous systematic reviews in this subject area were also hand searched. No data restrictions were put on searches.

Additional search strategy information can be found in the attached PDF document (link provided below).

Types of study to be included
Quantitative studies were included in this search. Studies that included pre and post outcomes measures. Studies that deliver some form of mindfulness intervention by qualified staff.

Exclusion criteria: studies that have no outcome data.

Condition or domain being studied
The effectiveness of mindfulness interventions on individuals with an Intellectual Disability.
Participants/population
Due to the minimal research in this area no age restrictions were placed on this search. Studies including child and adolescents and adults were included.
Inclusion criteria: Participants will have a borderline/mild/moderate or severe intellectual disability. Exclusion criteria: Participants with other developmental disabilities without an intellectual disability.

Intervention(s), exposure(s)
This review will cover any form of mindfulness intervention that includes the main areas of mindful breathing or body awareness or mindful movement. Interventions such as Mindfulness based stress reduction, soles of the feet mindfulness course and other forms of mindfulness training will be included. Interventions will be delivered in a group format by qualified staff.

Comparator(s)/control
Studies that have a wait list control or no intervention control studies will be considered. However, studies that do not include a control will not be excluded.

Context
As the anticipated number of studies is small no limitations on context of the study will be put in place. The review will include all studies that meet intervention and participant criteria regardless of where it was delivered e.g. inpatient hospital setting or community setting.

Main outcome(s)
The effects of intervention in improving any psychological factors such as anxiety, depression, quality of sleep or the effects on behavioural indicators such as aggressive behaviour. This will be determined by the change in outcomes scores from pre to post intervention.

Measures of effect
Studies will contain at least two outcome measures. Pre and post intervention.

Additional outcome(s)
None.

Measures of effect
Not applicable.

Data extraction (selection and coding) [1 change]
Articles will be fully read and inclusion and exclusion criteria applied to determine eligible studies. Once eligible studies have been picked based on inclusion and exclusion criteria, data will then be extracted from the studies. There will be one main researcher involved. To reduce subjective my supervisor will conduct a quality assessment using an AMSTAR tool to assess the quality of the review. All information relevant to the research question 'how effective is mindfulness based interventions for individuals with an Intellectual Disability' will be extracted. Descriptive information will be extracted such as whether the study participants were inpatient or community patient, where the mindfulness group took place, components of mindfulness used in intervention, how the diagnosis of intellectual disability has been obtained. Outcome information will also be extracted such as outcome measures used (and validity and reliability of these methods), control groups and statistical methods used and results of study. Other information that will likely be extracted is title of study, authors, hypothesis and key references. A PICO mnemonic form will be used for data extraction to keep the extraction of data consistent across studies and help avoid missing relevant study information. As data extraction can be error-prone, formal guidelines for this will be followed. For example PRISMA reporting guidelines for systematic reviews will be followed. Results will likely be systematically entered into a database and then presented in a table in the final report. Graphs may also be used to support information sharing. A potential problem for this systematic review is that multiple outcome measures exist and thus studies may report outcomes in different ways. This may mean that a meta-analysis is not feasible. If this does occur and a decision is made not to do a meta-analysis then this justification will be documented in the final review.

Risk of bias (quality) assessment
Depending on the design of the included studies a quality assessment tool will be picked to best suit the study designs included. Quality assessment tools that may be used are Health Technology Assessment (HTA) report, Critical Appraisal Skills Programme (CASP). Any others that the researcher comes across will also be considered.

Items that will be checked for in studies are Randomisation (allocation bias), comparability (confounding affect), Eligibility (selection bias), blinding (detection bias), withdrawals (attrition bias) and outcomes (outcome reporting bias).

A table of results for the quality assessment will be displayed.

Strategy for data synthesis [1 change]
The outcomes for each study will likely be synthesised. This will likely include ordinal data that falls in mild, moderate or severe categories for both before and after the mindfulness intervention. Depending on how much data this produces it will either be analysed as if it were a continuous outcome (if numerous categories exist) or the categories will be grouped together and treated as a binary outcome. Summary statics (relative risk, odds ratio risk difference) will be used to estimate treatment effect. This will tell us the direction and size of treatment effect. For example, the relative risk of being in a mindfulness group and experiencing mental health difficulties relative to those in control groups (if controls have been used). The odds ratio will help determine the reduction in odds for patients in the treatment group experiencing
severe mental health difficulties versus those in a control group. Confidence intervals will also likely be reported alongside the summary statistics to determine preciseness of treatment estimates. This strategy will be developed once the content of included studies is known. For example if assumption of homogeneity between studies is satisfied (by carrying out a subgroup analysis) then a meta-analysis will be conducted. This will depend on the four main criteria between studies; similar in patients used, same interventions and comparators, same outcomes and results of the RCTs should describe similar effects. If studies are of varying quality then a sensitivity analysis will be performed. For example, removing low quality results and rerunning the meta-analysis. This will help with robustness. The main difficulty I think will be found with different outcomes being reported as different outcome measures may be used. If a meta-analysis is not conducted then a formal textual narrative synthesis of the data is likely to be presented. This will include a combination of different evidence types. It will include narrative summaries of included studies such as population characteristics, design, methods and findings. These will be reported in a standardised way so that commonalities between studies can be identified.

**Analysis of subgroups or subsets**

None planned.

**Contact details for further information**

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**Organisational affiliation of the review**

The University of Edinburgh

**Review team members and their organisational affiliations**

Miss Sarah Gardner. Edinburgh University  
Dr Rachel Happer. Edinburgh University

**Type and method of review [1 change]**

Intervention, Meta-analysis, Narrative synthesis, Systematic review

**Anticipated or actual start date**

01 December 2022

**Anticipated completion date**

01 January 2024

**Funding sources/sponsors**

Edinburgh University (project reference CLPS264)

**Conflicts of interest Language**

English

**Country**

Scotland

**Stage of review**

Review Ongoing

**Subject index terms status**

Subject indexing assigned by CRD

**Subject index terms**

Humans; Intellectual Disability; Mindfulness

**Date of registration in PROSPERO**

14 November 2022

**Date of first submission**

06 November 2022

**Stage of review at time of this submission**

Stage

Preliminary searches

Piloting of the study selection process

Formal screening of search results against eligibility criteria Data extraction

Risk of bias (quality) assessment

Data analysis

Started Completed

Yes No No No No No No No No

The record owner confirms that the information they have supplied for this submission is accurate and complete and they understand that deliberate provision of inaccurate information or omission of data may be construed as scientific misconduct. The record owner confirms that they will update the status of the review when it is completed and will add publication details in due course.

**Versions**

14 November 2022
Appendix C: The Effective Public Healthcare Practice Project (EPHPP) Quality Assessment

QUALITY ASSESSMENT TOOL FOR QUANTITATIVE STUDIES

COMPONENT RATINGS

A) SELECTION BIAS

(01) Are the individuals selected to participate in the study likely to be representative of the target population?

1. Very likely
2. Somewhat likely
3. Not likely
4. Can't tell

(02) What percentage of selected individuals agreed to participate?

1. 80 - 100% agreement
2. 60 - 79% agreement
3. less than 60% agreement
4. Not applicable
5. Can't tell

<table>
<thead>
<tr>
<th>RATE THIS SECTION</th>
<th>STRONG</th>
<th>MODERATE</th>
<th>WEAK</th>
</tr>
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<tbody>
<tr>
<td>See dictionary</td>
<td>1</td>
<td>2</td>
<td>3</td>
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B) STUDY DESIGN

Indicate the study design

1. Randomized controlled trial
2. Controlled clinical trial
3. Cohort analytic (two group pre + post)
4. Case-control
5. Cohort (one group pre + post, before and after)
6. Interrupted time series
7. Other specify
8. Can't tell

Was the study described as randomized? If NO, go to Component C.

No   Yes

If Yes, was the method of randomization described? (See dictionary)

No   Yes

If Yes, was the method appropriate? (See dictionary)

No   Yes

<table>
<thead>
<tr>
<th>RATE THIS SECTION</th>
<th>STRONG</th>
<th>MODERATE</th>
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<tbody>
<tr>
<td>See dictionary</td>
<td>1</td>
<td>2</td>
<td>3</td>
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</table>
C)  **CONF Founders**

(Q1)  Were there important differences between groups prior to the intervention?

1 Yes
2 No
3 Can't tell

The following are examples of confounders:

1 Race
2 Sex
3 Marital status/family
4 Age
5 SES (income or class)
6 Education
7 Health status
8 Pre-intervention score on outcome measure

(Q2)  If yes, indicate the percentage of relevant confounders that were controlled (either in the design (e.g. stratification, matching) or analysis)?

1 90% - 100% (most)
2 60% - 90% (some)
3 Less than 60% (few or none)
4 Can't tell

**RATE THIS SECTION** | STRONG | MODERATE | WEAK |
---|---|---|---|
See dictionary | 1 | 2 | 3 |

D)  **BLINDING**

(Q1)  Was (were) the outcome assessor(s) aware of the intervention or exposure status of participants?

1 Yes
2 No
3 Can't tell

(Q2)  Were the study participants aware of the research question?

1 Yes
2 No
3 Can't tell

**RATE THIS SECTION** | STRONG | MODERATE | WEAK |
---|---|---|---|
See dictionary | 1 | 2 | 3 |

E)  **DATA COLLECTION METHODS**

(Q1)  Were data collection tools shown to be valid?

1 Yes
2 No
3 Can't tell

(Q2)  Were data collection tools shown to be reliable?

1 Yes
2 No
3 Can't tell

**RATE THIS SECTION** | STRONG | MODERATE | WEAK |
---|---|---|---|
See dictionary | 1 | 2 | 3 |
F) WITHDRAWALS AND DROP-OUTS

(Q1) Were withdrawals and drop-outs reported in terms of numbers and/or reasons per group?
   1. Yes
   2. No
   3. Can't tell
   4. Not Applicable (i.e. one time surveys or interviews)

(Q2) Indicate the percentage of participants completing the study. (If the percentage differs by groups, record the lowest).
   1. 80% - 100%
   2. 60% - 79%
   3. less than 60%
   4. Can't tell
   5. Not Applicable (i.e. Retrospective case-control)

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<tr>
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<td>2</td>
<td>3</td>
<td>Not Applicable</td>
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</table>

G) INTERVENTION INTEGRITY

(Q1) What percentage of participants received the allocated intervention or exposure of interest?
   1. 80% - 100%
   2. 60% - 79%
   3. less than 60%
   4. Can't tell

(Q2) Was the consistency of the intervention measured?
   1. Yes
   2. No
   3. Can't tell

(Q3) Is it likely that subjects received an unintended intervention (contamination or co-intervention) that may influence the results?
   4. Yes
   5. No
   6. Can't tell

H) ANALYSES

(Q1) Indicate the unit of allocation (circle one)
   community organization/institution practice/office individual

(Q2) Indicate the unit of analysis (circle one)
   community organization/institution practice/office individual

(Q3) Are the statistical methods appropriate for the study design?
   1. Yes
   2. No
   3. Can't tell

(Q4) Is the analysis performed by intervention allocation status (i.e. intention to treat) rather than the actual intervention received?
   1. Yes
   2. No
   3. Can't tell
GLOBAL RATING

COMPONENT RATINGS
Please transcribe the information from the gray boxes on pages 1-4 onto this page. See dictionary on how to rate this section.

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</table>

GLOBAL RATING FOR THIS PAPER (circle one):

1 STRONG (no WEAK ratings)
2 MODERATE (one WEAK rating)
3 WEAK (two or more WEAK ratings)

With both reviewers discussing the ratings:

Is there a discrepancy between the two reviewers with respect to the component (A-F) ratings?

No
Yes

If yes, indicate the reason for the discrepancy

1 Oversight
2 Differences in interpretation of criteria
3 Differences in interpretation of study

Final decision of both reviewers (circle one):

1 STRONG
2 MODERATE
3 WEAK
Appendix D: HISS Ethical Approval Letter

Hi Sarah and Team

Thank you for your revised application. Based on your responses the application meets the standards for favourable opinion from the Clinical Psychology, University of Edinburgh Ethics Committee. The signed ethical response sheet/application is attached – please note that this is fine to attach to your dissertation etc. If you require a formal letter of ethics approval (this is only required if you are approaching third parties, NGOs etc) then please contact the new ethics mailbox (ethics.hiss@ed.ac.uk) requesting this and a formal letter of approval will follow in due course. If you need to make any changes to the study, you should return your amendment to the new ethics email - ethics.hiss@ed.ac.uk, cc'd above with the changes clearly noted in the relevant section of the form.

Good luck with your project.

Appendix E: University of Edinburgh Sponsorship Approval

Sponsorship amendments - CLPS264 R3 23 Nov 2022

You forwarded this message on Mon 09/01/2023 16:07

CB
To: Sarah Gardner
Cc: Charlotte Smith

Hi Sarah

Thanks for making these final updates.

We can confirm that your study (A Qualitative analysis of a Multi-Disciplinary Teams Experience of Implementing Trauma Informed Care in an Intellectual Disability Service) has been reviewed and is supported by Sponsorship. Please could you now submit to HISS ethics (ethics.hiss@ed.ac.uk) and include this email as part of your submission. Once you receive HISS favourable opinion, please forward to us and we will send you instructions on submitting to R&D via IRAS.

Best wishes, Carol
Appendix F: Local NHS R&D Approval Letter

Ref: EU/TB 09/02/23

09 February 2023

Dr Sarah Gardner (sarahgardner93@imc.com)

Dear Dr Gardner,

**R&D MANAGEMENT APPROVAL – TAYSIDE**

<table>
<thead>
<tr>
<th>Title: A Qualitative analysis of a multi-disciplinary teams' perspective of implementing Trauma Informed Care in an Intellectual Disability Service</th>
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<tbody>
<tr>
<td>Chief Investigator: Dr Sarah Gardner</td>
</tr>
<tr>
<td>Principal Investigator: Dr Sarah Gardner</td>
</tr>
<tr>
<td>Tayside Ref: 2023MH01 NRS Ref: N/A IRAS ID: 317195</td>
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<tr>
<td>REC Ref: N/A</td>
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<tr>
<td>Sponsor: University of Edinburgh</td>
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<tr>
<td>Funder: No external funding</td>
</tr>
<tr>
<td>Tayside Reviewer: Elisabetha Ursuta</td>
</tr>
</tbody>
</table>

Many thanks for your application to carry out the above project here in NHS Tayside. I am pleased to confirm that the project documentation (as outlined below) has been reviewed, registered and Management Approval has been granted for the study to proceed locally in Tayside.

Approval is granted on the following conditions:-

- ALL Research must be carried out in compliance with the UK Policy Framework for Health & Social Care Research, Health & Safety Regulations, GDPR & data protection principles, statutory legislation and in accordance with Good Clinical Practice (GCP).

- All amendments to be notified to TASC R&D Office via the correct amendment pathway. Either direct to the R&D Office or via the Lead Co-ordinating Centre depending on how the study is set up.


- TASC R&D Office to be informed of change in Principal Investigator, Chief Investigator or any additional research personnel locally. Tay.tasc@nhs.scot

Version 14.0 – 04/11/2021 – 1 –
- Notification to TASC R&D Office of any change in funding or an extension to study timelines.

- As well as any obligations to your Sponsor, you are required to notify TASCgovernance@dundee.ac.uk of all serious breaches of GCP and Serious Unexpected Serious Adverse Reactions (SUSARs) for Hosted Clinical Trials of Investigational Medicinal Products (CTIMPs).

- As custodian of the information collated during this research project you are responsible for ensuring the security of all personal information collected in line with NHS Scotland IT Security Policies, until destruction of this data.

- All Eligible and Extended Review studies will be added to the Scottish Research Database (SReDA). Recruitment figures for Eligible and Extended Review studies must be recorded onto the Scottish Portfolio every month. It is the responsibility of Tayside Health board to ensure recruitment data is being routinely uploaded into SReDA by working closely with study teams across Tayside and gathering this information. For further information on how your study recruitment data will be captured and uploaded, please contact the local Portfolio team at in.tausportfolio@nhs.scol

- Annual reports are required to be submitted to TASC R&D Office with the first report due 12 months from date of issue of this management approval letter and at yearly intervals until completion of the study.

- Notification of early termination within 15 days or End of Trial within 90 days followed by End of Trial Report within 1 year to TASC R&D Office.

- You may be required to assist with and provide information in regard to audit and monitoring of study.

Please note you are required to adhere to the conditions, if not, NHS management approval may be withdrawn for the study.

**Approved Documents**

<table>
<thead>
<tr>
<th>Document</th>
<th>Version</th>
<th>Date</th>
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<tbody>
<tr>
<td>Protocol</td>
<td>1.0</td>
<td>27 October 2022</td>
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<tr>
<td>Patient information Sheet</td>
<td>1.0</td>
<td>27 October 2022</td>
</tr>
<tr>
<td>Consent Form</td>
<td>1.0</td>
<td>27 October 2022</td>
</tr>
<tr>
<td>Invitation e-mail</td>
<td>1.0</td>
<td>27 October 2022</td>
</tr>
<tr>
<td>Debrief sheet – background</td>
<td>1.0</td>
<td>27 October 2022</td>
</tr>
<tr>
<td>Debrief sheet – sources of support</td>
<td>1.0</td>
<td>27 October 2022</td>
</tr>
<tr>
<td>Interview schedule</td>
<td>1.0</td>
<td>27 October 2022</td>
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</table>

May I take this opportunity to wish you every success with your project.

Version 14.0 – 04/11/2021


- 2 -
Appendix G: HISS Ethics Application

School of Health in Social Science Research Ethics Application
The supervisor or primary investigator must complete and sign this form after checking that all relevant sections are completed, and relevant documents are attached. For all undergraduate (UG) and MSc student projects, it is the supervisor’s responsibility to submit this form and all attachments. Please note that failure to do this will result in the application being returned (and not processed) causing your research to be delayed.

<table>
<thead>
<tr>
<th>Supervisor (name and UUN): Rachel Happer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary Investigator (name and UUN): Sarah Gardner, S1114382, B014693</td>
</tr>
<tr>
<td>List of all collaborators (with affiliated institutions in brackets): NHS Tayside</td>
</tr>
<tr>
<td>Student’s programme of study (if applicable): Doctorate in Clinical Psychology</td>
</tr>
<tr>
<td>Project Title: A Qualitative analysis of a multi-disciplinary teams’ perspective of implementing Trauma Informed Care in an Intellectual Disability Service</td>
</tr>
<tr>
<td>Case Number (if known – assigned by Administrator at time of 1st submission):</td>
</tr>
<tr>
<td>Proposed Project Start Date: August 2022</td>
</tr>
</tbody>
</table>

Please indicate whether the primary investigator on this project is staff or student and select your subject area:

- [ ] Staff
- [ ] UG or MSc Student
- [x] DClin Student
- [ ] PhD Student
This is a:

☐ New application for ethical review – first submission
☐ Resubmission following reviewer comments
☐ Resubmission with requested amendments

Has been reviewed by an external ethical board, such as NHS IRAS or a UK HEI (multi-site studies only) with a favourable opinion? Level 1

☐ IRAS (NHS research ethics)   ☐ Other: [Text] Was told to submit university ethics before IRAS approval is sought but an IRAS R&D form will be submitted and a draft for your review has been provided.

Please tick one option that best describes your application:

☐ Collecting or generating new data involving other people: Level 2
☐ Extracting, re-coding and analysing existing data that contains sensitive information (i.e. identifiable information): Level 2
☐ Analysing secondary (archival) data that is routinely collected or is an existing anonymised dataset: Level 1
☐ Collecting new data BUT an external ethical review board (such as NHS IRAS; UK HEI – for multi-site studies; etc) has fully reviewed this project and generated a favourable opinion: Level 1

This application is complete with the following attachments (tick all that apply):

<table>
<thead>
<tr>
<th>Advert/flyer □</th>
<th>Caldicott application stating what data was requested □</th>
<th>Caldicott signed approval □</th>
<th>Consent form/s □</th>
</tr>
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<tbody>
<tr>
<td>Data collection tools (e.g. interview guides) □</td>
<td>Debrief with signposting □</td>
<td>IRAS application □</td>
<td>IRAS opinion letter □</td>
</tr>
<tr>
<td>Participant Information Sheet(s) □</td>
<td>Participant Information Sheet (young person version) □</td>
<td>R&amp;D application □</td>
<td>R&amp;D approval □</td>
</tr>
<tr>
<td>Risk assessment □</td>
<td>Standardised recruitment email □</td>
<td>Sponsorship Letter OR Email to confirm no sponsorship needed / statement explaining why sponsorship is not needed. □</td>
<td></td>
</tr>
</tbody>
</table>

Other attachments (please specify):

To be completed by primary investigator or project supervisor
By signing this front sheet, I confirm that I have prepared and/or reviewed this ethics application and related documents in accordance with ethical guidelines. I also confirm I have checked that all relevant sections of the application form are completed and relevant documents are attached.

Supervisor or/PI Signature: SGardner
Student signature: SGardner
Date: 25.11.22

On completion, this Word document along with the relevant attachments should be submitted to ethics.hiss@ed.ac.uk.

Note: Please note all undergraduate and MSc applications MUST been signed and submitted by the project supervisor.

Contents
LEVEL 1 and 2 – Confidentiality and Handling of Data 114
Section 1: Introduction 114
Section 2: Security-sensitive material 122
Section 3: Copyright 123
Section 4: Good conduct in collaborative research 124
Section 5: Good conduct in publication practice 126
LEVEL 2 ONLY – Participant Risk and Information 127
Section 6: Potential risks to participants and researchers 127
Section 7: Participants and data subjects. 131
Section 8: Participant or data subject information and consent 135
Thank you for your application. The review process has generated the following queries regarding your application. Please address the following items, and provide a note underneath each comment letting us know how you have addressed them:

Reviewer Comments 14/10/22

It's worth noting that this has been submitted as a level 1 however the applicant is collecting new data, therefore this should have been submitted as level 2. This means that half the application has not been completed however two reviewers have still reviewed it.

I have now completed the required areas for level 2. I was given the wrong guidance regarding this.

Ethics application
Q1 –

How are participants being recruited? The researcher will contact individuals via email (an email distribution list for individuals within the learning disabilities team already exists. The research already has access to this and this will be used to contact all potential individuals). A draft email has been attached along with a participant information sheet. Participants who are interested in the study will be asked to respond to the email stating their interest in participating. The researcher will provide extra information about the study if potential participant requests this. If the person expresses an interest in participating in the study, then they will be sent the consent form via email to be completed. An interview date and time convenient to the participant will then be agreed. If interview is in person (at an NHS Tayside location) then the individual can bring the consent form with them to the interview. The researcher will have copies of the consent form available if participant forgets to bring this to the interview. If the interview is agreed to be on MS Teams then the participant will be asked to email the consent form back to the researcher.

What is the inclusion and exclusion criteria? Inclusion criteria- professionals working within any one of the three NHS Tayside Intellectual Disabilities Teams; Professionals with regular direct contact with people an intellectual disability; Professionals who have worked with individuals with an intellectual disability and trauma history. Exclusion criteria- Professionals within Tayside Intellectual Disability Service but that have not had contact with an individual with an intellectual disability (past or present); participants who cannot speak English will be excluded.

Will potential participants be emailed, and a link be within the email that they click on that takes them to participant info sheet and consent or is there another way? The initial recruitment email is drafted below. This email will have the participant information sheet attached. Once participants have expressed an interest in participating in the study, via replying to the email, they will receive a further email with a consent form attached. An interview will then be arranged either in person or via MS Teams. If the interview is in person then the participant can bring the consent form to the interview. If the interview is online then the participant can email the consent form back to the researcher.

Dear colleagues
I am conducting interviews as part of my doctorate research. The interviews will take roughly 60 minutes and can be in person or via MS Teams. The interviews will be informal and the aim of this is to gain an understanding of trauma informed care within the Tayside Learning Disability service. More details of the study can be found in the attached ‘participant information sheet’. If you have any questions regarding the process of participating or about the study in general then please get in touch and I would be happy to provide further information.

If you are interested in participating then please respond to this email and an agreed method of delivery and time of interview will be agreed. I look forward to hearing from you. Sarah Gardner

Need more information about recruitment strategy and the actual steps a participant must do to take part.
Steps for participants 1. Reply to email which includes the participant information sheet saying interested in taking part or require more information. 2. If still interested in participating, they will be sent the consent form via email. 3. Participant will be able to ask questions regarding this study prior to completing consent form. 4. Researcher will contact participants via email to organise a time and date for interview. 5. Participant to send completed consent form back to researcher (via email if online interview or can bring in person if face to face
interview). 7. Interview will take place and last roughly 60 minutes. 8. Interview will be audio recorded. 9.
Participants will be given 1 week to ask for their responses to be removed and not used in study. After this
results will be anonymized and transcribed.

Under participants and procedure in the summary, who will be identifying the potential participants and how?
The researcher will contact individuals via email (an email distribution list for individuals within the learning
disabilities team already exists and this will be used to contact all potential individuals).

Will participants have a time gap (e.g. 24 or 48 hours) between initially agreeing to take part and the interview
taking place so that they have an appropriate cooling off period? Participants will be able to pull out of the
study prior to agreed interview should they change their mind. If they take part in the interview, then decide that
they do not wish their responses to be used then they will also be given 1 week to ask for their responses to be
removed and not used in study. After this, results will be anonymized and transcribed.

Are interviews audio or video recorded or both? Audio recorded.

What is the data storage and retention plan for any non identifiable data generated from the study, such as
transcripts, and how long will any identifiable forms be retained for? Any non-identifiable data will be stored on
the Edinburgh University network server. A folder for this data will be created and documents saved within this.
The lead researcher will be the only person with access to this folder. Remote access to this will be requested
once ethical approval has been obtained. Any identifiable forms e.g. consent forms will be stored electronically
separately to other study documentation, while physical copies of consent forms will subsequently be
destroyed.

Q7 –

need to outline how the audio recordings will be managed in this section. When will they be transcribed, and
audio recordings deleted? Will audio recordings ever be uploaded to the server? Where will these be stored
when transcribed? We recommend using the online server that is supported by the university. Also emails are
identifiable when will emails be deleted? is there any risk that the interviews could raise any issues or concerns
about clinical care or practice? If so, there needs to be a procedure in place for managing this, and this might
need to be reflected in study materials such as the PIS and consent form. How might the identity of participants
(and any clients discussed) be reasonably protected by the researcher? After the interview has taken place
and recording stopped, the recording device will be immediately connected to a secure computer that has
access to the Edinburgh University server and upload of interview will take place immediately. The recording
on the recording device will then be deleted. As soon as this has been transcribed and anonymised the
recording will then be deleted from the network. If the interview takes place in person then the recording device
will be transported to and from the agreed interview location within a lockable briefcase. Once the researcher is
back at the location with access to the Edinburgh University server then the steps above will be followed with
regards to uploading then deleting the audio recording from the device as soon as possible. Audio recordings
will be transcribed as soon as possible and within 1 week of recording. The audio recording on the server will
be deleted after transcription has occurred. Transcriptions will be saved in a secure, password protected, folder
on the Edinburgh University network with only the lead researcher having access to this folder. With regards to
emails. Once an agreed interview time has been scheduled any email exchanges will be deleted. Information
about the person’s name, identifiable number, email address and profession will be stored in a separate,
password protected location on the Edinburgh University Server. Consent forms will also be stored in a
separate password protected folder. This information will be kept on different locations on the Edinburgh
University Server in order to protect the identity of participants. It is unlikely that concerns for clinical care or
practice will be raised due to the nature of the questions being asked. The questions will focus on their
experience of implementing trauma informed care rather than specific aspects of their practice or others
practice. Any non-identifiable data will be retained for 5 years and any identifiable personal data will be stored
for 6-12 months.

Q9 –

it is recommended that data is stored on the secure online server rather than a laptop. This protects against
theft and loss. Remote access will be requested for access to The Edinburgh University Network server and all
data will be stored on this platform.

Q10 –
what happens if someone can’t attend the debrief session? It is standard practice that debriefs are provided. Can a debrief not be emailed to the participant so they have a note of key contacts as well as a reminder of how to obtain a summary of the findings. Also it is good practice to provide participants with an indication of the results of the study, but the researcher might consider producing a more digestible summary of these, rather than providing interested participants with the full thesis. The researcher has now created a debrief form that will be given to participants once they have completed an interview. A copy of this has been attached. Key contacts have been provided on this. All participants will also receive a summary of the results once the project has been completed. They will then be given the opportunity to request a full copy of the thesis should they be interested. They will also be invited to an information evening for discussion about the results.

Q12 – still need to answer this question before skipping to next section.  This question has now been answered. Answer= no.
Q15- is not completed. Please answer yes or no.  This question has now been answered. Answer= no.

PIS
isn’t clear in the PIS how someone will withdraw their participation or their data after they have taken part. For e.g. To withdraw participation at any time you can stop the interview. To withdraw your data you have up until one week after your interview to withdraw your data. After this point your data will be analysed and anonymised. A ‘what if I want to withdraw?’ section has been added to the participant information sheet and an updated version has been attached. This section states: If you do decide to take part you can stop completing the interview anytime, without giving a reason. During the interview, you may simply let the Principal Investigator know that you wish to terminate the interview and your data will be deleted. Please note that after the interview has concluded, interview data will not be able to be withdrawn after 1 week of the interview concluding. After this, such data will be stored securely and used in the research.

It
Need to make it clear when you will be deleting the audio recordings from the audio recorder so participants understand when their recordings will be transcribed. This has now been outlined under the ‘will my taking part be kept confidential’ section in the patient information form. It states that: All the information we collect during the course of the research will be kept confidential and there are strict laws which safeguard your privacy at every stage. Your interview responses will be recorded on an encrypted audio recorder. This audio recording will then be transferred and stored (until transcribed) to a password-protected computer files on secure University of Edinburgh Network server. Once the audio recording has been transferred to the University of Edinburgh secure network it will be deleted form the audio recording device immediately. The researcher will aim to transcribe the recordings within 1 week of the interview.

If its anticipated that interviews might last an hour then should say up to an hour on the PIS. Guidance on how long the interviews may take has now been added to the patient information sheet under section ‘what will happen if I decide to take part’.

Consent
Similar to PIS – suggest that there are two separate statements here about withdrawing participation and withdrawing data.
It’s a good idea to add a statement here about quotations from interviews being used in any research outputs ‘I understand that I can withdraw participation by stopping the interview at any point without any negative repercussions.’
‘I understand that I can withdraw my data by contacting the researcher within one week of my interview. After this point the interview will be transcribed and anonymised.’ These statements have now been added to the consent form and updated version attached.
This needs to outline what the study aims were and provide further reading if the participants are interested. Should also provide the key contacts again (researcher, supervisor, independent contact and complaints) and also remind the participants of how they can obtain a summary of the results. I have now completed and attached two debrief form. One which outlines the study aims, rationale and key readings and another with sources of support and advice on how to obtain a summary of the results.

Signature:

Position: Lecturer in Applied Psychology/Ethics and Integrity Lead

Date: 14/10/22

APPLICANT’S SIGNATURE FOLLOWING REVISIONS – to be completed by applicant

I confirm that I have addressed all of the queries generated during the ethical review process of my application. I have outlined in the box above underneath each comment how each request was addressed and/or provided further clarification.

Supervisor/PI Signature: Sarah Gardner

Student signature:

Date: 12/12/22

CONCLUSION TO ETHICAL REVIEW – to be completed by Ethics Lead

Thank you for providing responses to our comments. Some outstanding questions remain:

Where will the in person interviews take place? Will there be several different locations? Are these locations still within NHS premises? There is mention of carrying consent forms between locations is this in the same building as the applicant? If going to people’s houses etc additional safeguarding may be needed? Or lone worker risk assessment?

Face to face interviews will take place in an NHS Tayside location. Likely within the Learning Disabilities Department, as all potential participants will be part of the Learning Disabilities team. However, any confidential space within an NHS Tayside building may be used. All materials (audio recorder, consent forms) will be carried to and from the chosen NHS location in a lockable briefcase. The researcher will be the only individual with the access code to this briefcase. The researcher will not be going to people’s houses to complete interviews. If an individual is not able to meet at an NHS Tayside location, then an online MS teams interview will be offered. Therefore, no lone worker risk assessment will be needed.

Seems to be a lot of hurdles for participant recruitment i.e. email is sent, person responds, then is sent participant info and consent, person needs to print off consent and bring to interview or (assume scan it) email it back. Then interview is arranged. Is it not easier to include a link to a qualtrics in the email advertising the study? The participant can then click on this link if interested, read the participant info sheet, click to consent
then complete basic demographic data and availability times as well as preference for in person or telephone interview.

I feel that NHS email is a more streamlined way of liaising with potential participants as they will all have regular access to email/printer/scanners and use these as part of their daily routine (participants are NHS employees). I will also need to use email for arranging a times/location of interview with participant anyway as this cannot be done via qualtrics as clinic room availability will not be known until nearer the time of interviews. Therefore, having the recruitment process fully via email may be less confusing for participants than having some information provide via Qualtrics and some via email. The researcher will also have paper consent forms that can be used if the participant attends the face to face interview and has not been able to print off the consent form. This will capture individuals who have forgotten or are not able to access a printer.

Signature:

Position: Lecturer in Applied Psychology/Ethics and Integrity Lead

Date: 11/01/2023

that a favourable opinion has been provided for this project (for example as an attachment to MSc dissertations).

NOTE: Once reviewed please include the page on which this box appears as a formal document demonstrating that favourable opinion has been provided for this project (for example as an attachment to MSc dissertations).
If you are applying for amendments to a previously reviewed and processed project, please use the below form to detail the amendments you wish to make:

<table>
<thead>
<tr>
<th>This section is to be completed for amendments only</th>
</tr>
</thead>
<tbody>
<tr>
<td>AMENDMENT/S: REQUEST FOR APPROVAL – to be completed by applicant</td>
</tr>
</tbody>
</table>

I would like to apply for the following amendments to this previously processed project which had generated a favourable opinion:

Supervisor/PI Signature:

Student signature:

Date:

| CONCLUSION TO ETHICAL REVIEW OF AMENDMENT – to be completed by Ethics Lead |
The requested amendment satisfies the requirements for ethical practice and it has therefore received a favourable opinion.

OR

Additional information is required related to:

Signature:

Position:

Date:

NOTE: Once reviewed please include the page on which this box appears as a formal document demonstrating that favourable opinion has been provided for this project (for example as an attachment to MSc dissertations).
LEVEL 1 and 2 – Confidentiality and Handling of Data
Section 1: Introduction

External Research Ethics Approval:

Does your research project require the approval of any other institution and/or ethics committee, nationally or internationally?

Note: It is each researcher’s responsibility to check whether their project requires Sponsorship, Caldicott Approval, R&D approval, and/or IRAS (see https://www.ed.ac.uk/health/research/ethics/sponsorship-and-governance). The principal investigator is responsible for ensuring compliance with any additional ethical requirements that might apply, and/or for compliance with any additional requirements for review by external bodies.

☐ This research project does not require external ethics approval.
OR

If you require external approval, please state the name of the review body:
☐ IRAS (NHS research ethics) ☐ Local Authority ☐ Other:

____________________

NB: If you require external approval from IRAS/NHS/Caldicott, you must have external approval before submitting your application for School of Health in Social Science Research Ethics approval. You can only submit your application to us once external approval has been obtained, and you must include all documentation including your application to and approval of external approval as an attachment.

If you require approval from a local authority, you must first receive ethics approval from the School of Health in Social Science Research Ethics Committee, before submitting your application to the local authority.

Q1. Project summary

Please provide a brief summary of your proposed study. Do not exceed 1500 words. Our interest is in areas of your methodology where ethical issues may arise so please focus your detail on areas such as recruitment, consent, describing your participants and the nature of their involvement, and data handling.
Study Design
The proposed study is a qualitative, explorative design using semi-structured interviews. The purpose is to gain a richer understanding of an Intellectual Disability team’s experience of implementing Trauma Informed Care. Thus, Interpretative Phenomenological Analysis (IPA) will be utilised as a method of examining the data.

Study Population
Participation in this study will be voluntary. Participants will be professionals working within NHS Tayside’s Intellectual Disabilities Service. They will have an understanding of trauma and have worked with individuals on their caseload that have experienced trauma. The researcher will use purposive sampling to recruit participants.

Inclusion criteria- professionals working within any one of the three NHS Tayside Intellectual Disabilities Teams; Professionals with regular direct contact with people an intellectual disability; Professionals who have worked with individuals with an intellectual disability and trauma history.

Exclusion criteria- Professionals within Tayside Intellectual Disability Service but that have not had contact with an individual with an intellectual disability (past or present); participants who cannot speak English

Procedure and recruitment
The researcher will contact individuals via email (an email distribution list for individuals within the learning disabilities team already exists and this will be used to contact all potential individuals). This email will include a patient information sheet. Participants who are interested in the study will be asked to respond to the email stating their interest in participating. The researcher will provide extra information about the study if potential participant requests this. If participant is interested in participating, then they will be sent the consent form via email to be completed and sent back to the researcher via email. Once a participant has confirmed that they wish to participate in the study, a convenient date and time will be agreed. Participants will be made aware of the procedure of recording and transcribing the data and how this data will be stored. Both implied and explicit consent (via a consent form) will be obtained prior to the interview.

Participants will engage in 1-1 semi structured interviews. These interviews will likely take roughly 1 hour and will be audio recorded so that the researcher can transcribe the data at a later stage. It is hoped that the majority of the interviews will take place in person at an NHS Tayside location, however, participants will also be given the option of MS Teams. MS Teams has been used successfully in data collection during the COVID 19 pandemic. Participants will also be made aware of their right to stop the interview at any time without question.

Participants will be able to pull out of the study prior to agreed interview should they change their mind. If they take part in the interview then decide that they do not wish their responses to be used then they will also be given a week to ask for their responses to be removed and not used in study. After this, results will be anonymized and transcribed.

Steps for a participant to take part
1. Reply to email saying interested to take part.
2. Participant then sent the consent form via email.
3. Participant will be able to ask questions regarding this study prior to completing consent form.
4. Researcher will contact participant via email and organise a time and method of delivery for interview.
5. Send completed consent form back to research via email (if interview is online). Consent forms to be brought to interview if face to face. Researcher will have spare paper copies of consent form if needed.
6. Interview will either be on teams or in person.
7. Interview will take place and last roughly 60 minutes.
8. Interview will be audio recorded.
9. Participants will be given 1 week to ask for their responses to be removed and not used in study. After this results will be anonymised and transcribed.

Data Management

Personal Data
The following personal data will be collected as part of the research: name, profession and email address. This will be stored in a word document in a password protected folder on the remote Edinburgh university server. This is the only identifiable information that will be collected. Consent forms will be emailed to participants in digital format, however, paper copies of the consent form will be available for face-to-face interviews in case the participant forgets to bring it along. The consent form and audio recording device will be transported to and from the interview location in a lockable briefcase. If the interview is agreed to be on MS teams then the participant will be asked to email the consent form back to the researcher. This will be stored in a separate location to transcriptions.

Data Information Flow
After the interview has taken place and recording stopped, the recording device will be immediately connected to a secure computer that has access to the Edinburgh University server and upload of interview will take place immediately. The recording on the recording device will then be deleted. As soon as this has been transcribed and anonymised the recording will then be deleted from the network. If the interview takes place in person then the recording device will be transported to and from the agreed interview location within a lockable briefcase. Once the researcher is back at the location with access to the Edinburgh University server then the steps above will be followed with regards to uploading then deleting the audio recording from the device as soon as possible. Audio recordings will be transcribed as soon as possible and within 1 week of recording. The audio recording on the server will be deleted after transcription has occurred. Transcriptions will be saved in a secure folder on the Edinburgh University network. With regards to emails. Once an agreed interview time has been scheduled emails will be deleted. Information about the person's name, identifiable number, email address and profession will be stored in a separate location on the Edinburgh University Server. Consent forms will also be stored in this folder. This information will be kept on different locations on the Edinburgh University Server in order to protect the identity of participants.
A digital field journal will also be kept throughout this project and any details documented that are deemed important will be added to the data. This will be a paper journal which will be typed onto a Microsoft word document and stored on the Edinburgh university network server in a password protect folder. The lead researcher will be the only person with access to this folder. Remote access to this will be requested once ethical approval has been obtained.

It is unlikely that concerns for clinical care or practice will be raised due to the nature of the questions being asked. The questions will focus on their experience of implementing trauma informed care rather
Data Storage
Any personal data will be physically stored by the research team at NHS Learning Disabilities Dundee, Wedderburn House. The principle investigator will be the only individual with access to the filing cabinet in which the physical data will be stored. The key will be kept in a safe location on this premises. Personal data will be digitally stored by the research team using the Edinburgh University Server. Remote access will be sought for this and this will be accessed via a password protected computer. Folders on the secure network will be set up to keep data. A separate folder in another location on the server will contain the names, professions and email addresses of participants. The primary researcher and the academic supervisor of the project will be the only individuals with access to these files.

Data Retention
Personal data will be stored for 6-12 months. This is good practice guidance from the UoE Research data service and so will be followed. Any non identifiable data will be retained for 5 years.

Disposal of Data
Data will be stored electronically for 5 years once the study has ended. This data will be protected via a password protected computer for the duration and will be stored on Edinburgh University Server. It will be destroyed by shredding confidential paper information and disposing of this via NHS confidential waste. Any electronic information will be deleted from saved locations.

Q2. Will you collect or use NHS data?
☐ Yes ☐ No
If “yes” – what NHS data will you collect or use?
NHS staff will participate in the interviews and their verbal responses will be transcribed and analysed. Analysis will be conducted using Interpretive phenomenological analysis.

Q3. What information about participants/data subjects will you collect and/or use?

Their name, profession and contact details (email address) will be collected along with their verbal responses during interview.

Q4. What training will staff who have access to the data receive on their responsibilities for its safe handling? Have all staff and students who have access completed the mandatory data protection training on the self-enrolment page of Learn?

NHS LearnPro safe information handling completed by primary investigator.
University of Edinburgh self enroll Data protection training completed by primary investigator.
Q5. Will the information include special categories of personal data (health data, data relating to race or ethnicity, to political opinions or religious beliefs, trade union membership, criminal convictions, sexual orientations, genetic data and biometric data)?

☐ Yes  ☐ No

If “yes” – *Explain what safeguards e.g. technical or organisational you have in place; including any detailed protocols if this requires special and/or external processing, storage, and analysis.*

Q6. Please indicate how your research is in the public interest:

☐ Your research is proportionate
☐ Your research is subject to a governance framework
☐ Research Ethics Committee (REC) review (does not have to be a European REC)
☐ Peer review from a funder
☐ Confidentiality Advisory Group (CAG) recommendation for support in England and Wales or support by the Public Benefit and Privacy Panel (PBPP) for Health and Social Care in Scotland
☐ Other
Q7. It is essential that you identify, and list all risks to the privacy of research participants. You will then need to consider the likelihood of the risks actually manifesting and the severity of harm if the risks actually manifest.

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<tr>
<th>Risk</th>
<th>Likelihood of risk manifesting</th>
<th>Severity of harm</th>
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</thead>
<tbody>
<tr>
<td>Identifyable due to data linkage</td>
<td>Remote</td>
<td>Minimal</td>
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<td></td>
<td>Possible</td>
<td>Significant</td>
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<td></td>
<td>Probable</td>
<td>Severe</td>
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<tr>
<td>Identifyable due to low participant numbers</td>
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<td>Identifyable due to geographical location</td>
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<td>Identifyable due to transfer of data</td>
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<tr>
<td>Identifyable due to access of data</td>
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</tr>
</tbody>
</table>

Insert more rows as appropriate

Please use this text box to record any other risks and the likelihood of them occurring, along with the severity of harm. Please also use this when dealing with secondary data.

Failure to recruit sufficient sample size (low likelihood, Low severity of harm): The researcher has connection within the Tayside Learning Disability department and individuals from nursing, psychology, occupational therapy and speech and language have shown interest in participating in the research. Plenty of time will be allowed for cancellations of interviews due to illness/workload and thus interviews will be rescheduled should this occur.

Failure to locate appropriate room for interview (low likelihood, Low severity of harm): The intended participants will all be current NHS workers who likely have regular access to clinic rooms. Participants can also request to do the interview via MS teams if an issue with sourcing an appropriate room does occur.

Loss of data (low likelihood, significant severity of harm)): All research paperwork (consent forms, recording device) will be in a lockable filing cabinet in an office within NHS Tayside Learning Disabilities Department. It will be transported in a lockable briefcase to and from interview location. If interview is taking place digitally then after the interview has taken place and recording stopped, the recording device will be immediately connected to a computer and upload of interview will take place immediately. The recording on the recording device will then be deleted. As soon as this has been transcribed and anonymised the recording will then be deleted from the network. If the interview takes place in person then the recording device will be transported to and from the agreed interview location within a lockable briefcase. Once the researcher is back at the location with access to the Edinburgh University server then the steps above will be followed with regards to uploading then deleting the audio recording from the device. Audio recordings will be transcribed as soon as possible and the audio recording on the server deleted after this. Transcriptions will be saved in a secure folder on the Edinburgh University network. With regards to emails. Once an agreed interview time has been scheduled emails will be deleted. Information about the person’s name, identifiable number, email address and profession will be stored in a separate location to the audio recordings. Consent forms will also be stored in this folder.
This information will be kept on different locations on the Edinburgh University Server in order to protect the identity of participants.

Academic or Clinical supervisor becoming unavailable (low likelihood, Low severity of harm): The likelihood of both supervisors becoming unavailable during the duration of this project is low. In the event of a supervisor becoming unavailable, attempts will be made to find an alternative supervisor. If the clinical supervisor becomes unavailable, then there is another Clinical Psychologists within the Intellectual Disabilities Department that could oversee the project.

Participant becoming distressed (low likelihood, significant severity of harm): The researcher will provide space at the end of the interview for a debrief and any distress will be addressed through core therapeutic skills such as active listening, empathy and warmth (BPS, 2017). Further to this the participant will be encouraged to use their regular supervision arrangements to discuss any concerns. Participants will also be given a debrief form with key contacts.

Please identify measures you could take to reduce or eliminate risks identified as possible/significant or probable/severe.

SEE ABOVE

Q8. Will information containing personal, identifiable data be transferred to, shared with, supported by, or otherwise available to third parties outside the University?

☐ Yes ☐ No

If “yes” - Please explain why this necessary and how the transfer of the information will be made secure. If the third party is based outside the European Economic Area please obtain guidance from the Data Protection Officer.

Q9. Other than the use by third parties, will the data be used, accessed or stored away from University premises?

☐ Yes ☐ No

If “yes” - Describe the arrangements you have put in place to safeguard the data from accidental or deliberate access, amendment or deletion when it is not on University premises, including when it is in transit, and (where applicable) it is transferred outside the EEA.

Remote access will be requested for access to The Edinburgh University Network server and all electronic data will be stored on this platform. All research paperwork (consent forms, recording device) will be in a lockable filing cabinet in an office within NHS Tayside Learning Disabilities Department. It will be transported in a lockable briefcase to and from interview location (if interview takes place face to face).
Q10. Will feedback of findings be given to your research project participants or data subjects?

☐ Yes  ☐ No

*If “yes” - How and when will this feedback be provided?*

The researcher has created a debrief form that will be given to participants once they have completed an interview. A copy of this has been attached. Key contacts have been provided on this. All participants will also receive a summary of the results once the project has been completed. They will then be given the opportunity to request a full copy of the thesis should they be interested. They will also be invited to an information evening for discussion about the results. This will likely be through MS teams.

*If “no” - Please provide rationale for this.*

Q11. How do you intend to use/disseminate the results of your research project?

This research will be written up and submitted as part of The University of Edinburgh’s Doctorate in Clinical Psychology. Manuscripts will be available via the University of Edinburgh Research Archives. The study may also be submitted to a peer-reviewed journal. Possible suitable journals include

- The Journal of Intellectual Disabilities
- Journal of Applied Research in Intellectual Disabilities
- Advances in Mental Health and Intellectual Disabilities

Information may also be shared via poster at specific Intellectual Disability Events such as the yearly Specialist Interest Group event.
Section 2: Security-sensitive material

The Terrorism Act (2006) outlaws the dissemination of records, statements and other documents that can be interpreted as promoting or endorsing terrorist acts.

Q12. Does your research involve the storage on a computer of any such records, statements or other documents?
☐ Yes ☐ No (if you answered no to this question please jump to section 3)

If “yes” - Please type 'Yes' to indicate that you agree to store all documents on that file store

Q13. Might your research involve the electronic transmission (for example, as an email attachment) of such records or statements?
☐ Yes ☐ No

If “yes” - Please type ‘Yes’ to indicate that you agree not to transmit electronically to any third party documents stored in the file store

Q14. Will your research involve visits to websites that might be associated with extremist, or terrorist, organisations?
☐ Yes ☐ No

If “no”, please proceed to Question 15.

If “yes” - You are advised that such sites may be subject to surveillance by the police. Accessing those sites from University IP addresses might lead to police enquiries. Please type ‘Yes’ to acknowledge that you understand this risk

By submitting to the ethics process, you accept that your School Research Ethics Officer and the convener of the University’s Compliance Group will have access to a list of titles of documents (but not the contents of documents) in your document store. Please type ‘Yes’ to acknowledge that you accept this.

Please confirm that you have contacted your School Research Ethics Officer to discuss security-sensitive material by ticking ‘Yes’

☐ Yes, I have contacted my School’s Research Ethics Officer
☐ No, I have not contacted my School’s Research Ethics Officer
Section 3: Copyright

Q15. Does your project require use of copyrighted material?

☐ Yes          ☐ No

*If “yes” please give further details*
Section 4: Good conduct in collaborative research

Q16. Does your project involve working collaboratively with other academic partners?
☐ Yes ☐ No (if you answered no to this question please jump to section 5)

If “yes” - Is there a formal agreement in place regarding a collaborative relationship with the academic partner(s)?

If “no” - Please explain why there is no formal agreement in place

Q17. Does your project involve working collaboratively with other non-academic partners?
☐ Yes ☐ No

If “yes” - Is there a formal agreement in place regarding a collaborative relationship with the non-academic partner(s)?

If “no” - Please explain why there is no formal agreement in place.

Q18. Does your project involve employing local field assistants (including guides/translators)?
☐ Yes ☐ No

If “yes” - Is there a formal agreement in place regarding the employment of local field assistants (including guides and translators)?

If “no” - Please explain why there is no formal agreement in place

Q19. Will care be taken to ensure that all individuals involved in implementing the research adhere to the ethical and research integrity standards set by the University of Edinburgh?
☐ Yes ☐ No

If “no” - Please explain why care will not be taken
Q20. Have you reached agreement relating to intellectual property?
☐ Yes  ☐ No

*If “no” - Please explain why you have not reached agreement*
Section 5: Good conduct in publication practice

In publication and authorship, as in all other aspects of research, researchers are expected to follow the University’s guidance on [integrity](https://www.ed.ac.uk/governance-strategic-planning/content-to-be-removed/research-integrity). By ticking yes, you confirm that full consideration of the items described in this Section will be addressed as applicable.

☐ Yes  ☐ No

If you intend to collect new data, please continue completing the Level 2 application in the next page.

If you are NOT collecting any new data, you have now completed the Level 1 application. Please submit this document alongside all attachments to [ethics.hiss@ed.ac.uk](mailto:ethics.hiss@ed.ac.uk).
Section 6: Potential risks to participants and researchers

Q21. Is your research project likely or possible to induce any psychological stress or discomfort in the participants or others, indirectly associated with the research?

☐ Yes ☐ No

If “yes” state the types of risk and what measures will be taken to deal with such problems:

As this project is on the topic of trauma informed care there is the potential for it to induce psychological stress or discomfort. A debrief form with key contacts will be provided to participants. Participants will also be reminded that they can stop the interview at any time, without giving a reason should they want to. Participants will also be made aware that they can ask for anything recorded to be deleted within 48 hours of suspending or completing the interview.

Q22. Does your research project require any physically-invasive or potentially physically harmful procedures?

☐ Yes ☐ No

If “yes” give details and outline procedures to be put in place to deal with potential problems.

Q23. Does your research project require the use of privacy-invasive technology, such as CCTV, biometrics, facial recognition, vehicle tracking software?

☐ Yes ☐ No

If “yes” - Give details and outline procedures to be put in place to deal with potential problems.
Q24. Does your research project involve the investigation of any illegal behaviour or activities?

☐ Yes  ☐ No

*If “yes” - Give details of any illegal behavior or activities you may investigate*

Q25. Is it possible that your research project will lead to awareness or the disclosure of information about child abuse or neglect?

☐ Yes  ☐ No

*If “yes” - Indicate the likelihood of disclosure and the procedures to be followed if you become aware that a child has been or may be at risk of harm*

Q26. Is it likely that dissemination of research findings or data could adversely affect participants or others indirectly associated with the research?

☐ Yes  ☐ No

*If “yes” - Describe the potential risk for participants/data subjects of this use of the data. Outline any steps that will be taken to protect participants.*

Q27. Could participation in this research adversely affect participants and others associated with the research in any other way?

☐ Yes  ☐ No
If “yes” - Describe the possible adverse effects and the procedures to be put in place to protect against them.

Q28. Is this research expected to benefit the participants, directly or indirectly?

☐ Yes ☐ No

If “yes” - Give details of how this research is expected to benefit the participants.

The results of this study may provide information on what helps or hinders the implementation of trauma informed care for the learning disability population. Thus, it may provide insight into what has been successful and unsuccessful for the population they are working with and so could be indirectly beneficial for their future working with this population.

Q29. Will the true purpose of the research be concealed from the participants/data subjects?

☐ Yes ☐ No

If “yes” - Explain what information will be concealed and why.

Q30. Will participants/data subjects be debriefed at the conclusion of the study?

☐ Yes ☐ No

If “no” – Why will participants / data subjects not be debriefed?

Participants will be given opportunity at the end of the interview to reflect on how they found the interview. They will also receive a debrief form with key contacts. Once the study has been completed, participant's will receive a summary sheet with the main conclusions from the study. They will also be able to request a copy of the full thesis. An information evening will also be held for participants to gain an understanding of the results.

Q31. At any stage in this research could researchers’ safety be compromised, or could the research induce emotional distress in the researchers?

☐ Yes ☐ No

If “yes” - Give details and outline procedures to be put in place to deal with potential problems.
Please tick to confirm you agree with the following:

I will adhere to School guidance on risk assessment and health and safety and will seek advice on project and travel insurance prior to project commencement.

☐ I agree

☐ I do not agree

☐ Not applicable
Section 7: Participants and data subjects.

Q32. How many participants or data subjects are expected to be included in your research project?

10-12 participants

Q33. What criteria will be used in deciding on the inclusion and exclusion of participants/data subjects in your research project?

**Inclusion Criteria**
- Professionals working within any of Tayside’s 3 Learning Disability teams.
- Professionals with regular direct contact with people with an Intellectual Disability.
- Professionals who have worked with individuals with an Intellectual disability and trauma history.

**Exclusion Criteria**
- Professionals within an Intellectual Disability Service but without direct contact with people with intellectual disabilities.
- Professionals without a good understanding of spoken English.

Q34. Are any of the participants or data subjects likely to be under 16 years of age?

☐ Yes ☐ No

*If “yes” - Explain and describe the measures that will be used to protect and/or inform participants/data subjects.*

Q35. Are any of the participants or data subjects likely to be children in the care of a Local Authority?

☐ Yes ☐ No

*If “yes” - Explain and describe the measures that will be used to protect and/or inform participants/data subjects.*
Q36. Are any of the participants or data subjects likely to be known to have additional support needs?

☐ Yes  ☐ No

*If “yes” - Explain and describe the measures that will be used to protect and/or inform participants/data subjects.*

Q37. In the case of participants with additional support needs, will arrangements be made to ensure informed consent?

☐ Yes  ☐ No  ☐ N/A

*If “yes” – What arrangements will be made?*

*If “no” – Please explain why not*

Q38. Are any of the participants or data subjects likely to be physically or mentally ill?

☐ Yes  ☐ No

*If “yes” - Explain and describe the measures that will be used to protect and/or inform participants/data subjects.*
Q39. Are any of the participants or data subjects likely to be vulnerable or likely exposed to harm in other ways?

☐ Yes  ☐ No

If “yes" - **Explain and describe the nature of the vulnerability and the measures that will be used to protect and/or inform participants/data subjects.**

Q40. Are any of the participants or data subjects likely to be unable to communicate in the language in which the research is conducted?

☐ Yes  ☐ No

If “yes" - **Explain and describe the measures that will be used to protect and/or inform participants/data subjects.**

Q41. Are any of the participants or data subjects likely to be in a relationship (i.e., professional, student-teacher, other dependent relationship) with the researchers?

☐ Yes  ☐ No

If “yes" - **Explain and describe the measures that will be used to protect and/or inform participants/data subjects.**
Q42. Are any of the participants or data subjects likely to have difficulty in reading and/or comprehending any printed material distributed as part of the study?

☐ Yes  ☐ No

*If “yes” - Explain and describe the measures that will be used to protect and/or inform participants/data subjects.*

Q43. Describe how the sample will be recruited.

The researcher will contact individuals via email (an email distribution list for individuals within the learning disabilities team already exists and this will be used to contact all potential individuals). This email will include a patient information sheet. Participants who are interested in the study will be asked to respond to the email stating their interest in participating. The researcher will provide extra information about the study if potential participant requests this. If participant is interested in participating, then they will be sent the consent form via email to be completed and sent back to the researcher via email.

Q44. Will participants receive any financial or other material benefits as a result of participation?

☐ Yes  ☐ No

*If “yes” - What benefits will be offered to participants and why?*
Section 8: Participant or data subject information and consent

Q45. Will written or oral consent be obtained from all participants or data subjects?

☐ Yes  ☐ No

If “yes” – attach participant information sheet and consent form and detail the process you will follow.

If “no” – explain why not and what process you will follow regarding consent, or if consent cannot or should not be sought for some reason, please provide a clear case and rationale for this (e.g. in international contexts where speaking to foreign researchers is prohibited).

Consent form is attached.

Q46. Have you made arrangements to tell participants what information you will hold about them and for how long?

☐ Yes  ☐ No

If “yes” - what arrangements have been made?

This is stated in the attached consent form and in the participant information sheet. Participants will be encouraged to read this thoroughly before consenting to take part in the project.

If “no” – why not?

Q47. Have you made arrangements to tell participants whether you will disclose the information to other organisations?

☐ Yes  ☐ No  ☐ N/A

If “yes” - What arrangements have been made?

How a participant's information will be used and shared is stated in the attached participant information sheet and participants will be encouraged to read this thoroughly before consenting to take part in the project.

If “no” – why not?
Q48. Have you made arrangements to tell participants whether you will combine that information with other data?

☐ Yes ☐ No ☐ N/A

If “yes” - What arrangements have been made?

How a participant's information will be used and shared is stated in the attached participant information sheet and participants will be encouraged to read this thoroughly before consenting to take part in the project.

Q49. In the case of children participating in the research, will the consent or assent of parents be obtained?

☐ Yes ☐ No ☐ N/A

If “yes” - Explain how this consent or assent will be obtained

If “no” – Please explain why you won’t be obtaining consent

Q50. Will the consent or assent of children participating in the research be obtained?

☐ Yes ☐ No ☐ N/A

If “yes” - Explain how this consent or assent will be obtained

If “no” – Please explain why not
Q51. In the case of participants who are not proficient in the language in which the research is conducted, will arrangements be made to ensure informed consent?

☐ Yes ☐ No ☐ N/A

If “yes” – What arrangements will be made?

If “no” – Please explain why not
Q52. Does the activity involve using cookies or tracking individual’s activity on a website or the Internet in general?

☐ Yes  ☐ No

If “yes” – Describe the arrangements you have put in place to obtain informed consent for the use of these tools

You have now completed the Level 2 application. Please submit this document alongside all attachments to ethics.hiss@ed.ac.uk.
PARTICIPANT INFORMATION SHEET

A Qualitative analysis of a multi-disciplinary teams' perspective of implementing Trauma-informed Care in an Intellectual Disability Service

You are being invited to take part in research on trauma-informed care in intellectual disability services. Sarah Gardner, Trainee Clinical Psychologist, at the University of Edinburgh is leading this research. Before you decide whether to take part it is important you understand why the research is being conducted and what it will involve. Please take time to read the following information carefully.

WHAT IS THE PURPOSE OF THE STUDY?

The purpose of the study is to gain an understanding of different professional's experience of applying principles of trauma-informed care within Tayside Intellectual Disabilities Service. Traumatic experiences refer to life events that have caused an individual physical and/or psychological harm. NHS services have a duty to ensure a safe environment whereby individuals who have experienced trauma can access services without experiencing re-traumatisation. Individuals with an intellectual disability are more likely to experience traumatic life events, and yet are less cognitively able to understand and share their trauma symptoms. Thus, a safe environment whereby an individual can develop trust is extremely important for this population.

WHY HAVE I BEEN INVITED TO TAKE PART?

You are invited to participate in this study because you have been identified as a professional working within Tayside Intellectual Disabilities Service and have regular direct contact with people with an Intellectual Disability.

DO I HAVE TO TAKE PART?

No – it is entirely up to you. If you do decide to take part, you are still free to withdraw at any time and without giving a reason. Deciding not to take part or withdrawing from the study will not affect your employment.

Please note that it will only be possible to remove your study data up to 1 week after your interview. After this time it will be anonymised and may be used in the study write up.

WHAT WILL HAPPEN IF I DECIDE TO TAKE PART?

If you do decide to take part, please keep this Information Sheet. You will be asked to sign an Informed Consent Form to show that you understand your rights in relation to the
research, and that you are happy to participate. You will be sent this via email and asked to return to the researcher prior to the interview.

You will then be invited to a one-to-one interview with the researcher. This can be in person in a quiet location convenient for you or via MS Teams. During the interview you will be asked a number of questions regarding your experience of trauma-informed care in intellectual disability services. The interview will take place in a safe environment at a time that is convenient to you. Ideally, we would like to audio record your responses (and will require your consent for this), so the location should be in a fairly quiet area. The interview should take around 45-60 minutes to complete.

WHAT ARE THE POSSIBLE BENEFITS OF TAKING PART?

There are no direct benefits, but by sharing your experiences with us, you will be helping Sarah Gardner and the University to better understand the specific principles that Clinical Psychologists’ think are important when considering Trauma-informed Care for individuals with Intellectual Disabilities. It will also help us understand the current context of trauma-informed care in ID services around Scotland.

ARE THERE ANY RISKS OR DISADVANTAGES ASSOCIATED WITH TAKING PART?

There are no significant risks associated with participation. The interview may focus on aspects of psychological trauma as part of your work, which may be distressing/uncomfortable to discuss. In the event this becomes distressing, you are encouraged to notify the Principal Investigator and stop the interview. It is up to you if you chose to proceed with the interview or stop it completely after this. For the purposes of confidentiality, specific information relating to real-life patient narratives would be discouraged and focus kept on your own experiences and reflections on the work. We would encourage you to use your own clinical supervision and reflective practice to explore any issues arising from the discussion of work-related material. You may also access the below resources should you consider further psychological support to be useful:


National Wellbeing Hub - https://wellbeinghub.scot/

Workforce Specialist Service - https://www.practitionerhealth.nhs.uk/accessing-the-service-in-scotland

Contact your health boards’ local Staff Wellbeing Service

WHAT IF I WANT TO WITHDRAW FROM THE STUDY?

If you do decide to take part you can stop completing the interview anytime, without giving a reason. During the interview, you may simply let the Principal Investigator know that you wish to terminate the interview and your data will be deleted. Please note that after the interview has concluded, interview data will not be able to be withdrawn after 1 week of the interview concluding. After this, such data will be stored securely and used in the research.
WHAT IF I AM UNWELL?
If you feel unwell or have COVID-19 then please contact the researcher, Sarah Gardner, s1114382@sms.ed.ac.uk and we will postpone or cancel the research interaction.

WILL MY TAKING PART BE KEPT CONFIDENTIAL?

All the information we collect during the course of the research will be kept confidential and there are strict laws which safeguard your privacy at every stage.

HOW WILL WE USE INFORMATION ABOUT YOU?

We will need to use information from you for this research project. This information will include your name, position, contact details. People will use this information to do the research or to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

We will keep all information about you safe and secure.

Your data will only be viewed by the researcher/research team. With your consent, your interview responses will be recorded on an encrypted audio recorder. This audio recording will then be transferred and stored (until transcribed) to a password-protected computer files on secure University of Edinburgh Network server. Once the audio recording has been transferred to the University of Edinburgh secure network it will be deleted form the audio recording device immediately. The researcher will aim to transcribe the recordings within 1 week of the interview.

All electronic data will be stored on a password-protected computer file and all paper records will be stored in a locked filing cabinet. Your consent information will be kept separately from your responses in order to minimise risk.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

What are your choices about how your information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have. You can ask for your data to be withdrawn up to 1 week after your interview.

We need to manage your records in specific ways for the research to be reliable. This means that we won’t be able to let you see or change the data we hold about you.

Where can you find out more about how your information is used?

You can find out more about how we use your information at https://www.ed.ac.uk/records-management/privacy-notice-research by asking one of the research team

by sending an email to The University of Edinburgh Data Protection Officer at dpo@ed.ac.uk

The University of Edinburgh is the sponsor for this study based in Scotland. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The University of Edinburgh will keep identifiable information about you for 6 – 12 months after the study has finished and your anonymised data for a minimum of 5 years.
WHAT WILL HAPPEN WITH THE RESULTS OF THIS STUDY?

The results of this study may be summarised in published articles, reports and presentations. You will not be identifiable from any published results. Quotes or key findings will always be made anonymous in any formal outputs unless we have your prior and explicit written permission to attribute them to you by name. With your consent, your anonymised information may also be kept for future research. A summary of the findings from the study will be made available to participants who indicate they would like to receive this. This summary will be sent to participants by post / email.

WHO IS ORGANISING AND FUNDING THE RESEARCH?

This study has been organised by Sarah Gardner who is completing a Doctorate in Clinical Psychology and sponsored by the University of Edinburgh.

WHO HAS REVIEWED THE STUDY?

The study proposal has been reviewed by the Health in Social Science Ethics Committee at the University of Edinburgh. NHS management approval has also been obtained.

WHO CAN I CONTACT?

If you have any further questions about the study, please contact the lead researcher, Sarah Gardner, s1114382@sms.ed.ac.uk.

If you would like to discuss this study with someone independent of the study please contact Professor Elizabeth Gilchrist, .

If you wish to make a complaint about the study, please contact Dr Helen Griffiths, Programme Director for the Doctorate in Clinical Psychology, at . In your email, please include the study title and nature of your complaint.
Appendix I: Consent Form

PARTICIPANT CONSENT FORM

Study Title: A Qualitative analysis of a multi-disciplinary teams' perspective of implementing Trauma-informed Care in an Intellectual Disability Service

Researcher's name and contact details: Sarah Gardner, s1114382@sms.ed.ac.uk

Participant ID: _____________

Please initial boxes

1. I confirm that I have read and understood the Participant Information Sheet (Version 1 dated 05 Jul 2022) for the above study.

2. I have been given the opportunity to consider the information provided, ask questions and have had these questions answered to my satisfaction.

3. I understand that my participation is voluntary, and I can withdraw at any point without any negative repercussions.

4. I understand that I can withdraw my data by contacting the researcher within one week of my interview. After this point the interview will be transcribed and anonymised.

5. I understand that my anonymised data will be stored for a minimum of 5 years and may be used in future ethically approved research.

6. I understand that relevant sections of data collected during the study may be looked at by individuals from the Sponsor (University of Edinburgh), or from the NHS health board where it is relevant to my taking part in this research. I give permission for these individuals to have access to my data.

7. I agree to my interview being audio recorded.

8. By initialling this box I agree to the above consent points and to take part in the above study.
Name:

Contact details:

Appendix J: Debrief forms

PARTICIPANT DEBRIEFING SHEET – SOURCES OF SUPPORT
A Qualitative analysis of a multi-disciplinary teams’ perspective of implementing Trauma-informed Care in an Intellectual Disability Service
Thank you for taking part in this study.

This study was seeking to explore the experiences of clinicians implementing trauma-informed care in Tayside Learning Disabilities Services. Taking part in this research required you to reflect on your own experiences and approach to working with a complex group of people. If you have felt affected by the discussions during the interview, we would encourage you to explore work-related concerns within your own clinical supervision, line management and reflective practice arrangements. For further wellbeing support, information, and resources please consider the following:

- **National Wellbeing Hub** - [https://wellbeinghub.scot/](https://wellbeinghub.scot/)
- **Workforce Specialist Service** - [https://www.practitionerhealth.nhs.uk/accessing-the-service-in-scotland](https://www.practitionerhealth.nhs.uk/accessing-the-service-in-scotland)
- **Contact NHS Tayside’s Staff Wellbeing Service**

Please note that you may withdraw your questionnaire/interview responses within 48 hours of this interview concluding. You can contact the Principal Investigator and interviewer, Sarah Gardner, s1114382@sms.ed.ac.uk. You do not need to provide a reason for withdrawing your responses.

Who Can I Contact?

For more information about the study or to request a summary of the study findings, please contact the Principal Investigator, Sarah Gardner, at s1114382@sms.ed.ac.uk and [the research supervisor, Dr Rachel Happer, at](mailto:Dr.Rachel.Happer@nhs.net)

If you wish to discuss this study with someone independent of the research team please contact Professor Elizabeth Gilchrist, at [Professor.E.Gilchrist@nhs.net](mailto:Professor.E.Gilchrist@nhs.net).

If you wish to make a complaint about the study, please contact Dr Helen Griffiths, Programme Director for the Doctorate in Clinical Psychology, at [Dr.Helen.Griffiths@nhs.net](mailto:Dr.Helen.Griffiths@nhs.net). In your email, please include the study title and the nature of your complaint.

PARTICIPANT DEBRIEFING SHEET – Background and key references
A Qualitative analysis of a multi-disciplinary teams’ perspective of implementing Trauma-informed Care in an Intellectual Disability Service
Thank you for taking part in this study.

Rationale for Study

There is mounting research on TIC in addiction services, mental health services and women specific services (Cleary et al., 2020). However, little research has been conducted on TIC in intellectual disability services. Yet, people with intellectual disabilities are more likely to use services due to higher rates of co-morbid mental illness (Fuld, 2018; Osugo & Cooper, 2016). A qualitative study by Truesdale and colleagues (2019) examined health professional’s experience of supporting an individual with an intellectual disability and traumatic stress in a healthcare setting. One of the main themes on how to best support these individuals was for intellectual disability services to have a specific trauma care pathway and that this was applied by professionals who had trauma knowledge, skills and expertise to treat individuals with an intellectual disability. Yet this study lacks guidance on how intellectual disability services could implement specific trauma pathways. Goad (2021) reflects on the stages of implementation of TIC in an NHS England’s intellectual disabilities service and has created a visionary model specific to the intellectual disability population. Goad (2021) framework:

- Safety, trust, choice, collaboration, control, respect, empowerment, consistency and nurture.

The principles are similar to those outlined in the frameworks above, however, specific emphasis is placed on developing accessible literature for service users, carers and families in order to create respect and empower choice. This study compliments Truesdale and colleague’s 2019 study by considering not just what should be considered for TIC but how the changes could be made. It outlines different objectives such as making the environment more trauma-informed by creating easy read instructions on ‘what to expect from a first appointment’ booklet for service users.

A review of the evidence has suggested that limited studies exist on TIC within intellectual disability services. While the usefulness of TIC has gained recognition, how fully intellectual disability services have embraced the practice rather than the concept of TIC, is unknown. It is encouraging that there is increasing enthusiasm for services to become more trauma-informed as TIC can only successfully be implemented when there is willingness to change, capacity for change and enough knowledge to translate the concept into practice (Cleary et al., 2018). However, research for considering TIC in intellectual disabilities services are far behind general mental health services (Cleary et al., 2018).

Experiences from Clinical Psychologists around Scotland on what has helped or hindered the implementation of TIC in this population will provide valuable insight for the future direction of TIC in intellectual disability services. This will help provide insight into the stage of implementation in services across Scotland and the specific components that are useful to consider when supporting this population. This research is important to help with the shift towards equality of care for those with an intellectual disability compared to the general population.

Key References for further reading

Appendix K: Interview Schedule

**Interview Schedule**

A Qualitative analysis of a multi-disciplinary teams' perspective of implementing Trauma-informed Care in an Intellectual Disability Service

**Introduction**
Thank you for agreeing to take part in this research. We are interested in trauma-informed care in intellectual disability services. We expect the interview to last between 45 and 60 minutes, but we can stop to take a break at any point, and you can finish the interview at any time without giving an explanation.

[If participant has consented to be recorded, switch on the recorder]
May I double-check that you are happy for this interview to be recorded?
[Continue recording, if participant has confirmed their consent.]

**Outline questions**
1) Can you tell me about your experience of trauma-informed care within learning disability services?
   a. Follow up: Symptoms in this population
   b. How do individuals with an ID internalise or externalise trauma

2) Can you tell me what you think helps and hinders the implementation of trauma-informed care in ID services?

3) Are any specific guidelines/policies/procedures followed regarding TIC?
   a. Follow up: What pathway is followed if someone discloses trauma?
   b. Have service users ever been asked for involvement in this? Have there ever been amendments made based on feedback?
c. How well do you believe the concept of TIC has been integrated into the service?

d. Are any trauma measures used to screen routinely for trauma?

4) What trauma-focused training has been provided to you?
   a. Follow up: How do you make sense of trauma training to implement this into care?
   b. Do you feel you have the skills to recognise trauma in this population?
   c. Do you think the trauma focused training provided to you was adapted sufficiently for the population?

5) Can you tell me about accessible resources for trauma within your service?
   a. What type of resources are there for users, carers, families

6) Can you tell me what you do for self-care/self awareness that might mitigate the impact of hearing about others trauma?

Closing question
Is there anything else you would like to discuss that has not already been covered?

Thank you very much for taking part in this interview.

Appendix L: Example Transcript Analysis

<table>
<thead>
<tr>
<th>Transcript</th>
<th>Exploratory notes</th>
<th>Experiential Statements</th>
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<tbody>
<tr>
<td>Participant: oh probably a lot of non-truth. I don’t mean that in that people lie but I mean they probably say things that aren’t true. But if I look at that with an LD head on these are usually the people that are socially able but not cognitively able, so I quite often feel like the non-truths that come out are about socialisation and about having something to say and keeping something to say in a convo. Sometimes its utter nonsense. I had a full conversation with someone about what sandwich they had brought for their lunch and it turned out they hadn’t brought a packed lunch at all. There was no benefit behind it that I could see. Could have non-truths; interesting wording need to investigate things/look at things differently with ID pop. use of word non-truths again Trying to socialise means those with ID sometimes don’t talk the truth ‘no benefit that I could see’ Social conformity</td>
<td>Uniqueness of population detective work Trying to fit in/social desirability social conformity misunderstood population</td>
<td></td>
</tr>
</tbody>
</table>
easily said I’ve not brought it but it was that social conformity. We are talking about sandwiches and I will say I’ve got a ham lettuce sandwich. Higher up in services we see that with emergency service calling, those that phone police a lot, those that turn up at A&E saying they have taken 90 paracetamol but the toxic screen is clear and the care seeking behaviours that are not required for the issue that they are saying they do. They need that engagement. That’s the only way I know how to get that care when I need it. So yeah a lot of people account this as manipulative or working the service if you don’t look at it as a care seeking lens.

**Interviewer**- so that understanding of trauma and attachment helps you view the behaviour in a different way than someone who didn’t have that understanding?

**Participant**- I think the LD too. You know someone who is cognitively able and is seeking care for an overdose. Cognitively they know how many to take or not to take. They know how to cut without damaging. But if you add in an LD too they are more in danger of someone really hurting self or going too far and not seeing consequences of that. If they have a trauma background then impulse control will be different too but not having the cognitive component to then support yourself in that situation. For example oh I can phone a taxi, call family or go to a friends or call the police. But our individuals with an LD don’t have those problem solving skills to get out of the dangers that they get themselves into. It ends up with services either having to be quite heavy handed and sectioning somebody or having someone in a locked unit and even though they are socially very able and people are like well I’ve told them they shouldn’t do that but actually they just don’t have the understanding to make these choices. So capacity definitely comes in to that aswel.

| hierarchical view of services ‘higher up’ | increased use of services for wrong reasons seeking connection/engagement people have stigmatised views of this behaviour |
| risk taking behaviour unable to assess/evaluate risk link between trauma and impulse control limited problem solving skills different approaches services can take regarding presentations difficulty when social deficit is not in line with cognitive deficit assessment of capacity for risk/choice making | negative attitudes about individuals with an ID behaviours |

vulnerability of population

behavioral response to trauma

response of organisation differs depending on danger/risk

social and cognitive deficits cane make choice making poor
Appendix M: Reflexivity Statement

A reflective journal was kept during all stages of the study: participant recruitment, data collection and analysis. This process helped me keep account of any beliefs or perceptions I had throughout the process. I have included some elements of this journal in this reflective statement. To start with the recruitment stage felt unexpectedly easy. I had multiple responses to emails, and I was keen to get started with interviews. However, I recognised that by booking all the interviews in quick succession that this would not give me enough time to consider each individual interview or really get involved with the data. I therefore allowed sufficient time in between each interview. I noticed in my first interview that I stuck closely to the interview schedule, maybe due to anxiety, as this was my first experience of an IPA interview. After reflecting about this in supervision I managed to become more flexible as the interviews continued.

As a white, Scottish Trainee Clinical Psychologist who has completed a placement within the intellectual disability team that was being interviewed, I had previous professional relationships with some of the individuals who participated. I was mindful of the impact that this experience may have on my interpretation of the data as I felt I understood some individual’s beliefs and attitudes towards work/trauma prior to the interview. Furthermore, I had an awareness of the training and structures in place already to support trauma-informed care. Therefore, I was conscious about remaining open and not being leading with my questions. Additionally, I could feel myself resonating with a lot of what the psychologists (participants) were speaking about. I felt more connected to the language they were using than those from different profession and I was aware of this when analysing the data. Therefore, whilst immersing myself in the data, I had to think carefully about the true meaning behind specific phrases/language used and allowed this to guide my interpretation rather than sticking with what felt familiar. I occasionally felt defensive when individuals used words or expression that I felt were stigmatising or wouldn’t be how I would choose to express an experience. I was mindful of my non-verbal ques in these situations and reminded myself of the different experiences each person has been through.